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This is the tenth AIDS Review published by the Centre for the Study of AIDS at the University of Pretoria. These Reviews have been regarded as some of the most critical and interesting writing on HIV and AIDS in South Africa. They are widely prescribed as core reading in university courses in the United States of America, the United Kingdom, Australia, India and Brazil. All of the Reviews have had more than two print-runs. They provide a challenge and critique to the conventional wisdoms that have developed regarding HIV and AIDS, and the ways in which issues raised by the epidemic should be addressed. There is a troubling orthodoxy in many of the HIV and AIDS responses – the main function of the Reviews is to address such tenets, which tend to stifle debate and dissent.

At the time of publication, South Africa was poised to expand rapidly one of the biggest and most ambitious testing and treatment programmes in the world. Many doubt the wisdom of this. Many question the efficacy of testing as a tool to encourage behaviour change. Many more have expressed their concern that the ‘cattle-dip’ approach to testing has the potential to undermine human rights, as well as to set back prevention programmes and interventions. As Sue Kippax has argued repeatedly, people who test HIV positive may take action to protect their sexual partner/s, yet there is no evidence that testing changes the behaviour of people who test HIV negative. Despite the lack of proof and despite the recognised need for counselling and support for people who are to be tested, the new orthodoxy is that mass testing with reduced counselling will now succeed, even though in the past voluntary counselling and testing has failed.

As we have argued in previous Reviews, a policy such as mass HIV testing is often formulated in the absence of any real engagement with, or understanding of, social and critical theory. Plans are made without undertaking systematic and sustained research into how, two decades on, people are understanding and responding to the HIV and AIDS epidemics. Until we have intelligent research and serious engagement with social, political, cultural and individual issues we will continue to have policies and
programmes that fail to take account of our social understanding rather than being integrated with it.

Although it is not in itself a prevention strategy, treatment of HIV now also carries a huge burden in the form of expectation that it will succeed in enhancing prevention, since other prevention strategies have failed. Treatment is assumed to take on symbolic powers far beyond the actual task of reducing copies of the virus in the human body.

Past Reviews have placed under scrutiny the issues of human rights, sexuality and masculinities, food security, care and support, the political response, families, education and the public health system. The AIDS Review 2009: Magic continues in this tradition.

This Review looks at one of the consequences of testing: treatment and access to treatment. No one would deny that all individuals who wish to should have access to testing and then, if they qualify, access to treatment. However, what is at issue is the manner in which testing and treatment are framed and thereby understood. How do individuals understand the HIV test, its implications and its complex relationship to people’s lives, to communities and to society? What informs whether or not individuals decide to test? How do they understand treatment, how drugs work, dosages and side-effects?

Magic challenges the all-too-easy assumption that testing and treatment ‘normalises’ the disease and reduces HIV-and AIDS-related stigma. Magic seeks to address the influences in people’s lives that affect their response to antiretroviral treatments, i.e. what drives adherence or treatment failure? What are the factors that come into play in the complex lives of individuals and families, and how do these influences find a place in the multiple community networks that people inhabit?

Magic addresses how the traditional and modern worlds intersect and collide. When does modernity shape the response? When do traditional forms of belief, witchcraft and superstition override modern notions of disease and treatment? Extensive research in Bushbuckridge and Venda provides new stories about testing and treatment – stories that challenge our taken-for-granted certainties about illness, health and medicine. These are the stories that need to inform our understanding about treatment,
and its social and personal success. These are the stories that should inform how we develop and think about interventions. In the end it is these understandings and explanations that will drive access to treatment, and add in many fascinating and complex ways to treatment literacy and in equally complex ways to understandings of stigma and silence.

The views expressed in this Review are solely those of the authors and the Centre for the Study of AIDS.

Mary Crewe

Director, Centre for the Study of AIDS

AIDS REVIEWS

2000  –  To the edge by Hein Marais
2001  –  Who cares? by Tim Trengove Jones
2002  –  Whose right? by Chantal Kissoon,
       Mary Caesar and Tashia Jithoo
2003  –  (Over) extended by Vanessa Barolsky
2004  –  (Un) Real by Kgamadi Kometsi
2005  –  What’s cooking? by Jimmy Pieterse and Barry van Wyk
2005  –  Buckling by Hein Marais (an extraordinary
       Review)
2006  –  Bodies count by Jonathan D. Jansen
2007  –  Stigma(ta): Re-exploring HIV-related stigma
       by Patrick M. Eba
2008  –  Balancing Acts by Carmel Rickard
This year’s *AIDS Review* examines the uptake of antiretrovirals (ARVs) in two different South African rural locations, namely Bushbuckridge and Venda. As social anthropologists who have done intensive fieldwork in these respective areas since the onset of the HIV and AIDS epidemic, our aim is to examine how people who live with HIV use, or refrain from using, ARVs in everyday village contexts. Although a great deal has been written about the contestation of ARVs in South Africa’s public political domain, the perspectives and experiences of people who are infected and affected by HIV in the peripheral areas of the country often remain obscure. We adopt an ethnographic rather than a statistical approach to illuminate these perspectives, focusing upon how ARV use is negotiated in socio-cultural contexts that often foreground stigma and blame.

During the term of office of President Thabo Mbeki and his Minister of Health, Manto Tshabalala-Msimang, the South African government actively stalled the provision of ARVs. In the mid-1990s, government was unreceptive to calls by physicians for it to distribute azidothymidine (AZT) to women in the last months of pregnancy, to reduce the chances of transmitting HIV from mother to child. Instead, government pinned its hopes on virodene, a supposed ‘miracle drug’ developed by a chiropractic surgeon in Pretoria. However, the Medicines Control Council subsequently found that virodene was not only ineffective, but that it contained a toxic industrial solvent (Fassin 2007: 41-49).

In 1999 the South African Health Ministry also opposed calls to provide Nevirapine, a fairly cheap transcriptase inhibitor. It argued that Nevirapine produced side-effects, did not combine well with tuberculosis medication, and offered no protection against infection of the child through breastfeeding. President Mbeki became receptive to the arguments of dissident scientists who denied the existence of HIV, and insisted that the pharmaceutical industry promoted ARVs merely because it had a vested financial interest in selling the drugs. The dissidents claimed that people diagnosed with HIV were in fact suffering from various poverty-related diseases. Posel (2005) suggests that Mbeki’s denial of the sexual mode...
of transmission of HIV was partly a reaction to racist renditions of Africans as ‘promiscuous carriers of germs’, who display ‘uncontrollable devotion to the sin of lust’.

In 2001 the Treatment Action Campaign (TAC) filed a case in the High Court against the South African government, claiming that the government should distribute ARVs in order to satisfy citizens’ constitutional right to life. The Court ruled that the government should make Nevirapine available to pregnant women in all sectors of the public health system, in order to halt mother-to-child transmission of HIV. Yet, only in 2003, after the government had unsuccessfully appealed against the judgement, did it begin to comply with the Court’s directive (LeClerc-Madlala 2005).

Prompted by the Global Fund for AIDS, Malaria and Tuberculosis, and by the US Presidential Emergency Programme for AIDS Relief (PEPFAR), South Africa’s Department of Health approved a national public-sector ‘rollout’ of ARVs in 2003. The triple combination drugs effectively repress, but do not eradicate, HIV. There is indisputable evidence of the efficacy of ARVs: research in Uganda showed remarkable recoveries by persons with HIV, even in the latter stages of the disease (Illife 2006: 149). However, a lack of political will has greatly impeded the South African programme’s success, as made evident in the government’s failure to meet its own targets. In 2006 only 141 346 of an envisaged 456 650 public-sector patients who required ARVs were actually receiving treatment (Natrass 2006: 20). Manto Tshabalala-Msimang repeatedly described ARVs as toxic and encouraged the use of alternative remedies, including ‘traditional medicines’, multi-vitamins, garlic, and extracts of the African potato.

After a long and arduous struggle, treatment advocates emerged victorious. In April 2009, under President Jacob Zuma’s leadership, South Africa’s official policies on HIV and AIDS began to conform fully to international practice. According to UNAIDS, South Africa now has the largest number of people using ARVs in the world. In October 2009, South Africa’s new finance minister announced an additional R900 million for the provision of AIDS drugs, and declared the government’s commitment by early 2011 to treat 900 000 people living with HIV (or roughly 80% of those currently in need of ARVs) (UNAIDS 2009).

Yet health scientists have become increasingly aware that the challenges of responding effectively to the devastating epidemic go much further than merely distributing ARVs. Even in conditions of optimal supply, the uptake of ARVs and adherence to treatment have often been poor. In neighbouring Botswana, the government proudly announced in 2001 that it would offer free ARV treatment

According to UNAIDS, South Africa now has the largest number of people using ARVs in the world.
to all citizens with HIV. Yet two years after the launch of
this impressive programme, only 15 000 people (or 15% of
those in need) had presented themselves for treatment
(Steinberg 2009: 1). In a similar vein, many South Africans
have declined testing for HIV antibodies, have refused
ARVs, or have defaulted on treatment.

Workplace ARV treatment programmes organised to
offset employee morbidity and mortality have seldom pro-
duced the desired results. Data pertaining to seven large
corporations show limited participation by eligible employ-
ees, and a tendency to only seek treatment
in the later stages of the disease. By 2005
only 7 348 of the approximately 33 500
HIV-positive employees of the Anglo-
American group had enrolled in the com-
pany wellness programme: 2 936 employ-
ees had received ARVs, 29% had dropped out of treatment,
and 8% did not adhere to therapy (George 2006: 185-6).

An early study by Orrell et al. (2003) found that 90% of
individuals who received ARVs at clinics in Cape Town re-
ported adherence, and that 71% had achieved ‘undetect-
able viral load’. But these results leave little room for
complacency. Subjects did not represent a sample from
which findings could be generalised, as they benefited
from support provided by ongoing randomised control
trials. Moreover, the analysis excludes data for 52 subjects
(16% of the total) who abandoned ARVs before completing
48 weeks of follow-up (Gill et al. 2005: 245). Other studies
show significant discrepancies between self-reported ad-
herence and clinical success. A report from Durban was
most striking: with 100% of patients self-reporting 100%
adherence, only 57% actually achieved ‘undetectable viral
load’ (Brown et al. 2004).

There has been much debate about the causes of these
uneven results. Analysts readily single out a crucial factor
undermining treatment efficacy as being the longstanding
failure of government to ‘authorise’ ARVs
(Biehl 2007). However, the absence of bio-
medical knowledge does not appear to
be the most obvious barrier to ARV use.
Interventions by NGOs seem to have en-
sured the population has a reasonable
understanding of the causes of HIV infection, modes of
transmission, and ART adherence. A study of crucial factors
undermining treatment efficacy amongst clinic patients in
Soweto shows overly optimistic impressions of ARVs: 98%
of respondents believed these drugs could halt the pro-
gression of HIV, 49% believed that HIV and AIDS were
curable, and 36% believed the drugs did not have any-
side effects (Nachega et al. 2005: 198). The authors see
these attitudes as comparable to those of the general
population.
Experiences of stigma and ostracism have clearly discouraged persons living with HIV from seeking diagnosis and undergoing treatment. Even TAC activists who disclose their status at public events do not do so in their own communities (Ashforth & Natrass 2005: 293). The stigma regarding HIV is due not only to the condemnation of sexual misdemeanours, but also due to the perception of HIV as an incurable, inevitably terminal sickness. This perception generates fatalistic attitudes and raises questions about the pollution that an afflicted person may represent to others (Niehaus 2007). Being on ARV treatment does not reduce such stigma (Makoae et al. 2009).

Health professionals have been concerned that the existence of plausible alternative interpretations of sickness and alternative therapies might undermine the success of treatment programmes. In her moving account of the death of the popular Johannesburg DJ, Khabzela, McGregor (2005) shows how ‘township spiritual eclecticism’ can be counter-productive in the case of AIDS. Although Khabzela announced on radio that he was HIV positive, and although his employer agreed to pay all medical expenses, he refused to use ARVs. Khabzela came to see himself as a victim of witchcraft and used an ever-wider range of alternative remedies: prayer, various traditional healers and immune boosters touted as ‘miracle cures’. In the face of his impending death, South Africa’s health minister, Manto Tshabalala-Msimang, delegated a Dutch nurse to treat Khabzela with vitamins. What physicians diagnose as AIDS-related diseases, diviners and Christian healers may diagnose as signs of bewitchment (Ashforth 2002). This label may have the psychological advantage of shifting blame away from the person with HIV. Moreover, unlike clinicians, diviners and Christian healers do not regard diseases as incurable. This is to deny the power not only of medicines and the ancestors, and also ultimately to deny the power of God to restore life (Ashforth & Natrass 2005).

Gendered concerns and poverty have also emerged as barriers to effective treatment. Women are generally more likely than men to verify their HIV status and to accept clinical care. This may be because health facilities are more accommodating of women, and because of special initiatives to prevent the mother-to-child transmission of HIV (Skhosana et al. 2006). In terms of government policy, HIV-positive persons with a CD4 cell count of 200 or less are seen as incapable of working and are entitled to receive a monthly disability grant (valued at R780 in 2005). Such grants are a significant source of income for many households, and have produced unintended conflict between people’s health and welfare. LeClerc-Madlala (2006) observes that patients at public hospitals sometimes use poor health as a bargaining chip.
to negotiate for a greater income from social grants. Fear of losing their grants once their health improves may impel patients to default on treatment in order to drive down their CD4 counts.

This *AIDS Review* contributes to these debates by exploring barriers to effective treatment in Bushbuckridge and in Venda. Our discussion is divided into two parts. In the first, Isak Niehaus draws on the results of nearly 20 years of fieldwork in a village of Bushbuckridge. Niehaus contends that treatment literacy might not be the most crucial factor in assuring effective treatment outcomes. Far from villagers being ignorant of HIV and AIDS, he shows a super-abundance of information, provided by multiple diverse discourses. Stigma and silence surround HIV and AIDS: this is not due to the absence of knowledge, but is rather an outcome of, public health propaganda in the early days of the epidemic focusing on prevention and labelling HIV and AIDS as a terminal condition without hope. At the same time, political conspiracy theories and religious discourses foreground blame. In these contexts many villagers have refrained from testing for HIV, and from consulting medical practitioners. Niehaus contends that this scenario has changed since the provision in 2005 of antiretroviral therapy (ART) at a nearby clinic. With reference to three biographies of illness, he shows that the potential of ART to transform HIV and AIDS into a manageable, chronic condition has been unevenly realised. Illiteracy is frequently no barrier to treatment. Yet a plethora of other factors, including the operation of therapy management groups, pre-existing accusations of witchcraft, and adverse conditions in local hospitals, continue to undermine treatment efficacy.

In the second part of the *Review*, Fraser McNeill explores the broader social-cultural worlds that ARVs entered in Venda. McNeill adopts a less biographical approach than Niehaus, but draws upon intensive participant observation to depict the contemporary situation in greater depth. McNeill is struck by the public silence surrounding health, sickness and death. Yet, far from being an act of denial, he suggests that not speaking openly about HIV and AIDS should be understood as an act of self-defence against stigma. Knowing too much about causes of death generates suspicions by other community members about implication in fatalities.

McNeill focuses specifically upon the experience of women’s and children’s supports groups, showing how in both cases the survival of these groups depends upon their ability to remain shrouded in secrecy. However, in the case of the women’s group secrecy frequently raises suspicions and generates rumours. Men construct women’s transition
through ART from death to full life as magical, and often identify members of these groups as zombies. They perceive children’s groups as less threatening.

In the conclusion to the Review Niehaus and McNeill reflect upon the implications of their findings – notably knowledge and silence, the allocation of blame for HIV and AIDS, and the gendered and generational aspects of ARV use – for attempts to ensure greater treatment effectiveness.
Health activists frequently invoke the absence of ‘treatment literacy’ to explain poor uptake of antiretroviral therapy and poor adherence to treatment regimens. In the case of ARVs adherence is the most crucial criterion for good treatment outcomes: missing more than 5% of doses is linked to incomplete suppression of viral replication (Bangberg et al. 2001). However, health activists do not simply conceptualise treatment literacy as the capacity to effectively use ARVs. They also define treatment literacy as ‘the capacity to interpret information about HIV/AIDS prevention, testing and care’ and even as ‘the skills to prevent HIV/AIDS-related stigma and discrimination’ (Schenker 2006: 3). In doing so activists conflate HIV prevention and treatment adherence, and inappropriately associate treatment literacy with general education and with a commitment to biomedical ‘explanatory models’ (Kleinman 1978).

This broad definition was apparent when participants at an International HIV Treatment Preparedness Summit, held in Cape Town during 2003, outlined the need for education. They emphasised that ‘education is as important as medicine’ and that without ‘good education’ one cannot expect good treatment adherence (Schenker 2006: 26). After having fought for the provision of ARVs by public health care facilities for more than a decade, South Africa’s Treatment Action Campaign (TAC) has entered a new phase of activism by vigorously implementing treatment literacy programmes. Here a central question has been ‘how to signify concepts of the virus, immune system and antiretroviral drugs for people with limited education and limited exposure to biomedical theories of disease’ (Ashforth & Natrass 2005: 285). This question is especially pertinent in the case of South African provinces such as Mpumalanga, where only 48% of high school students passed their final year examinations in 2009 (Mbalela 2009). TAC treatment literacy practitioners explicitly use the language of biomedicine and dispel misinformation arising from the use of alternative remedies and alternative understandings.
of HIV and AIDS. There is a concerted attempt to democratisate science: knowledge is presented as a means of empowerment, and through the use of body maps participants document how social worlds, interpersonal violence and HIV affect their bodies (MacGregor 2009). In contrast, the KwaZulu-Natal Department of Health harnesses ‘indigenous knowledge’, describing infection as ‘dirty blood’, comparing HIV to ‘poisonous snakes’, and portraying the immune system as ‘body soldiers’ (Ashforth & Natrass 2005).4

In this part of the AIDS Review I point to the limitations of ‘treatment literacy’ in improving the uptake of ART. At a theoretical level the focus on ‘explanatory models’ is often unnecessarily microscopic and inappropriately treats medical meanings as entities outside the contexts of experience (Kleinman 1995). Moreover, it tends to view the cultural as clearly separable from the biological, and often ignores the contradictory, fragmentary and disconnected nature of meaning (Atkinson 1987). A more fruitful alternative approach is to focus more broadly on the ‘social life’ of ARVs, exploring how these drugs intersect with social and cultural factors in a village setting.

As a South African white male social anthropologist, I draw on the results of in-depth ethnographic research conducted in Impalahoek, a village situated in the Bushbuckridge municipality of Mpumalanga.6 My fieldwork commenced in 1990, well before HIV and AIDS assumed epidemic proportions. Since then I have visited Impalahoek for periods of at least six weeks each year. Apart from conducting a social survey of 89 households, I learnt as much Northern Sotho as possible, and undertook extensive participant observation by working as a typist at a local school, and by attending numerous local events such as political meetings, football games, church services and rituals such as funerals.

Since 2002 I have conducted in-depth interviews specifically on the topic of HIV and AIDS with many well-known male and female informants, and I have collected the sexual biographies of 35 men. For understandable reasons, women were reluctant to discuss these intimate topics with male outsiders. My discussion of women’s discourses therefore also draws on the research material of Gunvor Jonsson, a former woman anthropology graduate student at the University of Pretoria (see Jonsson 2004).

Far from being ignorant about HIV and AIDS, I recorded a super-abundance of information among villagers, provided by diverse medical, political and religious discourses. I
show how a plethora of factors that have little to do with treatment literacy have impacted negatively upon the uptake and effective use of ARVs. These barriers include the absence of ‘political authorisation’ of ARVs, persistent social stigma, the availability of plausible alternative diagnosis in situations of medical pluralism (Janzen 1978), gendered concerns, and widespread poverty, as outlined in the introduction to this Review, but also adverse conditions encountered in overcrowded medical facilities. Moreover, I contend that illiteracy and poor education are often no barrier to treatment adherence.

**IMPALAHOEK: AIDS IN A SOCIAL AND HISTORICAL SETTING**

Impalahoek is currently populated by about 20 000 Northern Sotho and Shangaan (Tsonga-speaking) people of diverse origins. After the advent of apartheid in 1948, the wider Bushbuckridge region in which it is situated constituted a native reserve, administered by an Assistant Native Affairs Commissioner. Residents were rent tenants, who paid taxes to the South African Native Trust for residential, cultivation and stock-holding rights. The residential pattern was initially one of dispersed settlement. However, many households who were displaced by the forestation of large tracts of land and by the mechanisation of production processes on nearby white-owned farms moved into the reserve. This created considerable pressure on rural resources, resulting in reduced agricultural yields and much soil erosion.

Having failed to acquire more land to accommodate the influx of additional households, the Trust was compelled to reorganise the utilisation of land in the reserve. In 1960 agricultural officials implemented a ‘betterment plan’ and subdivided all land into residential settlements, arable fields and grazing camps. Households were relocated fairly small stands, lost access to the fields they had previously cultivated, and were allowed to each keep only ten head of cattle. Labour migrancy by younger men to South Africa’s industrial and mining centres now became indispensable to survival. In the same year bantu authorities were introduced. Bushbuckridge was also divided into two ethnic zones: the Mapulaneng Regional Authority for Northern Sotho people in the west and the Mhala Regional Authority for Shangaan people in the east. During the 1970s these structures came to be affiliated to the Lebowa and Ganzakulu bantustans respectively. Although situated in Lebowa, Impalahoek has always had a sizeable minority of Shangaans, interlinked to Northern Sotho families through ties of marriage (Niehaus 2002).

In Bushbuckridge overt political resistance to apartheid started rather late. There was no local counterpart to the
Sebatakgoma Migrants’ Association that fought against the imposition of bantu authorities in Sekhukhuneland (Delius 1996). During the national uprising of June 1976, a few students fled Soweto for Bushbuckridge, but their talk of ‘black consciousness’ had little impact on the area. However, after the formation of the United Democratic Front (UDF) in 1983, political activity spread rapidly (Van Kessel 1993). Young male comrades assumed the forefront in political struggles. They organised late at night, challenged the management of local schools, boycotted white-owned businesses and forced the tribal authorities to close. They also committed themselves to eradicating ‘evil’ by conducting vigorous anti-witchcraft campaigns. Between April and May 1986, comrades attacked more than 150 ‘witches’, killing at least 36 of the accused (Ritchken 1995, Niehaus 2001).

With the unbanning of all liberation movements in 1990 and the return of political activists from exile and detention, ANC structures mushroomed throughout Bushbuckridge. Through participating in South Africa’s first non-racial elections in 1994, residents of Bushbuckridge sought to achieve ‘political being’ in national centres of power and saw African nationalism as eminently suitable for this purpose. The ANC won a dramatic victory – claiming more than 95% of all votes in the region. In 1994 all bantustan structures were dismantled and Bushbuckridge became a municipality, eventually incorporated into the newly constituted province of Mpumalanga. More than a decade and a half of democratic rule has since passed, but the region still displays many features of a ‘native reserve’, such as very high levels of unemployment, welfare dependency, morbidity and mortality (Niehaus 2006).

Between 1990 and 2003, unemployment amongst women in Impalahoek remained fairly constant at about 60%. However, unemployment amongst men escalated from 16% to 47% (Niehaus 2006). This was clearly a result of the negative impact of economic globalisation and of de-industrialisation. The greatest job losses occurred in mining, the steel industry (in Pretoria), the military forces and education. New employment opportunities in the service sector – for mini-bus taxi drivers and security guards – were not nearly as well remunerated.

The provision of social welfare improved significantly in the post-apartheid era. In 2004, no fewer than 145 people in a sample of 89 households received welfare grants. Seventy-five people received old age pensions of R750, and 18 received the same amount in disability grants. The Department of Social Welfare had introduced monthly child support grants of R170 per child in 2002, which were received by 52 women in the sample. These grants made a major contribution to household income. During 2003,
20 households (23% of the total sample) survived solely on social welfare. Moreover, poorer residents benefitted from the provision of free three-roomed Reconstruction and Development Programme (RDP) houses and food parcels. These distributions were a crucial reason for continued support of the ANC in local and national elections.

A comprehensive verbal autopsy survey, conducted on common signs and symptoms of death in the Agincourt area of Bushbuckridge, shows how the AIDS epidemic drastically increased mortality rates. Between 1992 and 2005, life expectancy in the Agincourt area of Bushbuckridge fell by 12 years for women and by 14 years for men (Kahn et al. 2007). Until 1995 the predominant causes of death in children were infectious diseases and malnutrition, in adolescents and young adults main causes of death were accidents and violence, and in adults and the middle aged, the principal cause was cardiovascular disease. However, between 1995 and 2002 AIDS became the predominant cause of death in all age groups (Tollman et al. 2002).

HIV was rapidly spread in the context of a migrant labour system that obliged spouses to live apart for extended periods of time, and contributed to dispersed sexual networks (Thornton 2008) and to concurrent sexual relationships (Epstein 2008). The economy of sex in Bushbuckridge was marked by multiple partners in diverse relationships: ranging from romantic love affairs in school to monogamous and polygamous marriages, long-term extra-marital liaisons, male-to-male sex in prisons, and brief sexual encounters arranged in drinking taverns. In a context of ‘structured gender inequality’ (Hunter 2002) the transfer of bride-wealth, gifts and money to in-laws, wives and lovers was a dominant theme in these relationships, and distributed resources towards the desperately poor. Whereas deceased men between 1995 and 2002 were amongst the ‘wealthier of the poor’, deceased women were more likely to be unemployed, single and to receive income from men.

Despite the catastrophic local effects of the epidemic, residents of Impalahoek responded to HIV and AIDS with measured silence. Until 2004 not a single person admitted to my research assistants or to me that they had tested HIV positive, or that they had the symptoms of AIDS-related diseases. They studiously avoided talking about HIV and AIDS at public events such as political meetings and funerals.

**KNOWLEDGE AND SILENCE, 1992-2005**

Despite the catastrophic local effects of the epidemic, residents of Impalahoek responded to HIV and AIDS with measured silence. Until 2004 not a single person admitted to my research assistants or to me that they had tested HIV positive, or that they had the symptoms of AIDS-related diseases. They studiously avoided talking about HIV and AIDS at public events such as political meetings and funerals.
Our informants spoke almost exclusively of HIV and AIDS in backstage domains where talk assumed the form of gossip (Stadler 2003), and sometimes also in interviews with relative outsiders such as anthropologists. But even here, they used euphemisms to avoid mentioning the terms ‘HIV’ and ‘AIDS’ directly. They would say that a person suffered from ‘germs’ (twatši), the ‘virus of pain’ (kukoana hloko), the ‘three letters’ (maina a mararo), or ‘the fashionable disease’ (ke ko lwetši bja gona bjalo). Other euphemisms were that a person purchased a ‘single ticket’ (in English), ‘was on diet’ (o ya dayeta), ‘ate herbs that cause people to disappear’ (moragela kgole) or that ‘the dog had crapped on its chain’ (mpsya a nyele ketane) and could not be untied.

The picture that emerged from interviews with informants nonetheless matches the epidemiological record. According to informants HIV came to Impalahoek in the mid 1990s, and in 1997 there were three AIDS-related deaths in Impalahoek. Since then there had been a rapid rise in deaths: nine deaths were identified in 2002, 21 in 2004, and by 2007 AIDS had affected nearly all families. My informants generally used criteria similar to those employed by Agincourt field-workers to describe the symptoms of AIDS. They spoke of drastic weight loss, persistent diarrhoea, hair loss, coughing, black sores and discolouration of the mouth. They also mentioned dementia in the final stages of illness, and that the lover or spouse of the person with HIV also suffered illness and death.

Public silence is not the result of ignorance – as in inattention, misunderstanding or a simple lack of knowledge – as treatment literacy campaigns sometimes suggest. Rather, public silence seems to be a corollary to the perception of HIV and AIDS as a dreaded, horribly stigmatised, and invariably fatal condition. This perception is an outcome of a super-abundance of information, provided by multiple, diverse discourses, in a situation of grave anxiety. These include conventional medical discourses, political conspiracy theories and religious discourses. Although often contradictory, they alike label HIV and AIDS as a terminal condition without hope of treatment, and foreground blame.

1. Medical discourses

To stem the transmission of HIV, health care providers initially emphasised awareness and safe sex. The scale and urgency of HIV awareness campaigns vastly exceeded the scale of previous public health campaigns on malaria, tuberculosis and family planning. By singling out HIV for
excessive propaganda, non-government organisations created the impression that this condition was much deadlier than other diseases.

In 1992 the Health Systems Development Unit (HSDU) and Reproductive Health Groups Project launched sexual health programmes. Staff members gave regular talks on sexual hygiene to various constituencies, including police, clergy, headmen, diviners and youth at schools. The organisations also trained teachers as sex educators. At the same time, unpaid volunteers of the Bushbuckridge Social Service Consortium provided information and support to people living with HIV.

In 2000 a loveLife Youth Centre was built four kilometres from Impalahoek. The centre aimed to promote a youth lifestyle and positive sexuality based on romantic love, being faithful, abstaining from sex and using condoms. It hosted motivational workshops, dancing, studio broadcasting, computer training, drama, basketball and volleyball (Wahlstrom 2000). A loveLife youth recalled that GroundBREAKERS at the centre often used scare tactics in HIV/AIDS education. At one workshop the attendants were told that AIDS is incurable and shown video-cassettes of Ethiopians dying of AIDS-related diseases. The only message they received about treatment was that those who ate fruit and vegetables might prolong their lives.

AIDS awareness has also become an important component of ‘life orientation’ classes in all local schools (Gallant & Maticka-Tyndale 2004). During each quarter teachers at Impalahoek Primary School divide learners into three groups for AIDS awareness classes: children between 8 and 12 years, boys older than 12 years, and girls older than 12 years. Teachers do not mention sex to the younger learners, but warn them not to play with scissors, razors and pins; not to touch bleeding friends; and also not to inflate any balloons (condoms) they find lying around the village. Teachers demonstrate safer sex to the older learners using stage props such as artificial penises and different kinds of condoms. AIDS activists target high school learners for more extensive propaganda and address them as often as twice a week. Far from being untouched, my younger informants said that they were over-saturated by these messages.

By focusing upon prevention, these campaigns create the impression that because AIDS is incurable, it is also untreatable, and that little can be done to assist any person who is HIV positive.
facilities reinforce this perception. Initially, a network of three hospitals and six clinics screened pregnant women for sero-prevalence, provided voluntary counselling and testing on request, and treated the symptoms of AIDS-related diseases. Only in 2003 did Masana Hospital (30 km away) begin to make Nevirapine available to pregnant women.

In Impalahoek women are most committed to biomedical discourses. This is largely owing to their ideological association with reproduction, and owing to the greater medicalisation of women’s bodies during childbirth and gynaecological examinations (Martin 1997). In 2004 Gunvor Jonsson interviewed 25 young women and found them to be fairly aware of biomedical explanations of HIV and AIDS. They also valued the expertise of nurses, doctors, love-Life groundBREAKERS, and even of AIDS activists who addressed them at school.

Patricia Mashile wrote her final year paper on HIV and AIDS and interviewed health-care workers. Women described HIV and AIDS as a disease contained in blood, semen and vaginal fluids, and transmitted through sexual intercourse. They commented that if one had a scratch one could also contract HIV by touching blood, and by using contaminated injection needles, and that pregnant women could transmit HIV to their babies. The only blatantly incorrect response was that one could contract HIV by ‘kissing boys with AIDS’. Moreover, young women explicitly asked their partners to use condoms, which they felt were a much better source of contraception than injections which, they said, made them fat and caused excessive menstruation (Jonsson 2004).

Men were more inclined to express confusion and to be puzzled by President Mbeki’s questioning of the link between HIV and AIDS. They were also more likely to distrust biomedical pronouncements, and openly criticised the loveLife Youth Centre for ‘promoting an American lifestyle’ whilst the United States ‘bombed’ Afghanistan and Iraq. The men whom I interviewed variously described HIV as ‘a virus’ (twatši), ‘an imbalance in one’s body’, ‘a disease of blood’, or as ‘something to do with white blood cells’. Although they generally agreed that HIV was transmitted by sexual intercourse, men sometimes misunderstood how this happened.
Joseph Dibakwane, a temporary teacher, remarked that during the sex act men and women exchanged blood: after ejaculating semen, a man’s penis sucked in his partner’s vaginal fluids. He argued, ‘I think that some men absorb too much blood from too many women. When there is too much mixture it breaks into AIDS.’ Another informant was adamant that lovers could not transmit HIV when they reached orgasm at different times. Some said HIV and AIDS had always existed, and that it was merely the name whites gave mafulara (an affliction unleashed by the transgression of funeral taboos). Men seemed far more fatalistic about the possibility that they might contract the virus, and described sex with condoms as unnatural, ‘like eating sweets with their wrappers on’. Some men actively distrusted condoms, suspecting that the lubricant in government-issued condoms might well contain HIV. Should one place the condoms in hot water or in the sun for a while, they alleged, one could see ‘AIDS worms’ floating about. Men were more likely to speculate about trans-local sources of the epidemic.

2. Political conspiracy theories

Political and religious discourses about HIV and AIDS were as prominent as medical ones, and men in particular invoked conspiracy theories to explain the onset of the
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epidemic (Farmer 1992: 230-243; Schoepf 2001: 341-342). These theories expressed discontent about persistent racism, social inequality, the failed materialisation of election promises and men’s humiliating expulsion from the ranks of the urban workforce. Central villains included Dr Wouter Basson, Americans, the military, whites, and corrupt government officials and businessmen.

In 2000 Dr Wouter Basson, the head of the apartheid government’s chemical weapons programme, was tried for murder in the South African Supreme Court. During the course of his trial details of numerous gruesome atrocities were revealed. These included revelations that operatives of the apartheid regime had contaminated the drinking water of refugee camps with yellow fever and cholera before Namibia’s elections in 1988, that they had dumped the bodies of ‘terrorists’ in the sea off the Namibian coast, and that they had conducted experiments with toxins for potential use against enemies of the state (Hogan 2000).

As these revelations were publicised, men in Bushbuckridge began to speculate that Dr Basson had, in fact, manufactured HIV to eliminate black South Africans. Some alleged that he worked with the assistance of Americans who, in the words of one informant, ‘funded his research’.

An alternative suggestion was that Dr Basson had brought HIV to South Africa from the United States (Some men told me that AIDS is an acronym for American Ideas to Destroy Sex). Dr Basson allegedly distributed HIV by various means. His operatives were accused of putting it into water reservoirs and food consumed by black people, into the injections given to hospital patients, and into the condoms distributed freely by the government. Black soldiers were seen as prime agents in transmitting HIV. Dr Basson allegedly placed the virus in rivers where members of the ANC’s military wing, Umkhonto We Sizwe (MK), drank water, and laced with HIV the malaria tablets given to black South African National Defence Force soldiers. He was also alleged to have purposefully created a slow-developing virus so that soldiers could spread it to many women. Some informants believed that Dr Basson was found not guilty at the trial because he alone could cure HIV and AIDS.

When in 1996 and 1997 white farmers dumped tonnes of surplus under-grade oranges and sweet potatoes at a shopping centre and at local schools, local residents claimed that these had been ‘doctored with blood containing HIV’. Parents were extremely suspicious of the motives of these farmers. They were hard pressed to understand how ‘racist whites’, who underpaid their
Men found it very hard to believe that HIV and AIDS were incurable, and criticised South Africa’s new government for being reluctant to develop an HIV vaccine. This led some men to speculate that wealthy businessmen might have bribed government to impede the finding of a cure for HIV and AIDS. Sitting under the shade of marula tree outside a spaza shop, two friends, Dan Mokgope and Glyden Mahungela, suggested that ordinary tablets for sexually transmitted diseases and even lemon juice could cure HIV and AIDS. Glyden was convinced that the government had already found a cure. He could not comprehend that Nevirapine could prevent mother-to-child transmission of HIV, ‘curing the foetus in the womb, but not the mother’. The two men speculated that mortuary operators, funeral undertakers, coffin manufacturers, surgeons, pharmaceutical companies and government officials benefitted from AIDS deaths, and were in fact involved in trans-national trade in human organs.

Dan and Glyden conjectured that undertakers tampered with corpses, and alleged that they secretly removed organs from the deceased, screened out HIV, and shipped these to faraway places such as China for transplants. Pharmaceutical companies were also believed to use the organs to manufacture drugs, and to sell the blood to blood banks. Moreover, Dan and Glyden alleged that some businessmen used the organs as potions to increase commercial profit.

3. Religious discourses

At the time of fieldwork there were 27 churches in Impalahoek with a combined total of nearly 6000 adult baptised members. Some 75% of Christians in the village belonged to Zionist-type churches, 16% to Pentecostal churches, and 9% to mission churches (Niehaus 2001: 31-36). The predominant religious emphasis was a concern for ‘this world’ and for pragmatically harnessing the Holy Spirit for purposes of reconstituting, empowering and healing the body (Comaroff 1985, Kiernan 1992). Like diviners, Christian healers treated clients in their homes, but acted as mediums for the Holy Spirit rather than for the ancestors.

By conducting all funerals in the village, churches played a very important role in framing people’s understandings of sickness and death. Christian communities provide social support to the sick and religious teachings clearly had the potential to make death more palatable. However,
through conceptualising and labelling HIV and AIDS, Christian discourses has done little to dispel the perception of HIV and AIDS as a dreadful, incurable and untreatable condition.

Biblical notions of disease and older vernacular concepts of pollution formed part of the interpretive framework through which Zionists and other Christians interpreted HIV and AIDS. Ministers, healers and ordinary church members often identified HIV itself, or at least the skin lesions of persons living with HIV, as evidence of leprosy. This association was informed by Biblical notions of leprosy or unclean skin lesions (za’ra’at in Hebrew) as a plague sent by God as punishment for sin. Lepers were seen in Biblical times as ritually impure and as having a mixture of living and dead flesh, thus standing opposed to the priests and the Nazarites who were dedicated to God and who avoided any contact with the dead. Lewis (1987: 607) writes that the Biblical leper ‘carried in his person a defiling taint which excluded him absolutely from any contact with holy things, even contact with clean people, even contact with the community’. Local Christians in Impalahoek described lepers as horribly deformed and badly ravaged persons whose flesh literally rotted away whilst they were still alive.

In Impalahoek the links between leprosy and HIV were apparent in at least three different ways. Both conditions were seen as signs of God’s wrath and as divine punishment for sin. In this respect, HIV and AIDS were a vehicle for talking about moral and political decay. Informants did not mention sexual transgressions per se, but talked of a whole range of what they saw as social ills, including the erosion of patriarchy, political corruption, the high incidence of murder and of rape, and the legalisation of abortion and of gay marriage.

As in the case of beliefs about pollution, a person afflicted with misfortune was not necessarily seen as the one who had transgressed the taboo. The following statement of a Christian nursing sister captures this concern:

AIDS is punishment from God. It is like Sodom and Gomorrah. We do evil and commit crime. God does not want us to kill another person. Exodus 20 says ‘Don’t kill’. But we kill each other. There are too many rapes – some men rape young kids. There is abortion. A girl can go to the clinic for abortion and pay 35 Rand. This is an evil thing. God will punish us like in the days of Noah. He will drown us all. We must come together and fast and pray to stop AIDS – like when we pray for rain. All nations must give thanks to God.
Second, like lepers, persons with HIV were perceived as tainted with death, and their bodies were said to comprise an anomalous mixture of living and dead tissue. Third, both conditions were deemed to be highly contagious. Leper settlements were generally places of isolation, where the Christian message was presented as a sign of hope. A comparative degree of isolation, albeit not in camps, was now deemed as necessary in the treatment of persons with HIV. But villagers recognised HIV as being somehow deadlier than leprosy, and less amenable to cure. Hence, public health, political and religious discourses alike inspired enormous fear by emphasising prevention and blame, and by portraying HIV as both incurable and untreatable. The association of HIV with death seemed to be the most important source of its stigma. Residents of Bushbuckridge regularly described persons living with HIV as ‘dead before dying’ or as ‘living corpses’ (setopo sa gopela), occupying an anomalous, liminal condition, betwixt-and-between the categories of ‘life’ and ‘death’ (Douglas 1971, Turner 1968). The use of euphemisms for HIV and AIDS resonated strongly with the manner in which people avoided direct reference to death when announcing that someone had passed away. This construction inspired local responses of silence, secrecy, denial and fatalism.

Villagers recognised the sexual route of transmission. But sexual promiscuity per se did not appear to be the source of HIV stigma. Informants recognised several sexually transmitted diseases, including gonorrhoea (toropo), syphilis (leshofela), and a condition known as ‘shudder’ (lešiši). The latter was generated by sexual intercourse between a man and a woman who had recently aborted or had been widowed, and was in a dangerous state of heat (fiša). ‘Shudder’ was potentially fatal. However, unlike HIV, men freely spoke to me about their own experiences of contracting these diseases. In fact, they often felt compelled to tell their relatives, so that together they could consult healers to seek a cure. The difference between these conditions and HIV appears to be the terminal nature of the latter.

The attribution of blame, so prominent in discourses about HIV and AIDS, and the very real potential conflict and violence that this created, might well be another reason for denial and silence. At a deeper level, owning up to having HIV amounted to a confession of guilt and an acknowledgement that one might have passed on a fatal disease to past and present sexual partners, and therefore bore responsibility for their impending deaths. HIV heightened suspicion between husbands and wives, and also more generally between men and women. Whereas men saw young women as vectors for infection, women
often blamed men for spreading HIV through unscrupulous sexual conduct. Abusive boyfriend and husbands were the central villains in their discourses. An archetypal figure was that of Tom Mhlangu, a womaniser, who used household money to purchase cars without leaving cash to support for his dependents. Tom assaulted his wife and infected her with HIV.

**EXPERIENCING AND TREATING AIDS, 1992-2005**

During 2004 Gunvor Jonson and I interviewed 50 men and women in Impala- hoek. Only seven of them (one man and six women) told us that they had tested for HIV antibodies. Most of our interviewees had refrained from testing, saying that they dreaded the possibility of discovering that they had been afflicted with a fatal and untreatable disease. They argued that knowledge of an HIV-positive result would hasten their deaths, causing them to die sooner from stress. Moreover, they feared that nurses would gossip about their status, and provoke others to discriminate against them. This is evident in the following statements by two men:

> I don’t want to suffer. I don’t want to be rude. If you test HIV positive you will lose your memory, thinking all the time about death and dying. People will not gossip about you because you screw, but because you are dead. They will take you as dead. They will take you as a living corpse.

We blacks are brought up to believe that death is a terrible tragedy. If they tell me that I am HIV positive I’ll think of dying. I’ll automatically think that I’m dead. I will see death in my mind and I will dream of a grave. Because people fear death so much they would not want to talk to me or even come close to me.

In many respects, villagers saw persons living with HIV as being in a very similar position to those dying from any other terminal illness. Followers of different churches avoided pollution at all times when caring for terminally ill persons and when burying a corpse. They secluded the terminally ill from other villagers. Only a select few people – usually a mother or a younger relative – nursed, washed and fed the sick person. These carers were expected to comfort and strengthen (*phorola*) the sick person verbally. Even if the situation was gravely serious, they were expected to never name the person’s disease, to say that he or she was about to die, or to speak of topics that might upset him or her. A constantly burning fire usually indicated sickness in a household and nobody was allowed to enter the sick person’s room without the carer’s permission.
Corpses were believed to release contaminating heat. Upon death, the breath (moya) and aura (seriti) of a deceased person separated from his or her corporeal body. These forces assumed a dark form (called thefifi) that polluted any object, item or person that came into contact with them. Concomitantly, at the funerals that I attended great care was taken to avoid pollution. Kin immediately took the corpse to the mortuary, where it was thoroughly washed and cleansed. At sunset on the Friday of the week of mourning, people fetched the corpse from the mortuary and placed it inside the home. Here widows – who had previously been exposed to the risk of dying – sprinkled ash on every window to minimise the heat of the corpse. At sunrise ministers conducted a funeral service at the home and a hearse then transported the coffin to the graveyard. Young men usually placed items such as blankets, walking sticks, cups and plates that had been polluted by the aura of the deceased, in the grave. Throughout the proceedings the widow covered her head with a blanket. After the funeral, Zionist healers cleansed all family members, the yard and all the rooms of the house with a mixture of water, milk, ash and salt. However, widows were still perceived as polluting and had to observe a year-long mourning period.

However, there was also a disjunction between HIV and AIDS, and other terminal illnesses. HIV and AIDS were marked by a peculiar compression of time, and the symbolic load of labelling seemed so overpowering that it immediately signified death. The very gradual progression from infection to illness to death that so frequently characterised HIV and AIDS did not seem to be culturally elaborated. Even the newly infected person was seen as ‘tainted with death’.

My informants described the bodies of persons with HIV as literally decomposing whilst they were still alive. According to one man:

In the final stages AIDS is so dangerous. It is as if your flesh dies, whilst your body is still alive. Your flesh will just fall off and the bones remain. It is also as if there is no blood in your body.

Skin lesions were the clearest indicators of death. But there were also other indices such as persistent diarrhoea, constant vomiting and coughing, which indicated the loss of breath, aura and life. Persons with HIV were also said to develop swollen glands, mouth sores and soft fluffy hair.¹¹ The sick person allegedly became darker in colour, showing loss or rotting of blood. Drastic loss of bodyweight and boniness were reminiscent of a corpse. In addition, my informants spoke about the progressive loss of body functions and of reason. I visited my former field assistant, Jimmy Mohale, only two weeks before
his death. Jimmy suffered badly from tuberculosis, and complained of feeling cold, powerless and paralysed, and also of the inability to breathe, walk or see properly.

The Jimmy that you did research with had only half a life. This life came from my maternal family. I only have ancestors on my maternal side. I am dead on my paternal side ... People around here know me as being dead. That is why I don’t have to be seen. You are speaking to a dead person.

Some of Jimmy’s friends suspected that he had died from AIDS-related illnesses: ‘One can say that he died before the actual death.’

Villagers saw persons living with HIV as exceptionally dangerous. Many dreaded the possibility that HIV-positive persons might intentionally set out to affect others. They also exaggerated the risk of contagion. Evidently, the identification of HIV and AIDS as a slow, living death implied that carers for people living with HIV or their visitors might be exposed to pollution. Hardly anyone trusted the biomedical pronouncement that HIV could only be transmitted through sexual intercourse. In local belief HIV could also be spread by touching; by sharing eating utensils, cutlery and toilets; by breathing the same air; by nursing a person without latex gloves; or merely by coming into contact with his or her germs, saliva and blood, especially if one had a wound. An archetypical story was that of an elderly woman who had nursed her sick daughter, and then died of similar symptoms, seven years later.

These perceptions underpinned excessive avoidance behaviour. Teachers informed me that learners often refused to play at school with the children of people with HIV. Doris Ubisi, a young woman, greeted her friends by hugging them. But one of them turned and walked away. She had apparently heard that Doris was HIV positive. Moreover, people tended to avoid using any of the same utensils as persons with HIV. It was believed, for instance, that a cup could be infected by germs from a sick person’s mouth sores.

Close kin and therapy management groups usually vehemently denied that a sick person had HIV, and claimed that they had been bewitched.

Close kin and therapy management groups usually vehemently denied that a sick person had HIV, and claimed that they had been bewitched. Ashforth (2002) observes that residents of Soweto often interpret the symptoms of HIV and AIDS as a type of slow poisoning inflicted by witches, called isidliso. Witches allegedly insert isidliso into their victim’s gullet in the form of a small creature that slowly devours him or her from the inside. Isidliso covers many symptoms – literally anything that affects the lungs, stomach and digestive tract – and leads to a slow wasting illness.12 He finds the association of
HIV and AIDS with witchcraft to be particularly appealing in contexts of increased insecurity and inequality, where anyone is capable of envy.

Unlike residents of Soweto, residents of Bushbuckridge clearly distinguished between HIV and AIDS and witchcraft, and did not believe that witches could infect people with HIV. In local knowledge a person died either of HIV or of witchcraft. However, several of my informants argued that witches were perfectly capable of creating artificial HIV: that is, a witchcraft-induced sickness that mimicked the symptoms of HIV and AIDS. In this manner, an informant said, witches took advantage of the epidemic and used it as a shield to mask their nefarious activities. This alternative label deflected blame and created some hope of cure.

Carers took extreme care to seclude persons with HIV. This was done as much to protect the sick person from others, as to protect community members from him or her. A teacher frequently tried to visit the terminally ill sister of a colleague, but was always told that she had been taken to relatives elsewhere. ‘Meanwhile, she was right there in the house.’ Isolation was also self-imposed. When I visited Michael Ngoni we heard the faint sounds of Christian songs being sung in the house next door. Michael told me that his neighbour had HIV, that she hardly ever ventured outdoors, and that she would not open the door, even if one knocked. Her husband and daughter had both deserted her, claiming that she was insane, and only her mother visited her.

Carers were terrified of contaminating exposure. Mothers, maternal aunts or siblings usually nursed the sick, but sometimes delegated these tasks to young people such as nephews or cousins. Givens Thobela took almost two years off from school to assist his frail grandmother in caring for his maternal uncle. Givens fed and cleaned him and because his uncle was lame Givens had to push him in a wheelbarrow to the nearest clinic, a kilometre away. Neighbours gossiped that Givens had contracted HIV, and he asked a nurse to explain to them that she had issued him with latex gloves.

Local funeral parlours sometimes wrapped the corpses of people with HIV in plastic bags, and warned family members not to open these, nor to prepare the corpses. Men were also known to have burnt the clothes they inherited from people who had died of AIDS.

Prior to 2005, patients and their carers tended to visit medical practitioners very late in the course of illness. This was evident in Pronyk’s (2001) study of 298 tuberculosis
patients at Tintswalo Hospital, 48% of whom were co-infected with HIV. He calculated a median delay of ten weeks between the onset of symptoms and the initiation of hospital treatment. In 14 cases the delay exceeded a year. Many patients first sought help from Christian healers and diviners (Ibid: 264). Persons with HIV were seldom hospitalised for more than a few weeks, and mainly used clinical services on an outpatient basis. Great secrecy surrounded therapeutic consultations, and even more so the use of ARV drugs, then obtained from Masana Hospital. Lakios Rampiri, who worked as a telephone exchange operator at the nearest hospital, recalled that his neighbours woke him very late one evening, and asked him to take their sister to the outpatients’ department by car. They covered the sick woman’s head with a blanket, as if she were a widow at a funeral.

Daniel, who was a medical doctor, asked Joe Ngobeni and his wife to look after Tsepo, a cousin, whose parents had both died from AIDS-related diseases. Daniel only told them that Tsepo had tuberculosis, and promised to provide them with medication and food, and to pay them R400 each month. However, Joe suspected that the cousin actually had HIV:

Each day at 5 [am] I had to give Tsepo five different tablets. Daniel did not tell me what they [the tablets] were for, but I saw ‘ART’ and ‘VIRUS GUARD’ written on the labels. I became so scared. I took the tablets to the doctor and nurses at Rixile, and asked them what they were for. They also did not tell me, but asked me to bring Tsepo for a blood test. Then, they said, they could write a letter to the social workers so that he could get a pension. I was very scared. I thought that maybe I was also HIV positive. I asked Daniel if I could be infected if Tsepo was HIV positive. But he said that I would be okay if I didn’t have wounds and our blood did not mix.

A nurse came to show us how to wash Tsepo and church-goers came to pray for him. Tsepo was very thin, his mouth was bleeding and he had diarrhoea all the time. If he slept on his left side we had to turn him around. We also had to feed him with our own hands. Tsepo used to shit like hell and we could only clean him when he was naked and wore no underwear. He was a living corpse. We sometimes thought he was dead when he slept. His mouth and eyes would be open. His ankles also straightened so his legs became like sticks. He was losing skin because he scratched himself so much. Some weeks he would only wake up for a few minutes. When you spoke to him you felt as if you were irritating him.

Although his cousin had died more than three months ago, these memories still haunted Joe.
At the funerals of those who had died of AIDS, kin did not announce the cause of death. They often held the funeral service early in the morning, even before sunrise, making it impossible for many mourners to attend. Durham and Klaits (2005) suggest that in Botswana concealment of HIV and AIDS in the public domain and also at funerals avoids creating antagonism and anger. Attributions of AIDS amount to a curse, implying that the widow would soon die.

Despite these precautions, it was not always possible to suppress and diffuse conflict. On at least one occasion, an accusation of spreading HIV was the pretext for homicide. Different informants told me about Job Dlamini, a forty-year-old taxi-driver, who had killed his wife. Job worked in Johannesburg. However, when his sister informed him that his wife had been making love to Disco, a teacher who was HIV positive, he immediately drove home to Impalahoek. Job was reportedly in a state of rage and drunk when he confronted her. He opened the door whilst she was asleep, then locked it, and proceeded to hit her, and beat her head against the floor. A neighbour eventually broke down the door and dragged Job away from her corpse.

USING HAART IN BUSHBUCKRIDGE, 2005-2009

Since 1999 medical personnel at Tintswalo have referred persons who test positive for HIV to the Rixile (‘rising sun’ in XiTsonga) Wellness Clinic. Although ARVs were only available at Masana Hospital (30 km away) the clinic hosted support groups, monitored CD4 counts, assisted people in applying for disability grants, and also helped obtain nutritional support. Between 2003 and 2005, 25% of all women receiving antenatal care, and 64% of the 4 000 people undergoing HIV tests at Tintswalo Hospital, tested sero-positive. Some 1 050 patients regularly attended the Rixile Clinic.

In October 2005 the Rixile Clinic began to supply free ART, and also to conduct comprehensive treatment literacy programmes. Patients were entitled to receive ART if their CD4 count was below 200 and they demonstrated ‘psychosocial preparedness’ to take up therapy. By 2008 the clinic catered for nearly 6 000 patients. Clinical evidence showed that reasonable retention rates were possible in under-resourced rural settings. Researchers monitored 1 353 patients who were initiated onto ART at Rixile between October 2005 and September 2007. Their median age was 37 years, their
median CD4 count 64, and 67% were female. After 24 months 84% (1 1 31) of the patients were retained on treatment: 9% (124) had died, 5% (63) had been transferred out, and 3% (35) could not be traced. The mortality rate was slightly higher than had been reported previously in urban South African settings, due to fairly late presentation and advanced immune-suppression. Rates of HIV infection nonetheless remained high – antenatal seroprevalence stood at 32%, and Rixile’s services reach only about 20% of those in need in its catchment area (MacPherson et al. 2008: 2).

The provision of ART can literally reclaim life from death, and can potentially transform conceptions of HIV and AIDS from that of a terminal sickness to a chronic, manageable condition. Within four months, the weight of one patient attending the clinic increased from 20 kg to 70 kg. Yet this potential was unevenly realised. The three cases described below of HIV-positive individuals whom my research assistants and I met, interacted with and interviewed during the course of fieldwork, revealed in greater depth some of the factors that facilitate the uptake of, and adherence to antiretroviral therapy. The case-studies point to the limitations of the concept of therapeutic literacy for understanding these processes, showing how under conditions of medical pluralism, knowledge does not imply unswerving commitment to either biomedical or folk explanatory models of HIV and AIDS. The cases also highlight the importance of stigma associated with medical labels, economic circumstances, kinship networks and actual conditions in hospital consulting rooms and wards in facilitating and impeding health care delivery.

Reginald Ngobeni: Denying AIDS, using ARVs

During August 2005 Reginald Ngobeni was desperately ill, suffering from the familiar symptoms of AIDS. He was very thin, coughed, had lesions on his body, and could hardly walk. Yet instead of seeking medical care, Reggie was undergoing training as a diviner’s apprentice. Although I asked his brother to take him to hospital, I felt pessimistic about his chances of recovery. During July 2007, I again visited the Ngobeni family. Hence, I was extremely surprised when Reggie greeted me at the gate. He appeared to be in perfect health, and was busy cultivating a new patch of vegetables. Reggie said that he had made a miraculous recovery since he joined the Zionist Christian Church (ZCC), and began drinking tea and coffee ‘prescribed by the Holy Spirit’. Later, he conceded that he had also taken ART, but he remained adamant that the church (and not the HIV clinic) had healed him.
Born in 1961, Reggie had lost his father when he was only five years old, and grew up with his maternal grandmother, mother, two older siblings and younger half-siblings. He became a high school dropout in 1977, and was known to have been a participant in a criminal network that looted general dealer stores, and stole from white-owned farms. Reggie was in excellent health as a young man, but experienced excruciatingly stomach pains in 1980:

It was on Christmas Day that my stomach became sore. It was so painful. I fell down and rolled from the pain. I felt pain whenever I moved my body … It felt as if there was something hot, burning inside my stomach. I went to many diviners and to many prophets. A diviner [ngaka] told me that spirits possessed me and a prophet called Dlamini said that I was bewitched. Dlamini lit candles and prayed for me.

Reggie encountered two contrasting accounts for his sickness, and although he found relief, he failed to identify the precise source of his distress.

As an adult Reggie worked in the lower echelons of Johannesburg’s labour market. He stayed in Soweto, found employment at an engineering company that repaired mining technology, and fell in love with a Swazi woman, Zanele Maseko, who worked at a crèche. Reggie described her as ‘the darling of my life, who satisfied my heart’. But Reggie’s security came to an abrupt end. In 1994 he was expelled from his residence for fighting with others late at night. The very next year he lost his job, and Zanele left him for another man. In July 1997, Reggie again found work, this time as an assistant and security guard at Cardies – a shop selling birthday, wedding, Valentine’s Day and Christmas cards, as well as gifts such as glasses. Reggie commented that the job provided him with the opportunity to meet new lovers:

I propositioned each and every beautiful girl who came into the shop to choose cards. It was really not too difficult. Many of them accepted. At lunch we would go [to have sex] to the flat of one of my friends in Plein Street, and at night we would sleep at my own place. I really don’t know how many women I had, but it was a lot. It happened every day. Maybe it was more than 80 or 100. My friends said that I was the principal of girls because I changed them so often. I tried to satisfy my painful heart … Most of the time I ate flesh to flesh [had unprotected sex]. I only wore condoms when the girls wanted it.

Reggie worked at Cardies for a year and a half, and often stole from the store to reward his lovers. But in 1998 the shop went insolvent and closed down. He then secured a new position as a security guard at an Eskom pay-point in a shopping mall and found accommodation near the George Gough migrant hostel.
In 2001 Reggie suffered retrenchment and was violently robbed twice. At Snake Park a Christian healer diagnosed that he was contaminated by misfortune (bati). The healer told Reggie to wash his body with water, in which he had to place an old brown cent coin, mutton fat and a chicken egg. Reggie then had to pray and pour out the water in the form of a cross, hide the egg in tall grass, and walk away without looking back. However, during the course of the next two years, he again suffered fever and stomach pains, and his sickness became increasingly severe.

Reggie was now in a desperate situation. On 27 April 2004 his half-brother, Aaron, came to fetch him by car in Johannesburg and brought him to his mother’s home in Impalahoek. Here Afisi Khomane, the wife of his brother, Petrus, who was a diviner, tried to nurse him back to health. She insisted that Bandzau spirits were afflicting Reggie and were calling him to become a diviner. These spirits always strike the stomach. Afisi thus arranged for her mother, who is an instructor of diviners (gobela), to train Reggie. For this Reggie’s kin paid R3 500, and also supplied her with a tonne of wood, maize meal and a new blanket. But Reggie’s training did not have the desired effect. Reggie’s health continued to deteriorate, and his instructor eventually felt compelled to take him to hospital:

One day my stomach was loose and runny. When I went to the toilet my intestines came out. I could not push them back, but a certain old man helped me. Hereafter, I felt relaxed and I slept on a mat. Then I felt no pain.

But my instructor phoned Petrus and asked him to take me to hospital. When we arrived she filled in the forms. But she wrote lies. She did not say that I suffered from the stomach. She said I was coughing. I did not cough and I felt no pain in my chest. It was nonsense. The doctor then took the file and she asked me what my problem was. I said ‘my intestines’. The doctor put on a glove and put her hand up my backside [anus]. She asked me if I felt pain and I said ‘No’.

After I slept in the hospital for three nights, they put something like toothpaste on my chest and took X-rays of my lungs. They said the screens showed that I had TB and then transferred me to the TB ward. After I slept there for two weeks my legs became dry. They were numb and they could not move. When Petrus and my instructor came to visit I told them about my legs. She said this was a sign that the spirits wanted me to dance.

Reggie described the tuberculosis ward as a smelly and polluted space of death with little water and food, and bleak prospects for recovery:

Each morning they woke us at six o’clock and gave me two tablets. Then we had to wash ourselves.
But there was no water in the taps in our ward, and the nurses would bring water in buckets. You also had to buy your own soap, washing rag and Vaseline. I did not wash because the space for washing was too small and because I don’t like standing naked with others … At tea-time they usually gave us tea and bread. Sometimes it was different. Then we would get Jungle Oats [porridge]. This is No 1 … There was nothing in the evening. If you wanted to eat you had to bring your own food. Each day there was a preacher, who preached and told us the word of God.

In the TB ward I wore cloth for the spirits. The nurses told me to take it off, but I refused. My mattress stank. It had the bad smell of urine … Six people died in the ward when I was there. One of them died this side of my bed. The other one died that side of my bed. They brought other patients, but they also died. They put something like a tent at the place where someone had died, and removed the dead bodies with noisy trolleys. I was so scared. I feared that I might follow them. I shivered. After the deaths there is a bad aura [seriti] and I feared that the aura might come to me. I was afraid. In that ward you never knew who would die next.

In hospital I had this dream of a very large snake with seven heads. The snake came to me. It flew like a strong wind. The trees blew in the wind and the snake was in the trees. The snake said the TB tablets won’t help me and that I won’t be healed in the hospital. The snake also promised to show me a place where there was lots of money.

Reggie claimed that whilst he was in hospital, no doctor tested him for HIV antibodies. After three weeks Reggie was discharged, and resumed training as a diviner. He defied the snake of his dream, and continued taking his tablets. Despite enduring great pain, he graduated as a diviner on 31 May 2005:

I returned to my instructor. I was not better, but I did not tell her about my pains … My instructor argued with me. First she said that the spirits affected my legs, but now she changed her story. Now she said that other people were against me, and that they laid xifulane [a witchcraft potion] on the path I used to buy cold drinks at the shop. She lied. The spirits now became xifulane. I no longer trusted my instructor. She treated me badly. She said that because I did not want to dance, I should pay her and go home. She still wanted R3 000. She said that if I do not pay her, AIDS would attack me.

Reggie’s condition deteriorated at his mother’s home. He had diarrhoea, his nose bled, and he slept in a tent outside the house, vomiting and coughing throughout the night. In June 2005 Reggie consulted a general practitioner, who did not test him for HIV antibodies, but prescribed tablets and told him to eat boiled, rather than fried, eggs. Petrus eventually took his ailing brother to Rixile clinic, where he tested HIV positive:
I heard about Rixile and I did not want to go there. But Petrus wanted to know what was bugging me. When I first went to Rixile they took blood from the second finger of my right hand. Then they said I had HIV and that my CD4 count was 94. They told me to drink ARV tablets. First I had to choose a time. I chose eight o’clock in the morning and eight o’clock at night. They showed me two tablets that I had to take in the morning and a big one – this was the ARV – I had to take at night. It is called ‘Aspen Stavudine’. They told me never to forget to take the tablets, and always to drink them at the right time. Otherwise the tablets won’t work. If I only miss one day I’ll die. The tablets won’t cure AIDS. They will only make the AIDS weaker.

They did not tell me from where I got the AIDS. But they said that I must not sleep with a woman without a condom. I must also not kiss someone with sores on the mouth. They also told me not to touch anybody when I am bleeding, and that I must wear gloves if I touch someone who is bleeding at an accident. The AIDS will jump. It can come to you with a scratch or a cut ... At the clinic they told me that it is a secret. But as I went out of the [hospital] gate the security guards could see that I had tablets. This is very bad. If people know that you have AIDS they do not want you. They think you will give them AIDS.

Reggie did not believe the test results, arguing that his instructor had bewitched him, so that he could display the symptoms of AIDS:

I don’t know if they are correct. This is because I don’t know what AIDS pains are like. Then, I did not believe the doctor. I thought that my instructor had bewitched me. This is because I started vomiting and bleeding through the nose at her home. She and her child put potions and stones in the corners of my room, and told me not to sweep. I did not give them permission to do so. I did not like this ...When someone promises you that you will get AIDS, you will remember it. I thought my instructor was responsible. I thought she gave me AIDS.

I don’t think I have HIV. My disease is the very same stomach cramps that started in 1980. I don’t know the name of this sickness. My disease does not come from sex. By 1980 I did not have a girlfriend. My girlfriends started in 1990. If it had been AIDS it would have killed me long ago. People with AIDS die in 15 years, not in 28 years. It is not sex. I never took dirty girls. I would only take good looking and clean ones ... AIDS might be there, but I selected my girlfriends.

Reggie, nonetheless, took the ARV tablets. His reasoning expressed his belief in the innate agency and power of words. In a manner similar to how his instructor had cursed him, he said, the doctor at Rixile told him that unless he took ARVs he would die. Reggie feared that these words might well bring about a tragic end to his life:

All of those who have HIV die. I only hear about HIV when people are dead. There at the Rixile Clinic
where I collect the tablets – some people die and some are still alive. I decided to drink the tablets because I’m afraid to die. If I do not take these tablets people will lie. They will say that AIDS killed me because I did not take the tablets or follow their instructions. I want people to be sure of what they’re saying.

The ARV tablets had severe side-effects and caused Reggie to dream uncanny dreams about money and death. But this did not dissuade him from continuing with treatment. Instead, these effects attested to the power of the tablets:

The tablets made me sweat and made me dream about dangerous things and about good things. Many times I dreamt about money. I once dreamt that I had R266 million. I dreamt that the whole plaza [shopping centre] and the sub-station [for electricity] was mine. I dreamt that the ancestors had given me these things. But it was not the ancestors – it was the tablets. Maybe there are drugs in those tablets ... They remind me about dead people and about forgotten things. Another time I dreamt that I saw seven-year-old kids. They had khaki uniforms and were holding cell [mobile] phones in their right hands. I did not know one of them, but I was meant to follow them. The kids were zombies. They were not living human beings. The tablets also caused me to hear voices of people calling me and promising me money ...

These visions articulated Reggie’s fear of death. Although money sustains life, it is also the basis of strife and of murder. Diviners recognise dreams of bronze and nickel coins as symbols foretelling death (Niehaus 2000).

On 26 December 2006, Reggie received a vision from his ancestors, telling him to go to the ZCC. Here a prophet gave him holy water to drink and pour at his gate to protect the home against witchcraft. The prophet instructed Reggie to drink Joko tea and FG coffee, and to take salt each day:

The prophet said that the witches will send snakes to my home and that I have to kill the snakes. So far I have killed about 13 snakes in our yard. I found one in the shack and one underneath the drum of water in the kitchen. There was one on the kitchen door and another in between the bricks ... These are not snakes from the ancestors [noga ya badimo] who bring luck to the family. They are the ones from the bush and they bring bad luck. They have the devil in them.

Since then, Reggie has attended church each Sunday, and has drunk Zionist coffee and tea each day. This, he said, facilitated his recovery:

When I was sick my mother did everything for me. At first I could not wash my own clothes. I was too
weak. I could not jump and I could not walk to
the plaza [shopping centre] or to church. I moved
very slowly. I only became better after I went to
church and took their prescriptions. Now I can walk
and I can run. I can also carry three 25-litre bar-
rels of water, and I can plough maize. They fixed
my leg and the pain is better.

Reggie had not yet received a disability pension. The nurses
at Rixile told him to consult the social workers and to
obtain an affidavit from the police station before for-
warding his application. He desperately needed a regular
income to purchase the proteins and veg-
etables that nurses recommended he
should eat.

May Mokoena: A lone AIDS activist

In 2007 one of my research assistants, a teacher, informed
me that a man called May Mokoena had recently ad-
dressed the staff members of his school about HIV and
AIDS. May disclosed his HIV-positive status, and spoke
of the advantages of voluntary counsellng and testing (VCT),
and of ARV medication. May was born in 1971 in a farming district
called The Oaks. He failed his final year at
school, noting that his mother and father
divorced at the time of his examinations.
May then accompanied his mother to live with his maternal
kin in Bushbuckridge. Throughout his adult life, he never
held down a stable job. But it is clear that he too spent
some time in Johannesburg.

In 2002 May contracted gonorrhoea. He suspected that a
woman, who is now married in Johannesburg, had infect-
ed him, because she had vaginal rush. But when he con-
fronted her she denied all responsibility. During the course
of the next three years, May developed various oppor-
tunistic infections, including herpes, shingles and marks
on the skin known as *lepanta* (belt) in Northern Sotho. ‘The period from 2002 and 2005 was a time of suffering’. May stayed alone in an RDP house and became virtually bedridden. ‘Nobody cared for me. Sometimes the neighbours came to cook for me and to wash my clothes. But my family did not like that. Only God knew if I was going to die.’

In May 2005, May tested positive for HIV antibodies at the Tintswalo Hospital, and registered a CD4 count of only 39:

The matron made me sign a consent form and gave me pre-counselling before the test. Then three months later I went for another test – this is the window period. This is when she told me that I was HIV positive. The matron said that it is not a death sentence and that HIV is a human – not an animal – disease. She said the pain is only stress and stigma. I did not believe her. They gave me a TB supporter certificate and I went for pension. By then I had diarrhoea and I had to wear Pampers [a brand of nappies]. When I first went for VCT they told us to eat fruit and vegetables – bananas, merogo, eggs and fish, cheese and milk, brown bread and brown beans.

I had stress and depression. The first person I told was my mother. But my mom said, ‘Don’t tell anyone! Keep it secret! People will laugh at you if they say you have HIV. The community will laugh at you. They don’t know that HIV and AIDS differ.’ I also told the neighbours who helped me. At that time I had a girlfriend in Wales. When she heard that I was HIV positive she did not accept and she argued with me. She said, ‘Leave me alone. You have many girlfriends.’ She blamed me and I blamed her. If you blame each other you do not solve the problem – you make it worse.

May did not belong to a church. But during 2005, during the worst of his sickness, he had an intense, life-changing, religious experience that gave meaning to his suffering:

To get tested is not a play. You ask yourself, ‘Who must I tell?’ Then you start to cry ... In 2005 I decided to commit suicide. I believed that others would harass me. But God told me not to do it because I still have much time to live. It came to me in a dream. My grandmother, who died in 1998, came to me like an angel at midnight. There was no roof on top of the house, only blue sky. My grandmother came from the air, stood on top, and raised her hands. She wore a white cloth and there were also some wings. She spoke to me saying, ‘My son. You’ll never die. You’ll survive. Go and preach the gospel.’ After a few minutes she went back into the blue sky. I’ll never forget this dream in my life ... The next day I asked a pastor. He said it was not my grandmother, but an angel from God.

In September, the matron at Rixile started May on a treatment regime of Bactrim tablets, to stop his diarrhoea, and boost his appetite and immune system. He also took
Lamivudine and Stavudine. Hereafter, she placed May on a daily regime of three ARV drugs: Stavudine and Lamivudine at 8 am, and Stavudine, Lamivudine and Stocrin at 8 pm. To obtain a new stock of tablets, May would wake at 5 am, arrive at Rixile clinic by 6 am, and usually collect the tablets between 10 and 11 am. There would normally be a queue of between 100 and 200 people at the clinic. May said that Stocrin caused him to have strange dreams ‘about cars, ghosts, and about people who died long ago’, but there were no other side-effects. May showed remarkable recovery, indexed by a rapidly climbing CD4 count: 246 in March 2006, 395 in September 2006, 571 in March 2007, and 781 in September 2007.

An unexpected consequence of his improvement in health was the loss of access to a disability grant. May started receiving a monthly grant of R750 in September 2005. The grant was renewed each year, but lapsed in May 2007, when his CD4 count exceeded 571:

> Some do not want to lose the grant. They stop taking ARVs and within a week the immune system breaks down. But I will never stop. What can you choose? You close life and forget about the grant.

May embarked upon a career as an AIDS activist, both as a means of earning an alternative income and to fulfil his religious obligations. He enrolled as a caregiver for an organisation called Obrigado (‘thank you’ in Portuguese). Obrigado is based in the village of Zoeknog and employs 35 volunteers. ‘We care for patients in their home villages and also refer them to the clinics.’ Yet, he was quick to add that this is no regular income. ‘Obrigado gives us a stipend – sometimes R466, sometimes R500. But three months can pass without getting any money.’ In addition, May volunteered to speak at schools, churches, police stations, in the Kruger National Park and to farm workers attending clinics in outlying rural areas. ‘When I teach I first say, “Let’s pray!”’

May met an attractive woman, whom he planned to marry, at a workshop in Polokwane. Like May, she has been HIV positive for six years.

He nonetheless experienced being an AIDS activist as a constant uphill battle, that sometimes offered little reward:

> It is better if you talk. If you keep quiet you kill yourself. You must voice out. I told myself that HIV is like sugar diabetes, high blood and asthma. But HIV is better. It has stages. With high blood you can collapse at any time.

At school I tell the kids to take care. I tell the younger children not to hold syringes and needles or someone who is bleeding. At secondary schools I teach ABC – abstain, be faithful and condomise.
It is only at the secondary schools that they give us problems. Some listen, others ignore. They will tell me that I am lying because an HIV-positive person is not [healthy] like me. They say he has signs and symptoms like a plague. But I am not lying. I’m telling the truth. They do not believe HIV is there – especially in the rural areas. They believe in witches, and will say someone is [be]witching you. Others do not trust – they trust traditional medicine.

I help the community, but the community does not help me. They call me here and there, but they don’t compensate me. Even when I speak at schools the teachers donate very little – they give me R145 for travelling, food and the advice I give. I used my own transport and gave a speech near Hoedspruit. But they paid me with mangoes. I worked with Wits at Agincourt. I gave a lecture each day for 21 days, in 21 villages, even on Saturdays and Sundays, but I received no compensation. I feel stress and depression. Many days I feel that I no longer want to help anyone.

On 27 June 2007 May’s sister, who was 40 years old, died in hospital from tuberculosis. Whenever he visited her, he saw only tablets for treating tuberculosis. Although May asked her to test for HIV, she refused. ‘She would tell me, “Wait! Not now!” ‘ To this he remarked, ‘You cannot force a horse to drink water.’ His mother cared for her two children, and received a monthly social welfare grant of R210 for each child.

May had hardly any contact with the urban-based Treatment Action Campaign (TAC). In 2006 he heard that TAC organisers led patients to demonstrate against drug shortages at the Mphilo Wellness Clinic, and he phoned a regional TAC office. The person who answered the call encouraged May to take ARVs, but did not ask him to join in their activities.

Merriam Segodi: A case of treatment failure

During July 2008, my fieldwork assistant, Ace Ubisi, told me that his girlfriend Merriam Segodi had become ill. Her body was in pain, she had flu-like symptoms, and she had been coughing up blood. We decided that Ace would take her to hospital and that I would provide transport, and pay for her consultations. Ace had spent a great deal of time in May Mokoena’s company, and wanted Merriam to test for HIV, because he realised that many tuberculosis patients were co-infected with HIV. Having listened to May describe the benefits of ARVs, Ace no longer perceived HIV-positive persons as ‘dead before dying’.

Ace cared a great deal for Merriam. She was born in 1981, attended secondary school in Hazyview for a few years, and lived in the nearby village of Mloro. Ace met Merriam
in October 2006, when she worked for a local businessman, George Thobela, who owned five bar lounges, and acted as a high-interest money-lender. Merriam earned about R700 per month and worked exceptionally long hours: from 4 am until 8 pm, except on Fridays, when she only finished work at 10 pm. She was expected to work on weekends, and only got off four days each month. One advantage of her job was that employees could easily steal from Thobela. Ace recalled that Merriam regularly gave him cigarettes, cold drinks, beer and money to develop photographs.

Merriam was once married, but divorced after she caught her husband making love to one of her friends. When Ace met Merriam, she lived with her mother (a pensioner), a younger brother (who was unemployed), and a seven-year-old child. Ace fetched Merriam from work whenever she was on duty near Impalahoek, and she regularly slept at his home. They sometimes quarrelled over minor issues, but were never involved in any serious disputes.

The very first time that Ace was introduced to Merriam’s mother, the old woman asked him to take special care of her daughter, whom she said had been born with **sefetswane**: 

> Some people have **sefetswane in the diaphragm. This is not a witchcraft thing, but it will eat you from inside, make you thin and cause you not to have appetite. With **sefetswane** you will cough time and time again and you won’t breathe very well.

Merriam became ill in 2008. She complained of pain in her chest and legs, and resigned from work, saying that she could no longer cope with working such long hours. Merriam first consulted a ZCC healer, who prescribed tea, but this had no effect. Hereafter, she and Ace, on advice from her mother, consulted a diviner (**dingaka**). The diviner rubbed herbs, mixed with goat’s fat, onto Merriam’s chest, and gave her herbs in liquid form. But Merriam refused to drink the herbs, saying that she was a churchgoer. Ace complained, ‘The herbs cost me R60, but it lay rotting at her home.’

Mrs Segodi wanted her daughter to consult a medical specialist, but Ace argued that it would be more appropriate to go to Tintswalo Hospital. Merriam agreed with Ace, and over the next month, the couple made six trips to hospital. Public medicine proved more expensive than anticipated. Merriam had to pay R28 for transport by mini bus taxi, R70 for consultation fees, and purchase a meal. Ace accompanied her, and together they endured the stress of waiting in long queues.

Ace described these visits as a harrowing experience:
On Tuesday we arrived at the hospital at 6.45 am [well before sunrise in winter]. Then there were already 300 to 350 people waiting. They started seeing us at 8 pm. We first had to queue to get a file and we got to the reception at 11 am [after 4¼ hours]. At the reception you pay different amounts for different diseases. We had to pay R70. They gave us her file and showed us where to go. First, we had to go for blood pressure. I did not know how many people were in front of us, but we queued for an hour. When we arrived they [nurses] took Merriam’s temperature and told us her blood pressure was 119/72. Then they sent us around the corridor to find the doctor. There were about 200 people in front, but someone did us a favour. He said, ‘I can’t wait any longer! I need to catch a bus to Manyelethi at 2 pm! Ace, you can take my place!’ Then we were lucky to be number 60. At 1 pm the doctor went for lunch. This is when I got pap [maize porridge] and chicken for us. It was past 3 pm when we saw the doctor.

The doctor asked about the problem. He said, ‘Breathe in and out’ and a student took Merriam to another room for a blood test. He said that she could have TB. He was not sure. It might also be asthma or an ulcer. He asked her to cough in a small plastic bottle and to bring the phlegm. Then he looked at the file and said, ‘Come back on Thursday’. Before going home we had to collect tablets and the small bottle. We received the medicine and took the file back to the reception. By then it was between 3.30 and 4 pm.

Outside the reception room a nursing sister was telling people about TB and AIDS. When we stood in the queue someone fainted. He was about 260 and they took him to the front. They took his file and he went straight to the consultation room. I did not see him again – he was either hospitalised or taken to the mortuary. People were dying. Some were vomiting and others had flying hair [a symptom of AIDS]. The toilet was not flushing and the ceiling was old. People complained, saying that they saw a doctor walking up and down, not tending to patients. At the hospital they sell food, but everything is expensive. A loose draw [single cigarette] costs R2. How can you sell cigarettes at a hospital? How can they allow people to smoke in the reception room and in the OPD [Outpatients’ Department] where people are coughing?

On another occasion Ace and Merriam queued to return the sample. Then they returned twice to get the results (as the first sample had been lost), to test for HIV and to collect tablets. The couple once returned because the queue at the hospital had been too long on the previous occasion:

The queues are too long. Sometimes there are no doctors. Another man was ill. He could not sit and he was bleeding. He was there for the whole week. They [the hospital pharmacist] told him that there were no tablets and that he should check later to see if they had delivered the tablets. Otherwise
he should buy then at Link [a private pharmacy]. This man came each day for the whole week, checking for tablets. This is a shit hospital. Imagine a hospital without an X-ray machine? Is that a hospital?’

Ace recalled that during their final visits the doctors confirmed that Merriam had tuberculosis, and advised her to undertake a test for HIV, which was completely voluntary. But the nurses saw Ace’s attention as an unnecessary interference. Ace once asked the nurses about the results of Merriam’s tuberculosis test, but they replied: ‘We know when to give you the results. The doctor knows what he is doing.’ About the HIV test, he recalled:

I comforted Merriam and we went to the OPD [Outpatients’ Department]. She went inside alone and when she came out, she told me the nurses said that she was HIV positive and that she had to go for medication. I read the file and saw that it was written like that. But I noticed Merriam was not so serious. She told me that she did not believe the nurses. She complained of sefetswane. I argued. I said to her: ‘Take it seriously! The nurses are not lying! Take the medication!’ Then she went home. When Merriam collected the tablets, I could see that they were TB-related.

For the next week Merriam studiously avoided Ace. She did not answer his calls, and she was not at home whenever he came to visit. Ace believes that her family (particularly her younger brother) were well aware that she might be HIV positive, but refused to accept the diagnosis. ‘They think AIDS is evil. They think it will spoil them.’ Mrs Segodi apparently believed that her former employer, Thobela, might have bewitched her because she stole from his stores. She also accused her former husband’s father of being the cause of Merriam’s poor health. The father wanted a grandson, but Merriam refused to give him the child. There were also allegations that the Segodi family were on bad terms with some of their neighbours. Merriam’s sister said that Merriam was not HIV positive because she did not suffer from diarrhoea and skin lesions, and because her hair did not soften.

Ace learnt from others that Merriam had been admitted to Masana Hospital (30 km away), possibly to the tuberculosis ward. About a month later, someone told Ace that he had seen Merriam at a diviner’s home. Ace also saw Merriam walking past, when he assisted his maternal uncle to sell vegetables on pension day. He eventually phoned Merriam’s younger brother, who told him that she had been admitted to Tintswalo Hospital:

The next day I went to the hospital, asked the nurses where she was, and went to her room. I found her in the TB ward. She asked: ‘Who told
you where I am?’ I said, ‘I could not find you at your place, so I went to the hospital’. Soon thereafter her mother, elder sister and brother came to visit. For the next three weeks I went there almost every day and brought her fruit. But whenever I asked about her sickness she became angry. I asked to see her file, but she refused. She phoned her parents, saying, ‘Ace comes to provoke me in hospital. He better not come here.’ I went to her mother and explained that I did not provoke her. I said that I only wanted to know about her health status so that I could advise her. I said I knew she was HIV positive. Her mother asked me whether I knew of a diviner [inyanga] who could save her. I told her that many of my friends are HIV positive. Even though they go to the diviners, they also go doctors, follow the procedures, and drink the [ARV] tablets.

In hospital Merriam was very ill. Some of the other patients told Ace that they could not sleep because she cried throughout the night, screaming that she wanted to go home. Mrs Segodi asked the doctors to release her so that she could consult their family doctor. Again Ace could not find her, but in January he learnt from her brother that she was staying with her elder sister in Hazyview, where the ZCC treated her. She explicitly asked Ace not to visit her. On 29 January 2009, Ace heard that Merriam had passed away.

The Segodi family requested that Ace assist them to acquire a tent, pots and plates for her funeral. He gave them R1 000 for this purpose, but heard that some of Merriam’s relatives demanded that he pay bridewealth. To avoid conflict, Ace himself did not attend the funeral, but sent his brother with another R500. Ace described the funeral as a shameful occasion. The family used a van instead of a hearse, erected only a small canopy, and offered too little food. Many mourners stood in the rain and left for home without eating. ‘I loved her and she loved me, but when she became ill our love went.’

These three cases show how, in situations of medical pluralism, knowledge does not imply unswerving commitment to one set of beliefs – be it viral infection, witchcraft or spirit possession – and to a single elusive truth. New concepts and beliefs are constantly tried out and added, and practical considerations often outweigh explanatory consistency. Different specialised authorities – diviners, Christian healers, politicians, general practitioners and HIV clinics – act as guarantors for the status of facts (Lewis 1993). In such contexts, healing is understood in terms of rapidly changing, constantly shifting meanings and expectations (Etkin 1992). As Helman (1984) reminds us, biomedicine itself comprises multiple, co-existing and competing paradigms. Consultations with biomedical practitioners do not necessarily imply diagnosis in terms of HIV, and might well impede effective treatment of HIV and
AIDS. Reggie Ngobeni was admitted to hospital as a tuberculosis patient, and consulted a general practitioner without being tested for HIV. Moreover, adverse experiences of waiting in long queues, having to deal with overworked nurses, and depressing conditions in spartan TB wards, all impact negatively upon the effective use of ART.

The case of Merriam Segodi highlights other factors, seldom considered by advocates of ‘treatment literacy’. It demonstrates how decisions about therapeutic consultations are not those of individuals, but are made by broader ‘therapy management groups’ (Janzen 1978) comprising carers and kin. The eventual decisions are often invariably the outcome of conflict. Reggie and Merriam’s experiences point to the complex emotional advantages of being a victim of witchcraft rather than of HIV. The pain, misfortune and interpersonal tensions that Reggie associated with witchcraft had a long history, preceding his HIV-positive diagnosis. Witchcraft was less stigmatising, perceived as more amenable to cure by healers who do not operate in dreaded hospitals, and also more tolerable to the self. Moreover, accepting an HIV-positive diagnosis would imply that certain individuals might have infected their sexual partners with an incurable illness. Yet the acceptance of an alternative label for his illness did not prevent Reggie from taking ART and from carefully adhering to prescriptions about their use. This was based as much upon their biochemical efficacy as upon the meanings they encoded. The milieu Reggie encountered at the ZCC complemented the effects of ARVs: providing much-needed social support and a powerful religious rationale for health maintenance, and refraining from smoking and drinking alcohol. Therapeutic efficacy can be attained in the absence of what physicians would regard as appropriate health literacy.

The case of May presents a more optimistic scenario that underscores some of these observations. May did not suffer from previous ailments, showed greater committed to ART and relied upon HIV support groups in the virtual absence of a therapy management group. May also had few lovers, and bore no guilt that he might have infected others with HIV. Yet his case also shows the depressing experiences of doing largely unremunerated work as a ‘career patient’ (Goffman 1971). James (2002) notes that health departments and NGOs inappropriately associate the position of a volunteer with charity work as a part-time middle-class pursuit, rather than a regular occupation for those who are otherwise unemployed.
The provision of antiretroviral therapy in the far north of Limpopo Province, the poorest area in the country, has generally lagged behind other South African provinces. By the end of 2005, Limpopo had reached only 12% of its target in the national ARV roll-out plan (Natrass 2006: 620). Limpopo’s disappointing performance has typically been blamed on inadequate resources within an overstretched infrastructure, and also on a lack of political will at all levels of government. Throughout the term of office of President Thabo Mbeki and Manto Tshabalala-Msimang, Limpopo was a key ANC stronghold and dissent from the party line was rarely rewarded.

However, politico-economic explanation remains at best a partial account for the apparent lack of success of the ART roll-out. In this part of the Review, I want to explore the broader social and cultural world into which ARVs entered, and the ways in which the roll-out has been both helped and hindered by the socio-cultural forces around it. In charting the social life of ARVs, I point to some of the unintended consequences of their provision in the previous homeland of Venda. Venda lies some 300 kilometres north of Bushbuckridge, in Limpopo’s north-eastern corner, bordering the Kruger National Park and Zimbabwe.

The ethnographic accounts presented here reflect both the initial failures and potentially successful new developments in ART programmes in this rural outpost. As in Bushbuckridge, the AIDS epidemic in Venda is gendered. Women are more likely to accept – at least partially – biomedical explanations, whilst men – in the midst of a ‘crisis of masculinity’ – are more prone to express politically motivated ‘folk models’ of the virus and treatment for it. But these distinctions are not absolute and generational differences cross-cut gender differences. It is also appropriate to ask whether adults and children responded differently to the provision of ARVs: if so, why, and in what ways?
There are three distinct parts to this analysis. First, I set the ethnographic scene in a discussion of the ways in which health, sickness and death are spoken about (and not spoken about) in Venda. This is an important starting point. Without a general understanding of the socio-cultural pressures and conventions that mould public discourse on these issues, we cannot begin to understand the ‘webs of meaning’ (Geertz 1973) that have been spun around ARV medication. Policymakers and academics alike sometimes misinterpret the public silence around AIDS and its treatment. Far from being acts of ‘denial’, evidence from Venda suggests that public silence should be understood as an act of self-defence in a context where deaths are rarely thought to occur naturally. There is a close relationship between publically expressed knowledge of a death and assumed experience of it, and so speaking openly about death, or about possible causes thereof, could suggest implication in the fatality. Consequently, knowledge about HIV and AIDS and treatment is dangerous and regarded with trepidation. In the context of the ARV roll-out, the desire to appear ‘not to know too much’ has perhaps surprising consequences. It functions, not to stigmatise, but rather to protect people on medication, regulating the public discourse around them and their dramatic recovery from sickness and ‘social death’ to health and productivity. However, there is no such regulation in backstage gossip, which is initially restricted to the private domain but soon becomes public through rumour. As we will see, those receiving treatment are the subject of many rumours regarding their abrupt return to health, but such rumours are unlikely to become open accusations.

In the second part, the focus of my discussion shifts to an investigation of ART support groups. Women who first received treatment in Venda established a support group – like countless others in the country – as a space in which they could talk about their illness and encourage each other to adhere to antiretroviral treatment. Here the group’s survival depends on its ability to remain shrouded in secrecy. Members are concerned that their secret will get out, and they practise highly selective disclosure, so that they are more comfortable telling an HIV-positive stranger about their status than they are about disclosing to a friend or relative. Various questions arise: Why must they meet in secret? Why is their transition from near death to seemingly full health thought to be magic? Why are they rumoured to be zombies?

The final ethnographic account offers a more optimistic counterpoint to the issues at hand. It tells the story of a
very different kind of ARV support group, possibly the first of its kind in South Africa: one that caters exclusively for children. The Vhutshilo Mountain School teaches around 60 orphans and vulnerable children, between the ages of 3 and 7 years, who have all been affected by the epidemic. Frustrated by the inability of elderly carers to reliably dispense ARVs to children on time – or at all – teachers devised a simple, and seemingly effective, solution. Early in 2009 they formed a monthly support group. With the help of pedagogic materials from a Pretoria-based NGO, the Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), they set about training the children in how to manage their own regimens effectively. This case-study raises several issues regarding disclosure and the perceived necessity to keep treatment a secret. It challenges us with ethical concerns about when a child should be told they are HIV positive, and different ways of letting them know. Whilst it is clearly far too early for any claim to success, the Vhutshilo model has already been endorsed by local health practitioners and would appear to have dramatically improved adherence, and thus the general health, of those involved.

There is a more important point to be garnered from the two support group case-studies presented here. I would like to demonstrate that the study of AIDS treatment programmes, or anything loosely termed ‘evaluation’ of them by those in the policy business, should be equally concerned with the actions and opinions of both those who do, and those who do not, receive medication. Focusing only on those who are on treatment reveals only half of the story. The actions of those receiving medication are influenced as much by the advice of biomedical experts as they are by a fear of invoking the suspicions of the general public. Recognising this demands a careful and flexible, methodological approach to programme evaluation and social research more broadly. Surveys and the generation of statistics – if they are to be at all useful – must be furnished with qualitative data taken from long-term ethnographic engagement in any particular field site. Only then can we move towards a nuanced understanding of what antiretroviral treatment programmes actually mean to people.

A NOTE ON HOW IT WAS DONE …

In the interests of transparency and reflexivity, I should describe my own history in the Venda area, bearing as it does on my research interests. I have visited Venda every
year since 1994, and at the time of writing I am engaged in a year of post-doctoral fieldwork in the Tshivhase region. My first sojourn was as a volunteer English teacher under the auspices of a UK-based ‘gap year’ organisation known as the Project Trust. Very early into this experience, I realised that as a 17-year-old unmarried and childless youth, I was in a particularly weak position to gain the respect of the adults that I had been charged with teaching. In an attempt to remedy this situation we agreed to split classes into two sessions. In the first session, I would teach English. In the second, I would be taught to speak Tshivenda. This strategy worked well, at least for me. By the end of my gap year I had learned far more than I could have hoped to teach. The strategy paid off, and I now speak Tshivenda fluently.

During this time, I befriended an American Buddhist monk with the name of Harold Lemke. After nursing a friend who subsequently died of an AIDS-related illness, Harold had become a self-styled AIDS educator. I became involved in several of his projects, which mostly involved driving around late night drinking spots to distribute condoms and addressing village councils (dzikhoro). By 1997 Harold’s informal meetings had become increasingly frequent. He applied successfully to various groups for funding to establish an NGO, which I shall call the Forum for AIDS Pre-vention (FAP). My PhD focused on the ways in which peer educators working for the NGO have harnessed the power of music to ‘sing about what they cannot talk about’ (McNeill & James 2009; McNeill forthcoming). In 2009, the FAP is still going strong.

Whilst conducting short spells of research for my undergraduate dissertation at the University of Glasgow, I became the lead guitarist in a popular local reggae band, fronted by the renowned Colbert ‘Harley’ Mukwevho. Like many musicians in South Africa, Harley is guaranteed several fully funded sell-out concerts every year, as he is enlisted to perform at government-sponsored celebrations. Through co-writing and producing two albums with the band (one of which received a regional musical award) and performing live on a regular basis not only in Limpopo but in the Venda quarters of Soweto (Tshiawelo – place of rest), I have become relatively well known among Tshivenda speakers.

This historical association with the region has ascribed me a particular status as ‘insider/outsider’ and upon my return in 2004 to conduct PhD fieldwork, convincing
people that I was now a gainfully employed anthropologist was not easy. My commitment to the band remained strong and we continued to perform in front of large crowds. This made it increasingly difficult, however, to maintain a background presence anywhere. I am thus primarily identified as a reggae musician rather than as an academic or, as I have often sought to reintroduce myself, as an anthropologist.

One advantage of this situation is that I have ‘conversational’ access to almost any group of men in Venda beer halls, most of whom are generally keen to satisfy their curiosity about the exotic stranger in their midst, and to hear stories of a band that receives generous airplay on local and regional radio stations. The spaces in which such conversations occur are the very sites in which gossip becomes rumour: stories and scandal are spread, and those suspected of being on antiretroviral medication are subjected to scrutiny in their absence. At the same time, through connections with the FAP, I have nurtured long-term contacts in Venda’s HIV and AIDS world, through which I gained access to the ARV support groups that form the basis of the case-studies below.
POST-APARTHEID VENDA

At just over one million in number, Tshivenda-speaking people (Mu\v{v}enda – singular, Vhavenda – plural) constitute the second smallest ethnic group in South Africa (about 2.3% of the population). This minority status is exacerbated by linguistic and geographical factors: Tshivenda is an unusual language in South Africa, and generally unintelligible in that it is not of Nguni origin (as isiZulu and isiXhosa are). Rather, it forms part of the Congo-Niger linguistic cluster that includes Shona in Zimbabwe and Lozi in Zambia.

The Venda region is also geographically remote, in the far north east of the country, bordering directly on Zimbabwe and the Kruger National Park. This physical and cultural distance from South Africa’s centres of power and influence has led to a stereotypical representation of the region and its inhabitants as mystical and highly secretive masters of the occult who possess extraordinary abilities to invoke witchcraft: a conviction that has been reinforced by the recent increase of ritual murders in the area. Despite such apparent peculiarities, however, the region shares broadly similar socio-economic and political characteristics with other parts of rural South Africa and, since the official demise of apartheid, has undergone significant political and economic change.

In economic terms, the neoliberal policies implemented by progressive ANC-led governments have exacerbated a very visible gap between rich and poor. A dramatic fall in the number of migrant labourers – and a more general rise in unemployment in the region – has impoverished many. Since 1994, the widespread practice of privatising the provision of public services and project implementation through bidding for tenders has seen a slow but steady increase in the provision of water and electricity, and the tarring of Venda’s notoriously bad dirt roads. However, many of those who are granted government tenders have strong political connections, and it is widely taken for granted that politicians – and those close to them – are entitled to enjoy relatively luxurious lifestyles, typified by the conspicuous purchasing of expensive vehicles.

Whilst a minority engage in criminal livelihoods – from petty theft to large-scale corruption – a majority in the region depend on extensive welfare handouts from the government (Seekings & Nattrass 2005). Others depend on funding provided by international donors to the plethora of NGOs in the region, which serve to cover a distinctly under-developed reality with a thinly veiled veneer of development. Owing to varying degrees of connection between local and regional levels of government, many of these NGOs would perhaps be better
termed ‘community based organisations’. The majority of them are concerned primarily with health-related matters, focussing on the prevention of HIV transmission through peer group education, palliative treatment through home-based care, and the promotion of voluntary counselling and testing (McNeill 2009).

In political terms, Venda’s incorporation in 1994 into the Northern Province (later Limpopo) under the democratic leadership of the first ANC-led government was preceded by a series of political manoeuvres that surprised many commentators. Most significant, perhaps, were the opportunities created for traditional leaders – widely accepted as implementers and beneficiaries of apartheid in the former bantustans – to participate in the structures of post-apartheid governance.

Reflecting global trends in the growing influence of traditional authority, post-apartheid South Africa has witnessed – especially in the former bantustans – a significant reinvention of traditional leadership. Policies of development have often been introduced and implemented in rural areas through – or at least with the approval of – these recently bolstered structures of traditional leadership. Kings, chiefs and headmen have thus taken a central role in the political economy of the post-apartheid era.

The processes of re-traditionalisation have not, however, promoted harmony in the corridors and courts of traditional power. In Venda, as in other parts of the country, these processes have entailed publically re-enacted conflicts between leading royal dynasties, each bent upon establishing itself, in response to government requirements, as the source of Venda’s true paramount chief by 2009/2010. This has exacerbated historical tensions between the rival centres of power, and encouraged the implementation of policies which highlight the ANC doctrine of African renaissance. Official attempts have been made to increase the number of headmen under specific chiefs (in a ceremony known as vhuhosi), and to increase the frequency of female initiation schools under the control of specific royal houses. By reinstating ‘forgotten’ knowledge at the core of royal polities, these have served to bolster the generational and patriarchal authority not only of traditional leaders, but also of older women as ritual experts.

This knowledge comes at a price. ‘Centres’ of tradition have been established to provide initiation (as part of a wider process of cultural education, including teaching the royal language and providing training in the arts of healing) in highly rationalised, commoditised ways that invoke the notion of development. Appropriated by
members of younger generations, this modularised packaging of knowledge has threatened the legitimacy of traditional authority and its associated sacred discourses. Paradoxically, then, traditional leaders have potential access to significant resources to facilitate development and economic growth for their subjects, but ultimately depend upon the ancestral past for their legitimacy. The need to balance these contrasting impulses pervades all of Venda social and political life.

As I describe below, the socio-cultural environment in the Venda region differed from much of South Africa in that it was not (yet) conducive to full public disclosure of HIV status. There was, quite literally, not one person in the region at the time of writing who was known as living completely openly with HIV. Whilst this was due in part to the socio-cultural factors I go on to explain, responsibility also lay elsewhere. The lack of activity in the region by organisations such as the Treatment Action Campaign (TAC) and the National Association of People Living with HIV/AIDS (NAPWA) has meant that there are currently no support structures to encourage or enable people to fully disclose their status. This, combined with the commonly felt desire ‘not to know too much’, means that HIV-positive people in Venda continue to live a public life of secrets, shrouded in rumours that are beyond their control.
The ways in which people speak, and don’t speak, about HIV and AIDS is an important starting point for understanding the social dynamics of antiretroviral medication in this part of rural South Africa. In this section, I want to compare the conversational politics around AIDS with the ‘public silence’ that engulfed a recent spate of alleged poisonings in the Tshivhase region of central Venda (for a more comprehensive account of this argument, see McNeill 2009). Stadler (2003) uses the term ‘public silence’ to capture the ways in which AIDS can be privately ‘acknowledged’ by families as a cause of illness or death, but publicly shrouded in secrecy. Whilst this term remains problematic for several reasons, it is nonetheless a useful point of departure for understanding the social processes involved in the obfuscation of AIDS treatment in the public domains. Stadler highlights the ‘distinct symbolic resonance’ (Ibid: 133) between AIDS, pollution, poison and the ‘epidemic of witchcraft’ (Ashforth 2002, 2005). Whist much of this recent research has mapped out some of the social processes of secrecy, silence and notions of ‘respect’ in the context of AIDS-related deaths, it has nonetheless failed to explain adequately what this public silence means for those who choose not to discuss AIDS or antiretroviral medication openly in their everyday conversations and, thus, to account adequately for why it may have developed in the first place.

To understand why so many people choose not to talk openly about such issues, it is constructive to look beyond notions of shame and stigma. This is not to reject the importance of these concepts, but rather to suggest that they must be contextualised within the wider framework of ways in which death in general – and not exclusively that which is AIDS-related – is not spoken about in public. In Venda, the cause of a death is literally and figuratively invisible. For example, on receiving news of someone’s death, a public response that enquires as to the cause is as unthinkable as it is pointless, since the bearer of the news would never admit to such knowledge in public. Should the conversation veer towards this topic, vague euphemisms and obfuscation are used consistently between friends and acquaintances in all manner of public social situations. If AIDS is suspected, people talk quietly of a generic, unspecific ‘sickness’, or comment that ‘he had many cherries’ (girlfriends) or ‘he was too fast’.

Moreover, every Friday evening, listeners to the popular Phalaphala FM radio station are subjected to a roll-call of people who have died in the previous week and who will be buried over the coming weekend. This information
is supplied directly to the radio station by grieving families, and the daily intimations follow a strict formula: name of the deceased, place and date of birth, employment history, names of surviving close kin, date of death, and the times and venues of prayer meetings and the funeral. On no occasion is a cause of death even alluded to. Further examples of this reluctance to reveal the cause of death are shown in two academic theses, written by Venda anthropology students studying for Masters degrees in the late 1990s and that took as their topics ‘A changing view of death in a Venda village’ (Mavhango 1998) and ‘The role of women in Venda burial societies’ (Rambau 1999). Having read them in detail in the hope of finding an early reference to HIV or AIDS, I found that in both documents there was not a single reference to any cause of death in the numerous but selectively detailed case-studies.

After death the secrecy is likely to intensify, most notably with the ‘cause-of-death’ entry on the death certificate. Although ‘pneumonia’ or ‘TB’ is commonly stated as cause of death by the coroner, AIDS-related deaths are usually recorded officially in much more nebulous terms. I give four examples of people I personally know to have died of AIDS-related illnesses:

Female, born 1978; cause of death: natural causes.
Female, born 1975: cause of death: gastroenteritis

This pattern of ambiguity continues at funerals, during which religious and community leaders inevitably improvise variations on the same theme; ‘a long sickness’, ‘an illness’, ‘a failing physique’ or ‘a recent lack of health’.¹⁹ This phenomenon has been incorporated into a song by a tshilombe guitarist – a liminal and spiritually sanctioned group of men who have historically contributed to social critique with the proviso that they are ‘mad’ and thus have limited responsibility for the content of their song lyrics (Kruger 2000, 2002):

No one can ever please the whole world.
Maybe this is what causes the pastors to tell lies at the graveside.
In the entire world no pastor can be perfect. (Solmon Mathase’s Tshidzumbe, see McNeill 2007).

The mourners at funerals I have attended in Venda were generally aware of the fact that their friend or relative had been HIV positive and had died from an AIDS-related illness. The references made to ‘sickness’ and ‘many cherries’, etc. to some extent constituted a code within which AIDS-related mortality could be spoken about respectfully in public without invoking social stigma against the deceased or their family. Although this is important to
recognise, the explanation fails to answer a crucial wider question: why does the naming of a specific cause of death invoke social stigma?

To answer this, we must turn to the widely held belief throughout southern Africa that deaths are very seldom natural (with the occasional exception of the very old or the very young). Many kin and neighbours will harbour suspicions that someone was responsible for their relative’s early passing. Talking about Shona conceptions of deaths, Aschwanden (1987: 17) states: ‘serious diseases or death are, as a rule, ascribed to people or spirits’. Whereas in the pre-colonial past this tension may have been relieved through a public accusation of witchcraft, accusing another of being a witch is illegal (and has been so since the 1930s under the Suppression of Witchcraft Act). This has led to a widely felt, but largely unarticulated anxiety that although there are growing instances of ‘unnatural’ deaths, the historically conventional recourse to justice is prohibited. It is not uncommon for people to believe that by upholding prohibitions against accusations, the South African state is actively involved in protecting witches (Niehaus 2001). Of course, this has not prevented families in mourning from harbouring suspicions – indeed, it has pushed the accusations underground and instead of being relatively public, they have become very private secrets.

In the spate of alleged poisonings to which I now turn, the substance at the centre of the controversy became known as seven days, named for the length of time a victim could purportedly live after its ingestion. Although the precise nature or source of seven days never became public knowledge, competing explanations circulated through gossip and rumour. The local Mirror newspaper and radio presenters on Phalaphala FM commented and contributed to this, but the public silence on the ground, which prevented people from talking openly about seven days, persisted until the panic had passed. It was big news and no news simultaneously. Then, as I was told one day in July 2005, after raising it with a friend in conversation, it had become ‘old news’, and I never heard of it again.

I argue in subsequent sections that it is precisely the forces of self-censorship revealed by the seven days debacle that act to protect ARV support groups from the rumours around them, and that have constructed treatment for AIDS as a public secret.
AN ETHNOGRAPHIC DETOUR:
THE MYSTERIOUS CASE OF SEVEN DAYS POISONING

On a Friday in late August 2004, I met as usual with my drinking buddies at Mapitas, a local tavern. Mapitas is advertised as a ‘complex’, and it qualifies for this title as it boasts a well-stocked shop, a payphone, butchery, tavern and a braai (barbecue) area at the back, nestled under huge, old and evergreen trees. Mapitas is situated at the bottom of the main road which cuts up into the Tshivhase Tea Estate, an important source of local employment which has recently been saved from closure by funds secured by King Kennedy Tshivhase through the Tshivhase Development Trust.

Just behind Mapitas, the modest Mutshindudi River provides young girls and women with water for cooking and washing, which is laboriously hauled up the hill in plastic containers to homesteads in the surrounding villages. As evening sets, men who drink take up their regular places in the tavern. Some play cards; others partake in animated games of chess or the Venda version of solitaire, mufhufha. My group of friends are an eclectic mix of farmers, teachers, musicians, traffic police, artists, full-time drinkers, traditional healers and civil servants. Conversation jumps between anything from football to women, chiefs to riddles, Johannesburg to Scotland, and, inevitably, back to women. The only females around, however, are girlfriends – cherries (actual or potential) and although sex workers drop in occasionally, it is not a regular spot for them. A polite, respectful man does not drink beer with his wife in public, and Mapitas tavern, as my father was told during a visit, is a ‘gentlemen’s’ bar, avoided by youngsters, who prefer the more lively night spots towards Thohoyandou.

It was still light outside when I saw the Mirror article on the counter of the butchery. The headline read:

“Mystery and secrecy surround an alleged attempt to poison the communities of Itsani, Maniini, Tswinga, Tshakhuma and Muledane during past weeks...”

It'sani – Mystery and secrecy surround an alleged attempt to poison the communities of Itsani, Maniini, Tswinga, Tshakhuma and Muledane during past weeks, after it was allegedly found that unknown tablets had been inserted in some of the public taps in the area. According to several members of the communities, they discovered unidentified white and red poison pills in their public taps. Although they are taking as many precautions as possible, the community members are living in fear for their lives ... The tablets are called ‘seven days tablets’ in the community which means you will live for only seven days after consuming one ... community members are living in
fear and were pleading with anyone with information regarding the poisoning of their water to report it (*Thulamela Mirror*, Friday 27 August 2004).

I read the article intently twice, and stuffed the already torn copy into my bag. As I was stashing the bag behind the seat of my van, the 5 o’clock news on Phalaphala FM was reporting the same feature. *Seven days* was big news. The drinking circle was busy that night as it was month-end. Mashamba, a close friend who had received his pay, bought me my first beer, and as usual delivered it unopened. If a beer is delivered already open then the bearer should take a large taste of it before handing it over. This convention serves to prove that the bottle has not been poisoned. It is common for beggars to be sent to buy beer, and they can manipulate this by returning with an open bottle, and consuming as much as possible in one gulp, to the anger of the sender and the general amusement of everyone else.

As Mashamba sat down next to me, he leant over and whispered that if I had to go to the toilet tonight I must not leave my bottle on the table. This was unusual in that the large bottles, known as ‘quarts’, were usually shared between two or three of us. I whispered back, asking why, and Mashamba answered, saying that tonight, we would just go at the same time. As the night progressed I waited with anticipation for the discussion to turn to the front page story. I rarely raised topics of conversation at Mapitas, choosing instead to participate in whatever was on the agenda. But the heightened state of alert in the group that night was starting to make me feel uncomfortable. I noticed that some of the men were even sitting with their thumbs firmly capped onto the top of their bottle, and, eventually, I asked why. Although I assumed that everybody knew the answer to this question, I wanted to know more about it. There was no response to my question, and my discomfort grew.

“Some things,” he said “we just do not talk about. It is very dangerous to know too much about these things”.

Mashamba signalled that we should go to the toilet (a pungent brick wall behind the butchery), where he scorned me for asking such a question in public. As one of my closest friends, he took pride in ensuring that I was fluent in Tshivenda and flawless with male protocol, and I protested that I was unaware of having breached the code. ‘Some things,’ he said ‘we just do not talk about. It is very dangerous to know too much about these things’. Then, as if to contradict himself, he whispered to me that he had overheard people talking on the taxi from work, saying that *seven days* had originated in a mortuary run by a Shangaan, not far from the beer hall. Body parts (spinal cords) were being ground into a paste and then left to dry in the sun. It was this deadly mixture, in powder
or tablet form, that people were calling seven days. One of the men we were drinking with worked as a driver for that very company and although Mashamba doubted that we were in imminent danger, he said we must be very careful. ‘These guys can even hide that poison under their fingernails’, he said. By the time we got back to the drinking circle, the driver in question had left for a night spot towards town. Mashamba looked at me with an ‘I told you so’ expression, and the subject was dropped.

Over the course of the next few months, stories circulated about people who had attended funerals, weddings, parties or beer halls, and had died within seven days of consuming food or drink there. My research assistants and I endeavoured to establish the source of and any patterns in the rumour. The original plan was to start at the hospital where the victims in the Mirror article had been taken, and to track down the ‘media liaison officer’ who was quoted as saying samples of the poison were being tested to confirm what substance had been used. All of my assistants completely refused to get involved in this, arguing that it would appear as if they were venturing to procure a sample for their own use.

We resolved to solve this by going together to the royal courts of the villages mentioned in the article and ask permission to talk with people in their own homes. They agreed on the condition that I organised someone to ‘invite’ and introduce us to the different areas, as it would appear suspicious if we to appear unannounced. I contacted a longstanding colleague from a youth NGO, whom I knew was an active member of the civic association at the village of Tswinga.

Even the media liaison officer at the hospital, like the local police in Thohoyandou, could not furnish us with any more information as they claimed to be ‘bound to agreements of confidentiality’.

After waiting several days for his response, he contacted me to explain that he had made inquiries and that it would be frivolous for us to go there, insisting that no one in his village knew anything about seven days. I tried several other contacts in Tshakuma (where I knew many HIV/AIDS peer educators) and Muledane (where a friend had a secret lover), and we drove without invitation to Itsani, where I had played in a soccer team in 1995, but no one was prepared to admit to us that they knew anything. Even the media liaison officer at the hospital, like the local police in Thohoyandou, could not furnish us with any more information as they claimed to be ‘bound to agreements of confidentiality’.
Why did people feel the need to adhere to a strict, but unspoken code in which open, public dialogue about *seven days* was avoided? How is this connected to ways of not speaking openly about AIDS and treatment? Connections between AIDS and *seven days* can be drawn on several levels, building on the foundational link that they are both intimately involved with relatively new modalities of suspicious, ‘unnatural’ deaths, and as such are avoided in open conversation by the general public. To answer these questions, however, we need to look in more detail at the consequences of breaching the public silence around the virus, in this case by groups of female peer educators working for the Forum for AIDS Prevention.

**HIV/AIDS PEER EDUCATION AND PATTERNS OF BLAME**

There are around 600 voluntary AIDS peer educators working with the FAP. It is intended that they facilitate ‘participatory’ approaches to health promotion (Campbell 2003). Groups meet weekly for ongoing training that gives peer educators the opportunity to rehearse for public meetings, to report back on the previous week’s activities and to eat together. On one day of the week they hold ‘house meetings’, during which they split up into groups of three or four, and randomly select two homesteads, to which they give advice on HIV transmission and treatment, and distribute condoms. Peer educators are mostly young unmarried women, some of whom – but by no means all – have a history of commercial sex work. They are instantly recognisable by their uniform: a bright red skirt,21 a white shirt with red writing and a bright red bag with ‘Community against AIDS’ printed on the front.

Every Friday the peer educators hold public meetings at beer halls, at clinics or in other public spaces. During these they sing a variety of songs designed to facilitate AIDS education and to advertise the availability of treatment at local clinics. The songs are usually well-known hymns, initiation songs or ‘freedom’ songs that the educators have adapted so that, for example, ‘Jesus is number one’ becomes ‘Condom is number one’. Whilst the actual number of peer educators using antiretrovirals is unknown, their songs often comprise collective confessions that they know about and use ARVs. For example:
This song is an adaptation of a very popular chorus used by several church groups throughout Venda. In the church context, most versions are sung when members of the congregation undergo rites of passage, such as christenings or weddings. In the peer education version, these sentiments of change and progress are at once harnessed and reframed to promote the newly available AIDS treatment. The peer educators also perform dramas and role-plays depicting rape, abuse and AIDS-related illnesses. There is a facilitated question-and-answer session, and, at the end, they distribute free boxes of condoms. The condom distribution is the climax of the performance, and involves a demonstration – with a large wooden model – of how to roll the condom onto the penis and how to remove it correctly. The phallic prop is passed around the audience, who participate with instruction – often to great hilarity – and condoms are then given to all present who want them.

In Venda, political pressure groups such as the TAC and NAPWA have a negligible presence. In their absence, government information campaigns have struggled to transfer HIV-related knowledge to the general population through a variety of media. For example, the free booklets and pamphlets distributed in newspapers and radio and TV dramas such as the (currently discontinued) Soul City endeavoured to present biomedical explanations in ‘trendy’ terms. Through the school curriculum, the Department of Education has also sought to disseminate this information to learners from Grade 6 (roughly 13 years) in ‘life orientation’ classes. Whilst these efforts have not been entirely futile, literature on the subject has questioned the extent to which teachers can discuss issues such as contraception and sexuality in rural African contexts (Gallant & Maticka-Tyndale 2004). Moreover, such governmental attempts at AIDS education are largely presented with a strong urban bias and against the backdrop of the government’s previously confusing and contradictory public statements on HIV and ARV treatment. As
a result, the depersonalised government information campaigns are largely received in Venda with a mixture of embarrassment, confusion and scepticism.

In the Tshivhase district of central Venda, volunteers for the Forum for AIDS Prevention have become the public face of HIV and AIDS, and a roving advertisement for testing and treatment. They compel people to confront the possibility that they may be HIV positive not through booklets, radio or TV, but through the medium of inter-personal communication ‘on the ground’.

Their message, however, is received in unintended ways. At the start of 2005, I issued 50 peer educators with diaries and encouraged them to write a daily commentary on their experiences. One of the most salient topics to emerge from this experimental methodology was their discomfort with the labels attributed to them by many people in the communities where they work. I quote at length in translation from the original Tshivenda:

As a peer educator most people look and see that I am teaching the community about AIDS and sexual illness. If we tell them, they will look and say ‘this one, she must be infected; she is the one who is positive’. Others ask, ‘How can you teach us about [blood] testing and counselling when you cannot tell us if you have gone for the test yourself?’

Our job really, it is not easy. Last week we went to [the village of] Dopeni for house meetings, we have not been there for some few months now. On the way walking there we were joking that the entire village will be infected now because of our absence! When we got there no one would let us past their gate, they would just hide and pretend to be not at home … they do this because they think we will infect them!

[I am] coming from the public meeting today. At least this one was better because there was a small group watching us and some youths even joined in. I really enjoyed that. We were all happy. It is so boring when no one comes to the meetings. Another group of men in the shebeen [beer hall] refused condoms from us, they say, ‘These condoms cause AIDS, if we fill them with water and leave them in the sun, you will find worms inside there, and these worms will get inside if you put on that condom, and the worms give you AIDS.’ They think like that, these Venda men of ours.

I heard women at the mill at Mandala saying we were working for the Americans, and they said that they had sent AIDS because it means the ‘American Institute to Destroy Sex’.

The quotes demonstrate clearly that target communities perceive peer educators as vectors for the virus they have
been charged with preventing. A partial explanation for this is the association made throughout southern Africa between ‘women’s sickness’, sexual transmitted diseases, and pollution of the blood (Ashwanden 1987, Leclerc-Madlala 2002, Heald 2005, McNeill forthcoming). An equally important explanatory factor – and our connection to the seven days debacle – is the way in which peer educators breach the deeply entrenched ‘public silence’ around HIV/ AIDS.

Their public performances and home visits are acted out against the aforementioned tapestry of deeply entrenched patterns of speaking, and not speaking, about causes of death. As self-styled ‘experts’ on the topic, peer educators have a detailed and very conspicuous knowledge of a suspicious and mysterious form of death that – like other causes – is rarely spoken of in public. Through their regular, open confessionals of this knowledge, they actively create an intimate connection between themselves and AIDS. Combined with the existing connection from the ‘folk model’ of sexual illness, it is widely believed that peer educators harbour and spread illness. The reference to ‘Americans’ in the fourth quote above speaks to the frequent visits of white ‘evaluation’ and ‘fact-finding’ teams, and to the notion that AIDS comes from contact with ‘outside’. ‘Americans’ are thought to be experts in the science of AIDS, and are, through this association, implicated somehow in its rapid distribution.

The ethnographic examples given above outline the dynamics of two quite different phenomena: Seven days poison, rumoured to have emerged from mortuaries and defunct tea estates, and AIDS, rumoured to be an ‘American Institute to Destroy Sex’. Both kill in very different ways. One is a white or red tablet that infects water supplies, food or drinks, and will run its course within a week. The other is a mysterious virus that kills very slowly and can be passed on during sex or even through the worms that many people believe lie dormant in sealed condoms. Both, however, are believed to be equally fatal causes of death. As a result of this, a form of public silence developed around both of them that reflected the general avoidance of discussing any cause of death.

To be sure, the codification of AIDS is also indicative of respect for grieving families. But it is fundamentally associated with the same social processes and pressures that prevented people talking openly about seven days. It is a safety precaution, collectively undertaken by individuals against the constant threat of guilt by association. If someone was to have come forward with information about the poisonous substance at the beer hall, or in other ways made themselves ‘experts’ on the topic, they would have been suspected, at least potentially, of implication in the controversy. The rhetorical question would always be asked: ‘How else would they know of such things,
unless they were somehow involved in its production or distribution?’ By invoking silence, coded language and obfuscation, degrees of separation are constructed that create distance between an individual and the ‘unnatural’ cause of another’s death. The act of refusing to name ‘AIDS’ is just as important for the individual making that choice as it is grounded in a motivation to protect the mourning family from stigmatisation. To call this an act of ‘denial’, which must be met with more education, is to seriously confuse the ‘winks’ and the ‘twitches’ (Geertz 1973: 1-33).

This, then, is a glimpse ‘behind the scenes’ of the socio-cultural context in which ARVs have recently become available in the Venda region. Even this brief look helps to explain the perceived need for strict codes of secrecy among support group members. As we see below, the perceived relationship between knowledge and experience also acts to protect those on ARVs, as individuals seek to minimise any potential connection between themselves and the magic through which support group members seem to have cheated the long, slow death that has become so familiar in post-apartheid South Africa.
FIRST YOU TALK, THEN YOU GET THE DRUGS

It is well-known that statistics can be misleading. A serious shortcoming of statistical data to measure the uptake of ARVs is that it rests on the assumption that if medication is offered, then it will be accepted. Low numbers of patients on ARV regimens are taken to represent inadequate standards of service provision and yet, as we saw in the first part of this Review, the reasons for why people accept or reject medication may have little to do with the actual standard of delivery. Having had regular access to an (initial pilot) project at which ARVs have been distributed through a rural hospital since 2004, it is apparent that many patients have refused and continue to refuse testing and treatment. This is either because they are suspicious of the efficacy of ARVs or because of the requirement that they will only be accepted onto a treatment programme if they disclose their status to a friend or family member. The former is a matter for another discussion. This section presents an analysis of the secrecy and suspicion practised by those who choose to disclose their status to someone and enrol in a treatment programme.

As we have seen above, the socio-cultural environment in Venda is not yet conducive to full public disclosure of HIV-positive status. For example, in an attempt to recruit volunteers for AIDS outreach projects, a local NGO (the Thohoyandou Victim Empowerment Trust, TVET) recently advertised widely for two HIV-positive Tshivenda speakers who had fully disclosed their status. It failed to find anyone who fitted these criteria. Instead, those who applied had disclosed only partially, to carefully selected, family members or very close friends.

Reinforcing this point, several of the women who attend the ARV support group at Vhutshilo School recently appeared on radio to tell people that they were HIV positive. Indeed, they told people, but they did not disclose anything through which listeners could trace their identities. Furthermore, an unprecedented attempt at full disclosure by a musician who is well known locally but not of Venda origin, had unexpected consequences. After making the announcement on a Phalaphala FM radio show, listeners phoned in not to support the musician, but rather with alternative explanations for his disclosure. It was suggested that he was not, in fact, HIV positive. Rather, through the fruits of his success, he had accumulated too many Venda girlfriends and could no longer afford to maintain them all. The listeners agreed that making the public statement that he was HIV positive was a sure way to frighten them off. Thus, instead of living positively with HIV, the musician in question now openly denies ever attempting to disclose...
his HIV status, sending an unspoken warning to people living with HIV to keep it to themselves. Whilst this demonstrates well the current xenophobic proclivity not to trust outsiders, it also reveals the extent to which people are uncomfortable with the personification of AIDS-related knowledge in the public domain.

Unlike much of South Africa – especially parts of Gauteng, KwaZulu-Natal and the Western Cape – there is no recent history of AIDS activism in Venda. With the notable exception of TVET, AIDS-related NGOs in the region, such as the Forum for AIDS Prevention, are partisan and have not (yet) demanded change. The song discussed above which advertises ARV medication was only composed and performed after the government had decided to go ahead with the roll-out. The concept of an openly ‘HIV-positive identity’, with no support networks or historical precedent to speak of, has thus remained elusive.

And yet, as we have seen, those who develop AIDS-related infections are effectively forced to disclose their HIV-positive status, to at least one other person, before they can enrol on an ARV programme. This has far-reaching consequences. Evidence from ARV support groups in Venda demonstrates that people are more comfortable disclosing to HIV-positive strangers than family members. In this they are motivated by a concern – for the benefit of all involved – to keep their status as secret as possible. Rumours flourish in which support group members are held responsible for practising witchcraft and for withholding the secrets of biomedical treatment, through which many of them have been dramatically transformed from sickness to health. They are thought by some to be zombies who have actually died. Simultaneously, and in reaction to this widespread suspicion, support groups attempt to disguise their true purpose and, in fear of victimisation, operate in a manner akin to secret societies.

It was widely believed, and indeed hoped, that increasing access to antiretroviral therapy would help to mitigate AIDS-related stigma through more people being open about their status (Norman et al. 2005, Eba 2007). However, in this case medical provision has actually exacerbated the stigmatisation of people receiving treatment. Whilst support groups in Venda increase the chances of adherence to ARV regimens, this comes at a price: a price that the women involved seem more than happy to pay. And yet, whilst they may be stigmatised by others in private – through gossip and rumour – the same social forces that prevented open discussion about seven days act to restrain any public accusations against them, and thus to shelter those on medication from public encounters regarding their recent return to health.
DISCLOSURE AND SUPPORT GROUPS AT PHULUSO CLINIC

Since the initiation of ARV pilot projects in 2004, the provision of treatment has been conducted from government-run clinics or hospitals. NGOs have thus far played a largely supportive role in identifying patients in rural areas and encouraging them to present for voluntary counselling and testing. In November 2004, Phuluso Clinic at Siloam Hospital in the Nzhelele region of eastern Venda (falling under Makhado Municipality) was selected (‘accredited’) by the Department of Health as a pilot project for the ARV roll-out in Vhembe district. Phuluso had previously been in operation as the ‘wellness clinic’, and had a core of about 100 HIV-positive patients who were monitored for CD4 counts and general health. In 2004, 106 clients from the ‘wellness clinic’ consented to begin antiretroviral treatment. In 2005, the clinic began to accept patients from government hospitals in Mussina and Louis Trichardt, with the number of patients growing to around 300. By 2007 Phuluso was treating just over 2 000 people. This saw the human and medical resources at the clinic stretched to the limit, and had a negative impact on the efficacy of its programmes and the health of its clients. Thankfully, not long after 2007 hospitals in Mussina and Louis Trichardt were also ‘accredited’ and could commence their own ARV programmes. This lightened the load at Phuluso, and in mid 2009 it was treating around 1 400 people, but still running close to capacity.

Phuluso Clinic is housed in a small, thin building, hidden well away at the rear of Siloam Hospital. Its geographic positioning is no mistake: it is concealed from those attending other hospital departments to protect the anonymity of its patients. Its location also allows for the inconspicuous picking up and dropping off of people who are unable to walk, and who have been brought to the clinic by vehicle. On a recent visit I assisted an elderly man to load his son onto the back of a truck. He had been forced to borrow a neighbour’s van, as his son could no longer sit up straight in a car seat: he had been lying down, the old man told me, ‘for a long time’. Having tried and failed with several traditional healers to locate the source of his son’s sickness, he had decided in desperation to bring him to the clinic. ‘I knew it was this thing [AIDS] killing him, but I did not want him to come to the hospital. People come here to die.’ After pulling the sponge mattress forward and dragging his son onto the middle of it, the old man carefully concealed the reason for his trip to the hospital under a collection of blankets and cardboard boxes which were then secured with a rope over either side of the truck. Satisfied that no one could make out his son lying in the back, he set off, promising to give his
son the medicine as directed, and to return and collect more if he thought it was working.

As a patient who has lost mobility, the man in the back of the van fell into what Sister Tshidzumbe at Phuluso explained to me was ‘stage four’ of HIV disease. At stage one of infection a patient is mobile, healthy, exhibits a high CD4 count and no visible symptoms. Stage two can be recognised through limited weight loss and some skin conditions. Stage three is identified by the onset of opportunistic infections. In stage four, when the CD4 count is below 200 and the immune system is under serious attack, a patient is entitled to begin a programme of antiretroviral treatment. This must be tailored to their specific needs and monitored for the rest of their life to make adjustments for variable viral loads and any side-effects.

Eligibility for treatment is not only met through physical deterioration. As Sister Tshidzumbe explained:

We ask them what they still believe in. If they still believe in traditional healers we encourage them to go home … we do not want to combine traditional herbs with ARVs because they will both be fighting the liver at the same time … the client must complete the package from the traditional healer, then start with the treatment. It is one or the other, and it is their choice.

But even with physical breakdown and the rejection of traditional herbal or spiritual remedies, a client still faces the obstacle of disclosure before they can commence with treatment. In 2004, with the much anticipated launch of a national roll-out, the Department of Health (DOH) released guidelines for the ways in which antiretroviral regimens should be managed by local health practitioners. Through this publication, the DOH ‘strongly recommended’ that clients disclose their positive status to at least one family member or friend before being accepted onto an ARV programme. Health-care workers interpreted the guidelines in terms of disclosure being an entry criterion for treatment (for adults, but not for children).

The DOH instructed those responsible for implementing the roll-out that:

It is essential to provide all patients with a comprehensive plan to support adherence. The plan must make use of multiple strategies and all members of the health care team, as well as family and community. Optimal adherence requires full participation of … patient, family and members of the community. [Health care workers must] encourage disclosure to family and friends who can support
the treatment plan (Department of Health, South Africa 2004: 52-54).

The concern with adherence in the government’s national guidelines is fundamental to the efficacy of the national roll-out. If patients do not adhere to their regimen by taking the right doses of medicine at approximately the same time each day it is likely that they will develop problems with their combination of ARVs. This has several potential outcomes. First, the virus begins to reproduce more efficiently in the blood. It is likely to occur if a client defaults on medication more than once. Second, it is possible that non-adherence may contribute to the mutation of treatment-resistant HIV. Crucially, the maintenance of a good diet with fresh fruit and vegetables, lots of exercise and as little alcohol and tobacco as possible serves to keep the body strong enough to metabolise the ARVs in its system. Moreover, a sober person is more likely to get into the habit of taking the pills at the same time every day.

Disclosure of one’s HIV-positive status is widely believed to facilitate adherence (Skhosana et al. 2006). Groups such as the World Health Organisation (WHO), MSF and TAC broadly agree on this, promoting disclosure as beneficial across the board. Telling a trusted friend or family member that one is HIV positive and embarking on a lifelong regimen, makes it easier for the patient to take their medication. It provides an extra helper to remember the time, to assist with a regular supply and preparation of medicine. In this way, the recipient of disclosure is converted into a so-called ‘treatment buddy’. Moreover, research suggests that upon disclosure a significant psychological burden is lifted. This relief, often described as ‘liberation’, is in and of itself conducive to well-being through the reduction of stress and related bouts of depression (Paxton 2002, Norman et al. 2005, Almeleh 2006).

The line between government recommendation and health worker stipulation is a blurred one. At Phuluso Clinic, if a client tests HIV positive, they are instructed to come to an ‘adherence meeting’ before taking the treatment, accompanied by someone they ‘reside with’. Yet as Sister Tshidzumbe admits, ‘There are problems with this forced disclosure. Women are afraid of being divorced or even killed if they tell their husbands’. And so the national guidelines on disclosure are applied in Venda in a pragmatic manner more suited to a cultural context in which those embarking on medication to save their physical beings engage in damage-limitation exercises to preserve their social selves.

Within a socio-political environment that is not conducive to disclosure, HIV-positive people in Venda tend to reveal
their status – preferably to other HIV-positive people – only when pressurised to do so. This moment arrives when HIV develops into AIDS, and a client becomes eligible for antiretroviral therapy. However, studies in other parts of South Africa have revealed more complex patterns of disclosure, against backgrounds of socially recognised AIDS activism. Norman et al. (2006), for example, describe the bewildering array of disclosure patterns that are common in the Western Cape and the Eastern Cape. Respondents in the comparative study reported divulging the news to mothers, but not to fathers; to sisters but not to lovers; to aunts but not to brothers. Each case of disclosure, they reveal, has its own subjective web of constraint and intrigue, through which a gradual progression is made from non-disclosure to full public disclosure.28

The quotes below, taken from extended life histories of people in ARV support groups at Phuluso Clinic in 2005, reveal the pressures felt by people as they explored their possibilities:

It took a long time [to disclose my status]. Honestly, I could not do it, so long as I did not look sick. I knew [I was HIV positive] from when I had my second child [three years prior to starting medication], but I did not want people to know. When the nurse told me I had to tell someone I cried, it was so painful for me, but [the nurse] introduced me to the support group and at least I told them. Even today, I have not told [my family] at home, but I will tell them soon.

I needed the medicine, everything else had failed [traditional medicine], the sickness was getting worse. I was desperate. My father told people I was bewitched [by her previous husband, whom she left after his heavy drinking and domestic violence], but I knew it was AIDS. [The ex-husband] has already died, and now I am getting healthy, so they believe my father. The clinic told me that these medicines are complicated and I needed help at home to take them, but who could I tell at home? If it was not for the [support] group, I would also be dead by now.

I was very depressed at that time. My third child was very sick, and people were blaming me. [AIDS] does that, just hiding it from everyone. I spoke to my friend [a nurse working in Pretoria], she told me the antiretrovirals could help [the child]. I went to the clinic, and look at us now! You would never know [how sick he was]. But people still look at us, and talk about it. They [outsiders] are very suspicious of us [support group members]. But we just keep quiet, people will not dare to ask.

Once a client is enrolled in an ARV programme, he or she is encouraged to join a support group with others on treatment, in which they can discuss the issues they face, organise
income-generating projects, boost each other’s morale, and keep updated on changes to treatment regimens. Attendance at support groups, however, is not a pre-requisite for treatment. The support groups in question are exclusively female. This is because women interact generally more with the health sector, and specifically because of their increased likelihood of testing for HIV at antenatal clinics. Women are thus more likely to know their status and have their CD4 count monitored through a local clinic, although figures from Phuluso Clinic demonstrate that men are presenting in greater numbers for testing and treatment.

These men, however, are usually the husbands of women who are already enrolled in ARV programmes. This has played into a broader gendering of the epidemic, insofar as women volunteer as AIDS peer-educators and home-based care workers, and – as we saw above – are often framed as experts on, and vectors of, the virus. Once support groups have been established as female spaces, the probability of men joining them is reduced substantially. This is one reason why some men refuse antiretroviral treatment: AIDS is perceived by many to be a disease of women. When men come to be tested independently of their wives, according to Sister Tshidzumbe at Phuluso, the recipient of their disclosure is likely to be one of their children, who remain under the strict patriarchal control of their father. During the pilot project in which ARVs were rolled out from Phuluso Clinic at Siloam Hospital in 2004, support groups of women starting their medication met at local clinics or at secluded wards at the hospital. Attending these meetings in 2005 – more in the guise of an AIDS educator than an anthropologist – involved infiltrating the close-knit groups, in which many were extremely sick with stage four AIDS, often also suffering the early side-effects of antiretroviral treatment. Many phone-calls were involved in arranging who would arrive when, and where they would wait for the meeting to begin. They could not all arrive or leave the meeting at the same time: this would be a clear indication that they were meeting as AIDS patients, and would leave them open to victimisation.

The early meetings took place in a darkened, stuffy room, with all the curtains drawn and all voices lowered. Speaking in hushed tones, people discussed the problems they were facing with ARVs, and received advice from nurses regarding adherence. They spoke of the fear that they would be exposed. One woman, who had actually disclosed to her husband, expressed her fear that ‘when he is drinking he will tell others, and they will come and kill me’. A young woman from Zimbabwe was worried that ‘They will see us leaving from here, and follow us home’, to which the nurse replied, ‘Yes, they may see you leaving the clinic, but you know...’
The nurse’s sentiments here are a direct reflection of the social forces that prevented people talking openly about seven days poison. The psychological burden placed on support group members in terms of upholding strict codes of secrecy was too much for some women. In the early support group days, therefore, some decided they could no longer attend, and they lost contact with the nurses at Phuluso Clinic altogether. A few were monitored by home-based care volunteers from the FAP, which sent occasional food parcels to their homes and provided ‘spiritual support’ in the form of prayers, but the fear of neighbours recognising AIDS-related volunteers visiting their home forced them to cut ties altogether.

Whilst support group members received a certain degree of protection from rumour and gossip through the widespread desire in the community ‘not to know too much’, their fears of victimisation were not without justification. A well-known example of AIDS-related persecution is, even today, often cited as evidence for why it is advisable to remain silent about being HIV positive. Not far from Siloam Hospital, in 2002, a local man and his family (three daughters), all of whom were HIV positive and some of whom were sick, received a visit from a stranger. The stranger introduced himself as a health worker from the FAP, and stated that he was there to document the family’s current situation, as a new funder from abroad had donated money that had to be distributed to those families most in need. The clearly sick man posed for pictures outside his crumbling house with his daughters, and told the stranger of their concerns that the community would discover the truth behind their ailing health.

The following Friday, the headline in the local newspaper screamed ‘AIDS hits Nzhelele’, under which pictures of the man and his daughters were surrounded by text in which his confession was printed. He had been duped. The visitor was not a representative of the NGO, but a ruthless, anonymous journalist. As a result of the family’s exposure, the children were stoned by teachers, parents and other schoolchildren alike as they tried to enter the village school. They were denied access to washing places at the river, and could not collect water for the communal tap unless they went under cover of darkness. Their father was beaten to within inches of his life, and their crumbling house was burnt to the ground, along with their meagre possessions. By the following Thursday, when I went with an FAP representative to take the family to a safe house in another village, they had disappeared, leaving behind only a letter to their support worker explaining why they had no option but to flee.
No one has seen or heard of them since. The lesson has been learned: nobody in the support groups around Siloam Hospital wants to be the next victim of a witch-hunt in which their lives could, quite literally, be destroyed.

The support groups did not meet on the hospital premises for long. It was perceived to be too risky, and only a matter of time before they were also caught out and exposed through the media. Moreover, some of the women had to travel far, from Mussina and Louis Trichardt, and Phuluso Clinic did not have a budget to pay for their transport costs. The FAP had donated a brick-making machine, from which it was hoped the women could generate some income to cover costs for transport and food, but the machine soon fell into disrepair. A local supermarket also donated some cash, which soon dried up. Before long, infighting started within the groups and accusations of theft and favouritism plagued the meetings. More women parted ways with the support groups, and things began to look grim. Around 2006, the support groups at Phuluso ground to a halt amid internal feuding, and the women were left without any institutional framework in which to discuss their HIV, AIDS and ARV-related concerns.

A SCHOOL, A SUPPORT GROUP AND A SECRET

As staff at Phuluso attempted to re-establish the support groups, some of the clients had begun to frequent Vhutshilo Mountain School during their free time. As one support group member recalled:

We started in the support group at Siloam. But it fell apart. We came here and asked if we could meet here. The group here at Vhutshilo is much better. We started to meet the children, and a few of their mothers, whom we were told were HIV positive. We can spend time here and enjoy it, not like going to the hospital.

The Vhutshilo Mountain School is the brainchild of Sue-Anne Cook, the former wife of the American Buddhist monk who established FAP. In 2002, Suzi – as she is known – began a small crèche in the mountains of Thathe Vondo. In her caravan she took care of pre-school children from the surrounding villages. Some of them were HIV positive, some had been orphaned by the epidemic, and some were HIV negative. Whilst the primary intention of the school has always been to support HIV-positive children, the philosophy has been to do this in an environment that is not defined by health status.
The small caravan could accommodate only about ten children, and Suzi converted her home into a pre-school facility for them. Space was at a premium. On a trip home, a young volunteer from Scotland embarked on a fund-raising mission for the school, and through the help of the Church of Scotland, he raised enough money to build a new school. In 2005, a new building was duly erected and Vhutshilo was relocated to the village of Tshikombani. To secure a permanent source of clean water for the building, a borehole was dug, and a tap was set up at the eastern fence to provide water for neighbouring villagers, several of whom are employed by the school as cleaners and cooks.

By 2009 Vhutshilo had grown to accommodate 60 children in two classrooms. It is often a bustling centre of activity.

Sponsors from South Africa, Britain, the United States and France paid school fees for orphaned children, whilst those who had parents who could afford it had fees paid by their parents. About half the children are HIV positive, and around half of the HIV-positive children are on ARVs. By 2009 Vhutshilo had grown to accommodate 60 children in two classrooms. It is often a bustling centre of activity. People come to purchase the second-hand clothes donated by overseas donors. There is a specially built building for this purpose at the entrance gate, which has been painted with bright murals by volunteers from the University of Glasgow and the Church of Scotland. Groups of visiting donors from France and America have recently been accommodated in the newly built ‘half-way house’, which also serves as a small conference venue and a nurses’ room. Vhutshilo has also benefited from the services of the UK-based Voluntary Services Overseas (VSO), which has deployed administrators, book-keepers and agriculturalists to the school.

The school receives funding from a plethora of donors, including the South African National Lottery, Oxfam Australia and the Nelson Mandela Children’s Fund. The school accepts children from the ages of 2 to 7 years (‘pre-school’, Grade R, Grade 1 and Grade 2), and employs several teachers, administrators and cleaning/cooking staff. Vhutshilo School has a close working relationship with Phuluso Clinic, and many children are referred by Sister Tshidzumbe to Suzi, and enrolled in Vhutshilo.

In addition to providing a crèche and teaching, Vhutshilo makes other services available. It has an outreach programme for orphans and vulnerable children in surrounding villages. Some of them are former pupils who have progressed to Grade 3 in a local state school. In this way, their families are kept in contact with Vhutshilo, and thus Phuluso Clinic. Through the outreach activities, food parcels are delivered to the children’s carers, they receive second-hand clothes that have been donated to the school, and they obtain continued advice on how to
deal with the bureaucratic necessities of accessing government grants.

As suggested above, Vhutshilo is also the site for an ARV support group, frequented by the women who were left frustrated by a lack of resources at Phuluso Clinic at Siloam Hospital. The ARV support group at Vhutshilo, like the one at Siloam, meets once a month. Beginning at the end of 2006, they started with zeal but soon lost enthusiasm, again through the failure of an income-generating scheme. Nonetheless, Vhutshilo had the funds to pay for the women’s transport, and had the added bonus of providing a good meal, and so most women stuck around. Staff at Vhutshilo decided to expand their modest garden into a full-scale orchard in which the support group could toil during their free time, and from which they could eat and sell produce. They grew vegetables and fruit such as spinach, watermelon, tomatoes, onions and carrots. The ground was fertile and the land well irrigated, and the orchard at Vhutshilo has grown to become a major feature of the school’s garden.

At its monthly meetings, the support group is visited by a nurse from the local clinic or a representative of local NGOs, who give motivational talks and encourage adherence. Members have been given watches, and know exactly when to take their medication. A local supermarket donated small notepads and pens, in which they record daily medicine intake and any side-effects they happen to experience. Through a combination of strict adherence to their antiretroviral regimens, lifestyle changes and a much improved diet from the orchard, those who were sick rapidly got better. Over time, more sick women were referred to them from the surrounding clinics. Some mothers of HIV-positive children who attended Vhutshilo decided to join them. Some of them stayed and got better. Some decided against it, and for their own reasons kept their distance.

There can be little doubt that members of these groups maintain strict adherence to their regimens. However, owing to their only partial disclosure of HIV status, adherence requires secrecy. The imperative to take ARVs at precisely the same time every day means that medicine is often taken at home. If family members or friends who are unaware of their relative’s HIV status are present to witness proceedings, then medication is taken with a dose of deceit. Support group members have developed a strategy, through which they tell family or friends that the pills are for a wide range of ailments: high blood pressure, stomach ulcers and headaches, as well as for oral contraception (cf. Skhosana et al. 2006 for evidence of similar tactics in Soweto). As a group member said to me...
in 2009, ‘The less other people know about my HIV, the better it is for all of us’. ‘But wouldn’t it be a relief to disclose to everyone?’ I asked. ‘No, at least not yet’, she replied. Privately, within households, there are various levels of disclosure to trusted family members, in whose direct interests it is to keep the secret in strict confidence, lest they be the victims of another anonymous journalistic exposé.

The extent to which support group members disclose to their boyfriends, husbands or occasional lovers presents them with a particularly difficult, and extremely private, conflict of interests, of which I have very little knowledge. I have heard them discuss strategies for condom use with boyfriends, and they consistently request, without success, regular supplies of female condoms. However it would be highly inappropriate for me to enquire about the intimate details of their private lives. If such information is not forthcoming, then as a researcher, one must respect the silent barriers drawn by the researched. Nonetheless one fact is certain: the support groups at Vhutshilo remain shrouded in secrecy, and the women who attend them remain constantly vigilant that their cover is not blown.

This was illustrated by a recent incident. As usual the meeting started with a round of introductions. It is not unusual for new members to appear unannounced, and no one objected to the strange face in their midst. A few of the regular attendees started by reciting the mantra-like statement: ‘My name is … and I am HIV positive’. The stranger waited her turn and announced: ‘My name is … and I am HIV negative. I came here because I heard there was a meeting on how to access welfare’. A very uncomfortable silence fell upon the room, and the woman was quizzed about her motives for attending. The other group members accepted that she had made a genuine mistake. Even so, it took them almost half an hour to be convinced that the stranger would not tell anyone about what she had seen in the meeting. Despite her protestations to the contrary, some regular members alleged that she would talk. As a group, including the stranger, they had a discussion about the potential implications of letting the secret out. The ARV group members claimed they would be potentially victimised, and that they would lose the fringe benefits of being part of the support group and associated with Vhutshilo. On the other hand, it was agreed that people would not believe the stranger’s story that she had gone there by accident. She did not want people to think that she was HIV positive, and so the discussion reached a checkmate. An agreement was reached that it would be better to forget the entire debacle. The stranger was given taxi money home, and never seen again.
‘SOME PEOPLE THINK WE ARE WITCHES’

To some extent the removal of the support group from hospital grounds to the more neutral and relatively stress-free environment of an orchard in the midst of a bustling school provided members with the opportunity to construct a less medicalised identity. Instead of staggering participants’ entrance to, and exit from a meeting in a dark, curtain-drawn room in a clinic full of sick people, they could come and go freely at a specified time into school grounds full of playing children amidst the bustling atmosphere of Vhutshilo. They could eat lunch together in the fresh air, and discuss adherence and HIV and AIDS-related issues in an HIV-friendly environment whilst tilling the land like any other member of the community.

And yet despite this pretence of normality, as we have seen, the support group goes to significant lengths to maintain a strict code of secrecy. Because of this, and in reaction to it, some people in the surrounding villages have grown suspicious of them. ‘You know’, a member said to me in April 2009, ‘some people think we are witches; there are lots of rumours’. ‘Why is that?’ I asked. ‘Because they think we are up to no good. Other groups meet to hold a stokvel, to have prayers or to practice traditions like dancing, but we, they don’t know why we just come here, together, to make this healthy orchard that is so green. They are jealous.’

Intrigued by this admission that some people are deeply suspicious of the group, and in a similar approach to our sociological interest in seven days, my research assistants and I endeavoured to track down and record the rumours. Following years of tried and tested anthropological methodology, we headed for the local beer halls. We were not expecting to hear much, at least not in such a public setting. As the ethnographic account of seven days poisoning demonstrated, there is a strong connection between publically expressed knowledge and assumed experience. This connection between being open with information and supposed familiarity with it acts as a double-edged sword. It can frame people who seem to know too much about something, whilst restraining others from making public accusations. This explains, as we saw above, why people do not talk openly about certain topics. They seek to avoid guilt by association, circumventing the inevitable ‘How do you know?’

Following this cultural logic, the men to whom we spoke in beer halls were careful to restrict their conversations to groups of friends, and sometimes to create spaces away from others altogether, where whispers could be heard.
and accusations could not be traced back to them. But these men were not ‘strangers’, in that we did not simply approach them ‘out of the blue’ and ask questions. Hence, we phoned men who lived in the same villages as the support group members to arrange a catch-up visit in a local bar. We bought the beer, they talked, and we listened. In the process, we identified groups of friends that would be comfortable talking about sensitive issues in each other’s presence, and instigated targeted conversation when appropriate. Such a methodological approach is necessary when investigating the ways in which gossip between friends becomes rumour among strangers. In charting the social life of ARVs in Venda and investigating the flip-side of secrets kept by support group members, a research team must be prepared to keep secrets of their own, at least in the early stages of the project.31

Once the conditions for discussion were in place, people began to talk. I quote below from three different conversations, each from different villages:

My wife used to work with one of them. She [the support group member] lost her job because she was very sick. They were expecting to bury her, but now they say she is working like mad up there [in the orchard], strong as a man! How can that be? Did they heal her by that green spinach? [laughing] Really, what is going on? If they know how to heal people they should tell us.

These women were sick, very sick. We used to drink with some of them here, in this very place. Some of us even fucked them. Now we see that they are becoming strong, working in that field and hiding away from everyone. They just go straight to their homes at night, we don’t know why. Are they inyangas [traditional doctors] or what? Witches, even, who can play around with sickness like that. It’s not natural.

You know here in Venda, we have strong people who can kill others and make them into zombies to work in the fields all night long, ploughing and planting. These women were dying in front of us, we saw them here, getting sick, and maybe they died after all, becoming zombies in that school orchard.

As these quotes demonstrate, there were distinct patterns in the backstage gossip about members of the support groups. No one mentioned the possibility that they might be taking antiretrovirals, or recognised Vhutshilo School as a space for children with HIV. Rather, suspicion had been raised by two perceived characteristics. First, they appear to operate in secret. Second, men with whom we spoke thought that women who frequented Vhutshilo orchard had cheated death: they had been transformed from illness to health. Taken as separate
entities, either of these attributes *might* give rise to rumours through which accusations of witchcraft – or other suspicious behaviour – are circulated. Taken together, however, they are almost certain to do so.

In the last quote, suspicions are raised that the women in question may actually have died, and become zombies (sing. *tukwane*, pl. *matukwane*). While this may sound ludicrous to some, there is in fact a well-defined discourse on zombies in Venda, and in southern Africa more widely, backed up by countless personal testimonies to their existence. These stories differ from the stereotypical ‘western movie’ notion of a zombie as someone who walks around aimlessly, in a trancelike state, with a menacing presence and possibly *en route* to kill. Zombie stories in Venda almost always contain reference to dead people being involved in the physical working of orchards, increasing the productivity of the land, to the profit of the land-owner who has somehow procured their services through sorcery. They invoke sentiments of wealth and value creation through an ‘occult economy’ that puts magical means to material ends (Comaroff & Comaroff 1999).

One of the most popular zombie stories, which has been in circulation for almost 15 years, recounts a farmer in the Duthuni region, not far from Mapitas beer hall. In 1994, there was a spate of mysterious disappearances in the region involving young men, some of whom were found dead whilst others remained missing. At the same, the farmer in question happened to reap a bumper harvest whilst his neighbouring competitors garnered below-average crops. Rumour spread quickly that the farmer had turned the young boys into zombies to work his field during the night, whilst the village slept. A trap was set. A group of around ten men, including one of my research assistants, lay in wait around the border fence of the farm as night fell. Without any explanation, all of the men fell into a deep sleep. When they awoke, in the middle of the night, they found the dead and missing young boys tilling the field. Nothing could distract the zombies, and although their eyes were closed they knew in what direction to turn. The men ran directly to the farmer’s house. They tried to beat him to death, but he escaped and was never seen again. Those who claimed to witness the zombies on his land all had connections, directly or indirectly, with the neighbouring farms that had been outperformed, and a sociological explanation would point to their vested interests in removing the competition.

Nonetheless, in a cultural context in which stories like this are widely held to be true, it should not be surprising that ARV support group members are constructed in the public
imagination as zombies. This idea, in which their transformation from ill health to good health is combined with the secretive nature of their enterprise, concurs with recent research conducted by Niehaus in Bushbuckridge. He argues that people with AIDS inhabit a liminal space ‘betwixt-and-between’ the world of the living and the realm of the dead (Niehaus 2007). In the Venda case presented here, members of the support group are similarly located. However, as a result of their strict adherence to antiretroviral regimens, it is not the gradual regression from life to death which has sparked suspicion, but rather the rapid, and secretive, progression from near death to apparent full health.

Moreover, the perception of women on ARVs as zombies may be related to the success that has seemingly blessed the fortunes of Vhutshilo School. Of the many attempts at developing profitable businesses and NGOs in the surrounding villages, Vhutshilo stands out as a success story. It has well-built and well-maintained buildings, and is expanding. The number of children attending has mushroomed, and so has the funding from donors. The orchard has grown quickly and is exceptionally productive. It is run by a white woman and white people from overseas often visit, leaving behind donations of cash.

To the outsider, who is unaware of the rational explanations for Vhutshilo’s success, it may appear to be in the same category as the 1994 bumper crop of the farmer from Duthuni. As women who are perceived to be betwixt-and-between life and death, the ARV support group members who till the orchard are thought to be, at least potentially, fuelling this success with the help of the mysterious magic – that they themselves seek to keep secret – which apparently saved their lives.

The perception of women on ARVs as zombies may be related to the success that has seemingly blessed the fortunes of Vhutshilo School.

But what impact do such rumours have on the functionality of the actual support groups? What is going on in the space between the rumours and the reality? To answer these questions we have to return to the story about seven days poisonings. The women who work in the Vhutshilo orchard are to some extent protected by the relationship between openly expressed knowledge and assumed experience that kept public discussion about the poison to whispers. To defend themselves from accusations of involvement, people do not want to be seen to ‘know too much’. Thus, whilst rumours and gossip circulate about the intentions and supposed occult activities of support group members, the people spreading such rumours are unlikely to make open, public accusations against them. In this way, the zombie rumour is confined to gossip.
However, the ethnography above has indicated that there may be exceptions to this rule: The *Mirror* newspaper article exposed an HIV-positive family, whilst a group of men hunted down the farmer after allegedly seeing his zombies. But an individual is unlikely to make an indictment such as that made by the *Mirror* journalist, who was reporting a confession, not making an allegation. Moreover, the men who sought to discredit the successful farmer, whilst working in a recognised register of zombie rumours, had vested interests in his downfall. By acting unilaterally, they took a risk that paid off by chasing away their competition.

Those who spread the ARV zombie rumour, on the other hand, have no vested interest in the downfall of Vhutshilo Mountain School. They do, however, have a desire to make sense of the ways in which such women have apparently cheated death, in the context of a flourishing school. However, were the men who whispered these rumours to make a public statement to that effect, then they would potentially be implicated with the surreptitious goings on: how could they know, unless they were somehow involved themselves? Thus, the art of deception is active on both sides of this story: the ARV support group remain at pains to hide the primary motive for their meetings, whilst those spreading rumours do so in a way that is intended to conceal their suspicions.

The result, in the end, is that rumours circulate, and the women in the support group get on with their business in the orchard. There would appear to be a symbiotic relationship between the two, in which a mutually beneficial curtailing of open conversation acts to protect the spreaders and the subjects of rumour.

To summarise my argument: The lack of a recent socio-political history of AIDS activism in Venda has made the process of HIV disclosure in this rural area fraught with potentially disastrous outcomes, more so than in other parts of South Africa where a legitimate ‘positive identity’ has emerged. Early disclosure to participate in AIDS-related political activities (Almeleh 2006, Paxton 2002) is unheard of in Venda, where people disclose their status only when they are faced with a choice between life and death.

In this context, the recipients of disclosure are usually other people receiving treatment, who have formed secretive clusters of social support. The complex relationship between publicly expressed knowledge and experience, however, acts to protect them from open accusations regarding their potentially occult, clandestine behaviour, through which they seem to have been dramatically transformed from sickness to health. Nonetheless, they remain subject to rumour and gossip, through which they are stigmatised as witches and zombies who have already died.
Paxton (2002) identifies a paradox to disclosure of HIV status. On the one hand, being open about one’s status may bring psychological relief from secrecy and shame, and the possibility of social support from friends and family. In the South African context, it ensures eligibility for free treatment. And yet at the same time, openness renders the individual vulnerable to social stigma. In the Venda case presented here, the paradox of disclosure is apparent, but it is mediated by local conditions. Through fear of victimisation, confessions are channelled selectively. The flip-side of this coin, however, seems to shield the ARV support groups from persecution in that AIDS-related stigma is mostly confined to rumour and gossip. But as Norman et al. (2005) usefully point out, disclosure should not be seen as a ‘once-off’ event. There are various stages between silence and full public disclosure in which specific people are told about HIV status for specific reasons. Following this line of thought, the support groups in Venda can perhaps be seen as a stepping stone: a ‘temporal stage’, to paraphrase Norman et al. (2005), connecting an individual’s once taciturn approach to their status with a public, positive identity.
CHILDREN, GRANNIES AND DRUGS

Despite the absence of encouragement or incitement for adults to live openly with HIV, the team of people around Vhutshilo has created innovative approaches to meet the emerging needs of its children. It has pioneered ARV workshops, possibly the first of their kind in the country, which ultimately function as a support group exclusively for children. The child ARV workshops are managed by Khatu Nemafhohoni, a 23-year-old woman who, despite her youth, has accumulated extensive experience of working with HIV-positive people. In 2006, whilst working for the Thohoyandou Victim Empowerment Trust (TVET), Khatu was involved in monitoring children on ARVs who had defaulted on their medication. In doing so, she collaborated closely with Phuluso Clinic, which referred sick children to TVET for incorporation into their ‘positive support’ section. Khatu explains how the child ARV workshops started:

I found out that the children had not been told they were HIV positive. They have no parents, these children, and grandmothers or aunties always have their own lives to lead. They can’t sit around and wait for 6 o’clock [or any other specified time to take the medicine]. They have to go out, to funerals and church, and you find they have not told the other siblings in the house that the child is HIV positive and needs the medicine. These children were dying. So, we said, how about we teach the children? … And then the idea just came. We were trying to solve the problem of defaulting. We agreed with the grandmothers that it’s not right to tell the cousins or others staying with the child, but we can at least teach the children the basics: know what time you take the pills, know the names of your medication, know what to do when you fall and bleed, and know that people will stigmatise you as you get older, and people get to know [that you are positive].

In 2007, Khatu co-ordinated the first workshop for 14 children. Ten of them were on ARVs, and four were positive but not on medication. There are currently 37 children in the workshop, ranging in age from 6 to 16 years, 26 of whom are on treatment. Many of the children know each other from attending Phuluso Clinic once a month on the days designated for children. Some of their mothers attend the ARV support group at Vhutshilo. The workshops are held quarterly, just before each of the four school holidays. Care-givers are not allowed to attend the meetings. Their absence is intended to facilitate ‘openness’ among the children, and set the space off as one in which they can speak freely without the presence of elders.
In the first workshop, the children were told collectively that they were HIV positive. Their grandmothers and aunts, having been told the children’s status at Phuluso Clinic, had generally hidden their HIV status from the children. They did not want anyone to know, and kept the secret to themselves. Some were also motivated by a concern for the child’s well-being: ‘What if I told him and he kills himself?’ one asked. Still, keeping the facts from the children removes them from any involvement in their treatment, and, in Khatu’s experience, significantly increases their likelihood of defaulting.

So the children had to be told. After receiving written consent from the caregivers, Khatu took responsibility for telling them. It was a tricky situation, as she recalls: ‘When I told them I didn’t feel sorry for them, I was not afraid for their lives … but there was some discussion around the issue of counselling. Some people felt that professional assistance was needed for the children before and after [being disclosed to]’. However, the decision was taken not to counsel the children. It was felt that individual counselling sessions could possibly have intimidated the children. Moreover, no one knew precisely what format any counselling would take: even nurses from Phuluso Clinic had never disclosed to children before. At the clinic, children were not even told that they had been tested; their care-givers received and managed all the information. It was new territory for all involved, and demanded an innovative solution.

Instead of any formalised counselling session, Khatu introduced the matter through a variety of culturally appropriate ‘ice-breakers’ in which the children were gradually told a story about a young girl who had a ‘little dragon in her blood’. The girl, named Brenda, has lost her parents from AIDS, and she is also HIV positive. She has to change her lifestyle and take medicine at the correct time. By taking the medicine, she keeps the dragon asleep; forgetting the medicine wakes the dragon up, with nasty consequences for Brenda’s health. Nonetheless, sometimes she gets sick, and people judge her but, in the end, she learns how to manage the sickness – to keep the dragon asleep – and plays normally with her friends. After hearing this story, and talking about some of the issues it raised, the children were told that they also had the small dragon in their blood, and that its name was HIV.33

‘It was amazing’, remembers Khatu. ‘Most of the children remembered the very day they went to the hospital. Some said, “The doctor took my blood, and I heard them saying HIV”’. It would appear, then, that many of the children knew something was wrong, but had never been told directly what the problem was. Most of them had been told the
medicine they were being given was for ‘flu’, ‘to help them sleep’ or simply ‘to keep them healthy’. Somehow they knew that they should not know the truth.

After a year or so, Vhutshilo made contact with Oxfam Australia, which provided it with materials developed by the Pretoria-based Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS). These materials are designed to promote treatment literacy among children, through which it is hoped that they will learn to manage their own medication. Khatu was inspired to receive them: they gave her something as a focus for the workshops and lent an element of professional support to her endeavours. They include a series of seven booklets, from a basic introduction to ARVs, guidelines on ‘daily life’ and medication, ‘my body and my treatment’, to the final ‘my future and my treatment’. The booklets are bright and clear, leaving space for drawings, but it is unclear how much the children actually learn from them. However, they act as a point around which to focus discussion, and provoke questions from the children. All the material is in English, and so requires the help of a facilitator for translation. In addition, the SAfAIDS material includes ‘The Knowledge Game’ (an HIV/AIDS version of ‘snakes and ladders’), a small ‘ARV adherence calendar’ and a set of ‘quiz cards’. The cards are used in groups, and each child takes a turn to ask a question such as ‘Name three common side-effects of ART’, ‘How do ARVs work?’ and ‘Why is nutrition so important for us?’ They are given watches, notepads and pencils to take home with them and keep a (secret) diary of when they have taken their pills.

At some stage during the workshops, usually towards the beginning, the children are asked to think about and engage with their emotions. Khatu tried to get them to make memory boxes but it didn’t work. Instead, she asks if they are happy, sad or angry. They then have to communicate this feeling to the others by drawing a picture of it, from which the group has to guess the emotion in mind. The pictures can be remarkable: a snake for feeling in danger, lightning for feeling that they may disappear (i.e. die) soon, rainbows for happiness and fancy cars for wanting to be rich. When explaining their sketch, they get a chance to talk about the reasons behind their choice, an option which some take and some don’t. The children keep their pictures, and the collection, over time, reflects their own emotional development. For Khatu:

This is more effective than making a box of memories, which reminds them of their death … we should all make [memory] boxes, we are all going to die. Why just focus of the ending? No, we
decided to help them recognise their own emotional journeys, so that they can see that being on ARVs is a process of living, not of dying.

In addition to drawing their emotions, a guest speaker talks to the children about their condition. So far they have had a nurse from the clinic, a volunteer from TVET, a visiting researcher, a dietician, a social worker and a pharmacist. This serves to break up the format and (theoretically) keep the children’s attention. After roughly three hours in the workshop, it draws to a close. On the way out, each child is weighed, given a small check-up by a nurse and a small gift, such as a set of pens, a mathematics set or a pencil case. The children are then fed a substantial meal, and sent on their way.

In the short space of time that they have been in operation, the monthly workshops have attracted an increasing number of children. When new children attend for the first time, they sit with a reliable, well-behaved group who then recount the story of Brenda, and the dragon in her blood, to the newcomers. In fact, older children are often given responsibility for teaching younger ones about how to take their medicines correctly, and in this sense the workshops are conducted by and for children.36 The intentions in this strategy are threefold. First, to break down the formality of teacher/learner relations and to encourage the children to form strong inter-personal connections. Second, to reinforce the importance of knowledge for the child acting as teacher: they use phrases such as ‘this information will save your life’. And lastly, child participation is intended to prevent fatigue, since the children may become bored with the same format.

Whilst it is clearly too early to herald the Vhutshilo model as a success, there are early signs that it has significantly increased the probability of adherence. To this extent it has begun to meet its primary objective.

Evidence from this comes from Sister Tshidzumbe at Phuluso Clinic, who has been instrumental in the growth of the workshops through identifying children who are starting medication or who have defaulted:

It is obvious when a child is attending the workshops at Vhutshilo. All of our nurses recognise them immediately. They really take the medicine correctly and we can see it in their CD4 counts, which are high. We used to see them once a month ... now if they are at Vhutshilo we can go for two months [before they need another check-up]. If a child is not taking [the medicine] correctly, or if we are telling a caregiver for the first time that ‘this child has HIV and needs ARVs’, then we always suggest they go to Suzi [Vhutshilo] ... she can even...
find them another carer, and pay for them to get to that workshop. Then, when they are there they hear everything and know what is going on. It is better that way. The gogos [grandmothers] are too easily confused and won’t tell anyone who can help. You should see the kids from Vhutshilo when they come to our clinic, they stand together. It’s like they know more than the nurses! Really, that is a strong support group that Suzi has created for these children.

A key contributing factor to this apparent success is the extent to which the child ARV workshops – like their adult counterparts – exist as a public secret: most people have a rough idea what is going on, but they don’t want to appear as if they know too much about it. Indeed, secrecy was integral to the very conception of the model. As Khatu says: ‘We agreed with the grandmothers that it’s not right to tell the cousins or others staying with the child [that the child is HIV positive]’.

But this perceived need for secrecy also reflects potential flaws in the Vhutshilo model, as it stands currently. Since the child workshops began, there have been several panics that the code of secrecy around them may have been breached. In early 2008, support group members reported that ‘people [were] starting to talk’, asking why only some children attend special meetings. Caregivers got worried. They were concerned that people outside would know the status of the children and victimise their families. But staff at Vhutshilo reassured them:

We [told] them that, no, people outside don’t really know, all they know is that the children are coming to the school. Who is going to tell them what [they are coming] for? Nobody can do that.

So, whilst people ‘know’ that something is going on, they don’t talk too much about it, just as the facilitators and adults involved do not openly divulge the true purpose of the workshops.

‘YOU KNOW, WE CAN’T CHANGE THE WORLD’

But there is more to it than this. The children’s workshops are not just protected by the relationship between publicly expressed knowledge and assumed experience. They are,
perhaps surprisingly, not stigmatised in the same way as women’s support groups, and are not the subject of zombie rumours such as those as discussed above. Why should this be?

Firstly, they take place within the grounds of a busy school, an obvious and seemingly natural environment for children to frequent without raising too many eyebrows. Many of them turn up with their mothers or aunts (often support group members), adding to the ‘naturalisation’ of proceedings. Meetings only take place four times a year, perhaps not enough for many people to notice their existence at all. Also, as Sister Tshidzumbe proudly reminded me, all the children appear to be healthy. They do not look like they are sick. All of this increases their chances of slipping below the stigmatising radar of rumour.

Ultimately, however, the difference between women getting better and children going to ARV workshops is marked by gendered understandings of the world. The rumours that we heard were being spread by men, and women are more attached than children to the production economy in Venda society. For the rumour-spreading men, however, the secretive consumption of what – for them at least – appear to be magical substances, and women’s seemingly miraculous regeneration from dying to living, is experienced as a threat. It represents a clear and present erosion of male influence over female productive and reproductive capacities. The male construction of such women as zombies is a reflection of this perceived loss of control, and is a symptom of the wider crisis of masculinity in post-apartheid South Africa, wrought through rising unemployment (Comaroff & Comaroff 2004).

Children occupy a very different social space. They are more removed from the production economy in that, beyond the contribution of occasional labour, their input to social reproduction and household economies is limited by their lack of knowledge of how the world around them works. For this reason, Tshivenda-speaking people will often casually, and jokingly, refer to a young child not with the prefix for humans – *mu* – but rather with the prefix for things, animals and non-human animate objects – *tshi*. They thus present significantly less of a threat to men who are trying to secure their waning capacities to act on the world. As a result, the child ARV workshops have not yet been demonised through local rumours. Perhaps the emphasis here should be on yet: Like the children who form it, the ARV workshop is still young and, as we heard above, ‘people are starting to talk’. Still, Khatu’s attitude to such concerns points to the approach with which any rumours, if they do surface, will be met:
You know, we can’t change the world ... and people are entitled to their opinions. They will talk when they feel like it, but we will not listen to them, as they will not listen to us. The difference is that our children will grow up knowing the truth, and for us that is the most important thing.

In the second part of this Review, we have explored some of the ways in which antiretroviral medication is experienced by those who take it, and by those who do not, in the former homeland of Venda. In doing so – in trying to establish how these seemingly magical drugs are ascribed with polyvalent meanings that change over time – we have distinguished a few ‘winks’ from the ‘twitches’. The public silence around HIV, AIDS and ARV treatment in Venda cannot be read – as it has been by academics and policy-makers alike – as denial. Rather, it is a safety precaution in a socio-cultural context where people constantly seek to evade being caught in the web that connects public knowledge with assumed experience. This principle has been the cornerstone in our understanding of why stigmatising rumours that compare women on ARVs to zombies do not, in the end, have much effect on the actual efficacy of ARV support groups. In the absence of organisations that could provide a support network for such women to live openly with HIV, they, in turn, withhold their HIV status from the public domain as an act of self-defence. ARV support groups – for women and for children – are thus constructed as public secrets.
We want to single out two of the foremost issues that have been raised by our comparative ethnographies from rural South Africa. The first is the issue of ‘treatment literacy’. This relates to our ethnographic representations of how people with HIV learn about their regimens of medication and the potential for different generational responses to – or the need for – this knowledge. The second of these, the issue of gender, relates to the ways in which ARVs have been mapped onto competing ‘patterns of blame’ between men and women. Together, these point to the need for ‘explanatory models’ in medical anthropology to be firmly embedded in the often fragmentary contexts of lived experience (Kleinman 1999).

Evidence presented in this Review suggests a rather uneven relationship between ‘treatment literacy’ and ‘therapeutic efficacy’. This relationship is especially misleading when health activists conflate prevention with treatment adherence, and equate ‘treatment literacy’ with general education and with a commitment to biomedical models. In both Bushbuckridge and in Venda, knowledge about HIV and AIDS bears the status of ‘deep knowledge’ (Apter 2007: 101-103). It is actively hidden from discussions in the public domain and concealed behind a veil of silence and discretion. The extent of such knowledge thus escapes quantification, and can only be gauged through intensive participant observation and engagement in private domains of gossip where talk about these topics takes place. But in either case, ordinary villagers seem to know a great deal more about HIV and AIDS than they are willing to admit, at least to health workers. Moreover, the biochemical efficacy of ARVs themselves and a plethora of other factors in the lived experience of our informants affect their uptake and use.37

In addition to this, evidence from Bushbuckridge shows that education and unswerving commitment to biomedicine is not always necessary for effective adherence. The life history of Reggie Ngobeni provides a case in point. Whilst Reggie dismisses any suggesting that he may be HIV positive or have AIDS, he nonetheless adheres strictly to his antiretroviral treatment regimen. But he does not take ARVs because he thinks they will prevent the
replication of HIV in his blood, support his immune system and ward off opportunistic infections. His compliance is the result of the power of words. He takes the pills because the doctor told him that if he didn’t, he would die. In a social context where people believe that words can curse or cure, Reggie took the doctor at his word. He complied perfectly without any need, or desire, for greater biomedical education.

The children’s HIV workshops at Vhutshilo Mountain School in Venda present us with a different set of issues in relation to ‘treatment literacy’. Children do not have life experience against which to define their illness in the way that adults have. The elderly grandmothers who have been left with the burden of raising their HIV-positive grandchildren had, until the Vhutshilo workshops, experienced the illness – and treatment for it – as an exercise in damage limitation. The grandmothers in Venda, along with the general public, expressed their conviction about the power of words through their refusal to name HIV and AIDS in public. The simple act of doing so would inevitably draw unwanted attention to their families and risk persecution. To ensure complete secrecy, they generally did not inform the HIV-positive children in their care that they were infected with HIV, nor did they risk attracting suspicion by frequenting the clinic to collect medication. As a result, the children received their medication irregularly and were prone to defaulting. Without a well-protected immune system, many children in Venda died because their elderly caregivers were trying to protect them, quite literally, from the power of words. Children were told (and thus told others) that the pills they were taking were for a range of mild conditions such as flu and headaches. Whilst the children knew something was wrong, they were kept in the dark about the details, and had no idea what the problem was or how to manage it.

Against this background the strategy adopted at Vhutshilo to ‘empower’ children with limited information of their condition, and how doctors monitor and treat it, would appear to have shown early signs of success. According to local health practitioners, the workshops have become support groups, and the 60 or so children who attend them are significantly healthier since the support group began in 2007. It is likely that children, with their limited life experience and limited prior health-related knowledge, more easily accept the authority of biomedical practitioners than adults. Moreover, it is less of a burden for them to do so: grandmothers are without doubt more troubled by ‘AIDS talk’, and more concerned about its
potential consequences, than the children in their care. The kids involved have limited knowledge of biomedical science, but quiz each other on basic facts of HIV, AIDS and ARVs at every meeting.

This case demonstrates the advantages of a more restricted, narrower, approach to ‘treatment literacy’. Perhaps it is precisely because of the power of words that the child ARV workshops have achieved adherence among their target group. Children take the medicine because they have been singled out for special treatment, and have been told to take it by people who seem to know what they are talking about. The children, especially the younger ones, cannot reasonably be expected to ‘understand’ with any level of sophistication the biomedical explanations for HIV or how to treat it. However, give them a metaphor about a small dragon in a young girl’s blood that must be kept asleep, and they are more likely to ‘get it’. With the Brenda story as an introduction to other ideas, they go on to learn about (and one would hope ‘believe’) the basic medical facts about their condition. As they learn to recognise the ways in which their bodies react to the medication, this knowledge is compounded. The extent to which ARV adherence among children and adults in Limpopo is the result of knowledge or the power of words thus remains unclear. It would seem more appropriate to think of a messy amalgam of both in which the distinction between the two is unclear.

In Bushbuckridge and in Venda, women and men appear to have more or less equal access to biomedical knowledge. However, commitment to biomedical discourse is highly gendered. Women are generally sympathetic to the conventional biomedical understanding of HIV and AIDS, view condoms in a positive light and are more likely to accept antiretroviral treatment. In Bushbuckridge 67% of the patients initiated onto ART at the Rixile Clinic were women (MacPherson 2008: 2). This trend is also apparent in Venda where peer educators, the public face of the epidemic, are exclusively female, as are the members of ARV support groups. This reflects a wider, regional, ‘feminisation’ of HIV and AIDS, in which women are more likely to be tested and treated for HIV, reinforcing patriarchal ‘folk models’ that frame women as vectors of the virus.

Men, on the other hand, are more likely to respond to the epidemic in political terms. Men in Bushbuckridge readily implicated agents of the apartheid regime in spreading HIV and blamed the post-apartheid government for blocking cures for AIDS. Men spread zombie rumours about women using ARVs in Venda. This occurred in the midst of a ‘crisis in masculinity’ brought about by de-industrialisation,
the closure of mines, feminisation of certain sectors of the workforce, and by increased unemployment (Reid & Walker 2005). Former working class men are less successful than their fathers and can no longer provide effectively for their households. Their frustrations are exacerbated by the high economic inequality and by the conspicuous wealth of the politically connected elite so characteristic of post-apartheid South Africa. Men are not only more likely to view trans-local forces as threatening, and to resist the pronouncements of biomedicine: they also see dependence brought about by a debilitating, chronic sickness as a direct assault on masculine domination within the domestic domain.

The rejection of biomedical models and the acceptance of alternative explanations for sickness can be seen as an attempt to reclaim traditional authority.

Whilst our ethnographic studies show a greater proclivity for women to embrace ARVs, this proclivity is by no means absolute. In Venda, for example, groups of elderly women, in their capacity as ritual experts, actively promote a ‘folk model’ of sexual health during female initiation. Through this, they construct HIV and AIDS as the result of inadequate respect for ‘traditional’ moral codes. Like men, older women perceive a crisis in social reproduction (Comaroff & Comaroff 2004, McNeill forthcoming).

In these contexts an effective response to HIV and AIDS requires more than simply distributing ARVs and promotion of biomedical knowledge. As effective as they may be, ARVs require ‘political authorisation’, if not by the state, then by organisations such as the Treatment Action Campaign (TAC), Medicines Sans Frontieres (MSF) and the National Association of People Living with HIV/AIDS (NAPWA). Social and political support is essential for people living with HIV in Venda to come out of the orchards, into a healthy, productive public life. Barriers to treatment adherence such as the loss of access to welfare grants and overcrowded conditions in rural hospitals also need to be removed for optimal treatment efficacy to be achieved.

In contexts of medical pluralism, health workers can ill afford to ignore local conventions of speaking about HIV and AIDS, and alternative systems of belief and treatment. We are not suggesting that the rural poor are somehow unable to comprehend the complexities of biomedical explanation. But in many perplexing situations of life biomedical
explanations alone seem unconvincing. In these situations political conspiracy theories, religious discourses and allegations of witchcraft come into play. Health workers need to think reflexively about the limitations of biomedicine: about the manner in which health propaganda has contributed to stigma, and about how women’s privileged access to ARVs has raised suspicion and gossip in the context of a crisis in masculinity. We have shown, through numerous examples, that biomedical explanations represent only one side of the story: ARVs have been woven into complex webs of meaning in which folk models provide alternative explanations for why people take the drugs, and for why they are thought to work. The current proclivity to privilege biomedicine over alternative ways of understanding sickness represents a lost opportunity to engage in culturally appropriate interventions which respect the cosmological realities of those in need of, and receiving, treatment. Pathbreaking attempts in this vein, such as the recent public information campaign explaining AIDS and ARVs in terms of pollution, ‘heat’ and ‘cooling’ by the Provincial Department of Health in KwaZulu-Natal, have gone relatively unnoticed and have not been replicated, or refined, in other parts of the country.

It follows that evaluations of the national roll-out’s successes or failures must not only take statistical measures into account, but also provide a phenomenological contextualisation of the ways in which ARVs are experienced. An understanding of the rumours around ARVs – and around those who use them – is fundamental to our comprehension of why men are more likely to refuse treatment than women: AIDS is understood by men to be a ‘women’s disease’. Understanding the power of words is central to this, and helps to explain why in certain contexts the notion of ‘treatment literacy’ shields us from the actual reasons for adherence. The methodological implications of this seem to be clear, and point to the need for long-term ethnographic engagement to give meaning to the numbers through which we have come to conceptualise success or failure.

In the end, however, the final analysis is not ours to write alone. If the ethnographic data presented in this *AIDS Review* is to be of any lasting worth, it must be taken up by those who design and implement treatment programmes. Anthropologists and policymakers alike urgently need to engage in informed, sustained and self-critical dialogue about the ways in which treatment for AIDS can be more effectively applied in specific socio-cultural settings.
By 2009 an estimated 2.8 million South Africans had died of AIDS-related diseases. This figure is amongst the highest in the world.

I wish to thank Eric Thobela and Eliazaar Mohlala for their assistance during fieldwork, and also Tim Allen, Mary Crewe, Fraser McNeill, Jonathan Stadler and Sjaak van der Geest for their suggestions. All words from local languages are in Northern Sotho.

Graham et al. (2007) claim that a robust association exists between literacy and treatment adherence. In the United States, they found that 64% of patients with at least ninth grade reading levels took 95% of their ARV medication as indexed by pharmacy refills, compared to only 40% of patients with lesser reading skills.

Critics argue that such material communicates ambiguous messages and risks connecting with fears about witchcraft. These messages ignore the culturally specific meanings of different types of snakes, as sources of body power, manifestations of the ancestors and witch-familiars. Moreover, the language of ‘attack and defence’ is similar to the language people use to describe witchcraft-induced poison (Ashforth & Natrass 2005).

Following Appadurai (1986), some anthropologists use the ‘social life’ or ‘biography’ of pharmaceuticals as an analytical starting point for understanding therapeutic efficacy. This approach implies following ARVs as they move through different phases: production, marketing, distribution, purchasing, prescription, consumption and the evaluation of treatment outcomes. In each phase the drug enters a new context, marked by a different set of actors, and by a distinct ‘regime of values’. It has been contended that pharmaceutical companies produce ideas about sickness, and sell diseases before they sell drugs. These meanings, as well as the distribution, cost and side-effects of drugs, shape assessments of efficacy (Van der Geest & Hardon 2006).

To protect the identities of my informants I have used pseudonyms for all personal names.

In a survey medical anthropology students at the University of Cape Town interviewed 480 young adults. Their most striking finding was that their interviewees were ‘sick and tired of hearing about AIDS’. Discourses about the disease were usually couched in terms of debates about safer sex (Levine & Ross 2002).

Clinically, leprosy, or Hansen’s disease, is much more benign, curable and less infectious than popular images suggest. Leprosy is a chronic disease of the skin, eyes, internal organs, peripheral nerves and mucous
membranes. It seldom produces severe disfigurement, and multi-layered drug therapy can render a patient non-infected in six months. Leprosy is amongst the least contagious of human pathogens (Barret 2005).

9 In colonial Africa, Christian mission societies undertook responsibility for the treatment of lepers and projected powerful disease symbols onto Africa. Leper settlements were places of isolation in which the Christian message was presented as the only sign of hope (Vaughan 1991, Silla 1998).

10 Villagers signified death by means of symbolic reversals, such as turning the logs in the fire at the home of the deceased person and placing their thick ends in the centre. The euphemism for death included the sayings that the deceased has been ‘taken by hyenas’ (tšerwe ke phiri), ‘gone to the place of the ancestors’ (o ile badimong), that the widow’s ‘house has fallen’ (o wetše ke ntlo), the ‘water had dried up’ (meetse a pshele), or ‘the sun had set’ (dikeletswe ke letšatsi).

11 The emphasis on the loss of hair is significant. A haircut accompanies rites of transition, including funerals. A corpse’s hair is shaven and the hair is placed alongside him or her, inside the coffin.

12 Studies elsewhere in Africa have also documented a proliferation of witchcraft accusations and a resurgence of witch-finding and witch-cleansing movements in response to the epidemic (Probst 1999, Schoepf 2001, Yamba 1997).

13 Diviners identified three different kinds of spirits: the Malopo, who were Sotho spirits; the Ngoni, those of Tsonga, Zulu, and Swazi ancestors; and the fierce Ndau, who came from Musapa in Mozambique. Spirit possession involved a degree of culpability, and spirits usually possessed the descendants of those who killed them in ancient battles. In a ritual, which included drumming, the possessed person danced until he or she experienced a trance. The instructor then exhorted the spirits to speak through the mouth of the afflicted person and to state their demands. In this manner they aim to convert the spirits from a hostile to a benign force.

14 In the South African Lowveld snakes are often associated with money and other forms of wealth. Goldminers from Bushbuckridge widely believed that the true owner of the earth’s wealth was a mystical snake whom they called the ‘owner/boss of the mine’ (mong wa mmaene). The snake lived in waters deep underground and only allowed management to proceed with mining operations after they had sacrificed to it. Here I find the association of the mine snake with water – the basic source of prosperity in the agricultural era – to be very significant. In addition, my informants also alleged that persons who lusted after fortune might purchase a snake called ‘mother of the river’ (mamlambo in Xhosa) from urban marketplaces. This snake sometimes assumed the form of a white lover, collected money for the witch, or predisposed him or her to luck in
financial matters. But in return it demanded large quantities of beef, chicken and human blood, and might even feed on the witch’s close relatives (Niehaus 2000: 39-41,45-46).

15 Witches allegedly changed their victims into zombies (singular, *setlotlwane*; plural, *ditlotlwane*), by first capturing their aura or shadow (*seriti*) and then progressively taking hold of different parts of their bodies, until they possessed the entire person. But witches would deceive the victim’s kin by leaving an image of him or her behind. The kin would believe that the victim was dead, but they would actually bury the stem of a fern tree that had been given the victim’s image. At home witches employed zombies as servants to do domestic work, herd cattle and cultivate fields. All zombies were said to be a metre in height and without tongues, being unable to speak out or question any commands (Niehaus 2005).

16 I wish to gratefully acknowledge suggestions made on earlier drafts of this section by Mary Crewe, Robin Hamilton, Isak Niehaus, Jimmy Pieterse, Lizzie Hull and Mushaisano Tshivhase.

17 Officially, ‘Venda’ no longer exists. The former bantustan was incorporated into the new political landscape of the post-apartheid era in 1994. The region in which I conduct fieldwork is officially known as the Vhembe district of the Thulamela municipality of the Limpopo Province of the Republic of South Africa. Following conventional usage, however, I continue to use the term ‘Venda’.

18 A pseudonym.

19 Different practices pertain elsewhere in South Africa. At Xhosa funerals in the Eastern Cape, religious leaders make a customary ‘cause-of-death’ speech at the graveside, but avoid mentioning AIDS (Dolosi, personal communication). In Bushbuckridge, mourners at funerals refer in comparatively more explicit terms to ‘Omo’ (a brand of washing powder with 3 letters), or to a ‘House in Vereeniging’ (with its acronym spelling out H-I-V).

20 Such a diverse group of men, differing in age, class and status, would not normally be in the same drinking group. However over the years, these men have joined me at Mapitas, initially in competition to impart their knowledge of Venda. In my absence, they drink within their own peer groups.

21 Peer educator uniforms have recently changed from red to blue. This change was welcomed by the educators, as the colour red is associated throughout southern Africa with danger, pollution and sickness: hardly the symbolic associations required for the safe and complete transfer of scientific knowledge about the virus.

22 Vhufuli here refers to Donald Fraser Hospital, close to King Kennedy’s palace in Mukumbani.

23 There is no space here to elaborate on an explanation as to why some people (for example politicians, nurses,
journalists, religious leaders and traditional healers) under certain circumstances, can breach the public silence around causes of death with impunity (see McNeill, Forthcoming).

24 The Thohoyandou Victim Empowerment Trust (TVET) is a Venda-based NGO focussing explicitly on human rights and providing services for rape survivors and victims of domestic violence or sexual abuse. TVET has established several AIDS outreach programmes.

25 At the time of writing, TVET has secured two volunteers who have agreed to disclose their status via a local poster campaign. After serious consideration, the two young women are set to appear on posters throughout Venda, advertising the TVET’s services. Whilst it is hoped that this will encourage others to live positively, the volunteers are fully aware of the potential consequences for them and their families.

26 The number of people receiving ARVs through private medical insurance in Venda is difficult to estimate, but given the economic situation of most people in the region, I assume it is not a significant number.

27 In some pre-roll-out ARV projects, such as that at St Mary’s Hospital in Mariannhill, KwaZulu-Natal, disclosure of status was a primary prerequisite for entry into the Ithemba programme (Health Systems Trust 2004). At MSF’s ARV project at Lusikisiki in the Transkei, disclosure was ‘encouraged’ – but with the support provided by the TAC, most participants chose to disclose willingly (Robins 2004).

28 In a similar vein, Almeleh (2006) describes how HIV patients in Khayelitsha township, near Cape Town, disclose their status at different stages of infection, and with diverse motivational factors behind each disclosure: from the desire to become an AIDS activist while still healthy, to the desperate need for medication upon the onset of sickness.

29 There is a great and inexplicable shortage of female condoms in South Africa (Susser 2009). Between 2008 and 2009 the South African national Department of Health distributed only four million female condoms. During the same period the Department had promised to supply 450 million male condoms, but only around 300 million were actually distributed (The Sunday Times 22 November 2009, p8).

30 A stokvel is a South African term best translated as a rotating credit and savings association.

31 My research assistants have often commented that anthropological research of this nature, bordering on the covert, is perfectly suited to certain characteristics they perceive to be ‘Venda’. In this they were drawing connections between the multiple layers of secrecy and deception that are the cornerstone of Venda social interactions. Of course, we came clean in the end, and told anyone who was interested the true nature of inquiries. No one refused us permission to write about what they had said.
32 I stand to be corrected here, and apologise if another child support group does actually exist. No one I have spoken to has come across one, and a literature search was fruitless. However, with the speed of developments in the AIDS industry it is quite possible that a similar model has emerged elsewhere.

33 The story in question appears in a book called Brenda: U na tshivhanda tshituku malofhani awe (Brenda has a small dragon in her blood). It was written by a Dutch woman, who is the foster-mother of a young girl upon whom the story is based. Through an organisation called ‘Biblionef South Africa’, which donates books to children in deprived areas of South Africa, many copies of it were translated into Tshivenda and donated to Vhutshilo School. The ‘Brenda Book’ as it has become known, was published by Garamond (see Vink 2005).

34 SAfAIDS was started in 1994, and is based in Pretoria, with offices in Zimbabwe and Zambia. See www.safaids.org.za for more information. The material produced for children on ARVs was co-funded by the American Jewish World Service, Firelight Foundation, DIFID, HIVOS, Irish AID, SIDA and UNAIDS.

35 The existence of such material would suggest that child ARV workshops have been piloted in other parts of South Africa, or southern, Africa. However I have been unable to locate any.

36 Perhaps unintentionally, this strategy is similar to the highly stratified transfer of ritual knowledge in Venda girls’ initiation schools. See McNeill (2007, forthcoming).

37 Many African countries with high HIV prevalence rates also have high national literacy rates. In 2006 ‘HIV prevalence’ in South Africa was 21.5%, and literacy 86.4%. The comparative figures for Mozambique were 12.2% and 47.8%. In addition, HIV prevalence amongst South African health care professionals and teachers was similar to that amongst the general population (Schenker 2006: 17, 19).

38 Between 1993 and 1999 the number of South African men employed in the South African gold mining decreased from 428 002 to 195 681, in coal mining from 51 267 to 21 155, in manufacturing from 1 409 977 to 1 286 694, and in construction from 355 114 to 219 797 (SAIRR 2001: 336-338).

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The Centre for the Study of AIDS (CSA) is located at the University of Pretoria. It is a ‘stand-alone’ centre which is responsible for the development and co-ordination of a comprehensive university-wide response to AIDS. The Centre operates in collaboration with the deans of all faculties and through interfaculty committees, to ensure that a professional understanding of the epidemic is developed through curriculum innovation and through extensive research.

Support for students and staff is provided through peer-based education and counselling, through support groups and through training in HIV/AIDS in the workplace. The CSA, in partnership with the Campus Clinic and staff at Pretoria Academic Hospital, offers a full antiretroviral rollout with counselling, testing and treatment. A large number of student volunteers are involved in the various CSA programmes, as are many community groups, ASOs and NGOs.

To create a climate of debate and critique, the CSA publishes widely and hosts AIDS forums and seminars. It has created web and email-based debate and discussion forums and seeks to find new, innovative, creative and effective ways to address HIV/AIDS in South African society.

Together with the Centre for Human Rights and the Law Faculty at the University of Pretoria, the Centre has created the AIDS and Human Rights Research Unit. This research unit continues to conduct research into the relationship between AIDS and human rights in Southern African Development Community (SADC) countries, is engaged in the development of model legislation, conducts research in AIDS and sexualities and sexual rights, and is involved in the placement of interns in various sub-Saharan parliaments and with parliamentarians, to strengthen the role of parliaments and governance. In collaboration with the Faculty of Education, the Education and AIDS Research Unit has been established.

and entitled *Whose right?*, addressed the relationship between AIDS and human rights in eight of the SADC countries and how a rights-based or a policy-based approach has determined the ways in which people living with HIV or AIDS have been treated and the rights of populations affected.


The latest *Review, Magic*, authored by Isak Niehaus and Fraser McNeill, looks at uptake of ARVs and the forces that come into play which determine how people and communities respond to the ‘magic’ of treatment – the physical effect on the body, as well as ‘supernatural’ effects. *AIDS Review 2010* will address the impact of AIDS on orphans.

The CSA operates in consultation with an advisory reference group – TARG – comprised of university staff and students from faculties and service groups as well as community representation. The CSA has furthermore developed a close partnership with a number of Southern and East African Universities through the Future Leaders @ Work Beyond Borders initiative as well as the Imagined Futures programme to develop university-based responses that address the needs of students and staff living with HIV and AIDS.

Amongst other partners, the CSA works closely with the SADC PF based in Windhoek on model legislation and issues of criminalisation, and has interns placed in other African universities. Through an extensive community-based programme in Hammanskraal paralegal and community-based health and human rights workers are trained and supported. The CSA also has two stigma projects in Hammanskraal, through which it works with magistrates, the police and other agencies on issues of HIV and AIDS-related stigma.
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