

## CHAPTER ONE

### INTRODUCTION

#### THREE FUNERALS AND A PARTY

SisMinah Khomani (58 years old) sat in her front yard holding her three-year old granddaughter in her arms, spoon-feeding her soft porridge. The infant was unwell and SisMinah was worried; the girl suffered persistently from diarrhoea and vomiting. Her constant illnesses affected her physical development; she was small for her age and could barely support herself on her puny limbs. The child's father had died shortly after she was born. Neither SisMinah nor Susan (the child's mother) attended his funeral nor did they visit his grave to pay their respects. Contrary to custom the family did not inform SisMinah of his death until after the funeral. SisMinah recalled that this had hurt her deeply; it was as if they blamed her for the death of their son. That day SisMinah confided to me in a whisper that Susan too was very ill but refused to seek care. Susan never spoke to me and usually hid away when I visited her mother. At SisMinah's request, Susan eventually agreed to come with me to a hospital located 20 kilometres from SisMinah's home<sup>1</sup>. Susan and her daughter were tested for HIV in the hospital clinic. After a long day of waiting in queues they were given an assortment of pills for herself and bottles of syrup for her daughter.

Soon after our trip to hospital, SisMinah's granddaughter died. Unable to afford a wooden coffin, SisMinah buried the tiny corpse in a cardboard box. A neighbour offered

her R100, and asked the other funeral attendees to donate money to buy a proper coffin. However, it was late and SisMinah was keen to complete the ceremony. The burial took place at the communal graveyard sited between the village and the open bush. When they returned to SisMinah's homestead, the small gathering ate bread with sweet black tea. By nine o' clock in the morning the funeral was over. Susan remained indoors the entire time.

These events occurred in January 2002, long before the widespread provision of antiretrovirals (ARV) to treat AIDS. About 18 months later I heard that SisMinah was ill. When I visited her she complained of aching legs and head pains. She started to make mistakes at her employer's house in Hoedspruit where she worked as a domestic assistant; she burnt the ironing and then ruined supper after she passed out at the stove. Her employer dismissed her without paying her wages.

The Khomani household depended on hand-outs from neighbours. Almost daily SisMinah crossed the road to ask for maize meal, sugar and tea from her neighbours. The family ate porridge with okra (*guxe*) and bitter spinach (*kaka*) that grew wild in her garden. Close to tears she described how her neighbours had loaned her food on so many occasions she feared that she had overstretched their generosity. She laughed bitterly as she recalled the R50 bridewealth (*ndzovolo*) her estranged husband had paid, and then left her to look after his four children. Her husband was an abusive man: once he stabbed SisMinah in the leg and punched her in the neck.

Over the next few weeks, SisMinah's illness steadily worsened. Eventually she retreated from her patch of shade under the tree in the yard to lie in her room. She complained of dizzy spells and aching bones which she attributed to 'high blood'

(hypertension) and ‘nerves’ because, as she put it, of ‘thinking too much’. She was admitted to hospital and placed on an intravenous drip for two days after a severe bout of vomiting and diarrhoea. The nurses confided to a neighbour who visited SisMinah: ‘we just want to tell you that your sister [friend] is HIV positive’. To me, SisMinah said:

I am dying. Since I became sick I will never become better again. I am just waiting for the day [I die]. I can’t eat beef, even chicken. I can only eat fish and *guxe* [okra]. Ha! They sent me to the AIDS people [clinic]. Agh! Even if people think I have AIDS I don’t care.

NwaSamuel, SisMinah’s neighbour, was indignant that SisMinah did not tell her that she had AIDS. Over the fence dividing the two properties NwaSamuel shouted in the direction of SisMinah’s room: ‘You don’t need to hide this disease. Hey you! Why were you hiding from me! This disease is not something you can hide. It will show itself and then you cannot hide anymore’

SisMinah’s closest friend, also a domestic worker, NwaMbembe confessed to me that she was terrified that she may also be infected. SisMinah and NwaMbembe occasionally had sex in exchange for beer with farm labourers, flush with cash after pay day, on the grassy pavement outside Wings, a tavern frequented by soldiers and working men in the small town of Hoedspruit. NwaMbembe recalled ‘Mr Jersey’ (*Manjezi*) the name given to a white railway employee who had sex with farm workers and domestic workers in exchange for jerseys worn by railway employees.

The evidence seemed to point toward SisMinah having acquired HIV from one of these sexual contacts. However, another woman speculated that it was possible that SisMinah acquired HIV from handling her granddaughter, accidentally coming into

contact with her bodily fluids. Either way, SisMinah's illness settled uneasily in the minds of her neighbours and friends.

A few months after these conversations I was surprised to see a party in full swing in SisMinah's front yard. Meat was roasting on a fire and a large pot of porridge (*pap*) was on the boil. The party was for Dudu, SisMinah's youngest daughter, who had turned 21. The birthday girl was dressed in high heels, a black mini dress and wore multi-coloured hair extensions. Loudspeakers were pumping *kwaito* music<sup>2</sup> and youths were jiving, holding ciders and beers and plates of food, chanting 'yes, yes, yes'. SisMinah made a brief showing at the party. Her daughters dressed her in a clean white blouse, blue pleated skirt and matching hat, and positioned her on a chair, under the shade of a tree.

SisMinah's neighbours were shocked by her daughter's behaviour in the presence of their mother's suffering. Earlier that day, two neighbours suggested to Dudu that it was disrespectful to hold the celebration. Dudu rebuked them and said she was 'happy her mother was dying' because she would no longer have to bear the humiliation of seeing SisMinah begging food from her neighbours. She even accused her neighbours of jealousy, insinuating that they wanted to bewitch her, and more ominously, that they had bewitched SisMinah. I shared in the older women's indignation at this insensitive display.

Later, I realised the significance of the party and its juxtaposition with the terrible predicament of SisMinah's small household. The consumption of feast food countered the image of SisMinah going from house to house with an empty tin begging for maize meal. The dancing and celebrations erased the memory of the pathetic cardboard-box funeral held for SisMinah's granddaughter. The party was a rebellion against suffering and poverty, a refusal to accept this fate, to be defined as 'the poorest of the poor'. Dudu

had (as the slogan goes) ‘declared war on poverty’, and the disease that was destroying the family.

In the months following the party SisMinah hid away and died a slow and painful death. She was buried by her children. In Johannesburg, a while after my final visit, I heard that SisMinah’s daughter, Susan had also died. She was taking antiretroviral (ARV) tablets sponsored by the United States Agency for International Development (USAID) but apparently ‘threw her pills away’<sup>3</sup>. According to my informant, Susan did not see any point in continuing to live. She no longer had a child to support. Her funeral was described as ‘decent’. Susan used a portion of her state welfare disability grant to contribute towards membership of a burial society.

This account of three generations of AIDS death reveals the horrendous and destructive impact of the epidemic. Over a period of about two years almost half the membership of the Khomani household died from the same disease. At the same time, the responses to illness and death, as vigorously asserted by Dudu’s party, articulated in the words of SisMinah, and perhaps in Susan’s refusal to take her ARVs, actively resisted and redefined their suffering. In essence, the act of forgetting illness and death allowed life to proceed.

In thinking about this tragedy and the reactions of household members, neighbours and friends, I am reminded of Scheper-Hughes’ accounts of premature death in North Eastern Brazil. In the following vignette she writes about the death of an infant juxtaposed with a child’s birthday party:

The cake was baked and decorated, a few balloons purchased, coca-colas were lined up and ready. The infant in its cardboard box was prompted up on the table

next to these party favours, and the birthday well-wishers came and celebrated Patricia's birthday while barely noting the dead baby as the counter-centrepiece to the birthday cake (2008, 44).

Scheper-Hughes argues that actions such as this reveal the normalisation of suffering and peoples' resilience to extreme adversity. She concludes:

...while theories of human vulnerability and trauma acknowledge the weight of the world on the lives of the poor, the excluded, and the oppressed, human frailty is matched by a possibly even bio-evolutionarily derived, certainly historically situated, and culturally elaborated capacity for resilience. While for many years searching in the nooks and crannies of oppressed and excluded communities for political mobilizations and organized resistance in the face of terror as usual, I found, instead, forms of everyday resilience (2008, 52).

Similarly, I am drawn to understanding peoples' responses to suffering in the midst of a devastating epidemic, of debilitating illness and death. The history of AIDS in South Africa is one marked by fierce opposition to state policy that withheld lifesaving drugs to treat AIDS. Although the story of the prominent political struggle between AIDS activists such as the Treatment Action Campaign (TAC) and the South African state are worthy of social analysis, I am more concerned with ordinary peoples' quotidian struggle for survival.

In Bushbuckridge where my research took place, AIDS is ubiquitous yet concealed and censored in public: the bodies of the AIDS ill, and talk about the disease are hidden. The public silences deny the reality of the horrendous illnesses, deaths, and the implications this has for the living. This has significant public health implications for diagnosis, prevention, treatment, and community mobilisation.

This thesis chronicles what the silence and concealment of AIDS means for HIV spread, illness and death. I argue that despite the silence and concealment surrounding AIDS, subaltern forms of social discourse such as gossip, rumour and witchcraft beliefs are strategies employed to manage the effects of the epidemic, albeit not always successfully. These strategies and their deployment reveal the agency of the most vulnerable.

In the following I explore social responses to AIDS in the anthropological and public health literature, describe the research context and end with an account of the research process, stressing the value of the ethnographic perspective in AIDS research.

## **THE PARADOX OF AIDS IN SOUTH AFRICA: DENIAL, FATALISM AND CULTURE**

The end of apartheid was a historic and momentous moment in the life of South Africa. But our suffering has not ended. Just as we were bringing to a close a terrible chapter in our history, another crisis was just beginning. Back in the 1980s, in the midst of our struggle against apartheid who could have foreseen that another tragedy that of HIV/AIDS was just starting to unfold? (Desmond Tutu, Archbishop Emeritus, July 2003, Cape Town cited in: Kauffman & Lindauer 2004)

(...) in developing countries this silence [about HIV] is even more oppressive because it is mixed up with the pathologies of poverty and deprivation: gender inequality, illiteracy, violence against women, acquiescence to undemocratic powers of chiefs and unelected rulers. Further, people whose poverty often means that they are already beset by disease make an easier accommodation with a new disease, even HIV. For the poor, the aetiology of a disease may be irrelevant if the symptoms and causes are much the same (Heywood 2004, No page numbers).

At the same time as South Africa achieved political liberation in 1994, the country has been consumed by the spread of HIV and death from AIDS. An estimated 5.4 million

people out of 48 million are infected with HIV (Dorrington et al. 2006). Furthermore, the forces that were engaged so successfully in the struggle against apartheid have not mobilised around the battle against AIDS (Karim & Karim 2002, 40). Instead, the optimism surrounding the birth of the new democratic South Africa has been steadily worn away by the AIDS epidemic (Fassin 2003). As Fassin notes: ‘the spectacular spread of the epidemic in the past decade, runs in terrible counterpoint to the happy narrative of national reconstruction’ (Fassin 2007, xvi). Although apartheid is no longer, the AIDS epidemic reveals the resilience of social inequalities; the indigent experience worsening poverty resulting from AIDS illness and death and new forms of discrimination emerge, directed at people infected and affected by AIDS. ‘AIDS is the new apartheid’ declared Archbishop Desmond Tutu (Independent Online 2001).

In 2003, twenty years into the AIDS epidemic the response of the South African government to this crisis was completely inadequate, marked by public denial, conflict, and delays in implementing prevention and treatment. This resulted in thousands of preventable deaths. These failures are largely attributed to South African AIDS policy under the government of Thabo Mbeki, the former president of South Africa. Yet, apart from vocal opposition from AIDS activist movements such as the Treatment Action Campaign (TAC), the massive threat that AIDS poses has not engendered widespread public action at the local level. Indeed, despite the overwhelming visibility of AIDS, South Africa ‘has been produced as a site of secrecy, silence and denial’ (Reid & Walker 2003, 85). Only in 2004, South African AIDS policy underwent a complete transformation: antiretroviral drugs to treat AIDS began to be rolled out in the public



sector and provided for free to patients. AIDS was recognised as a disability and government sponsored cash grants were provided to patients meeting the requirements.

### **Silence as denial**

Denial is seen to underlie the partial and incomplete silences and veiled communication about dreaded and incurable diseases. This is often inferred from speech that avoids direct mention of the disease. For example, cancer is seldom mentioned by name but by euphemisms such as the big ‘C’ (Balshem 1991; Sontag 2001). In South Africa, AIDS is referred to as ‘the three letter disease’, ‘three numbers plus bonus’ (a winning score in the lotto), a BMW Z3, OMO (a brand of washing powder), House In Vereeniging (spells out the acronym HIV) (Stadler 2003a).

These verbal avoidances are mirrored in performances of suffering; AIDS sufferers are concealed in homes, hidden from the public view, and alienated from society (cf. Nzioka 2000). This is also reflected in society’s attitudes toward people living with AIDS. For example, in a survey published in 1992, 38% of those interviewed expressed the opinion that people living with HIV/AIDS should be separated from society (Stadler 2003b).

Denial of the biomedical reality of HIV has special significance for public health and disease control, as is apparent from the uptake of HIV testing. For instance, in a survey of 2 500 residents in the mining town of Carletonville, respondents were offered free and anonymous HIV testing but not a single person volunteered (Ashforth 2002). Denial also impacts on disclosure of status. In a survey of 726 HIV positive patients, 92% had not told anyone of their status (Pawinski & Lalloo 2001). Patients often opt out of

receiving results of their tests, seriously undermining the effectiveness of treatment programs (Doherty et al. 2005). Ironically, health policy and medical practice actually reinforce secrecy. In South Africa, AIDS is still not a notifiable condition, despite various attempts to implement notification (Sidley 1999)<sup>4</sup>.

The maintenance of secrecy has had a direct impact on the effectiveness of providing treatment to prevent the transmission of HIV from mother to child (PMTCT). Pregnant women who test positive for HIV during antenatal care visits are scheduled to enter the PMTCT programme. Their clinic cards contain vital information relating to their pregnancy, including HIV status encrypted using an alphabetical code that uses the first name of their maternal grandmother as the key to unlock the code. This is not a fail-safe system and results in many pregnant women being miss-identified<sup>5</sup>.

Kubler-Ross (1970) classified ‘denial’ as the first of five psychological stages that individuals experience when faced with extreme trauma and knowledge of impending death. Denial prevents one from thinking about reality and therefore reduces stress and anxiety; it acts as a mental ‘buffer’ (cf. Brandt 2008, 14). This is thought to have a direct bearing on individual behaviours. A person may be aware of the dangers that a particular behaviour poses, but chooses to expose themselves to these dangers due to their being ‘in denial’. Therefore, the concept of denial is able to explain the apparently irrational behaviour of individuals who knowingly have unsafe sex. The widespread nature of denial is explained by its manifestation as ‘collective denial’. This occurs when a threat such as AIDS is highly prevalent, or where stigma is strongly associated with the threat (Parker & Aggleton 2003).

However, to assume that the absence of explicit discussion about HIV/AIDS is denial can be misleading (Wood & Lambert 2008). Moreover, denial may be better explained, not only as personal disbelief, but due to social and economic context. Soboo (1995) explores the political and economic ‘logic of denial’. Her research amongst inner city women in the US focussed on the social and economic context of women’s everyday lives in understanding their denial of personal HIV risk and their resistance to condom use. Risk denial is actually encouraged by AIDS education messages that recommend condom use in the context of ‘multiple partners’, ‘casual sex’ or ‘unfaithful lovers’. Women invest in a ‘monogamy narrative’ characterised by love and trust, in terms of which condoms are inimical.

What is classified as denial may constitute resistance against the stigmatising character of biomedical categories that promote blame; for example Haitian conspiracy theories of AIDS are counter discourses against US categorisations of Haitians as the dangerous other (Farmer 2005). Similarly, Mbeki’s questioning of the causal link between AIDS and HIV can be seen as attempts not to deny but to actively *resist* the allocation of blame on black<sup>6</sup> South Africans. In particular, Mbeki sought to resist the idea that Black South Africans spread AIDS because of uncontrollable sexuality (Schneider & Fassin 2002).

Furthermore, the interpretation of public silences literally as denial ignores the social and cultural meanings of silence. For example, McNeil (2009) argues that the reading of public silences of AIDS as collective denial risks simplifying a far more complex issue. The silence surrounding AIDS reflects conventions of silence that

surround death in general. In this sense, McNeil suggests, silence is a protestation of innocence of personal culpability.

### **Silence as fatalism**

A related concept that is used to explain why people fail to react to the threat of AIDS is that of fatalism, hence the use of the term ‘AIDS fatalism’ in the literature. As a cognitive-behavioural construct, fatalism is linked to hopelessness, and a lack of self-efficacy to change and conceptualise a future. A South African study found that 30% of respondents aged 18 years and over who reported fatalistic views about AIDS also ‘lacked self-efficacy’ and expressed hopelessness (Meyer-Weitz 2005). Fatalism is seen to predispose individuals against behaviour change (cf. Hess & McKinney 2007), limiting an individual’s ability to act on personal intentions (Paiva 2000). In public health discourse, fatalism is opposed to the adoption of ‘healthy lifestyles’. This is articulated as a struggle between modern rational knowledge and ‘an atavistic culture of “fatalism”’ that must be destroyed and replaced by a lifestyle approach to health (Davison et al. 1992, 676).

Caldwell *et al.* (1992) propose a cultural basis to fatalism. They argue that according to African beliefs in witchcraft and the ancestors, destiny is predetermined, and ‘outside the control of individuals’ (Caldwell et al. 1992, 1175). Therefore, the ‘extraordinary stoicism about death’ in African societies needs to be understood in the context of a belief in ancestral spirits and ‘survival after death in one form or another’ (Caldwell et al. 1992, 1178). Similar ideas appear in various guises in other writings. Kaler’s Malawian male informants define fatalism as inevitability: death is ordained from

God or witchcraft or vengeful spirits (2004, 290-291). Liddell *et al.* (2005) argue that beliefs in malevolent forces such as witchcraft shape a fatalistic outlook.

Fatalistic world-views are particularly manifest in societies that are oriented around the ‘image of limited good’ following Foster’s (1965) formulations. Everything good is seen to exist in limited quantities, and ‘God’s will’ determines individual fate; one person’s good fortune represents another’s loss. This outlook is thought to result in a lack of progress and change. Applying this idea to health, Nations & Rebhun (1988) surmise, ‘this cognitive orientation leads to a resignation toward sickness, a view of it as a punishment from God, and a consequent lack of whole-hearted attempts to treat it’. Scheper-Hughes (1992) argues that fatalism underlies maternal neglect of weak infants; extreme poverty compels mothers to selectively neglect their children, nurturing those who are seen to be likely to survive and neglecting those who they believe will die. Scheper-Hughes’ perspective has attracted criticism, largely because it ignores the material barriers to care seeking as well as the extent to which women will go to try to save their children’s lives (Nations & Monte 1996; Nations & Rebhun 1988).

The concept of fatalism has been drawn on to understand peoples’ apparent lack of will to mobilise against the AIDS epidemic. For instance, Leclerc-Madlala (2005) suggests that South Africans are highly fatalistic as a nation. She argues that fatalism is

Inevitable in societies beset by daunting and uncontrollable forces. Fatalistic attitudes coupled with a careless and reckless approach to life and the desire of some people not to “die alone” which further adds to the spread of AIDS’ (Leclerc-Madlala 2005, 855-856).

Campbell (2003) suggests similarly that fatalism is related to peoples' sense that they lack control over their lives. Fatalism, she suggests

... may be particularly common among people who are persistently faced with difficult life situations over which they have little control, or who have had few experiences of situations in which they have succeeded in meeting their hopes or achieving their aspirations (2003, 183)

Therefore, the life experiences of men and women of desperate poverty, disempowerment and exploitation engender world views of limited control over the self.

The material circumstances of sexual relations may also cause fatalistic attitudes. Unprotected sex in exchange for material support may be the only means for women's survival (cf. Preston-Whyte et al. 2000). For men, multiple sexual relationships are the sole means through which they are able to assert their masculinity (Campbell 1997). In situations of extreme poverty and dire need, AIDS becomes secondary to the more pressing demands of simply surviving day-to-day life. For example, boys who live on the streets in Mwanza, Tanzania regard HIV/AIDS as a distant threat in comparison to the more immediate threat of starvation and violence and will therefore risk HIV infection through commercial sex (Lockhart 2002, 2008).

The idea of 'AIDS fatalism' is derived from the 'culture of poverty' model, according to which structural impediments form barriers to people being able to change their lives or even wanting to change. AIDS is experienced as yet another hardship endured by the poor and oppressed against which they are powerless. And, impoverished people do not invest in their health because they have so little to lose (Oster 2006).

A critical failing of the ways the concept of fatalism has been applied lies in the underlying assumption of cultural conservatism. To paraphrase Herzfeld (1982) who writes on modern Greek society, fatalism is regarded as a ‘passive resignation to the future dictates of chance’. This suggests a certain backward looking-ness, ‘the worst kind of inefficiency’ that stands against progress. It is a ‘rigid barrier’ to the ‘practical’, implying that people are caught up in culture and tradition, or ‘cultural sclerosis’ (Herzfeld 1982, 644). In contrast to these orientations Herzfeld proposes that statements about fate and destiny may reflect the incorporation of new ideas and experiences into already existing and familiar ways of seeing the world. Furthermore, rather than asking how fatalistic statements about life shapes social and personal action, the question is how such ‘declarations about fate constitute a form of action’ which Herzfeld calls the ‘performative action of excuses’. These are performances that ‘invoke the idea of fate through oblique allusion’ (Herzfeld 1982, 657).

Statements that allude to fatalism do not necessarily reflect a fatalistic attitude or disposition, or indeed predict behaviour. For example Balslem (1991) points out that the apparently fatalistic statements about cancer in working class American society can be interpreted as ‘purposeful acts in a discourse of resistance’ (Balslem 1991, 153):

...the community view is tied to strong feelings about access to power in society. Community members are disinclined to accept their assigned position as "targets" of a health education campaign. They have seen themselves labelled sick and they have turned this around to label their social and material environment sick. They have considered blaming themselves as victims, and they have rejected the notion. Scientific authority, clearly, does not consider their interpretations of experience valid. So they use rhetoric about fate as a shield, and charge the scientists with hubris (Balslem 1991, 165)

Statements about fate may be regarded as irrational and conservative, yet can be employed as rhetoric in contestations between Western biomedicine and ‘local’ knowledge. Implicit in this is a particular use of the concept of culture, often employed in public health and anthropological writings on AIDS.

### **Culture, AIDS and blame**

Culture often features in explanations for the apparent lack of change of sexual behaviours in sub-Saharan African society in response to AIDS and the continued high prevalence of HIV infections in the sub-continent (Marshall 2005, 2520). For example, researchers have focussed on witchcraft (Mshana et al. 2006; van Dyk 2001; Yamba 1997), and traditional healing (Green 1994; Peltzer et al. 2006). Sexual behaviours are also believed to be strongly influenced by traditions such as widow cleansing by having sexual intercourse (Campbell & Kelly 1995; Chipfakacha 1997), the levirate and sororate (Sow & Gueye 1998), polygamy (Cleland & Ferry 1995), bridewealth transactions (Wojcicki et al. 2010), and sexual promiscuity (Caldwell et al. 1989). Therefore the failures of disease prevention are conceptualised as African cultural failures to respond to prevention messages (Heald 2006, 30).

This analysis influences policy, directing resources toward combating cultural practices and traditions. For instance a recent report published by the United Nations Economic Commission for Africa asserts that culture plays a ‘major role’ in ‘gender inequalities’, ‘wife inheritance and widow cleansing’, ‘polygamy’, ‘domestic violence including marital rape’, and ‘harmful practices like female genital mutilations’ (Commission on HIV/AIDS and Governance in Africa 2008, 18-20). The report



specifically focuses on risky sexual practices, their link to culture, and the need to change cultural practices to reduce the spread of HIV on the continent.

Culture is further thought to promote unsafe sex. ‘Dry sex’ which causes vaginal lesions creates an entry point for HIV is believed to be a cultural preference of men in Africa (Brown et al. 1993; Brown & Brown 2000; Runganga & Kasule 1995; Van de Wijgert et al. 2001). And as a result of patriarchy and male dominance, women are seen to be unable to insist on condom use (Campbell 1995). A strong link is made in the literature on AIDS in South Africa between culture and the risk of HIV acquisition. For example, Leclerc-Madlala (2001, 41) writes that ‘Zulu sexual culture’ is characterized by:

...gender inequity, transaction sex, the socio-cultural *isoka* [masculine] ideal of multiple sexual partnerships, lack of discussion on matters of sexuality in the home and between sexual partners, the conditioning of both men and women to accept sexual violence as “normal” masculine behaviour along with the ‘right’ of men to control sexual encounters, and the existence of increasingly discordant and contested gender scripts.

Anthropologists have questioned and critiqued the exclusive focus on culture in explaining the spread of AIDS (Gausset 2001) and discuss social, economic, political (Farmer 1992; Parker 2001; Schoepf 1995) and biological factors (Stillwaggon 2002, 2003). The adoption of ‘culture’ as a variable detracts away from examining how political, economic and social processes influence the ways in which a disease spreads and the response to the disease (Parker & Harper 2006); a failure to recognise the political economy of AIDS (Farmer 1992; Schoepf 1995; Setel 1999), and the social contexts in which HIV transmission occurs (Delius & Walker 2002).

Perceiving the spread of HIV as a problem of culture effectively de-politicises the AIDS epidemic. Blame is directed toward local cultural knowledge and practices. And, by insisting that biomedical knowledge and technologies can alone provide the answers the focus shifts away from peoples' everyday struggles.

The thesis provides an alternative reading of the social response to the AIDS epidemic by exploring the social meanings of silence and censorship, avoidance and concealment of AIDS. Although these discourses appear to deny and suppress the reality of AIDS, I suggest that they are active attempts to deal with the AIDS crisis: gossip and rumour allocate blame and construct a local epidemiology through which the epidemic can be monitored; interpreting AIDS as witchcraft creates the possibility of avenging death. These discursive forms are critical in informing individual and social responses to the AIDS epidemic. While the absence of public acknowledgement of AIDS as a cause of illness and death suggests denial and fatalism and appears to limit public action, subaltern discourses create shared secrets to manage the AIDS epidemic at the local level. Furthermore, these discourses may constitute a form of resistance against biomedical models of causality.

### **AIDS IN BUSHBUCKRIDGE**

The effect of the AIDS epidemic in Bushbuckridge is visible even to the most disinterested observer. By the early 2000s, the impact of the disease was particularly evident in the growth of a local AIDS industry. Newly established funeral homes and mortuaries jostled for space near hospitals and shopping centres. A prominent businessman and also a (somewhat distasteful) medical doctor established a massive

mortuary where there once was an open field. Such growth was also evident in the mushrooming of organisations with complicated acronyms geared toward AIDS care and treatment and HIV prevention. The Bushbuckridge Health and Social Services Consortium (BHSSC) provided counselling and condoms, loveLife erected billboards and walk-in youth centres, the Health System Development Unit (HSDU) conducted intervention research projects. Numerous village-based organisations were established with funding from the Department of Health and Welfare to generate incomes for those households infected and affected by the AIDS epidemic.

Funeral processions choked the roads on Friday afternoons delivering bodies to all night vigils. Burials occurred daily even on Christmas and New Year's Day. The scene was comparable to the aftermath of the terrible tsunami of 2004, yet the effects of AIDS were far more far-reaching. I was told about shocking scenes in state mortuaries with bodies stacked on top of each other; and of a funeral home that resorted to hanging corpses on meat hooks to save space. The health services were unprepared to cope with the rising numbers of patients. The sick were often sent home from clinics with little more than 'Panados' (headache tablets). Hospitals were 'places to die'<sup>7</sup>. Nursing staff were rumoured to be in league with mortuary owners; to boost profits they suffocated or poisoned the terminally ill to hasten their deaths<sup>8</sup>. The ill and the dying were neglected and alienated by their own kin who appropriated and squandered their inheritances. Attempts to prevent the spread of HIV were perceived as futile: condoms were believed to be contaminated with HIV; infected persons purposefully spread the virus so 'not to die alone'; there was no guarantee that sexual partners would remain faithful; rape was

commonplace. The picture of AIDS in Bushbuckridge was of a ‘hopeless epidemic’ (cf. Smith 2003), one of passive resignation and acquiescence to the most extreme suffering.

What was most striking was that AIDS was not even spoken about publically as a threat to public health or well-being. Suffering was performed in secret and the sick and dying withdrew from the social world, becoming ‘living corpses’ (cf. Niehaus 2007). Actual mention of AIDS was carefully avoided, expressed through metaphor, and buried within rumour and neighbourhood gossip (Stadler 2003a). The silencing of AIDS created considerable barriers to public action against the epidemic. Despite efforts to educate and inform, the image of coherence that is so often projected in biomedical and epidemiological constructions of the epidemic was not shared at the local level. AIDS was imbued with multiple, contradictory meanings. The silences and ambivalences that surrounded AIDS challenged biomedical sureties and epidemiological confidences (Setel 1999, 184).

The reaction to the AIDS epidemic is puzzling in the light of a recent history of community mobilisation in response to other social injustices and crises amongst residents of Bushbuckridge. Political activism in the area was relatively low-key in comparison to other areas of the country up until the mid-1980s and early 1990s. In this period, witch-hunts occurred sporadically throughout this period as groups of self-identified ‘comrades’ sought to purge the communities of witchcraft (Niehaus 2001). Their actions gained popularity in the face of rising tensions, unexplained misfortune, illnesses and death. In some parts of Bushbuckridge, vigilantes patrolled the streets to protect residents against thugs and rapists as a response to the failure of the authorities to effectively protect residents (Ritchken 1995). On the eve of political liberation, school

children revolted against the use of corporal punishment in schools and called for an end to the repressive ‘Homeland’ government (Stadler 1995). Political activism did not fade after the 1994 elections; in 1997 residents of Bushbuckridge led violent protests against their incorporation into the Limpopo Province (Niehaus 2002b; Ramutsindela & Simon 1999) .

In contrast to these instances of activism, the public response to the AIDS epidemic is little more than a murmur. Unlike the deaths associated with the struggle against apartheid, deaths from AIDS are devoid of meaning; they occupy spaces external to the body politic. For example, former anti-apartheid activists are recognised by the naming of public spaces; for example Matsikitsane View in Green Valley<sup>9</sup>, the Merriam Mogakane Hall, and the Matthews Thibela branch of the African National Congress. The ‘fallen heroes’ of the anti-apartheid struggle are also resurrected in political speeches. In his public address, the Mayor of Bushbuckridge, Miton Morema listed those ‘cadres who died in action’ and asked that ‘their revolutionary spirit continue to bless the unity of the people of Bushbuckridge for sustainable service delivery and development’. In contrast, Morema mentioned AIDS only fleetingly, tagged onto a public service announcement about drink driving:

Please always arrive alive. Don’t drink and drive and speed kills. Always apply ABC as HIV/AIDS is still a monstrous killer. Let us test to know our HIV status and be counseled (Morema 2011).

The obfuscation of AIDS is particularly poignant in the silences in the numerous funerals of young men and women who embody the promise for the future survival of households, and in whom huge investments have been made. Funerals are public rituals,

well attended sometimes by thousands of people. This stands in stark contrast to the hasty and almost hidden funerals such as those held for SisMinah's granddaughter.

It is this contradiction between the high visibility of AIDS, its omnipresence and at the same time, its public censorship that shaped the contours of my research and lies at the heart of this thesis.

The reasons for these responses can be analysed from many different perspectives. Biologically, HIV is an invisible infection. Although the mode of HIV acquisition is commonly recognised as sexual, the paths of HIV infection are seldom visible. HIV infections only become realised when individuals test or when infections manifest as illness and death. Yet, the point of infection and illness are events separated in time; 'the epidemic silently creeps through the population', only later manifesting itself years later as actual illness and death (Whiteside et al. 2002, 1). Personal risk of infection is therefore seldom self-evident; it is hidden from view and lies outside the immediacy of personal sexual relations. Therefore, despite epidemiological sureties (Setel 1999), the delinking of infection from illness and asymptomatic carriers creates the space and indeed the need for alternative interpretations of the illness and deaths that result from AIDS.

Second, the diagnosis of AIDS has massive implications for social relations among the living. As the account of the Khomani family shows, AIDS does not only infect individuals, but affects relationships between spouses, lovers, parents and children, and neighbours. Revealing HIV and AIDS threatens to expose the failure of intimate relations, kinship and good neighbourliness. Concealment is therefore also a strategy to avoid the potential conflicts that can arise from a HIV positive diagnosis. Yet, acts of

concealment also generate suspicion and tension, and ultimately reveal that which is supposed to be secret.

Third, because AIDS is concealed and unmentionable, it is impossible to deal with the threat it poses. To accuse another of infecting oneself or others with HIV is to confess to have been infected, and to experience shame and social death. This presents a conundrum: how can one know about something that is not even acknowledged? And how can one act against a threat that is rendered invisible?

As I found out quite soon into my fieldwork, the silence and concealment of AIDS also poses particular challenges to doing research.

### **DOING ETHNOGRAPHY IN AN EPIDEMIC**

Several years ago, the anthropologist, Ralph Bolton (1995) charged anthropology with an inadequate response to AIDS. To a certain extent his criticism holds true today. Despite the massive literature on AIDS in the social sciences, very few full length ethnographic studies of AIDS have been produced<sup>10</sup>. Initially, the absence of anthropology from the AIDS research field may have something to do with an anthropological disinterest in researching sexuality. Anthropological research focussed on the observance of public behaviour; sex as a private behaviour was hidden from view, and lay outside of the observational gaze. Despite the apparently open nature with which anthropology dealt with conventionally taboo topics (Lindenbaum 1991; Vance 1991), surprisingly few shared Malinowski and Mead's enthusiasm (For example: Malinowski 1929; Mead 1928) for researching sexuality (Sanday 1996)<sup>11</sup>.

While anthropology was initially slow to respond to the challenge of research on AIDS in the early 1980s, this changed rapidly with a growing interest within biomedical research on sexual behaviours and meanings between different ‘cultural groups’ (Marshall & Bennett 1990). This research has produced an agenda that, as Fassin (2007, 25) bluntly states, focuses on the ‘customs of the natives’ that promote the spread of AIDS and anthropological knowledge tends to be exoticized. Farmer (1997, 517) agrees:

The Scenario most commonly evoked was one in which ethnographers, steeped in local lore after years of participant-observation, afforded epidemiologists and public health authorities detailed information about sexual behaviour, childbearing, and beliefs about blood and blood contact. This knowledge transfer was held to be indispensable for determining which "behaviours" put individuals and communities at risk for HIV infection.

Mimicking these international trends, South Africa has produced very few anthropological studies of AIDS, and even at the height of the epidemic displayed a disinterest in studying the epidemic. In 2003, at the conference for the Association for Anthropology in Southern Africa (AASA), only two presentations based on original research were about AIDS<sup>12</sup>. This situation has since changed, perhaps in response to the availability of funding for AIDS research in the social sciences, but also since the topic has become more topical.

South African writings on AIDS have tended to focus on the public and political contestations between the Treatment Action Campaign (TAC) and the state (For example: Fassin & Schneider 2003; Hoad 2005; Robins 2006; Schneider 2002). This body of research is important, yet tends to exclude the experiences of ordinary peoples’ everyday



lives, the ‘ordinary experiences of AIDS, the most personal, intimate suffering’ (Fassin 2007, 276-277).

AIDS research tends on the whole to favour epidemiological and behavioural approaches. Anthropological methods and approaches do not always suit the AIDS research agenda that is preoccupied with an urgent need to find solutions. Short-term consultancy research typically employs knowledge, attitudes, and sexual practices (KAP) surveys to provide quick answers. Yet, there is growing recognition of the limitations of surveys. Surveys often fail to reveal why ‘practices’ seem to contradict ‘knowledge’, as these methods lack insight into the context of knowledge and action. Qualitative methods such as focus groups and structured interviews are employed to fill this gap. However, these methodologies construct artificial settings for the research (cf: Heald 2006, 31). Consequently, the data that results often reflects the perceptions of the researchers rather than the experiences of the research participants.

In contrast to these rapid methodologies, ethnographic research is long-term and takes place in natural settings. Ethnography strives to locate the actions of individuals within the cultural context that gives them meaning and that of the political and economic setting that structures everyday life experience.

Moreover, insights into suffering and the daily struggles of life are possible only from the researcher’s personal involvement in the ‘quotidian life - the humble, familiar, and mundane aspects of everyday experience’ (Green 1998, 3). Anthropological research is an attempt to articulate the complexities and the contradictions of peoples’ lives and by doing so anthropologists become part of the lives that they are researching. Upon return from the ‘field’ we have two languages: the language of theory and also the ‘language of

peoples' practices' (Green 1998, 6). The challenge is to try to make linkages between these two perspectives.

Anthropology also stresses reflection and introspection. The research process is an extremely personal experience, influenced by who we are and our own histories. This shapes the questions we ask and influences the way we make sense of what people say (Clifford & Marcus 1986; Marcus & Cushman 1982).

The personal account of my research begins in 1990 when I first came to the Bushbuckridge area as a post-graduate student in anthropology. Over a two-year period I spent eight months conducting research on generational relationships. My research was concerned with youth participation in popular resistance against apartheid and the impact this had on domestic relationships, intergenerational struggles and negotiations over authority. I was particularly interested in the use of tradition in contestations over generational authority within the public and domestic spheres of life (Stadler 1995).

When I completed my research I worked for the Witwatersrand University Rural Facility (WRF), located a short distance from the village where I had done my research. The WRF aimed to create a learning environment for students from the university and thereby encourage professionals to work in the area on community development projects. However, by 1995 when I left WRF, I was disillusioned with the idea of 'community development'. The research and development agendas promoted by the projects implemented by WRF seldom directly addressed the basic needs of the villagers who were targeted by their projects. For example, using biogas (from fermenting cattle dung) as an alternative energy source ignored the realities of imminent electrification in the area and the paucity of livestock (necessary to produce the dung).

In 1995, I began work as a researcher for the Health Systems Development Unit (HSDU), based at Tintswalo Hospital in Acornhoek. At this time national and international public health concerns focussed on teenage pregnancy and the social and health issues this engendered. The US-based Henry J Kaiser Family Foundation funded research to establish ‘adolescent friendly’ services in three villages. Sexual and reproductive health was a neglected area particularly for adolescents; hostile nursing staff and adult oriented services alienated adolescent patients and were unable to address their complex needs. At this time AIDS was lurking on the horizon but was an unimaginable threat. I left Bushbuckridge in 1998 having spent five years living in the area.

In 2000, I returned to Bushbuckridge, this time working on an evaluation of loveLife, a national program that aimed to reduce HIV infection in adolescents by 50%. The intervention included the establishment of youth centres (*Y-Centres*), one of which was built in Acornhoek in Bushbuckridge. Talking to people in the area about the AIDS epidemic I became aware of the absence of local knowledge and contextual understandings of the epidemic in the formulation of the loveLife intervention. For example, attempts to introduce local cultural practices into the Y-Centre activities were frowned upon by the donor. At the Acornhoek Y centre, the portraits of Ramahlodi (Premier of the Limpopo province) and Thabo Mbeki (South African President) hanging on the wall were hastily removed when Washington DC-based representatives of the donor organisation paid a visit. It was clear who controlled the ‘loveLife brand’. Community conversations reflected a growing awareness of mortality from AIDS. Many expressed disbelief and confusion regarding the cause of death, disputing the validity of stories of AIDS in the media. Public health propaganda that urged condom use,

monogamy and abstinence was also regarded with scepticism. I was frequently challenged by youth who expressed disbelief that there indeed was an AIDS epidemic. Although the number of ill and dying were steadily increasing the sense of the unreal pervaded.

These experiences inspired me to begin research toward a PhD. Between 2002 and 2005 I completed 12 months of fieldwork in a village settlement I call KwaBomba<sup>13</sup>, located near a site where I had worked several years before (Shackleton et al. 1995).

The project is a culmination of several years of involvement in Bushbuckridge, on and off over 15 years, as a student, as a part time resident, and as a member of a large extended family through my marriage to Conny whose family are from the area. Over the years I have developed a strong sense of identity with the area. At times I feel like a migrant worker; earning a living in the city and returning home to rekindle social relations by participating in funerals and other rituals. I also experience guilt when I do not visit my 'home'. My wife spent her childhood years in the Bushbuckridge area and many of her kinsfolk live there. She continues to regard Bushbuckridge as home; my feelings are more conflicted.

White South Africans, particularly of the anglicised middle-classes such as my own seldom have much to do with their kin. We may celebrate Christmas or Easter together and keep in contact through email and telephone calls. As by way of example, my paternal grandmother's funeral was a small affair attended by only close family members; enough to fit around the dining room table. In comparison, funerals are *the* chief ritual in Bushbuckridge.

As an in-law of family from Bushbuckridge I am part of a large and complex kinship network. The network spans across the villages of the lowveld and into the urban settings of Johannesburg, the East Rand and beyond. Kinship operates as an inclusive system, assimilating members rather than defining those who do not belong. Thus, depending on who I meet, I can be a grandfather (*kokwane*), a grandson (*ntukulu*), brother (*buti*), uncle (*malume*), father (*bava*), cousin (*mzala*). With these kinship categories come responsibilities and expectations. I attend family rituals, participate in family discussions, and contribute financially and in other ways toward the welfare of my kinsfolk.

This ‘insider identity’ has distinct advantages for research but also poses challenges. During my fieldwork, my in-laws (*vakonwana*) involved me in everyday and ritual life. I attended funerals, ritual cleansings, bridewealth payments, and ancestral rituals (*ti mhamba*) as a kinsman. I also participated in the more mundane aspects of running a household and dealing with family issues, debates and feuds. This occasionally involved suspicions and accusations of witchcraft. For example, at the funeral of my wife’s step-brother an emergency meeting was held to discuss the lack of funds for the burial. The family did not belong to a burial society and it was up to the salaried members of the family to make up the difference. At the same time, on the side-lines of these discussions were insinuations of witchcraft that identified a family member. My inclusion in the practical discussions about finances and my willingness to assist meant that I was included in these more private discussions. Therefore I observed and participated in both the mundane and the magical aspects of everyday life.

Yet, as a white, middle-class English-speaking South African, and as a researcher, my position was often tenuous. I experienced a sense of ambivalence and at times

schizophrenia in ‘doing research’ on the one hand, and participating in rituals and everyday life as a kinsman on the other; a process captured well in the phrase ‘stepping in and out of society’ (cf. Powdermaker 1966). To do anthropology seemed disloyal to my position as an in-law as it suggested a hidden agenda. But, failing to collect information and record what I heard and saw meant failure as a student of anthropology. At family gatherings I longed to take out pen and notebook to record an interesting comment or conversation. When I did so, comments were made about me ‘being on duty’ (at work). Clearly ‘doing ethnography’ did not always mix well with ‘doing kinship’. However, the ambivalence and the contradictions regarding my identity encouraged greater reflection, born from a sense of distance and intimacy at the same time (cf. van der Waal 1992).

I am not suggesting that kinship is solely a means to gaining insider knowledge; nor am I suggesting that my personal circumstances provided me with better access. Indeed, my personal circumstances meant that I was bound by the same etiquette and rules of censorship when it came to discussions about AIDS and associated death as other villagers. My status as a local meant that I had little excuses to make mistakes. However, ethnographic fieldwork demands a level of intimacy and personal involvement that other forms of research do not usually require. There are many different ways in which an insider view can be developed. Furthermore, my position as an insider also meant that I had to exercise my own form censorship when sharing life stories with my informants.

My research experiences pose ethical questions, particularly from the perspective of the field of bioethics that centres on the process of informed consent. In biomedical research each interaction with research participants is mediated through an informed consent procedure; the aims and procedures of research are explained and a signed or

verbal agreement is made. In more formal interviews this is possible and desirable. Yet ethnographic research makes it extremely difficult to make a clean distinction between research and normal interaction in daily life. Informed consent in the context of participant observation poses ludicrous expectations on the part of the anthropologist and those with whom he or she is interacting (cf. Fassin 2006). The formal contract of the informed consent procedures is at odds with the nature of the social interaction required in building relationships of trust and respect (Oxlund 2009). I am aware that research on a topic such as AIDS creates sensitivities; I have to the best of my abilities protected the identities of those who I quote in this thesis by replacing informants' real names with pseudonyms and a fictitious name for the village where my fieldwork took place.

The more formal or structured process of my research occurred in three stages. I began by gathering sexual life histories, experiences and perceptions of AIDS through interviews with young men and women. I hung out with a group of younger men who were involved in HIV prevention activities in the village and used their personal networks to identify other informants. I was interested in understanding peoples' personal histories of AIDS and the implications the epidemic had had for their sexual relations. Young men's sexual biographies were easier to collect than women's, although access to women's experiences was facilitated through key informants. At the same time I collected oral histories from older men and women (Table 1).

**Table 1: Interviews conducted in KwaBomba, 2003-2005**

<i>Number of interviews</i>	<i>Description</i>
10	Sexual biographies of males / older youth / young adolescents
5	Young men life histories
6	Older women life histories
4	Older men life histories
7	Young women life histories
4	Teachers (including one high school principle)
3	Nurses
2	Medical doctors
3	Pastors
6	Traditional Healers
3	Faith healers
63	

Quite soon into my fieldwork I started attending funeral rituals. I remembered from the early 1990s that these are important events that are well attended. Those who fail to attend funerals face a lonely burial when they die. The AIDS funerals that I attended were markedly different from what I remembered from previous years. Funerals in the 1990s started in the mid-morning and lasted well into the afternoon, feasting on beer and beef. During my fieldwork, I attended funerals that were brief, almost hastily conducted events. On some days up to five burials occurred in the village. Feasting was restricted to kin and friends and those from afar. This apparently was in response to a directive from the local headman (*nduna*). Funerals were bankrupting families who had limited funds and who were not members of burial societies. Moreover, it was rumoured that witches were killing people in order to benefit from the feasts provided at the



funerals. Indeed, funerals were an important opportunity to eat meat. People joked that some attendees even brought salt, pepper and packets of chilli powder to flavour the rather bland funeral food.

Although funerals are silent about the cause of death, accounts of suspected AIDS death were voiced ‘in the corners’ these gatherings once the deceased was buried. Due to my visible presence at funerals I was privy to the secretive conversations during which gossip about the cause of death was expressed. I explored these whispered accounts in more detailed interviews with neighbours, friends and kin. These investigations form the basis of the material presented on AIDS mortality and secrecy.

In addition to funerals, I also participated in other social events such as weddings (I attended one), children’s birthday parties and ancestral rituals. Traditional dance (*muchongolo*) contests are held weekly in Bushbuckridge. I attended these whenever they were held in KwaBomba, interviewed the song writers and recorded several of the songs about AIDS (see Appendix A).

At this point in my research I had not met anyone who was open about their HIV status. AIDS was a subject that people wanted to avoid. Although people ‘talked’ about AIDS, this was usually in very general terms or as rumour and gossip. My informants seldom made specific references in their accounts of the AIDS epidemic. Instead they pointed to general characteristics of people who were thought to be infected or have died from AIDS. While this frustrated my objective of gathering information about the epidemic and its impact at the local level, secrecy and concealment emerge as major themes in the thesis.

I noted too, that there was a distinction between public and private accounts of death. In public accounts, AIDS death was insinuated through euphemism. This response was a way of avoiding talking about dangerous topics. Private conversations with people close to the deceased revealed a different set of concerns. Although my informants admitted AIDS to be the cause of death, they also expressed uncertainty and the suspicion of witchcraft.

Hanging around at peoples' homes and listening to gossip was an important component of my fieldwork. NwaAbraham – who I visited almost daily – always had visitors at her home. The midday meal attracted children and friends from the neighbourhood. Neighbours often stopped to have a chat. Because of her status as a respected and kindly woman, many villagers treated NwaAbraham as a confidant and sought her advice for their personal problems. Illness and the circumstances surrounding death were often reported to her. I recorded these conversations as best I could and pursued the issues they raised in my interviews.

In the final phase of my research I gained insights into the experiences of suffering. I was approached by individuals asking for practical assistance with access to disability grants, Unemployment Insurance Funds, unfair dismissal, and mysterious illnesses. Word also spread that I was interested in AIDS and that I was a resource that could be used to access care and support. I was also identified as a medical doctor. This resulted in my involvement in individual struggles to seek care. It led me to meet Pinkie and Solomon, Sizwe, Khayellhle, SisMinah, MaKwaMary-Jane, and Robert. Their stories provide insights into the everyday struggles to deal with a terminal illness and the social suffering that it engenders.

Doing fieldwork in an epidemic as devastating as AIDS is in South Africa calls into question whether as observers we are able to comprehend and understand the experience of suffering. Autobiographical accounts of AIDS provide authoritative voices on the experience of suffering from AIDS, although these are often from privileged positions (For example, Cameron 2005). To what extent is it possible for anthropologists to comprehend suffering without having first-hand experience of this? The anthropologist, Renato Rosaldo could only comprehend the anger and desire for revenge expressed by Ilongot head hunters once he experienced the personal tragedy of the death of his brother and his wife (Rosaldo 2004). Sontag's struggle with cancer led her to write from personal experience and later extended this to her analysis of AIDS (Sontag 2001). Some anthropologists write about AIDS from the intimate perspective of having lost friends, lovers and companions (E.g.: Bolton 1995).

Because of the nature of the anthropological enquiry, anthropologists are bound to deal with the immediacy of the suffering of others. This can be emotionally draining and extremely stressful. Emily Frank wrote about her fieldwork on AIDS in Zambia:

It is too difficult to work with people who are dying or who have just lost someone. It is frightening to work with illness and death. It is hard to talk about and difficult to become emotionally involved with people who will not be around when you return the following year for fieldwork. (Frank 2005)

During my fieldwork I witnessed the illnesses and deaths of people I had grown to know and with whom I felt that I had established a relationship. In some cases I faced the dilemma of recognising signs of infection and illness in a person I knew and not knowing how to express my fears that they were possibly infected. A young man I had interviewed

several times approached me complaining of a skin rash and diarrhoea. I feared the worst and offered to take him to consult at the hospital. Yet, I could see that he shared my suspicions and was not prepared to admit to what was obvious to both of us. I did accompany several individuals to hospital. The experience was wearisome and depressing. I often felt in these circumstances a ‘social and political impotence’ (Schoepf 1995, 346), due to the callous and unsympathetic medical staff.

I believe that the intimacy of the ethnographic perspective promotes a moral obligation to communicate the experience of suffering. Research in an epidemic cannot be regarded as a neutral act (cf. Castro 2004). For example, Shao (2006, 536) has this to say about his fieldwork conducted in the ‘AIDS villages’ of Henan, China:

As ethnographers, we cannot avoid taking a position within the very social worlds in which we carry out our research. No matter what position is taken, it is implicitly or explicitly political and has political consequences

I feel strongly that there is a moral imperative to expose and lay bare the realities of suffering from AIDS. Writing about suffering from an ethnographic perspective is distinct from epidemiological and biomedical discourses that tend to reproduce the official discourses of disease and death<sup>14</sup>. Irving (2007, 204) points to the invisibility of people in scientific writings on AIDS:

For a literature concerning a blood-borne disease, much of it is surprisingly bloodless; the person’s thinking, emotions and dilemmas, their very flesh and being, are reduced to statistics, the biological body or social structures. Surprisingly few *people* inhabit these texts (...) [original emphasis]

Absent in these accounts are the intimate details of human suffering which are so important if we are to start to comprehend the impact of the AIDS epidemic. Without this perspective, the suffering of others is obscured. Furthermore, this legitimises and reinforces indifference to suffering by rejecting our common humanity and by denying identity (Herzfeld 1992, 1).

Recognising the limitations of the epidemiological ‘official’ data on infant mortality in Brazil, Nations remarks on her research:

I resolved to come to grips with the human face of infant death. To get down to the flesh, blood, and souls to understand it, to live it in the households of impoverished parents who suffer its tragic consequences’ (Nations & Amaral 1991, 205).

Sharing in the personal tragedies of the AIDS epidemic was a critical component of my fieldwork. This involved escorting sick people to hospital, waiting in queues, sometimes late at night, only to be told that there were no beds available, no treatment for ‘this disease’, and witnessing first-hand the effects of AIDS. One specific instance that stands out in my fieldwork was the death of a young woman, Pinkie Mnisi, whose story I recount in detail here.

### **Pinkie’s story**

Pinkie Mnisi, a young woman who I return to later in the thesis (Chapter Seven), died from bronchial pneumonia early in 2006. Her husband, Solomon died the same year from tuberculosis. Both were HIV positive. When I first met Pinkie in 2005 she was emaciated and weak, an unbelievably small figure hunched under blankets. There was no

one to care for her except her husband who was also extremely ill. At this initial meeting I was shocked that so little was being done for them and that their family seemed so resigned to her illness and death. A day before Christmas, 2005, I accompanied the young couple to the hospital in Acornhoek to fill a prescription of medication and vitamin supplements. My field notes recorded the following:

We arrived very early (8:30 am) at Tintswalo Hospital on the day before Christmas and still the queues at OPD [Out Patients Department] were very long. Pinkie and Solomon went to the Rixile [AIDS] clinic. However, the clinic was closed from the 24<sup>th</sup> until after New Year. There was a sister on duty at Rixile. She explained that she was only doing VCT [voluntary counselling and testing]. She had no clients but several patients seeking medication found their way to the clinic. They were also turned away. Eventually she closed the clinic because she said she was tired of sending people away without really helping them. She suggested we return to the OPD to seek assistance. Here we were referred to a consultant who was running a hypertension and diabetes clinic. But when we arrived we found the nurse was mistaken. The doctor was not in. Instead we found a dentist who was running a dental clinic. We went to the pharmacy. They told us to go back to OPD and get a new file for Solomon and Pinkie. We returned to OPD. The desk nurse looked at us and asked her colleagues ‘what do these people want?’ [*U lava yini*]. This phrase is usually reserved to talking to a nagging child. I asked if we could fill Pinkie and Solomon’s scripts. They insisted that the only way was to wait for OPD to open a new file. I was worried as Pinkie was really tired and Solomon’s feet were hurting. It was cool outside but the OPD was stuffy and sweaty. An old man was wheeled in. A young woman limped in on crutches. A victim of a car accident was brought in on a stretcher.

My friend who had accompanied us tried to push in the queue. She begged the other patients to let Solomon and Pinkie in. A woman complained saying that she was also sick and also needed to see the doctor. To us it seemed like the doctors were hiding in their cubicles to avoid the patients. A poster on the wall depicted a baby with pellagra. Someone had drawn a speech bubble coming from the baby saying ‘Feed me’ to which was added ‘Help - I have AIDS’. Defacing this shocking image created a distance between people and the horror of disease and death.

Outside I talked to a senior administrative clerk who remembered me from the time when I worked at the hospital. I remarked on the signs of beautification at

the hospital. Attractive new plants and water features and ornate concrete benches had been set up on the grounds presumably for patients and visitors. He told me that the hospital had insufficient funds to rebuild the decrepit paediatric ward, but the hospital did not want to report an under-spend to the provincial government. So the hospital administration decided to use the money to beautify the grounds. He also pointed out the new ornate wall clock for the sisters' station in OPD. My old friend told me that it is important for the hospital to appear like a place where healing happens. I wonder if he saw the irony in this.

A few nights later I was awoken by a phone call from Pinkie's aunt. Pinkie was seriously dehydrated and was unable to hold down solids or fluids for two days. I drove to her home and picked her up to take her to hospital. The young female community service doctor examined Pinkie. She scolded me for bringing Pinkie in at such a late hour and told me that it was a waste of time to put Pinkie on a saline drip and that we could have simply given her an energy drink. Nonetheless she eventually agreed to admit Pinkie for that evening and to monitor her progress.

The long queues, the hostile responses of the medical staff, the obvious wastage of funding on frills, the scolding doctors are inimical to the needs of the ill and dying. It is in the microcosm of the hospital waiting rooms and consultation booths where one can start to understand peoples' reluctances to access care until extreme desperation sends them there<sup>15</sup>.

Over the next few months I continued to follow Solomon and Pinkie on their journeys to the hospital, clinics and 'traditional healers'. On the day she died Pinkie awoke before anyone else and assembled her sister, grandmother and aunts and led them in hymn. Later, her grandmother told me that this was Pinkie's way of saying goodbye to her family, 'because she knew she would not be returning'. I arrived soon after this intimate family gathering to take Pinkie and her husband to hospital.

The journey over the bumpy roads to the hospital was extremely painful for Pinkie sprawled on the back seat of my car. She was so thin the veins had atrophied leaving dark bruises on her almost translucent skin. When we entered the hospital grounds she groaned and begged me to take her home, crying that she could not go back to hospital again. The doctor met us in the car park, took one look at Pinkie and said ‘Jonathan she is going, she is going’ and urged me to get to the emergency ward. I drove fast braking hard at the entrance to the emergency ward. I opened the car doors and lifted Pinkie up, but I was already too late. As her eyes rolled back in her head she let out a few last gasps struggling to breath and died in my arms. Shaken, I placed her on the back seat. Curious onlookers cast frightened glances at me and after peering in the window looked away hastily. I covered the body with a blanket and waited.

I returned with Solomon to Pinkie’s grandmother’s homestead in absolute silence. To my dismay I was called upon to explain to the family what had happened at the hospital. I had barely opened my mouth to say the words ‘I am sorry to tell you ...’ when I was silenced by one of the most terrifying displays of grief and anger, and one of the most moving experiences of my adult life. Pinkie’s sisters and aunts screeched and cried, beating their fists against their heads, hurling themselves on the cement floor of Pinkie’s room, tearing out hair and ripping off their clothing in an orgy of grief. Solomon sat and sobbed holding his son in his arms rocking back and forth. I sat numb, unable to move or express anything.

This lasted for what seemed an hour although it was probably only a few minutes followed by absolute calm. Pinkie’s sister was pregnant at the time and had injured herself by throwing herself on the floor and required immediate care. The older women



set to brewing tea and sending the children out for loaves of bread and bottles of cold drink. Phone calls were made to close relatives in the area to arrange to meet the hearse that would be transporting the body to the mortuary. I was soon outside the house sharing a smoke and having a light-hearted chat with Pinkie's uncle. The calm and efficiency at which people dealt with the immediate practical needs of organizing a large funeral were a dramatic contrast with the chaos and disorder I had witnessed only moments previously.

## ORGANIZATION OF THE THESIS

The thesis is divided into two parts: the first tells the story of the rapid spread of AIDS in Bushbuckridge and locates this within social history and contemporary sexual relationships; the second part explores public concealment and censorship of the epidemic in the public domain, and discusses the implications this has for individual suffering.

**Chapter 2** 'Origins' is a social history of the AIDS epidemic in Bushbuckridge and documents, through the lens of my fieldwork in KwaBomba, the dramatic spread of the disease, its impact, and official responses. By the turn of the 20<sup>th</sup> Century, political and economic transformations had disrupted social, gender, and generational relationships, and created the ideal conditions for epidemic spread. This is reflected in the demographics of reported AIDS deaths amongst predominantly young unemployed women and older employed men. Official responses to the AIDS epidemic in Bushbuckridge promoted awareness of the disease, yet failed to create an open public discourse and address the underlying social and economic foundations of the epidemic.

**Chapter 3**, ‘Infections’, continues to explore the spread of AIDS, by examining the social structure of contemporary sexual relationships. I argue that a broad spectrum of forms of sexual relationship create opportunities for overlapping, multiple sexual relationships that shapes the structure of sexual networks. Because these networks are largely invisible, spread over a wide geographical area and are socially undifferentiated, the potential for HIV transmission within them is extremely high.

Although AIDS is a widely known affliction, its existence is often disputed and seldom discussed in public. Questions about the verbal and visual avoidance of AIDS are addressed in **Chapter 4**, ‘Secrets’. Here I argue that AIDS is subjected to cultural censorship in everyday public speech, while suffering is hidden from public view. Censorship is explained in relation to fears associated with the power of the spoken word and the idea of dangerous knowledge. The concealment of the AIDS body is a reaction to anxieties about what the sick body reveals about social relations. Yet at the same time, concealment and censorship are never absolute and contain the potential to reveal.

Given the censorship and concealment of AIDS, **Chapter 5** ‘Evidence’ asks how it is possible for proof of the epidemic to be generated at the local level. I argue that the oral performative genres of gossip and rumour are instrumental in this process of assimilating ‘data’ about the epidemic. Yet, at the same time, gossip and rumour are also moral texts about peoples’ behaviour and are attempts to attribute blame. These texts have the power to mobilise and catalyse social action, yet ultimately fail to do so.

In **Chapter 6**, ‘Revenge’, I continue to show how AIDS is made local through witchcraft. I argue that witchcraft beliefs create the possibility for avenging AIDS as well as offering protection by recasting AIDS through the idiom of witchcraft beliefs. The

chapter explores the analogical parallels between AIDS and witchcraft: although AIDS is not believed to be sent by witches, beliefs about AIDS and beliefs in witchcraft share distinct similarities. Witches are also believed to send an affliction that is similar to AIDS. By interpreting AIDS as witchcraft people are able to exert a form of control over the epidemic. Witchcraft therefore can be seen as a therapeutic resource. It allows for open talk of illness and death and vengeance for death.

In **Chapter 7** ‘Suffering’, the final ethnographic chapter, I document in semi-biographical style the experiences of living with and dying from AIDS. The chapter revolves around extended case studies of two men and follows their accounts of infection, illness and ultimately their deaths. Their experiences illustrate the ways in which the concealment and silences surrounding AIDS are played out in peoples’ experiences of suffering. In particular, the chapter reveals the consequences of AIDS for men’s capacity to perform masculinities.

My conclusions in **Chapter 8** are concerned with exploring the significance of the material presented in the thesis in the context of recent changes in AIDS policies to provide antiretroviral (ARV) drugs to people living with HIV. ARVs offer the promise of a regeneration of life, by visibly reversing the effects of the disease. Yet, the optimism and hope surrounding AIDS treatment tends to obfuscate and effectively silences dissenting voices, and brings to the fore the inequalities in health care provision that continue into the ‘treatment era’.

## END NOTES

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- <sup>1</sup> There are two large public hospitals in Bushbuckridge: Tintswalo (450 beds) and Mapulaneng (350 beds), as well as Sekororo (100 beds) and a public-private Life Care facility, Matikwana (150 beds). There are 45 Primary Health Care (PHC) clinics in the district, including two health centres.
- <sup>2</sup> *Kwaito* music is a uniquely South African blend of hip hop and gangster rap popular amongst youth.
- <sup>3</sup> The Johannesburg based Perinatal HIV Research Unit (PHRU) was awarded Presidential Emergency Funds for AIDS Relief (PEPFAR) funds through the United States Agency for International Development (USAID) to run an ARV clinic (called *Rixile*) based at Tintswalo Hospital.
- <sup>4</sup> This is not unique to AIDS or to South Africa. In Italy, a cancer prognosis is often withheld to spare the patient and their family members the stress of knowing (Gordon & Paci 1997).
- <sup>5</sup> Personal communication: Dr Vivian Black, Faculty of Medicine, Witwatersrand University.
- <sup>6</sup> The words ‘black’ and ‘white’ are used mainly in the emic sense and are therefore not capitalised.
- <sup>7</sup> The roll out of antiretroviral treatment (ARV) for AIDS started in late 2003. By 2004 only 50 patients were on ARV at the only distribution site in Bushbuckridge, Mapulaneng Hospital and three years later one of the distribution sites was seeing 1200 patients per month, of which 500 were on ARV (Lurie et al. 2008).
- <sup>8</sup> Tintswalo hospital had an extremely negative reputation and was referred to by some as ‘Acornhoek Dogs’ (Acornhoek *Njanja*). An informant reported that she overheard a nurse saying ‘I haven’t managed to get all my cattle today’ which meant that she had failed to collect enough corpses to earn her commission from the funeral parlour.
- <sup>9</sup> In the 1950s, Matsikitsane and Segopela Mashile led tenant struggles against the use of child labour by white farmers and joined the ANC (Niehaus 2006b, 529).
- <sup>10</sup> There are a few notable exceptions to this (Farmer 1992; Fassin 2007; Hyde 2007; Setel 1999).
- <sup>11</sup> See Herdt’s (1981) ethnography of ritualised homosexuality.
- <sup>12</sup> A student from Malawi and I presented our papers to a tiny audience in a parallel session.
- <sup>13</sup> KwaBomba literally translated means the ‘place of swaggering’. This name was suggested to me by my young friend who described his daily routine of walking around the neighbourhood where he lives as ‘to swagger’ (*ku bomba*).

- <sup>14</sup> The focus on predicting outcomes creates distance from suffering. ‘Predicting outcomes is a legitimate sociological pursuit, yet its effect in terms of language use and in terms of a framing of time is one of distancing’ (Henderson 2004, 48).
- <sup>15</sup> Unlike the ‘emotional labour’ that receptionists and health personnel perform in mediating conflicts in waiting rooms in medical clinics in the US (Strathmann & Hay 2009), health staff at Tintswalo Hospital often simply ignored the predicament of patients arriving at the casualty ward.