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Catherine Campbell, Yugi Nair, Sbongile Maimane and Jillian Nicholson

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# 'Dying Twice'

## A Multi-level Model of the Roots of AIDS Stigma in Two South African Communities

CATHERINE CAMPBELL  
*London School of Economics, UK*

YUGI NAIR  
*University of KwaZulu-Natal, South Africa*

SBONGILE MAIMANE  
*University of KwaZulu-Natal, South Africa*

JILLIAN NICHOLSON  
*KwaZulu-Natal, South Africa*

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ADDRESS. Correspondence should be directed to:  
CATHERINE CAMPBELL, Social Psychology, London School of Economics,  
Houghton Street, London, WC2A 2AE, UK. [email: c.campbell@lse.ac.uk]



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### Abstract

We highlight the complex interplay of psychological and social factors driving AIDS stigma, drawing on a study of community responses to HIV/AIDS in two communities in KwaZulu-Natal, South Africa. We draw on 120 semi-structured interviews and focus groups, in which open-ended topic guides were used to explore community responses to HIV/AIDS. Drivers of stigma included fear; the availability and relevance of AIDS-related information; the lack of social spaces to engage in dialogue about HIV/AIDS; the link between HIV/AIDS, sexual moralities and the control of women and young people; the lack of adequate HIV/AIDS management services; and the way in which poverty shaped people's reactions to HIV/AIDS. We discuss the implications of our findings for stigma-reduction programmes.

### Keywords

- *AIDS*
- *dialogue*
- *interventions*
- *morality*
- *poverty*
- *stigma*

If you have AIDS you die twice because the first thing that kills you is being lonely when everyone discriminates against you, even your family members. The second one is the actual death. (Young man, high school learner)

## Introduction

THIS ARTICLE seeks to contribute to the development of actionable multi-level understandings of the causes of HIV/AIDS stigma, drawing on our recent study of community responses to HIV/AIDS in South Africa. HIV/AIDS is a leading cause of morbidity and mortality in sub-Saharan Africa. Stigma is increasingly regarded as a key driver of the epidemic (Ogden & Nyblade, 2005). This is through the role it plays in undermining the ability of individuals, families and societies to protect themselves from HIV and to provide assistance to those affected by AIDS. There is an urgent need for the development of understandings of the causes of stigma to inform stigma-reduction interventions.

Psychological studies have been dominated by social cognition approaches that focus on individual-level drivers of stigma. They focus on properties of the conscious rational individual, such as lack of knowledge or negative attitudes, with inadequate attention to the social influences on these individual-level phenomena (Parker & Aggleton, 2003). Furthermore, they pay no attention to the role of unconscious factors in driving stigma (Joffe, 1999). To date, the majority of stigma-reduction interventions in sub-Saharan Africa have taken the form of information-based awareness programmes designed to reduce ignorance about people living with HIV/AIDS (PLWHAs). However, while levels of AIDS-related knowledge are often inversely correlated with stigma (Kalichman et al., 2006), providing people with factual information about stigmatized health conditions does not lead to widespread stigma reduction (Deacon, Stephney, & Prosalendis, 2005; Hayes & Vaughan, 2002). People's responses to health risks are shaped by a wide array of factors in addition to factual knowledge, ranging from the intra-psychoic (e.g. competing unconscious motivations) to the macro-social (e.g. socio-economic position or gender) (Campbell, 2003). There is an urgent need for more nuanced models of stigma that take greater account of its complex and multi-level nature (Campbell & Deacon, 2006). There is also a need for actionable

models, which define stigma in ways that point to possible strategies for stigma reduction. This article seeks to contribute to both these challenges.

Some authors distinguish between stigma (understood as negative attitudes or ideologies) and discrimination (negative behaviours), taking account of the fact that stigmatizing attitudes do not always result in overtly discriminatory behaviours (e.g. Deacon et al., 2005). Others characterize stigma to include affective, cognitive and behavioural responses, with the primacy of each factor resulting from variable interactions between the nature of the stigma, the context in which it is encountered and individual differences among interactants (e.g. Heatherton, Kleck, Hebb, & Hull, 2003). We adopt a similarly inclusive definition, defining stigma as any negative thoughts, feelings or actions towards people infected with HIV or living with AIDS. We do so on the basis of our belief that, irrespective of whether they are at the receiving end of explicit acts of discrimination, people know they are devalued through their more general awareness of the negative social representations of their stigmatized characteristics.

The starting assumption of our work is Joffe's (1999) account of the intra-psychoic drivers of stigma. Drawing on Melanie Klein's writing, she argues for the existence of a universal unconscious human fear of collapse and chaos. This fear becomes intensified in the presence of a particular risk or danger, such as a widespread HIV/AIDS epidemic. People may cope with such fears by constructing negative representations of PLWHAs, and subjecting them to various forms of exclusion and discrimination as a way of distancing themselves from the threat.

The psychological tendency towards the 'othering' of identifiable out-groups is a universal one, present in all societies. Throughout history out-groups (e.g. people with mental illness, members of particular ethnic or religious minorities, the poor) have been demonized (Gilman, 1988). However the groups that become targets of stigma often vary from one context to another. A key challenge facing stigma researchers is understanding why particular groups come to be stigmatized in particular social contexts at particular moments in time. Part of the answer to this question lies in developing understandings of the types of social forces that 'become sedimented in people's inner experiences' at particular times and places (Joffe, 1999, p. 1).

Within this context, this article maps out the complex interplay of psychological and social forces that drive HIV/AIDS stigma in one particular

context—in the form of a six-factor model. We do this through drawing on our research in KwaZulu-Natal (KZN) province in South Africa, where around 40 per cent of pregnant women are HIV-positive, and where levels of stigma are high. In outlining what we believe are the six key factors driving stigma in this context, we draw interchangeably on the academic literature on stigma and on our own empirical research. The impact of some factors (such as unconscious fears) is often subtle, and referred to directly in interviews. In these cases we rely heavily on the academic literature in constructing our framework. The impact of other factors (such as lack of HIV/AIDS treatment services, or conservative sexual moralities) featured prominently and explicitly in research participants' accounts of their experiences of AIDS in the community. In outlining these factors we draw on both the academic literature and our own empirical research material.

## Empirical research methods

This article draws on a total of 120 in-depth interviews and focus groups in two communities: Entabeni, a deep rural community near Eshowe, and Ekuthuleni, a peri-urban area near Durban. We have already reported on the Entabeni interviews elsewhere (Campbell, Foulis, Maimane, & Sibiyi, 2005) in an article discussing the role of stigma and sexual moralities in policing youth and women, and the need for critical thinking about power inequalities in stigma-reduction programmes. In this article we expand on this material through: (1) adding additional material from our rural study; (2) refocusing the material to inform an actionable six-factor multi-level model of the causes of stigma; and (3) providing a detailed account of the implications of this model for an expanded programme of action to reduce stigma, informed by our ongoing involvement in a community-led HIV/AIDS management intervention in Entabeni, our rural study site.

Entabeni and Ekuthuleni are fairly typical KZN communities of Zulu-speaking residents, living in resource-poor conditions, with high levels of unemployment. As already stated, levels of HIV are high and PLWHAs have limited access to health and welfare support. At the time that our interviews were conducted (2004) antiretroviral drugs were not available to residents of our study communities. Social relations are patriarchal, with adult men having considerably more power than women or young

people in the economic, political and private realms of life.

Interviews and focus groups were conducted with a range of community residents to generate a rich array of information about local community responses to HIV/AIDS. These included: PLWHAs; carers; community health volunteers; local leaders; young people; male and female community residents; peer educators; school principals and teachers; non-governmental organization (NGO) staff; traditional healers; doctors and nurses; social workers; church ministers; government officials; and representatives of businesses and factories close to our research sites.

An open-ended topic guide elicited information we believed might be relevant to developing understandings of local responses to AIDS, including informants' views of the South African political context, local community life, the causes of HIV/AIDS, its impact on the community, the role of different groups in HIV/AIDS management and the potential of peer education, grassroots participation and multi-stakeholder partnerships as strategies for HIV-prevention.

In both our rural and urban sites, community entry was facilitated through trusted HIV/AIDS-related community organizations who had specifically invited us to assist them in developing understandings of those dimensions of the social environment that were facilitating or hindering their work. In the peri-urban community, a religious NGO sought feedback on factors shaping the outcomes of their peer education programme. In the rural community, a group of community health volunteers sought advice about how best to improve their efficacy. Over time, the rural research evolved into a long-term intervention—based on a partnership between the community and the researchers (Campbell, Nair, & Maimane, 2007). Within these contexts, the researchers were welcomed into both communities, and informants spoke freely—most expressing tremendous relief at the opportunity to discuss the taboo topic of HIV/AIDS under conditions of anonymity and confidentiality.

For the purposes of this article, interviews were subjected to thematic content analysis, involving two stages. The first involved reading and re-reading the data to highlight information relevant to the manifestations and impacts of stigma. This material is presented immediately below under the heading: 'Context of the study'. The second stage of analysis (presented in a later section entitled 'A six-factor

model of the roots of stigma'), involved identification of any information relevant to the individual, community or macro-social causes of stigma. Immersion in this material, hand in hand with our ongoing reading of the social science literature on stigma, led to the progressive refinement of this material into six core influences on stigma: fear; availability/relevance of information; lack of social spaces to talk about HIV/AIDS; the link between HIV/AIDS, sexual moralities and power relations; the lack of adequate HIV/AIDS prevention and treatment services; and poverty. The picture of stigma that emerged from our rural and peri-urban samples was very similar, so these data have been collapsed below, except when we specifically indicate otherwise.

## Part one: context of the study

### *Manifestations of stigma*

In our study communities, various forms of stigma were common (Campbell et al., 2005). Those perpetuating stigma included families, neighbours, health workers in settings such as hospitals and clinics, teachers, people linked to religious groups and members of the community at large. Various sources of stigma will be referred to in the course of this article. Here we begin by looking at the way in which stigma was often perpetuated within families. One anecdote after another referred to the negative responses towards HIV-positive family members. Family members sometimes hid away sick relatives, limiting their access to health care or support. Families sometimes disowned dead relatives, refusing to collect their bodies from the mortuary, for example.

Amid stories of rejection and prejudice, there were a few stories of care and compassion among family members. However, even in those families it was often the case that neither the dying person nor family members ever referred to the fact that s/he had AIDS, even when everyone was fully aware of this. One woman said that even after her sister's death, the family colluded in saying she had died of tuberculosis, although everyone knew she had died from a wider range of AIDS-related illnesses. PLWHAs who did disclose their status to family members often did so in indirect ways. One informant told us how his brother wrote the family a letter shortly before his death, in which he disclosed his status, rather than telling them face-to-face. When our informant told mourners at the funeral that his

brother had died of AIDS, friends and relatives were shocked at what they perceived as our informant's disloyalty to his brother.

Stigmatization of people with AIDS was often supported by various forms of denial. Despite the obvious presence of the problem in a community where levels of HIV are very high, and funerals of young people are a regular occurrence, many informants told us firmly that there was no AIDS in their community. Thus for example, some members of a focus group of male high school learners spoke with disgust and disbelief of a young man from the community who had disclosed his HIV status while participating in an interview. They said that this disclosure had 'let down the whole community'.

*Informant X:* We haven't seen anyone with HIV/AIDS here.

*Informants Y and Z:* This is not so, AIDS is a problem in this community and we cannot hide it.

*Informant P:* A local guy disclosed his status on a TV programme recently. This guy has embarrassed all of us. I didn't ever think there would be a person from this community who would disclose his status in public. Anyway most people say that he was lying. (Male high school learners)

Even those who acknowledged the existence of HIV/AIDS often avoided referring to AIDS by name. This was the case not only with lay people, but even some community health workers—who referred to HIV/AIDS as 'this thing', or 'this disease', or more generally as 'sickness'.

However, there was also evidence for care and love shown to PLWHAs. Some had managed to find others in a similar situation to confide in, and who had derived great comfort from the receiving and giving of support with others who had first-hand experience of their difficulties. Furthermore, while people with AIDS were still reluctant to disclose their status to others in our two study communities, elsewhere in South Africa, there are some who have found support in groupings such as the Treatment Action Campaign (TAC), a national activist group fighting for universal access to AIDS drug treatment. The TAC seeks, among other things, to raise awareness of the way in which stigma and social inequalities increase people's vulnerability to HIV/AIDS and undermine their ability to cope with its ravages.

In our rural study community, a group of unpaid women had come together to form a group of

community health volunteers, who worked with dedication and selflessness to help the most desperate AIDS-affected households—often walking hours in searing heat from one homestead to another to render assistance, often of the most menial form, cleaning soiled bodies and bedding and collecting wood and water for suffering families. These women were always ready to offer assistance, kindness and consolation—despite the fact that they sometimes received a hostile reception from families unwilling to admit that they had an AIDS sufferer in their home.

Furthermore, some of the non-infected people we spoke to, while confessing that they engaged in stigmatizing thoughts or behaviours, said that they realized that this behaviour was wrong, and said that they would be open to learning more about HIV and AIDS in the interests of improving their attitudes.

### *Impact of stigma on HIV/AIDS management*

Stigma is one of the biggest factors undermining prevention as well as care. A key determinant of effective HIV-prevention and AIDS-care is the existence of a humane and supportive environment for people with AIDS (Ogden & Nyblade, 2005).

In relation to HIV-prevention, people living in a context where they see people with HIV/AIDS being treated with kindness and care are far more likely to acknowledge their vulnerability, to seek out information about how to protect themselves or go for voluntary counselling and testing and to take precautions in their sexual relationships. Stigma serves as a strong deterrent to young people seeking individual HIV/AIDS-related counselling at a local centre, or attending community outreach meetings: 'We call outreach meetings, but youth don't come in big numbers. They fear if their parents see them at such meetings they will want to know why they feel they need to attend them' (Youth worker). Many spoke of the way in which churches actively undermined HIV-prevention, with one NGO worker reporting how a church minister threatened any youth attending a life skills meeting—dealing with sexual health issues—with expulsion from his congregation. Peer educators spoke of negative responses to their attempts to set up a programme in one school, where the school principal described their attempts to talk openly about safer sex as 'pornography'.

Stigma is also a major obstacle to appropriate AIDS-care:

Families hide the person away from the community once they discover they have AIDS. They take him away from the community and we end up not knowing what has happened to that person. They don't even allow him or her to go to the clinic or to seek out any help at all. (Young woman, youth leader)

Community health workers said it was often hard to get people to apply for AIDS grants when they are reluctant to disclose their status. Furthermore while antiretroviral drugs are still not widely available in either of our study sites, many people speculated that stigma would deter some people from coming forward to ask for them once the roll-out of drug treatment took place.

Stigma also greatly reduces access to social support networks. When a person is sick and depressed, as people with AIDS often are, it is important to feel supported, loved and respected. Social isolation can undermine people's immune systems and their ability to fight the ravages of AIDS, intensifying their suffering and shortening their lives. Sadly stigma deprives millions of people of this support. Many spoke of relatives who were scared to look after AIDS patients: 'There are patients who are alone at home with no one to feed them. Their relatives run away from their sickness and they are left alone' (Clinic sister). Community health workers spoke of how difficult it was to care for and advise a patient who did not disclose:

We can't take the liberty of assuming that someone has AIDS if they haven't even opened up to their family members—no matter how much we suspect this is the case. This makes it difficult to follow the correct procedures when we are caring for them. (Volunteer health worker)

## **Part two: a six-factor model of the roots of stigma**

Below we highlight the complex interplay of factors involved in the stigmatization of PLWHAs in our study communities. As stated earlier, our starting assumption is that stigma is rooted in universal unconscious fears, with the shape of these fears being influenced by particular aspects of people's social environments—at both community and macro-social levels. We begin with a brief outline of Joffe/Klein's account of the psychodynamics of projection and 'othering', before highlighting five inter-linked aspects of people's social environments

which make people with HIV/AIDS such a potent target for stigma in our study context.

### *Fear*

As discussed earlier, human beings respond to anxiety-provoking risks through the unconscious process of projective identification (Klein, 1946). This intra-psychic mechanism involves projecting the fears aroused by the general uncertainty of the human condition, coupled with the threat of particular risks and dangers (such as HIV/AIDS), onto identifiable out-groups. Members of these out-groups are then subjected to various forms of exclusion or discrimination. This process of 'othering' produces feelings of comfort and security in the stigmatizer, as well as a sense of psychological distance from a risk, which may otherwise seem overwhelming. In this way the stigmatization of PLWHAs serves to give others a degree of psychological invulnerability in the face of their daily experiences of AIDS-related suffering and death—in a context where many people continue to have unprotected sex. These feelings of invulnerability decrease people's chances of taking precautions against HIV/AIDS, and thus serve as a key obstacle to HIV-prevention efforts. Furthermore, the associated discrimination against people with AIDS and their families causes great misery and undermines the likelihood of their receiving optimal care and support.

Below we highlight context specific factors that make PLWHAs such a potent target for stigma, and some of the community and macro-social dynamics which shape people's negative psychological responses to them.

### *Information*

The first factor relates to the availability of information about HIV/AIDS. Several study informants commented that stigma was caused by ignorance, saying that people discriminated against those with HIV/AIDS because they incorrectly thought that the disease could be passed on by casual contact (e.g. sharing plates, or sitting next to someone in a taxi):

People have strange perceptions that they can contract this disease from even coming near an infected person. (Married woman)

It's a shameful thing to have AIDS in this community. I think they would make a big gap between my desk and other learners' desks at school. (Male high school learner)

They repeatedly said the solution to stigma was to give people more information about HIV/AIDS transmission and prevention.

However, as discussed earlier, giving people factual information about the contagiousness of illnesses is not enough to lead to widespread stigma reduction. Furthermore, our interviews suggested that while some people lacked information, most had basic factual information about HIV/AIDS—even in the remote rural area where people had limited access to television or radio, where little HIV/AIDS awareness work had been done and where poor roads and unaffordable transport limited people's contact with the outside world. Despite the random and piecemeal nature of people's information sources, they tended to have a fair grasp of the basic facts about HIV/AIDS (sexually transmitted; no accessible cure; abstinence, faithfulness and condoms as prevention measures).

However it was clear that many experienced this information as quite alien. Despite having grasped basic factual information about HIV/AIDS, people battled to 'translate' this information in ways that made sense to them. Thus for example one young man expressed great fear and uncertainty about the claim that condoms would protect his sexual health, in the context of his belief (commonly held in his community) that the lubricant in condoms (which looks like tiny 'worms' when a condom is filled with water) was in fact the HIV virus, implanted in condoms by malicious supporters of the old apartheid regime seeking to kill black South Africans:

There is no one here who is qualified to help us address our concerns about the worms in the condoms. We need people who can help us in terms of giving us correct information. How do they make these condoms? What materials do they use to make them? (Male high school learner)

Various factors undermine the likelihood that people will be able to translate 'information' into terms or action plans that make sense in the wider contexts of their lives.

*Competing beliefs* Some people had difficulty in acting on HIV/AIDS information because it competed with other important beliefs. Prominent among these was the belief, linked to traditional African cosmology, that HIV/AIDS was caused by witchcraft, and more particularly the bewitching of the sufferer by someone who was jealous of them:

If an improving household has a sick member, they go to the traditional healer who tells them that they have

been bewitched by a neighbour who is jealous of their (economic or educational) success. (Young man)

Accusations of witchcraft fly around easily in a remote community such as ours. There is little trust around here, and old enmities are quick to flare up, and this is often the case when someone has HIV/AIDS. (Male high school learner)

Some people did not believe in the traditional healers' explanations, saying that such explanations served as a convenient smokescreen for denial of the problem:

People find it easier to say they are suffering from evil spirits than to say they have HIV/AIDS. (Adult man)

Saying that a person has HIV/AIDS is a shame to the community as a whole. It sounds better to say they have been bewitched. (Adult woman)

*Lack of power to translate information into action* Some informants simply lacked the power to translate information into action. Thus for example rural women commented on the complete impossibility of using condoms with their husbands, even when husbands had many extra-marital relationships:

If we suggested condoms to our husbands, we would be chased away from our homes. They say they have a right to sex because they paid cattle (bride-price) for us. As a result they can demand anything from us and we have to oblige. If we refuse they will report us to our parents, and the old people will support our husbands, saying to us: 'Ha, we never heard of such behaviour.' (Rural woman)

We know our husbands have affairs, and some of us even suspect our husbands are HIV-positive, but we can't suggest a condom. Sometimes it feels like a living death to be a woman in this situation, we are dying whilst we are alive, we feel as if we commit suicide every time we have sex, yet we can't do anything because we are married. (Rural woman)

This point is taken up later in our discussion of the link between HIV/AIDS stigma and the stigmatization of sex.

### *Lack of social spaces to talk about HIV/AIDS*

Clearly the provision of basic information about HIV/AIDS and its methods of transmission is an important first step towards stigma-reducing social change, but on its own it is unlikely to have much impact. Our work suggests that what people lack is

not always information, but rather social spaces in which they feel safe to discuss this information.

Low-Beer and Stoneburner (2004) argue that one key reason for the relative success of the HIV/AIDS struggle in Uganda, as compared to countries such as South Africa, is that significantly more Ugandans have heard about AIDS through a personal network than South Africans, who are more likely to have heard about it through an impersonal source such as the media. Rather than more didactic information programmes, there is an urgent need for participatory initiatives that provide people with the opportunities to discuss the information that they have, to work through collectively their doubts about its truth and relevance in their own lives and to engage in dialogue about the extent to which it is possible for them to change their behaviour or attitudes in the light of this information. Such initiatives should provide people with the opportunities to discuss AIDS with trusted peers, and to work towards feeling safe enough to discuss it in their families and communities. Such discussions form the building blocks of 'critical thinking', which we will discuss at length later. This involves the transition from a state where people see themselves as helpless victims, in favour of being able to define the world in an actionable way, and to develop the confidence to engage in action to create a healthier social environment (Cornish, 2006).

### *Link between HIV, sex and sexual morality*

The psychological processes of 'othering' that drive stigma may often reflect wider social interests and power relations (Link & Phelan, 2001). Various forms of stigma act to reinforce other forms of social exclusion and inequality such as poverty, racism and religious conflict (Parker & Aggleton, 2003). As such, stigma often serves to legitimize already existing power inequalities—playing what Jost and Banaji (1994) call a 'system justifying function'. Our findings highlight the link between HIV and a conservative sexual morality closely linked to the control of women and young people by adult men (see Campbell et al., 2005).

The most potent determinant of stigma seemed to be its sexual nature. In our study communities, sex and sexual relations were regarded as something shameful, not to be mentioned or discussed:

This disease is still considered shameful because people fear others will look down on them and say they have been sleeping around. Because of this



fear, there are some that don't disclose their status, even to family members. It becomes their secret. (Community health worker)

The stigmatization of sex was particularly marked in relation to the sexuality of young people and women. People repeatedly spoke of adult refusal to acknowledge the existence of youth sexuality, of parental refusal to discuss sex or sexual health with their children:

This is a very conservative community, where parents simply don't talk to children. Parents don't even try to talk to their children about sexual health, or anything involving sex, because they switch off the TV when something about sexual issues comes up. (Young man)

There is an incredibly strong resistance by parents to facing up to reality of youth sexuality, even in the context of a deadly sexual epidemic which is killing youth in their thousands:

No one will talk about condoms here because they don't expect young people to have sex. (Female high school learner)

Our parents say that this is their culture not to talk about sex—and that they can't change it. (Young man)

Young people are most likely to protect their sexual health in social settings where adults feel comfortable talking about sex (Aggleton & Campbell, 2000). In our study communities, many adults showed a strong unwillingness to acknowledge their children were sexually active. Such a context excludes the possibility that parents might provide a supportive context for the promotion of safer sexual behaviour by young people. Some of the more frank adults in our sample wryly commented that this adult posturing was unconvincing, given that sexual activity among young people had always been common:

If AIDS had been around when I was growing up, it would have spread as it spreads today. We had many girlfriends. Not two or three, but more than 10. We have no right to blame young people by saying they are not behaving themselves. (Father in his early 40s)

As discussed in an earlier article, this adult refusal to face up to the reality of young people's sexual lives, and their failure to respect young people's rights to protect their sexual health is part and parcel of the wider political, social and economic exclusion of young people in South African society (Campbell, Foulis, Maimane, & Sibiya, 2004). Many young

people don't receive effective care and support from their families. Negative images of youth as 'mad, bad or deviant' were common in our interviews. The fight for greater respect and recognition of young people's sexuality and their right to protect their sexual health needs to go hand in hand with efforts to promote their social and political participation, increase opportunities for their economic empowerment and challenge negative social representations of youth.

This denial of young persons' sexual desire and relationships was particularly strong in relation to young women. They said the sex education they received from their mothers was not useful, given that they were often already sexually active and keen to know how to protect themselves from STIs and pregnancy. Sex education from mothers often consisted of little more than veiled and cryptic comments that young women should avoid sex at all costs to avoid 'destroying' their lives. This denial of young girls' sexuality is related to the more general blaming of women that the epidemic has provoked in sub-Saharan Africa (Joffe & Begetta, 2003; Leclerc-Madlala, 2002). Many of our informants said the epidemic was caused by women who were too weak or immoral to refuse sexual intercourse outside of monogamous marriage. Within this context, it is not surprising that many girls sought to hide their sexual activities, and were reluctant to be seen to be seeking out information about sexual health or to carry condoms.

The denial of young girls' sexual rights was mirrored in the lack of respect for adult women's sexual autonomy, particularly in our rural study. We have already referred to rural women's claims that they had no power to influence any aspect of their sexual relationship with their husbands because *lobola* (bride-price) had been paid for them:

When having sex I always pray to God to be with me because I am at risk. Quietly I say, 'You see me Lord, I don't have a way to refuse or run away!!' I don't even enjoy what I am doing. I just continue praying until we finish having sex. (Church women's group leader)

Stigma feeds on, and in turn reproduces, wider patterns of social disadvantage facing women and youth. Adult restrictions on the sexuality of young people have long been a feature of adult control. Male restrictions on the women's sexuality have long been a feature of male power over women. The power of adults and men has long been supported by various overlapping systems of authority, the

church being one such system, and the traditional leadership system being another.

The shame associated with sexuality has historically been one of the mechanisms that motivated youth and women to conduct sexual relationships in secret. In Foucault's (1980) terms, they 'policed' their own behaviour in ways that maintained the appearance of adult and male control—reinforcing the confidence and social status of men and adults. However, the arrival of the HIV/AIDS epidemic makes it increasingly impossible for HIV-positive youth and women to disguise the fact that they have been sexually active. In such a situation, stigma is part of a conservative reassertion of power relations, as well as a public reinforcement of social institutions whose moral authority rested on their ability to control sexuality, or at least on the appearance of such control. In such a context, the stigmatization of PLWHAs serves as a social mechanism for highlighting the deadly punishment for youth or women who have dared to challenge the traditional control of adults and men (Campbell et al., 2005).

### *Lack of HIV/AIDS management services*

Many studies have found that the stigmatization of AIDS is worst when there is a shortage of resources, particularly money and services (Bond, Chase, & Aggleton, 2002). Human beings are most likely to extend compassion to the sick and dying when there are sufficient or surplus resources (Orr & Patient, 2003). Later we discuss the link between poverty and stigma. In this section we discuss the lack of health and welfare resources in our two study communities.

**AIDS-care** The fear of HIV/AIDS may be particularly acute in contexts where adequate health services are not available. In our rural area, this problem was particularly acute. The community had a mobile clinic, which visited the area once a month. Hospitals were some distance away. In emergencies, it would cost local people around R300 (£30) for transport to the hospital and many families did not have access to this kind of money. Furthermore, even if people managed to raise the money to get a seriously ill AIDS patient to hospital, a shortage of hospital beds in both urban and rural settings meant they were seldom admitted, and were rather simply treated and sent home again no matter how sick they were.

The cost of transport also limited the ability of poor people to visit welfare offices to apply for grants for PLWHAs or orphans. Those who did manage to get to

the offices were often turned away because of lack of appropriate documentation (a particular problem in a remote rural area where many people could not read or write), and could not afford to go back again.

Even in our peri-urban area, which was less geographically isolated, people commented regretfully on the shortcomings of government services for HIV-prevention and AIDS-care. Hospital treatment was limited, people often lacked the money to pay for medication for opportunistic infections, and delays in welfare grants for people with advanced AIDS were such that they often only arrived after the patient was dead:

Hospitals often don't do proper counselling when they tell people they have AIDS, the nurses are badly trained, many are not dedicated. The nurses must stop calling people names, give them love so that their family members will also accept them. (Health worker)

In both our peri-urban and rural sites, potential health and welfare service users spoke of gaps in government services and of incompetent or unsympathetic local government employees. From the service provider perspective, many public sector workers such as nurses and social workers felt that they had to work under challenging and under-resourced conditions often lacking appropriate HIV/AIDS-related training to inform them in their contact with PLWHAs. They said that resource constraints prevented them from providing adequate support to PLWHAs.

Research conducted elsewhere in Africa has found that health workers are most likely to mistreat patients when there are limited resources available for their care, suggesting that such a situation leads health workers to feel powerless and ineffectual, and to take out the associated anxiety on their patients (Deacon et al., 2005).

In our peri-urban area, both the school principal and the clinic director said they were puzzled by frequent media publicity highlighting the availability of government funds for HIV/AIDS management, saying that such resources had never materialized at their schools or clinics. People also remarked on poor networking between different health and welfare departments, professionals and NGOs involved in caring for PLWHAs.

People were confused about how long it would take before antiretroviral (ARV) treatment was widely available, and desperately longed for this to be hastened. It is increasingly common to hear arguments

that the provision of free and accessible medical treatment for PLWHAs will contribute to the end of stigma (e.g. Castro & Farmer, 2005). Clearly one dimension of the fear and denial surrounding HIV/AIDS is linked to its incurable status for those who do not have access to drugs. The availability of drugs will make a significant contribution to providing support and humanity to people with AIDS, and to fighting stigma. However our findings suggest that treatment will not, on its own, be enough to eliminate stigma. Even after treatment is available and HIV/AIDS is no longer fatal, the link between HIV/AIDS and 'bad (= sexual) behaviour' will still exist in ways that associate the disease with shame and embarrassment. In the absence of initiatives to tackle stigmatization of sex, the potential impact of treatment on stigma will be reduced.

*HIV-prevention* The lack of adequate resources and infrastructure often went hand in hand with lack of action within schools, despite the fact that many pupils would have been infected or affected by AIDS. In our rural study community, both the school principal and teachers said that they did not regard HIV-awareness as a high priority because of the conservative nature of the community, steeped in cultural restrictions around sexuality, including practices such as virginity testing. They said that such restrictions hindered young people from sexual activities. Opposed to this, in our study both male and female learners in these very schools spoke openly about having unprotected sex in a way that suggested how out of touch the principal and teachers were with the realities of their pupils' lives. As one schoolboy told us: 'young people regard sex as a necessity these days'.

In sharp contrast to his rural counterpart, the school principal in our peri-urban study community fully acknowledged the negative impact of HIV/AIDS on his pupils, estimating that up to half his pupils might be infected. However, he said that despite his compassion for affected pupils, his school did not have the resources or time to take any action in relation to AIDS. It could not take up a problem of this magnitude without counselling and welfare backup, which was simply not available.

### *Poverty*

You can't blame the family for stigmatizing the sick ... your child gets thinner and sicker, yet suddenly refuses the porridge you make for her, asking for

expensive things like meat or an apple that the clinic has told them to eat. The question you ask is, 'Where am I going to find money to buy all these things you demand?' You end up getting angry—and it looks like you are stigmatizing her. (Adult woman)

Orr and Patient (2003) argue that in conditions of poverty, people will often reject others who are already, or soon to become, non-productive and non-contributing members of the community. We have already said how much research has shown that the stigmatization of people with AIDS is the most acute in conditions of poverty, especially within families. The burden of caring for a person with AIDS almost always falls on women—who are generally already burdened with multiple household, family and child/elderly caring responsibilities before the demands of the AIDS patient kick in. They often lack knowledge about how to deliver effective care, and end up suffering from physical and emotional burnout and exhaustion. In conditions of poverty, the additional burden of caring for a dying person, who may, for example, have diarrhoea up to 15 times a day in a homestead with no bedding, and where water may have to be carried from some distance away, may be almost unbearable—particularly in the absence of any support or assistance from any kind of health or welfare services. Furthermore, the costs of caring for an AIDS patient may sometimes cripple already poverty-stricken households. This situation may sometimes (although certainly not always) lead to bitterness and resentment against the patient, and an anger that 'they brought this sickness on themselves by their bad behaviour'.

This is why a vital component of fighting stigma is to mobilize local communities (neighbours, friends, volunteers) to assist carers—and also to fight for carers and patients to access whatever grants, health and welfare services and assistance is available. It is also vital that carers are provided with knowledge and skills about AIDS and how best to care for an AIDS patient, and with necessary equipment for home nursing (gloves and so on).

Poverty also exacerbates stigma in a more indirect and complex psychological way. In our study communities, networks of older women constituted the pillars of community survival, united by their commitment to 'respectability'. It was these women who often held struggling communities together—emotionally, financially and practically. According to social identity theory, human beings have a fundamental need for positive self-esteem, which they

achieve by making favourable comparisons between themselves and others (Hogg & Abrams, 1988). Two forms of 'social competition' lie at the basis of these comparisons. Objective competition (competition for material resources, e.g. money) and subjective competition (competition for symbolic resources, such as respect or recognition).

In our study communities, sex and alcohol use constituted two key ways in which a person's respectability might be compromised. In the context of poverty and disempowerment, many lack access to the conventional social advantages of a highly materialistic society (e.g. expensive clothes or television sets) and thus to those objective resources that might boost their self-esteem. Symbolic resources—such as respectability—come to constitute valuable currency in individuals' efforts to enhance their self-esteem. For many, a vigorous 'othering' of PLWHAs becomes one way of asserting one's respectability (Campbell et al., 2005).

## Conclusion

Psychological studies of stigma have tended to focus on cognitive properties of the conscious rational individual, with little attention to the way in which cognitions are shaped by factors at the unconscious, community and macro-social levels of analysis. The six-factor model we have presented above seeks to address this gap. In this final section we discuss the implications of our model for stigma-reduction interventions.

Our study highlights some of the complex reasons why the provision of factual information about HIV/AIDS is a necessary but not sufficient condition for banishing stigma. Given the complex and multi-layered array of factors feeding into HIV/AIDS stigma, it needs to be tackled at a number of levels in addition to the level of health education.

Much has been written about the need for various 'top-down' interventions to address stigma, including programmes to fight for the legal protection of PLWHAs within a human rights framework, and large-scale poverty relief (Parker & Aggleton, 2003). We fully agree that such interventions would make a significant contribution to the reduction of AIDS stigma. However, the challenges of reducing poverty and promoting human rights in sub-Saharan Africa have long been pursued with varying degrees of success by a range of actors and agencies of various stripes, and are unlikely to be met in time to help the millions of people currently living with HIV/AIDS.

Furthermore our data suggest that without parallel 'bottom-up' efforts to address stigma, such 'top-down' efforts may have limited success. This is because of the embeddedness of stigma in collectively negotiated social representations and practices which are constructed, reconstructed, reproduced or challenged in the ongoing interactions of communities of peers going about their lives on a day-to-day basis. Immediate efforts to tackle stigma need to build on communities' own understandings of the problem, and on solutions formulated by the very people who are at the frontline of perpetuating and/or suffering from stigma. (Furthermore, as will be discussed later, in ideal circumstances, mobilizing grassroots people against HIV/AIDS stigma could provide a platform from which marginalized people might start to formulate and articulate their demands for wider social changes linked to poverty reduction and the promotion of human rights.)

The starting point of facilitating local community responses to stigma would involve the provision of social spaces in which people felt safe to discuss the often literally 'unspeakable' topic of HIV/AIDS. Such spaces would ideally provide contexts within which people could collectively work through their doubts and uncertainties about this new and still unfamiliar disease and its relevance to their own lives. Through a process of dialogue they would ideally work to make this information relevant to their own lives—by processing the information in ways that are compatible with their own pre-existing frames of reference, vocabularies and social practices. Such work would usually best be done in single-sex groups, where participants are matched as much as possible in terms of age, given the role that inequalities in age and gender have played in fuelling the epidemic and undermining effective responses.

In this regard, we believe that Freire's (1970, 1973) concept of critical thinking has much to offer anti-stigma activists. According to Freire, critical thinking is the dialogical process through which a group of people develop an understanding of the social roots of particular problems they are facing, and actively work together to develop and implement strategies for alleviating the negative impacts of these social forces.

Such Freirian ideals are increasingly emerging in HIV/AIDS management plans across the world. One particularly clear implementation of these ideas lies in the United Nations Development Programme's (UNDP) 'Community Conversations' approach in Ethiopia (UNDP, 2004). This method

involves training local facilitators to facilitate small group discussions in which people can identify the problem of HIV/AIDS in terms that make sense to them, as well as identifying their own solutions. Aided by trained local facilitators, such groups provide contexts in which people can talk openly about taboo topics, often for the first time; identify their own norms and values that are fuelling the epidemic; delve into the deep and sometimes uncomfortable issues relating to sex and death which permeate people's responses to the epidemic; and brainstorm the way in which local community networks can be mobilized to create more 'health-enabling' social attitudes and social environments.

The UNDP argues that gains achieved in these groups are amplified by 'resonance', a concept akin to Rogers' (1983) 'social diffusion', where group participants share lessons with other community members not present in the groups. More ambitiously, over time, these community group 'conversations' would ideally become a platform for the voices of socially excluded people—women, young people, the poor—which would be channelled into shaping the activities of local HIV/AIDS management efforts by government, NGOs or other branches of civil society. Ideally, these voices would also eventually be channelled into wider networks of local and national governance, enabling the views and needs of marginalized groupings to be transmitted to more powerful policy and decision-makers outside of the immediate community.

Such needs and views would hopefully include demands for the types of poverty relief and effective human rights legislation referred to above. To quote Bulhan 'power is never conceded without a demand' (cited in Seedat, 2001, p. 17). Social elites, be they men, the affluent or adults, seldom voluntarily cede access to power or wealth, without a vigorous demand from socially excluded groups. Large-scale changes in the social hierarchies that fuel the spread of HIV and the suffering of people with AIDS are unlikely to occur in the absence of forceful demands from below. In this regard, we see the provision of social spaces for critical dialogue as a small stepping stone in the long-term challenge of building youth and women's and poor people's capacity to articulate their needs and interests in the wider societies in which they live (Alinsky, 1973; Wieck, 1984).

In order to be optimally effective, the facilitation of social spaces should aim to promote four processes. The first of these is a critical awareness of the social roots of stigma (including an understanding of the

role played by both macro-social and local community environments), and of the way in which AIDS stigma undermines effective HIV-prevention and AIDS-care, significantly weakening the solidarity and social support needed for an effective response to the epidemic. Here it might be useful to generate debate about the way in which stigma fuels the fear that facilitates the epidemic—with many people too frightened to seek out information about how to protect their sexual health, or to find out about their HIV status, because they see the cruel way in which many people with HIV are treated in the community. A key aspect of the fight against HIV transmission needs to be the creation of social contexts where people with AIDS are treated with care, love and respect.

The second of these is to work with community members to identify key individual and group strengths available as community resources to tackle HIV/AIDS more effectively. In deprived communities, where people are often not able to solve the many problems that face them, some people may start to believe that all problems are overwhelming and insoluble, thinking of their problems within the framework of 'problem-based stories', which spell out the multi-layered obstacles to any solution (Boal, 1974). These are stories in which the actors have no agency or power to address the problem, and in which they portray themselves as helpless and pathetic victims of forces beyond their control.

Against such a background it is sometimes useful to discuss problems in group contexts, in ways that help people identify individual or collective strengths and abilities that may have been masked by life problems (Sliep, Weingarten, & Gilbert, 2004). A key challenge facing communities is to identify and name problems and their causes, and also to identify individual and collective strengths. Putting people in touch with their individual and collective strengths is a key strategy for mobilizing them to take on the challenges posed by a problem as complex as stigma. Such strengths might include the tremendous love and sacrifice involved in helping people with HIV/AIDS in some families. They might also include the kindness, dedication and courage of volunteer community health workers—with group facilitators working with participants to identify ways in which local people might create networks of support for volunteers and their work.

The third process that would need to be facilitated in community conversation workshops would be a sense of 'community ownership' of the problem,

and a sense of personal incentive for tackling the problem—rather than a distancing strategy that locates HIV/AIDS in a stigmatized out-group. This is most likely to happen through promoting a sense of identification between community members and those who are suffering from HIV/AIDS, and a sense of how vulnerable each and every individual and family in the community is to the risk of HIV infection.

One approach might be for group facilitators to generate discussion of the indisputable fact that few families in the country are unaffected by HIV/AIDS in a context where at least one in five adults is infected. Even if participants are not aware of such a family member at the time of the workshop, workshops might emphasize that at some stage participants' family members may also become directly affected by HIV/AIDS—and for this reason they have a direct interest in ensuring that proper support systems are in place for those who do need help.

The fourth process to be facilitated in such community dialogues involves working with participants to think creatively about forming links with organizations outside the community that might assist them in managing HIV/AIDS more effectively. Much research has shown that community-led anti-stigma interventions are most likely to work when there is collaboration and networking between community-based organizations, the public sector (especially health and welfare) and the private sector (business and workplaces and so on) (Deacon et al., 2005). Collaboration between multiple anti-stigma efforts will often have the potential to lead to a more effective response. There are growing moves to promote anti-stigma programmes in health and NGO and workplace settings in South Africa, for example. Frontline health and welfare workers are increasingly calling for more expert guidance and training on the most constructive way to fill their complex roles in relation to HIV/AIDS.

Ideally facilitators of community dialogues would also work with participants to identify possible support organizations such as the Treatment Action Campaign, which fights directly for the rights and needs of PLWHAs at the national level; and organizations aiming to promote the empowerment of women, youth and the poor—groups who are all disproportionately affected by both the stigmatization of sex and the stigmatization of HIV/AIDS.

In this section of the article we have provided abstract guidelines that we believe should inform stigma-reduction interventions. We are currently implementing these guidelines in our rural study

site, in the form of a programme seeking to promote 'AIDS competence', through facilitating the development of capacity, resources and partnerships to strengthen local community responses to HIV/AIDS (Campbell et al., 2007). This programme is still in its infancy, and we hope to report on concrete ways in which programme partners have sought to implement these principles in future articles.

Given its embeddedness in deeply rooted psychological and structural processes the challenge of fighting stigma is a strong one. Anti-stigma programmes carefully informed by the meticulously 'bottom-up' approach laid out earlier, could make a key contribution to meeting this challenge. Facilitating awareness of the causes and consequences of stigma could serve as one useful stepping stone for empowering individuals and local communities to start thinking of ways in which they can contribute towards the challenge of creating nurturing social environments. Environments in which people affected by HIV/AIDS are treated with love and humanity—in the first instance in people's own immediate communities, with this work ideally coming to form the building blocks for greater grassroots involvement in wider social advocacy for social change.

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## Author biographies

CATHERINE CAMPBELL is Professor in Social Psychology at the LSE, where she is Director of the MSc in Health, Community and Development. She is author of *Letting them die: Why HIV/AIDS prevention programmes fail* (2003).

YUGI NAIR is Senior Researcher at the Centre for HIV/AIDS Networking at the University of KwaZulu-Natal (HIVAN). She is also Co-director of the Community Responses to AIDS Project, serving as external change agent on a community-led social development project.

SBONGILE MAIMANE is Fieldwork Co-ordinator at the Centre for HIV/AIDS Networking at the University of KwaZulu-Natal (HIVAN), and manages fieldwork and community liaison on the Community Responses to AIDS Project.

JILLIAN NICHOLSON is an independent consultant based in Durban. Having worked for many years as a trainer and social researcher, she now specializes in making academic research accessible to non-academic audiences.