

Five isiZulu women living with Aids:
illness, anti-retrovirals, selves and life-stories

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Table of Contents

i)	Acknowledgments	iv
ii)	Abstract	v
1.	Introduction	1
2.	Literature Review	4
	2.1) Epidemiological Data	4
	2.2) The Politics of HIV/AIDS Prevention and Treatment	5
	2.3) A Gendered Epidemic	9
	2.3.1) Biological Factors	
	2.3.2) Social, Cultural and Economic Factors	
	2.4) Stigma and Discrimination	13
	2.4.1) Representations of Disease	
	2.4.2) Lived Experience	
	2.4.3) Subjectivity	
	2.5) Stigma in Developing Countries	19
	2.6) Benefits of Antiretroviral Treatment	21
	2.7) Critical Health Psychology	24
3.	Narrative Theory	27
	3.1) Storied Identity	27
	3.1.1) Language	
	3.1.2) Temporality	
	3.2) What Work can Narratives do?	30
	3.3) Narrative and HIV/AIDS	33

4. Research Methodology	36
4.1) Research Approach	36
4.2) Study Design	36
4.2.1) Accessing Research Participants	
4.2.2) Data Collection – In-depth Interviews	
4.3) Ethical Considerations	41
4.3.1) Access and Anonymity	
4.3.2) Translation	
4.3.3) Reflexivity	
4.3.4) Validation	
4.4) Narrative Analysis	46
4.5) Data Analysis	48
5. Analysis	51
5.1) Reading 1 and 2 – Background and Voice of “I”	51
5.1.1) Narrative Identity	
5.2) Reading 3 and 4 – Relationships and Socio-cultural Context	72
5.2.1) Poverty	
5.2.2) Relationship with Partner	
5.2.3) Stigma and Discrimination	
5.2.4) Support	
5.2.5) Acceptance/Religion	
5.2.6) Hope and Strength	
6. Concluding Comments	98
7. References	104
8. Appendix 1 – Interview Questions	113

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Abstract

The South African HIV/AIDS epidemic has reached startling proportions in the last decade. Although the disease itself makes no distinction between age, race or gender, for a variety of historical, cultural, biological and socio-economic reasons, it currently affects more women, particularly black women, than men. Therefore this study examines the narratives of HIV positive, black, resource-poor, mothers who have gained access to free antiretroviral treatment. The aim of this study is to explore the effect of this treatment on their lives and how they cope with having HIV/AIDS. Their narratives were collected during interviews and then a modified version of Mauthner & Doucet's (1998) voice-relational method was used to analyse the data. The five transcripts were firstly discussed as separate stories, focusing on their background and the voice of I. Subsequently, six central shared themes were examined, these were: poverty, relationship with partner, stigma and discrimination, support, acceptance/religion, hope and strength.

Chapter 1 – Introduction

The explosion of the HIV/AIDS epidemic in South Africa in the last decade has naturally resulted in a massive growth in all related aspects of the HIV/AIDS research field. This particular research aims to add to the field by focusing specifically on isiZulu-speaking mothers and their experiences of living with HIV and AIDS. The study explores these issues within a South African context, where the politics of HIV/AIDS treatment and the shortcomings of the public health system still prevent access to care at broad public health levels. The participants in this study are only able to access antiretroviral treatment through a privately funded clinic rather than within the public health system.

This research elicits and explores participants' life-stories to understand the subjective experience – in temporal, storied, metaphorical and psychological perspective – of diagnosis with a chronic disease. These stories were analysed using a version of narrative analysis - the voice relational method – to facilitate an analysis which examines individual narratives for the voices of the women but, at the same time, highlights central themes which occur within all the stories. This is vital because although seeking to hear the separate stories of the women, ultimately we want to learn how contextual factors, such as poverty, mediate their experience of illness.

By focusing on isiZulu-speaking, resource-poor, HIV positive women who are mothers and ART-patients, this research contributes to social scientific knowledge in the following way. First and foremost, it explores the subjective experience of an HIV positive diagnosis and the long-term need for medication in order to remain healthy, on one's taken-for-granted existence and

expectations for the future. This has been shown to be particularly traumatic for women who are mothers for they will probably not be able to parent their children to adulthood; instead they must try to plan for their children's future when they are gone.

Secondly, it explores the psychological effects, in terms of a sense of 'self' or 'identity', of the knowledge that one has a potentially fatal disease, together with the social consequences of stigmatisation and marginalisation. Research has shown that most individuals eventually accept their situation and even show a determination to live life to the fullest, in spite of the disease. The focus is on what leads to this acceptance, determination and hope.

Thirdly, it looks at what it means for these women to have gained access to ART: this will include topics such as whether ART can be considered as contributing to psychological well-being in terms of increased optimism and motivation for the future; treatment issues such as side effects, resistance and keeping healthy.

The research was conducted whilst ever-mindful of the particular South African contextual factors mediating both the experiences themselves and the stories that are told about those experiences within the interview context.

The vast amount of available literature on the topic of HIV/AIDS meant that a great deal of specificity was necessary when writing the literature review or it could have become unfocused and unmanageable. Therefore the review moves in a very particular way. It starts off with an examination of the current statistical data, in order to clarify the extent of the HIV/AIDS problem in South Africa. It then explores contextual factors, such as poverty and our Apartheid history,

which contribute to its spread while at the same time presenting a seemingly impossible challenge for intervention efforts. Following on from this, the review looks at issues of stigma and discrimination against those living with HIV/AIDS. As stigma and discrimination are rife in South Africa, one added benefit of ART is the possibilities it presents for confronting this problem. Other possible benefits are those already mentioned such as hope and motivation, as well as prolonged life expectancy and even prevention efforts. It then looks at some studies which have already been conducted focusing on this topic. Finally, linking up with the Narrative theory chapter, some theoretical background to the critical research approach is provided, this also advocates the use of narrative to explore the subjective experience of the participants.

Chapter 2 - Literature Review

HIV/AIDS is more than simply a biological disease which infects individuals; it has massive economic, political and social implications. The long-term consequences for South Africa are still being played out but, if the disease is allowed to continue spreading unchecked, it will have devastating results in every sector of our society. To obtain a clearer idea of the impact HIV/AIDS has already had, and could potentially have in the future, it is essential to examine statistical data, as well as the economic, political, cultural and social context of the South African epidemic.

2.1) Epidemiological Data

Statistical measurements of HIV prevalence are vital for providing an ongoing assessment of the strength and pattern of the epidemic in all countries. In South Africa, the primary way in which these statistics are constructed is through testing blood samples taken from pregnant women who are attending public health antenatal clinics (Department of Health, 2004). These figures are then used for predictive modelling for the entire population. What this means, very crudely, is that statistics for the general population are worked out from the rate of infection of these women. However, as Wilbraham (2005) points out, these surveys are specifically carried out with pregnant women, who are obviously not practising safer sex. Also, HIV infection leads to a reduction in fertility, therefore these surveys may be omitting large numbers of HIV positive women who cannot get pregnant (UNAIDS, 2005). This leads to a slightly biased HIV prevalence when compared with the total female population. Other problems with this

assessment method include the high refusal rate, which has been reported as being as high as 24-42% (Department of Health, 2004).

In spite of the problematic nature of these projective methods, they are the only means currently available for assessing the extent of the HIV/AIDS epidemic, and it is vital to have statistical measurements of current and future infection levels for intervention planning and health budget purposes. According to recent projections, it has been estimated that 5,300,000 South Africans are living with HIV and AIDS (Joint United Nations Programme on HIV/AIDS, 2004). Of these 5,300,000 HIV positive persons it has been estimated that about 500 000 people urgently require antiretroviral treatment (ART) or they will die (Dorrington, Bradshaw, Johnson & Budlender, 2004). However, by October 2004, only 19 500 people were receiving ART in the public sector, less than four percent of those in need. The vast discrepancy between the number of people who will soon die without ART and those who are actually receiving ART is the subject of an ongoing struggle to make ART available to all who need it.

2.2) The Politics of HIV/AIDS Prevention and Treatment

The debate over the effectiveness of South Africa's response, in terms of treatment, to the HIV/AIDS epidemic in this country still rages on. Many feel that it has thus far been unequal, contradictory and ineffective. The focus has been primarily on the prevention of further HIV infections through the creation of national awareness and mass media education campaigns, such as loveLife. Of course it is essential to have such prevention and education measures in place, but this should not be at the expense of other equally vital responses such as treatment for those who are already infected. Aside from this, past and current awareness campaigns have drawn

criticism on many levels. One such example is the loveLife campaign, which has been criticised as consisting largely of idealised representations of what it means to be a young, healthy South African – educated, determined, and going places (Thomas, 2004). This fails to address the unfortunate socio-economic realities most South African youth are faced with, which will prevent them from ever coming close to achieving these ideals. It also fails to display any of the 5,300 000 South Africans who are already HIV positive. In fact the slogan ‘love life’ implies that those persons who are positive did not try hard enough to avoid infection (Thomas, 2004). If the majority of South African youth cannot relate to these images, it does not seem likely that they will lead to a reduction in HIV infection rates. Research has shown that, for a number of reasons, high budget broad-based programmes such as these do not have enough impact in communities (Kelly, Parker & Oyosi, 2001).

Added to this, although South Africa’s epidemic is still about five years behind that of Northern Africa, we are nonetheless moving into the stages of an advanced epidemic where transmissions are still rife but at the same time many people are developing full-blown AIDS and dying (Mugabe, 2001). Therefore, according to Kelly, Parker and Oyosi (2001), although prevention programmes are still vital, these should be conducted on a more coordinated local level where they can address specific local problems related to structural, organisational, capacity and development issues. And these programmes should run parallel to full scale ART programmes, as well as anti-stigmatisation drives.

Unfortunately, at this time, access to ART is highly restricted because of budgetary constraints and because of global drug prices and patent procedures, resulting in thousands of preventable deaths. In 2003, with the South African government’s announcement that it would be making

free antiretroviral treatment available it appeared that there would finally be an improvement in the situation (Nattrass, 2004). Added to this, after many years of activism against both the major pharmaceutical companies and foreign governments from organisations such as the Treatment Action Campaign, previously expensive antiretrovirals are being made more accessible to developing countries. Drug prices have fallen and generic versions are being mass-produced locally (Irwin, Millen & Fallows, 2003). But is this making it any easier for the majority of HIV positive South Africans to gain access to these drugs? Already, last year, the government's 2004-planned ART rollout program experienced difficulties in providing the drugs because of fears that there was not a sustainable supply available. And currently, the rollout falls far short of promised numbers.

While it is tempting to lay the blame entirely at the ANC government's door, it must be recognised that these problems occur within a global and local context, which hinder the progress of the national rollout. As mentioned, some of the difficulties exist as a result of international drug prices, and although first line ART drugs have now fallen in price, the same has not happened for second and third line drugs. A possible result of this could be that, "At a management level the temptation will be to develop vertical systems that only focus on the provision of treatment" (Chopra, 2005, p.3).

This kind of approach is extremely short-sighted because it means that patients developing a resistance to first line drugs will not have alternative treatment options available. ART resistance is an enormous problem in South Africa, occurring as a result of poorly developed or interrupted medication regimes (Chopra, 2005). Patients who are taking medication must adhere to a complicated regime of tablets, which have a number of unpleasant side effects. Failure to

achieve a high degree of adherence can result in the patient developing a resistance to that combination of drugs, and therefore a new combination of drugs will be needed (Tromp, 2003). Without other treatment drugs available, this is not possible.

Secondly, historical and economic factors within the public health system provide a major stumbling block to an effective ARV rollout. South Africa's previously racist policies left large sections of the population in conditions of extreme poverty, unable to maintain healthy standards of living. The health system was also racially divided meaning that those most vulnerable to disease and illness were least likely to have access to health services (Mazabow, 2002). After the transition to democracy in 1994, thousands of previously disenfranchised people suddenly became a part of the public health facilities. Minimal time and resources have been available to adequately address the considerable expansion of the public health system; consequently a massive gap still exists in terms of access to adequate medical services between the rich, who can afford private treatment, and the poor, who rely entirely on public health facilities. The public health system has been further burdened by the increase in patients as a result of the current HIV/AIDS epidemic.

Chopra (2005) points out the dangers that exist when attempting to rollout an ART program on such an unprecedented scale with such an unbalanced and fragile public health system as the one existing in South Africa. The shortcomings of the South African public health system include a lack of proper infrastructure, a shortage of well-trained and motivated staff, and very limited resources available to change this situation (Chopra, 2005; Stein, 2005). Until these problems are addressed, the ART rollout will remain imbalanced and inadequate. Chopra (2005) states that this reality makes it tempting to bypass the public health system and rely on NGOs to deliver

treatment but this would not achieve the long-term target of treating all those infected with HIV, even in the most remote and disadvantaged areas.

This should give some idea of the problems within the South African public health system and the impact this has on the rollout of antiretroviral treatment and ultimately the difficulties experienced by those who cannot afford to pay for private treatment. It is evident that the vast majority of resource poor, HIV positive people will never gain access to ART and therefore they will eventually die.

2.3) A Gendered Epidemic

South Africa has what can be referred to as a 'gendered' HIV/AIDS epidemic, because one's gender determines the likelihood of becoming infected, the ability to access treatment, and the survival rate. This is demonstrated by the fact that the number of females of childbearing age living with HIV far exceeds the number of men. Although 5,300,000 South Africans are said to be infected with HIV, this does not highlight how HIV infection rates are skewed in terms of gender. Of these 5,300,000 people, 2,900,000 are women between the ages of 15-49 years and 230,000 are children between 0 and 14 years (Joint United Nations Programme on HIV/AIDS, 2004). More recently, it was found that the national HIV prevalence of persons in South Africa older than two years is 13.3% for women but only 8.2% for men (HSRC, 2005). This higher rate of infection in women is the result of a complex interaction of factors that leave women more vulnerable to HIV infection biologically, socially and economically than men (Allen, 2003; Pauw & Brener, 1997; Strebel, 1995; Tromp, 2003).

2.3.1) Biological Factors

The World Health Organisation (2000, as cited in Tromp, 2003) states that women engaging in unprotected vaginal intercourse with a man, are up to four times more likely to become infected than the male because they are biologically more susceptible to catching the disease. This is due to a number of reasons: the mucus membrane in the vaginal area is extremely thin therefore it can be broken during rape, rough sex, or even ordinary sex, allowing the virus to enter the bloodstream; the exposure of the inner uterine lining during menstruation leaves multiple entry points for the virus; young women who have sex are not fully developed therefore they are more vulnerable to infection; semen stays longer inside the body (a few hours) and is exposed to more skin area (mucus membrane inside vagina) than vaginal fluids; semen also has a higher concentration of HIV than vaginal fluids (Tromp, 2003). Women are also more likely to have undetected STIs and vaginal infections because they are often hidden inside the genital tract and are asymptomatic. This greatly increases the chances of infection as sexually transmitted infections (STIs) create tiny lesions or even open sores in the genital area allowing entry for the virus into the bloodstream.

Therefore, in multiple ways, women are biologically more vulnerable to infection through sexual activities. However, this in itself cannot adequately account for the vast discrepancy between the infections levels of women versus those of men. This discrepancy can only be understood by examining how women's biological vulnerability to infection is exacerbated by social, economic and cultural factors existing in South Africa.

2.3.2) Social, Cultural and Economic Factors

In general, South Africa can be considered as a patriarchal society; therefore men are positioned as more powerful socially, politically and economically than women (Kistner, 2003).

Patriarchy defines the personal, physical and institutional power that men exert over women (Kiguwa, 2004, p.288).

Gendered power relations dictate how men and women are situated in relation to each other. As a result of historical and cultural factors, women are more likely to be unemployed and thus live in conditions of poverty, or rely on a male breadwinner for material needs for themselves and their children (Strebel & Lindegger, 1998). Consequently, it becomes impossible to insist on certain sexual practices, such as the wearing of a condom, because if the man finds another partner, they may be left without any material support (Bruyn, 1992). Women's limited economic position increases the probability of their engaging in high-risk sexual behaviour such as commercial sex work or transactional sex. These two terms describe a variety of sexual interactions in which sex is 'bartered' in return for money or goods (Bruyn, 1992; Tromp, 2003). They may also take part in risky cultural practices such as 'dry sex' in which a substance such as methylated spirits is used to dry out the vagina during sex. This leads to more friction which causes lesions, increasing the chances of being infected.

Another example of gendered power relations increasing the risk of HIV infection is that of gender-based violence. This link works in two ways; firstly, women who are the targets of violence are more vulnerable to HIV infection, and secondly, women who test HIV-positive and then share this information, can become the victim of increased violence from partners. There are four possible contexts in which this link between HIV/AIDS and gender-based violence

overlap in women's lives (Maman, Campbell, Sweat, & Gielen, 2000). Firstly, being the victim of rape massively increases the risk of a female contracting HIV. Secondly, abusive intimate relationships, combined with economic need and reliance on a male partner for material needs, limits women's ability to negotiate faithfulness from partners and condom use. Thirdly, the experience of childhood sexual abuse may lead to engagement in risky sexual behaviour later in life and this will increase their risk of HIV infection. And lastly, working in the opposite direction, women who discover that they are HIV positive and then disclose this information to partners may be at increased risk of partner violence (Maman et al., 2000).

Therefore, as a result of the cultural gendering of sexuality, many South African women are infected by their husband or long-term partner. Their economic powerlessness runs parallel with a cultural norm which positions men as masculine only if they exercise power over women and have many sexual partners (Holland, Ramazanoglu, Sharpe & Thomson, 1998). Strebel and Lindegger (1998) conducted focus groups with black, predominantly female participants to explore power inequalities in gender relations and sexuality. They found that because of these economic and cultural factors, women were relatively powerless within relationships. Men were able to have multiple sexual partners; this was in fact almost expected because males are viewed as having an 'uncontrollable sex drive' (Strebel & Lindegger, 1998). And condom use was extremely limited because if a woman requests that her partner uses a condom it implies a lack of trust, or could be taken to mean that she has been unfaithful.

So, as a result of the strongly gendered economic, cultural and social structures in South Africa, women, especially black women, are most often the victims of poverty, violence and HIV infection. Not only are they more susceptible and have the highest rates of infection, they also

have the least access to treatment, carry the major burden of caring for the sick and have the shortest survival rate (Gilbert & Walker, 2002). Unfortunately these women are also likely to be confronted with stigmatisation from families and communities.

2.4) Stigma and Discrimination

Those who are uninfected have generally negative perceptions of positive people: they often lay the blame solely on the person for allowing him or herself (most often herself) to become infected whether through promiscuity, infidelity or pure stupidity (Orr & Patient, 2004; Wilton, 1997). Another source of stigma arises from fear of becoming infected and a desire to protect oneself from those who are seen as 'sick'. These perceptions are imposed on to the HIV positive person and thus their experience of illness is mediated by dominant social discourses of stigmatisation and discrimination. This section will examine stigma from two perspectives, namely representations of disease, and the lived experience/interaction of disease and stigmatisation.

2.4.1) Representations of disease

It is important to deconstruct public representations of HIV/AIDS because these will mediate perceptions of those who are infected and could lead to stigmatisation and discrimination. The extreme stigma associated with being HIV positive results from a complex combination of historical and social factors. Historically, disease has been viewed as retribution for sins committed (Turner, 1996), and this belief still exists in some forms today. Added to this, for the

first years of the epidemic (and beyond), it was considered to be a disease primarily affecting homosexual men. Indeed the first name for the cluster of symptoms that we now know as HIV was GRID or Gay-Related Immune Deficiency (Oppenheimer, 1992). As a result, there seems to be a prevailing belief that only promiscuous and deviant sexual behaviour is a factor in its spread (Irwin, Miller & Fallows, 2003). In South Africa, the primary mode of infection is through sexual activity and thus it is commonly believed that infection occurs because of sexual promiscuity, and therefore that positive persons actually deserve to be infected (Orr & Patient, 2004).

Connected to this, some Western theorists have attempted to find an answer to the cause of the prolific spread of HIV in Africa by examining what is labelled the 'African sexuality' (Oppong & Kalipeni, 2004). Traditional cultural practices such as polygamy and a so-called 'culture of sexual permissiveness' are said to be major factors in this spread. Of course these kinds of practices can lead to the spread of the disease. However to focus only on these sexual practises serves to ignore other important historical, social, and economic factors, such as colonialism, poverty, the migrant labour system, and of course the Apartheid system which have created a prime context for the rapid transmission of HIV. For many years during Apartheid, the powerful white government used their position as a political tool to regulate black sexual behaviour and reproduction, for example through forced sterilizations (Oppong & Kalipeni, 2004). Thus, current HIV/AIDS intervention efforts encouraging sexual abstinence and condom use are interpreted as continuing attempts by more powerful forces to control black sexuality and reproduction. This is simply one example of a historical factor complicating attempts to deal with the HIV/AIDS problem.

2.4.2) Lived Experience

What does stigmatisation actually mean for the person living with HIV/AIDS? Goffman (1963, as cited in Alonzo & Reynolds, 1995) says that stigma occurs because of a failure to meet social expectations of desirability and normalcy, and thus being perceived as immoral or deviant in some way. This negative characteristic, whether psychological or bodily, deviates from group norms. The 'abnormality' is not inherent in the difference but is treated as such by the community because norms are accepted as simply common sense notions of how the world operates. Illness and disease are often stigmatising but, as pointed out by Sontag (1978), this is a social and historical process that depends on the particular illness (Alonzo & Reynolds, 1995). Stigma and discrimination are linked to power and dominance; they reproduce current relations of economic, social and political power and control, which determine who is powerful and who is excluded from that power (Parker & Aggleton, 2003). To be perceived as 'abnormal' is to be denied access to social mechanisms of power and often to be acted against by the dominant, 'normal' group. For HIV positive women, this leaves them disempowered in multiple ways: economically, socially, and culturally.

Crawford (1994, p.1347) says that the "AIDS epidemic is clearly both a social crisis and a crisis of identity", calling into question the bounds of what is considered to be normal and acceptable. Health is considered to be an important and desirable aspect of the post-modern lifestyle. Because of this, the 'unhealthy other' is perceived as a threat not only to the healthy person's body but also to their identity. Individuals shape their identities by drawing invisible boundaries between what they consider to be part of the self, and what is rejected. This 'individual' process depends on social prescriptions of normality (Crawford, 1994). Within this process certain

identities, such as being 'unhealthy,' lose legitimacy as an acceptable identity and thus must be guarded against lest they undermine those more acceptable identities. HIV/AIDS is a perfect example of an unacceptable identity, because of its ties with poor health, with the unknown and with 'deviant' sexuality. If this kind of identity were not othered in this way and illness portrayed as something not part of the 'normal' self, it would be difficult to avoid the knowledge that serious illness and disease can happen to anyone. In this way, stigma works as a defence mechanism against vulnerability and a painful death.

Orr and Patient (2004) feel that the lack of access to life-saving AIDS drugs, along with the fear-based methods used in media awareness campaigns, have established the idea that because HIV infected people will become burdens and ultimately die, they do not merit the investment of resources and energy. In this sense, stigmatisation becomes a means of protection from the burden of the sick (Orr & Patient, 2004). Thus stigma is largely a result of misinformation, entrenched cultural beliefs about illness and sexual norms, and fear of the unknown and invisible. Those who are infected are 'othered', and perceived as deviant and promiscuous, in order to make those who are not infected, or at least who believe that they are not infected, feel free from risk. It is vital to recognize that stigma against any person does not arise because of some internal defect within that person, but rather because of already existing ideals of what is acceptable and 'normal' within a society.

2.4.3) Subjectivity

These stigmatising views of the person are intrinsically flawed in two ways: firstly, the person is presented as having inner, stable personality traits that lead to them becoming infected, such as

promiscuity. Secondly, health and illness are viewed as binary opposites in order to 'other' those that are ill and distance them from those that are healthy.

Recently however, there has been an increasing move away from the view of an inner, stable 'core' personality, towards a realisation that human identities are fluid constructions, constantly being created and re-created in our continuous interactions with the social world (Billington, Hockey & Strawbridge, 1998; Freeman, 1993; Sampson, 1989).

Identities are never unified, and in late modern times, increasingly fragmented and fractured; never singular but multiply constructed across different, often intersecting and antagonistic, discourses, practices and positions....constantly in the process of change and transformation (Hall, 2000, p.17).

The multiplicity of different social experiences that a person has throughout their life means that they are always renegotiating their own identity in terms of their social environment. Thus it is impossible to label the person as inherently flawed in some way.

Mama (1995) rejects the psychological conception of a unitary and fixed identity; instead she refers to the person's sense of selfhood as subjectivity,

I use the concept of subjectivity instead of the psychological terms 'identity' and 'self' to indicate my rejection of the dualistic notion of psychological and social spheres as essentially separate territories: one internal and one external to the person. Instead I regard both as being continuously constituted and changing, as being locked in a recursive relationship of mutually advancing production and change (Mama, 1995, p.1).

Mama (1995) deconstructs the notion of a static identity because she feels that this idea “is responsible for the narrow and simplified constructions of ‘the negro’ and ‘the black’” (p. 1). Although she focuses on the experiences of black women in Britain, she extends her theories to all marginalised and oppressed groups. Such groups are objectified by the dominant group and regarded as simply part of a homogenous ‘other’ group rather than as subjective persons with different experiences (Mama, 1995). This ‘othering’ of particular groups leads to the perpetuation of racist stereotypes and stigmatisation by members of the dominant group. Conceptualising HIV/AIDS in this way allows us to consider both the individual experience of being HIV positive and the effect of the social on this experience. Furthermore, it enables us to deconstruct the ways in which HIV positive people are marginalized by ‘othering’.

At the most basic level, othering is a fundamental way in which our language system operates, Derrida (as cited in Burr, 1995) sees language as a self-referent system. What this means is that signifiers (words) can only refer to and gain their meaning from other signifiers because there is no other way in which they can be defined. For example, in applying this idea to the individual/society dualism we can see that one cannot exist without the other, because they are each defined by their opposite term, “The nature of things lies in the relations between them rather than in the things themselves” (Ibid, p.107). Furthermore, within ideologies these binary oppositions are organised in such a way that one term is given greater value than the other. This leads us to think that one is more important than the other but in reality they cannot exist and make sense in isolation from each other (Burr, 1995).

Therefore all HIV positive persons are to some degree marginalised simply because they are not perceived as being ‘healthy’. Labelling ‘healthy’ and ‘ill’ as binary opposites leads to precisely

the kind of 'othering' which Mama (1995) describes. The 'healthy' dominant group can protect their sense of immunity from the disease because they are not like this minority of 'unhealthy' people who have been infected. In keeping with Derrida's (as cited in Burr, 1995) notion of meaning as being created in the relations between things, we need to recognise that health and illness are not binary opposites. They are simply "ways of being-in-the-world" or modes of existence rather than being discrete categories used to define an 'other' (Kugelmann, 2004). This is especially true with HIV because in many circumstances the person may be diagnosed as HIV positive yet show no symptoms and be otherwise perfectly healthy. Many people may live for years with no sign that they are sick; others may go through stages of being visibly ill but recover and lead a symptom free life until they become sick again (Wilton, 1997). In this case it is possible to be both 'ill' and 'healthy'. For example the women in this study are infected with a deadly virus yet because they have access to ART they have very few symptoms and are getting on with their lives, does this mean that they are healthy or sick?

2.5) Stigma in Developing Countries

A number of studies have examined the stigmatisation and marginalisation of people with HIV/AIDS within the developing world and, more particularly, in the South African context. These studies have found that experiences of stigmatisation and marginalisation are complex, multiple and contradictory.

In research conducted recently by The Panos Institute (Sleap, no date), into HIV-related stigma in four developing nations, namely India, Ukraine, Burkina Faso and Zambia, they found that in each country it is largely women who are stigmatised and discriminated against. This stigma

results from the fact that they are female, they are HIV-positive, and they are pregnant or have children, and could therefore pass it onto the child. Stigma can arise even when they have not been tested for HIV but they are ill or their babies die soon after birth, so it is assumed that they are positive. This stigma leads to women refusing to be tested. In the case of mother-to-child transmission, the very phrase "mother-to-child" itself may be stigmatizing (Sleap, no date). The assumption that the virus is passed on to the child through pregnancy, labour, or breast milk lays the blame for infection squarely on the mother, without considering that the father of the child may be the cause of infection.

IRIN PlusNews (2004) says that socially stigmatising beliefs about HIV/AIDS impede prevention, diagnosis, and care. In research conducted in two townships outside of Cape Town it was found that misinformation and traditional beliefs about the causes of HIV/AIDS lead to stigmatising against people living with the disease. These kinds of beliefs are that HIV/AIDS is caused by spirits and supernatural forces rather than simply being a biological disease. Walker, Reid and Cornell (2004) suggest that often stigma within African communities is not a result of the sexual nature of HIV/AIDS, but is because it is seen as the result of witchcraft and this leads to a high level of fear towards those people.

On a more positive note, IRIN PlusNews (2004) found that the more people knew about HIV/AIDS, the less likely they were to stigmatise others. This clearly indicates that HIV/AIDS education efforts may effectively reduce stigma among people who hold these traditional beliefs. Along the same lines, Akintola (2005) conducted interviews in poor communities with volunteer home-based carers. He found that participants had contradictory experiences of stigma with some finding the community appreciative of their work and supportive of patients while others

found that stigma against their patients was rife and they were neglected, ostracised and blamed. However, many people were open to acceptance when properly educated about the disease (Akintola, 2005). One possible way in which to promote education and improved knowledge about HIV and AIDS is through the extensive pre- and post-test counseling which is provided when being tested for HIV, and counseling is usually ongoing when one is on anti-retroviral treatment. In fact ART is increasingly being regarded as more than simply a regime of medication but as an opportunity to increase knowledge of the disease and possibly even to address issues of stigmatization within families and communities (Stein, 2005).

2.6) Benefits of Antiretroviral Treatment

Antiretroviral treatment is beneficial in a number of ways; first and foremost, it obviously increases health and prolongs life expectancy. This is demonstrated by projections developed by The Burden of Disease Research Unit, The Actuarial Society of South Africa and The Centre for Actuarial Research. These projections are based on a thorough analysis of a range of epidemiological and demographic data and they predict the impact ART could potentially have on the course of the HIV/AIDS epidemic in South Africa (Dorrington, Bradshaw, Johnson & Budlender, 2004). For example, it has been projected that by 2010, there are likely to be around 381 000 AIDS deaths per year because of ART availability rather than the 495 000 expected. This is assuming that ultimately only about half of South Africans who need ART will be able to access it. If we assume that only 20% manage to access ART then the estimated number of AIDS deaths in 2010 increases to 450 000 (Dorrington et al., 2004). Already, the HIV/AIDS pandemic has taken about 13 years off life expectancy. Life expectancy is thus 51.0 years, rather than the

63.9 years it would have been without HIV/AIDS. Without the ART programme, the decrease in life expectancy would be 18 years by 2015.

Aside from the primary advantage of increased health and prolonged life expectancy, ART has a number of other potential benefits. Stein (2005) has looked extensively at a wide range of empirical research conducted largely in South Africa and has found that there are a number of biological and psychosocial benefits to being on ART, these are:

- It reduces the viral load (the amount of virus in all bodily fluids), which means that the person is less infectious to others.
- It requires that the HIV positive person be supported and given HIV/AIDS counselling, this leads to greater awareness of prevention methods and can potentially decrease unsafe sexual practices.
- The transformation of HIV/AIDS into a manageable disease rather than a death sentence decreases psychosocial trauma by providing some degree of hope and purpose.
- Both the disclosure to others and the fact that the disease becomes manageable can potentially lead to a reduction in stigmatisation.
- The prolonged life of HIV positive adults means that the next generation will not be left as vulnerable orphans at a young age and they will hopefully then have improved stability and resources.

Understanding these biological and psychosocial benefits requires more research into the effect which ART has on the lives of those who would die without it.

An example of research which has been conducted with South African mothers who are positive is that of Allen (2003). She worked with HIV positive women who participated in the PMTCT

programme while pregnant. The participants discovered out that they were positive as a result of their pregnancy and thus had to cope with their own illness as well as the knowledge that they could potentially infect their unborn child. They felt fear, guilt and anger that they were HIV positive and had to face the new possibility of death, this was especially difficult because they had children. Although they took part in the PMTCT programme, none of the women remained on ART after the birth of their children. They all expressed concern over how their children would cope when they died (Allen, 2003). However, although they had multiple concerns about the future for themselves and for their children, they had reached some level of acceptance of being HIV positive. One of the themes which is central to the study is, "I've learned to live with it..." Participants had all found some way of coping with being HIV positive whether it was through religion, support groups or simply through taking action to maintain health levels (Allen, 2003). These black mothers were from a township in Cape Town and thus are very close demographically to the participants in this study, apart from the fact that they did not have continued access to ART. It seems likely that being able to access medication would have provided a context for even greater levels of coping and renewed hope for the future.

The Bambanani Women's Group (hold each others hands) is a South African support group for women with HIV and AIDS. They have access to MTCT and antiretrovirals because of overseas funding and Medicins Sans Frontieres (Morgan & Bambanani Women's Group, 2003). They have created a book that tells their stories in their own words along with photographs and pictures. It is a book about HIV but it is also about lots of other things in their lives and serves as a poignant reminder that HIV/AIDS does not take place in a vacuum but rather in a complicated human life,

Before, I was a dead person and the medication bring life and light....My hope is to live long and I want to do things that I was dreaming of when I was young (Morgan & Bamnanani Women's Group, 2003, p.68).

Medication brings hope and motivation and (for obvious reasons) is much more likely to result in a story that goes against the infected-tested-diagnosed-and died framework. This research aims to add to these available stories by looking at how ART produces hopeful lives: to look at how ART might not only be biologically beneficial, but also contributes positively to psychological well-being by providing a degree of optimism and motivation.

2.7) Critical Health Psychology

An entire field of psychology is devoted to understanding the psychology of health. This field has until recently, relied entirely on traditional scientific methodologies to investigate biopsychosocial issues of health and illness in quantitative terms. Statistical analysis is conducted on psychosocial variables (such as attitudes, and coping strategies) as well as on biomedical variables (of the disease) to determine how these are related (Crossley, 2000). Through analysis, general theories are developed to predict health and illness related behaviour in order to control, manage or to prevent its occurrence. A prime example of these principles in practice are the Social Cognition Models, such as the Health Belief Model, the Theory of Planned Behaviour and the Theory of Reasoned Action (De Wit & Stroebe, 2004). These models are empirical and aim to develop a theoretical understanding of the determinants of health behaviour. They systematically abstract the person from the context in order to make universal claims. They assume a rational person who wishes to act in their own best interests

and who will therefore act accordingly if given the necessary information. For example, in terms of this model, if people are informed of the high risk of HIV transmission through sexual contact, they will then use a condom during sex to protect themselves (Campbell, 2003).

However, it has been repeatedly demonstrated that having knowledge, or even having formed the intention to act, does not necessarily translate into action (Campbell, 2003; Pitts, 1991). There is a need to understand why people often do not act in accordance with these predictions. HIV occurs within a socio-economic, cultural and historical context which cannot be ignored.

Conditions of poverty and a deeply entrenched patriarchal system means that many women are not in a position to insist on a condom in their sexual encounters (Walker, Reid & Cornell, 2004). Issues such as desire, alcohol, sex for money/goods, within a trusting relationship, all make prevention effects more complex than simply being the choice of individuals (Campbell, 2003).

Human beings are complex creatures residing in an even more complex social world; thus accurately predicting behaviour is impossible (Crossley, 2000). Critical Health Psychology recognises the limitations of the strictly rational, quantitative approach, and attempts to overcome these by including qualitative data gathering, such as interviews and focus groups to capture the nuances of human meaning and motivation. This aims at understanding the lived experience of the person in the context of their life and exploring the stories of people outside of a symptomology of the disease (Crossley, 2000). What has been missing in health psychology is recognition of the fact that health and illness do not occur to rational, homogenous persons; they occur in, “‘a subject’, with subjective thoughts, feelings and interpretations which affect his/her interaction within the world” (Crossley, 2000, p.6).

This study will examine the experiences of women who are infected with HIV and currently on ART, using a qualitative analysis of the narratives of the participants. In order to explore the experience of being a black mother who is HIV positive and on ART, it is necessary to hear these women's stories about their belief systems and cultural context, and how HIV/AIDS fits into this story (Crossley, 2000; Frank, 1995). This will enable a proper understanding of what it means for them to live with HIV and AIDS, and will explore sensitive and complicated issues, such as stigma, marginalisation and discrimination.

Chapter 3 - Narrative Theory

3.1) Storied Identity

Mama's (1995) notion of 'subjectivity' as a means of re-conceptualising identity is a useful one; however, it still does not explain how this subjectivity exists (in what form), and how it can be fluid, yet still constant enough to be experienced as an identity. One way of understanding this fluidity is through a narrative, or storied, approach to subjectivity. The concept of a storied identity provides a framework for understanding how the social experiences of the person are organised internally in a meaningful way. We organise our experiences in storied form and construct a self-narrative; organising and framing experience, both past and present, into an internalised dialogue about the self (Currie, 1998; Garro & Mattingly, 2000; Murray, 1999). Through the active construction of stories about our experiences, and through the practice of narration (telling these stories to others) our subjectivity is shaped and re-shaped. Stories are not static because they must constantly be changed in the light of new experiences or different audiences.

Defining the parameters of what exactly constitutes a narrative is difficult as a variety of definitions exist depending on how narrative is to be studied (Andrews et al., 2000). For the purposes of this study, Polkinghorne's (1995, p.5) definition is most useful:

...narrative refers to a discourse form in which events and happenings are configured into a temporal unity by means of a plot.

To plot the narrative is to select and order narrated events according to time, and in this way to render them meaningful within the complete account (Roberts, 2002). According to this definition, narrative is constructed through 1) discourse (language) and 2) temporality (time).

3.1.1) Language

Narratives are constructed and told through the medium of language, and in this way the social world mediates the stories that we construct, because although we construct our own narrative through language, at the same time we are using linguistic and narrative frameworks which already exist in the world (Andrews, 2004 in Squire, 2004).

...our stories are not and can never be wholly personal...ultimately how we construct, interpret, digest and recount for others our own experiences bears a strong relationship to the storylines which are already 'out there' (p.11).

These frameworks or storylines are socially acceptable ways in which to tell particular stories. For example when one is sick, the narrative could be about how one goes to the doctor and takes medication and ultimately is cured.

In this way, our narratives are cultural products; however this understanding of narrative is inadequate because people's narratives are more than simply cultural products because they are formed out of human experience,

...stories also seem to have intimate...connections with the nature of human experience, narrative research incorporates other dimensions – notably those of historical time and subjectivity – that were in danger of being left out of other language – or discourse-based research (Andrews et al., 2000, p.2).

Narrations are a negotiated expression of discourse and experience (Mogenson, 1995). They make it possible to combine the objectifying (discourse) with the subjectifying (experience). The difficulty lies in balancing the agency of the individual in choosing how to tell their stories, with the fact that socially acceptable storylines or frameworks already exist. The fact that narratives are constructed by the person, although this is a cultural product, focuses attention on the importance of agency and subjectivity, even while recognising the discursive relation between subject and structure,

Using narrative, the 'self' can be located as a psychosocial phenomenon, and subjectivity seen as discursively constructed yet still as active and effective

(Andrews et al., 2000, p.1).

3.1.2) Temporality

Roberts (2002) writes that the conception of the human self as existing in narrative or storied form, opens the way for a connection to the past or, more significantly, to memories. Narratives are an attempt to organise human life in a meaningful way and this is done through imposing linear temporal structures on human experience in order to construct a life narrative (Andrews et al., 2000; Crossley, 2000). Temporal means that they are organised in terms of time, or in the sequence in which the events/experiences occur, and they have a coherent past, present and future, thus narratives can be seen as, "...webs which make sense of the past and inform future choices" (Fay, 1996, p.179). Through understanding the past in a narrative form, the person has a connection to past experience. This provides a continuous sense of their history while situating them in the present, as well as impacting on their intentions for the future.

In keeping with the idea of narrative as temporal, Freeman (1993) refers to the human self as a history-memory-narrative triad. These three concepts are central to any examination of a human life. Our self is constituted through our history, or our previous experience of the world, therefore through our memory of events and experiences. Our ability to be self-conscious is essentially recollective, referring to what is past, however, human memory is not merely the recollection of events and experiences but rather the individual's interpretation and construction thereof. The narratives that we tell about our life are therefore interpretations of our memory, which are made meaningful through being told in a storied form,

...the history one tells, via memory, assumes the form of a narrative of the past that charts the trajectory of how one's self came to be (Freeman, 1993, p.33).

Freeman (1993) explains the link between memory and narrative in that through interpreting the past (memories) we are also 're-writing the self'. New experiences become new memories and in this process we are continually revising and reconstructing our narratives.

3.2) What Work can Narratives do?

So how can narratives help us to better understand an individual within their social context?

This depends on how we interpret the link between discourse and experience. On the one hand, narrative theory shows how the stories that we tell are the result of the social context in which we are embedded (Andrews et al., 2000). In this view, narratives are forced to fit the frame of conventional discursive formats and to apply restrictive social norms that do not easily allow for resistance. They can conceal difficulties of the subjective life, as well as with social power relations. Frank (1998, as cited in Crossley, 1999) questions whether the telling of a story is an

example of agency or empowerment or whether it is still an example of the self as being constructed discursively,

Is it possible to tell stories of illness which empower even though those stories are framed within structures of power? Do technologies of the self, such as storytelling, potentiate new 'positive' forms of subjectivity? (Crossley, 1999, p.1689).

In terms of this, by encouraging individuals to tell their stories, we could simply be forcing them to choose from the 'culturally available discourses' and produce an acceptable account of events which is shaped by dominant frameworks (Plummer, 1995).

On the other hand, narrative can restore some sense of agency for the person rather than seeing them as discursively-operated robots (Andrews et al., 2000). In this view, narratives provide a means of resistance and progression within the same frameworks. Narratives are representations constructed by the person rather than merely being imposed upon them therefore the person has the ability to construct their own story that may run counter to dominant narratives (Reissman, 1993). Andrews (2004 in Squire 2004, p.11) says that,

As a researcher, what has fascinated me most are those situations in which people fashion stories which challenge – either implicitly or explicitly – those master tales, revealing alternative versions of how those stories we know best might be retold.

The assumption that stories must fit into the limited narrative frameworks provided implies that human beings have no agency to decide which stories they will tell and the form that these stories will take. However, stories told by the individual can resist dominant restrictive frameworks and even completely contradict these "culturally available discourses". Even though stories are cultural products, storytellers still have their own agency and self-reflexivity,

...relation...between...this particular life story and the social world the narrator shares with others; the way in which culture marks, shapes, and/or constrains this narrative and the ways in which this narrator makes use of cultural resources and struggles with cultural constraints (Chase, 1995, p.20).

Plummer (1995) eloquently sums up the dual discursive/agentive nature of narratives by describing them as having, "...conservative, preservative, policing control tasks – as well as transgressive, critical, challenging tasks" (p.176).

Stories are strongly affected by the 'interpretive community' in which they are told (Plummer, 1995). Frank (1995) supports this notion as he says that stories are always social because they are told to someone. Squire (2004) also uses this idea of interpretive communities in her work around disclosure narratives to explain that people disclose as HIV positive within a particular community of support and interpretation, "The notion of 'story' always entails 'audience' as well as 'storyteller'" (Squire, 2004, p.5). The extent to which these interpretive communities are accepting and supportive, is highly influential with regard to how the person perceives her/himself and the illness.

Plummer (1995) discusses rape, and lesbian and gay stories which historically would have been silenced, but have gradually become acceptable because of the proliferation of people coming forward with these stories. Thus narrative can allow a wide range of diverse stories into the social realm – stories which do not fit easily into available social frameworks of understanding – to create new discourses. They, "...can empower people by giving more intimate understandings of their lives and contexts" (Roberts, 2002, p.116). As a result of this capacity to explore the

lives of marginalised persons and allow their stories to be heard, narrative research works extremely well in studies of this kind. Through examining narratives we can explore more deeply, the complex and conflicting experiences of diagnosis, disclosure and the lived experience of being HIV positive.

3.3) Narrative and HIV/AIDS

Narrative analysis will allow for an analysis of these stories of isiZulu women living with HIV and provide a space for exploring the private worlds of the participants while situating these stories in the context in which they were constructed. This means that because they are HIV positive, resource-poor mothers, who live in a patriarchal South African society with its political, economic, and social environment; all this will frame their stories in multiple ways. However, they also have their own individual strengths and agency which will impact on how these stories are told (Andrews, 2004 in Squire, 2004).

The study will essentially be attempting to do two things. Firstly, to explore how illness, and more particularly HIV/AIDS, is represented in the narratives that the women tell about themselves and their lives. If we assume that identity is held in storied form, does severe illness disrupt the person's narrative? Although these women are sick, they have access to antiretrovirals and this should restore hope for the future, so how do they speak about their future plans, hope and motivation? With HIV/AIDS it seems that the only possible ending to the story is death; however, in looking for positive stories about being positive, are we not ultimately searching for stories which do not necessarily subscribe to traditional narrative frameworks of living with HIV/AIDS? This will hopefully provide an alternative to the 'infected-tested-

disclosed-and died' story. Secondly, the study will explore these marginalised stories and look at the relationship between the individual narrative and the social, economic and political environment in which the women live. This will include looking at what resources are available to them, how they experience stigma, what social support they have and so on.

Narrative theory is useful in illness research because it aims to understand how the individual's life narrative is dramatically challenged by the unpleasant realities of major illness, and especially with learning to live with chronic illness (Crossley, 2000; Lindegger, 1999; Murray, 1999; Squire, 2004). It works very well as a means of exploring the experience of being ill because it is a temporal way of understanding human experiences. According to Davies (1997), Frank (1995) and Ezzy (2000), the temporal framing of a human life is upset by serious illness and assumptions about the future, which form part of the life narrative, must change as a result. Confronting the very real possibility of an early death destroys anticipated temporal horizons and future dreams, and the anticipated plot no longer works. The shock to one's taken-for-granted existence and the knowledge of shortened life expectancy disrupts expectations for the future, *...disruption in their routine orientation towards time and the way in which this has the capacity to affect their lives more generally* (Davies, 1997, p.561).

In the South African context, black mothers live at a vulnerable intersection of poverty, gender inequality and lack of access to resources. This is intensified when they become HIV positive because they often cannot access food or basic medical treatment; they experience stigma and discrimination and often have no possibility of receiving ART. How is it possible to have any hope for the future, both for yourself and for your child, within such a bleak and marginalized position? This must have a significant effect on how their world is viewed and ultimately on

their sense of 'identity'. Thus the aim of this study is to explore how the subsequent access to antiretroviral treatment impacts on feelings of hope and motivation for the future and whether it has helped restore their narrative.

Chapter 4 - Research Methodology

4.1) Research Approach

Kvale (1996) provides a very useful metaphor to illustrate the juxtaposition between a modern approach and a post-modern approach to research. The modern notion of researcher as miner implies that the interview process is about finding knowledge which already exists within the person and is simply waiting to be discovered. The meaning of this knowledge does not change over transformations from the spoken to the written to the analysed form. In comparison, the researcher as a traveller has a post-modern understanding of research as a process of meaning construction during which information is obtained from the person in qualitative form (Kvale, 1996). The meaning construction takes place within the interaction between the researcher and the participant, in the shift from the spoken to the written, and during the data analysis. Thus the final product of this knowledge has a multitude of potential constructions depending on the outcomes of the research process. This study positions the researcher as a 'traveller' rather than a 'miner' because it recognises that all research is a subjective, interpretive process rather than a search for the 'truth' of human experience.

4.2) Study Design

4.2.1) Accessing Research Participants

Initially, I was hoping to conduct interviews at a provincial government clinic or hospital that

provided antiretroviral treatment [ART] within the public health system, but this proved to be impossible. These rollouts of ART were evaluated within formal research projects that had their own agendas, and were therefore not open to the idea of an external researcher conducting interviews. Eventually, I managed to obtain permission from a clinic in Durban; this clinic was funded outside of government structures and run through a University Medical School. Permission was generously granted from the Medical School for access to these participants.

The female participants were approached at the clinic where they receive ART and medical services. They were asked if they would be willing to take part in two interviews with a female Zulu translator and myself. The interviews would take place at the clinic on the day on which they attended the clinic each month. This was convenient for them and also meant that they would be in a familiar place where they hopefully felt comfortable and not intimidated. I was aware that being in the clinic might cause them to see the interviews as connected to the clinic and their treatment, rather than as independent; the implications of which will be explored later.

4.2.2) Data Collection – In-Depth Interviews

Sampling Method

The research participants were selected using non-probability sampling methods because of problems with accessibility, as a result of the sensitive nature of the study. Qualitative research seeks to explore depth rather than breadth and is looking for insight into particular human experiences rather than generalisation therefore it is best to make use of a small, purposive sample which will allow a topic to be explored in detail (Ulin, Robinson, Tolley, & McNeill,

2002). Purposive sampling does not mean that the sample is convenient, rather that it is picked with a particular purpose. Therefore participants were selected who fulfilled the necessary criteria for the study: female, mothers, HIV positive, isiZulu, and resource-poor.

The aim of this exploratory study is to conduct an in-depth analysis of the life-stories gathered in the interviews in order to gain some understanding of what it means to be a woman and a mother under these difficult circumstances of illness, resource-poverty and risk. As such the sample size is small and only five participants were interviewed. These participants were required to take part in an introductory interview of 15-20 minutes and then two narrative interviews of about one hour each. The interviews were fairly unstructured in order to elicit the life-story of the individual in their own words. The participants are isiZulu-speaking and thus an isiZulu research assistant conducted the interview, thereafter it was translated into English for analysis purposes. The research assistants were both female Psychology Honours students and so they were aware of the narrative methodology used and the area of investigation, as well as the ethical requirements of sensitivity and confidentiality. Additional training in these areas was provided by the researcher.

Interviews

The interviews were conducted using Seidman's (1991) in-depth, phenomenologically-based interviewing method. Phenomenology has an explicit focus on the lived world and concrete experiences of the person, therefore it ties in well with a narrative framework. Seidman (1991) proposes a three series set of interviews. This allows researchers time to establish a relationship with the participants and hopefully collect more meaningful data. The first interview serves to set up a context for the participant's experience, the second to concentrate on the actual

experience that is central to the study and the third to reflect on the meaning that this experience has for them. This method works well because rather than focusing on the entire biography of the participant, it examines a particular life experience, in this case that of HIV/AIDS, in detail and then ties it into a more general life history.

For the purposes of this study it was necessary to combine the three sections into two interviews. The women only came to the clinic once a month so the interviews took place a month apart. It was felt that a third interview would be too far from the first interview. To compensate for this, I attended the clinic one month before the first interview and spoke to the women with the in-house researcher. I had a ten to fifteen minute introduction with each woman during which they were told of the research, its aims and what the interviews would involve, and I answered any questions that they had. This helped to put the women at ease during the first interview, as they had already met me, and they were familiar with the research goals and the interview procedure.

This study adapted Seidman's (1991) guidelines along these lines and aims:

1) *Life History and details of experience*

This session aims to find out the personal details of the participant such as age, marital status, number of children and so on. It also focuses on the details of their experience of being tested and finding out that they are HIV positive.

2) *Reflection on their lives at this moment and orientation towards the future*

This session looks specifically at what it means for the participant to be able to access ART. Questions were asked around what changes had occurred in their lives as a result of going on to ART. The aim was to find out any psychosocial benefits related to ART such as motivation and hope for the future.

During each of the interviews, open-ended questions were asked and each respondent was asked the same basic questions in the same order. However this process was very flexible because I was looking for narratives, so the interviewers were encouraged to respond to how the interview proceeded rather than relying strictly on the questions (Ulin et al., 2002). They were also encouraged to probe with follow up questions in order to encourage the person to discuss more deeply their previous answer.

The interview process did not run smoothly as most participants lived quite far from the clinic and were very hard to contact outside of their monthly visits. Aside from the fact that some did not have phones at all, others shared phones and it would have been very difficult to contact them without risking a breach of confidentiality. Therefore I could only find out when they would be attending the clinic from the clinic diary. A number of times I arrived at the clinic on their scheduled day and they would be coming on a different day or they just did not show up. This made the whole process extremely difficult as it meant another wait, added to this, the translators also had to be organised every time. Unfortunately this resulted in two of the women only being interviewed once rather than twice. Fortunately most of the necessary data had been obtained in the first interview; the second would have been mainly a follow-up interview, so there was enough data to include them in the analysis.

4.3) Ethical Considerations

4.3.1) Access and Anonymity

As already mentioned, the study took place in the ART clinic of a University Medical School. This meant that fairly strict guidelines were in place for how ethical clearance would be given (and rightly so given the sensitive nature of HIV/AIDS). Thus ethical clearance was obtained from the UKZN higher degrees committee; and then a comprehensive protocol was required detailing the aims and methods of the study, which was then passed by the Medical School. A copy of the completed research report will also be given to the principal clinical researcher of the ART project at the Medical School.

The fact that access was granted in this way and that the interviews took place in the clinic context could have resulted in a belief among the participants that this research was closely connected with the clinic and thus that they were almost obliged to participate. Price (1995) refers to this ethical issue around access as 'gate-keeping' and it can have an effect on how participants chose to tell their stories.

Participants were informed that the interviews would all be tape recorded and then written up but that their own names would not appear in any of the writing, thus assuring anonymity (Ulin et al., 2002). They were given the choice of selecting a pseudonym to be used instead of their own name or one would be chosen for them. Other subjective data such as age, marital status, number of children and so on, was left unchanged as it is highly unlikely that potential audiences

of this research report such as University or Medical School staff would be able to identify participants from this information. Although they did not sign a consent form, verbal agreement to participate was given at the introductory session.

4.3.2) Translation

As I only speak a little isiZulu, there was a need for the interviews to be conducted by isiZulu interviewers and then for these to be transcribed and translated into English. This necessitates a consideration of the effect that this process has on the research data. Firstly, in terms of conducting the interview in isiZulu: I put some consideration into whether to have the translation done during the interview so that I could at least take part, but it felt like this would be too disruptive and that it would be better for the interviewer to develop some connection with the participant rather than making it a three-way process. However, this was fairly frustrating for myself, as I ended up in the not-so-glamorous role of babysitter while the interviews were taking place. However, it did mean that the participant and the interviewer could have a less disruptive interaction which would hopefully result in more meaningful data. It is also probable that even though I did not take part in the interview, my simply being in the room at the time may have impacted on the interview process. This aspect is covered in more detail in the reflexivity section.

Secondly, in terms of the translation process, in keeping with a hermeneutic/constructionist approach to language, Swartz (1998) writes that because different languages develop different systems of vocabulary for feelings it is not enough to simply give the closest English translation. In the process of translation, a particular meaning is being produced and it is vital that this

meaning remain as close as possible to the original meaning. This point has had particular importance within this study. In the early stages of the transcribing/translating process, the interviewees were used as transcribers/translators. Unfortunately, I found myself reading transcripts in which the participants spoke perfect English, because they had very kindly made every effort to change the transcripts where necessary so that they made more sense in English. As a result the transcriptions were flat and devoid of a nuanced translation of the metaphorical and allegorical nature of the isiZulu language.

I was unhappy with this rather uninspiring material and asked an isiZulu-speaking colleague to listen to the tapes and give me his opinion. On his advice I had the tapes re-transcribed after providing more specific instructions on how they were to be translated and the difference was startling. Instead of a nicely sanitized Standard English version, I now had much richer data, with all its metaphors and untranslatable meanings, which may have not been in perfect English but which was much closer to the original isiZulu meaning. This has really taught me the importance of firstly providing detailed explanations of what is required, and secondly of keeping as close as possible to the data.

4.3.3) Reflexivity

A further aspect that must be considered is around how my very obvious differences from the participants affected the way in which they told their stories within the interview context. My otherness – white, English-speaking, childfree, educated, and feminist, positions me very differently from these women. The most obvious difference lies in the language barrier: I chose to conduct interviews with isiZulu-speaking women even though I speak very little Zulu and this

meant that I had to make use of interviewers and translators throughout the process. Why did I not simply interview English speaking women? Well, as a result of the challenges I have had in doing this research I have asked myself this a number of times, and yet I do not regret the decision. I feel that speaking to these isiZulu women who truly experienced all the social problems of poverty, unemployment, lack of nutrition, poor medical access and little social support gave a much better idea of what the majority of women who are on ART would go through. Also, in light of the difficulties in accessing the participants and then interviewing them, it seems unlikely that these stories are going to be told unless researchers make the necessary effort to gather them.

I have dealt with this issue of otherness by being extremely reflexive throughout the research process and I do not feel that my differences from the participants has detracted from my ability to interpret their stories; on the contrary it is possible that it may have enabled a more in-depth analysis. As Fay (1996) says, "The ability to make sense of others' behaviour and its results sometime is enhanced by similarity between interpreter and interpreted, but sometimes it is not" (p.26). A researcher who is very similar to the interviewee could omit to highlight aspects of a narrative because it feels very familiar to them and thus is perceived as unimportant whereas a researcher as 'outsider', who has some distance from the world of the interviewee, might be more observant, exploring the participants world or story from the 'outside-in' (Kelly, 1999).

Mauthner and Doucet (1998) advocate strongly for reflexivity throughout the research process, but most especially during the analysis stage as this is when transcripts are being processed and extracted from. Failure to be reflexive could result in words being dissected from their story and

used out of context, or simply to fit the aims of the researcher therefore reflexivity is a key component of qualitative research.

4.3.3) Validation

Verification of knowledge in terms of post-modern qualitative research does not make the same claims as that of positivist research. It is not looking to make any attempt to generalise findings or to measure its reliability in any quantitative sense (Kvale, 1996). It recognises that interpretation of data is subjective and there are “multiple ways of knowing and multiple truths” (p.231). Thus validation can only occur as a notion of the ‘quality of craftsmanship’ (p.240). The best way to ensure quality is by checking findings with other experts, with the participants or against other work. One way in which this was done was through an examination of work which has already been done in this field to see if there are parallels between the findings. A second means of validation, especially important as a result of the cultural and language differences between the researcher and the participants, was a continual interaction with an isiZulu colleague. Thirdly, the research supervisor read through a number of drafts to ensure that the work was of a high standard or “quality”. And lastly, constant reflexivity throughout the analysis provided an opportunity to check for alternative explanations or interpretations of the data.

4.4) Narrative Analysis

Narrative analysis is a huge and varied field without strict guidelines for collection techniques and analysis. It is therefore difficult to select how to go about conducting interviews and analysing the data. One must first find one's paradigmatic positioning and then select a method of analysis. It would appear that narrative analysis can be differentially conducted within descriptive phenomenological, interpretive, and constructionist frameworks and it is necessary to conduct a thorough reading of previous studies in order to select an approach which best suits the research aims.

Examples of these approaches make these paradigmatic positionings evident. Firstly, Allen's (2003) study on HIV and women's experiences is a naïve phenomenological approach to analysis which seeks to descriptively present women's lived experiences without attempting to provide interpretations or causal explanations. Secondly, Crossley (2000) and Riessman (1993) offer more interpretive/hermeneutic approaches to analysis. This approach examines the relations between the parts and the whole meaning (Kelly, 1999). For example, Crossley (2000) has conducted interviews with people living with HIV/AIDS but she dissects and interprets these personal narratives in terms of what she views as the three most important parts of narratives - tone, imagery and themes – and upholds the notion of the agentic story-teller in weaving together unifying meanings.

And thirdly, Squire (2004) made use of a constructionist approach by using genre analysis to analyse her narrative data. She gained access to participants through faith-based organisations and then conducted interviews with HIV positive persons in townships around Cape Town.

Genre analysis involves looking for the ways in which stories can be constructed to fit particular narrative frameworks, for example Squire (2004) finds that two genres appear regularly in her analyses of South African stories around HIV; those of a 'talk-show model' and of a 'conversion narrative' which was strongly tied into religion.

The framework for this study is broadly interpretivist as the stories are made sense of in terms of a particular theoretical orientation. It was decided to make use of an amended version of the voice-centred relational method; this version was developed by Mauthner and Doucet (1998). The reasons for selecting this method are threefold; firstly, it is based on the concept of relational ontology, which understands individuals as completely embedded within a social context rather than existing as independent, separate individuals, and looks at how we can understand the link between the so-called autonomous, agentic individual and the broader social, political, structural world. Secondly, it attempts as far as possible to keep the voices of individual respondents alive in this process rather than simply looking for themes that occur across interviews. Thirdly, it takes into account the fact that the research process is an interaction between the researcher and the participant (and in this case the interpreter as well). Although the participant tells a story, this story is a product of the interview context and it is then written up by the researcher (influenced by a particular methodology, theoretical orientation, translation process, and research aims) into a new story (Kelly, 1999; Kvale, 1996).

Their version is deeply rooted within a feminist tradition and was developed to look at the narratives of marginalised women within their social environment (Mauthner & Doucet, 1998). Mauthner's (1994) original research examined the experience that women had of motherhood

when they suffered from postnatal depression. She explored this topic within the social framework of support, social services and employment conditions.

4.5) Data Analysis

This method of voice-centred relational analysis involves a number of intensive readings of the interview data. It focuses on tracing voices within transcripts rather than simply linking themes across interviews and this reveals an individual journey (Mauthner & Doucet, 1998). It is then possible to examine the analysed transcripts and look for shared themes with a very thorough understanding of the individual stories. This avoids the stories simply being lost when they are broken down into themes.

Reading One: Reading for the plot and our responses to the narrative.

This first reading looks for the overall plot of the story. This initial broad look at the narrative gives emphasis to understanding the protagonists, the events, and the underlying imagery. It also highlights any contradictions, inconsistencies, metaphors and so on (Mauthner & Doucet, 1998).

At the same time the researcher needs to consider how they personally respond to the text. No researcher can approach a text as completely neutral; instead the subjective emotional and intellectual response of the researcher is grounded in their particular background, history and experiences (Mauthner & Doucet, 1998). Reflexivity is vital, as personal and theoretical assumptions and views will have an effect on how the data is interpreted. They suggest a personal reflection as part of the data analysis process, in order to make the researcher aware of how she is situated in relation to the respondents.

Reading Two: Reading for the voice of the 'I'.

This reading looks for personal pronoun statements such as 'I' and 'we' to get a sense of how respondents see and represent themselves (Mauthner & Doucet, 1998). By focusing on the 'I' within the narratives, it is possible to examine experience from the perspective of the individual rather than simply imposing that of the researcher onto the data. This is important when one is attempting to highlight identity shifts and the active agency of the person in choosing how to tell their story. It involves looking at the multilayered nature of narratives.

Reading Three: Reading for relationships.

Relationships will include both interpersonal such as those with a partner, family, friend, and broader social networks within the community, the church, the clinic, their working environment (Mauthner & Doucet, 1998).

Reading Four: Placing people within cultural contexts and social structures.

This reading is about understanding how the respondents' narratives and experiences are placed in terms of the broader social, political, cultural and structural contexts (Mauthner & Doucet, 1998).

Although these four readings were separated out during the analysis stage, as part of the write-up they are written as separate sections. Firstly, the first and second reading of each of the five participants is written up separately to retain the individual stories and circumstances of the women's lives. Secondly, the third and fourth readings are written up as central themes that are shared by the stories. These two readings are very closely intertwined and the themes were

shared by all the participants therefore to write each one separately would have meant repetition.

Chapter 5 – Analysis

5.1) Reading 1 and 2 - Background and Voice of “I”

This first section will serve to introduce the participants and contextualise their stories in terms of their demographics, economic situation, their home life and so on. It will give a brief summary of the salient points of their stories, as well as highlighting any distinguishable features that provide a better understanding of the participant. In some instances, aspects from the first section may appear in the second thematic section. This occurs because these points are fundamental for situating the individual stories, but are also shared themes which must be considered in terms of the literature and research which already exists.

GUGU

During the interview and even throughout a reading of the transcripts, Gugu comes across as a very strong, vibrant woman. She laughs a lot throughout the interview and although it could be suggested that this is a result of nervousness, it seems to stem instead from a very active sense of humour. Gugu is 30 years old and lives in a township in Durban, she has been on ART for nine months. She is married and has two children, they are 3 years and nine years old and both are HIV negative. She did give birth to another child after the eldest, but sadly it died of AIDS

complications when it was only a few months old¹. During her second pregnancy she was tested and informed that she was HIV negative, therefore it was not suspected that the third baby could be HIV positive. However, after a few months, the child became sicker and sicker and eventually died. It was subsequently discovered that the baby had in fact been HIV positive.

... after delivering my child, it became sick, it was coughing and it became clear that I must go straight to... the doctor did not see anything wrong. So I would wake up and go back there and it was clear that this child is really coughing two months, three months....he checked it and did not find any TB. He asked me what he should do because I could see it in my child's body that it was dying.... he then said that it would be better if he were to take the child's blood. I agreed and signed the forms. Then when I came back after maybe two weeks, the child died. After I had finished burying him/her I went back to get the test...He then said that the child had the problem of HIV (Gugu)

Both of her parents are deceased, but she has disclosed to her in-laws and to her sister and they have been very supportive. She did not directly disclose to her in-laws but her two sisters-in-law are positive and one of them is also a patient at the clinic so it became fairly obvious that she was positive. She has not yet disclosed to her brothers but has intentions of telling them.

Their family seem to be managing quite well economically. Although they live in a township, they have a decent house that is subsidised by the government, and only the four members of their nuclear family live in the house; herself, her husband and their two children. Her husband has a job and he works very long hours and on the weekend. She does not work at all and is therefore very dependent on her husband to look after herself and her two children. Her husband

¹ The isiZulu language makes no distinction between him and her/he and she, therefore it was sometimes impossible to tell whether the children were male or female.

has been tested and is also HIV positive and she is almost certain that he has infected her as she has never been unfaithful to him. On the other hand, he has often been unfaithful and she even refers to him as “*isoka*” which means “player”.

In spite of this, they still live together and even had a third child after the second one died.

Although she knows he has been unfaithful to her in the past, and has probably given her a deadly disease which has ultimately led to the death of their child, she does not feel that their relationship has changed in any way since she found out that he has given her HIV. More disturbingly, she thinks that he is still sleeping with other women,

Oh shame I would be lying, there is nothing because even if he does have his naughtiness, he does not do it in front of me. The man really respects me, shame he does anything I want. There is no difference because I do not work, I am like everybody else
(Gugu)

Gugu regards her husband as having respect for her because he does not sleep with other women in a way in which she would become aware of it. It is hard to decipher what exactly she means by saying that she is like everybody else. Does she mean that her husband treats her like everybody else? Or that everybody else is also unemployed? This could be a factor in her acceptance of his being with other women and probably infecting her and their child. The link between economic reliance on a partner and HIV/AIDS will be discussed in more detail in the next section.

The death of her child resulted in her feeling an enormous sense of guilt both because of her inability to stand up to the medical doctor and demand better care for her sick child, and because she has allowed her husband to infect her and their child with HIV,

I could not believe it, shame the way it happened. That was something that I just did not tell myself....The thing was that I just went crazy. I then went home but it was very painful, it was very painful....I waited for my husband...and I just kept on crying...I then told him that, "You see all your naughtiness, they said the baby had HIV..." (Gugu)

She felt intense disbelief and shock when the baby was found to be HIV positive, and she then realised that she had unknowingly passed the virus onto her child. This discovery is a double-blow because not only does she find out about the child but it is also obvious that she must be positive, so she is not only crying for the baby but also for herself and her husband.

The only way that she can deal with her positive status and the death of her child is by asking God for courage and it is only through this faith that she can accept what has happened,

...I felt very bad but again I asked God to give me courage and he gave me and then I accepted, yes I accepted (Gugu)

Thus religion plays a major role in her ability to find the courage to go on with life. She moves between her personal space of feeling what a mother feels when they face the death of a child, and a religious space of being expected to forgive her husband and accept what has happened as simply the 'will of God'.

An interesting aspect of her narrative is her very apparent need to appear problem free. She initially says that she has not had any problems as a result of being HIV positive except for a slight weight loss,

I was a little stressed because I had lost weight but I was not ill but the body it was clear that I am decreasing, but that there is a problem that I had, no there is none (Gugu)

During the interview she attempts to gloss over the more unpleasant symptoms of the disease and side-effects of the medication. It is quite important to her that she is not considered to have any problems yet she mentions some very serious symptoms and side effects,

Just before I received the treatment, I had sores all over my body, it was all over my body, but then I was not ill....but I see that the body is not the body that was mine and also just tiredness....I do not have a problem, just you know I do not, even a small one. Because when I started using the treatment, I was troubled by the fact that my heart was so small (inhliziyo encane). I was not eating at all, I was even throwing up the pills and trying again, that was for three weeks. After that I got used to them, I eat everything, I do not have a problem and the body is alright, I am getting fat that is just my problem (laughter) (Gugu)

There are a number of possible explanations of why she has this need to seem as though she experiences no difficulties with being ill. This could possibly be her particular protection device - if she denies the negative aspects of the disease and the treatment, perhaps this serves to alleviate their effect on her. She actively chooses to tell her story in this way in order to position herself as strong rather than being the passive victim of a disease. Additionally, this denial could be connected to her positioning within the interview situation. The interview takes place within

the clinic setting where she receives free life-saving medication, thus the very real possibility exists that she perceives a connection between the interview and the clinic. As a result, she could be attempting to be a 'good participant' who is appreciative of the help she is receiving and thus does not wish to dwell on any negative aspects experienced in case it jeopardises her access to the clinic. Another interesting aspect of this extract is she talks about the disease and how it is affecting her body. She talks about it in an embodied way and says that her body is not the one she used to have. This ties in with Squire's (1997) notions of how illness is not simply discursive but is embodied.

BONGI

Bongi is married and lives with her husband and their young child. Both she and her husband are unemployed although she does sell things to make some money. She discovered her positive status while pregnant with their child. At three months she agreed to be tested while attending an antenatal clinic and she was informed that she is HIV positive. Fortunately, she was immediately able to go on Nevirapine to prevent the child from becoming infected, and thus the child has remained negative. She strongly believes that she contracted the disease from her husband as he was involved with a number of women. Thus far, she has only disclosed to her husband and no one else, not even to other family members. She tells her family that she attends the clinic so often because she has tuberculosis,

Even though one was ill, it was because of TB, because I began taking the drugs when I was not ill, after I had begun I had TB, they came to see me and after that I was alright because I started taking the treatment for TB, so I became alright. There was no problem, because they asked me what the problem and I told them that I had TB and they also

found out that I was taking the treatment for TB and I was alright and it ended there

(Bongi)

That they accept this explanation of tuberculosis rather than HIV/AIDS is perplexing. TB actually has as many stigmatizing associations as HIV/AIDS and it is far more infectious than HIV (although it can of course be cured) and thus they stand more chance of catching it from her. Yet it is still more acceptable than being sick from HIV/AIDS. This could stem from the inability to cure HIV/AIDS, or from better public knowledge of TB, or it could be connected to perceptions of how HIV is passed on through sexual activity or witchcraft.

Two aspects of this story stood out from the others, firstly the constant reference to religion, and secondly the verbal interaction between the interviewer and the participant. In terms of the religious theme, although most of the women mention religion at some point in their stories, for Bongi the thread of religion runs throughout both her interviews. She has a belief that she is meant to receive ART as a kind of right for being so devout, and thus she will live longer than others who also have the disease, because she has been chosen by God,

And I always say that to anybody, that I am still going to live, I say God I am still going to live, I always trust God. God makes me believe in him even more, because there are many people who die in front of me, people who come here because they hear that there is help here, but because there is a certain way to get in they end up dying without receiving that help. God found a way for me to receive this help, its not my doing but its his work and I really believe in him, not that I did not before, before it was believing in him like a young person, but now I believe in him like an adult, because God is amazing,

when you believe in him he does miracles for you, people die and I will still live on

(Bongi)

She believes that she will eventually be free of HIV/AIDS. She does not however say that there will be a cure for all, but rather that she herself will be cured.

...oh I think one day I will be cured completely (Bongi)

Her strong belief in God and religion allows her to accept that she has been infected and also to believe that she will not die of the disease. This aspect of religion has become one of the most important threads running through the interviews and will be discussed in more detail in the next section.

Bongi's transcripts are also very interesting in terms of the interaction between the interpreter and the participant within the interview context. Neither the interviewer nor Bongi will say the words for HIV or AIDS, this is especially apparent in the second interview. They both seem very reluctant to discuss certain topics and use certain words, and they skirt around sensitive issues with hints, euphemisms and incomplete sentences. The following extract demonstrates this reluctance quite clearly,

Int: *I want us to begin with your community, perhaps there are other people...*

Bongi: *What kind?*

Int: *People who are ill that are perhaps your friends... We just want to know if there are others that you know...*

Bongi: *Those that are ill (abagulayo)²?*

Int: *Yes.*

Bongi: *Those that I walked with outside or just others?*

Int: *Those, those, those, (stuttering) those that have the same disease that you have.*

Bongi: *Those that I walked here?*

Int: *Yes, but even those that you did not walk with here but you know...*

Bongi: *Those that I walked with here we do chat about our health, lives and just how things are going, things like that. We do chat. However, those I did not walk with, I have never chatted with them, and I have never really told them about myself, the way that I am.*

Both are isiZulu and it would appear that this is a result of the cultural interaction which is mediated by the unusual circumstances of an interview context. The interviewer was slightly younger than the participant so this could be about the age gap and the need to have respect for your elders. In discussing this with isiZulu colleagues this was the suggestion in terms of cultural explanations. The age-deference dynamic is constituted in the relations between the younger interviewer and the older participant. This requires special negotiation in this interview context because the younger speaker is ostensibly in a more powerful position than the older speaker, and is asking extremely sensitive questions. But in terms of age, Bongi should be in the more powerful position, and this contradiction results in the strange interaction between the two.

Bongi makes use of a number of euphemisms such as, “*Those that are ill (abagulayo)*”, “*Those that I walked here*”, “*the way that I am*”, to steer clear of more specific terms like HIV positive,

² Sick and ill

AIDS patients, and so on. This linguistic device allows her to avoid labeling herself and in this way distance herself from the negative associations of HIV/AIDS. There are proper isiZulu words available for HIV and AIDS so she is actively avoiding these terms.

SIMPHIWE

Simphiwe lives with her unemployed sister and her sister's two children. She was studying fashion design but became pregnant and had to leave; she has been unable to return to her studies and is currently unemployed. In 2000 when she was pregnant with this, her only child, she experienced chest pains and was therefore sent to be tested for HIV. This is how she discovered her positive status. The child is also positive; however it is relatively healthy with a proper diet and multivitamins and does not yet require treatment. She is still with the father of her child but he has not been tested. She has disclosed to her family and some of the neighbours know that she is positive but she is not willing to disclose completely. She is quite ill most of the time with HIV-related complications such as tuberculosis and other symptoms such as a skin rash.

Simphiwe was probably the least responsive of the women and it was difficult to get the thread of an ongoing narrative. She treated the interview as a question and answer session, and seemed very reluctant to tell her own story or even to expand on her short answers. This is probably connected to a misunderstanding of what it means to tell a story. She has a tendency to generalise her answers by making use of "you", "we", and "they", rather than the active "I".

It hides and they take time to discover that you have it. You can become very sick and don't eat but vomit. There are many things that happen in your life that makes one to

suffer....They sometimes discover it when you have already lost weight that hey, this person is suffering and in the end they are able to help you (Simphiwe).

It seems that this use of the passive operates as a protective measure by distancing her from the disease. She would not tell a story with herself in the protagonist's role because this would require that she situate herself in the sick role of person living with HIV/AIDS. This could be a means of denial or it could be a more active rejection of being labelled as such.

The one instance where she makes repeated use of the active "I" is when she is listing the improvements that have occurred in her life now that she is on ART.

I am now better in health and also able to do my chores and to move around the house just to go around in the house since if you are sick you are always in bed...I can now keep food in my stomach, or feed myself, I can walk around, I can do my washing, I can clean my house, I can do many things. I am able to take my child to the clinic without any problems (Simphiwe)

Even within this short extract it is possible to trace the shift in the pronoun self-referencing from the active "I" when listing the many household activities which she can do now that she is healthier, to the passive "you" when she makes reference to being sick and confined to bed. However, as this is a translated transcript there could be alternative cultural interpretations. Moving away from a linguistic focus she, like Bongi, is also presenting her experience with ART in a particular way. She is highlighting the number of positive improvements that have happened since she started on the treatment; almost as if to show that she deserves to be on ART because she does not 'waste' its effects.

The only time during the interviews when she really spoke extensively was to warn against having unsafe sex, to give information about the disease and discuss how to live a more healthy life. She does not have a story to tell, but instead focuses on the embodied/material identity,

There is no story that...I could share it with you, except for that when you are sick especially when you have this disease you have to take care of your health. You have to have a special way of behaving especially sexually, you have to use condom when having sex if you have a partner. You have to be careful of what you eat...And that you have to make sure that you are protected against flu and take precautions when you have it like going to clinic and not wait until it is worse or complicated since a minor mistake costs your life (Simpfiwe)

This is also done in the passive and it is difficult to say why exactly she feels the need to tell us this information. Possible reasons could be that she is trying to appear knowledgeable and prove that she has appropriated the relevant medical language and is following the recommendations given by the clinic. She must have undergone extensive counselling before accessing ART and she could be simply repeating a story that she has been told by counsellors. It is noticeable that she appropriates the bio-medical story to again avoid telling her personal story. Alternatively, because she is strongly influenced by the religious discourse, it is as if these have become immersed in her doctrine and are now almost religiously followed. Perhaps she is slipping into a speech which she has told to others many times before.

She is quite willing to tell stories about the experiences of other people, who are also HIV positive or have full-blown AIDS. One such example is of a young woman, like herself, who has contracted HIV,

There is one that makes all us so sad, she had stayed for four years without a man saving herself. When she got married she married a person with the disease, after sleeping with her, he told her that he had the disease...he knew...(inaudible)...He married her just to leave her and this disease is so painful, it is painful....You find that you are saving yourself avoiding it then comes a person to give it to you, knowingly....She stayed, she stayed and was patient, but it was only death (Simphiwe)

Although it would not be ethical to claim that this is in fact her own story, it is possible that this story resonates quite strongly with her experiences. She is the only participant who avoids discussing whether she has been infected by her partner. However, when reading the story about this other woman, it is significant that she says,

***You** find that **you** are saving **yourself** avoiding it then comes a person to give it to **you**, knowingly... (Simphiwe)*

She moves out of talking purely about this woman from the story and generalises the experience by using “you” rather than “her”. It would not be stretching interpretation too far to suggest that she is generalising about herself as well.

AYANDA

Ayanda is thirty-six years old and lives with her partner and their three children in a township in Durban. The children are 11, 5 and 1 year old and are all HIV negative. Neither she nor the

father of her children is working. She tested positive last year when she was pregnant with her last child and has been on ART since then. She had previously had a number of miscarriages, and was therefore sent to the clinic and persuaded to undergo tests in order to protect the child. She has disclosed to her husband and to her sister-in-law, who then told her brother. She has received tremendous support from those who know her status, however she will not disclose to any other family or friends. Most strikingly, she is too scared to tell her mother because she feels that her mother would be unlikely to be supportive, as she is extremely discriminatory towards those in their community who are HIV positive,

...I think if my mother were to know she would not be able to handle that thing because she would be very upset. I sometimes say that maybe I will tell her when it is forced [upon me] or maybe when I am lying down (death). That would be the time that I will say that I am like this (Ayanda)

She says that it is very likely that her husband is the one who has passed on the disease to her. However he has never gone to be tested and still has no idea whether he is positive or not. When she refers to their having to use condoms she says that it is because they know that she is positive, which leaves her as the sole responsible infected partner. However, despite this refusal to be tested, he is extremely supportive of her. He is very willing to wear a condom, he is very knowledgeable about what is necessary for her to keep healthy, and he ensures that she adheres to her treatment regimes,

...he doesn't, he supports me, he reminds me about the pills. He gets upset maybe when time passes me; maybe eight has come and gone. When I haven't taken the pills, he shouts and says that why haven't I set the cell? (Ayanda)

He clearly knows how important it is for her to take the pills at a certain time during the day. His reference to the “cell” is about setting the alarm in the cell phone for Ayanda to take her pills. As mentioned in the literature, (Chopra, 2005; Tromp, 2003) treatment adherence is vital to avoid resistance to the drugs developing.

Ayanda spoke extensively of her experience of being tested and diagnosed as positive. She highlights her emotions of utter shock and disbelief when she was told that she is HIV positive,

I did not believe when it was said that I am positive... I cried, a lot really, it took a long time for me to leave the house [because] I did not believe (Ayanda)

She had been tested for HIV with both the other children and was found to be negative and so she thought that she was safe. Therefore she was extremely shocked to now be diagnosed as positive. She seemed to go into a kind of frozen state,

Eyh, I will never remember that day, because I just saw myself when I was in the house.

When nje I was walking nje along the way I was like a dizzy person... (Ayanda)

Her partner also displayed this sense of disbelief when she told him the positive results of her test. He desperately searches for another explanation,

He was shocked too, he got this shock. He did not believe, he asked me thoroughly if the results were really mine or if they had not made a mistake, a mistake with the blood

(Ayanda)

When her baby becomes sick, she is terrified that it is because the child is HIV positive so she takes it to the hospital,

I took him/her to the doctor; the doctor said I must take him/her to King Edward. In King Edward, when I came I just confessed my status. I did it because I wanted them to check everything. Well, by then, here at the clinic they had checked and said that he/she is negative (Ayanda)

Her use of the word “*confessed*” suggests that she is admitting to a dirty and sinful secret. This word has religious connotations for ‘confessing’ sins. She is not currently practising her religion but has been religious in the past so it is possible that she feels that this is a dirty, sinful secret.

When asked if she attends church she said that she does not anymore as,

...even church people it seems that they have not accepted HIV positive people. So, if I were to go to church I would have to explain to the congregation what life I live.

Perhaps that traumatizes me (Ayanda)

She does not find religion to be a support as the other women do because she feels that she will be judged by the ‘church people’.

Ayanda has a clear way of talking about HIV/AIDS and the way she understands it working in her body. She represents her immune system as “soldiers” defending her from the onslaught of the disease,

...I fell pregnant and I tested. They checked my CD4 count... Eyh the way it was low, it was 12. ...have pneumonia and was admitted to King Edward. Then I asked the doctor in the ward about the time I wanted the results “I saw you just exclaiming, what did the results really say”. Then he/she said no, it was your CD4 count... It was very low; your CD4 count... your soldiers of the body that defend you from diseases....it was 12. I thought that it just meant that just because it is 12, the following day will set with one

soldier dead... Then by tomorrow another one dies. It means that by the end of the following week I will not have any soldiers. It means that by the following two weeks I will be dead/buried (Ayanda)

When the doctor informs her that her CD4 count is twelve this refers to the fact that she has only 12 CD4 per about 1000 cells/mm of bodily fluid. She interprets this literally to mean that she has 12 lonely soldiers marching around her body. This military metaphor has probably been a result of HIV/AIDS counsellors attempting to make the process easier to understand. Connelly and Macleod (2003) have highlighted the extensive military representations of HIV/AIDS in the media. This occurs as a means of positioning the virus as an enemy against which South Africa is fighting a war. Thus the construction of HIV/AIDS as a war zone occurs on many levels.

ZAMA

Zama is 28 years old, unmarried, with two children of six years and four years old. She was tested for HIV in 1998 and was negative; at that time she was with the father of her eldest child, however he was killed in a shooting incident soon after the child was born. She fell pregnant in 2001 with her second child, by her current boyfriend and she says that she did not date anyone else after her first boyfriend died. She therefore thinks that she was infected by the current boyfriend, who is a 'playboy'; however he has tested and was found to be negative. Both children are also negative. She has a part-time job two days a week and he also has a part-time job but these are very poorly paid.

After diagnosis, she told no one except for her boyfriend that she was positive but soon after she started on ART she disclosed to her cousin. She has also told some friends and all have been supportive. On the other hand, her boyfriend has been very unsympathetic. He stayed with her for one year and one month after she disclosed but then left her,

After that I went back to tell this brother who got me pregnant, I went to the clinic and it was said that I am positive. He had that disbelief he did not believe it. We carried on with life and then after that he left me and took other women.... (Zama)

He eventually returned and they are currently living together, however they are not getting on. He discusses her illness with other people and has revealed that she is HIV positive. He also hates using a condom during sex but she insists because she is aware of how essential this is to prevent him being infected and possibly herself being re-infected.

Zama initially had some major problems with ART side effects such as a severe skin rash. The clinic subsequently changed her onto a different combination of drugs just over a year ago and she has since improved a great deal,

...the ARVs really helped because my CD4 count had decreased, it was about 222, after that it had increased, because it has reached 300 and is going for 400..... they said that my skin problem is due to the decrease in my CD4 count, since I began the drugs I no longer have a skin problem, I feel right. When I began the drugs I gained weight, I was a 60 whereas my normal weight was 50. But now it has gone down, I think it is because of the stress, I am not saying it is because of the drugs, the drugs are treating me well (Zama)

She has always wanted to study nursing, however her parents did not have the money to send her for tertiary studies. She now volunteers as a community health worker through the clinic and takes great pride in her work. She is determined to use her situation to help others who are going through the same experiences. This seems to go some way towards fulfilling her desire to become a nurse,

...I became a volunteer at the clinic, and I told them that when I visit my patients I tell them that, my brothers you must check your blood, know how your life is going.... There is not even one person in those that I helped who died or was not helped, they are all still alive and surviving... (Zama)

She has had some experience with public hospital staff discriminating against her simply because she is HIV positive and this causes her some distress because of her respect for the medical field. She finds it incomprehensible that these nurses do not have respect for the patients because in her opinion nurses are supposed to be caring and compassionate towards the sick. In the following extract she describes one such incident which occurred in a public clinic. She shows a great deal of strength in herself not to give in to the nurse's bullying,

Also that I have seen that people who have Aids are badly treated in clinics and hospitals, not a clinic for only HIV positive people, but a public clinic.... I once went to...hospital when I still had the problem with sores and my skin.... This nurse says to me "listen here you, you know your problem, and you know your illness, as you want to go to the skin clinic". I also had eye problems. The job of this nurse was to place the stamp when you had finished or return the chart to the sorting station, at that time that was her job, she says to me, "First of all, the medicine at the eye clinic is finished, and the medicine at the skin clinic is finished". I then said, "Listen here I am not here for you, I

am here to see doctor Hlela at the skin clinic, I do not know the other doctor but I know where I am going". She took advantage as she read that I am HIV positive. I just said, "Sorry, another thing is that I paid my own money, I do not want my emotions to be disturbed" (Zama)

Zama does not fall into the trap of allowing herself to be passively ordered around in the face of the white uniforms of the all-knowing medical staff. She stands her ground and demands her rights as a patient. She also does not let herself be overwhelmed by the dreadfulness of her illness but instead focuses on what she has learnt as a result of being infected. She feels that she has learnt what is important to her,

I have improved in my life, I have gained a lot by contracting this disease, also how I should carry myself. I found out who my true friends are, I know the person in my family that loved whole-heartedly. Even in love if a man is able to go out and tell people that you are like this, that person did not love you. There are things that are secrets in love, things that are not supposed to get out, that person was just using my body (Zama)

It is very clear that she is not going to let HIV/AIDS defeat her or tear her life apart but instead that she will draw on her many strengths to make the most out of what could otherwise be a destructive experience. She is even planning on leaving her partner because of his lack of support and his discussion of her personal affairs with other people.

5.1.1) Agency

Before moving onto the next section, which will be a more analytical examination of Readings 3 and 4 (Relationships and Socio-cultural context), it is necessary to briefly consider in what ways agency appears in the women's individual stories. Crossley (2000) finds agency in the subject or story-teller, in that they can choose how to tell their story in particular ways (and not others), which is the core of "reflexivity" (30-31). The ability to be reflexive allows for a sense of purpose (or agency) (Crossley, 2000). The agency which is demonstrated in these narratives is not what would be considered an idealistic feminist notion of agency. This would involve an active rejection of that which restricts you. However, this is a simplistic Western understanding of what it means to be agentic and is dependent on contextual factors which allow for this kind of active agency.

For the women in this study, and for others in the same circumstances, their ability to be agentic is heavily constrained by external factors such as poverty, patriarchy and culture which they are relatively powerless to change. Therefore they can be agentic but only in particular, limited ways; Crossley (2000) refers to this as linguistic agency because through the person presents their story in a fluid, flexible way which is dependant on the context and audience. In this story, micro-choices and subtle presentations of self happen in "moment-by-moment situated experience" (p.30). However, the socio-structural – or broader discursive stories (being black, female, HIV positive and poor) stay the same, and cannot be changed or challenged, and these should also be told (Squire, 1997). This will be done in the following section.

A central example of how this agency occurs in the stories is the religious theme. In situations where there is no choice because of economic, cultural and social restrictions, religiosity can be a means to preserve agency. Surrendering yourself to a higher power is an active choice of how to deal with your situation. This could mean the women are able to leave their embodied identities by believing in something beyond this lived realm of suffering; or they are enabled to explain their oppressive circumstances to themselves (reflexively) in particular ways.

In this way, participants actively position themselves within the interview situation. They can choose how to tell their stories, both to the researcher and to others, in order to present themselves in a certain light. For example Gugu glosses over her very serious symptoms/side-effects so that she appears to experience no problems, this is done both for the audience (in the clinic setting) and for herself. This “flight into health” is well-documented in medical interviews, for example, breast cancer survivors’ retrospective accounts of the nausea, hair loss and bodily disfigurement that they suffered as a result of chemotherapy. Instead of focusing on these quite distressing side-effects, they tell stories of how they are healthy now or about what they have learnt from the experience of being ill (Charmaz, 1990). They are re-constructing their illness narratives in particular, positive ways.

5.2) Reading 3 and 4 – Relationships and Socio-cultural Context

This section will integrate thematic analyses of the five stories with a more analytical and theoretical interpretation of the data by linking these thematic dimensions to other studies on HIV that have used narrative approaches. Six central themes that are shared by the participants

have been highlighted, these are: poverty, relationship with partner, stigma and discrimination, support, acceptance/religion, hope and strength.

5.2.1) Poverty

It is vital to understand the pervasive effect of poverty on the lives of the participants as this contextual factor dictates their living conditions, their access to resources, and in fact every aspect of their lives. This research focused specifically on black mothers living mostly in conditions of extreme poverty in townships, who have gained access to free ART through a clinic, because they could not afford to pay for the medication themselves. All of the five participants and four of their partners are currently unemployed, or have poorly paid part-time work; therefore they have limited access to basic necessities such as food. The one woman whose husband does work full-time is the only one who does not mention anything about difficulties with money.

Staying healthy while HIV positive requires a certain way of living, and this is not within the reach of those existing below the poverty line. It is recommended that one should keep the immune system strong by eating a balanced diet with plenty of fresh fruit and vegetables, drinking fresh water, taking vitamins, and avoiding stress as far as possible. When one is on ART there is an added need to eat before taking some of the medication or it can have unpleasant side effects (Tromp, 2003). Obviously this is not always possible when neither the participant nor their partner/husband is working fulltime and they are not able to get support from the government,

Yes... I get hungry a lot, but that causes a problem because the situation is not right,

even my husband is not working. That is the problem that they make me very hungry

(Bongi)

Irrespective of possible side effects, they were sometimes forced into taking the pills on an empty stomach,

As I am taking them it is a must that before I take them, there is a thing that I must eat, to put in my stomach. You find that it is not there at the time when the children's father was not working. And me, I was also not working. It was hard but I had to take them. I took them anyway (Ayanda)

When faced with a choice between risking the unpleasant side-effects and risking the possibility of death without medication, the choice seems obvious.

Some of the women have been granted a government disability grant but this process is extremely problematic. Ayanda had a CD4 count of 12, which is well below the normal CD4 count of about 1000 cells/mm. If it is much lower than this level, the immune system is being compromised, and anything under 200 would be considered as final stage HIV infection or AIDS (van Dyke, 2001). Ayanda was initially turned down for the disability grant as it was claimed that even if her CD4 count is 12 she is not 'sick', presumably because she is being given ART at the clinic. That this access is the result of intensely impoverished conditions is not taken into account,

It was hard. It even came to the point where the doctor from King Edward made me.... The doctor here wrote me a letter, so that I can apply for a grant... He did not succeed. They said that I am healthy/fine and that my CD 4 count does not mean anything even if it is 12, and I am living like this it does not mean that I am sick (Ayanda)

There is no grant available specifically for those who are HIV positive or living with AIDS; instead they must apply for a disability grant of R700 per month. Applicants are only considered for this support if they are incapacitated to the point that they are unable to work (HIVAN, 2004). It is unclear who decides or what measure is to be taken to assess this 'incapacity'. Thus even an applicant whose CD4 count is 1 percent of what it should be can be turned down if it is decided that they are not sick enough.

Fortunately, she did eventually appeal and managed to get the grant. However, this is an even more complicated and actually completely incomprehensible process,

Because we have a problem that as we take drugs, CD4 count increases, when the CD4 count has increased, eh when you revive the grant it is said that you can't get it because the CD4 count has increased, whereas still you are HIV positive and these drugs want you to have eaten. How are you going to eat when you are not working? The disability grant has finished, where are you going to get money to buy food and you can't take these pills when you are hungry. Do you see that law that maybe the government can look at it, the one who has taken drugs must earn just for life. When you are not working...it can be taken away from them because you can buy them....I earn five months, it was said that I must reapply. Now...I am waiting so that I can reapply and hear that it is closed my request is not accepted....because it is said that I take drugs. And that thing I see as really unfair. The problem that I encounter is that I take drugs and as I take them, have not worked my whole life. It is possible that my disability grant can finish at any time.(Ayanda)

For persons living in such conditions, who were not working even before they became sick this is not really a decision that they can make. If they had been working before they became ill and had been booked off as 'sick' then they would have access to the grant, but because they have always been unemployed and poor, they cannot. Therefore they are stuck in a 'catch-22' as they must be poor to get the drugs and must be sick to get the grant and must get the grant to get the food to take the drugs...but if they get well from the drugs then they can't get the grant to get the food to take the drugs.

Swartz (1998) refers to this as "sick role legitimisation", as it involves fitting into norms of what 'being sick' involves: going to the doctor, being diagnosed, being booked off work and given medication to make you well. This is one reason why the cluster of symptoms which we now know as AIDS, has been constructed into a diagnosable 'syndrome', so that it fits into this medicalisation process.

Simphiwe had the experience of being quite ill with HIV/AIDS related illnesses but she could not afford the treatment at that stage because it was still R700 per month and she had not yet managed to access the disability grant,

The time that I was still pregnant with him/her there was no treatment yet and 'all illnesses' (Zulu medicine that treats all illnesses) was scarce. So they took me to and those at had the treatment but you had to pay for it, it was seven hundred rand and some change and I was not receiving my pension money as yet. So they gave me the pills for other illnesses that were on the side (onomathupha). I was being helped but I could see that I was really ill (Simphiwe)

Luckily, within a few months she was admitted to the free ART programme at the clinic and her health has improved dramatically,

When these people then said they have the treatment they said you must now come back to us because you can not be helped over there. They then took me and I began the treatment (Simpfiwe)

Thus living in poverty leaves women such as these at the mercy of the government social welfare and public health system which more often than not lets them down. The participants are very fortunate that they were able to access ART through a privately funded clinic however they often cannot access other social assistance to allow them to live healthily and therefore make the most of the treatment.

5.2.2) Relationship with Partner

The conditions of poverty and unemployment in which participants live, also opens them up to potential mistreatment by their partners because of economic, cultural and historical factors. Economic reliance on a male breadwinner can leave women in a fairly vulnerable position, unable to demand faithfulness or safer sexual practices (Bruyn, 1992; Campbell, 2003; Strelbel & Lindegger, 1998). In terms of patriarchal socio-cultural norms, ideals of masculinity are tied into having multiple sexual partners, even while being committed to a wife or long-term girlfriend (Holland, Ramazanoglu, Sharpe & Thomson, 1998).

In the same vein, the women in this study all have partners who they say have been unfaithful. Every one of the participants have at least one child to look after, and most live with their

partners and although at this time only one partner was employed full-time, the potential exists for these partners to bring in some much needed money. This means that the women cannot leave them even when they are unfaithful, if they wanted to. Also, regarding condom use, they have most probably never used a condom within their primary relationship and it is unknown whether they used them with other partners. The reasons for the lack of condom use are multiple and complex and are tied into entrenched cultural beliefs around the use of condoms within a 'trusting' relationships (Strebel & Lindegger, 1998). Thus cultural and economic realities have resulted in them not using condoms within their relationship, and this has led directly to their becoming infected.

I had initially thought that in every case it would be the men who infected their partners and that they would then probably leave when they found out that she was positive. However the truth is far more complex and it is almost impossible to determine. I ended up being far more sympathetic towards the male partners than I had thought possible. Four of the five participants strongly suspected that their husband or their long-term partners had infected them. The fifth did not mention how she became infected but analysis of her transcripts strongly indicates that she also suspects her partner was responsible.

However, there seems to be some misunderstandings about the transmission of the disease. All of the participants believed that because their partners were sleeping around with many other women they would be most likely to be infected in that way (and of course this is certainly true to some extent). But, they did not make any mention of the fact that biologically it is much easier for women to become infected through one sexual encounter than men (Tromp, 2003). And that they could have been infected even if they had only slept with one other man,

There is that when there is someone who is of course positive, you suspect each other. Nobody wants to say it is me... me personally I say it is him because...me I was not the person that sleeps around (Ayanda)

I can say that it was my husband, he was naughty (ubegangile). He was the type of person who loved women a lot, so even he did not know that in the end there would be problems like these (Gugu)

I think I got it because of my husband, he had many girlfriends, and I will not lie about that, he had many girlfriends. I am married but he still had girlfriends and when I found out that I have it, I went and told him, and he did not deny it, he said it be from me because I know that I am the one who slept around, I am sorry but there is nothing I can do now... (Bongi)

Zama's partner has actually tested negative but she still suspects that he has infected her, this could be because she does not want to admit that she has had other sexual partners, either during this relationship or before,

I am not guaranteed for sure but for me to find out that I have the virus I was dating the father of this child, the one who is still around...Really I can not say for certain that I contracted the virus from him, I'm not sure but he is a person for women, I can say he is a person who is a playboy you see, so I can not guarantee....It could happen that I got it from him or else maybe at that time it was hiding because we are told that it could hide you see (Zama)

All participants in this study told stories about their HIV-infection as if they were the innocent victims of 'naughty men'. These innocent-victim (gendered) stories are well-documented in literatures on HIV/AIDS (Crossley, 2000; Strebel, 1992; Squire, 2004). They achieve this through blaming their unfaithful partners for their becoming positive. I am not suggesting that this is never the case, but it does seem unlikely that not one of the participants has had unprotected sex outside of their relationships, especially since Zama's partner has been found to be negative.

Research suggests that women living in conditions of poverty are often very unlikely to have access to medical treatment (Gilbert & Walker, 2002, Tromp, 2003). Again, because men are more likely to be employed, they are more likely to go to the doctor when ill in order to be booked off work; women will instead rely on cultural remedies or over the counter prescriptions. However, it does not seem to be as straightforward within this particular South African HIV/AIDS context. This is because Neviropane was the first ART to become freely available when it was granted to pregnant mothers to prevent their unborn children from becoming infected; after this, some mothers were able to continue with ART. Men often don't undergo testing for HIV because they have little reason to unless they become sick; whereas, as a result of the careful surveillance of women's reproductive health, women are encouraged to undergo an extensive screening process when pregnant. Consequently, all of the women in this study were tested for HIV as a result of attending the antenatal clinic, thereafter they were given Neviropane to minimise the chances of mother-to-child transmission (cf. Allen, 2003).

Out of the male partners, three of the five had been tested and two of them are positive however the other two refuse to be tested; they claim that there is no reason to as they are not feeling sick and therefore they must be fine,

Yes, I always beg him, I say he must come, he does not want to come. But he is still fit, right and he sees himself as having no problem (Ayanda)

He does not want to, no he does not want to....We come here on our own to the clinic, he says bye and if he gives money he gives it, but he just says he has nothing (Simpfiwe)

When partners refuse to be tested, it leaves the responsibility for being positive solely with the partner who knows their status.

Three of the women mention that they now use condoms with their partners because of what they have learnt at the clinic. Although the other two did not make mention of this, they would be strongly encouraged to condomise by the HIV counsellors. Two of the men were fine with this but the third complained, however his partner insisted. Ironically the one who complained was the one who is negative but not for much longer though if he is not interested in condoms,

It is right, we use condoms, no sex without condoms, because he knows and I also know about my health/life that if I have sex without a condom, the new virus will enter into the old one and that kills the soldiers of the body that I have. In so much as this thing helps me because of the way in which my CD4 count keeps rising and rising (Ayanda).

He knows and it is he that you should tell more than others, because you can take the pills but if you still have unsafe sex you are stuck behind. He knows and he does not have a problem (Simpfiwe)

Quite often the male partners were very supportive. Only one had left his partner some time after finding out that she was positive. He has since returned but their relationship is not very good. The rest provide a lot of comfort, concern and care. Bongi's partner has tested positive and he attends the clinic with her.

It is just that he welcomed me, and even when I said, because at that time I came crying, he was still working. When he came home I was crying and I told him, I was crying, he was the one who comforted me and told me that I am still going to live because god is still here. Just because this has happened it does not matter. I am surprised that you are the one who is crying, as you are a believer. You are the one who should be making me strong. You know it was he who just became free and I then felt strong. I was like that for a whole year without taking anything and no problems, nothing (Bongi)

Most of the participants found it far easier to firstly disclose, and then discuss being HIV positive, with their long-term partners than with anyone else because the trust had already been established and also because the partner has to be included in the behaviours needed to 'Live Positively', such as condom use³. Ayanda and her partner have not told anyone outside of their relationship, because they wish to avoid being stigmatised within the family or by the community,

That we are just like this, there is nothing we can do. But we had an agreement that it must be something that is of our knowledge, between the both of us. Because going and telling people won't help us with anything. In fact the person that you tell will go and talk about you; you will find yourself that you are all over the place (Ayanda)

³ Living Positively is a component of pre-and post-test HIV/AIDS counseling which teaches the person how to stay healthy when HIV positive.

5.2.3) *Stigma and discrimination*

Stigma and discrimination against HIV positive people and people living with AIDS is rife in the communities where the participants live. Therefore, for all of the participants, the extent of their disclosure to others was dependent on how they thought they would be received. Perceptions that disclosure would lead to stigmatisation by the community or rejection by their family and friends led to an unwillingness to openly disclose, or else they would chose to disclose to a select group of people whom they trusted. There was a general fear of being spoken about behind their backs,

They don't know because I told myself that my letting them know will make, will bring me hurt/grief. Because I will hear that somewhere, someplace discussions were had about me, do you see that thing? (Ayanda)

These participants had varying degrees of disclosure but none was prepared to come out fully to the whole community.

The potential for stigmatisation and discrimination does not only occur through direct disclosure but can also be a result of the watchful eyes of the community who seem to be on the look out for any suspicious signs of illness,

Well, people do talk since they are quick to judge you especially when you happen to lose weight. They are quick to associate losing weight with this disease, saying it is now this and that but I don't entertain them (Simpfiwe)

HIV has come to be known as a disease which leads to weight loss and so when someone in the community loses weight they are often assumed to be positive. One of the more pleasurable

results of ART is that it patients usually put on weight quite quickly. Other symptoms of HIV or side-effects of ART can also be indicators that one has the disease,

I began the ARVs last year, it was July. I started with Nevirapine. It treated me well at first, but after a month, it was August, it gave sores on the mouth. People really began to avoid me, others realised then, but I was fit with no problem....The only problem was at the mouth, you see. People began avoiding me; maybe she has the boys (abafana)
(Zama)

In this case, instead of being sympathetic and supportive, people began to avoid her because she showed signs of HIV. Although directly translated “abafana” refers to boys, it can also be a metaphor for HIV/AIDS. Unfortunately, some of the symptoms of HIV and the side-effects of ART cannot be easily hidden.

There seems to be a general need in the community to be almost vigilant and guard against individuals who are HIV positive. Community members discuss how this person is losing weight and that person has been going to the clinic an awful lot. This doesn't appear to be out of a desire to help that person but simply to find out what is going on in order to protect oneself against it,

...when you have just begun using the drugs you come to the clinic every week. So the community does say “you went to the clinic last week and you are going again this week” things like that. It is better when you only come once a month. However, there are those times when you are asked, “are you ill? Who is ill? Is it the baby? What's wrong with him?” They keep asking too many questions because you are always going to the clinic. So they do have those talks (Bongi)

The participants were quick to defend themselves against these accusations which suggests that the consequences of admitting to being 'sick' are severe. The vigilance is strongly connected to fear, fear of the invisible, unknown other. As Goffman (1963, cited in Alonzo & Reynolds, 1995) states, when someone fails to fulfill group norms they are perceived as deviant and abnormal. Being 'unhealthy' is very much an example of being abnormal, especially with a disease such as HIV/AIDS as it is spreading so rapidly throughout South Africa, and it is also associated with certain death. In the same vein, Crawford (1994) says that social prescriptions of normality determine what kind of 'identity' is acceptable and what must be rejected. This rejection, or 'othering', is based entirely on fear as it is an attempt to defend oneself against that which is not 'normal'. Therefore stigma against those living with HIV and AIDS is a means of rejecting the possibility that this diseased person is 'like me', and that I could therefore also become infected.

One of the most significant instances of stigmatisation in the interviews was that of Ayanda and her refusal to disclose her positive status to her mother. She has disclosed to almost all of her other family members and she has been fortunate to receive a great deal of support from them. The only remaining family member who has yet to be told about her illness, is her mother, however she is not willing to disclose to her as she has seen how her mother reacts to those in their community whom she thinks are HIV positive. Ayanda is simply not willing to risk being treated in this same way,

...maybe the thing which makes me not tell my mother, I even explained it here in the clinic, that my mother is a kind of person that laughs at people like this. She does not have sympathy for them; you see if she sees any sick person in our community, she simply

associates him/her with this thing... Now, I have seen that if she can say [this] why would she not say it to me? She has no sympathy....I don't want to bring something which is going to upset me. Because it could go two ways. It might happen that she sees it or maybe a change happens, or maybe she does not see it and she goes and tells people that this thing is now in my home. And me, how will this make me feel? (Ayanda)

The initial response to this extract is that it must be devastating for Ayanda to be too scared to tell her own mother about her illness and in this way share her burden. However, what has come to be viewed as the ideal of 'disclosure' is not the best solution for every situation. It sounds as though she is not quite sure how her mother would react but she would rather remain ignorant and maintain a relationship with her mother, than risk a negative response. She makes a choice about how she wishes to present herself to her mother; she needs to show a kind of self that is acceptable and worthy of love. And this can actually provide a more supportive environment for her than one in which she discloses to her mother and is rejected.

A third way in which stigmatisation can occur is through cultural understandings of how HIV/AIDS is caused, such as witchcraft. IRIN PlusNews (2004) and Walker, Reid and Cornell (2004) claim that in South Africa, ignorance about the biological causes of HIV infection lead to traditional beliefs, such as witchcraft and other supernatural forces, being used to provide explanations. This leads to stigmatisation as a result of the community's fears of such powerful and uncontrollable things,

We have problems here in the community; our neighbours are suspecting us of witchcraft (bayasinuka). There was one who suspected me and said I was the one who bewitched her, she eventually died. I can bewitch a person as positive as I am and going

to the clinic? All that I can say is that they must check their blood, they will receive help. They must not look at being bewitched, there is no such thing as witchcraft....I would have helped her, but I could not because we did not get along....after she died her parents came clean because they had uttered the witchcraft word (Gugu).

In this instance, the parents were fully aware that their daughter was living with AIDS yet they chose to spread rumours of witchcraft against Gugu rather than admit this publicly. The participants, and many others in the community, are at a disjuncture between cultural and biomedical understandings of the causes of HIV/AIDS. However, as a result of their participation in the ART rollout, for the women in this study the biomedical story is more powerful and it stamps out other cultural knowledges. Billington, Hockey and Strawbridge (1998) claim that this is because the 'expert' medical profession has come to extend a certain degree of power over people's lives as a result of its privileged knowledge about the internal workings of the body and the control of disease.

Stein (2005) states that one potential benefit of antiretroviral treatment is that it requires the HIV positive person to disclose to at least one other family member or friend in order to have someone helping them to adhere to the treatment regime. This does not have the direct effect of reducing discrimination in the general community, as disclosure is most often confined to close family and friends, but with so many people now positive perhaps it is more effective in reducing stigma when it comes from someone to whom they are close. It is difficult to 'other' someone who is part of your family.

5.2.4) Support

One vitally important aspect of participant's lives was the amount of support which they had received from those who knew their positive status. Support is found in a variety of places: family, friends, the clinic, religion, sometimes even the community. It is difficult though for patients to initially find support because it involves disclosing to another person, and even though this may be someone whom they trust, it is impossible to foresee how they will react to this kind of news. Thus,

I was not able to tell anybody but when I began taking the drugs I did have that feeling that there has to be at least one person in my family that I tell, because one day I might have a problem and need help, but they will be blank and know nothing. I do have my sister that I told. People say she is actually my cousin. I told her; she did not have a problem (Zama)

All of them were required to disclose to at least one other person as a prerequisite of being given ART, this was most often their partner/husband, although some women came out to their sister or cousin. The care and support received from their partners has already been discussed so it will not be repeated in this section. In the following extract, Gugu mentions that the support that she received from her cousin gave her courage to deal with her disease rather than just give up and wait to die,

The person who helped me was my cousin, the one who worked at the...offices. She was advising me that I will not have a problem, because I am positive it does not mean that I will die. Eat food like this. She put me in contact with social workers. As I say she is the person who gave courage and then I told my sister...she has also accepted and has

no problem, although it was painful because when I was pregnant again she shouted at me, but I said that I did not know that I fall pregnant so quickly (Gugu)

This leads directly to her contacting social workers, starting to live more healthily and disclosing to someone else. From this it is possible to see what a difference this support has made to her attitude towards the disease.

At the clinic, they are given the appropriate counselling to prepare them for disclosure and in some cases they can bring the person they have chosen to tell to the clinic where counsellors will mediate the disclosure,

It was difficult to tell them and I was being eaten by this thing inside all by myself until I decided no, even at the clinic I getting counselling but they would say that they would not give me the pills if there was no one I was talking to at home. When you take the pills there must be someone who knows that if you become ill like this what the matter is because they do give you problems they have side-effects. So I came with my sister she was told, she listened, this was the time I was still in school studying. I went home and I told them and they accepted. (Simpfiwe)

However, once they have disclosed to one other person and that person accepts their illness and provides some support, it becomes much easier to consider the possibility of telling others to whom they are close. Many of the participants had disclosed to a number of other people amongst their family and friends and had for the most part been received very sympathetically. Even small gestures such as a phone call to enquire after their health made them feel that they were cared for,

No, no, no, they [friends] are fine, they treat me nicely even when I am sick they care for me, they phone me and even those that are not near my house, but they phone to check on me how I am. If I am sick they encourage me to go to the clinic and they are very caring (Simpfiwe)

No, they [family] do not have it, shame, they do not have it. They receive me well; even my brother receives me well. Because even my brother, when he first heard he really cried when he told me, really cried (Ayanda)

A major source of support is the clinic where they all receive the ART. There are two main reasons for this, firstly it involves contact with others who are also HIV positive and will therefore not be judgemental, and secondly there is support from the counselling and medical staff for both medical and psychosocial problems,

...coming here to the clinic has really helped me,....Here I see people that are open and talk, that I have also had this problem you see, to share ideas, to see that my problem is small compared to those of others, because I found out that another persons CD4 count was 8, so if a persons CD4 count is 8 and they are still alive, what will stop me from living and I am also proud and those people that were teaching us at the PL really helped, giving us hope, they taught me a lot. I felt relaxed, I do not have a problem, and I understand that I have a disease that anyone can also have (Zama)

Support and counselling increases knowledge of the disease, how to prevent its spread, and how to look after oneself when HIV positive (Stein, 2005). Some of the participants mentioned that

they felt more supported and able to deal with their illness when they have knowledge about it such as how to Live Positively in order to keep as healthy as possible.

5.2.5) Acceptance/Religion

Religious beliefs have just a passing mention in the literature review as it was not suspected that this would be such a central thread within the stories. However, it proved to be a fundamental means of support for most of the participants.

There is not a great deal of research on the issue of faith/religion within the sphere of HIV/AIDS. A very early Strebel (1992) study exploring the experiences of poor, black women did find religious overtones expressed by a number of the participants. The Strebel (1992) study has strong parallels with this study, except at that stage there was no such thing as ARV. The participants also thought that their partner had infected them but, much like the women in this study, they mostly did not display anger or resentment but rather acceptance of their fate. It was not concluded why this was so but some of the possibilities included the women's powerlessness, their inability to change their status, and their reliance on partners for economic support. Many of the women refused to come out about their diagnosis and therefore partners were their only means of support and care (Strebel, 1992). Although not one of the conclusions reached, it does seem possible that their religious backgrounds could also contribute to this acceptance of their status.

In a more recent study, Squire (2004) gained access to participants through a religious organisation and she found that the narratives were mediated through a religious framework.

She states that it is almost to be expected that one finds religious narratives when speaking to South African township women as they spend a great deal of their life engaged in religious activities, during the week as well as weekends. She found a religious genre of conversion and witnessing when they were first diagnosed. This would be followed by a sudden, abrupt acceptance and evangelical efforts to keep themselves living positively and attempting to help others to do the same (Squire, 2004). In most cases, religion also provided a community of support and acceptance.

In this study, religion was mentioned both in passing, as part of how one learns to accept that one is infected, as well as being a thread running throughout some of the narratives. All of the participants had religious backgrounds prior to becoming infected and four still attended some kind of church. There were very strong parallels with both the Strebel (1992) and Squire (2004) studies. Along the same lines as Squire (2004), participants spoke of their acceptance as something which just happened almost effortlessly,

So, we just accepted it (Ayanda)

I am better; I am alright compared to before, how I was before. I am alright, I am living. Also that I have accepted my situation, I do not have a problem anymore (Simphiwe)

Their seemingly undemanding acceptance of being HIV positive is strongly tied into a religious narrative. It does not adequately account for how they came to this level of acceptance and presents this as happening overnight when in reality it could have taken a long time. They may still have moments of anger and denial. It seems possible that the Christian ideal of forgiveness

and acceptance of everything that happens as part of God's will, is the main factor in their needing to present themselves as having completely accepted their HIV positive status,

This thing goes with to accept and when you have accepted it is also about how God has planned how you will live and how long you will live because another person will just get sick and die (Simphiwe)

Also, their belief in a higher power shifts responsibility away from them and helps in providing the courage to deal with being positive,

It is just to pray and to tell yourself that there are people that you see on TV and it is said that they are positive, they are fresh. I told myself that the Lord must now just give me courage (Gugu)

The Christian belief that the power of life and death lies in God's hands and that you will die when he decides that it is your time makes it easier to cope with the possibility of death.

Although none of the participants mentioned anything about going to a hereafter, such as heaven, when they die, it seems likely that this notion would also help in dealing with the knowledge of a shortened life-span,

I am making plans for my future because in my heart I know that I will not die right now, the time has not come. The time that God gave me when he was creating me. I always tell myself that I am still going to live although I have this disease, I will live that time. You will find that another person will die sooner although they do not have this disease because they were meant to go early. I just tell myself that it will be the time that God set out for me. Therefore, I must make plans, because I have this baby so when I die

I must leave something for him behind. I will try all that I try because there are still so many things that I want to do (Bongi)

One possible negative aspect of their strong religious beliefs is that HIV/AIDS can be interpreted as a punishment from God for sins that they have committed. Zama does not specifically state that this is how she sees her disease but it is implied in this extract from her narrative,

I can say that I believe in God, I did go to church when I lived in the rural areas. My eldest child's father died, when I gave birth to it, it did not know its father. Today he/she is 6 years but does not know his/her father. I kept myself busy with church, because I liked it, and I was right. Here in town you only come as a visitor, but when I am in the rural areas I go to church. I do not forget God, another thing is that you find some things are a punishment from him, because we do not; live right, to have a baby before marriage, we sin everyday. So I believe in him a lot (Zama)

Also not all churches have such a high level of tolerance and acceptance of HIV positive persons, as was mentioned in Ayanda's narrative. She refuses to attend church because she thinks she will be judged.

Religion mediates their stories in a number of ways: Firstly, the religious narrative is a prime example of their stories being shaped by "culturally available discourses". They use this religious framework of acceptance to tell their story in a particular way and thus we must question whether this is their actual experience, or is this the story they have chosen to tell? Secondly, as was mentioned in the section on their relationships with their partner, they have a need to position themselves as the victim in their stories of infection and disease and this could

be tied into their religion. Judeo-Christian religious discourse praises the martyr who is sinned against but still preaches forgiveness and acceptance. Both of these examples draw attention to the women using their limited agency to position themselves in a way which benefits them the most.

5.2.6) Hope and strength

A great deal of their hope does come from religion but it is also connected to the fact that they now have access to ART and this is improving their health and lessening their symptoms. This leads directly to increased hope and motivation,

They make it possible for me to carry on with my life, in the way that they give you hope. You see other people who are ill right in front of you and then you see them well again. There are people who were so ill that they could not even walk, but today you would not be able to tell that it is them, they are so well. Somebody that was toileting on her/himself without realizing and they just saw people changing them, but today you can hardly tell that it is them (Bongi)

No, there is nothing that is causing me discomfort. I was not really ill when I started taking the drugs; they tested me and discovered that my body soldiers are too few; I then began taking the drugs. However, what I can say is that I see myself gaining weight. Since I began taking the drugs my weight has increased, that is the only difference. That gives me hope that my life will still go on because the soldiers are also increasing (Bongi)

As a result of being diagnosed as HIV positive, individuals must adjust their self to an alternative time orientation and ultimately revise how they live in the present and make plans for the future; thus their life narrative is disrupted (Frank, 1995). Davies' (1997) found that HIV positive persons have to contend with the difficulty of living between life and death with a constant awareness of the possibility of death even while making plans for the future. However, ultimately most people had managed to integrate this into their lives. It is important to keep in mind that Davies is writing within a resource-rich and developed context with wide access to high-quality medical care and lifesaving medicines. This means that HIV positive people have a good chance of living healthily for a number of years and thus can more easily adjust their narratives to include an HIV positive diagnosis.

For many South Africans, living in conditions of extreme poverty means that they have limited access to medical care, antiretroviral drugs and even to nutritious food. It has already been discussed how poverty affects the lives of the women in this study. However, regardless of their poverty at home, these participants now have access to ART through the clinic and this will of course mediate their experience of the present and expectations of the future. ART gives renewed hope for the future

Eyh, I feel that I have hope that I am going to live a very long time. I do not have that negative attitude anymore that I used to have, that of counting tomorrows. I keep telling myself that hayibo, that 2010, hawu (Ayanda)

...there was a time where I thought that I was going to die just because I am HIV positive, but now since I have lived for so long, since 2001, 2002, 2003, 2004, 2005,

this is the 4th year it is going for 5. At the beginning of each year, I have a budget and I do not tell myself that I am going to die (Zama)

They were also excited about the fact that they could do so much more now that they were feeling stronger. This renewed optimism leads to increased strength within themselves and a desire to make plans for the future,

Never, it will never prevent me now. It was preventing me from many things but it will not prevent me now. It was preventing me from many things, but not now, now I can do anything that I want (Simphiwe)

That is what I say, I say I can do everything that I need to do and there is nothing that I will not be able to do just because I am ill. In my heart, I tell myself that I am well like other people and I must make plans like other people. All that I am able to do, that I have the power to do I do. What I do not have is because I cannot afford it or I do not have the power to have... (Bongi)

Chapter 6 - Concluding Comments

6.1) Major findings and Contributions

In the first section, the stories of Gugu, Bongzi, Simphiwe, Zama, and Ayanda were examined descriptively in terms of their separate backgrounds and how they made use of the voice of I. This ensured a thorough understanding of the separate lives and circumstances of the five participants. Any prominent features of their narratives were highlighted and discussed. The most significant feature of this section proved to be a consideration of how **agency** appears and what work it does in the stories of the women. The most noteworthy aspect that emerged was the contrast between a situated negotiation of the personal story, compared to the more socio-structural stories.

Following on from this, **six central themes** shared by the participants were examined more interpretively and linked to the literature, these were:

- **Poverty**

Poverty was a pervasive aspect of the women's lives as most of them and their partners were unemployed or had part-time jobs that did not pay well. They also had difficulty accessing government disability grants because they were often not considered to be 'sick' enough. This meant that although they had access to ART, they battled to find money for necessities such as food, and the medication often has to be taken on a full stomach to prevent adverse side-effects. Poverty also meant that the women had to accept certain aspects of their lives

such as unfaithful partners because their economic situation left them relatively powerless to either demand change or to leave their partner.

- **Relationship with partner**

All five of the participants were still in relationships with the same partner whom they were with when they found out that they were HIV positive. They had all disclosed to their partners and most of the women had experienced much-needed support. All of the women either openly stated or more covertly implied that they thought they had been infected by unfaithful partners. Only three of the partners had been tested - two had tested HIV positive, one was HIV negative - and the other two would not be tested. The participants tell their stories of infection with themselves in the role of innocent victim, and their partner as the only possible source of infection. Even the participant whose partner tested negative is fairly sure that he is responsible for her being positive. This seems to be connected to a strong religious background which requires that they must be the one who is sinned against and not the sinner.

- **Stigma and discrimination**

Stigmatisation appeared in three different ways in the narrative: Firstly, through disclosure, secondly, through their symptoms being interpreted by the community, and thirdly, through traditional cultural beliefs of the causes of HIV/AIDS such as witchcraft. The community is quite vigilant and guards itself against those who could be infected.

- **Support**

All of the participants had experienced fairly high levels of support from at least some family members and friends. Other sources of support include the clinic where they receive ART and for most of them their church or religious beliefs.

- **Acceptance/Religion**

Religion was included in the interview schedule mainly because it was anticipated that this would provide some degree of support for participants; however, it proved to have an effect on their lives and on their narratives in a number of ways. Every one of the women came from religious backgrounds, although Ayanda is not currently attending church because she fears how she will be received. Religion provided a framework for them to tell their stories of how they had accepted their HIV positive status. This was a Christian story of how they had been sinned against by their unfaithful partners but they had forgiven them and had accepted the consequence of becoming HIV positive.

- **Hope and Strength**

The knowledge that ART will prolong their lives and enable them to make plans for some kind of future, is a strong motivating force and helps them to be resilient in the face of the disease.

The stories shared by the participants about their lives as HIV positive, resource-poor, black mothers are likely to be shared by thousands of women across the country, who are also constrained by existing cultural, historical and socio-economic factors. This research aimed to gain a clearer understanding of how these women cope with their disease, what support they

have, the effect that negative issues such as poverty and stigma have on their lives, and the impact of their access to ART. What has become clear is how important it is to empower women in their situation. The ways in which this can be achieved is through continuing their access to medication, ensuring that they are given a disability grant to help them to remain healthy, ensuring that they and their partners are supported and knowledgeable through extensive counselling at the clinic, and taking into account alternative sources of support such as their faith.

However, this is not to imply that the women in the study came across as completely disempowered. All five showed themselves to be strong and motivated; they were not waiting around to die of this disease but rather were planning for the future, both for themselves and for their children. They were making the most of the opportunities which they had been granted, most especially the opportunity to access ART.

6.2) Limitations to Transferability

An intensive reading of the literature around HIV/AIDS in South Africa cannot fail to result in at least one reference, probably multiple ones, to how South African men are often to blame for spreading the disease. This is because of the patriarchal society in which we live which deems it acceptable that men have more than one sexual partner whilst condemning women for the same behaviour. It is for this reason that my initial reaction to these stories was of disbelief that the participants could bring themselves to stay with their partner/husband. I found it hard to accept that at least three of the women's partners/husbands have been unfaithful and have given them this terrible virus that will ultimately kill them, and for some their children as well, yet they still

stay together and the women all seem to accept this. They all seem to be very strong women and this makes it even more difficult for me to see why they would stay with such partners.

However, it soon became clear that this was actually connected to conditions of poverty and their learnt acceptance through religious discourse. But there is also something more than that. When I realised that I was analysing the transcripts armed with a very strong theoretical weapon, I took another look while consciously putting aside any previous interpretations. I discovered that I had been missing some important nuances of the stories. While I had been holding high the feminist banner and discussing the sad state of affairs in which the women now found themselves, I missed a very important contradiction in the data. The participants did not necessarily experience their marriage/relationship as problematic; rather many of them had been strongly supported by their partners. Not one of the participants had been deserted when they disclosed their HIV positive status to their partners. Most of them mentioned that they now practised safe sex. One of the women even said that her husband now accompanied her to the clinic where he was also receiving treatment. Therefore their partners are a source of support and care.

The reason that I am highlighting my initial mistake is to demonstrate how vital the role of reflexivity is in qualitative data. In most research, the process of analysis is hidden and the findings are presented as if they simply emerged from the text and they are the truth of the situation. But in keeping with Kvale's (1996) researcher as traveller, it is crucial that the researcher be extremely vigilant not to impose their own subjective understandings onto the data and then claim to be a neutral party. Therefore, although it could be said that my quite obvious remove from the world of the participants has meant that I could not understand their lives; I feel

that quite the opposite has happened. Because I was so aware of this divide in our experiences, I became even more vigilant about how I approached the data and in retrospect it seems that this distancing has provided more insight into the research process and the stories.

A second point which could have affected the outcome of this research is the ART clinic setting through which the participants were accessed and in which the interviews took place.

Participants could have felt that because they were being given access to free ART that they were obliged to take part. It could also have resulted in them telling stories which would place the clinic and their treatment in a particular positive light. In fact because of the politics of ART in South Africa, most research into ART is carried out within government clinic settings. In future research, it would be helpful to conduct interviews away from this context and see if this has an effect on the material.

6.3) Possibilities for Further Research

A number of possibilities for further research have emerged from this project. Aspects which were not central to the aims of this study have subsequently been found to be central to the stories and thus need to be examined in more detail. The most obvious of these is the role of religion or faith and how this ties into participants accepting that they have HIV/AIDS.

Secondly, exploration is needed into how couples negotiate relationships in the face of HIV. Questions that are particularly important are how initial disclosure can be best achieved, how couples learn to Live Positively together, and how sero-discordant couples (where one partner is positive and the other is negative) negotiate this situation, such as in the case of Zama and her partner. This will give insight into the difficulties faced by such couples.

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Appendix 1 - Interview Questions

Ask if she would like to choose another name for the interviews. But emphasise that her name will never be used in the research.

Explain about confidentiality.

Explain the aims of the research: These are to understand how it feels to be diagnosed as HIV positive and to be undergoing treatment. Hopefully this will make it easier in the future for others to be tested and to get medicine.

NB. I am looking specifically for stories so this should not simply be a question and answer session but should involve her telling detailed stories about her life.

Personal Details

Age? Marital status?

Number of children?

Where do you live (town or city)?

1. A FOCUSED LIFE HISTORY AROUND HIV

- When were you diagnosed as HIV positive?
- How was it that you came to be tested?
- Do you have any idea how you became infected?
- How did you feel when you were diagnosed?
- What happened after that?
- When did you disclose (if you have disclosed) and who did you disclose to?
- What hardships did you encounter as a result of being HIV positive?
- How did you overcome these?
- Have you ever experienced stigma as a result of being HIV positive?
- What effect has your HIV positive status had on your life (in terms of work, family, children, health and so on)?
- Are you still with the same partner? How has this affected your relationship?
- Is your partner positive? On treatment?

- Are your children positive as well?

2. *CURRENT EXPERIENCE OF ARV TREATMENT*

- How did you become aware that you needed ARV treatment?
- How did you get on this treatment?
- How do you see your illness now compared to when you did not have treatment?
- How do you feel about your self now compared to when you did not have treatment?
- What has helped or hindered you?

3. *THE FUTURE*

- What do you see for yourself in the future?
- Is this different to what you had seen for yourself before becoming ill?
- What does this illness mean now in terms of where your life is going?
- What support structures and networks do you have? Such as family, friends, support group, church and so on?
- What are your religious beliefs?
- How do you feel the treatment has affected your future?