

## CHAPTER FOUR

### SECRETS: REVEALING AND CONCEALING AIDS

Personally, I don't know anybody who has died of Aids (...) I really, honestly don't (President Thabo Mbeki in an interview with the Washington Post; Robinson & Tabane 2007).

According to my view I do not see anyone who has AIDS in this village

He is right because a person who is HIV positive is just like you or me – they do not have AIDS.

Our problem is that we have seen people dying, but they are hiding. They are not saying that he or she was killed by AIDS, but that they are killed by this or that.

AIDS is a big problem but people are not open. You can read what is happening...you can see what is happening, a number of people die in the same way and show the symptoms of AIDS but people can't say it is AIDS. I have seen a number of people dying the same way. There are about four – some are ill and I suspect it is AIDS. But you can't tell that that person is dying from AIDS.

(Members of the KwaBomba HIV/AIDS Youth Committee in a group discussion, April 2002)

Former president Thabo Mbeki and my youthful informants quoted above articulated similar uncertainties about AIDS. However, while Mbeki's position on AIDS can be interpreted as a challenge to the racist casting of AIDS as an affliction of unbridled African sexuality, the youths I quote allude to another set of concerns. They note the paradox of the invisibility of the disease in the presence of the obvious and rising rates of morbidity and mortality<sup>1</sup>. As they observe, HIV is not only invisible, but the

epidemic itself is surrounded by excessive secrecy and avoidance. For them, AIDS has an ephemeral character; it is omnipresent but hidden under layers of secrecy, coded talk and metaphor. Many of the ways of talking about AIDS in public and private settings are coded (Lambert & Wood 2005), or communicated in other ways, such as song (Lwanda 2003).

In this chapter I explore the reasons for the secrecy and concealment that surrounds the AIDS epidemic. Public health messaging and AIDS activists make repeated calls for people to test for HIV, to reveal their status, and to be open about the disease. Secrecy and concealment are regarded as barriers to effectively combatting the spread of HIV. Yet in spite of the massive investments to ‘break the silence’ this continues to characterise the public response.

In the AIDS literature, concealment is a ‘barrier to behaviour change’ and ‘silence is equal to death’. Challenging concealment or ‘breaking the silence’ (the catch phrase of the 2000 International AIDS Conference) has become a ‘global *leitmotiv*’ in AIDS awareness campaigns and marketing (Schneider & Fassin 2002, S46). The predominantly urban based activist group, the Treatment Action Campaign (TAC), subvert silence, adorning brightly coloured t-shirts declaring the words ‘HIV Positive’. At AIDS rituals, HIV positive participants bravely disclose their status and are loudly applauded<sup>2</sup>. The metaphors, rumours and concealed talk about AIDS are vehemently condemned as misinformation, myth, denial and avoidance, and a reason for the continued stigma of AIDS.

Despite the loudness of the voices calling for people to break the silence and overcome stigma, AIDS is extremely difficult to talk about in a direct way and therefore

is hard to act against<sup>3</sup>. Part of the reason for this response is that many South Africans are simply unaware of their HIV status. Government voluntary counselling and testing services launched in public health services expand access to testing, yet many infected people only test for HIV antibodies once they become sick or even terminally ill.

In the literature, disclosure of HIV status is regarded as a positive affirmation of having the disease and also part of the process of healing, a liberation from the burden of secrecy and shame, reducing stress and assisting in coping with a positive sero-status (See for example: Almeleh 2004; Paxton 2002). There has also been some mention in the literature of the subjective experiences of HIV testing; in Australia as a symbolic reinforcement of self (Lupton et al. 1995), as a ritual of regenerative confession in the US (Sheon 1999), and as type of moral regeneration in the setting of a clinical trial in Soweto, South Africa (Stadler et al. 2008). In these cases, the HIV test reinforced perceptions of the healthy self and transformed the way in which HIV and AIDS was conceptualised. Adopting a broader socio-political focus, Robins' (2006) accounts of AIDS sufferers who are placed onto effective treatment regimens of ARV highlights their transformative experiences and their newly forged identities as AIDS activists and 'responsibilised citizens'.

The early diagnosis of HIV infection has material benefits for patients in facilitating access to care, and preventing the further spread of HIV. Despite this common sense, many of those I interviewed were disinclined to be tested for HIV and preferred to wait and see if they were infected by monitoring their own health status. Others used proxy measures of their own status, for example the health of a sexual partner or new born child. As a result patients often arrived seeking care when they were critically ill,

resulting in extremely poor prognoses for recovery. Those who did test seldom collected their results<sup>4</sup>.

Ironically, South African public health policy reinforces the concealment of HIV. Following a bioethical tradition that is founded on an individual rights-based approach, AIDS is not a notifiable disease (unlike tuberculosis); efforts to make it so were strongly, and successfully resisted by NGOs and community groups in the late 1990s (Sidley 1999). Unlike the situation in countries such as Cuba where AIDS is handled as a public health emergency (Scheper-Hughes 1994), the protection of individual autonomy and the right to privacy is of paramount importance to the ethics of HIV/AIDS (Robins 2006).

I suggest that the silence and concealment of AIDS may be usefully understood as ‘cultural censorship’ (Sheriff 2000). Cultural censorship implies that silence about a particular issue are ‘socially shared’ and the ‘rules of its observance are culturally codified’. ‘Unlike the activity of speech, which does not require more than a single actor, silence demands collaboration and the tacit communal understandings that such collaboration presupposes’ (Sheriff 2000, 114). Cultural censorship is distinct from ‘political’ and ‘self-censorship’ by its social and customary nature. Yet, as Sheriff points out, silence is informative, perhaps more so than that which is verbalised. Leap (1995) observes the uses of silence in conversations about AIDS as a way of conveying information:

Sometimes, when AIDS is the topic under discussion, people explore their thoughts and feelings in great verbal detail; other times, they make their thoughts and feelings known by saying nothing at all. All discussions of AIDS are rule-governed speech events (Leap 1995, 227-228)<sup>5</sup>.

Along these lines I suggest that secrecy and concealment can be revealing acts, or performances, that offer visual and verbal clues as to that which they seek to hide. The act of withholding information reveals at the same time as it attempts to conceal; secrecy itself is a form of communication that imparts information. Therefore the censorship of the cause of illness and death can never be complete.

It is also often assumed that the secrecy of AIDS owes itself to the shame associated with the sexual cause of its spread. While, talking about sex is governed by rules of etiquette and respect, it is not the association between AIDS and sex, but with death that results in fear and avoidance. The construction of AIDS as a deadly disease, early in the epidemic created a lasting impression and generated much fear and avoidance. The association of AIDS with death imparts symbolic power to the act of naming the disease. Words are regarded as powerful in their capacity to concretise concepts, to call them into being<sup>6</sup>. This explains the avoidance of the terms ‘HIV and AIDS’, and the fears associated with biomedical testing procedures for HIV.

The identification of illness and death as due to AIDS also threatens social relations and identities by exposing causal pathways of blame. As Setel (1999, 103) writes: ‘the emerging AIDS epidemic was like turning on the lights in a room long kept intentionally dark’. AIDS as a disease not only threatens to expose secret sexual relationships, it also creates the atmosphere of blame and the prospect for revenge. And within the context of the funeral it threatens to declare this in public. The disease and its pronouncement have the potential to foreground the deadly networks that connect people and transmit the virus. A public announcement of death from AIDS raises questions of culpability and promotes blame. Therefore, to borrow McNeill’s phrasing (2009, 368),

silence can be regarded as a ‘safety precaution’ or a ‘protest of innocence’ ‘against the constant threat of guilt by association’.

The concealment of the AIDS body raises somewhat different concerns from the censorship of AIDS talk. Concealment is integral to the performance of suffering from AIDS. This is due to in part the physical effect of the disease on the body and the ways in which this is interpreted. The AIDS body evokes horror and repugnance. Narratives about the effect of the disease on the corporeal body highlight the inner decay that threatens to burst through the epidermal covering. Sores, pimples, skin lesions and the inability to consume and contain are evidence of this degeneration. In this way the body reveals that which is concealed.

The discussion below starts to explore the public health construction of AIDS as a deadly disease and then proceeds to examine how this was articulated through cultural censorship and avoidance in different contexts.

### **‘AIDS IS DEATH’: CONSTRUCTS OF A NEW DISEASE**

AIDS was initially encountered as an idea (cf. Pigg 2001, 481), constructed through the media and health propaganda. Stories about AIDS in the popular press were important in shaping the ways in which people responded to the disease. Many of the early reports highlighted that AIDS is incurable and deadly. These stories were also highly stigmatising (cf. Connelly & Macleod 2003). Gabriel was a young university student when he first heard about AIDS. An article in *Pace Magazine* discussed the dangers of AIDS; a picture of doctors, wearing face masks and surgical gowns surrounded a coffin that had been tied up with ropes. Gabriel interpreted the picture:

The ropes were to prevent the doctors from touching the coffin and the masks were to prevent them from inhaling anything from the corpse. I was really frightened by this. It meant that if you have AIDS people will be afraid to bury you and will not touch you

These initial impressions of the disease as extremely deadly and highly contagious continued well into the epidemic (cf. Niehaus 2007). AIDS is avoided because it is something to be feared and is codified as ‘the killer of the nation’ and ‘the three/four letter thing’ (Lambert & Wood 2005). Riot, was a schoolboy when he first heard of AIDS: ‘I took it seriously because I knew it can kill. I take it into consideration that AIDS kills’. Marks, commented: ‘AIDS is living and it kills’. A young girl recalled:

I heard on TV that AIDS is killing people. They start vomiting, having diarrhoea, they become thin and end up dying. I see people sick from AIDS sometimes the person is always sleepy and around the mouth will have sores

These impressions were reinforced in public education activities. A poem read out at the graduation ceremony for home based care volunteers offered a vision of the epidemic in which being HIV positive was associated with rape.

AIDS you are a monster  
Where do you come from?  
You have no respect  
You kill everyone young and old  
Rich and poor  
Everyone is being raped everyday  
Young children as young as nine months are being raped  
Young children are being raped  
AIDS is spread through rape  
AIDS is spread through rape to the African Continent

Church programs for young people focussed on the deadly effects of AIDS and promoted blame. A young man attended the International Pentecostal Holiness Church:

They talk about AIDS in the church. This was where I heard about AIDS a lot. They say that AIDS is living and it kills. If you go out and have sex with ladies in taverns or ladies who linger around who have many boys then you can find AIDS

Conspiracy theories about the origins of the epidemic were also widespread. An early rumour speculated that AIDS originated from humans having sex with monkeys, baboons and dogs. Mandela, now a young man, recalled the talk at his high school about AIDS in the mid-1990s, where he heard that the disease was caused by men sleeping with monkeys. Yet, Mandela did not take the story seriously. He said:

No, no, no. I don't believe that if a monkey can live with this disease it will kill a human being. What is the difference between a monkey and a human being? The blood is the same and the disease lives in the blood.

Others speculated that the apartheid government manufactured the disease to kill black South Africans (cf. Niehaus & Jonsson 2005). The idea that AIDS was a government conspiracy was not restricted to the apartheid government. Some theories attributed the absence of a cure for AIDS to pharmaceutical profiteering. Medical researchers suppressed the discovery of cures by traditional healers as this would undermine their power. A young man had heard debates on the radio and concluded:

They [medical researchers] are worried that the AIDS cure will be made locally and in the traditional way. They will lose their profits. This is why they cannot make it know to the people that there are cures for AIDS available.

While AIDS was an imagined disease for most of the early 1990s, by the early 2000s, the disease became horribly real, inscribed in the bodies of the ill and evident in the increasing numbers of funerals. The personal experience of seeing the ill and dying was critical in changing the way people thought of AIDS. As a young man stated, the



‘dream’ became ‘real’. ‘Others tell us that it is just a joke, a dream. *They* are dreaming’. He pointed out that many people had died in the village; ‘So now they can see that AIDS is real’. Mandla recalled that he started to believe that AIDS was real when he was visiting his mother in hospital and he saw a woman with AIDS. ‘After I heard that she had passed away I felt scared, yeah’. Cornelius, a young man of 24 had a similar experience:

Jonathan: Can you remember the first time you heard about AIDS?

Cornelius: Ya, um, it’s toward the end of 1999. Many people talked about AIDS, but I took it as a joke. I thought that maybe it can’t kill a person, it’s not really cruel. Yeah, so around 2000, the end of 2000, I saw a person. It was 16<sup>th</sup> November. So that when I started to realize it is a disease and it kills. That person was my cousin. So on the Friday we saw him in the mortuary, so the doctors, told us that, she died because of AIDS.

Despite these experiences and public knowledge of the disease, suffering and death remained private issues.

## SECRECY AND SUSPICION

In KwaBomba, as in many other similar settings, public reference to AIDS is usually avoided; euphemisms, acronyms, signs, slogans and metaphors are used in everyday talk to denote AIDS<sup>7</sup>. Quite appropriately then, AIDS is sometimes called the ‘disease with many names’. The aliases used to stand for AIDS often play on the fact that the acronyms HIV and AIDS are made up of three and four letters respectively. For example ‘**H**ouse **I**n **V**ereeniging’, a ‘taxi trip to Johannesburg’ - three fingers are held up to signal for a taxi to Johannesburg, and a popular brand of washing powder ‘OMO’, like

HIV is an acronym of three letters<sup>8</sup>. The nicknames awarded to AIDS reveal linkages between AIDS and conspicuous consumption; for example ‘Z3’ (BMW sports car); ‘three numbers plus bonus’ from the national lottery in which three numbers equal three letters that spell out A I D, the bonus was the ‘S’ suggests the desire for instant wealth and AIDS, but also the risky gamble that sex had become in this era (Stadler 2003b).

At funerals, AIDS is never referred to directly as the cause of death, although mourners sometimes signal their suspicions by exchanging glances and showing three fingers spelling out H-I-V (Stadler 2003b). ‘They talk at the corner of the funerals – not in the speeches’ remarked a young woman.

Church ministers I spoke to agreed that the silence about AIDS is problematic. Yet, few did anything to challenge the silences. At the funeral of a man who died of AIDS the minister stated obliquely that the man ‘was responsible through his actions’. David Madonsella, a minister of the church and a member of the umbrella inter-faith body ‘Faith Organisations in HIV/AIDS Partnership’ (FOHAP) worried that the silences around AIDS are seldom confronted by ministers in the church. Although many church sessions with the youth discuss HIV/AIDS, this was usually only in terms of promoting abstinence before marriage. David once spoke about AIDS at a funeral, but admitted that out of respect for the family of the deceased only spoke in very general terms. ‘You can’t expose the sickness without their consent’, he remarked, and ‘Human rights can cause problems’ – alluding to the confidentiality of HIV status.

Regular events are organised at which openness and full disclosure is encouraged. In 2001, World AIDS Day was held in the town of Bushbuckridge. Gospel singers Solly Makulu, Mumsy Ndlovu, and *kwaito* star Spokes H performed for the entire Limpopo

Provincial cabinet and thousands of residents. After the entertainment the huge crowds were divided into regions each of which had their own tent for catering. ‘They spent millions’ I was told. During the day’s proceedings a number of people appeared on stage and announced that they were HIV positive. This was in the spirit of openness, to fight against the stigma of AIDS. ‘But’, as one observer said, ‘they were probably paid to say this’.

AIDS was not mentioned in the political campaigning leading up to the national elections in 2004. In the ANC’s door-to-door campaign people were asked to list problems that they were experiencing, AIDS was never mentioned. Niehaus cites a ward chairman in Impalahoek saying ‘No! We were never asked a single question about AIDS. People don’t like talking about it’ (Niehaus 2006b, 540). These sentiments are reinforced in the words of a teenager who attended the loveLife Y-Centre in Acornhoek:

No one comes out and says ‘I have HIV, come and see me, I want to be an example for you’, no one! But there are many people who have HIV, but they will not come out and say ‘come and see me’ as an example, because they have it and it’s a dangerous disease. So that’s why I think that many people they have it. Even me; I think that maybe, it may be possible that I have it.

As he notes, the act of concealing the disease is not sufficient to quell others suspicions. Secrecy is incomplete and concealment is not absolute. Moreover, concealment as a practice of everyday life subtly and sometimes not so subtly reveals and conceals (cf: Piot 1993). Goffman (1963) in his frequently cited book on stigma notes that people strive to maintain a balance between concealment and disclosure of information, in different contexts and situations, with different categories of individual. ‘To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to

lie; and in each case, to whom, how, when, and where' (Goffman 1963, 42). In Bushbuckridge, AIDS was indeed a secret, but one that everyone knew about but never alluded to directly. Jean Comaroff points to the subtleties of concealment and exposure in talk about AIDS:

The inaudibility of talk about AIDS is often less a matter of brute repression or secrecy than of complicated communicative practices in the context of radical uncertainty. Nuanced registers and indirect forms of speech flourish in a field haunted by the ubiquitous presence of the disease. For death is the unspoken referent around which much everyday signification has been reoriented (Comaroff 2007, 202).

Concealment was not simply silence, but entailed a studied avoidance, partial censorship, and insinuation. Metaphor was a key device in the process of telling and of partially revealing. Importantly, as Piot (1993, 358) notes, the use of metaphor as a way of revealing creates ambiguity, and an 'on-going interpretation and reinterpretation'. This is aptly illustrated in a schoolboy's account of a school teacher's funeral. The oratory at the funeral had identified diabetes as the cause of his teacher's death. I asked the schoolboy if he thought this was true.

Ah no! (JS: *Did anyone believe that?*) Ah no! (JS: *So, why did they say it was diabetes?*) I think it is in our culture that at a funeral we are not allowed to say this one died from an embarrassing thing. For example if he was shot when he was robbing some place like a *xigavenga* [thug] you won't mention that he died in that way.

As the boy quoted above noted, silences are interpreted culturally as a way of communicating suspicious circumstances. Suspicions of AIDS are precisely *suspicious* based on incomplete evidence channelled through local gossip. Disclosure in the public space of a funeral has significant implications for social relations. Funerals are focal

points in which attention is drawn to the conduct of an individual. For example, the number of people who attend the funeral is a statement about the deceased's status while he or she was alive. My informants told me that if they failed to show support for others by attending their funerals, their own funeral may be poorly attended. Moreover, not attending a funeral creates suspicions of complicity in death. In the context of an AIDS death, announcing the cause of death would amount to a 'public curse', a statement that those connected to the deceased would themselves also die (Durham & Klaitz 2002).

Disclosure of AIDS was contained within the domestic, private domain. Matthews, a college student, talked to me candidly about his sister who had died two weeks previously.

She was my father's brother's daughter...she was born in 1978 ... many people didn't understand about this it is not the sort of thing that you can speak about openly – even my friends don't know that my sister died of AIDS, we can only speak of it in the family. I didn't explain to them I just told them that my sister is dead. Her friends may know that she died of AIDS because they went about with her everywhere. The younger sisters don't believe because they didn't see her symptoms. She was fat but just before she died she became very, very thin. She was single but she had a boyfriend he was a taxi driver that is why I believe that because they have AIDS.

Matthews' comments on the death of his sister raise the distinction between the public denial of AIDS and its private acknowledgement. AIDS is something that can only be spoken of within the family, as Mathews put it. However, even so, Mathews' sisters were not made aware of the facts of their sister's death.

McNeil (2007) suggests that public secrecy in the context of funerals needs to be contextualised within wider-ranging attitudes towards death and suspicions of witchcraft. In his analysis of AIDS deaths that occurred in the Venda region, McNeill suggests that

avoidance of identifying the cause of death and naming it is a strategy to avoid direct association with the deaths in order to ‘seek diminished responsibility for the recent increase in what are believed to be unnatural deaths.’ (McNeill 2007, 260) The avoidance of identifying, naming and indeed talking about death cannot solely be attributed to AIDS denial.

Paradoxically, secrets often have a way of surfacing; and silence and avoidance became inadvertently an acknowledgement of AIDS; its negation tends to confirm its existence. For example, my informants claimed that Mbeki refuted AIDS because he was infected with HIV himself.

Although AIDS was subjected to censorship, AIDS was a revealing disease, one that rendered visible that which was said to lie beneath. This is due to the natural history of HIV infection. During the early or acute stage the infected body may display signs of infection, such as a severe rash. However, as the viral load of HIV in the body reduces over time, the body may appear healthy. It is only once opportunistic infections such as tuberculosis and diarrhoeal diseases attack the body that disease really manifests itself physically. Sontag notes the irony of a disease that attracts the most secrecy is also the most revealing: ‘The illness flushes out an identity that may have remained hidden from neighbours, job-mates, family, friends’ (2001, 113).

Avoidance around AIDS presents a conundrum for research, HIV prevention, treatment and care. Despite the intimate nature of ethnographic research, anthropology does not hold an especially privileged position with regard to the research of secrets and concealed or ‘deep knowledge’ (Apter 2005). Certain areas of everyday and ritual life are secret and hidden from public view. An example is the highly secretive initiation rituals.

Initiation ceremonies for example included public rituals, but for the large part were restricted to the neophytes and the initiated (Stadler 1995). Knowledge about witchcraft was also highly secretive, restricted to older men and women who possessed the knowledge and the capacity to commit acts of witchcraft. Importantly, knowledge of the craft implied the capacity to commit acts of witchcraft (Stadler 1996). Research about AIDS confronts similar barriers. Secrecy also meant that the sick and dying were often hidden, denied care and proper treatment by family members and were shunned by their neighbours and work colleagues (Cameron 2000; Campbell 2003; Delius & Glaser 2005; Niehaus 2007)

Silence and concealment may also be regarded as an effective manner of revealing and indeed performing suffering and affliction. Vena Das' (1997) reflections on her conversations with Indian women provides some insights into the reasons for the elusiveness in their narratives of their traumatic experiences during the Partition:

When asking women to narrate their experiences of the Partition I found a zone of silence around the event. This silence was achieved either by the use of language that was general and metaphoric but that evaded specific description of any events so as to capture the particularity of their experience, or by describing the surrounding events but leaving the actual experience of abduction and rape unstated (Das 1997, 84)

Women conceptualised their bodies as repositories of 'poisonous knowledge'. However, contra to the idea of the need to release and expunge through verbalising their experiences, their silences protected them and allowed them to continue with their lives. They were able to carry on – not by bearing witness through speech, but through silence (Das 1997, 85).

The silences around AIDS are somewhat analogous. Although my informants did not allude to the metaphor of poison to describe the concealment of AIDS, their narratives alluded to the dangers of breaking the silence, of revealing their suffering and the extremely negative impact thereof for themselves and their surviving family members. HIV was an extremely powerful secret, and as I explore below, a dangerous form of knowledge.

### **DANGEROUS KNOWLEDGE**

The avoidance of HIV testing is partly attributable to the widespread rumour in Bushbuckridge that nursing staff were purposefully, or accidentally, infecting patients with HIV. The nursing sister in charge of testing at a community clinic complained that she had heard people in the village saying that she infected her patients with HIV. She linked this to a dramatic reduction in requests for testing.

Yet, the fear of testing seems to run deeper than this. It concerns not only on the possibility of being infected by careless or malicious nursing staff, but a belief that the HIV test communicates deadly knowledge that results in illness. A middle aged woman expressed her concerns of what a HIV positive diagnosis would mean to her.

They say you don't know if you have got it [HIV]. I will go and have a test. Then I will know that I am HIV positive so I will start to become thin because of *ku vilela* [worry].

In contrast to public health narratives that highlight the benefits – both medical and psychological – of HIV testing, a sero-positive test result was potentially detrimental to one's health. As a 24 year old woman remarked, this could even result in death: 'I



cannot test because one week after hearing that I am HIV positive I will just die. I will become thin from the worry’.

Anxiety and worry result in an affliction called *mbilu va vabye*, literally ‘heart sickness’. This is similar to the popular concept of ‘stress’. A person who has heart sickness has ‘given up hope of ever being cured’, their ‘heart is lost’ (*mbilu yi vava*) or ‘they have lost hope’ (*ku ka u ’nga tsembe*). This was widely recognized and classified by traditional healers in KwaBomba as a deadly, but treatable affliction. NwaKhomani, a female traditional healer, often treated patients with herbs who as she put it, have ‘lost heart’. ‘Sometimes we give them *muthi* to make their heart feel free, to be free of pain. This is to make them feel happier’. NwaKhomani reinforced the idea that a painful heart was from ‘thinking too much’<sup>9</sup>. Jamaica, so named from the days he wore dreadlocks and played football for a club in KwaZulu-Natal also dealt with patients who had heart sickness. He explained in some detail:

*Ku fa hi mbilu* [death from heart] is when a person who thinks too much and becomes very angry; his heart will pump far too much. He will be caught by the *mbilu yi vava* [heart sickness]. A person will think too much if there is always fighting at home. Usually it is the wife who is affected but the fights are between the husband and the wife. The body starts to change – the veins will start to show underneath the skin. The person is always unhappy, always looks sad. You can die from this – usually you will have a heart attack. People don’t want to know that they have AIDS because they fear that their lives will be miserable.

However, it was not only the diagnosis that people feared. The test itself was a powerful intervention that could transform the body. The logic of this can be elucidated by examining another procedure which is commonly performed by traditional healers (*tin’anga*) called *ku tlhavela* (literally, ‘to cut’). A healer (*n’anga*) makes small incisions on the back of the knees, elbows, breast bone, wrists and nape of the neck using a razor

blade<sup>10</sup>. *Muthi* (medicinal substances, usually a grey or black powder) is rubbed into the incisions. The joints are the points at which the body is most vulnerable to attack because it is here that blood is closest to the surface of the skin. This procedure fortifies the body against witchcraft, a sort of ‘ritual immunisation’ (Jolles & Jolles 2000). People who felt vulnerable to occult attack regularly (often at Christmas time when family members gather together) performed the ritual as a prophylaxis against witchcraft. A similar ritual was performed on the corpse of a person thought to have died from witchcraft to return the witchcraft back to its owner (For a similar account see: Niehaus 2001, 26)<sup>11</sup>. The symbolic potency of this ritual is realised by the action of cutting into the skin and mixing the *muthi* into the veins, and at the same time uttering the words ‘let this illness return to the one who sent it’ (see Chapter 6).

It may be that the perceived potency of the HIV test lies in its symbolic association with the *ku tlhavela* ritual. The hypodermic needle injection used in biomedical treatment is often regarded as having symbolic potency, perhaps seen in a similar way as the incisions made during the cutting ritual; as van der Geest and Whyte (1989, 360) observe the ‘metonymic associations are especially strong’<sup>12</sup>. When faced with new biomedical technologies – such as diagnostic testing procedures that may not be well understood, new meanings are constructed that refer to practices which are more familiar, in a process of the domestication of the new and unfamiliar. Drawing blood in the HIV test was therefore viewed as an intervention in itself. This action combined with the disclosure of the results had the power to transform the body from a state of health to illness. In the cutting ritual, words are spoken, to ‘activate’ the power of the medicine which the *n’anga* has used. Likewise the words ‘HIV positive’ achieved potency because

of the association with the insertion of the needle into the skin, but also because these were secret words. It is in this sense that testing for HIV was regarded as dangerous knowledge, given added potency through the clinical procedure of piercing the skin and withdrawing blood. In terms of this local model, testing was much more than disclosing information about a patients' HIV status<sup>13</sup>.

Lastly, the avoidance of testing reveals a fear not only of the results of the test itself, but a fear of the words 'HIV' and 'AIDS'. The play with the lexicon of AIDS highlighted at the beginning of this chapter suggests a fearfulness of naming the disease, as if this has an innate power. Certainly, in the context of extremely high rates of mortality, the acronym AIDS has assumed symbolic status; it has become an immensely powerful and dangerous word<sup>14</sup>.

Up till now I have talked more generally about responses to testing and peoples' ideas about this. A distinction needs to be drawn between the experiences of men and women in this regard.

### **SHY MEN AND SUFFERING WOMEN**

Discourses about the censorship and concealment of AIDS reflected on the divergent experiences of men and women, their respective vulnerabilities and strengths. Men were described as being naturally 'shy', unwilling to talk about sensitive issues, preferring to keep intimate experiences of suffering away from the public gaze. Men were more hesitant to talk about AIDS, more likely to deny its existence and less likely to test for HIV. Men, it also appeared, had more to lose than women, by having their HIV status known. In contrast to this weakness and vulnerability, women bore suffering and had

greater strength in absorbing the pain of illness. Women also had more experience and were far more familiar with the world of biomedicine. This was due to their participation in clinical services in accessing gynaecological examinations, health talk, contraception and other services, through which women's bodies were medicalized (cf. Martin 1992).

The gendered nature of concealing and revealing of AIDS was corroborated by the clinician in charge of an AIDS program at Tintswalo Hospital. She observed that women tended to be in the majority at support group meetings. Men, she remarked, were wary of attending these sessions and much preferred to be dealt with in private consultations. In December 2008 the clinic recorded a total of 6638 users; 2381 of those are men and 4257 are women (Mfecane 2010). Their suffering was not something to be revealed in public.

The gendering of AIDS discourses can be partly explained by the general tendency of women to trust in and utilise biomedical services, experience higher rates of use of clinical services and therefore possess more knowledge about biomedicine. Most women are first exposed to biomedical knowledge and allopathic therapies when they start to use hormonal contraception that is dispensed at public health clinics. Many clinics hold health talks and well-baby clinics at which they also lecture on AIDS. HIV testing is mandatory at antenatal clinics. Outside of the biomedical setting, in various churches, the regular prayer of the mothers (*xikongela wa manana*) hold discussions about AIDS.

In contrast, men had limited experiences within the biomedical setting of the clinic. They were 'matter out of place' in the public health clinic waiting rooms as these were feminised spaces, dealing with 'women's business'<sup>15</sup>. Men often preferred to self-diagnose and self-treat or consult a 'private doctor' or traditional healer. This gendered

dynamic reflects on a public health service that feminises HIV and AIDS. Women are more susceptible to HIV infection and therefore women are targeted in HIV prevention efforts.

These ideas were conceptualised as embodied. The female body was regarded as weaker and more susceptible to illness due to the strain of childbirth, the loss of menstrual blood and the build-up of polluted substances in the body from sexual intercourse. In the popular imagination, women were likely transmitters of hidden disease, more so than men.

For example sexually transmitted diseases (STD) are hidden within the womb and were often asymptomatic. Men in contrast displayed the symptoms of STDs. Male accounts of disease and infection was also quite different to women's. In an exercise of 'body mapping' conducted at Tintswalo Hospital a group of young men and women were asked to draw separate diagrams to portray a body infected with a STI. The female group drew the basic outline of a faceless woman, with a detailed diagram of the fallopian tubes and the womb, showing the site of infection. The male group presented a drawing of a man, fully clothed, with stained trousers and an unhappy look on his face. They explained that the man was embarrassed because the discharge from his penis leaked through to his trousers, nor could he walk properly because of his discomfort. The contrast between the masculine concerns about the social aspects of disease, versus the female preoccupation with the inner body was striking.

Women and men's subjective experiences and interpretations of disease were quite distinct. Men were seen to be more vulnerable than women to the pain of knowing they are infected, while women had greater strength and could sustain the pain. In this

way a woman's body was a more appropriate site of suffering than the male body. A woman's heart was the location of her strength and her emotions. The heart, it was said, can be the 'biggest witch' (*mbilo wa noyi*). If a woman has been wronged (usually by a man) she absorbs this pain and suffering into her heart. Yet, the heart could also do great damage to those who had wronged them. At night the painful heart causes the sufferer to cry tears and call out the names of those who had wronged them.

The gendered nature of thinking about illness and resilience was articulate in men's tendency to conceal HIV and women's tendency to reveal. For example, I had much more success in talking to women about HIV than men.

Men were extremely open about secret love affairs, but conversations about AIDS were quite the opposite. I often chatted to Goodwill, a young unemployed man, and considered him as a relatively willing informant. When I asked Goodwill about AIDS his entire demeanour changed. The following extract is from a recording of an interview with Goodwill. It starts at the point when I began to ask him about the deaths from AIDS in KwaBomba.

*When did you start noticing the deaths?* In 1999

*What happened?* Ahem – you know why I cannot talk about this ... I do not know where you are going to play this tape. Someone from KwaBomba is going to hear this and will know it was me who spoke to you.

*So you are worried about mentioning something about AIDS and someone who has AIDS? What would happen if someone heard this interview?* Ahem ... it is illegal to talk about such things, maybe they will sue me.

*They would sue you?* Yes and I do not have enough money to pay for the case

*Where did you get the idea that it is illegal?* It just seems that it is (...) I do not know how I can say this ... I am not feeling relaxed.

Mandla [my research assistant intervenes]: He is actually saying he is afraid to talk about it.

Goodwill hesitated and then eventually refused to talk about AIDS because he did not want to be labelled a gossip but also as he suggested because AIDS-talk was illegal. This confirmed what I had heard from others; that to identify someone as HIV positive could result in criminal prosecution or a fine of one cow in the headman's (*ndhuna*) court. Moreover, Goodwill was particularly concerned regarding my recording the conversation.

Another extract, this time from an interview with a male school-goer reflects similar sort of fears in revealing personal information about AIDS.

I have just heard that there are a lot of people here [who have died of AIDS] but I don't know them...I don't know them...if someone dies from AIDS then they are afraid to say that someone died of AIDS so I can't say that I know someone that died, ... I can't say that.

Sometimes the memory of those who had died from AIDS was completely expunged. I recall an interview with a young man who denied the existence of his sister who had died two years prior, apparently of AIDS illnesses. David, my research assistant, was shocked at his denial and remarked that it was as if the young man's sister had never even existed, that he had erased her from memory. When we had finished the interview, David said 'He knew that I knew that his sister had died of AIDS. But how can he just forget her!'

While conversations with men about AIDS often encountered these sorts of barriers, women were far more willing to open up and talk about their subjective experiences of the epidemic. I recall standing in Gladys Shai's yard while her elderly mother identified one by one those who she suspected had died of AIDS, pointing to the individual homesteads in the street, only holding back on actually identifying the individuals concerned. NwaMbembe, a middle aged domestic worker, suggested that mandatory testing should be conducted at schools to expose HIV positive youth. At our first meeting I asked her when she had heard about AIDS.

I started hearing this last year because most people were dying then.

*Where did you hear about it?* From the radio, watching TV and seeing relatives dying. Another relative - they are burying him tomorrow because of AIDS (...)

*Is this is the first time you have seen someone dying from AIDS?* No it is not the first time. My sister-in-law, and my brother's daughter, also died from AIDS. They were sick and they were even admitted to Tintswalo [hospital]. I visited them...they put her in her own room. She was very thin and *ku tsuka* [light in complexion]. They also took her to the *n'anga* [traditional healer] and ended up taking her home. They wrapped her with a nappy. Where she slept she looked like a tiny parcel...it is a horrible disease if you know you have got it you will end up killing yourself [laughs].

Women were also more likely to express their personal concern that they perhaps could be infected with HIV. NwaMbembe commented on the possibility that she could be infected.

It will be you left Jonathan. You will be alive because you know a little bit about this disease. But at the back of the small hill near the railway line, I used to have sex with men, so you won't know if I haven't got it.



Older women were also open in discussing sex and the transmission of HIV. The following transcript of an interview with NwaEphraim illustrates the ways in which sensitive information was communicated:

Jonathan: *So, you have heard about AIDS?*

NwaEphraim: AIDS? Yes I know it. I heard that if you lie on your tummy with a man you get AIDS. The time you are doing this you are pressing each other and so you get AIDS, but I can't exactly say what's going on. I mean it is not like a cow that goes moo. That moo is saying everything.

Women were also more likely to ask me for advice and practical assistance with a sick child, brother or husband or if they themselves were sick with AIDS.

### **CONTAINING THE AIDS BODY**

They can build our underground tunnel so we can meet each other and talk about *vu vabya* [illness/sickness]. So if they find we have got this disease we will be going under the ground praying down there and singing and we will be just consoling ourselves.

These words were spoken by a middle-aged woman who had admitted to me that she was somewhat unsure about her own HIV status. She evoked a macabre vision of people buried before death, living and even singing and praying. Her statement was even more ghoulish considering the widespread belief in the zombies (*xindhachani*) who occupy the land of the living at night carrying out chores for witches owners (Niehaus 2001). Most of all, her commentary drew attention to a concern with secluding the AIDS body. Concealment and containment is a familiar strategy in dealing with the ill and the dying. Being kept within the confines of the homestead was a sign of illness or a state of

vulnerability. People in a state of pollution (menstruating women for example) are often confined to the homestead. Certain afflictions that are revealed on the surface of the skin (leprosy, small pox, measles) also result in seclusion.

Seclusion, I suggest has to do with peoples' thoughts about the AIDS body. Narratives about AIDS focussed on the physical appearance of AIDS sufferers and highlighted wasting and erosion, and the need to contain this. People with AIDS were 'tiny parcels', 'skeletons' and 'clothes hangers', and also 'rotten' (*borile*). AIDS slowly ate away at a person from the inside of the body. The sores that appear on the surface of the skin were regarded as manifestations of the erosion of the body inside. HIV was commonly conceptualised as a microscopic worm that grew and reproduced itself until consuming the body. A woman was described as having rotten breasts; another's perineum had eroded away. A healer (*n'anga*) induced diarrhoea in her patients. She claimed that this expelled male and female maggots and their offspring – hundreds of tiny maggots. A story I first heard in Soweto in 2005 and soon thereafter in the lowveld told of an AIDS patient whose vagina was inhabited by a large maggot. According to the account, staff at Tintswalo Hospital charged a R10 entrance fee for spectators to see the maggot emerge from the woman's vagina, having first been enticed by a piece of pink meat or ox liver<sup>16</sup>. These accounts draw attention to fears about the permeability of the body and how AIDS resulted in the exposure of the corrupted interior of the body. They create images of the erosion and decay. The images of the AIDS body were extremely disturbing and disquieting. Talking about his neighbour, a young man recollected that he had been so frightened when he saw her shrunken state that he had run away.

The ideas about the AIDS body were inspired in some part from AIDS awareness campaigns that highlighted the strong association between the disease and death.

Although AIDS awareness campaigns consciously moved away from scare tactics and promoted more positive imagery about AIDS, the association between AIDS and death remained strong in the popular imagination.

Niehaus (2007), commenting on the stigmatisation of AIDS sufferers in the lowveld offers a convincing interpretation for this response: ‘persons with AIDS are symbolically located in an anomalous domain between life and death, and are literally seen as ‘corpses that live’ or as persons who are “dead before dying”.’ (Niehaus 2007, 848)<sup>17</sup> Therefore, seclusion and concealment was an appropriate response to dealing with the liminal body of the AIDS sufferer, best hidden away ‘in tunnels’. And as I discuss later in the thesis, this was also an important part of the repertoire of how people ‘do suffering’ (Struhkamp 2005). Concealment and secrecy are also strategies to avoid harm coming to other household members.

### **‘A house hides a lot of things’: concealment in everyday life and death**

Peaceful Ndlovu was in her early twenties and still attending school when she became ill with AIDS. She resided with her parents in a large household of 22 people, including her brothers’ wives and their offspring. The household relied on the migrant incomes of two working men, resulting in a serious strain on household resources. My narrator put it in this way: ‘the *vakothi* [daughters-in-law] would make a huge pot of porridge and then each person must find their own relish [to accompany the plain starch]’

Peaceful’s illness had worsened after she had given birth to a baby girl. Like many other women, childbirth was a massive strain on her health and she had been

admitted to Tintswalo hospital for several weeks after experiencing uncontrollable diarrhoea and vomiting which had left her weak and dehydrated. Neglected and unwell, her baby died at 16 months. Peaceful was visibly ill and her family must have suspected that she had AIDS. Peaceful herself was first made aware of her status during routine testing at the antenatal clinic. Lucas, her older brother (recently retrenched from Telkom) was the only family member who she told. One day in desperation she told him that she felt like killing herself. When he asked why Peaceful told him she intended to ‘go out there’ and spread HIV. Lucas talked to her and looked after her. When she was desperately ill, Lucas took her to hospital and visited her there. No one else in her family came to see her. Peaceful had spoken to Lucas about her fears of disclosure. She felt that if her family were told that she was HIV positive, this information may be used against her when she was fighting with her other siblings or her parents. Her fears were not unfounded. Peaceful had seen how her cousin Mamela was taunted by her siblings. Mamela received food parcels from the local civic association and was the recipient of a government disability grant. Her sisters often squabbled over Mamela’s money, claiming that she did not deserve this. Moreover, Mamela’s grandmother frequently drank too much home brewed beer (*xikhapakhapa*) and in her inebriated state sang about her granddaughter’s illness while walking home from the *shebeen* at night. Risking public humiliation was too large a price to pay.

When Peaceful died Lucas met with his parents and informed them that Peaceful had disclosed her HIV status to him. Lucas claimed that he had kept her HIV status secret because he wanted to spare them the stress and shame they would experience if they

knew. Perhaps, he speculated, they would have killed themselves because of the humiliation.

Peaceful Ndlovu's case illustrates how concealment from family members created barriers to seeking care. Yet, at the same time it reveals how concealment is a strategy to avoid the destructive effects of disclosure on intra-household relationships. In this case withholding information was used to protect Peaceful, but at the same time to protect her parents from stress and shame. Peaceful had chosen to confide in Lucas to relieve herself of the burden of suffering alone, and because of their especially close relationship. These sentiments were well articulated by a young unmarried woman who talked about the social repercussions she imagined would result if she had to die of AIDS and this became known to people in her community. The emotional and social harm resulting was so awful that she would consider suicide.

If I know I had AIDS I would drink Two-Steps [rat poison]. My parents and children will be worried that the children at school will laugh at my children. They will say 'she died of AIDS'. And this disease takes a long time. The parents will sit at home and worry. Even after I die the children will continue to laugh and say – your mother died of AIDS. Your family will end up getting bad luck. Even the other villagers won't like your family – they will think that the whole family has AIDS

The idea of the contagious nature of 'bad luck' (*xinyama*) and the emotional impact on others is clearly expressed. It is important to read the quote carefully – the speaker did not say that she will commit suicide for her own benefit – like euthanasia but to avoid the social harm that could befall her parents and her children who would be tainted by her illness and death. Hers was a form of self-sacrifice.

## CONCLUSIONS

This chapter has lent some support to observations made elsewhere regarding the social and cultural basis to the secrecy and concealment of AIDS. In KwaBomba, reluctance to test for HIV and talk about AIDS, and the concealment of the AIDS body was not attributed to individual denial, but the prevention of exposure to dangerous knowledge. The material presented in the chapter also showed how disclosure and revealing has divergent meanings in different contexts and with different categories of person. Importantly, men were regarded as more private than women, and less resilient to suffering.

A theme, critical for understanding the social response to AIDS has emerged from this chapter. Concealment and secrecy has implications not only for the care and support of the AIDS ill, but also with regard to peoples' capacity to deal with the AIDS epidemic at a social level. Citing Bellman's work on the Kpella, Piot (1993) draws attention to the idea of

(T)wo realities: one that everyone knows about but which agree to conceal, and the other 'the realm of discourse that indirectly refers, through what Bellman calls "deep talk" (allusive metaphorical speech) to the real'. The existence of this second reality creates a field of varying, ambiguous, and often conflicting interpretations of the real. One never knows for sure whether one "got" the message or not

I have suggested that in KwaBomba, talk about AIDS, particularly in the public domain occupies the second realm of 'deep talk'. This has not only created ambiguity but has also contributed towards the mystification of the AIDS. This has very significant consequences which are observable in the widespread failure of 'communities' affected

by the AIDS epidemic to act against it; to make demands for services; to seek out treatment and care; to mobilise resources to support the sick and the dying.

The most pertinent example of the reluctance to act against the epidemic are the secret funerals organised in KwaBomba<sup>18</sup>. A contrast may be drawn with the funerals of the mid 1980s and early 1990s that were sites of political activism, and were ideal opportunities for dramatizing peoples' suffering and mobilising against apartheid (cf. Van Kessel 1993). Funerals were extremely evocative moments, instrumental in mobilising people into action. Yet, the concealment of death and the obfuscation of its causes in the era of AIDS rendered deaths from that disease, meaningless.

## END NOTES

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- <sup>1</sup> HIV is linked, but separated in time, from AIDS. At the initial stage of acute infection, standard tests are unable to detect the presence of HIV in the infected body. After the 'window period' of three months, the immune system responds to the presence of HIV and this response is detectable. The infected person may remain asymptomatic for some time until Stage Three HIV infection begins and the person is now considered to have full blown AIDS (Evian et al. 1993).
- <sup>2</sup> Bravely because of the dreadful consequences this public disclosure has had for AIDS activists such as Gugu Dlamini who was murdered after declaring her HIV status (Stadler 2003a). Almeleh (2004) notes that public disclosure is often selective (Cited in: Ashforth & Natrass 2005), and is sometimes thought to be disingenuous (Levine 2005 cited in Ashforth & Natrass 2005).
- <sup>3</sup> For example the judge and AIDS activist Edwin Cameron's address to the 2000 International AIDS Conference held in Durban, South Africa made an impassioned call for an end to discriminatory practices against people with AIDS (Cameron 2000).
- <sup>4</sup> In a survey of HIV testing in 2000, conducted in Agincourt in Bushbuckridge only 10% of patients at one facility and 15% at another returned to receive their HIV test results (Pronyk et al. 2002).
- <sup>5</sup> I am aware of the large anthropological literature on ritualized and ritual secrecy. However, the main focus of this discussion is on the use of silence and the obfuscation of AIDS in everyday interactions and in everyday language which is somewhat distinct

from ritual secrecy where secrecy is an ‘esoteric phenomenon tied to formal ritual contexts’ (Piot 1993, 353)

- <sup>6</sup> Following Malinowski’s lead in his description of spells, Tambiah (1968) explores the notion of the power of the spoken word as represented in Christian, Buddhist and Trobriand belief systems: ‘deities or first ancestors or their equivalents instituted speech and the classifying activity; man himself is the creator and user of this propensity; finally, language as such has an independent existence and has the power to influence reality’ (Tambiah, 1968:184). Tambiah’s concern here was with the power of words. Words had a different degree of power depending on how and where they are spoken. They can be audible but not understood by all; as words audible and understood; and ‘secretly uttered’ and thus private.
- <sup>7</sup> These are sometimes extremely creative and meaningful. For example in Zimbabwe HIV was **Henry the IV** (Andersson 2002), in Tanzania AIDS was the Acquired Income Deficiency Syndrome (Setel 1999), and in Malawi *zomwezi* (the usual) or *matenda a boma* (the government disease) (Lwanda 2003, 113).
- <sup>8</sup> This combination of seemingly unrelated and often opposing phrases or objects to stand for the acronyms HIV or AIDS is reminiscent of Lévi-Strauss’s concept of *bricolage* (Lévi-Strauss 1966 [1962]).
- <sup>9</sup> The aetiology of *ku fa hi mbilu* shared similarities with a folk illness often described in the literature as nerves (Low 1985), and associated with headaches, dizziness, fatigue, weakness and stomach-ache, and as being generally associated with sadness, anger, fear, and worry and was more frequently a feature of females than males (Rebhun 1999b).
- <sup>10</sup> Most healers I observed requested patients to bring their own razors in the interest of preventing accidental infections.
- <sup>11</sup> A Mozambican refugee described another version of this. After the incisions were made a live chicken was placed inside a plastic bag and buried in the soil. The idea was to cause the suspected witch to choke to death.
- <sup>12</sup> Vaccination campaigns in various African contexts reveal the believed potency of injections (See for example: Feldman-Savelsberg et al. 2000; Samuelsen 2001).
- <sup>13</sup> In many contexts the diagnosis of life threatening disease is withheld from patients in order to protect the patient (Lupton 2003, 71).
- <sup>14</sup> In certain contexts words and naming have the power to harm and even spread misfortune (*xinyama*, lit. shadow or cloud) (See for example: Chapman 2006). Witchcraft could also occur through cursing and through talking. For example, I was often warned to avoid talking to strangers who may greet me and thereby steal my money using magic (*saramusi*). By opening the mouth the unsuspecting victim allowed the thief to transport the money into their pockets, replacing it with useless newspaper.



- <sup>15</sup> This refers to the practice of women making certain forms of knowledge of female physiology and reproduction secret in order to maintain control over this aspect of their lives, and exert some power over men (See for example: Browner & Perdue 1988).
- <sup>16</sup> This evokes the infamous scene from the film *Aliens* (Ridley Scott, 1979) in which an alien bursts out of the chest of one of the crew members.
- <sup>17</sup> A similar interpretation is offered by Jackson (2005, 332) who notes that in relation to chronic pain sufferers: ‘transitional states and ambiguous beings and objects, being neither one thing nor another, are disturbing and threatening; I argue that chronic pain sufferers’ liminal status invests them with similar threatening powers’.
- <sup>18</sup> Funeral ‘culture’ has been transformed in many settings from the high death toll due to AIDS (See for example, Kiš 2007).



**Picture 7: Mourners hasten to the graveyard – heads covered to show respect  
(Photo: Jonathan Stadler)**



**Picture 8: The hearse leaves the mortuary (Photo: Jonathan Stadler)**



**Picture 9: Witnessing a burial (Photo: Jonathan Stadler)**