

CHAPTER SEVEN

SUFFERING: BIOGRAPHICAL ACCOUNTS OF ILLNESS AND DEATH

Until now the thesis has focussed largely on public responses to the AIDS epidemic, rather than individual experiences. This chapter seeks to fill this gap. In the chapter I draw on the biographical accounts and illness narratives of two men and to a lesser extent one woman. Their accounts highlight the failure of health services to provide palliative care and lifesaving drugs. They also highlight the failure of kinship and good neighbourliness in caring and supporting the ill and dying.

The neglect of AIDS sufferers are often explained in relation to stigma based on an moralising discourses that associate AIDS with sexual promiscuity (Deacon et al. 2005; Stein 2003). The sexual conduct of men often attracts moral opprobrium; in gossip men who have many sexual partners are labelled ‘womanisers’ while women are called ‘loose’ prostitutes. They are identified as carriers and transmitters of HIV and may be blamed for its spread. While these discourses can create moral panic, they do not necessarily result in stigma. Men’s capacity to have multiple sexual partners is often construed as a sign of their success (because women cost money) and an affirmation of their identity as potent, skilful men (*wanuna ntiyela*). My male informants talked openly about their sexual conquests without fear of censure from either myself or my research assistants. Men also appeal to fictive traditions of polygamy and ideas of a natural male sexual drive and the need for release to legitimise their sexual conduct. Women who had multiple sexual partners were accused of sexual impropriety, greed and avarice. Yet, their sexual conduct was also interpreted more sympathetically as a legitimate survival

strategy; they sought men to support their children in the absence of reliable husbands. By so doing they framed their relationships with men as productive activities (See Chapter 3).

An alternative explanation for AIDS stigma can be found in the strong association between the disease and death. As I argued earlier (Chapter 4), considerable fear and anxiety surround HIV testing and even the word ‘AIDS’. This, I suggested, is due to the biomedical construction of AIDS as a fatal illness that inevitably results in death. Because death is regarded as a process of transitioning from life to death rather than a once off event, ‘... persons with AIDS are symbolically located in an anomalous domain between life and death, and are literally seen as ‘corpses that live’ (*setopo sa gopela*) or as persons who are ‘dead before dying’ (Niehaus 2007, 848). The idea of the living corpse resonates with local constructs of AIDS as an affliction that gradually consumes the body, rotting it from within. The belief that the virus is like a tiny worm that grows into larger maggots that feeds off the flesh of its victims further contributes to the vision of decaying corpses. So do descriptions of the AIDS ill as skeletons.

I suggest that this construction of AIDS underline care givers and close kin’s fears of the AIDS body and is dramatized in their attempts to conceal and contain its contaminating influence. The management of the ill and dying is a dramatic performance of the liminal status of the HIV positive person.

This response to illness is not unique to HIV/AIDS. Historically, people who suffered from leprosy were often secluded and kept apart from other family members. A traditional healer showed me a small hut (*ndumba*) she had built some distance from her homestead where she would house long-term leprosy patients, as recently as 1994. She

fed the patients through the doorway, never entering the hut. Another kept his patients chained to blocks of cement in his yard to prevent them from moving around the homestead (or escaping). Pregnant women are also kept secluded for a period of time after giving birth to protect them against the harmful pollution of sexually active bodies. Medical protocols for dealing with infectious patients reinforce notions of contamination. Tuberculosis patients were isolated in a ‘TB village’; a cluster of prefabricated huts built on the outskirts of Tintswalo Hospital, surrounded by a wire fence.

In their personal accounts of their illnesses, my informants described spatial seclusion and alienation, and their diminished sociality. They recognised and to a certain extent acquiesced to the cultural constructs of AIDS as a polluting condition that required them to be isolated and contained. In this sense their illness experiences were interpreted according to prevailing discourses of how to suffer. Yet, their experiences of illness and death cannot be solely understood in terms of these cultural meanings.

I suggest that in order to fully comprehend their experiences it is necessary to explore the details of their wider lives and that this can only be revealed through a more detailed biographical approach. Biography serves as an antidote to the relative absence of personalised accounts in the literature. Despite interest in the experience of illness and dying in the context of AIDS, there are few examples that deal with how AIDS sufferers themselves interpret their experiences¹. The promise that this approach holds is not in terms of the representivity of individual biographies for the general population but in terms of the insights they offer regarding the experience of living with illness. This approach, as Farmer (2005) writes, reveals the ‘texture’ of appalling affliction and how larger scale social forces shape individual experiences of AIDS that lies beyond the

‘biomedical voice’ (Riessman 2003). Biographical accounts reveal how broader social processes and events are ‘translated into personal distress and disease’, and how macro processes such as racism and poverty ‘become embodied as individual experience’ (Farmer 2005, 30). Social forces structure individuals’ vulnerability to infection, and shape their illness experiences. This is conceptualised by the notion of social suffering.

Social suffering is not an objective fact that can be measured, or enumerated, but is a social construct with multiple meanings that vary in different contexts (Kleinman et al. 1997). For example Bourdieu (1999, 4) highlights the problem of relying on gauges of material poverty in present day France as the ‘sole measure of all suffering’. This he argues ‘keeps us from seeing and understanding a whole side’ of suffering. The process of defining and categorising suffering as an objective fact may result in the denial of care and exclusion of individuals from membership of the moral community. As Morris (1997, 40) suggests, suffering is often defined according to notions of nationhood, race, ethnicity, religion, gender or class (Herzfeld 1992). Moral texts exclude certain categories of person from the dignity afforded to others.

Farmer’s (2005, 59-66) disturbing account of the treatment of HIV positive Cuban political refugees by the US forces in Guantánamo is particularly revealing. Inmates were identified as HIV positive by wearing bracelets, lived in a camp surrounded by barbed wire, and ate maggoty food. The American forces forcefully injected female inmates with hormonal contraception. Inmates who offered resistance were beaten and arrested. The unhealthy conditions and overcrowding led to rapid co-infection with tuberculosis amongst the inmates.

The concept of ‘social suffering’ is also an attempt to go beyond biomedical and public health constructs. Kleinman and Kleinman (1997, 2) offer a two-part definition; first, social suffering is a ‘collective mode of experience that shapes individual perceptions and expressions. Those collective modes are visible patterns of how to undergo troubles, and they are taught and learned, sometimes openly, often indirectly’. Therefore, the expression of suffering and how this is interpreted is socially constructed. The second part of their definition refers to the social interactions that participate in ‘illness experiences’ and how these form a core role in the experience of suffering. Most importantly, they point to how both aspects of suffering are shaped and reshaped ‘by the distinctive cultural meanings of time and place’.

An important tool that is used in understanding the experiences of suffering is the ‘illness narrative’. This is a story of the illness experience told from the perspective of the sufferer. It is also an attempt to construct meaning from suffering and thereby to alleviate pain (Kleinman 1988). However, it is important that we do not assume that the creating meaning necessarily has benefits for individuals. Indeed, the performance of suffering may exacerbate distress and present a barrier to accessing care and treatment (Leavit 2008).

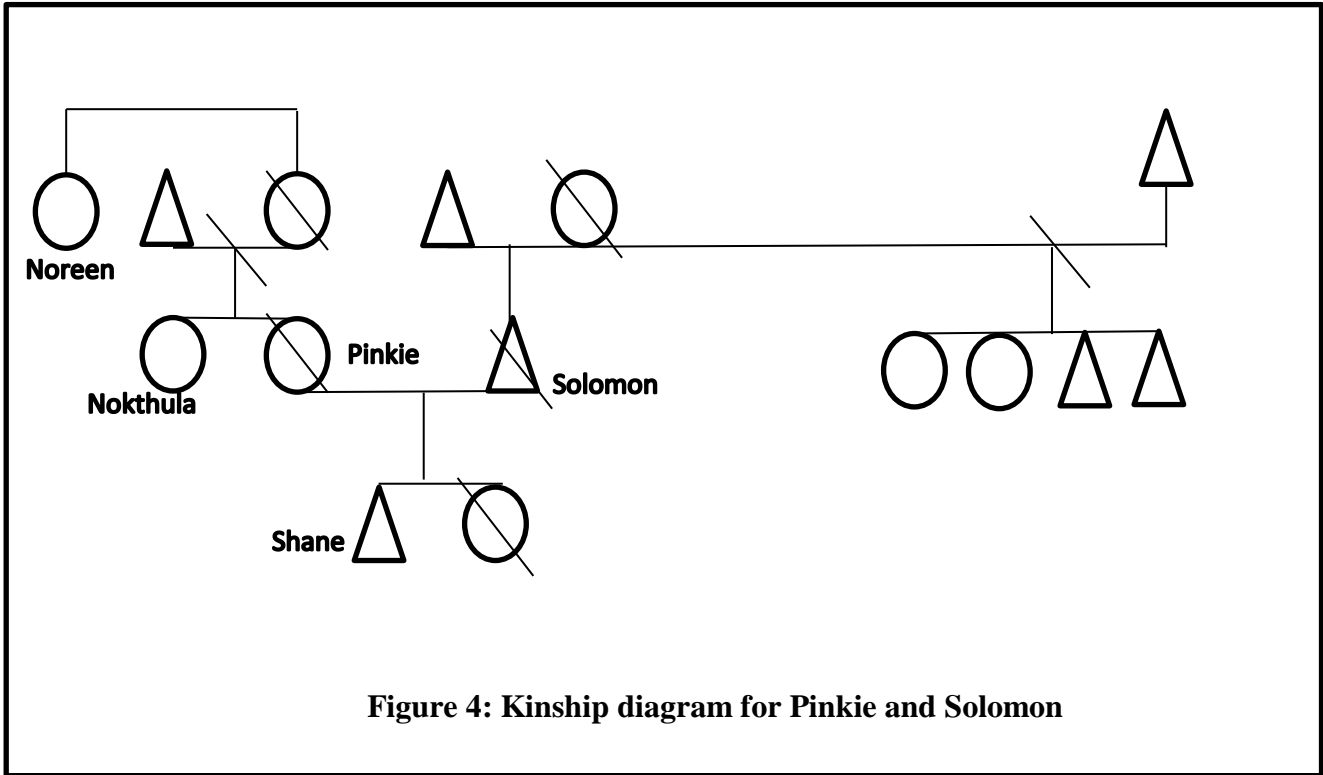
The accounts presented in this chapter draw attention to particular meanings of suffering, specific to social context and history and in particular that of social censorship and concealment. They provide insights into understanding how social responses to AIDS contribute toward the experiences and expressions of affliction.

Both accounts draw attention to the devastating loss of agency and personhood, specifically in relation to masculine identity. The secrecy that surrounds AIDS suffering

denies men who are afflicted with AIDS from performing masculinity in the public arena and therefore restricts their sociality. Being ill means being relegated to the domestic domain, cut off from social and sexual networks, unable to participate in reciprocal activities such as labour, drinking, and sexual relationships. Being physically incapable to work means financial insecurity as well as denial of social worthiness. The physical effects of AIDS illness which is characterised by an inability to consume, to grow, and to contain bodily processes is a metaphor for the erosion of sociality. Henderson (2004, 45) aptly describes the AIDS body as ‘vertiginous’: ‘The failure of bodies to hold, to maintain a modicum of coherence is externalised and mirrors an experience of collapsing sociality’. In another respect, the image of illness and death surrounding once healthy and vital bodies casts shadows over the notion of ‘traditional’ masculinities associated with sexual prowess and multiple sexual partners. Hunter’s (2004) historical analysis of the Zulu playboy (*isoka*), suggests that this social identity has become corrupted, linked to the spread of a deadly disease.

SOLOMON AND PINKIE

I first met up with Solomon and his wife Pinkie in May 2004 in Johannesburg and followed their progress from December of that year in Bushbuckridge until April 2005. I conducted five formal interviews with Solomon and spent several evenings and early mornings accompanying him and Pinkie on trips to the AIDS clinic and casualty ward at Tintswalo Hospital in Acornhoek. The following account is structured around my participation in trying to seek care for the couple and the conversations and interviews that took place.



Leaving KwaBomba to build a new life: 1970-2000

Solomon was born in 1970 on a commercial farm called Kiepersol near Hazyview. His mother was married to the Mnisi of Kasteel, an impoverished family with little means of support. Tiring of the endless struggle to survive, she left her husband and took her children to live with her brother in KwaBomba. As she was still married to Mnisi, she acquired a stand under that name and built a house in KwaBomba. As a single mother, Solomon's mother sought the work of desperate women as an unskilled labourer

picking oranges on the citrus estates. It was here that she met Solomon's father and together they raised Solomon.

Solomon spent his early years on Kiepersol Farm. He learnt how to speak Afrikaans and drive a tractor, skills that were vital for his later employment. In the mid-1970s, Solomon's mother and father left Kiepersol and returned to KwaBomba. They were amongst hundreds of households who left the white – owned farming estates at that time. Mechanisation and farmers' preference for seasonal and casual labour forced farm labour households to live on the newly created Bantustans. Solomon's mother was enthusiastic to relocate closer to schools that were being built to accommodate mother tongue Tsonga speakers.

The move to KwaBomba united Solomon with his stepsiblings. However, when Solomon's mother died of cancer in 1985 the step-children confronted Solomon's father and demanded he leave the homestead. They claimed that the homestead belonged to the Mnisis, and that he had no right to live there with them.

Solomon felt aggrieved at how his siblings treated his father. Escalating tensions between Solomon and his stepsiblings led him away from KwaBomba to seek work in the East Rand town of Brakpan. Solomon started work as an apprentice boilermaker and was soon earning a good wage as an independent contractor.

Solomon first met Pinkie in KwaBomba when she was visiting a neighbour. He fell in love with Pinkie and boasted to his friends that he would marry her.

I asked her to marry me and she agreed because she said she didn't want to play around anymore. It was very important to complete the *lobola* [bride wealth] payments because if you don't then you get shit from your in laws if your wife dies.

The couple moved to Tsakane and celebrated their marriage with a party. Only Pinkie's kinsfolk attended the wedding. This symbolised Solomon's complete detachment from his family in KwaBomba.

Over the years, Solomon built up his home. His son, Shane, attended a decent school. Solomon financed a second-hand Audi and Pinkie learned to drive. They purchased furniture, a television, and a music system, a fridge and a stove. Like many migrants Solomon also built a second homestead in KwaBomba. Yet his investments in the Tsakane homestead stood in stark contrast to the pathetic two-roomed structure he erected in KwaBomba. This symbolised his lack of attachment to and interest in his rural family. Pinkie and Solomon were able to exist independently of their respective families. Pinkie's sister (Nokthula) and her mother's sister (Noreen) were their only link to KwaBomba. Pinkie's father was unknown to her and her mother had died when she was still young.

Illness and the loss of autonomy

Solomon first started to fall ill in 2001. He was weak, had a severe cough, and chest pains. A private physician diagnosed Solomon with pulmonary TB and promptly referred him to the Far East Rand Hospital. Solomon's lungs were drained of fluid and he remained an outpatient for eight months. Solomon continued to take TB treatment administered by a local clinic near Tsakane. His recovery took far too long and it was almost 18 months before Solomon was well enough to return to work in 2003. However, even then he often became ill and would take off one week out of every four. His doctor advised him to request early retirement. Unfortunately, this spelt financial ruin for Solomon. He was behind on his car repayments and had to cancel his plans to build a new

house. In November 2003, Solomon suffered a minor stroke and his employer placed him on extended sick leave.

Solomon claimed that throughout his illness he was unaware that he was HIV positive. He speculated ‘the doctors were too scared to tell me I had HIV’. He imagined that his ‘chest problem’, as he put it, was caused by inhaling dust from the grindstone he used at work. Many of his co-workers said that this dust caused tuberculosis. Nonetheless he had a niggling worry that he may have HIV.

When I think too much about this disease I can get heart sick. This is what caused the stroke. I feel pain, I cannot breath, I feel hot, and I sweat. I was so worried and I never told anyone. I think maybe I have got AIDS and I worry. If you don’t know then nobody can help you. If you don’t explain then they can’t help you. It is good if the Doctor says you have this and you must take that [treatment]. I would worry but I never thought of killing myself. I prayed to God and thanked Him for making me better. I also worried when my wife was sick and I prayed that she would be better. I was suspecting that she had HIV.

Pinkie was diagnosed with HIV in 2003 after she fell pregnant for the second time. Their baby only lived for 18 months. Solomon claimed that he was unaware that his child had died of AIDS and was unaware that Pinkie was HIV positive. Solomon recalled his reaction when he discovered he was HIV positive.

I had heard of HIV – in fact, I thought maybe this is HIV. But, when the Doctors told me I was shocked and I cried for a little while. Then I told Nokthula [his sister in law] and she said that many people at home [in KwaBomba] have this disease...I told her to tell Pinkie. I was really scared to tell her. But, she [Pinkie] was not angry when she found out. She just asked me ‘why didn’t you tell me before? Don’t worry you must go to work again. You are still a man. Other people also have this disease. You must forget about it. You will get heart sick again if you worry too much. We have always heard about this on the radio and now it is happening to us as well. You must behave like a person who has not got the disease – otherwise it will simply get worse’. She never blamed me. I never blamed her.

In these accounts Solomon draws attention to the need to avoid thinking about the disease and Pinkie's insistence that Solomon could continue to function normally as a man.

My relationship with the couple happened by chance. In May 2004, I received a telephone call from Pinkie's sister telling me that her sister and brother-in-law were ill. She knew that I was interested in AIDS and thought I may be able to offer advice. At the time Pinkie and Solomon were living in Tsakane. When I visited the couple in Tsakane Pinkie was severely ill and appeared shrunken under the heavy blankets on her bed. According to her sister, Pinkie refused to eat solid food, preferring porridge with the consistency of baby food. Solomon was slightly better off, but extremely gaunt and walked with obvious pain. I decided to take the couple to the Johannesburg General Hospital. Despite being armed with a referral letter from a physician colleague of mine our visit did not last long. The matron in charge of the clinic dismissed me without even having seen Pinkie or Solomon, or my letter. Our next stop was the Lillian Ngoyi Health Centre, located within the sprawling grounds of the Chris Hani Baragwaneth Hospital in Soweto. Here we met with similar resistance. The senior clinician instructed us to consult first at a primary health care clinic and to be referred to Lillian Ngoyi. We had clearly cut out a step the health system had designed to avoid over burdening tertiary care institutions with walk in patients. The clinician did not try to conceal her irritation and hostility toward the three of us. She chastised Solomon of using 'a white man' to get favourable treatment. She told me 'many whites bring their garden boys here and I tell them the same'. My presence was obviously more of a hindrance. After some haggling and pleading a kindly nurse gave Pinkie and Solomon files and were soon seen to by the

physician. HIV tests were conducted and the results were discussed. During their consultation the doctor speculated that Pinkie was the source of the infection as she appeared to be at far more advanced stage of disease progression than Solomon. She also claimed that Solomon's condition was partly due to his use of traditional medicine that had a positive effect. Solomon and Pinkie were told to return to collect their CD 4 counts and were prescribed vitamin pills.

I suspect that Pinkie and Solomon lost hope of finding a medical solution in Johannesburg because later in 2004 the couple moved back to Bushbuckridge. Here they lived with Pinkie's aunt, Noreen in her three roomed house in Thulamahanshe. When it became apparent that the couples' health was not improving, family members, notably Noreen and Solomon's mother's brother (*malume*) encouraged Solomon to consult with traditional healers. In 2004, Solomon consulted with more than ten healers. He was extremely cynical. 'Healers don't help – they just take your money' he complained. Traditional healers were expensive and Solomon still owed thousands of Rand to various healers in Bushbuckridge and in Tsakane. One healer bathed him in chicken's blood. Solomon, doubting the efficacy of this treatment, took the chicken home and ate it. Another healer claimed that Pinkie bewitched Solomon. Yet, Solomon regarded this as a ludicrous supposition and simply the healer's attempt to 'make me afraid and get more money'.

Table 8: Solomon's consultations with healers

<i>Reason for consultation</i>	<i>Treatment</i>	<i>Charged²</i>	<i>Paid</i>
1. Paralysis resulting from stroke	1. Divination and liquid medicine	R800	R450
2. Burning sensation in foot	2. Soil rubbed on foot	R350	R350
3. Pustules on head	3. Snuff and Vaseline mixture rubbed on sores.	R50	R50
4. Body weak	4. Divination	R150	-
5. <i>Ndzaka</i> (coughing, night sweats, weakness, weight loss)	5. Caused by having sex with Pretty after child died. Prescribed muthi to drink and to inhale.	R50	R50
6. <i>Ndzaka</i> (as above)	6. Perform <i>ku mhamba</i> (ancestor ritual)	R50	R50
7. <i>Ndzaka</i> (as above)	7. Bath in chicken blood	R50	R50
8. Weakness in body	8. Herbalist provided Philemon with 5 litres of herbal mixture. Had good results. Lasted for 40 days.	R1200	R600
9. <i>Ndzaka</i>	9. Divination and sacrificed chicken	R50	R50
10. Weakness	10. Prayed for Philemon and laid hands on his body.	Free	--
11. Gonorrhoea	11. Private physician in Springs treated Philemon.	R230	R230
12. Passed out at work	12. Taken to private physician and revived.	R140	R140
13. AIDS ill	13. Lilian Ngoyi Clinic, Soweto. Anti-biotic, vitamins, HIV test and CD 4 count	Free ³	Free
14. General weakness, psoriasis on feet and legs, sores on head.	14. Purchased medication from local pharmacy	R240	R240
15. General weakness, coughing, diarrhoea, loss of appetite, headache (general AIDS symptoms)	15. ZCC healer potion consisting of: FG tea (strong tea), Trekker coffee (chicory blend), olive oil, raw garlic, brake fluid) sold in a ten litre bucket to be taken by the spoonful every hour.	R350	R350

In December 2004 when I visited Pinkie and Solomon I found that their conditions had improved slightly. They were eating well and were well looked. Noreen

met a ZCC priest (*mufundise*) who claimed to have developed a treatment for AIDS, a concoction of FG Tea (herbal emetic), Trekker Coffee (strong instant chicory), olive oil, garlic, ginger and motor car brake fluid. The mixture sold for R300 per bucket. Solomon and Pinkie finished an entire bucket in one week. The mixture was predictably foul tasting. However, they claimed it gave them appetite and energy. Solomon felt that it relieved his chest: ‘It goes to the wounds in my chest and patches these’ he remarked. After taking the mixture Solomon told me proudly that he could now walk the 500 metres to the river from the house. Pinkie was able to sit up in bed for the first time in weeks and come outside to greet me. Although I was doubtful of the efficacy of the medicine, I felt hopeful. However, the benefits were short-lived. Solomon and Pinkie were plagued by diarrhoea and vomiting and lost their appetites.

The couple also enrolled at the AIDS Clinic called ‘Rixile’ (‘The Sun Rises’). Doctor Martins, Pinkie’s physician told me that she suspected that Pinkie had contracted a rare type of pulmonary TB but the diagnosis and treatment were not easily available and prohibitively expensive. Doctor Martins said:

You know, Jonathan...if this were a first world clinic situation like in Germany she would be put on ARVs and TB medication and steroids and we would save her. As it is there is very little we can do for her. I think she is not going to make it.

Doctor Martins was correct. Pinkie died late in January 2005 (See Chapter One). Solomon continued to seek treatment, but died soon after Pinkie in August 2005.

After Pinkie's death

Up until Pinkie's death, Solomon lived with Pinkie's family in KwaBomba. Although he had little money, Pinkie's family supported and cared for him as best they were able. As soon as Pinkie died, Solomon moved out of her room into an outside hut. One week later, after the ritual cleansing Solomon moved back to his house in Tsakane. I heard rumours that he had started a new relationship with a woman who worked for a home based care organisation.

I understood Solomon's desire to leave Bushbuckridge. Solomon's illness meant that he could no longer maintain his independence and faced a major dilemma: to return home to his unkindly stepsiblings or live with Pinkie's relatives who had showed compassion towards him. Solomon harboured strong suspicions that his stepsiblings were waiting for him to die so that they may inherit his car, the house in Tsakane, and its contents. They were also aware that Solomon stood to receive severance pay from his employers. Solomon had a reoccurring dream in which his stepsister visited him in hospital, and offered him food to eat. In the dream, he cried out asking her why she wanted to poison him.

Resolute that his stepsiblings would not acquire any of his accumulated possessions, Solomon transported his furniture, television, video machine, beds and couches to Noreen's house. Even though his car had long been repossessed by the bank, he pretended that it was being repaired to make his stepsiblings, as he put it 'think they will get my beautiful car when I die'. Solomon was open about his resentment towards his stepsiblings:

When I was sick they ran away, they want my car. They are saying ‘I want this car when he dies’ But not one of them helped me. Not once! My sisters only want to see whether I am dead because they want my car and they want my house

After he moved away from KwaBomba, I lost contact with Solomon. According to Noreen, the day before Solomon died his older brother visited him in hospital and demanded Solomon’s bankcard and secret pin code. The brother withdrew the balance of Solomon’s severance pay. He then shared the money amongst his brothers and sisters who feasted on meat and beer for the entire week.

Solomon’s account draws attention to tensions that many men experience between maintaining their ties with their rural home and kinsfolk and playing a role within these networks, and at the same time, establishing their own households and independence identity. In a context of extreme poverty, wage earners are placed under considerable pressure to support their wider extended family. In many cases men desert their kin and attempt to establish themselves independently in the urban areas. This was illustrated in Solomon’s case by the financial investment placed on building a home in the urban areas while neglecting to do the same in KwaBomba. Men who make large financial investments in building houses in the rural homestead show their intentions to retire at home. Solomon made it clear that he did not consider KwaBomba home, owing to the failure of his relations with his half-brothers and half-sisters. The significance of his illness was that it eroded his independence from his extended family. His distress during his illness and after the death of his wife focussed on a struggle to maintain his independence that he ultimately lost. In a metaphorical sense, Solomon’s body was consumed by a disease that also consumed his social identity.

KHAYELLHLE MHLANGA

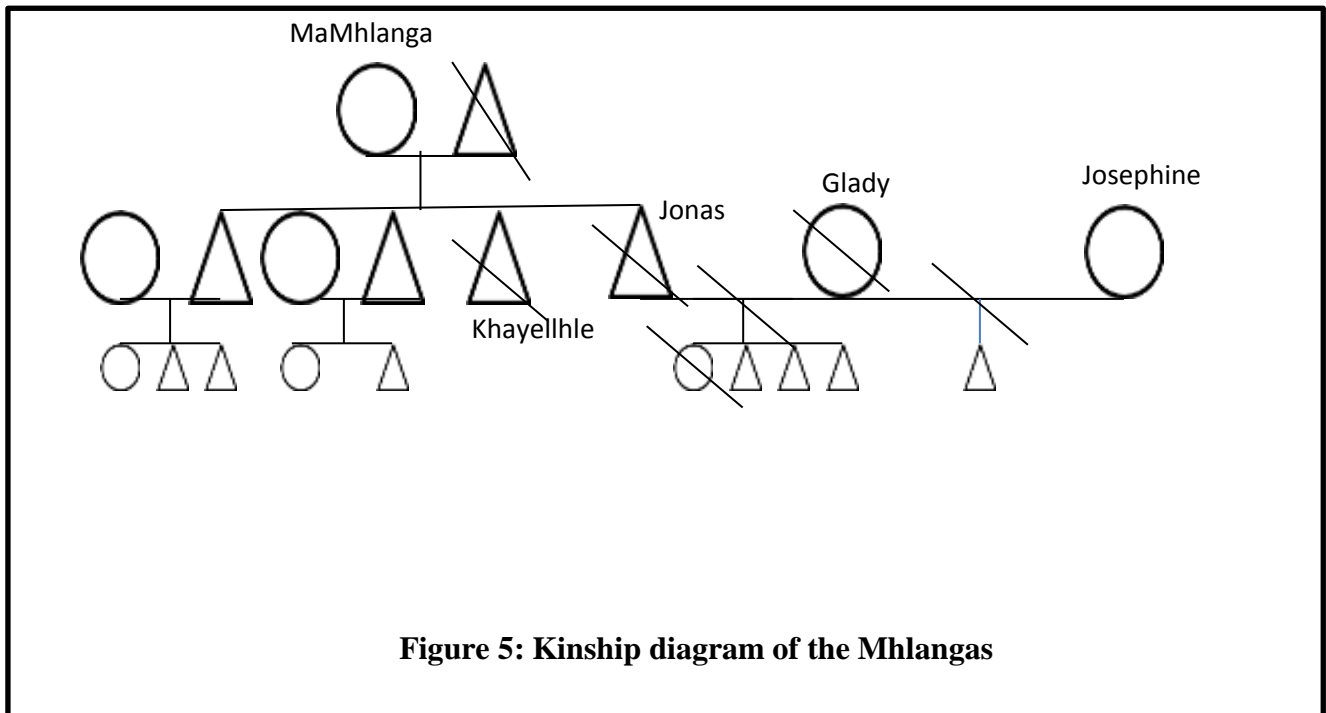
Khayellhle Mhlanga was 46 years old; he was strong and wiry from a life of hard physical labour, but his face betrayed the severity of his illness. Khayellhle's cheekbones were gaunt, his cheeks looked bruised, his lips were pink with fresh scar tissue, and he wore a woollen hat to hide his thinning, downy hair. MaMhlanga initiated my first meeting with her son. She had heard about my interest in AIDS and wanted me to assist with Khayellhle's application for a government disability grant. The application was successful but Khayellhle benefited for only one month before he died.

During our first meeting, MaMhlanga did most of the talking while Khayellhle coughed and nodded in agreement. He seemed physically drained and I felt hesitant to interview him. Over the next 18 months his health fluctuated dramatically from good to bad and I learnt to expect the worse every time I returned to visit him.

The household had limited financial resources to support a person as ill as Khayellhle. MaMhlanga was unemployed. She received a state pension of R750 per month supplemented by selling mats woven from plastic bags. These funds were used to buy E-Pap (maize meal mixed with vitamins), fruit and vegetables, and the taxi fare to the hospital⁴. The household comprised eight adults and seven children. Three children received a Child Support Grant (R170 per month per child). Most of the household lived in a four bedroom house, paid for by Khayellhle's father's life insurance policy. We usually met on the veranda, shaded by a leafy creeper.

In our meetings, Khayellhle spoke softly but candidly about his history of infection, illness, failed relationships with women and his violent past. A prominent theme that emerges from his narrative is his growing inability to exercise agency, the

sense that AIDS had stripped him of his masculinity. In order to understand how and why this occurred, it is necessary to view his illness within the broader context of his life.



‘I started to run wild’: work and women (1958 – 2000)

Khayellhle was born in KaGomane village, one day’s drive from Maputo in the Gaza Province of Mozambique. Khayellhle’s father worked on a South African gold mine and was absent from home until Khayellhle was about eight years old. Until six years of age Khayellhle lived with his father’s mother and looked after her cattle. Khayellhle recalled the constant struggle to find food: ‘The problem was hunger – everyone was hungry. But my grandmother made sure that we always had something to eat before we went to sleep’. They ate boiled dried game meat (*biltong*) served with wild fruit mashed into a pulp. Like the other herd boys, Khayellhle hunted mice and collected termites to

eat during the day. Khayellhle's father returned home when Khayellhle was eight years old and sent him to school. Khayellhle loved school but performed poorly as he had to herd the cattle in the mornings and afternoons.

When Khayellhle was twelve years old, witchcraft suspicions and accusations broke up the family. One day, while playing, Khayellhle's little brother Ozeus disappeared, appearing hours later in a hole in a tree. The children suspected that their grandmother was responsible for his mysterious disappearance. Khayellhle's grandmother became furious when MaMhlanga questioned her about what had happened to Ozeus. Suspicions of witchcraft hardened after Khayellhle's older brother Jonas died after a short illness. After Jonas was buried, MaMhlanga reported mysterious sightings of the boy. She suspected that her mother-in-law had transformed Jonas into a zombie (*xindhachani*) to work for her in her fields (cf: Niehaus 2005).

Fearing for her children's lives Khayellhle's mother fled with them to South Africa. This was in 1969 long before the influx of refugees from Mozambique into South Africa. The family travelled by train to the border and jumped the fence and walked the remainder of the journey. MaMhlanga's brother lived in KwaBomba and he helped her find a stand and paid for Khayellhle's schooling. Back at school, Khayellhle was happy. He did well and was content.

I remember sitting together with Joyce [his best friend] at school. I was promoted from Sub B [Grade One] to Standard One [Grade Three] because I was really bright. I was appointed as a prefect to report on the noisy children in the class. They would get beaten with a *sjambok* [leather hide whip] when I reported them.

Unfortunately, Khayellhle's school career was short lived due to a lack of funds. Khayellhle's uncle (*malume*) came to his assistance and found him work as a shop

assistant in the East Rand township of Brakpan. Life in the city was hard for a young Shangaan-speaking man and the savvy townfolk took advantage of his inexperience. They called him ‘*barrow*’ (a naïve country boy) and teased him for his ignorance of the ways of the town. ‘I couldn’t speak their language [IsiZulu] and so they thought I was stupid’. At night when Khayellhle locked up the shop, gangsters (*tsotsis*) beat him up and tried to take the shop keys. Khayellhle soon learnt to protect himself and carried a long stick. The next time the gangsters threatened Khayellhle he beat them up.

As he now earned a small income, Khayellhle intended to marry Joyce, his friend from school. ‘She was my only friend at school. I didn’t have a male friend’. However, his mother forbade the union. Joyce lived immediately next door to Khayellhle’s family and marriage and neighbours did not mix well; suspicions of witchcraft and theft are common sources of conflict between neighbours and would threaten the marriage. Instead, MaMhlanga negotiated with the Mathonsi family from Acornhoek to marry their first born, Gladys. Joyce was furious. Khayellhle laughed when he recalled the battle between the two young women: ‘They fought with each other until they bled. Joyce really wanted to marry me. She knew that I was working in Brakpan and I could have supported her quite well’.

Khayellhle had few memories of his marriage to Gladys and he possibly regretted the loss of his friendship with Joyce. Khayellhle’s first born son lived with them in their backyard shack in Tsakane. However, the family soon outgrew their lodgings. Khayellhle built a small two-roomed house in KwaBomba and Gladys returned to the village with their three sons. In 1981, Khayellhle secured a well-paying job with Grinaker, a large

construction company. He was often on the road, laying railway sleepers and working on building sites Witbank.

This was also a turning point in Khayellhle's sexual history. Khayellhle had only played at sex (*matanyula*) with Joyce before marrying Gladys. Like other boys of that age, first sexual contacts were limited to playing *ku-ku* (hide and seek) with girls of the same age, and simulating sex fully clothed. Yet, after marriage Khayellhle had numerous extra-marital affairs:

I had never thought of this before I was married. [After marriage] I started to run wild – I had many girlfriends. I started off with one and then had the other. This was a surprise to me. When I was young I had never experienced women. I had a friend called Dlamini. He would visit together with his girlfriend and her friend. So I got involved with her. So that is how it started. A friend can make you do things that you don't really want to do. Dlamini told me straight – here is a woman! When I was living in Brakpan I told myself that I must love one woman in Brakpan and one woman at home.

Back home in KwaBomba, Gladys became friends with another woman who frequently travelled to Randfontein on the West Rand. They exchanged sex for gifts and money with the men who worked the goldmines in the West Rand. News of Gladys' activities reached Khayellhle. The Mhlanga and Mathonsi elders discussed the problem and agreed that Gladys would return to her parent's home, while the Mhlanga family would retain custody over the children. Khayellhle had paid the full bridewealth and he had rights over his children.

Thoroughly disenchanted with the way his relationship had turned out, Khayellhle broke up with his paramour (*xigangu*) and remained chaste for an entire year. Two years later Gladys died of unknown causes.

Three murders and jail (1989-1991)

In the late 1980s, Khayellhle's life course changed dramatically. In 1989 Khayellhle spent eight months awaiting trial in Moderbee prison for a double murder. At the time he was living in KwaThema on the East Rand. Walking home after a night of drinking, a gang of sixteen boys attacked Khayellhle and his companion. As the boys circled in, Khayellhle's friend fled. Reminiscent of his early days defending himself against the thugs of Brakpan, Khayellhle sought to defend himself. He recalled: 'My aim was to use my knife on one of them. Once they heard him scream they would run away. I stabbed two of them and killed both...I aimed for the throat'. Khayellhle felt his actions were legitimate: 'I was happy that I was alive. Instead of me dying, two of them died'. As he predicted the thugs fled. The police arrested and charged Khayellhle with murder. Khayellhle served seven months awaiting trial in Moderbee prison.

In prison, Khayellhle had to defend himself again. Two men demanded Khayellhle's new overalls and attacked him in the showers. With soap in his eyes, Khayellhle grabbed the one man's neck and bit as hard as he could, and killed him instantly. Fortunately the prison authorities regarded the incident as self-defence and did not charge Khayellhle. After this event, leaders of the 28 prison gang invited Khayellhle to join them. The 28 were South Africa's oldest prison gang, with a reputation for savage violence. In 1996 the 28 gang in the Barberton jail killed a man, 'dissected his body with knives and actually ate the liver' (Niehaus 2002c, 89).

Khayellhle explained the advantages of belonging to a gang in prison:

There were about 40 or 50 of us in the cells. Eh it is true – there is a lot of rape in jail. I saw this many times. You were only protected if you had someone who

knew you from outside. Then he would say ‘Hey don’t touch this guy. I know him from *lokshen* [location or township]. But me I had no one. When they lock you up there is only one police officer [prison warder] to protect you. They are too scared to intervene. The reception office was far away. If there was a rape then they had to go far to call the other warders. It was only like this for me when I first arrived. But once I joined the 28s they know you can fight. Then you can smoke with them – they are your big friends. They used sharpened spoons to cut out the heart and they ate it.

After he joined the 28s, Khayellhle was marked with a tattoo on his torso: a dagger tattooed on his left arm and on the right a dagger piercing a heart. On his chest, a snake coiled around a lion and a mermaid:

The lion is powerful like me. I am a lion. I can kill someone, like the 28 are the most powerful group. The snake is a woman. So is the mermaid. The 28 don’t trust women. They say it is better to trust a man than a woman

Having found that Khayellhle acted in self-defence, he was released from jail in 1991. Fortunately he was re-employed by Grinaker. However, he was soon retrenched along with thousands of other workers. Despite his long service to the company, management claimed that there were too many retrenchments to pay out workers in full. As Khayellhle put it ‘A Sotho man from Tzaneen stole our money’. Depressed and angry Khayellhle returned home. This anger translated into excessive drinking in the tavern lounges and shebeens in KwaBomba. Khayellhle favoured Solly’s tavern, a run-down shell of a house. He was often the centre of fights at Solly’s and was arrested on two occasions.

Infection, accusation and revenge (1992-2003)

Where migrant life had disrupted his role as a father and a husband, urban crime and violence further hardened Khayellhle. Desperate for work, in 1992, Khayellhle found

work with a swimming pool construction company in Nelspruit. The work was poorly paid and infrequent. Khayellhle felt exploited and claimed that the owners were corrupt. However he then met Josephine Komane, a single mother of three and moved in with her in KaNyamazane near Nelspruit. In contrast to his previous relationships, Khayellhle had fond memories of Josephine. ‘She was a good, good woman, a born again [Christian]’. Khayellhle and Josephine had a son and they lived together until 2002.

Despite his good intentions, Khayellhle was often away from home and had several casual relationships with women that he met while on site in Witbank and Johannesburg. For Khayellhle, like many other men, contract work provided temporary relief from poverty. Many men drifted between construction work and informal selling, while others gradually slipped out of the market, becoming permanently unemployed, and unemployable. Commitment to a long-term relationship as a spouse or as a father was impossible under these circumstances.

Khayellhle started to drink heavily again and had affairs with the women he met while drinking in taverns. In 2002 he met an attractive young woman named Simpiwe and stayed over at her house for several days. Josephine learned about his infidelity and threw him out. Khayellhle moved in with Simpiwe, a move he later regretted.

Simpiwe was younger than Khayellhle and had several lovers in KaNyamazane. She was also extremely abusive. Khayellhle spoke at length the nature of his relationship with Simpiwe:

The person who destroyed my spirit was that woman that I stayed with [Simpiwe]. She would come home drunk and would wake me up and start to insult me and do horrible things to me. She really killed my spirit. She insulted me about my mother’s panties and she would say anything she liked to me. And she could fight! She beat me on the mouth. She would never get tired, from morning

to night. She would drink a lot. When I was at work I was relaxed but when it came time to go home I would become afraid. If she hadn't seen me that day she would question me when I got home: 'Who did you talk to?' She would argue with me. Eventually I would just stay silent when she spoke to me. When my son [from the first wife] visited me she would get really angry with me: 'What are you talking about with him?' It [her anger] was sudden. We would be sitting together and laughing together and then she would just go mad. Her eyes would go white. When I got home from work she would give me food and water. But later in bed she would change and become mad. It is better to learn about a woman first before you go and stay with her. Even if I had done nothing wrong she would take a broken bottle and stab me on the arms and on the stomach and on my hands. She once burnt my head with a [clothes] iron. She would start hitting me. I wouldn't beat her back because I was afraid of being arrested. Once I called the police and they sent me to the hospital to get a letter [to provide proof of the assault]. They never arrested her though. Once when I was fighting with her she called her daughter and told her 'boil some water, I want to burn your 'father' [not his biological daughter]'.

Prior to her relationship with Khayellhle, Simpiwe was involved with a man who had died. His relatives suspected Simpiwe of witchcraft and when they buried him, the family elders threw Simpiwe's clothes into the grave. Khayellhle thought 'they wanted Simpiwe to follow him to the grave'. Indeed, soon after the burial Simpiwe became ill and consulted a faith healer who revealed that her former lover's family had tried to bewitch her. Khayellhle was convinced that the man had died of AIDS and that Simpiwe had passed the infection to him.

She walks with the disease. She knew that her boyfriend died of AIDS. This woman wants to give everyone [AIDS]. When I was not there she would go to the *shebeens* to have sex with as many men as she could find. This woman just wants to give everyone [AIDS]. She had a big body, big legs. But now she looks way too slim. I found her slim. But she started to get worse when I was with her. Straight, she gave me HIV. I know that for sure. Straight! Straight! Straight! [Definitely]

In 2003, Khayellhle started to become ill. At first, his illness manifested as a skin rash. He was constantly tired and developed sores on his head, torso, and legs. At a

hospital in Nelspruit he was told that he had to be tested for HIV. When he heard he was HIV positive he was shocked.

I had heard about HIV before on the radio for a long time. But I really didn't expect that I would end up getting this disease. It is strange because when I was in Johannesburg I was really running around with women. This was long before I had heard about AIDS. But the time I settled down that is when I got it. [When I was told that I had AIDS] I cried. I was very upset. I sat at home and played Gospel music.

In February 2003, Khayellhle confronted Simpiwe and accused her of infecting him. He recalled the confrontation: 'After this, the way I feel, I think it is you [who infected me]. But she said 'No! You found me well and now you are sick but I am still healthy'. Simpiwe completely neglected Khayellhle. Even though they were living in the same house, she drank beer and even had sex with men in the same room. When Khayellhle visited hospital for a few days, Simpiwe invited a white man who paid her for sex, and even paid her daughter R2.00 to keep her quiet. Later that year Khayellhle broke off his relationship with Simpiwe and returned home to KwaBomba.

Khayellhle did not inform his mother that he was HIV positive. MaMhlanga consulted a ZCC priest (*mufundise*), a faith healer (*maprofeta*) and several diviners (*tin'anga*) to find the cause of her son's afflictions. Khayellhle's health deteriorated rapidly and fearing for his life MaMhlanga took Khayellhle to Tintswalo hospital. Khayellhle was re-tested and he disclosed to his mother that he was HIV positive. 'I told her that those healers she had spent money on were not going to be able to help me'.

Khayellhle was then determined to confront Simpiwe and to get revenge 'for what she had done to me'. He returned to KaNyamazane and accused Simpiwe again of infecting him. Simpiwe became enraged and attacked Khayellhle, biting his arms and

hands. He fled and never returned. Yet, Khayellhle's anger towards Simpiwe grew stronger. He plotted to confront Simpiwe again, intending to kill her before killing himself. He was sure that Simpiwe had infected him as she seemed strong and able while he was weak. He explained that the infector was always healthier than those they infect. 'She took my strength when she infected me'. Khayellhle also resented Simpiwe for the way she had changed his character. As he put it: 'She poisoned my spirit. So now I have no patience. I can get angry about the smallest thing'.

The machine inside controls me: Final days (2004-2005)

Dealing with anger and frustration was a constant battle for Khayellhle. He was especially concerned with becoming 'heart sick' (*vu vabya mbilo*) and constantly sought peace and quiet and avoided situations of conflict. He described his struggle to control his emotions:

I don't need to get angry. I feel weak if I see something that makes me angry. I have such a short temper. If someone doesn't reply to me when I speak to them I feel like running away from them. If someone makes me angry I feel like just looking at them without replying to them. It stays for a long time in my heart what that person has done

Khayellhle attended the AIDS support group at the Rixile AIDS Clinic at Tintswalo Hospital. Fellow members advised him to avoid becoming 'too upset'. They said that keeping calm and avoiding stress extended life. Yet, the greatest challenge that he faced was managing the tedium of illness.

Khayellhle's days were monotonous and repetitive. Apart from me, his only other regular visitor was his brother. One day Khayellhle helped his brother make cement

bricks in the yard, but after only a short while he was exhausted. ‘He does nothing here’ commented Ma Mhlanga. Khayellhle agreed:

I am very bored. No one visits me. I can’t chat to the youngsters in the homestead. I just listen to the radio and sleep. I don’t really have many friends. Before when I used to drink I had friends. Now I no longer have any friends. I just sit and listen to the radio. I would like to talk to other people who have this disease but they are just not interested. They are also scared to talk. I don’t know how to talk to people. It is easy for me to talk in the support group. But, I don’t want it to seem that I am pushing other people to do something that they don’t want to.

The response of other household members reflected increasing anxieties regarding Khayellhle’s physical appearance and potential contamination. When Khayellhle first returned home ill with AIDS, he slept in the living room in the main house. Later he moved to a dilapidated hut in the yard, usually reserved for the young men (*lawu*) situated at the entrance to the homestead. The *lawu* was considered private space, normally associated with the young men’s (*vajaha*) sexual autonomy. The separation of young sexually active men from other members removed their polluting bodies from those of the younger children.

These fears were further illustrated by the behaviour of other household members toward Khayellhle. Early one morning Khayellhle sneaked into the kitchen before anyone was awake and cut slices of bread from a fresh loaf. His younger sister discovered him eating and demanded that MaMhlanga throw the bread away. MaMhlanga smiled as Khayellhle recounted this event, and unconvincingly claimed ‘I ate the bread – just to show them it was okay’. She shrugged off the bread incident and claimed that the girl who had caused the incident was ‘not right in her head’.

Khayellhle's preoccupation with Simpiwe faded with time. He felt no anger towards her and no longer sought revenge. Instead, his thoughts turned towards his current predicament, his concerns for his children's welfare and future. Khayellhle prayed every night with his mother. His prayers were always the same: 'When I pray at night I ask God to give me more days to be alive to be alive for my children'.

In November 2004, Khayellhle left KwaBomba to seek work. His former employer wanted him to build swimming pools in Witbank. Khayellhle completed the first three months of his course of TB medication and felt well enough to return to work. He was painfully aware of the unkind gossip at home that accused him of wasting household resources. His grandmother made it clear that supporting Khayellhle was a waste of food. A neighbour overheard her saying 'What is the point in helping him if he was just going to die?' Khayellhle's younger siblings were respectful toward him while they were in the homestead, but he was aware that they gossiped cruelly about him with their friends from school and in the neighbourhood. Khayellhle consoled himself saying 'at least I know my status. Those ones are still in the dark'.

Khayellhle returned home in December 2005 extremely ill. His journey to Witbank was a failure as he had been too weak to work and had lost his job and wages. Khayellhle's mother cared for her son, feeding him soft porridge, cleaning him up when he had diarrhoea and bathed him. Khayellhle felt that he was close to death, a sensation confirmed by a reoccurring dream. In the dream several men and women appeared, walking around his room, accompanied by an old man dressed in white (the colour of the ancestors) who carried a big stick or staff such as those held by apostolic faith healers.

The man entered the room and left out the back through a door that did not exist. The dream frightened Khayellhle, although the presence of the old man made him feel better

I felt happy and better when I saw him. I didn't feel scared at all. I really want to know where these people came from, although they were not real people. I can dream this dream every night for a whole week. In the dream, I also saw another Khayellhle (laughs) there were two Khayellhles. I tried to talk to 'Khayellhle Two' and asked him 'do you feel the same way as I feel?' When Khayellhle Two wants to reply I always wake up

Other people I talked to about the dream said it indicated that Khayellhle was in the process of dying, that he was already 'gone'. A young woman said 'this showed that he was actually dead at that time'.

At the height of his illness, Khayellhle started to feel as if he was no longer able to exercise control over his physical self. To describe this sensation, Khayellhle talked of his body as if a machine had possessed it.

When I want to vomit, I just start and I can't control it. It is like there is a 'machine' [he used the English word] in my chest that controls my appetite. Sometimes if it doesn't want me to eat then I can't. When I am eating if it has decided I have had enough then it stops me. When I want to go to sleep and if it wants me to sleep on one side and not the other then I will start coughing until I move over to that side. It is the machine inside me that controls me. Even eating it controls me. It is like an automatic machine. If it wants me to stop then it stops and makes me feel uncomfortable. It has been like this for two or three months. It has never been like this before. But if I eat *morogho* [spinach] and pap then it is okay. But if I eat meat it says 'stop'. At home they boil my meat without any oil. I enjoy eating meat and pap but it is the machine that controls me. I believe that there is something that is controlling me. It started when I became really ill and it has become a lot worse. It makes me vomit. Yesterday it was the second time I just simply couldn't control it. It pushes. Vomit, vomit, vomit! It makes me want to vomit. This is when I feel like it is a machine. I can't control it.

Khayellhle's belief that a machine controlled his body resonates strongly with ideas of the body invaded by an external agent, often expressed in witchcraft beliefs.

Witches send snakes and frogs disguised as food through dreams to choke their victims. It is also significant that Khayellhle chose the image of being taken over by a ‘machine’ to convey his loss of control over his body. Machines had a special significance for him. As a young migrant, the image of the machine represented the hard, cruel world of post-industrial capitalism in which men’s bodies were dispensable. The idea of loss of control over the body also speaks to a rupture between mind and body, where his body represented by the machine did not obey his mind. This metaphor gives us an insight into a man’s pain at having lost all hope for a recovery, and his sense of disembodiment.

In our final interview, Khayellhle reflected on his life and infection with HIV with some regret. ‘The way I grew up I was well behaved. If I had continued like that I would never be sick like I am now’. In this statement, he clearly accepted personal culpability for his disease. Yet after a lengthy pause and some thinking, Khayellhle added ‘But even Mandela’s son died of AIDS.....’⁵

I was not present in Bushbuckridge when Khayellhle died. His mother called me on the phone to tell me he had passed. I asked why she had not called me earlier; perhaps there was something I could have done. She said that Khayellhle refused to allow her to contact me and said that there was nothing I could do for him.

Reflecting on the account pieced together from interviews, observations and informal conversations, I realise how Khayellhle presented clues in his narration of his life story of what was to come. His story is as much about his life before becoming ill as it is about his illness. The story describes the constant struggle to maintain control of his personal life, over his sexual desires, of women, and other men, and ultimately of

becoming completely impotent and being controlled by the ‘machine’ – a metaphor for AIDS.

CONCLUSIONS

The case studies presented in this chapter illustrate the experience of social suffering, defined as a loss of autonomy and power. The implication of this loss is particularly poignant for men of Solomon and Khayellhle’s generation. For both men this meant a failure to perform their roles as providers to support the futures of their children. Their loss of autonomy was most poignantly expressed in Solomon’s real or imagined fears that his siblings were waiting for him to die to appropriate his money. In Khayellhle’s case his loss of control was expressed through the metaphor of being controlled by a machine. As the disease progressed Solomon and Khayellhle experienced the general collapse of their bodies. Their emaciated physiques countered the ideal image of the fattened body; their skin drawn tight over their bones and the sores revealed an internal disorder; their inability to eat and retain food. The nature of their afflictions reflects the collapse of their social status and position.

Anthropologists who bear witness to AIDS face the task of rendering suffering meaningful (Henderson 2004). This is particularly critical in a context where deathly silences surround the AIDS epidemic; silences that the social and medical sciences are prone to mimic. The over-reliance on survey type instruments, focus groups, and rapid appraisals detach the observer from the realities of suffering. Ethnography provides a vantage point to witness and record the immediacies of peoples’ suffering. The biographies presented in this chapter have tried to convey this by situating suffering

within the broader context of everyday life and history. Importantly, writing about suffering is not simply about empathetic description. In trying to write about social suffering and AIDS, I have been especially mindful of Farmer's (1999) observation that sympathetic prose on suffering is not in itself a sufficient response. However, it is critical that peoples' experiences of suffering and trauma are written about in such a way that their dignity is preserved. Nordstrom (1997, 9) reflects on her writings on the trauma of war torn Mozambique:

Treating a person's experience of violence with dignity is arguably the most important part of studying and writing about violence, and it is certainly the most complicated.

In South Africa, suffering is defined according to biomedical calibrations of disease progression decided upon by global health agencies such as the World Health Organisation (WHO) and is used to determine access to medication and government grants. The continued failure to provide adequate care and support for people living with AIDS contributes toward their experiences of suffering.

END NOTES

¹ An exception is Fassin et al. (2008) who chronicle the life and times of Magda M, a young South African woman. Her story is of rape as a young girl, entering into sexual relationships with men to survive in Johannesburg, and ultimately death from AIDS illnesses.

² A standard amount of R50 is usually charged for throwing the bones. This is paid up prior to the consultation session in order to appease the ancestors. It is not included in the charge for treatment which is extra. It is common practice to pay for treatment only if the treatment offered by the healer is effective.

- ³ Free clinic services are provided for patients. However, Philemon incurred debt as he had to pay a neighbor to drive himself and Pretty to the clinic when I was not available.
- ⁴ A single return taxi trip to Acornhoek from KwaBomba cost R20. The availability of fresh fruit and vegetables was limited despite the lowveld being a major producer of oranges and tropical fruits. The local supermarkets sold a range of vegetables and fresh produce, but this was often expensive and required regular shopping expeditions that incurred transport costs. Not surprisingly people favoured non-perishable food such as packet soups eaten as a relish with the staple maize meal. Salads (beans and greens) were ‘Sunday food’. Many households continued to eat ‘traditional food’ (*swakudya xa xintu*) such as okra (*guxe*), groundnuts (*timwembe*) and wild spinach (*morogho*). These foods are believed to have healing properties and health benefits. Yet, despite the rhetorical claims of their benefits, villagers displayed preferences for status foods such as meat, rice, and potatoes.
- ⁵ In 2005, Nelson Mandela announced in the public media that his son had died of AIDS.