

**Embodied subjectivities: Exploring the stories of HIV-positive African women  
through body mapping and narrative theory.**

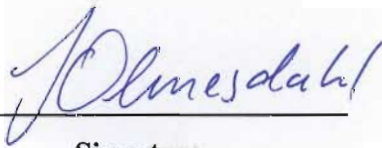
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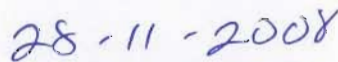
## Declaration

Submitted in fulfilment / partial fulfilment of the requirements for the degree of Master of Social Science, in the Graduate Programme in Psychology (Counselling), in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa.

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. It is being submitted for the degree of Master of Social Science in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other university.



**Signature**



**Date**

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## **Abstract**

This qualitative research project attempts to consider how HIV-infected African women position themselves, through the stories that they tell, within the dominant discourses of HIV in contemporary South Africa. The research is couched within the theoretical framework of social constructionism which upholds that there are no absolute truths but rather that individuals inhabit different 'realities' and possess different 'knowledges' relative to their social and cultural context. In this view language is the medium through which discursive practices inscribe identities with meanings. Seen through a Foucauldian lens, these discursive practices, in the case of South Africa, operate as forms of surveillance and social control to 'silence' those living with HIV. Through cultural and patriarchal norms operating in conjunction with the racialising legacy left by apartheid, women, particularly African women, have come to be the group most infected with HIV. Despite their often-difficult circumstances, narrative research has shown that, through acts of storytelling, many African women are able to construct positive versions of their lives. Using body mapping in conjunction with narrative interviewing, a small group of African women of varying ages and from diverse locations, but all belonging to a single Durban-based HIV support group, were asked to tell stories about their lives and how their experiences of themselves had been impacted by HIV. Their body maps and stories showed that, while dominant discourses about HIV/AIDS do function to limit their positions for positive self-definition, these women also produced counter-narratives that resisted some of the discrediting social constructions of the illness. Four dimensions relating to self in time, self in relation to others, HIV as a disruptive event, and spiritual beliefs and morality were found to be operating in their narratives. In addition, a fifth dimension, looking at how research practices themselves are 'situated' and construct 'subjects' in particular ways was considered and this called on 'the researcher' to deconstruct the subject positions of his (in this case) own discursive positioning.

## Chapter 1: Introduction

South Africa is the country estimated to have the highest number of people (about 5.5 million, or 12 % of the population) living with HIV in Sub-Saharan Africa and, with possible exception of India, in the world (Nattrass, 2006; Sienart, 2007). Prevalence rates within the different subgroups of South Africa's population mirror the social and economic disparities created by apartheid in that those who are most infected and affected by HIV/AIDS are generally also the poorest (Walker, Reid & Cornell, 2004). People living in poverty are susceptible to higher rates of malnutrition and parasitic infection which, in turn, undermines immunological response and accelerates the progression of the disease (Brandt, 2006). Comparisons between different subgroups in South Africa show a higher prevalence of HIV amongst women, and poor women in particular (Shisana, Rehle, Simbayi, Parker, Zuma & Bhana, 2005). There is also a higher prevalence rate amongst African<sup>1</sup> women compared to women of other race groups (24.4% versus 20.2%) corresponding with the African population as being the poorest of the overall South African population (Shisana *et al.*, 2005). KwaZulu-Natal, where this study is located, is reported by the Department of Health (DOH, 2006) to be the epicentre of the epidemic with the percentage of women testing HIV-positive at antenatal clinics in the province in 2005 being 39.1%, as compared to the national prevalence rate of 30.2%.

The sharp divisions between rich and poor in South Africa are a legacy of apartheid that have not only left certain populations more vulnerable to infection, they have impacted on the management and containment of the disease (Nattrass, 2004). While, according to Nattrass (2006), South Africa is now second only to Brazil in terms of the number of people receiving Highly Active Anti-Retroviral Treatment (HAART), there is a huge discrepancy between those actually receiving it and those still needing it - estimated to be at least 866 000 as of June 2005 (WHO, as cited in Nattrass, 2006). This is because South Africa's rollout has been poorly implemented and been situated against a political backdrop of antipathy and denial (Nattrass, 2006). The initial years of President Thabo Mbeki's presidency were framed by his alignment with the 'dissident' scientists who questioned the science linking HIV and AIDS. While the president subsequently withdrew

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<sup>1</sup> The term 'African' has been used here in preference to the term 'Black' because of the latter's connotations of the classificatory system of apartheid in which people were reduced to their racial status. The term 'African' acknowledges the identity politics that have arisen in post-apartheid South Africa and is therefore more in keeping with the spirit of the present inquiry.

publicly from the debate and the government announced the nationwide rollout of antiretrovirals (ARVs) in 2003 (after considerable pressure and a constitutional court ruling), Health Minister Manto Tshabala-Msimang has continued to refer to ARVs as 'poison' (Nattrass, 2008).

The position of the South African government has been situated within political discourses of resistance that see Western medicine as a form of colonial subjugation (Vaughan, 1992). These discourses, by portraying African culture as being corrupted by Western influences, construct healing through indigenous medicine as the automatic corollary. By constructing ARVs as toxic and undesirable, and situating preferred treatments instead within indigenous culture, these discourses have continued to politicize the personal, lived experience of HIV in a country long given to the racialization and politicization of illnesses.

Operating within these political and cultural dimensions are gendered social norms that render women more susceptible to HIV infection. Differences in prevalence rates between men and women in South Africa, and between African women and women of other race groups, reveal "the profoundly social nature of the disease and the fact that HIV is both fuelled by and fuels gender inequalities and the feminisation of poverty" (Brandt, 2006, p. 3). It is for this reason that HIV/AIDS has been described as a 'gendered epidemic' (Patton, 1994). Women are socialized into being subordinate, dependent and passive and are thereby placed at greater risk of infection. Paradoxically, these gendered norms demand from women that they take responsibility for negotiating their sexual relationships in the context of male-dominated gender relations where it is not possible for them to do so (Hoosen & Collins, 2004). Moreover, many women must look to their male partners to financially support their children and families. The roles that they are expected to occupy means that they must often forego educational and economic opportunities. This leads Treichler and Warren to state that, "[o]ne might even say that women contract HIV infection not only because of 'what they do', but because of 'who they are'" (Treichler & Warren, 1998, p. 112).

However, while it is the interrelationship of poverty, culture and constructions of gender that characterize the social context of HIV in South Africa, it is important to recognize that individual experiences of living with the disease differ qualitatively from person to person. Thus, African women should not be seen as 'victims' passively awaiting infection (Berger, 2005) as might be

implied by the polar constructs of 'domination' and 'submission'. Such an overly simplistic view ignores the gradations and variants of masculinity and femininity and how these constructs are constantly evolving within the broader discourses of the times. Hence, a more useful view is one that recognizes that power in relationships and its meanings are constantly being contested and redefined. This gives rise to an understanding of individual subjectivities as being constituted by the discourses in which they are embedded. Hence, identities are not fixed but transmutable, not singular but plural, not coherent but contradictory (Best & Kellner, 1991).

This view of identities as discursively embedded is in keeping with a social constructionist outlook and is the departure point of the present inquiry. Social constructionism maintains that the knowledge circulating in discourses is socially produced and is necessarily context-bound (Gergen, 2000). Hence, there are no universal truths but only a range of historically and culturally conditioned meanings (Gavey, 1997). In the case of HIV/AIDS these discourses function as meta-narratives at the collective level and through stories, rumours or gossip shared at the interpersonal level. These discourses are sustained not because they are true, but rather because they are deemed useful (Anderson, 1997). They may function to account for the origins of the disease, determine who is at risk, apportion blame and shape individual behaviour (Liddell, Barrett & Bydawell, 2005). They reveal not only the various ways in which the meanings attached to HIV/AIDS are socially constructed but also, in turn, how individual subjectivities are produced by that knowledge.

In this regard Foucault (1977; 1981; 1984) offers an explication of how individuals are produced as 'subjects' through the different practices of culture. In the Foucauldian view, cultural and political discourse function as 'technologies of power' through which individuals participate in their own subjugation by performing 'technologies of self' on their bodies and thoughts. Implicit within this conceptualization is the recognition that the lived experience of HIV encompasses "a plural collectivity of embodied subjectivities, experiences and body management practices" (Malson, 1999, p. 137). To this end the research question attempts to consider in what ways the HIV-positive African women in this study willingly participate in the 'technologies of self' through which "a *subjectivity* is produced in discourse as the self is *subjected* to discourse" (Parker, 1989, p. 64).

In the case of South Africa, the subjectivities of African women living with HIV/AIDS (and the stories that they have to tell) are very much embedded within the legacies of apartheid. These legacies are reflected in the ways in which race coincides with material hardships and with greater susceptibility to HIV/AIDS (Lindegger & Wood, 1995). In this regard, Zaina (2005) sees the conditions of apartheid as having imposed 'silences' on the oppressed and that these silences have been perpetuated through the current government's denialist stance regarding the scope of HIV/AIDS epidemic. But, inasmuch as the oppressed are subjected to silences, Foucault (1984) also points out that silences can function as a form of 'resistance'. This is especially true in the context of moralizing and stigmatizing discourses about HIV that impute individual accountability for contracting the virus.

Acknowledging these theoretical dimensions, the current research utilized a narrative approach (White & Epston, 1989; White, 1991) in conjunction with body mapping (Morgan & Thomas, 2003) to create a 'space' in which the women could share their stories. Body mapping, which entails a life-size tracing of a person wherein stories, signs and symbols of personal significance are annotated, is a participatory exercise that allows a person to gain, not only a sense of their biography, but also to understand how HIV has accumulatively impacted on their lives (Wienand, 2006). In this way the exercise serves to draw attention to how subjectivities are produced as necessarily embodied. But more than this, it serves to 'undo' the 'silences' imposed on those that are infected. Its use as a facilitative research 'tool' is particularly relevant in contexts where participants, whose lives are already vulnerable to subjugating discourses of HIV, might experience research practices themselves as alienating forms of oppression (Almeleh, 2004a). In this case, differences in language, gender, race, culture and HIV-status between the participants and myself represented barriers that could easily lend themselves to 'othering'. This necessitated not only using a methodology in which participants were invited to actively 'own' their productions of meanings, but an acknowledgement that my involvement as 'the researcher' meant that I was implicated in the co-production of those meanings. This begged for a deconstruction of my own positioning and the discursive resources to which I might appeal when making interpretations.

By recognizing that subjectivity is multiply produced and that the interaction of the participants and researcher shapes the accounts produced, the research upholds a social constructionist

paradigm. In this understanding the position of the 'researcher' shifts from ways of knowing through 'looking at' to ways of knowing through 'being in contact with' (Shotter, 1992). While it had not been my original aim to focus on the ways in which research practices themselves might be implicated in co-constructing the accounts, it became apparent, through the process of engaging with the participants and collecting their stories, that the practices of knowledge carry agendas which, in the case of South Africa's racialised past, it would be unconscionable to ignore. These agendas have insured the respectability and authority of their knowledge by rendering their underlying biases and motivations invisible.

To this end I have drawn upon the approach adopted by Zaina (2005) who, when interpreting the stories of her HIV-positive research participants, deconstructs her own position as 'the researcher' by offering multiple perspectives from which the accounts can be read. Her approach, drawing on Bakhtin's (as cited in Zaina, 2005) notion of 'dialogical exchange', is in keeping with a social constructionist outlook in which knowledge is never finalisable, but open to multiple interpretations depending on the position of the reader (Gavey, 1997). By acknowledging the 'polyphony' or 'multi-voicedness' implicit in accounts and how this contributes to the layering of subjectivity, we are able to begin to deconstruct the political agendas that claims to unitary knowledge serve and how these might be experienced as subjugating of people's lives (Zaina, 2005).



## Chapter 2: Literature review

### 2.1. The discursive constitution of self

Social constructionism offers a useful way of understanding how a person's identity is shaped by the social systems of meanings or discourses in which it is embedded. In this view self is inextricably dependent on, indeed constituted of, the same linguistic devices used in everyday life to make sense of ourselves and of others (Crossley, 2000a; 2000b). The emphasis on language as the medium through which self is generated means that, unlike the modernist conceptualization of a 'true' or 'authentic' self awaiting to be discovered or uncovered, there are a multitude of selves dispersed in the present, historically and cross-culturally (Potter & Wetherell, 1987). The meanings of what is said, and insofar as it is understood, are constructed by the local discursive systems within which the utterance is embedded. Hence, language does not function as a neutral and transparent medium through which 'reality' is presented. Rather, it functions to produce 'reality' and from this it follows that language cannot be value-free (Cheek, 2004). From a social constructionist position, we are incapable of knowing 'reality' outside of discourse because 'reality' is discursively produced.

The way in which 'discourse' is used here refers to "a systematic set of beliefs, ideas or knowledge and practices specific to particular social situations or locations" (Billington, Hockey & Strawbridge, 1998, p. 33). In understanding how individual subjectivities are embedded within and produced by these sets of knowledge and practices, it is useful to draw on the Foucauldian (1977; 1981) notion of the modern 'subject'. According to Foucault (as cited in Deacon, 2003), the rise of democracy and capitalism in the West in the modern era opened up new relationships of power which needed to be controlled through the practices of liberty. Foucault (1984) sees this as a shift from overt forms of sovereign and state power to that of self-control "exercised through the invitation implicit in modern discourses to assume full responsibility for our acts and intentions" (Zaina, 2005).

In *Discipline and Punish*, Foucault (1977) sees power not as something observable and exercised by a dominant agent over a subordinate one, but dynamic and distributed throughout all forms of



social interaction. Hence power is *productive* (rather than repressive or prohibitive), in that it is constitutive of people's subjectivities, and *decentred*, in that its workings permeate every-day forms of social interaction and cannot be fully 'seen'. For Parker (1989) it is the knowledge that circulates within discourses and the claims to 'truth' that these discourses purport to hold that is the currency of everyday social interactions of submission and domination. He states:

What is spoken, and who may speak, are issues of power. As well as organizing and excluding forms of knowledge, discourse relates and helps organize social relations as power relations (Parker, 1989, p. 61).

For Foucault (1977) control in modern society, what he terms 'technologies of power', rests on people's awareness that they are being watched (what he calls 'surveillance') and that this operates in conjunction with hegemonic discourses that promote personal accountability. Parker (1989) sees this as a dualism that operates from both *within*, through responsible agency (i.e. acts of confession in which we believe we are speaking the 'truth' about ourselves), and from *without* through forms of surveillance and discipline.

Individuals thus participate in their own subjugation through practices that police their bodies and minds. These practices, what Foucault (1977) terms 'technologies of self', invite individuals to effect certain operations on their bodies and minds in pursuit of 'truths' that promise to bring them fulfilment or liberation. In order for this to have been possible within Western modernity a certain type of body, a 'docile body', was required, one that could be regulated through objectifying sets of procedures or 'technologies of normalisation' (Foucault, in Dreyfus & Rabinow, 1982). These technologies of normalization, according to Foucault (1981), rested on the creation of abnormalities and deviances that society must treat and rehabilitate. Such a reading, applied to South Africa, sees HIV-positive bodies as a threat to social cohesion and necessitates the silent operation of disciplinary power "leveraged through belief systems emphasizing personal agency and, hence, responsibility and culpability" (Zaina, 2005, p. 170).

Foucault (1981) sees individuals as submitting themselves to surveillance and discipline through acts of 'confession' in which 'truth' is spoken thus purging the self of hidden, troubling secrets. Not only does this produce a context in which 'deep-felt needs' are experienced as 'authentic' or 'real', it makes their discovery a necessary precondition for liberation (Parker, 1989). Thus,

individuals seeking their own enlightenment through ‘confession’ are paradoxically ensnared in discourses that uphold certain cultural norms under the guise of truth. For Foucault, it is in sexuality that the deepest truths are believed to be found and that “it is in the confession that truth and sex are joined, through the obligatory and exhaustive expression of an individual secret” (Foucault, 1981, p.61). The connotations of sexual and moral deviance that HIV carries turns ‘confession’ (about one’s status) into a powerful form of social control, inviting as it does, the enactment of discipline and censure from both within and without.

The notion of rationality and choice, which Foucault (1984) argues has underpinned Western modernity, has given rise to discourses that serve to locate illness *within* the individual. These discourses, by upholding the notion of human beings as rational agents and therefore accountable for their actions, function as a ‘punitive rationality’ (Foucault, 1984) that leads to the social construction of stigma and blame. This has been particularly so in the case of HIV/AIDS in South Africa where, according to Marais (2000, p. 9), “codes of sanction [have] slotted neatly into moralistic narratives of deviance accountability and just punishment.” In illustrating how illness might be seen as a social construction, one that represents the prevailing themes and concerns of a particular society at a particular time in history, a Foucauldian reading allows us to make sense of how power and knowledge, in the context of South Africa’s racialised past, function to produce the individual subjectivities of those living with the disease.

## **2.2. The gendered construction of HIV**

In the context of South Africa, where HIV transmission is predominantly heterosexual, understanding gender relations is crucial to understanding the dimensions of the disease (Strebel & Lindegger, 1998). This understanding needs to be further situated against the backdrop of post-apartheid political discourses that have functioned to silence those with the illness (Zaina, 2005). These silences have been enacted through inter alia numerous forms of denial such as President Thabo Mbeki’s initial alignment with the dissident view that HIV is not necessarily the cause of AIDS, Government’s initial refusal to make ARVs available through the health system, the Health Minister’s references to ARVs as ‘poison’ (Nattrass, 2006) and through well-intentioned HIV-prevention programmes which have sought to empower women but have ignored the context of male-dominated relationships where women are not able to exercise effective choices (Strebel &

Lindegger, 1998). Because African societies have been traditionally arranged along patriarchal lines, men are the ones to exercise power in relationships, families and communities (Macheke & Campbell, 1998). This leaves women economically, psychologically and socially dependent on men and, in turn, influences the ways that they are able to negotiate their sexual relationships (Strebel & Lindegger, 1998; Walker, Reid & Cornell, 2004). In a context where women are wholly dependent on men for their survival, food and shelter easily become a greater priority than the potential risks of sexually contracted diseases (Hlatshwayo & Stein, 1997). As one of the African women in a Durban-based study by Hoosen and Collins (2004, p. 495) stated:

The problem is money, that is why we always listen to our man every time, even when he say I don't want to use a condom, because of money. We have children; no one will support our children.

The social construction of sex as an expression of love has naturalized women's experiences of pleasure into being dependent on ensuring men's pleasure (Hoosen & Collins, 2004). Penetrative, condomless sex is seen to be the most pleasurable for men and, as such, it is implied that, in order for a woman to satisfy her male partner, she should acquiesce to his demands (Campbell, 1995; Hoosen & Collins, 2004). While it is men who dominate sexual relations, women are nevertheless expected to bear the responsibility for contraception (Strebel & Lindegger, 1998). However, women's ability to insist that men wear condoms vies against other social constructions that associate sexiness with submission. Indeed, in South Africa where women are often expected to prove their fertility by bearing children, even before marriage (Heise & Elias, 1995), condom use may be seen as incompatible with the social prescriptions of masculinity and femininity. Women may fear that insisting on safe sex practices, discussing sexually transmitted infections (STIs) or HIV might result in violence, abandonment, or loss of economic resources and that this could, in turn, threaten their very survival (Heise & Elias, 1995). In a study of the gendered discourses of a group of Western Cape African women, Strebel and Lindegger (1998, p. 12) found that economic vulnerability featured strongly in how the participants positioned themselves in relation to HIV/AIDS. As one of the participants stated:

Another woman's marriage came to an end because the husband told her to leave when she advised him to use a condom in order to protect themselves from diseases. He took it as if she is also using it with other men, he told her to pack her things and leave the house.

In South Africa, HIV education programmes designed to empower women by stressing awareness and rational 'choice' nevertheless fail because they do not take into account the localized contexts in which gendered power relations play out (Hoosen & Collins, 2004; Preece & Ntseane, 2004). By promoting rational choice at the individual level they have tended to reinforce Western discourses of accountability that deny the lived realities of those that such campaigns are designed to target. Furthermore, these discourses have often been overlaid with socio-cultural attributions that are situated within the legacies of inequality engineered by apartheid. For as Irwin, Millen and Fallows (2003) point out, the issue of 'choice' rests on the assumption that the same menu of lifestyle choices is available to everyone and that those who become HIV-positive have therefore exercised poor choices. Not only does this ascribe an inflated degree of agency to people, it becomes a convenient basis for seeing people with HIV/AIDS "...as authors of their own misery [...] who have acted hedonistically or recklessly and are now suffering the consequences" (Irwin, Millen & Fallows, 2003, p. 21).

### **2.3 The social construction of HIV as a signifier of difference**

While the emergence of HIV/AIDS in the West has often been associated with 'deviant' and 'high risk' groups (male homosexuals, intravenous drug-users and sex workers) (Sontag, 1989), in the context of South Africa, where HIV transmission is predominantly heterosexual, meanings about the illness have been shaped instead by an array of social, political and cultural dimensions that reflect the country's racialized past (Lindegger & Wood, 1995). These interacting dimensions drive the subjective experiences of living with HIV and how individuals come to view themselves, view others, and are viewed by others.

According to Stein (2003) accounts of how stigma operates have tended to rely on individualistic models of psychology using the work of Goffman (1963) as a departure point. In these accounts a person who becomes HIV-positive becomes the recipient of aspects formerly attributed to the 'other'. As this happens the person becomes bound to "a deviant identity which is seen as offensive and repellent in the broader society" (Joffe, 1999, p. 47), what Goffman (1963), in his classic account on stigma, terms a 'spoiled identity'. For Goffman, stigma is any "attribute that is deeply discrediting" (Goffman, p.13) and which serves to set the person apart from society as 'deviant' or 'different'. Goffman (1963) identified three types of stigma: 'abominations of the

body' associated with physical deformities or deviations; 'blemishes of individual character' which refers to blemishes in an individual's identity or way of being; and 'tribal stigma' in which a person is negatively evaluated depending on their association with a particular group. These different forms of stigma represent the different levels at which a person becomes evaluated negatively. In combination these give rise to HIV as a powerful signifier of difference (Ariss, 1997).

While Goffman (1963) stressed the importance of the *visibility* of stigma as the basis upon which difference is signified, other dimensions have been identified in terms of how stigma is read in society. These relate to its concealability, its course (in the case of a disfiguring illness or condition), its degree of disruptiveness, its aesthetic qualities, its origins and its peril (Jones, Farina, Hastorf, Markus, Miller & Scott, 1984). In this regard stigma will have greater charge if it is not easily concealable, if it is a condition such as an illness in an advanced stage, if it disrupts or impedes social interaction, if it is deemed to be aesthetically unpleasing, if the stigmatized person or his/her group are blamed for its origins and if it brings death. Importantly, it is through social interaction that these dimensions by which a person becomes 'discreditable' become apparent.

Drawing on psychodynamic ideas, Hollway and Jefferson (2000) define stigma as a constantly evolving dialectic between personalized meanings and the way that the illness is constructed socially. For Hollway and Jefferson (2000) it is not just that stigmatizing experiences are internalised, but that these experiences are subjected to internal processes aimed at managing and minimising its effects on the individual. They devise the notion of the 'defended subject' to explain how social experiences of stigma interact with the person's internal experiences to result in a complex formation of self-identity. What is instructive about their argument is that individuals are not passively produced through discourses, but that they position themselves in such a way as to *invest* in particular discourses in order to defend against threats to the self. It is these threats to the self that generate anxiety and precipitate defences against these threats. So while people internalise stigmatizing views of themselves, they are also dynamically engaged in managing their identity so as protect themselves against the anxieties of a 'spoiled identity'.

In a paper entitled, '*We are not fresh*': HIV-positive women talk of their experiences of living with their 'spoiled identity', Gibson and Rohleder (2006) used psychoanalytic concepts within a social

constructionist framework to explore how a group of HIV-positive isiXhosa women, all living in Khayelitsha, Cape Town, dealt with their stigmatized identity. What was found was that, in order to resist seeing themselves as 'bad', these women resorted to a type of splitting that, ironically, is the same process of stigmatizing an external 'other' described earlier by Joffe (1999). In some cases the 'bad other' became those who were ignorant of their HIV status and, as such, it was they (the unformed others) who were the ones deserving of pity or derision. As one of the women in Gibson and Rohleder's study (2006, p. 36) said:

I think it makes a difference because I know my status. 'I am not like the ones who doesn't know their status [...] I think very badly about those people who don't know their status yet, because what they do are they taking it as a joke.

Thus, in positioning themselves in this way these women were making their situation seem more admirable. Another strategy observed in these women was that of the splitting of self into a past unhealthy self and a present healthy self. All the women in the study were being treated with antiretrovirals and were thus in a position, having received their medication, to locate the undesirable aspects of their illness safely in the past, or with others that were visibly ill. In this way the women were able to distance themselves from the threat of the illness, most especially the inevitability of AIDS itself.

In examining how HIV/AIDS functions as a signifier of difference, Kowalewski's (1988) study with gay men found that, in appealing to discourses to construct the HIV/AIDS subject as the 'unhealthy other', one who is morally accountable, a double stigmatization is produced in which the person becomes not only diseased but also morally corrupt. Crawford (1994) argues that the construction of the 'unhealthy other' through moralising discourses is necessary in order to preserve the concept of self as 'healthy' and, by extension, 'moral'. Thus, for Crawford (1994, p. 1347) the "pursuit of health has become the pursuit of moral personhood." In this way stigma functions as an 'exercise of power' (Gilmore & Somerville, 1994) that reinforces socially constructed norms by denying those deemed to be 'undesirable', 'dirty' or 'deviant' full participation in the social practices that confer meaningful personhood. This can be particularly devastating in cultures considered to be traditionally 'collectivist' where self is inter-relationally defined. It highlights how Western constructions of HIV/AIDS, reliant on notions of choice and



accountability, are breaking down traditionally 'collectivist' African societies (Mwamwenda, 1999).

Nzioka (2000, p. 2) notes how moralising discourses about HIV/AIDS in Kenya have constructed HIV/AIDS as a "moral and physical contamination" that not only stigmatizes the person during their lifetime, but also in the afterlife. Because of the 'shameful' circumstances of the person's death, they are often denied a proper burial. By holding individuals accountable these moralising discourses impute blame and thereby function as a 'punitive rationality' (Foucault, 1977). In South Africa anticipation of the negative reactions that disclosure might elicit have been borne out by actual instances of job loss, social isolation, physical violence and even murder (Maughan Brown, 2004; Shisana & Simbayi, 2002; Stein, 2003). Disturbing instances to have made their way into the South African media are Nkosi Johnson, who was prevented from attending a specific school, Gugu Dlamini, who was stoned to death by her community for declaring her HIV-positive status, Lorna Mlofane, who was gang-raped and subsequently murdered when she disclosed her status to her attackers and Mpho Motloung, who was murdered with her family by her husband who then placed a sign on her head which read, "HIV Positive Aids" (Almeleh, 2004). In this way stigma fuels an atmosphere of silence whereby those who are ill may choose to keep their illness a secret.

'Experienced stigma' (Maughan-Brown, 2007) comes from the 'knowledge' that one has been infected with a virus that is incurable and can infect others. This leads Green (1994) to put forward that there are three types of 'sexual careers' open to an HIV-positive person: 'the path to celibacy' - the avoidance of sex altogether; 'the path of behaviour modification' - adjusting one's sexual practices; or the denial that others can be infected through a failure to modify sexual behaviour. In the case of HIV-positive women, managing their 'spoiled identity' has implications not only for their sexual behaviour but also for their role in bearing and raising children. Because the roles of 'mother' and 'carer' are embedded within communal norms that confer a sense of value, many women may fear that disclosing their status may incur the loss of these roles and, with it, their self-esteem (Ciambrone, 2003). This can be especially devastating in cultures that emphasize childbearing as an indicator of fertility and, by extension, desirability.

## 2.4 The politics of the HIV-positive body

The way in which the body serves as the medium through which subjectivity is constituted is outlined by Foucault (1981) in his concept of 'bio-power'. What he asserts is that in modern society the body has become the site whereupon knowledge and power converge, producing what he calls the 'political technology of the body' (Foucault, 1981). This is because power-knowledge relations "have an immediate hold upon it; they invest it, mark it, train it, torture it, force it to carry out tasks, to perform ceremonies, [and] to emit signs" (Foucault, 1977, p. 25). The 'natural' body has thus been replaced by "a fantastic simulacrum of body rhetorics" that renders it a "floating sign-system at the intersection of the conflation of power and life" (Kroker & Kroker, in Malson, 1999, p. 146).

Varas-Díaz and Toro-Alfonso (2003) draw on Foucault's notion of the regulation of bodies through regimes of discipline and punishment to locate the corporeality and visibility of the body as the site central to the contestation about the meanings of HIV. Because HIV is transmissible and incurable (Herek, 2002) HIV-positive bodies are constructed as invasive agents who threaten the social order (Sontag, 1989). They are read as being unfathomable and out of control and as such "inaugurate a crisis in those systems of power concerned with the regulation of bodies" (Thomas, 2001, p. 8). Thomas believes that the crisis in regulating HIV-positive bodies in South Africa has led to "regimes of representation which make the lives and bodies of some visible and place others under erasure" (Thomas, 2003, p. 1). This has been particularly evident in Government's denialism in which the President's initial alignment with the AIDS dissidents, who questioned the link between HIV and AIDS, left "the bodies of those dying with AIDS without access to medication and care" (Thomas, 2003, p. 1).

But, inasmuch as the body can be read as a social 'text', it should not be forgotten that it is also an organic entity that, in the case of illness, brings a corporeal dimension to subjectivity (Tamboukou, 2008). Tamboukou (2008) goes on to identify illness narratives as the site where embodied knowledges are deployed. This is because, for her, memories too are embodied and influenced by the physical trajectory of the illness. The ways in which the lived experience of illness is situated within the materiality of the body, in combination with the ways in which the body is socially 'already inscribed' (Foucault, 1981), gives rise to what Turner (1992) calls the 'embodied actor'



whose body becomes an important 'discursive resource' in the production of narratives. In conceptualizing the body as a discursive 'vehicle' that is at once both 'organic' and 'social', Turner points to the body's capacity to function as a site of resistance capable of counteracting the practices of disciplinary power as outlined in Foucault's (1981) concept of 'bio-power'. By aligning their bodies with particular accounts of their illness individuals are able to construct counter-narratives that resist the damaging social constructions of HIV/AIDS. Viewing the body in this way, as simultaneously encompassing "constraint and resistance" (Turner, 1992, p. 192), highlights how it mediates the lived experience of HIV as an embodied subjectivity.

## 2.5 'Speaking' bodies: Re-presenting the HIV-positive body

Given how those living with HIV/AIDS in South Africa are subjected to 'silences' (Zaina, 2005) re-presenting the HIV-positive body constitutes, for Thomas (2003, p. 5), "the scandal of HIV-positive bodies that speak: their speaking is a means for the dissolution of the boundary between the body that speaks and the body that listens." This is because, according to Thomas (2001, p. 8), "sick bodies remind us of our own bodies and the fragile hold we have on our own health." In response body maps have the capacity to "transgress the silences imposed on HIV-positive bodies and serve as visible markers of the forms of injustice to which they are subject" (Thomas, 2003, p. 1). By generating powerful counter-narratives these works vie against popular and media portrayals of HIV-positive bodies as sick, fragmented and deteriorating (Varas-Díaz & Toro-Alfonso, 2003). Moreover, their genesis into beautiful works deconstructs commonly held views that associate 'illness' with 'ugliness' (Gilman, 1995).

A body map is a life-size tracing of a person's outline wherein personalised references can be written, drawn or painted. These include anatomical images, symbols, as well as written references to place names, significant others and important dates. Through their visual means body maps function at both the *personal* level, where they open up a multiplicity of new insights and connections for the maker, and at the *political* level, where they speak out against hegemonic Western bio-medical discourses which reduce HIV to being the consequence of decisions taken at a personal level. Furthermore, like other art-based modalities, body mapping is a therapeutic process in itself involving "the person as a whole, including sensory motor, perceptual, cognitive, emotional, social and spiritual aspects" (Karkou & Glasman, 2004, p. 61).

The concept of the body mapping derives from a collaborative research programme undertaken in Khayelitsha involving a group of HIV-positive women, the Bambanani Women's Group (BWG), between 2001 and 2003. The programme formed part of the Memory Box Project, an outreach programme of the AIDS and Society Research Unit (ASRU), Centre for Social Science Research (CSSR) based at the University of Cape Town (UCT). The ASRU's original memory box programme was conceived at a period when the South African Government was resisting the nationwide rollout of antiretroviral treatment on the grounds that it would be too costly and that there was insufficient evidence available on the toxicity of their side-effects (Nattrass, 2004). The 'memory box' concept, derived from memory box projects that had been used in Uganda with illiterate rural communities, was envisaged as a tool through which HIV-positive parents could plan for their children's future by decorating baskets or tins within which they could place objects of sentimental and historical value, including important documents like birth certificates, that would be able to "assist with succession planning, grieving and also providing children with a sense of their roots and family history" (Wienand, 2006, p. 3).

In 2001, based on the work done in Uganda, and drawing on narrative models of therapy, memory box workshops were conducted with HIV-positive people in Khayelitsha. These workshops, designed to train the participants themselves in facilitating workshops, led to the emergence of two teams of women that came to comprise the Bambanani Women's Group. In 2002 the ASRU launched the Longlife advocacy project aimed at documenting the life-changing benefits that ARVs had for these women. In keeping with its advocacy agenda, a decision was taken to showcase visual material generated by these women (i.e. their body maps) alongside their personal stories in a book entitled, *Long Life: Positive HIV Stories* (Morgan & Thomas, 2003). According to Almeleh (2004a, p. 6) the result was that they shifted "the ARV debate out of the economic, structural and clinical spheres, and into the personal sphere of lived experiences." As one of these women (cited in Morgan & Thomas, 2003, p.85) stated:

Many people in the government say poor people are too stupid to understand how to take the ARVs. We love these drugs. If we are out we hunt for a tap to take them. We put them in a smaller box if we know we are going out the time we need to take them. We never forget. This is the most important thing to us. Like air.

Through their narratives these women were able to resist the stance put forward by the South African government that ARVs were hazardous. What their body maps highlight, for social research, is the importance of facilitating “symbolic spaces” (Almeleh, 2004a p. 7) in which personal stories, and the dominant discourses within which they are situated, can be shared.

## 2.6 Narratives: It's all in the telling of the story

The field of narrative theory encompasses a number approaches each differing in emphasis (Squire, Andrews & Tamboukou, 2008). These include, amongst others, *event-centred* approaches (what happened to the narrator in time) (Labov & Waletzky, as cited in Squire 2008), *experience-centred* approaches (concerned with the subjective world of the narrator) (Squire 2008), *constructivist* approaches (concerned with perceptual and cognitive views of reality insofar as they are constructed by underlying mental processes) (Crossley, 2000a) and approaches concerned with the *co-constructedness* of accounts in which meanings develop through exchanges of communication (Squire, Andrews & Tamboukou, 2008). What is central to these approaches is the view of self as a phenomenon “characterized by interpretation, variability, relativity, flux and difference” (Crossley, 2000b, p. 529). However, unlike the anti-humanist view put forward by Foucault (1977; 1981), and adopted by many other social constructionists, which problematises the notion of human agency by regarding self as a product of social and cultural discourses operating at a particular time in history (Burr, 1998), narrative approaches maintain that, while discourses do constrain individuals, individuals are also capable of resisting or challenging dominant discourses through the stories they tell (White, 1991).

Narratives are frames through which the narrator comes to experience, judge and make sense of the everyday circumstances of his/her life (Heydén, 1997). They order the meanings attached to the experience of time and temporality and in this way function as the “organizing principle of human action” (Sarbin, in Crossley, 2000a, p. 46). This is because meanings are understood and interpreted in relation to the dimensions of *activity* incorporating as it does both *time* and *sequence* (Crossley, 2000b). Thus, the sequence of events is extremely important, not as they might have happened in a factual sense, but in the way they have been selectively configured so as to ascribe particular meanings. These relationships and connections shape the “webs of interlocution” (Taylor, 1989, p. 39) that form the basis of self-understanding and gives structure to the flow of

human experience. Squire (2008, p. 43) emphasizes that it is this “sequential temporal ordering of human experience into narrative” that *makes* us human. It is this web linking experiences of the self, temporality, relationships and morality as they unfold in time that constitutes a narrative.

The concept of time, in so far as the temporal orientation towards projecting into the future is concerned, is especially important when attempting to understand the disruptive and devastating effects a chronic illness such as HIV can have on a person’s life (Crossley, 1999a, 1999b). Descriptions such as ‘narrative wreckage’ (Frank, 1995) or ‘biographical disruption’ (Bury, 1982) highlight how previously taken-for-granted assumptions about the future lose their ontological certainty in the face of an HIV-positive diagnosis. Davies (1997) uses the term ‘provisional existence’ to describe the existential dilemma that is imposed on people who receive an HIV-positive diagnosis. This, she asserts, disrupts the individual’s capacity to project into the future with any certainty and necessitates alternative ways of living that compensate for the loss of a future that once existed. It is this ontological security conferred in having a future that contributes directly to the sense of meanings attached to one’s actions (Davies, 1997).

Frank (1995) believes that people who are ill are wounded not only in the body but also in voice and hence “need to become storytellers in order to recover the voices that illness and its treatments have taken away” (Frank, 1995, p. xii). The act of constructing a story about the illness, what Heydén (1997) calls an ‘illness narrative’, serves to renegotiate and re-order the disruptions caused to self, relationships and time by the illness. ‘Time’ is thus critical element in illness narratives because it provides the structure by which otherwise chaotic events are rendered coherent and meaningful (Gergen & Gergen, 1984). Importantly, for the storyteller, the illness narrative serves a dual purpose: “Relationships with others are reaffirmed and the self is reaffirmed. Serious illness requires both affirmations” (Frank, 1995, p. 56). But, as Crossley (2000b) points out, we can only ever claim partial authorship of our stories because of the social and cultural discourses in which our lives are embedded. Frank (1995, p. 80), for instance, notes how the normalizing expectations of modernity give rise to the ‘restitution narrative’, a culturally preferred narrative that upholds that “for every suffering there is a remedy”. While this highlights how the stories we live by intersect with dominant narratives to constrain authorship, it is at this same juncture that the telling of stories, as suggested by White and Epston (1989), opens up a ‘space’ for the emergence of a multiplicity of meanings.

Narrative therapists such as White and Epston (1989) restore the notion of agency that is rendered problematic in the Foucauldian view. They maintain that, while as human beings there are no *essential* truths, our lives are daily constituted by *experiential* truths. White and Epston's (1989) pioneering efforts were organized around a set of therapeutic techniques that allow people to reclaim their lives from the subjugating 'gaze' of dominant discourses. These two authors believe that dominant discourses perpetuate viewpoints and practices that serve those who benefit most from them while marginalizing the possibilities offered by alternative narratives. These authors believe that when these stories can be told in an affirming and non-judgmental context, the practices that produce dominant and oppressive narratives can be deconstructed and new perspectives can emerge.

Deconstruction, for White (1991), entails the objectification of problems through 'externalizing conversations' which invite people to develop counter-language in relation to that which they find problematic in their lives. Through externalizing conversations, as opposed to internalizing ones, individuals can begin to recognize the extent to which they have been recruited into the policing of their own lives and the lives of others through 'technologies of self' (practices which subjugate self through the discipline of the body and mind) and 'technologies of power' (practices which subjugate individuals through constant surveillance, evaluation and comparison) (Foucault, as cited in White, 1991). This process of linking meaning-making with action encourages people to identify how dominant cultural knowledges come to frame the particular stories that guide their lives and relationships and which give rise to their identities (White, 1991). It is this process of linking the 'personal' with the 'political' that deconstructs Western, neo-liberal discourses of responsibility and accountability that locate problems within the individual.

White (1991) believes that it is the stories that we tell about ourselves that embed our lives within particular discourses. Through the process of externalization White (1991) believes that individuals are able to regain a sense of personal agency and thereby escape the 'passengerhood' experience of life. As White (2000, p. 62) states, "it is not one's motive that shapes action, but one's account of one's motive that has been socially derived in narrative negotiations." Thus, for White (1991), stories have very real, not imagined, effects in determining the structure that shapes a person's life, for stories not only determine the meaning given to experiences but which aspects of the experiences are emphasized. Through a process of 're-authoring' White (2000) believes that

individuals can reconstruct their narratives and thereby reclaim their lives from dominant discourses. He believes that re-authoring of stories can be therapeutic because it allows people to be “other than who they were” (White, 2000, p. 75).

## **2.7 Living with HIV: Storying the disruption**

According to Kleinman (1988, p. 55), the experience of illness “is created out of the dialectic between cultural category and personal signification on the one side, and the brute materiality of disordered biological processes on the other.” Hence, one’s understanding of one’s illness is informed by multiple sources ranging from various health practices to understandings and images circulating within media. Together these comprise an epistemology that reproduces or challenges a person’s understanding of his/her illness. In the West, according to Bartos & McDonald (2000), the ways that subjectivities are constituted in relation to living with an HIV-positive diagnosis have shifted with the advent of the ‘new treatments era’. The availability of newer treatment modalities has changed the trajectory of the illness and, with it, the meanings attached to HIV/AIDS. These changes to the expected lifespan have had implications for treatment compliance and sexual practice that has heralded a new phase of what it means to be living with a ‘HIV-positive identity’ (Zaina, 2005).

In this regard Davies (1997), drawing on research with individuals who have been living with their HIV-positive status for at least five years, outlines three available temporal orientations: ‘living with the philosophy of the present’; ‘living in the empty present’; and ‘living in the future’. Davies (1997) maintains that living in the empty present is the least fruitful temporal orientation, while living with the uncertainty of the future makes the present meaningful when referenced against the possibility of imminent demise. Davies (1997, p. 565) believes that living with HIV entails “two mutually contradictory orientations or ways of being”, one orientated towards the closing off from the future, a retraction from the busyness of life and a reconciliation towards the end; the other, an orientation towards life which demands a reconfiguration of present living insofar as it is referenced against an imagined future. This stance of two mutually exclusive positions is exacerbated by lay theories in which people are depicted as dying because they “gave up the fight” (Davies, 1997, p. 564). This implants the nagging doubt for infected individuals as to whether or not they really do have control over their illness and the extent to which the decisions



they take could affect its course. What Davies suggests is that the degree to which individuals are able to challenge the dominant social and biomedical discourses about HIV leading to AIDS, determines how they ultimately come to experience their lives. What this suggests is that, inasmuch as HIV/AIDS is a social construction, individuals are nevertheless able to, through the meanings they attach to the disease, affect the path of the disease even if they are not actually able to cure themselves.

Crossley (1998; 1999a; 1999b), in her studies with individuals living with long-term HIV-positivity in the United Kingdom, correlates the above three categories put forward by Davies (1997) with three of her own. These Crossley (2000a) calls: 'the conversion/growth story' (Internal story); 'the normalising story' (External story); and 'the story of loss'. Crossley (2000a) maintains that what they represent are the three key areas implicated in the reorientation of the physical, psychological, emotional and spiritual aspects of self towards time so as to be able to continue living meaningfully with HIV. Building on Bury's (1982) conceptualization of chronic illness as a 'biographical disruption', Carricaburu and Pierret (1995) put forward the concept of 'biographical reinforcement' as a way of explaining how people reconstruct the individual and collective aspects of their pasts by accentuating certain parts of the identity prior to living with HIV. Crossley (1997), for instance, conceptualizes these identity processes as drawing on oppositional constructs of self as 'survivor', living in accordance with all the possibilities available to someone who is HIV-positive, and 'others', those who succumb to seeing HIV as leading to AIDS and death. The narratives of the Bambanani women (Morgan & Thomas, 2003) are a case in point that demonstrates the potential for 'survivor' stories to have positive connotations (Almeleh, 2004a). These stories, in which the women constructed positive identities for themselves despite often appalling treatment by significant others and the discrediting social attributions of HIV/AIDS, provide alternative ways by which those living with HIV/AIDS might see themselves and be seen.

The Bambanani women's narratives also illustrate the importance of having a sense of belonging or connection to others when coming to terms with HIV. In their case this was provided at one level by the group and its commitment to providing a 'space' in which their experiences could be shared. According to Josselson (1996) it is the sense of belonging or 'embeddedness' that serves to ameliorate the devastating experience of isolation and/or ostracism that HIV can bring. In addition,

it allows for the appraisal of self in relation to communally held definitions of 'moral goodness' (Taylor, 1989). In this regard a small ethnographic study by Hlongwana and Mkhize (2007) considered how the members of a Durban-based, HIV support group drew on their Christian beliefs to make sense of their illness. They found that the support group represented a "constructed community of need" (Carr, in Hlongwana & Mkhize, 2007) in which the members were able to construct and reconstruct their identities by rationalizing their illness through Christianity and the Bible (Hlongwana & Mkhize, 2007). In making and remaking their identities through references to their spiritual beliefs the women in this group were engaging in constant reappraisal of their 'commitments and identifications' (Taylor, 1989). From a social constructionist perspective, what the group represented was a discursive resource for the storying of HIV into their lives.

## **2.8 Positioning the 'I' of the researcher**

Social constructionist conceptions of the self as decentred, fragmentary and interpersonally 'distributed' (Bruner, 1990) have problematised the notion of authorship because they question the notion of the 'I' of the author existing prior to a text and call, instead, for an acknowledgement that the author's voice is multiply constituted (Zaina, 2005). Accordingly, Zaina (2005) draws on Bakhtin's (as cited in Zaina, 2005) notion of 'polyphony' or 'multi-voicedness' as a way of de-centring and deconstructing the power implicit in the singular 'authorial' voice. Zaina (2005) developed relationships and conducted interviews with HIV-positive individuals or those living with or affected by HIV/AIDS over a period of three years (2001-2003) through support group discussions held at the East Bank Hope Clinic, Alexandra, and through individual therapy sessions at the Agape Healing Community, Mamelodi, and the Family Life Centre, Parkiew, Johannesburg. Her aim was to engage these individuals in conversations and, through a Foucauldian or post-structuralist discourse-analytic lens, facilitate the deconstruction of dominant social constructions of HIV/AIDS inherent in political and cultural discourse. Her intention was to open up spaces previously silenced by the moral attributions of liberal humanism that function to hold individuals accountable for their actions and, by extension, their illness.

In her readings or interpretations of the resultant material, Zaina (2005) offers four voice positions through which the narratives might be understood. These are: The Academic; The Reflexive Re-



searcher; The Therapist; and The Philosopher/Poet. She states that adopting multiple positions serves to:

...foreground the constructed nature of any one 'reading' of a text and to juxtapose different interpretations or constructions on the basis of the ways in which these variances in social position translate into differences in access to discourses and the impact this has on meaning. In aiming to deconstruct the 'authoritative author', the idea of offering alternative readings of a text is also that it might be experienced by the participants as empowering in the sense that the author does not claim to 'know' or to be able to provide a 'definitive reading' (Zaina, 2005, pp. 55-56).

By opening up multiple positions Zaina (2005) believes that meanings are able to emerge through the dialogical exchange of different voices that thereby resists the representationalism of the singular view implicit in 'monologism'. She devises a format in which she presents chunks of the participants' narratives as 'storyboards'. She then reflects on these storyboards through the different 'lenses' of the positions mentioned above.

By adopting these different voice positions she aims to open up dialogue and discussion between the different voices that have informed her own positioning and how this has given rise to the ways she sees others. So, from the perspective of The Academic, she gives voice to her intellectual understandings of the ways in which the social world has been conceptualized and how it demands of her the organization of her thoughts into rational and linear sequences. She fears that, from this position, she easily becomes trapped in 'mind' because the disconnection from her heart has her speaking '-isms'. From the position of The Reflexive Re-searcher she reflects on her capacity to be an ethical practitioner and to militate against the abuses of power that occur when researchers are unwilling to acknowledge their own epistemological assumptions in order to ensure that their 'findings' are valid and representative. She notes how, in attempting to be a reflexive researcher, she is easily ensnared in Foucault's (1981) notion of 'confession' and how this positions her to be an executor of 'disciplinary power' by holding other researchers accountable for the ways they position themselves and their subjects.

From the position of The Therapist she strives not to let 'analysis' give mind precedence over heart. From here she differs from the Academic in that she reads texts with her 'gut' with the knowledge of what it means to access, beyond words, the meaning of another's experience. She

sees her own embeddedness in Western models of psychology and how human problems are contextualised within the 'political'. And from the voice of The Philosopher/Poet she has a desire to deepen the 'reading' of texts and the ways they might have been shaped by timeless archetypes and images. From this position she desires to transcend moralizing discourses that give rise to cultural dogma and institutionalised religion. She "aspires to give expression to the complexity and subtlety of life and our inability to know things completely" (Zaina, 2005, p. 59).

What is instructive about Zaina's (2005) approach is how, in adopting these different voice positions, she avoids the trap of didactic monologue and is thus able to dismantle the authority implicit in the 'authorial perspective'. Her approach is relevant to aims of this study for the way it gives expression to the multiplicity of voices informing both her own position as well as the narratives of her subjects. In addition, the voice positions she has chosen correspond closely with the voice positions of my own trajectory in that, like her, I have gone through a Psychology Masters programme and a subsequent internship and, like her, have felt at odds with the ways that these programmes appeal to modernist psycho-medical constructs to legitimise the situating of illness within individuals. And like Zaina (2005) I too come from a white, middle-class background and am conditioned by having a 'privileged' perspective. I therefore recognize that there is a need to be critically reflexive when approaching a topic such as HIV/AIDS, especially given how the inequalities of the past have functioned to render some more vulnerable to the disease than others. While the space constraints of this dissertation do not permit me to make the extended reflections of the different voice positions that Zaina (2005) does, I am nevertheless informed by her approach, for it not only acknowledges the constructedness and multi-voicedness of texts and their interpretations, it contributes towards an accountable human sciences research.

## Chapter 3: Method

### 3.1 Conceiving of the research

The research design was envisaged as comprising two components: First, a body mapping workshop would be held with a small group of HIV-positive individuals; second, an in-depth narrative interview, building on the body mapping experience, would be used to explore how each of the participants discursively positioned themselves in relation to living with HIV. The use of body mapping was thus conceived to provide a contextual framework that could enrich the narratives given in the interviews.

Given the vulnerabilities of those who are HIV-positive and the ethical issues arising from differences in language and culture between the participants and myself, the use of body mapping was deemed to be an appropriate exploratory 'tool' for eliciting stories. As Cornwall and Jewkes (1995, p. 1671) point out, "the process of constructing a visual representation is in itself an analytic act, revealing issues and connections that local people themselves may not have previously thought of." The workshop was also envisaged as a 'space' in which to develop rapport with participants prior to the commencement of their interviews. While body mapping comprised one part of the design, the other was the use of in-depth narrative interviews to capture 'thick' or experience-rich accounts and thereby enter the psychosocial worlds of the respondents. A narrative approach is particularly appropriate for present study because it recognizes that, through acts of storytelling, as envisaged by White (1991), individuals are able to construct powerful counter-narratives.

My own interests in using body mapping as a facilitative research tool were piqued by the book, *Long Life: Positive HIV Stories*, by Jonathan Morgan and the Bambanani Women's Group (2003). The book confirmed for me what I had long believed about the possible therapeutic uses of art, especially in overcoming the obstacles posed by illiteracy and language differences (Cornwall, 1992). Having used art-making as part of my research methodology at Honours level, in this case an adapted body mapping exercise to allow disabled children to reflect on their identities (Olmesdahl, 2005), having participated in body mapping training conducted by HIVAN (2006)

and having conducted one body mapping workshop already, I felt equipped to run the present body mapping workshop.

As in the case of the Bambanani Women's group (Morgan & Thomas, 2003), a narrative approach allowed for the capturing of stories that enhanced the body maps and vice-versa. In my case, having studied isiZulu up to third year level at university I felt reasonably equipped to converse with the participants in their own language should the need arise. However, I also realized that there would be differences in language, gender, race, culture and HIV-status and that these carried the potential for 'othering' to occur. While I did not believe these were grounds to not proceed with the research, I knew it would necessitate a sensitive approach that acknowledged how these power differentials might impact on the process. Part of this would entail a willingness to be accountable for my own situatedness so as to deconstruct the power implicit in the positions of the 'researcher' and 'author'. This is performed later in this chapter, and in Chapters 5 and 6.

### **3.2 Locating the participants**

The stigmatized nature of HIV in South Africa means that there are serious ethical issues that need to be considered when attempting to locate HIV-positive research participants. For this reason it was deemed preferable to have participants all belonging to an existing support structure (i.e. an HIV support group) than forming a group for the purposes of this research only. It was felt that those who were part of an existing HIV support group would be more familiar with each other and thus more likely to share their personal stories within a group-based body mapping activity than individuals who were unfamiliar with each other. An existing group would also be more likely to derive long-term benefit from the sharing of its members' stories and would be able to continue supporting its members in dealing with any of the emotions that might emerge as a result of body mapping or story-telling.

However, obtaining a group proved extremely difficult. Several KwaZulu-Natal-based HIV/AIDS organizations were approached and asked for the contact details of the coordinators of Durban-based HIV support groups. Some coordinators who were contacted expressed a general wariness about researchers approaching them, as I was, from the 'outside' with the unfamiliar (to them) concept of 'body mapping'. Some support groups based on the fringes of the greater Durban area

(i.e. peri-urban) were deemed, for practical reasons, to be too inaccessible. They furthermore consisted of members with extremely limited English fluency that would necessitate the additional involvement of a translator. The difficulties in obtaining a group of participants for a one-off body mapping workshop outside of a broader funded project bore out several difficulties, namely the ways in which attitudes about HIV/AIDS have turned it into a guarded and politicized terrain, very different from other chronic illnesses (e.g. cancer) not laden with imputations of moral accountability.

A Durban-based HIV support group that had been functioning for several years was eventually found. Contact was initiated with the coordinator of the group and a meeting between her and myself was scheduled. During this meeting the research proposal was presented to her. Body mapping procedures were explained and that a follow up interview would be required from each of the participants. It was agreed that, as coordinator, she would assume a 'gate-keeping' role by contacting the members individually, explaining what would be entailed and organizing with them to attend the body mapping workshop. Signed consent, indicating that participation was voluntary, that withdrawal was permitted at any stage and that confidentiality would be assured was to be sought from all the participants prior to the commencement of the workshop. The consent form also drew their attention to the availability of counselling services at the Centre for Applied Psychology (CAP), University of KwaZulu-Natal (UKZN) (see Appendix 2).

The original group (i.e. present on the day of the body mapping workshop) consisted of ten women. One woman did not complete all aspects of her body map and was not included here, another withdrew after the body mapping workshop and did not wish to be interviewed. In the interests of anonymity individual descriptors of the remaining eight participants included here have not been given. All participants, the coordinator and the names of any other persons referred to have been given pseudonyms. All eight women received their HIV-positive diagnoses within the last five years with the most recent diagnosis being in November, 2007. The youngest was 19 years old, with the oldest being 53. Seven of the participants were isiZulu-speaking while one (Grace) was Sesotho-speaking. All except one (Phumzile) were capable of conversing fully in English. For this interview the coordinator was present throughout to facilitate conversation by putting forward the questions (in isiZulu) and translating the responses (into English). This

interview is given special consideration in Chapter 5 (see 5.2). All the other interviews were held in English.

### 3.3 Process

The gathering of narrative material consisted of two stages: (i) An initial one-day body mapping workshop; and (ii) a semi-structured, narrative interview, adapted from McAdams (1993), was conducted with each of the participants in the second or third week following the workshop. Each of these stages in the process is discussed in more detail below.

#### 3.3.1 The body mapping workshop

The body mapping procedures used in the current research followed and built on the body mapping procedures laid out in the in the CSSR's, *Mapping workshop manual: Finding your way through life, society and HIV* (Almeleh, 2004b). The manual outlines a step-by-step procedure to be used for body mapping. Each step poses a question (including, later, HIV-related questions) to the participants about an aspect of their lives, which they are then asked to draw or write onto their map. Through the visual means afforded by the body map, the person is provoked into thinking about how their body has been accumulatively affected by HIV from both '*within and without*' (Almeleh, 2004b, p. 12). The adapted instructions used in this research consisted of four main headings (supportive others, personal power, personal experience and HIV) with a set of questions under each heading (see Appendix 3). The body maps were intended to stimulate discussion and not replace it, for not only did they generate interesting visual material that enriched the narratives given in the interview, they also served to facilitate discussion amongst the participants on the day of the workshop.

The first part of the data gathering process consisted of a one-day body mapping workshop held at a venue in Durban with which the participants were already familiar. Prior to commencement signed consent was obtained from all participants (see Appendix 2). They were informed that the process entailed a body mapping exercise and a one-hour interview to be arranged for another day. Participants were then taken, step-by-step, through the process of making their body maps (a detailed outline of each of these steps appears in Appendix 3). During the morning the participants

worked on their body maps; after lunch they had an opportunity to discuss with others the significance of their pictures and stories. The body maps were all digitally photographed (see Appendix 5). In the interests of confidentiality, all persons' names appearing on the body maps have been removed using computer software.

### **3.3.2 The semi-structured narrative interview**

The second part of the data gathering process consisted of a one-hour interview held with each of the participants in the second or third week following the body mapping workshop. A semi-structured narrative interview protocol adapted from McAdams (1993) was used (see Appendix 4). The protocol, which in this case was amended to include HIV-specific questions, comprises the following seven key areas: (1) life chapters; (2) key events, notably, high and low point experiences, turning point experiences, earliest memory, important childhood, adolescent, adult, and other memory; (3) significant people; (4) future script, outlining aspirations, goals, plans and dreams; (5) stresses and problems; (6) fundamental beliefs and values; and (7) discerning a life theme.

The interview protocol was translated into isiZulu so that whenever a question was not understood, it could be given in the person's own language. All except one of the participants were sufficiently conversant in English to answer questions without requiring the presence of translator. One participant (Zanele) spoke partially in isiZulu but did not require the presence of a translator. One (Phumzile) answered all questions in isiZulu and required the presence of a translator to read the questions and facilitate further discussion. For this interview the head of the support group served as translator/facilitator. This particular interview, in which three voices were present, highlights how multi-layered the construction of narratives actually is. It exposes the naiveté implicit in the assumption that when the interviewer and interviewee are alone, as in the case of the other interviews, they can co-produce an account that momentarily leaves aside the 'voices' of those not physically present. These issues are analysed in more detail in Chapter 5 (see 5.2)

Two interviews (Noloyiso and Zanele) were conducted at the Centre for Applied Psychology (CAP) rooms at the University of KwaZulu-Natal (UKZN) while the remainder were conducted at the group's usual meeting venue in Durban. Those who were interviewed at the university were



available for their interviews prior to the others (i.e. on weekdays) who were only available on Saturdays. Four interviews (Grace, Nondumiso, Phumzile and Thandeka) were held on the second Saturday after the body mapping workshop, with the last two interviews (Londi and Zinhle) on the third Saturday.

At the interview each person was presented with a digital colour print of their entire body map as well as close-ups of details. All questions pertaining to each body map were referenced against these prints during the interview. At the end of the interview each person was given a set of these prints to keep. The original body maps were deemed to be too large (2m x 2m) and unwieldy to bring to the smaller space in which the interviews took place. Participants were however asked if they wanted to take their original body maps. For practical reasons relating to their size, none did. Interviews were tape recorded and later transcribed. All responses given in isiZulu at the time of the interview were later translated into English. Where quoted, for the purposes of discussion, isiZulu is followed immediately by the English translation in square brackets. Reproductions of the body maps have been included in Appendix 5.

### **3.4 Data analysis**

The 'data' in this study comprises transcribed material derived from the interviews as well as the body maps containing both written and pictorial references. A semi-structured interview (McAdams, 1993) provided a framework for exploring the narratives of the women. Using this interview as a departure point, four key areas of narrative, representing the 'webs of interlocation' (Taylor, 1989) that render self meaningful, were devised. These are: (i) self in relation to time; (ii) self in relation to others; (iii) biographical disruptions; and (iv) personal beliefs. Each transcript was systematically read and narratives relevant to any one of these four lenses were gathered together. Once all eight transcripts had been 'thematized' according to these dimensions each dimension was unpacked into smaller qualifications and experiences. Sub-headings were devised by grouping together responses relating in some way to a more specific experience. Thus, for example, the first main heading, 'Self in relation to time' was broken down into two sub-headings, that of 'self in relation to the past' and 'self in relation to the future'.



Beyond the narrative dimensions above, my analysis draws on Crossley (2000a) who suggests that it is useful to identify three elements of personal narrative, namely: (i) imagery; (ii) themes; and (iii) narrative tone. These can be read as indicators of how subjectivities are constructed within the context of available socio-cultural resources. Imagery is best understood as the way in which people portray themselves through “personally meaningful images, symbols and metaphors” (Crossley, 2000a, p. 89). These constitute our personal myths (McAdams, 1993) and are situated against collectively held images and their associated meanings. Themes are underlying patterns that carry across time and place and inform a person’s sense of purpose. McAdams (1993) maintains that the two most fundamental, and often conflicting, themes underlying narratives are what he calls, the need for agency (encompassing power, achievement, independence, mastery and justice), and the need for communion (encompassing love, intimacy, interdependence and belonging). These themes, he posits, constitute the generativity of personal stories, the way in which adults script the dynamic tension between these conflicting motivations. Because, according to Crossley (2000a), imagery is often indicative of particular themes, she recommends looking for them both together when searching through transcripts. Narrative tone, for Crossley (2000a), refers to the way in which the content of a narrative is characterized. In this regard McAdams (1993) interpretively invokes a psychoanalytic lens in suggesting that the most persuasive influences on the tone of adult narratives is the extent to which secure attachments were formed in a person’s early years of life.

In selecting extracts for discussion I have paid attention to both the generativity of personal stories as conceptualized above (Crossley, 2000a; McAdams, 1993) but also to how these stories are situated within and constrained by dominant discourses of HIV/AIDS. In this way I have hoped to highlight how the respondents produced competing and sometimes contradictory narratives and how these give rise to the multiple selves. For the purposes of discussion written references appearing on the body maps have, where relevant, been inserted alongside extracts from the interviews. Treating the body maps as equivalent ‘texts’ and making reproductions of them available as appendices serves to lift the silences that are discursively imposed on HIV bodies. In addition, these works, by lending themselves to multiple interpretations, stand as a counterpoint that resists the imposition of any singular interpretation of the narratives.

While Chapter 4 consists of an analysis of the themes that emerged in the women's narratives, as described above, Chapter 5 draws on longer excerpts from two interviews (Noloyiso and Phumzile) to reflect on how research processes aimed at 'capturing' stories are the selfsame processes implicated in their co-construction. The extracts from these two interviews highlight how multiple voice positions operate not only for 'subjects' but for the 'researcher' too and, as such, beg for a deconstruction of authorial position and its implied singularity and coherence (Zaina, 2005). Again, references from the body maps have, where relevant, been inserted into the transcript excerpts. These references from the body maps represent dislocated inter-texts that function as additional 'voices'. Their inclusion attends to my reflexivity in co-constructing the accounts.

### **3.5 Ethics**

In view of the discrediting and stigmatizing constructions of HIV/AIDS that abound, there is a great need to be extra sensitive in ensuring the anonymity of participants. However, at the same time, the potential for 'anonymity' to transform actual people (with real identities) into 'subjects' allows for the production of potentially subjugating 'truth regimes' (Josselson, 1996). There is therefore a tension between allowing subjects to 'speak' and the extent to which a researcher is prepared to acknowledge his/her own processes in choosing what aspects of the subjects are presented (Parker, 1992). As Gready (2008) points out, the question of who controls the narrative and what happens to it after the interview is a highly contentious topic and one that is not easily resolved.

This presents an inescapable dilemma in that the researcher must either assume the position of 'naïve realism' (Parker, 2005), in which accounts are presented as empirical or experiential truth, or acknowledge his/ her own positioning and thereby enter a 'confessional space'. For the feminist writer, Krieger (1991), it is the latter that represents the most ethical way of engaging in social research because it entails a deconstruction of the privileged position of power of the author. She believes that claims to scientific 'truth' are misrepresentations because all knowledge is necessarily perspectival. She maintains that whenever we discuss others we are always talking about ourselves. This leads her to conclude that "[w]riting personally has become a way that I can feel I am doing social science in a responsible manner" (Krieger, 1991, p. 2). To this end

deconstructing the authorial voice and its implicit power represents a way of ethically managing the bind in which the 'anonymity' of the participants can function simultaneously to subjugate them (Zaina, 2005).

Careful consideration was also given to how the participants might experience themselves (during or after the process) as a result of their interaction with me. It was therefore crucial that the participants belonged to an existing HIV support group, both in terms of being already familiar with and trusting the other participants and in terms of having access to ongoing support once the research component itself was concluded. My introduction to the participants was handled through the group coordinator who played a 'gate-keeping' role and reported back to her members. Prior to the commencement of the body mapping workshop signed consent was sought from all the participants. At this time they were also made aware of counselling services offered at the Centre for Applied Psychology (CAP).

During the interviewing stage one referral for follow-up counselling was made. In this particular case the respondent appeared to become distressed when discussing her mother's uncertain state of health and this necessitated the setting aside of the interview questions in order to allow her to compose herself. What this interview showed, in terms of ethics, is not just how the telling of a story, according to White's (2000) narrative therapy model, can be therapeutic, but how porous the divide is between 'doing research' and 'doing therapy'. The switch that occurred on my part, from that of 'researcher' to that of 'counsellor', highlights how the power differentials implicit in these voice positions shapes, not only shape the type of narrative produced, but also how the narrator might come to experience herself thereafter. These different positions are considered in greater detail in Chapter 5.

### **3.6 Trustworthiness**

According to Squire, Andrews and Tamboukou (2008) there are no overarching rules or standards by which narratives should be gathered or can be evaluated. While the current study has borrowed from several narrative theorists (Crossley, 2000a; McAdams, 1993; Squire, 2008; White, 2001, White & Epston, 1989), it has also, by drawing on Bakhtin's (as cited in Zaina, 2005) notion of 'dialogical exchange', paid special attention to the co-construction of accounts. Also important is

the recognition that accounts are contextually-dependent and contain within them multiple and divergent voices. Preserving or acknowledging the context in which a narrative emerges has a direct bearing on how it is subsequently 'heard' or 'received' (Gready, 2008).

As already indicated, it was important to work with individuals who all belonged to an existing HIV support group. This meant that the members were already familiar with each other and were more likely to disclose their personal stories. While they were unfamiliar with me, and vice-versa, the body mapping workshop provided an opportunity for greater engagement and interaction than would have been the possible with the interview alone. Based on their experience of the workshop, participants were able to decide whether or not to commit themselves to the follow-up interview.

Indepth interviews (see Appendix 4) were held so as to facilitate the capturing of rich descriptions. Questions about the body maps helped to further contextualise the narratives and to provide reference points against which interpretations could be triangulated. However, it is important to recognize that the stories told here represent one of a number of potential sets of narratives that *might* have emerged through the interaction of a researcher and participants. In this regard the body maps serve as reminders that meanings of HIV/AIDS and selves are not fixed. It is the very inexhaustibility of these images in lending themselves to multiple interpretations that makes their inclusion here most appropriate.

Researcher reflexivity is also an integral part of how a story is conveyed or its 'hearability' (Gready, 2008). This is especially important in that the position of the 'researcher' cannot ever be neutral and should therefore, as Parker (2005) suggests, offer an explication of the procedures used as well as an acknowledgement of the researcher's own discursive positioning. Providing an 'audit' of the research process in this way ensures that the procedures used, and reasons for using them, are clearly detailed so that the means by which interpretations were reached remains transparent.

## Chapter 4: Narrative analysis

### 4.1 Self in relation to time

#### 4.1.1 Self in relation to the past

While all the women recounted different memories of their early years, a strong underlying theme to emerge was how, for most of them, their childhood years were characterized by an absence of one or both parents. Grandmothers and/or aunts often occupy a significant place in their childhood memories. Thandeka describes her life as having been bereft of the love of a parent. She was only two years old when her mother died and so was raised by her grandmother. Her father, who had been living and working away from home and who had subsequently remarried, was killed in a car accident in the same unfortunate year her grandmother died. She thus characterizes her early years as having been joyless because she never got to experience the emotional closeness of a parent.

She states:

[...] I didn't know my mother. She passed away when I was two years old. And then...I was raised by my grandmother. My grandmother passed away in 1986. She was sick. And my father got an accident with my stepmother and they passed away same time. It was in 1986. In fact, in my life, there's been no joy. There was no joy at all because I didn't get that love of mother...the love of the mother. And then I got a husband and get married. In fact we married in 1987. (Thandeka T: p. 1, 8-14)

**(Thandeka BM: left-hand side)**

“Wangikhulisa ngishiya uMa wam ngine 2 years wangikhulisa” [She raised me from when my mother left me when I was 2 years old.]

In the extract below Thandeka describes how, as a result of her father and stepmother's death in the car accident, she was not able to complete her schooling. She states:

No, I didn't finish school because of that stepmother, She don't care of other women's children...so my father didn't bring no money for me to go to school. And I was supposed to go to school. He said, before he got accident, he promised to me I can go back to school the next year. But... on the way...

*So your father promised you school before his accident?*

Ja, because he was working in Johannesburg, in Springs. So when he was leaving Umzimkhulu to go back to work he promised me to...by next year I'll go further. Then I met this man who was my husband... (Thandeka T: p. 2, 60-69)

Nondumiso describes how, because her father left her when she was young, she never got to know him and was raised by her mother, aunt and grandmother. She states:

When I'm young my father was leave my mother, was going to work in Johannesburg. So I'm not know my father. Then my mother take me to stay to at Umbumbulu. That year, it was... 1985...I think so. So, I was being raised there by my aunty and my grandmother, and my mother was working, selling fruit and vegetable. So, together it was my mother, my aunty and my grandmother who was raising me. Actually, there was no man, like I can say, a father in my life. (Nondumiso T: p. 1, 11-16)

Phumzile grew up without knowing either her mother or father. She spent her early years believing that her grandmother was her mother until she reached grade 7 when she was told that her biological mother had abandoned her when she was three months old. This shattered her sense of belonging and set her on the path of wanting to find her biological mother. While she did eventually locate her, her mother was dying of AIDS and did not live for very much longer. Thus, Phumzile was consigned to live without ever experiencing the care of a parent whom she could appeal to in times of need. She states:

Ja, kuyaye kuvuke lokho mhlambe uma ngisenkingeni mhlambe kukhona into engiyiswele kuvuke lokho ukuthi mhlambe ubekhona uma ngabe ngiyamutshela kodwa umnqondo ubuye ungitshela ukuthi angkaze vele uthando lokuba nomzali ngibenalo, angkhohlwe indaba zomzali ngoba vele uthando oluthi baba nomama.  
[Yes, it's sometimes that I get those thoughts when, say, I have a problem and there is something that I don't have, or that I need, I get the idea that, maybe, if I had a mother, I would be able to tell her, but then what comes to mind is that I've never received the love of a parent. I should forget about the preoccupation with parents because I've never received the love of a father or mother.] (Phumzile T: pp. 11-12, 526-543)

In addition to not knowing her parents, Phumzile was often derided by her grandmother and this inculcated feelings of low worth. As a result, she did not adjust well to school nor develop any close friends. The vestiges of these hurts still linger in the account she gives of her past:

Kusho kuthi nje ngisemncane engikukhumbulayo okwakwenzeka ngisuka ngo-first year mhlambe ngize ngifunde oFive ngangithi noma ngiphasile kufane nokuthi ngifeyilile ngoba kwakungekho ongincomayo, obongayo athi, "Wenze into enhle uphasile", ngoba umgani ngangingenaye.



[What I remember is that when I was young, from my first year of school until maybe up to Standard 5, it did not seem to matter much whether I passed, or whether I failed, as there was no acknowledgement of me, no praise saying, "You've passed well", because I did not have a friend.] (Phumzile T: p. 1, 10-29)

**(Phumzile BM: lower right)**

"Ngisemcane NGAphatheka kabi ngoba ngingenaye umZALi. NGAkhula kanZIMA ngangakwazi zinokufunde kahle isikhole." [When I was young I struggled because I was without a friend. I grew up with difficulty and did not do well at school.]

Zanele describes the pain of seeing her mother struggling to make ends meet after her father left to go to Johannesburg. This prompted her to leave home when she was only seventeen years old. She states:

I remember... my mother married my father. It was 1969. In 1970 I was born, me. 71...72...73...74...75, I think so, my father left my mother, become divorced. It was seven years I think so mother was working in Durban. So this thing made me cross. Even now I'm angry about that because my mother was sick about asthma. He does not support these two kids because my father was having a nice time in Joburg. So I left home...it was...standard 6, I haven't got no shoes to go to school. Even uniform too. It's terrible. Even food on my stomach because my mother left me on granny. So granny's depend on government money. My mother, when she's not working, no money. My mother is better or sick, no money. So I decide, no, I must leave this home. It's better to send money home. I'm start working. I was 17 years. Then I found my husband after, I think, six months working on domestic. Another lady, she's a Christian and is a teacher to me before, she help me because 17 years is too young to start working, but I'm start working. Then my...my husband take me when I'm 17 years old. So that's why I said I've got problems when I'm young. That's why I leave school early. (Zanele T: p. 4, 152-165)

Noloyiso also grew up not knowing her father and was raised by her mother. When asked about her the early years of her life she stated:

It's just that I'm still young. I live with my mother. I've only got one parent...ja, it's my mother. My father passed away when I was still small...I didn't know him. When I was young I wished I could know my father because it was only me and my mother. (Noloyiso, p. 1, 8-10)

The above accounts are redolent with images of abandonment, neglect and helplessness. They highlight how, as McAdams (1993) suggests, formative experiences come to characterize the narrative tone of the stories produced by adults. Many of the women above experienced similar sorts of treatment from their husbands and partners as they witnessed their mothers receiving from



their fathers. Stories thus link people, not only to their own past, but also to the experiences of close others, as is evident from the extract below:

When I see how is my life, I see that I'm having the same problems as my mother was having. She was not getting the support of my father and my child too, is not getting the support. So I know it's going to be painful if my child can grow without knowing her father because it was painful to me to not know my father. So it seems as if her life...it's just repeating those things of my life. (Nondumiso T: p. 7, 323-327)

What the above illustrates is the constitutive role narratives play in the ongoing making of self. For it is not only through stories that people are linked to the past, but how the stories that they tell predispose them towards experiencing a particular version of themselves in the future. Thus, it is not merely that people *tell* stories, but rather that they *live* them.

#### 4.1.2 Self in relation to the future

Some of the women, in speaking of their future selves, associated well-being with signifiers of material wealth such as cars, houses and money. Images of cars and houses appeared on some body maps (Londi BM: left-hand side; Nondumiso BM: lower right; Zinhle BM: top left) and in the narratives:

**(Nondumiso BM: lower right)**

“Lo umuzi wami nemoto engifisa ukuba ngakho emva kweminyaka emibili ezayo” [This house of mine and car that I wish to have in two years time.]

[...] The only thing I can see is for me to be getting my own home. So now I wish to build my home, then stay there. And maybe one day, in the future, I wish I can be driving my own car (Nondumiso T: p. 4, 147-149)

**(Zinhle BM: top left)**

“I see myself driving my own vehicle”

Ja, the most important thing for my future is that continue working where I am now. Then, maybe one day, I will be able to afford a car...and maybe if I can get my own place to stay. (Zinhle T: p. 4, 149-151)

These aspirations were similarly expressed by Zanele who stated:

Ngingasho, engikufisayo impilo e-right...kusho ngibe nomuzi omuhle, ngibe nemali, ngibe wumuntu o-right nje. [What I wish for is to have a good life, to have a nice home, to have money and to be a good person.] (Zanele T: p. 7, 308-312)

In many respects these images represent an escape from not only poverty, but also from the nihilism of HIV/AIDS and its associated images of decay and deterioration. As Noloyiso, for instance, stated when speaking about her view of the future:

I can say it's far away, ja. I see my future getting a better job, doing better things in my life...buying a nice car, ja. Maybe I can be living in Umhlanga, or Durban North. (Noloyiso T: p. 3, 116-117)

In her case the need to secure a future of well-being arises from deep anxieties and uncertainties about being dependent on a sole parent:

What I fear is that all those things won't happen and I'll see that my future is not bright anymore. And I fear what can happen to me if my mother stays sick because she's not working at the moment. (Noloyiso T: p. 3, 142-144)

What this highlights is how, for some of the women, their material well-being rests on very fragile support structures. In the context of living with HIV it gives rise to a dualism whereby being financially and emotionally dependent on others simultaneously intensifies the need to protect against the vulnerabilities of being dependent, by becoming autonomous. As Grace states:

I believe it can change when I believe to God and I must stand for myself, not to stand with other man. I think like that...that I can change. I'm happy if I can stand on my own feet. (Grace T: p. 9, 409-411)

However, for people living with HIV, working so as to be self-sufficient is offset by not being able to predict with any certainty how long they would continue to remain 'fit' for work. Hence both Zinhle and Londi described a future preoccupied with keeping the effects of HIV at bay so that they could continue working and earning a salary. They state:

Ja, maybe to stay healthy even though I've got this HIV inside me. But on the outside, not to be sick, then I can continue working, continue living. (Zinhle T: p. 4, 176-177)

I must only live now... and what I know is... I must continue working and continue taking my ARVs. (Londi T: p. 4, 146-147)

Work creates the trajectory for experience of self. Unemployment compounds the lived experience of HIV because not having work denies individuals the opportunity to take the responsibility for their illness in the ways they are imputed to have. The implications of not having a fixed source of income are painfully evident in the case of Phumzile:

**(Phumzile BM: central right)**

“[I]nto engiyifunayo ngiFisa ukuthola umsebenzi nendawo yokuhlala”  
[The thing I wish for is to get work and a place to stay.]

Interviewee: Inkinga enginayo ukungatholi umsebenzi. Umsebenzi engiwezayo owakubamba izinsukwana. Uma ngingathola umsebenzi ongapheli ngingakwazi ukubhekana nenkinga.  
[The problem is that I do not have work. The work I get is temporary. If I can get permanent work then I will be able to handle my problems.]

*Facilitator: Problems she is facing it's the work. She doesn't have permanent work and she still needs something like that. And to deal with her problems...if she can get the permanent work she can deal with all the problems. (Phumzile T: p. 7, 314-323)*

Another strong theme to emerge, for those women who are mothers, was how much of their children's futures they would live to see. Many mothers expressed anxieties about what their death might mean for the futures of their children:

Ngidinga ukuphila nje, impilo engcono, ngihlale ngikhulise izingane zami.  
[I want to be able to live, to have a better life and be able to live long enough to raise my children.] (Phumzile T: p. 5, 221-224)

My hope is that my children will finish school and then they will live like...once they finish school I know that they will get a key to success. Like my first one is doing standard 10 so by next year she wants to be studying to be a biologist. So now I pray that God must help me to raise my children until all of them finish the school and I want...I would like to see them working, taking me with their cars. And I wish to see my grandchildren and to raise them also. (Thandeka T: p. 5, 231-236)

My problems for me is that I want my son must go to school and finish the school. He must be something when he's big. My son say...to me, he say he want to be a lawyer. He said to go study to UNISA. Money, I haven't got problem about money. I only got problem for this...about my status. Maybe I can die soon before my son is taking a wife. It's only that thing. I pray to God he must help me to see longer. That's the only problem. (Grace T: p. 7, 302-307)

The above accounts illustrate how self is embedded in 'webs of interlocation' (Taylor, 1989) that function in relation to time and to others in time. In this case, the women's imagined futures are rendered meaningful through references to the futures of their children. The projection of self into the future, through stories about their children, serves to preserve the narrative continuity that, as mothers, their deaths to AIDS might deny them. The theme of the future and how it overlaps with children reoccurs again under section 4.2.3 below.

## **4.2 Interconnectedness with others: Self as rendered meaningful through relationships**

### **4.2.1 Parents**

Given that many of the women grew up without fathers the caregivers most often mentioned were mothers, aunts and grandmothers. Zanele mentions her mother as being been the most supportive person in her life. She states:

It's my mother. That's why I'm say, it's my mother. ("MatHAR" [Mother] Zanele BM: left centre). When I'm telling her I'm HIV-positive, she was crying. I'm say, "No, mom, don't cry because I'm not sick."  
It's my mother. Even now, when I'm phoning her and tell her, "Ay, today I'm not feeling well, she says, "What's wrong?" and I'm start to say... and she say, "Zanele, you must go..." and I say "No, mom, I'm not dying, I'm not dying now. One day I'm going to die, but I'm not dying now."  
So it's my mother. Even now, sometimes, I'm not tell her I'm sick because she's cross, she angry if I tell her somebody do this and that to me. That's why I'm saying it's my mother. She is close to me. (Zanele T: p. 5, 215-224)

Zinhle, in speaking about her father, describes him as having been unreliable and emotionally unavailable. She states:

No. I can say my father was just... a... useless man. He used to like to be drinking always, then fighting with my mother. After fighting, then just leave my mother for few days, then come back. And gambling too. He used to take the money which he was bringing at the end of the week, then go gambling. So there was no love from my father for us. And between my mother and father...there was nothing. (Zinhle T: p. 3, 105-109)

The less than satisfactory relationship she had with her father meant that she developed a close bond with her mother. Her decision to disclose her status had, however, to be weighted against the impact that it might have on her mother's health. She states:

Ay, I only told my mother later because I'm worried about her, about her health. So I don't wish to bring more problems to her. So, when I told her, she said to me I mustn't lose hope, God will look after me, and I must abstain from sex. So, she's accepted it but she is worried about me. She always reminds me, asks me if I'm taking my treatment every time and I answer, "No, Ma, how can I forget my treatment? If I forgot about my treatment, it's just as if I've just forgotten about my whole life!" (Zinhle T: p. 4, 206-211)

Given the heightened sense of vulnerability that goes with living with HIV, the decision to disclose one's status is often mediated by a need to sustain a close connection with significant others, in this case, a mother. However, disclosure often incurs moralizing and sometimes discrediting responses even from those looked to for support, as can be seen in Grace's disclosure to her mother below:

One day I tell my mother after to hear I'm HIV-positive, I ask my mother, "Ma, you know about this HIV?"

She say, "Yes, why you talk about it?"

I say, "What can you say when one of your children can say she got HIV?"

She say, "Ay, ay, don't tell me that! I'll fight with them."

It was on Saturday night, Sunday I must come back. She just ask me, "Why you talk about this because this is terrible?"

I say, "Mother, I've got that HIV thing. I'm one of that people."

Then she feel bad, say, "Maybe I'm play with you."

After that, when I arrive at home to Ladysmith, I phone again, I say, "Ma..."

Then she say, "No, my daughter, I can't say nothing, but don't fucker up with the man because you got this and you must know you'll die!" Maybe she was think I was fucker up with the man... I'm say, "No..."

And then just...

*How long ago was it that you told her?*

It was last year, after May. I test on May and then after test I tell her. Maybe it was on June. But now it's alright. When I go home she ask me, "How you feeling?"

I say, "No, Ma, I'm alright because I just tell myself that I can't do nothing. I must just only lie down without to sleep with other man's"... because I'm staying alone now without having any boyfriend. (Grace T: p. 4, 170-191)

In the case of Noloyiso both her mother and her aunt occupy crucial positions in her life. She states:

**(Noloyiso BM: right-hand side)**

"MOTHER She is my role model, because she is there whenever I need something. She plays a special role in my life"

It's my mother and my mother's sister. She's living at Sydenham. They support me, be there for me. When I discovered about my status they were there for me. (Noloyiso, p.3, 99-100)

In contrast to the trend above, only one of the women spoke positively about the role her father played for her in her life. Londi states:

Ay, I can say it was my father. He was the one to...to give me direction in my life. I saw from him not to give up easily. He helped about school at that time, gave money to pay for fees, and he helped me and about finding a job. He showed me that you must always try and you mustn't give up... no matter if your life is not looking perfect, no matter what. (Londi T: p. 3, 118-122)

This is also borne out on by her body map where she states that her father's death was a significant event for her:

**(Londi BM: right-hand side)**

"When I lost my father [,] she[he] played an important role on[for] me, she [he] also helped me on [with] schoolfees and also getting a job"

#### 4.2.2 Siblings, cousins and relatives

Implicit in many of the narratives of the women is a special importance placed on the support received from family members. As Grace states:

Oh, it's my sister I'm write here [pointing to the words "My sister"] (Grace BM: bottom left). Yes. My sister I'm told her I'm HIV and then my sister tell me how I must behave because she hear about this HIV before. She knew what it was. She say, "Be careful. You mustn't sleep with the man. If you want to sleep with the man you must use the condoms...what, what, what." Yes.

*Was she the first person you told about your positive status?*

Yes. It was the first person. She just care for me and correct me how to live. Then after that it was my mother. [...] (Grace T: p. 5, 216-225)

The important roles family members play in offering support was also reiterated by Thandeka:

My children...and my sisters...and all my relatives... are important to me. They support me. They know my status...almost all of them...my cousins and my sisters. They didn't reject me. (Thandeka T: p. 4,181-183)

**(Thandeka BM: bottom right)**

“Ikhaya lami nezingane zami ziyangisaphotha uma ngingaphilanga noma ngingenkinga ziyangi[d]uduze ngiyazithanda kakhulu.” [My home and my children support me whether I’m well or whether I have a problem. They console me. I love them very much.]

In contrast to the above, where family members are looked to for support, those of the women who are working saw themselves as also playing a supportive role for other family members. As Londi, for example, states on her body map:

**(Londi BM: bottom left)**

“When I get employed Because I managed to support my family [family]”

Because of the financial support they provide these women expressed anxieties about who would continue supporting their families should they no longer be able to. As Zinhle, for instance, states:

My fears is, if something can happen to me, who can look after my family because I’m the only one in my family supporting them. So, the only thing is to help them. I know that if I become sick they will look after me. But who is going to be supporting them during that time? I’m the only in my family who is working now. (Zinhle T: p. 4, 158-161)

The themes above highlight the extent to which the women are dependent on their families for their sense of place in the world, especially given their heightened vulnerabilities due to HIV. Embeddedness within a family confers a sense of belonging that makes the experience of personhood meaningful. In the case of HIV, where society can often be experienced as alienating, the families of those who are ill take on crucial importance.

### 4.2.3 Children

The mothers in the group spoke of their children as being a source of pride and hope. As Nondumiso states:

The good... it’s when I was when I was having my child. (Nondumiso T: p. 2, 63)

**(Nondumiso BM: bottom right)**

“Mhla ngithola umntwana wami wentombazane ngajabula kakhulu. Kumanje uy[a]khula kahle akanankinga ngiyamthanda” [The day my little girl was born I was elated. She is growing well now without any problems. I love her.]



Children also carry the potential to receive those things their mothers were denied when growing up. This is apparent, for instance, in Zanele's expectations of her children:

Ja...ngifuna bafunde. Yonke into yakhiwa right because i-future i-bright ngokufunda.  
[Yes...I want them to be educated. A good education is the foundation of a bright future.]  
(Zanele T: p. 8, 346-348)

But while many of the women conveyed hope about what their children might become, there was also an implicit tone of despair arising from their dependencies on others for ensuring the well-being of their children. This dependency undermines the level of agency the women are able to exercise. As Nondumiso indicates:

Now? Her father is helping to support her. He's giving me money. And my grandmother is helping with the pension which she's getting at the end of every month. So it's those two things. And I wish, maybe, if I can get the child grant to support my child. (Nondumiso T: p. 4, 162-165)

As noted earlier (see 4.1.2) many of the narratives about children were referenced against the future and were tempered with anxieties about whether they, as their mothers, would live long enough to see their children reach adulthood. As Nondumiso states:

My hope is that I can live to see my child growing. So, I just wish to make sure that I look after my health and look after my daughter. I wouldn't like her to see me get sick and die. I want to watch her grow bigger so that she can know her mother. One day I hope I will be able to tell my child about her status. I hope God can let me to live that long. (Nondumiso T: p. 4, 169-173)

These anxieties were also expressed by Grace, Phumzile and Thandeka in respect of their children:

Yes. I'm afraid of when I can die my son is going to stay alone, and then, no relative, no family. Now maybe people maybe...because my husband got children outside...now that children can come and then they say they want to stay with my child then after that maybe they will kill my child and then from there they must eat my property... everything. Because my family it's far! If I'm die I want to die there so that my relative can look after my things and my son. (Grace T: p. 6, 282-287)

**(Phumzile BM: bottom left)**  
"Izingane zami" [My children.]

Ja, ngiyakusaba ukuthi izingane zami angeke usayibona vele...nanokuthi, uma ngifa zoba yini zona zingagcinwa ubani? [Yes, I am afraid that I won't see my children again... and also that, if I die, what will become of them, who will look after them?] (Phumzile T: p. 6, 245-249)

If I can die now my children will suffer because there's no one who can help them... instead they will come and take what I've managed to buy for them...those in-laws and family. And another thing I fear...if I can die before my child who is positive, my fear is that who can look after him?  
(Thandeka T: p.5, 229-243)

As a result, many of the mothers had concerns about making the necessary preparations to help ensure the financial security of their children's futures. As Zanele, for instance, states:

Ja... something. Even if it's a one cent, it's ok because my son he knows his mother is not a professional. Even if I get two cents... one cent... one cent... it's two cents, it's ok because I leave something before I'm die. (Zanele T: p. 6, 285-287)

What the above accounts highlight is how, for the women in this study, personalized meanings are derived through the temporal dimension within which their relationships with their children are situated. By investing their children's futures with aspirations, hopes, dreams and ambitions, their children come to function as narrative resources that preserve narrative continuity in the potentially obliterative face of AIDS. Preparing for their children's futures, in which they, as the mothers, will potentially be absent, allows the experience of the present to be charged with meaning. In this way, referencing their children against the future, serves to mediate the meaningfulness of present self-experience.

#### **4.2.4 Husbands and partners**

For many of the women marriage heralded a change in their life circumstances that brought difficulties along with it. Often these related to the treatment they received from their husbands or their husbands families. Zanele describes the early years of her married life as being characterized by hardships brought on by her husband's family. She states:

My mother-in-law, on his side, on that family side, is not like me. My sister-in-laws are fighting with me everytime. Otherwise, on my side, my home side, no nothing, no problems. Otherwise, I got problems on this side of my husband and sister-in-law...to fight

me, to treat me... I'm Pondoland...this side we stay is Port Shepstone line. So problems like that... so, Zulu and Xhosa. So, when my mother-in-law was passed away I leave the home, Port Shepstone side, and I stayed this side...with my husband. After that, last year, I finished my house, my own home, another place in Mashisini. (Zanele T: p, 5, 199-205)

Thandeka characterizes her married life as having been without happiness. Her sense of exclusion and disempowerment in the marriage is apparent from the extract below:

When we got married there was no happiness. There was no happiness because he didn't tell me anything because he was running taxis. But he excluded me from his business, so I was sewing and selling some clothes. He was staying here at Durban and I was staying at Umzimkhulu. So we fight because he only pay me...maybe... if he came at 8 o'clock, maybe by 12 o'clock he's coming back to Durban. Or, if he came 12 o'clock in the night, by 7 o'clock he's going...coming back to Durban. So he decided to buy a place here at Adam's Mission so that we can stay together. (Thandeka T: p. 2, 85-92)

In the following extract it becomes clear just how the circumstances described above left her susceptible to HIV infection. She states:

And after that we came back here. We got a site at Adam's Mission and we build a house there. When we came back in 1996 I was pregnant with my last-born child. I was so sick when I was pregnant but I didn't know that I'm HIV-positive because at that time it was not so strict to be tested when you are...if you are pregnant. So since I got pregnant it was until the birth of the child I was always sick, sick, sick. (Thandeka T: p. 3, 106-108)

When asked about where her husband is now, she stated:

He passed away in 2002. And he didn't tell that he was positive but when I see...he knew about this thing because he started to change. He don't like beef, whereas it was something he used to eat, to roast the beef. And drink, he said he don't like. He wanted lemon juice and vegetable. Which means he knew that he was positive but he didn't tell me about the virus. (Thandeka T: p. 3, 127-133)

A short while later, when probed about whether she thought her husband had known his status, she stated:

I think so. I think so because one of his friend's told me...he asked me, "Why are you always going to hospital every month?" and I told him the real thing...that... my last-born child is sick, is positive. And he said, "Hawu, it means it was real because he told me." He told his best friend but he didn't tell me. And I felt very angry from that time because maybe I would never be giving birth to a sick child. (Thandeka T: p. 3, 141-145)

Several of the women told stories indicating that, while they knew it was their husbands or partners who had infected them, their financial dependence on them meant that they continued to live with and have sexual relations with them. As Zanele attests:

Me I'm old now. I'm 37 years, so I can't change my husband. It's ok and it's my husband and he's love me. Because, why, he does not put me in trouble. He doesn't. He even did not know he's HIV-positive. Me, I'm first to go to test, then my husband second...follow me to test. So...I'm not angry about my husband...you see... God. (Zanele T: p. 14, 651-654)

In the case of Nondumiso her financial dependencies preclude her from discussing her status or her partner's status as can be seen from the following extract:

I fear if my boyfriend, the one who is the father of this child, can find out about my status and then he can stop giving me money to support the child. He's the one who is supporting the child. So it's difficult for me because... ngiyasola ukuthi [I suspect that] he's the one who gave HIV to me.

*So he doesn't know about you being HIV-positive?*

Hayi, he doesn't know. Maybe he knows about his status, I don't know. But we never discuss about my status...and we never discussed about his status.  
(Nondumiso T: p. 4, 181-188)

Retaliation by a partner, husband or family member is one that can have very real repercussions, as Phumzile attests:

Kusho ukuthi zaqhubeka inzikinga ngoba nami ngazama ukuthi ngitshele abanye njengabantu basekhaya nobaba wengane lena encane. Ubaba wengane encane wathi imina enginalo, yena akanalo, wase esishiya kanjalo-ke.

[The problems continued because I tried to tell other people, for instance, people at home and the father of my youngest child. The father of the youngest child said that it is me who has the virus, he doesn't have the virus, and he left just like that.] (Phumzile T: p. 8, 353-360)

The above accounts show how financial dependence has often constrained these women in their relationships and marriages. These circumstances, which make it difficult for them to assert themselves, form the path by which they have become infected. In response to those that infected them, several women expressed an attitude characterized by acceptance more than anger. As Thandeka states:

No. I decided to accept that I'm positive and to feel strong, especially for my children. Because if I concentrate on this thing, the virus, I'll lose...even my CD 4 count will go down. So I'm always thinking about this thing. And then the support group also strengthened me. (Thandeka T: p. 4, 151-156)

Like Zanele earlier, and Thandeka above, Grace also stated that she is not angry with the man whom she believes infected her some years after her husband's death. She states:

Ay...I don't feel cross because maybe he didn't know. (Grace T: p. 8, 378)

The attitudes of the women are situated within discourses in which men's irresponsibility is attributed to the 'helplessness' of their sexual urges. Through this entrenched cultural acceptability men cease to be accountable for their sexual behaviour or knowledge about their status. Hence, the women's responses to their husbands or partners are constrained by social constructions of masculinity that serve to exonerate men.

#### 4.2.5 Friends

While many of the women did not speak directly about the social isolation resulting from their HIV-positive status, it was often implicit:

Abantu mina angibanaki anginandaba mina ngoba angeke angisize ngalutho. Umuntu ukuthanda uma ekubona engathi uzokusiza uma esesithele ngale akanandaba. [I don't care for people because they never help you with anything. People like to appear as though they will help you until it is that you go to them, then they are nowhere to be found.] (Zanele, T: p. 13, 592-596)

The capacity for friends to impose normalizing judgments is evident in the following comment from Londi:

I can say that HIV, it makes you to become aware of which person is your friend...yabona? [you see?]. ...because when they discover about your status, you find they just judge you negatively, as if you've just done this to yourself, as if it's your fault... even though they know, sometimes, it's somebody that infected you! There was one person which I know, she was my friend, and she did that to me and I was very angry. So I have seen that, when you are HIV-positive, it's not just anybody who can accept you if you tell them your status. Even if you are accepting your status, it doesn't mean others are going to accept you. (Londi T: p. 6, 240-247)

The social construction of personal accountability in respect of HIV serves to impute blame that leads to the social isolation of those who are ill. In the extract below Zanele highlights how those who are themselves ill, can often be expected to be punitive towards those who infected them.

[...] But now, when I getting HIV, everything is changing...because uzohlekisa ngami [they will turn me into a laughing stock]. You understand? They said I must leave my husband. I'm saying, "It's my husband. I can't leave my husband because I love him." They said, "Ooh, you are stupid. Even me, I leave this, then I starting this fresh guy." (Zanele T: p. 14, 651-654)

Generally, however, most of the women described friends as occupying crucial supportive roles. For Phumzile, the disclosure of her status and the resultant rejection by her family and partner left her relying heavily on her friends such as Nomawethu, the head of the support group. This can be seen from her body map and the following transcript excerpt:

**(Phumzile BM: upper left)**

"Mngane wami uNomawethu ngiyamthanda ngoba uyangisiza kakhulu ezinkingeni zami"  
[My friend is Nomawethu. I love her because she helps me a lot with my problems.]

Interviewee: Uyena...kusho ukuthi uma ngixaxekile ngitshela yena, manginenkinga ngitshela yena, noma ngabe kuthiwa ngiyagula noma kuthiwa ngiswele into engizoyidla ngitshela yena. [Her...when I am in need of anything I tell her, if I have a problem I tell her, even when I'm sick or if I'm without anything to eat, I tell her.]

*Facilitator: When she's having a problem, if she's hungry, she tells the person if she needs something.*

*Researcher: And anyone else who has been supportive, her husband maybe, the grandmother?*

Facilitator: The grandmother used to swear at her about her status, insult her. (Phumzile T: p. 4, 153-166)

Thandeka and Zanele also highlighted the important role played by Nomawethu as friend and head of the support group:

Ja, like Nomawethu. She's gives support every time if my child is sick...even if I am sick... she tell me I mustn't lose hope and trust to God. (Thandeka T: p. 4,187-188)

Ja...Nomawethu is a hero for me because she take me...like...she said to me, "You see me, I've got 11 years, 11 years positive...so you must take this, and not take this, you must put this..." and even now she says, "Zanele...", says Nomawethu, "...you must talk on national about HIV because if you keep on your heart, this thing is wrong because it's paining you. If you talk to someone this thing is not...even now, I don't worried about HIV. Even if you put me and say, "Zanele you must go, I've got someone important, I need someone to help me to talk about HIV." I'm proud because I'm stand up and saying, "I'm Zanele, I'm HIV-positive, I'm getting this year, and HIV's living with me in my body like this, so you must do this, you mustn't do this, you must eat like this..." So, that's why I'm saying Nomawethu is important for me. Even now, she tells me I must go to take CD 4 count again. She care for me, you understand? (Zanele T: p. 5, 233-243)

The body maps of Nondumiso and Zinhle also highlight the supportive role played by their friends:

**(Nondumiso BM: left-hand side)**

"My Friends it was important in my life it was teach me about HIV and give me a nolege [knowledge]. I love this girl. And kubalulekile ukuba Nomgani ukunika okukuphilisayo kunokulahlekisayo." [It is important that you have a friend who encourages you than to have one who will mislead you.]

**(Zinhle BM: left-hand side)**

"My friend. She is a good listener. She provides me with information. We've got our own terminology to describe the medication, stress, behaviour. She lives near the sea."

Friends provide networks of advice as to how illness might be managed. They provide an interpretive context, one in which recommendations made about healing are complied with or ignored. However, mobilizing such a network entails the willingness to disclose. What the above extracts illustrates in this regard is that, while friendships do function as important additional support structures to those offered by family members, they often necessitate 'disclosure' and can thereby function as forms of 'policing' (Foucault, 1977).

## **4.3 Biographical disruptions**

### **4.3.1 The HIV diagnosis as a disruptive 'event'**

Receiving an HIV-positive diagnosis disrupts a person's experience of lived time because it undermines the extent to which previously held assumptions can be projected into the future with any certainty (Crossley, 2000a). Descriptions such as 'biographical disruption' (Bury, 1982)



convey the sense of disjuncture that occurs in a person's identity, self-concept and moral responsibilities. For some of the women in this study the biographical disruptions represented by HIV are situated within life stories where other serious life disruptions have occurred. These other disruptions represent the marked differences between those living in relatively stable Westernized contexts and those living in developing countries whose lives are subject to structural poverty, violence, social disruption and disease (Walker, Reid & Cornell, 2004). These differences often mean that, for those living in developing contexts, their disruptions have more far reaching consequences because there often are fewer resources to deal with them. So, while not denying the significance HIV has had on the lives of the women in this study, their accounts must also be read in the context of their already disrupted lives.

Zanele's account below relies on narrative detail to reconstruct the events at the time of her diagnosis. In this reconstruction, her HIV-positive certificate functions as the irrevocable 'truth' of her status when confronting her husband. The account illustrates how HIV-testing functions as one of the practices whereby subjects are produced. These practices, which depend on responsible agents to seek out and uncover the 'truth' about their status, function as a site of surveillance and disciplinary control (Foucault, 1977; 1981). Her account evokes the sense in which she has participated in her own subjectification by taking up the meanings socially ascribed to HIV insofar as they relate to her future and to her husband.

It's hard. It's hard...because I was sick with diarrhoea. Then I went to the clinic...doctor to the clinic said I must check the blood.

I said, "Ay, I'm not ready."

He said, "No, I must go now. I'm going to take an HIV test."

Another lady was counselling me first. Then take my blood, then tell me I'm positive. I was tired that day. But when he said I'm positive, I stand up quickly.

I said, "What did you say?"

...said, "I'm positive."

I'm crying.

I'm say, "No, there's too much people outside the clinic", I don't want people to see me sometimes come to that counselling see sometimes there's a problem. I'm going home. I'm sleeping on my bed. Sometimes the time my husband is nearly out from the work...ten past four, I'm start cooking, cooking, I'm finish. When I'm finish, my husband is coming half-past five. I'm dish up his supper. When I'm finished dish up his supper, he's sitting. When he's finished eating, I'm take juice, then when he's finished drinking juice he's going to the bath, then sleep.

I said, "I want to spoke to you."

He said, "Why?"  
I take my certificate put on... the...I give to my husband, said he must read.  
He say, "No, Zanele..."  
I said, "No, it's for me, it's the future."  
He said, "What you say?"  
I said, "It's the future." I'm say, "You know this thing?"  
He said, "No, I'm not know nothing."  
I say, "But it's the future. Everyone is sick."  
I'm crying because I know I'm not running away anymore. So that's why I'm said it's hard for me. After about 3 months I found Nomawethu, then Nomawethu was counselling me.  
(Zanele T: pp. 8-9, 375-401)

While Zanele's response to her diagnosis was to confront to her husband, some of the other women did not have this opportunity because they had already lost their husbands or partners to AIDS. In the extract below Phumzile attests to the shock and pain of receiving her diagnosis after having witnessed her partner's death due to AIDS. While his symptoms had confronted her with the possibility that she herself could be infected, she delayed getting confirmation through an HIV test.

*Facilitator: Awuchaze ngosuku owathola ngalo ukuthi unegciwane leHIV?  
[Can you explain what happened on the day you received your HIV-positive diagnosis?]*

*Interviewee: Ngaphatheka kabuhlungu ngoba into engangiyilindele. Ngakwazi ukwamukela noma ngingamukelanga kahle.  
[I was filled with pain because it was something I had not been anticipating. I was able to accept it but not fully.]*

*Facilitator: She felt bad after getting HIV because was not aware that she is HIV-positive and after that she was so shocked. But after that she came to accept it.*

*Researcher: What made you go to test?*

*Facilitator: It's because her partner passed away and she has seen the signs and symptoms with him. So she had to go for a test. (Phumzile T: pp7-8, 229-345)*

Thandeka came to know her status indirectly through her last-born child who was continuously sick and tested HIV-positive. In her case her child's diagnosis meant that it would be impossible

for her not to be infected. But, as she explains, she delayed getting confirmation of her status until much later.

In fact, my child, this one who's sick, he was admitted to hospital. So the doctor who was there ask me did I take HIV test because if I can see that my child is not growing well, is under age. So I said I didn't think of HIV test. So they said... she said...it was a lady doctor...she said I must be strong so that they can know what is wrong with the child. So she sent me to where I can test. So I tested him first, before...I felt strong...I didn't cry... I felt strong. Even him, on that day, he looked strong, like he knew what's happened...he became strong like there's something new about his status. After that it took me long to go for test...maybe one year and then I started to go for myself. I knew that it's impossible not to be positive because I gave birth to him. (Thandeka T: p. 6, 253-262)

The reluctance to test is often situated in discourses that construct individuals with HIV/AIDS as blameworthy and 'other'. These constructions, often charged with images of horror and death as the inevitable outcome of the disease, contribute to the discursive silencing of those who are ill forcing them to adopt a position of denial. Zinhle's initial reaction to her diagnosis typifies the response that likens HIV to a death sentence. She states:

Getting told that I'm HIV-positive. There was never anything like that before in my life! It's because you know you can't get better. At that time when they told me, it was just like they were just giving me a death sentence. Ok, maybe you can live for some years, but what I see [...], people are dying from HIV every day. (Zinhle T: p. 2, 59-62)

Social constructions of HIV/AIDS carry ramifications for how subjective experiences are orientated towards future outcomes of longevity and quality of life. The looming spectre of death in being diagnosed HIV-positive is alluded to by Nondumiso who states:

**(Nondumiso BM: lower left-hand side)**

“[U]suku olangiphatha kabi mhla ngithola ukuthi ngine[g]ciwane. Usuku Engeke ngakhohlwa empilweni yami” [The worst day ever was the day when I found out that I have the virus. That day in my life I have never forgotten.]

I can say it's the same, to become HIV-positive, because I've seen that if you get this thing then you can die. So I was thinking about what can happen to my life? How long I'm still going to be living? And if now I die, what is going to happen to my child? (Nondumiso T: p. 3, 108-110)

While Noloyiso also experienced her HIV-diagnosis as signifying death, she highlights the constructive role counselling played in enabling her to contend with her future.

**(Noloyiso BM: left-hand side)**

“When I discovered about my status”

When I became positive, I didn't believe. Before, when they told me about my status I was, let's say... ignorant. I didn't know what does HIV do in your life. But then, when I got my test results, I thought, “Ay, sooner or later I'm gonna die.” But after that I got counselled, then I started see how I can live longer. (Noloyiso T: pp. 4-5, 216-219)

The role of counselling in breaking down the associations between HIV and death is also alluded to by Grace. In her case she came to know her status through an HIV-awareness and testing programme brought in to her place of work. She remembered the day as follows:

Ay, I got a headache...a headache. I didn't sleep that night. And then I just phone for Nomawethu because she told me when she give me my results. Say if there is something wrong you can phone me even at night. Nomawethu, she came to our factory and test everybody at the factory at Ladysmith. They just test us that day and tell us the results same time. They was give us the counselling. (Grace T: p. 7, 311-315)

What emerges from the above accounts is how each of the women's experiences of their HIV-positive diagnosis has, in part, been determined by the particular social and cultural context in which their lives are embedded. In South Africa, where these contexts are dominated by social constructions of HIV/AIDS that function discursively to silence those with the illness (Zaina, 2005), there are often limited social resources available to deal with the diagnosis. This affects not only how the diagnosis is subjectively experienced when received, but also the anticipation of how others are likely to respond to it. For the women in this study, their diagnosis carries very different connotations than it might if they were living in a context where they were less constrained by their social, cultural and economic conditions.

#### **4.3.2 Disruptions to self-understanding**

The reconfiguration of meanings required to construct a meaningful existence in the face of HIV positions individuals as having to confront the 'conversion/growth story' (Crossley, 2000a). This means abandoning future possibilities in favour of living with the 'philosophy of the present' (Davies, 1997). In coming to terms with a diagnosis initially experienced as a “death sentence”, Zinhle has produced a counter-narrative that resists seeing HIV as leading to death. Her narrative, which breaks down this association, has allowed her to adjust to living with HIV. This corresponds

with the view put forward by Davies (1997) that those who are able to deconstruct the dominant constructions of HIV as a death sentence are more able to overcome the 'empty present' and adjust more effectively to living with their illness.

[...] Before, I did not want to accept anything about my status. But later I did accept it. When you accept it, you become relieved. Your mind is no longer disturbed. And I see that to accept my status doesn't mean I have to accept that it's going to kill me. So, it's better to accept and get support because when you talk about your problems it makes you feel better. You find out that there are others who have been living with this for many years and they are still living. (Zinhle T: p. 6, 241-247)

However, for Londi, being HIV-positive carries with it the need to live carefully so as to minimize the threat of opportunistic infection and disease. She draws on discourses of personal responsibility which position individuals as being responsible for the management of their own illness:

Ja, because when you're getting HIV, you know, for sure, you will be getting sick in the future. But after I got more knowledge and counselling I saw that other people are living for many years with HIV even though they do have some health problems. But what I saw is that you must be careful! You must live carefully! (Londi T: p. 3, 111-114)

In the case of Nondumiso, she has had to re-orientate her outlook from seeing 'others' as infected to becoming one of those who is herself infected. The description she gives below highlights how the support group has been integral in mediating her changing view of herself and others. By situating her understanding as emerging from the group, she constructs for herself a sense of belonging or 'embeddedness' (Josselson, 1996) that is a crucial in overcoming the disconnection or loss-of-place that comes from living with HIV.

Ja, I can say that, before, I was not know properly about this thing called HIV. Then, when I came here to support group, they was telling me some things I wasn't know before. So now, I can say I've more knowledge than before. So now, I can just say, if you see somebody with HIV, don't quick to...judge him[/her] because sometimes you don't know how HIV is coming to him [/her]. Because, maybe you judge someone only to find this HIV, it's also coming to you. (Nondumiso T: p. 6, 256-261)

Zanele's conversion/growth story has entailed the spiritualising of meanings attached to HIV. In doing this she inverts the demoralizing images of HIV by reconstructing the event as having brought her to a closer knowledge of God. This inversion allows the 'bad', usually associated with

HIV, to be situated in her past while constructing the 'good' as willingly intentioned by God. In this way HIV becomes the 'liberating' event that has freed her from the ignorance of her past:

I'd write all from the nice, from the bad, and to the end. From the bad, from the nice, from get HIV test and NOW, because when I get HIV-positive my problems finish. Secondly, when I get HIV-positive...um, chaza uthini? [how do I say this?]. . .I know the God because I not know the God before. I was playing before. Before I didn't even stay one day to pray the God. But now I know the God is a God because when I'm here it's just God. When I'm wake up in the morning, it's God. Everything I do, it's God. Everything, it's for God and my life is changing, it's God. And God has put me in this problem of the HIV. It's not a mistake. Because me I'm forget God before. That's why I'm saying, when I get HIV-positive everything's changing for me in my life, for husband and for me. Everything's changing for me because I not know God before. (Zanele T: p. 3, 101-110)

The above accounts illustrate how narratives function to make sense of the interruptions brought on by HIV and construct alternative ways of meaningfully living with the 'philosophy of the present' (Davies, 1997). In order to do this the women have invested in particular discourses. In this way their subjectivities are produced, as Parker (1989) suggests, through processes in which self is subjected to discourse. Here an important aspect of managing one's identity involves the restitution of one's morality from the damaging imputations associated with HIV. This is discussed in more detail under section 4.4.4.

### **4.3.3 Disruptions to motherhood**

HIV, in so far as motherhood is concerned, throws into conflict women's decision-making regarding childbearing. For whereas childbearing has been traditionally read as an indicator of fertility and social standing, HIV/AIDS has turned it into a site of disciplinary surveillance by holding mothers morally accountable for the health of their children. Nondumiso has only one child. When asked about whether she would be having any more children she stated:

Ay, no...because of HIV. There's going to be a risk to my child that he/[she] can be positive. And another thing, if I can become sick and die in front of my child, who is going to make sure my child finishes school...things like that. (Nondumiso T: p. 2, 77-79)

In the case of Zinhle, the ways in which HIV affected her womb, and the resultant operation she had to undergo, has precluded her from the possibility of having any children. Her comments reflect the implicit loss of social prestige associated with the loss motherhood. She states:

**(Zinhle BM: bottom left)**

“The worse thing: when I was told by the Doctor that I have to go for an operation to remove the woumb [womb]”

And another thing, which came later, they told me I must have this operation for my womb, to remove my womb. They said there are signs of cancer there, so I will need this operation. I was afraid. I didn't know how am I going to be after the operation because I knew I'll never be having my own kids, whereas my sisters do have their children. (Zinhle T: p. 2, 59-66)

In the case of Noloyiso, who was diagnosed at towards the end of 2007, there is an apparent disjuncture between the disruptive impact of HIV on her life and the culturally dominant discourses of motherhood within which her identity as a woman is embedded. Her responses below betray the recentness of her diagnosis and show that its implications have not yet been fully understood.

*And your own family, would you like to have children?*

Ja, I'd like to have children.

*Do you see children in your future?*

Ja [laughs]...obviously if you're a woman how can you not see children in your future?  
(Noloyiso T: p. 3, 123-131)

The impact of HIV, in terms of motherhood, brings to the fore the conversion/growth discourse, as conceptualized by Crossley (1999a; 1999b; 2000a), for it entails stories of 'loss' in which women must often not only abandon the hope of having children, but the prestige and social standing they confer.

#### **4.3.4 Disruptions to the body**

Disruptions caused by HIV to the body, as mentioned on the women's body maps and in their interviews, were numerous. These disruptions show that, inasmuch as the body can be read as a 'text' of social discourse, the body also has an organic basis in terms of lived experience (Tamboukou, 2008; Turner, 1992). Headaches/migraines, and in some cases meningitis, were indicated (with dots) on some of the women's body maps (Grace BM: top centre; Londi BM: top centre; Zanele BM: top centre) as well as in their interviews. Zanele, for instance, stated:



Ok...ngangineproblem ye-headache la [pointing to the dots on the head of the body map figure] (Zanele BM: top centre) [Ok...I had the problem of headaches here.]...headache and diarrhoea... ngesikhathi udokotela angenze ukuthi ngiHIV-positive [that was the time when the doctor told me that I'm HIV-positive]. (Zanele T: p. 15, 699-702)

Stomach ailments and diarrhoea, experienced prior to, and after receiving their HIV diagnosis, were reported by some of the women (Phumzile BM: central; Londi BM: centre; Nondumiso BM: central; Zanele BM: centre). In some cases stomach ailments persist as, for example, can be read on Phumzile's body map:

**(Phumzile BM: central)**

“NESISU SAMI Sibuhlungu KAKHU[LU]” [My stomach is very sore.]

Bladder problems were also indicated (with dots) by Phumzile on her body map:

**(Phumzile BM: bottom centre)**

“Ngiphethwe isinye NGiZE S[E]NZE amaphilisi” [I had bladder problems until I took pills.]

Pain experienced in the feet and calves, most likely a peripheral neuropathy, was indicated (with dots) by some of the woman on their body maps (Grace BM: bottom centre; Thandeka BM: bottom centre; Nondumiso BM: bottom left; Zinhle BM: bottom centre). Thandeka, for example stated:

**(Thandeka BM: bottom central)**

“Inyawo zami zibuhlungu” [My feet are full of pain.]

My feet were painful...they are burning like I put them on fire coal. (Thandeka T: p. 6, 271)

Symptoms affecting the womb were mentioned (and indicated with dots) on the body maps of three women (Grace BM: lower centre; Thandeka BM: lower centre; Zinhle BM: lower centre).

As Thandeka wrote on her body map:

**(Thandeka BM: central)**

“Symptoms of cancer womb”

Oh, here, from the hospital the doctor suggested I must go for a pap smear. So the results of pap smear said that I have symptoms of cancer in my womb. (Thandeka T: p. 6, 279-280)

Two of the women's body maps mentioned TB (Grace BM: centre; Londi BM: bottom left) while a third, Phumzile, who did not mention it on her body map, mentioned it in her interview:

*Researcher:* In what ways did HIV affect her body?

*Facilitator:* Waba ne-T.B. angithi? [You had T.B. didn't you?]

*Interviewee:* Ehe. Ngabe neT.B. nekhandanda. [Yes. I had T.B. and headaches.]

*Facilitator:* She developed T.B. and meningitis. (Phumzile T: p. 8, 365-371)

**(Phumzile BM: top centre)**

"Ikhanda Liyan[ke]ketha" [My head was aching.]

Grace's description of the ways her body has been affected by the illness encompasses many aspects of HIV symptomatology. She states:

Like, maybe feet [points to feet on her bodymap], swollen feet, swollen glands. And then from there, at the heart, I had TB, at the hear, like it's HIV [points to the chest on her bodymap]... you see? And then the glands here [points to the head on her bodymap] and headache...and diarrhoea. (Grace T: p. 8, 339-342)

The impact that HIV has had on the bodies of these women and how they have attempted to manage them represents one of the ways 'technologies of self' (Foucault, 1981) are enacted. For, in managing their bodies, these women are simultaneously involved in managing their identities.

#### **4.3.5 Managing the disrupted body**

Adjusting to life with HIV encompasses a personal embodied dimension as well as a social dimension framed by cultural ways of making sense of the world. These interacting dimensions produce an individual's subjectivity and the ways in which life with HIV and AIDS is managed. A regimen of vitamins (for those with a CD 4 of above 200) or ARVs (in the case of those whose CD4 is below 200) has become an integral part of these women's lives. These treatments

represent ways of preserving the continuity of the disrupted self. As can be seen below, several of the women indicated on their body maps the role of medication in their lives:

**(Zanele BM: top centre)**

“ngiSEBE[N]ZISA AMAPHILisi” [I take pills.]

**(Noloyiso BM: central)**

“MEDICATION MAKES ME strong”

**(Nondumiso BM: bottom left)**

“Ngisebenzisa esibhedlela kunamaphilisi engiwaphuzayo – But i[‘m] no’t [not] Beta [better]” [I go to get pills from the hospital - but I’m not better.]

It is also worth noting here how biomedical constructions of HIV/AIDS, which uphold disease management through pharmacological intervention, function discursively to open up certain subject positions (for example, future orientation) while foreclosing others (for example, child-bearing) (Davies, 1997). In Zinhle’s case, medical interventions have included an operation to her womb.

Ay, what I used to wish for before, it’s about children, maybe to have children and my family...but it’s impossible now...after the operation. So there’s nothing I can say about that. (Zinhle T: p. 4, 170-173)

While the biomedical model constructs HIV as a ‘manageable illness’ in the West, and increasingly so in South Africa following ARV rollouts through public health systems, it nevertheless brings to awareness the vulnerable condition of one’s health, as Nondumiso attests:

The only thing, it’s sometimes you become sick and you must go to clinic. Now, when you become sick, it makes you to think about the future, about what can happen to you in the future. Because, you’ll never know about the future when you become sick. It’s only God which knows your future. So, no matter if doctor give you some medicine, no matter you doing all the right things he’s telling you that you must do, you can still die. (Nondumiso T: p. 6, 246-251)

The implications of not adhering to one’s treatment regimen is also hinted at by Thandeka:

**(Thandeka BM: top left)**

“I take my treatment correctly everyday and I keep on praying everyday”

As long as I'm still taking these ARVs and vitamins...because if I didn't take them...maybe I wouldn't live so long. (Thandeka T: p. 5, 217-218)

But following a strict treatment regimen brings its own problems, especially in a social context where there are stigmatizing attitudes regarding HIV/AIDS. As Londi states:

Problems sometimes about HIV, like making sure you don't do the wrong things which can jeopardize you and cause you to become sick. And you must always make sure you take your medication at the same time, no matter if it's by the work or wherever. But, sometimes, it's difficult because others don't know about your status. So it means, sometimes, you must be secretive. Where I'm working there's not everybody who knows about me, about my status. What if some colleagues wish me not to work with them anymore? There is lot of stigma and discrimination... (Londi T: p. 4, 163-169)

By subscribing to treatment regimens constructed as 'life-saving', individuals are implicated in medical discourses that impute personal responsibility for managing their illness. However, this often vies against social contexts in which stigmatizing attitudes prevent those who are infected from outwardly acknowledging their status. Hence, 'pro-life' discourses intersect with, and are contradicted by, discourses that serve to silence those who are infected. This can promote a climate of apathy and denial in that knowing one's status is not perceived to have benefits in terms of being able to manage it.

#### **4.3.6 The body as a site of resistance**

Since the body is the vehicle through which people interact with the world, it cannot be separated from the experience of living with HIV/AIDS (Varas-Díaz & Torso-Alfonso, 2003). Because the body is constantly on 'display' during social interactions and is interpreted by others, it mediates the ways in which identities come to be inscribed with social meanings (Foucault, 1981). Many of the women's accounts reflected concerns around minimizing the deleterious effects of the illness on their bodies. Nondumiso alludes to how, by keeping the visible signs of the illness at bay, she is able to remain 'creditable' in the eyes of others:

How I see my life now since HIV? It's still the same...because, if you look at me, there's nothing which shows I'm positive. If you look my child, there's nothing which tells...ukuthi umama walengane use-positive [that this child's mother is positive]. So, my life, the way I see it now, it's still the same. (Nondumiso T: p. 5, 239-242)

Because social constructions of HIV/AIDS function to hold those who are ill accountable for how they manage their bodies, the appearance of symptoms is often read as the loss of bodily control. Visibly ill, HIV-positive bodies are perceived to threaten the social order (Sontag, 1989) and, as such, necessitate forms of discipline as suggested by Foucault (1977). In this regard stigmatizing attitudes function to single out those whose out-of-control bodies pose a threat to society. The various levels at which social stigma can be directed at the body, and thereby render a person 'discreditable', is alluded to by Zanele:

[...] you see I'm fit, I'm pretty lady, I'm not ugly lady, I'm not sore, I'm not sick. Only thing, I'm positive, but the blood...my blood is dirty...said, it's positive. (Zanele T: p.8, 339-340)

What the above points to is how the invisibility of symptoms contributes to social constructions of the 'healthy ill' (Zaina, 2005). While these constructions function discursively to silence those who are ill (Zaina, 2005), they also highlight the extent to which the body, by remaining 'asymptomatic', can act as a site of resistance against damning and moralizing discourses (Turner, 1992). The extent to which HIV-positive bodies are able to remain 'asymptomatic' determines how the experience of HIV/AIDS is storied into the person's identity. Thus, once individuals become 'symptomatic', they must search for alternative ways of storying their experiences that acknowledge the visibility of their illness. In the extract below, Thandeka contends with the visible changes to her body by developing a narrative in which others nevertheless continue to support the person who inhabits her body. She states:

There's no change because...there's nothing that changed even though my legs became thin, it's only my body. They said there's no change, all those who know me, they said there's no change. My body is changed, but about me, they said there's no change. (Thandeka T: p. 7, 314-316)

What the above comments illustrate is the centrality of the body in mediating the subjective experiences of living with HIV. Importantly, what they show is how the women drew on their bodies as a resource in order to resist their identity being constructed solely in terms of their HIV-positive status.

## 4.4 Beliefs

### 4.4.1 Personal spirituality

All the women drew on their Christianity to help them make sense of the disruptions caused in their lives by HIV/AIDS. While several of the women professed to having followed Christianity for much of their lives, discovering their status led to an intensification of their spiritual beliefs and practices. In the excerpt below Zanele sees HIV as having brought her to a closer understanding of God. She states:

Changing everything in my life. Everything. Yashintsha impilo yami. Yashintsha konke [It changed my life. It changed everything]. I said it's God. Everything, I'm saying, "God, Thank you", because... kwaba icebo lakhe ukuthi ukuze ngimzuze kufanele ugenze kanje [it was God's plan that, in order for me to be saved, He had to do this to me] because wayekhombisa ukungithanda [He was showing me His love]. That's why Jeremiah is written, "He knows me on the womb, on my mother's womb, He knows me." (Zanele T: p. 11, 493-500)

By choosing to see HIV as a demonstration of God's love, Zanele narratively reconstructs her experience of HIV in a way that allows her to overcome the damaging imputations associated with HIV/AIDS. By constructing the illness as something not merely to be accepted, but rather something, paradoxically, of value, she enables herself to experience the illness as an opportunity for growth. The experience of HIV as leading to a deepening awareness of God was also expressed by Grace, who states:

It [HIV] change my life because now I like to go to church. I pray God. I say, "God, I know You. Anything can happen when I'm ask it to You, You can do." Before, I didn't take care about God. Since I'm HIV I'm take care about God. (Grace T: p. 382-384)

All the other women alluded to the significance of their spiritual beliefs in allowing them to cope with their illness. This is evident on several of their body maps (Londi BM: left-hand side; Noloyiso BM: left-hand side; Nondumiso BM: bottom middle; Thandeka BM: right-hand side; Zinhle BM: bottom right) and from their responses during the interviews.

**(Nondumiso BM: bottom middle)**

"UJesu ubalulekile kumuntu onezinkinga. Like me. Ngo[b]a uma uphila nezifo Egazini kubalulekile uhlala ukhul[e]ka ka-uDumise uJehova ngoba uyisiqalo nesiphetho uyikho

konk[e] kimi. Ngiyafis[a] ukungakhohlwa uJesu – Ngiyamthanda wangisiza zonke izinkinga zami zaxazululeka” [Jesus is important to someone who has problems like me. Because, when you are living with sickness in your blood, it is important that you always pray to the Almighty because He is the first, the last, and everything to me. I hope to never forget Jesus. I love Him. He has helped me overcome all my problems.]

I believe that God is the Saviour. He has a plan. It’s His plan. So you’ll never know why some of the things are happening in your life. Only He knows. It seems as if it’s confusing...maybe why did this person get sick and another one didn’t...maybe... why this person died now, and someone lived for a very long time? So that’s why I’m saying, if you keep believing that God does have a plan, then you won’t become discouraged, even if in your life, you’ll never know what is that plan. (Zinhle T: p. 8, 339-344)

The comments above illustrate how the women’s beliefs function to make comprehensible the chaos brought on by the illness. In this sense their spirituality is an important narrative resource in the re-storying of meanings that resist the dominant social constructions of HIV/AIDS. Making sense of their illness in terms of their spiritual beliefs serves to biographically reinforce (Bury, 1982) the continuity, coherence and connectedness of self. For these women their spiritual beliefs are further reinforced by their support group and the churches they belong to.

#### 4.4.2 Collective spirituality

It is significant that all the women in this study belonged to a support group with a strong Christian orientation. They were thus situated within a “constructed community of need” (Carr, in Hlongwana & Mkhize, 2007). In this way the support group can be thought of as providing scaffolding to assist in the re-working of their identities. As Phumzile states:

Interviewee: Okusho ukuthi nje engikholelwa kuyona manje... kusho into engisizayo engiphilisayo ikhona ukuthi ngixhumane nabantu abazongipha uthando ngixoxisane nami.  
[What I believe in now...what helps me now and lets me live is to mingle with others who offer me affection and whom I am able to talk to.]

Facilitator: *She believes that if you get people who give you support and love it’s good... and she attends church services to have a healthy soul.* (Phumzile T: p. 9-10, 425-433)

The sense of ‘community’ conferred by the support group is, for the women, extended to the churches they belong to outside of the group. The collectivities represented by the support group



and, outside of it, their churches, serve as *mediating* contexts in the making of their identities. As Nondumiso states:

Praying... to God...and the people I find to the support group....because, if you are staying with HIV only to yourself, it's easy for you to give up. So, it's better to find support on the support group and by the church. Everytime, I get lot of support from the people in my church...and there are others in my church which are HIV-positive. So, everytime, we meet, we sing, pray. (Nondumiso T: p. 6, 274-278)

The above illustrates how belonging to a collective affords an individual a sense of 'embeddedness' (Josselson, 1996) that counteracts the meaninglessness of a 'provisional existence' (Davies, 1997) when living with HIV. In terms of social constructionism, the support group represents a discursive context that makes possible the storying of an HIV-positive status into a life narrative.

#### 4.4.3 Responses to traditional/cultural conceptions of HIV

All of the women resisted appealing to cultural/traditional constructions of HIV as a way of making sense of their illness. While, at one level, their accounts reflect the Christian orientation of their support group; at another, they suggest an interpellation into the discourses of liberal humanism and its notions of rationality, responsibility and progress. As Zanele says:

Mina, I'm believe in God nje. Only God. Akukho nje engi-kubeliwayo... because... uyena owaziyo ukuthi ngizolala ngidleni, uyena ongaziyo ukuthi nginjani namhlanje, yena owaziyo ukuthi ngizogula, angizugula. So, ukuthi ngibelieva ukuthi isangoma sizongisiza isangoma siguga kuNkulunkulu sicele...because no doctor... uthi, "God siza lomphefumulo", asizakele angangijova ngento ezongenza ngibe right but ngishone before ngisizakala". So, inhlanhla ikubani uNkulunkulu. [There's nothing else I believe in... because... He knows what I'll eat before going to bed, He knows how am I doing today, He knows whether I'll be sick or wont be sick. So, to believe that a sangoma will help me, a sangoma prays to God above...because even a doctor says, "God, help this soul", and gives me an injection to make me feel better, but I may die before I get well. So, fortune lies with God.] (Zanele T: p. 10, 466-477)

When asked whether she followed traditional practices before she was diagnosed HIV-positive she stated:

Ngangibelieva traditional, ngisebenzisa futhi. [I believed in traditional medicine and used it too.] (Zanele T: p. 11, 489-491)

Her response here is in keeping with her earlier description of HIV as the event that initiated a shift in her belief system. Her conversion to Christianity represents a redemptive narrative that becomes a powerful resource for transcending the despair inherent in constructions of HIV as leading to death. However, inasmuch as this story is experienced as 'healing', the potential for the moralizing and religious discourses to become coercive, threatens to foreclose the possibility for true self-definition. This begs the question whether, as Foucault (1981) suggests, one 'snare' is substituted for another in the pursuit of redemption. In the extract below Zinhle invokes the notion of 'progress' implicit in discourses of liberal humanism by dismissing traditional/cultural conceptions of illness. She states:

Hayi, no. What do you want them for? He can tell you life is like this because so and so did this and this and you must do this and this only to find after it didn't help and you are still having those problems. No, I don't believe in traditional. They cause lot of problems and they don't give you hope. They tell you must come back to them and after you have been back, you still have that problem, or maybe you've got another problem. (Zinhle T: p. 7, 30307-312)

This view was reiterated by Londi:

Ja. It's part of my culture but me, I don't go there. If others want to get help there they can go there. But not me, I don't see how it can help. (Londi T: p. 5, 208-209)

The accounts above show that the women resisted aligning themselves with cultural constructions of HIV. Their investment in Christianity and its prerogative of 'choice' has allowed them to 'resist' their identities as culturally predefined.

#### **4.4.4 Constructing the moral self**

Narratives with an implicit moral orientation describe not how the narrator's world *is*, but rather how the narrator believes their world *should* be. In cases where the narrator sees the listener or imagined audience as having more authority, the moral orientation may reflect not what the narrator actually holds, but rather what the narrator thinks that the listener believes. Thus, stories are told not only in relation to the idea of what the narrator believe it means to be a good and, by

extension, moral person, but also by what the narrator believes the listener holds as moral. This is the inter-subjective dimension in which narratives about moral selfhood are constructed.

In the extracts below the women attempted to reconstruct their morality from damaging imputations associated with HIV. Zanele constructs a moral identity predicated on (through disclosure) a willingness to help others infected with HIV. Her disclosure represents the taking on of a 'HIV-positive identity' including the risk of its associated imputations of blamefulness. She is even willing to reinforce her position by producing the certificate indicating the 'truth' of her status:

Nokusiza abantu abaseningeni abangakhoni ukusizakala. Uma kukhona indlela nami engisizakala [ngayo; ngithi] hamba uye endaweni ethile uyozama sometimes ungaba nayo inhlanhla usizakale because...ngisizakele ngingathandi ukuba kudle mina ngedwa asishere sonke. Nayoke into engiyithandayo. Even now, uma ngihlangana nomuntu ngimbona ukuthi uyagula, uyasaba ukusho ukuthi u-positive, uyazi ukuthini? Ngisho ukuthi, "Nasi isitifeketi sami ngihamba naso esikhwameni. Buka, isitifeketi sami ngi-positive." So, ngobe ngi-positive ngisizakala ukuthi ngilande amaphilisi e-Sangro House. Hamba uye la uma uyazi ukuthi uyagula, noma khona omunye omaziyo ogulayo thatha leliphepha ulihambise kulomuntu asizakale because abantu bosaba ukusho kuwe ukuthi ba-positive. [And to help people with problems who cannot see how to help themselves. If there is a way I am able to help guide them out from there I will try to. Sometimes they are fortunate and can be helped because...I do not like to stay with it alone, let us all share it. That is something I like. Even now, when I meet someone who I see is sick and is afraid to say that he/she is positive, you know what I say? I say, "Here is my certificate which I carry with me in my bag. Look at my certificate, I'm positive. So, when I became positive I was helped by getting pills from Sangro House. Go there if you know you are sick or know of someone who is sick. Take this certificate with that person so that they can be helped because people are afraid to tell you that they are positive.] (Zanele T: p. 7, 316-334)

Advocating disclosure as a moral prerogative, corresponds with Foucault's (1981) conceptualization of 'confession' as being one of the instrumental means through which bodies, in this case HIV-positive bodies, are controlled. What it demonstrates is how power is not a function limited to institutions, but includes lay people, who, through their social 'policing' contribute to the construction of moralizing discourses. However, what the moral positioning of Zanele does not take into account is the extent to which silences may, for some, constitute a form of resisting the overwhelmingly damning and moralizing responses that disclosure can bring and which can result in rejection and social isolation (Zaina, 2005). This demonstrates the operation of Foucault's 'snare' in that by seeking to liberate individuals from their silences, they are subjected to

discourses which impute accountability for their suffering. This shows how discourses, depending on the individual, are taken up and used differently insofar as they intersect with other discourses in the person's discursive repertoire.

Discourses that emphasize knowing one's status as a matter of personal responsibility construct the decision not to test for HIV-positivity, or to not know one's HIV-status, as a form of denial. In this way, constructing oneself as 'morally good' is inextricably linked to being an informed and responsible agent who insures that he/she does not infect others. Hence, the extent to which an individual is able to conceive of him/herself as 'good' depends on the extent to which that individual is able to construct him/herself as 'moral'. In this regard Crawford (1994) draws attention to how constructions of 'morality' and 'responsibility' are appropriated into discourses about 'health' wherein preserving the notion of self as 'healthy' and 'responsible' depends on a binary whereby others are constructed as 'unhealthy' and 'irresponsible'. By constructing a version of 'infected others', whose lives are worse than hers, Phumzile is able, in the extract below, to distance herself from the damning moral imputations associated with HIV:

Interviewee: Ngibona ngingenankinga ngoba bakhona aba-positive kodwa impilo yabo ebhedayo eyami i-positive kodwa ngi-right anginankinga nje.  
[I see that I don't have a problem because there are others who are positive but their lives are worse than mine but I'm doing ok without problems.]

Facilitator: *Things are fine now. But the first time she heard it was a shock to her and she says that there are some people who are HIV-negative who are not living as healthy as I am.* (Phumzile T: p. 10, 463-471)

The restitution of moral personhood from the damaging imputations of HIV, in terms of sexual behaviour, often entails the modification of sexual practices. For Phumzile, as the facilitator points out, this means adopting a 'sexual career' of 'protection' or 'abstinence' (Green, 1994). In this way, social prescriptions about what constitutes acceptable sexual conduct function as forms of social control. By constructing morality as the prerogative of 'choice' sexually active, infected individuals who fail to modify their sexual behaviour are constructed as being immoral.

Facilitator: *What I can say is that she protects herself or she decides to abstain. It's one of those two.* (Phumzile T: p. 11, 480-485)

The ways in which social constructions of HIV/AIDS function to locate illness within the individual, imputes accountability for its management too. This is apparent in the comments by Grace:

Ay, my life changed since I hear I'm HIV and then I accept. And then I know to make sure I don't like any man because I give HIV to that man...maybe that man haven't got HIV. So, I'm scared to give other one. Yes. (Grace T: p. 8, 372-374)

It is also apparent how other 'voices' are operating here in the construction of her morality, most notably the responses of her mother and sister to her disclosure of her status (cited in earlier extracts). These voices function in the Foucauldian sense by seeking to socially regulate the potential threat posed by unfathomable HIV-positive bodies (Thomas, 2001). In the comments below Grace constructs herself as 'enlightened' by knowing her status and thereby distances herself from potential suitors and other women who remain ignorant of theirs. She states:

Ay, no. I'm old now...because they want me but they have their wife. I tell them, "No, me, I'm HIV-positive, I don't want you." And then they just they run away. I'm not scared. You see? I'm not scared. I say, "I don't know you. Maybe you didn't go to test. You don't know how...what is your status. Me I know my status." (Grace T: p. 5, 195-198)

Grace's construction of herself as proudly aware of her status gives impetus to the construction of herself as admirable. It also serves as the basis for prescribing moral conduct to others. It is not so much that Grace is disapproving of the conduct, having engaged in it herself, but rather the 'usefulness' it serves in allowing her to appropriate the moral high-ground by distinguishing between her 'self' and the 'other'. When asked how she feels when she tells others that she is HIV-positive she stated:

I just feel happy that they say, "You, you are lying! People with HIV, they don't talk like this! They don't want to talk about that. You, why you talk proudly like this?"  
I say, "No, I must tell you so that you must be careful...mustn't come to me. You must know, if you sleep around, you'll get this."  
I don't say me, I was sleeping around but I was sleeping without condom and then now I've got that thing, that HIV. (Grace T: p. 9, 415-420)

For Zinhle disclosure represents a strategy for managing the damaging moral imputations of her HIV-positive status in her relationships with men. While disclosure renders her vulnerable, it also enables her to retain a sense of herself as moral. She states:

[...] And I'm not looking for any man. There are some, those who talk to me, but I try to be honest about my status because if we become serious then they must know. I believe you can still love yourself if you are having this HIV, if you are honest and direct, and they can love you too. But sometimes it's difficult to disclose to a guy because you can find his in-laws will reject you when they discover about your status. They want to know why you bringing this thing to them. (Zinhle T: p. 5, 221-227)

However, these disclosures are not always supported within the socio-cultural contexts in which they are made, as Zinhle tries to tell me:

You see, James, one problem for us African women, it's our men. They are just refusing to use condoms. If you tell him he must use a condom he will just think ukuthi [that]...you are having another man than him. So now, if you don't want to cause him to be jealous, how can you ask him to use a condom!? And if you know about your status, you are still afraid to tell him, even though he's the one who brought this HIV to you! (Zinhle T: p. 5, 219-235)

What she alludes to here is how prevailing discourses of sexuality construct condom use as an impingement on men's 'natural' sex drive (Hoosen & Collins, 2004). This leaves it up to women to ensure their own sexual protection and, by implication, holds them responsible for preventing the spread of the virus without the power to necessarily enforce it (Strebel & Lindegger, 1998). But because women's dependence on men is economically and culturally entrenched, their positioning means that they are often unable to insist on protection. Gendered constructions, in which condoms are read as implying sexual infidelity on the part of women, may further disincline women from using them. This damned-if-you-do, damned-if-you-don't scenario places women in a double bind in that, in order to maintain their relationships with men, they are rendered susceptible to infection. Thus, for women, sexual relationships are often characterized by competing discourses wherein they must wrestle to construct their morality and safety.



## **Chapter 5: Reflection on the process of gathering narratives**

This chapter reflexively considers some of the problems implicit in gathering narratives. These problems reflect the social constructionist questioning of the extent to which ‘the researcher’ and ‘the subject’ can ever claim to occupy coherent and distinct positions. Moreover, they question whether research processes are capable of ‘capturing’ stories without, at the same time, acting on subjects to co-produce them. This recognition, that it is not only ‘subjects’ who are multiply-constituted, but the ‘researcher’ too, warrants a consideration of the positions of each.

Two interviews have been chosen to highlight some of these concerns. The first, from the interview with Noloyiso, considers how the different ‘voices’ informing the position of ‘the researcher’ contribute to the shaping of the narrative that is produced. In this particular case these voice positions highlight the permeability of the boundary between ‘research’ and ‘therapy’ in a setting where emotionally fraught personal stories are being told about illness and deleterious life circumstances. The second, from the interview with Phumzile, pays special attention to the multiple voices functioning within a narrative and how the processes of attempting to ‘capture’ the narrative, contributes an added dimension to its co-production. Excerpts highlighting these considerations have been drawn from each interview and are discussed further below.

### **5.1 The porous divide between ‘therapy’ and ‘research’**

Noloyiso was 19 years old at the time of the study and was diagnosed HIV-positive towards the end of 2007. Her age in this case is relevant because it contextualises the additional vulnerabilities within her life-world of having been diagnosed HIV-positive. What follows below are four extracts taken from her interview that illustrate how the practices of research, as an academic domain of interests, aims and products, intersect with very real lived human experiences of people in adverse circumstances. Because of its theoretical domain, research ‘findings’ tend to produce ‘subjects’ who are dislocated from the world in which their everyday lives are embedded. This means that in gathering material, especially in the case of personal stories of poorly resourced, HIV-positive African women, there is a flow of power operating (Parker, 2005) in which the



respondent's perception of uses to which her information will be put, intersects with her strategies of 'resistance' (Foucault, 1984) aimed at preserving the integrity of her personhood.

In the excerpt below, I am confronted by the problem of what happens when the emotional world of the respondent threatens to 'derail' the interview and calls on me to shift subject positions from that of 'the researcher' to that of 'the therapist'. While empathy is a prescribed fundamental for the ethically-informed researcher, it does not answer why 'diversions' such as these are bracketed off and do not in themselves qualify as 'research'. The first excerpt leads up to the point where Noloyiso becomes emotionally overwhelmed when discussing the condition of her mother's health. Up to this point I had been following Crossley's interview schedule and had not been anticipating the reaction.

### **Excerpt 1**

*You've talked a bit about your plans. What problems are you having right now?*

Ay, the problem is that I'm having no money and my mother's getting sick, going to hospital...coming back. She was going there since...I think it was... November. She had gallstones and then they made an operation, and now she went back there, yesterday, she's got swollen tonsils and she will need another operation.

*So you've a lot of worries about your mother right now?*

Yes. Since she's been not working there's no money. It's been hard [becomes tearful].

(Noloyiso T: p. 4, 146-156)

At this point in the interview the need to offer some containment of the respondent's emotions becomes apparent. Reflexively, I become aware of two competing subject positions within me, that of 'the therapist' and that of 'the researcher'. As the researcher I recognize that my questions have raised a sensitive area for her and, having framed the research within my own mind as a way of undoing the silences imposed on the participants, I feel compelled to offer her some form of containment. Sensing the magnitude of her despair and the disintegration occurring before me, I change tone and voice position to that of 'the therapist' so as to begin exploring how much support (if any) she has available to her.

## Excerpt 2

*Are you able to talk to anyone about this problem to anybody?*

No.

*[A while later] Are you ok to continue with some other questions?*

Yes.

(Noloyiso T: p. 4, 157-164)

The brevity of the excerpt above belies the duration of time that passed between the first and second questions. During this (bracketed off) time I realize that, from what she had told me earlier about her mother having gone into hospital for an operation the day before (see excerpt 1), she is extremely sensitive; and being limited by the time allowed by the interview session, I offer her a referral to the Centre for Applied Psychology (CAP). In doing this I stress the importance of her having someone to talk about her anxieties over mother's state of health. After some time has passed and sensing that she appears to be 'contained', I inquire as to whether she is willing to continue. Feeling assured by her answer, I return to the questions of the interview schedule and the voice of 'the researcher'.

## Excerpt 3

*I want to talk to you about some of the things you said on your body map. Can you tell me what happened on the day you got your positive HIV diagnosis?*

I went hospital and they said I must test for HIV. Then afterwards they said I'm HIV-positive.

*What made you go to test?*

I had warts on my privates. So, they asked me if I want to take this test. So, I said, yes. Then they took me, they did some counselling, then they did the test, then I found out I'm HIV-positive. They phoned to my mum and told her my results, that I'm HIV-positive.

(Noloyiso T: p. 4, 165-177)

At this point, interpreting the hospital's actions as intrusive and representing a breach of confidentiality, I ask her how she felt about the hospital contacting her mother. In phrasing this question I am implicitly seeking an answer that confirms my own interpretation, namely, that she should have been angry. The question represents my shift into a voice position informed by my experiences in VCT (*Voluntary Counseling and Testing* programme in the primary health care clinics). The subsequent questions I ask, while all referring to events that had already happened in her case, mark the same route of questions I would be likely to use in hypothetically exploring with someone what they planned to do once they knew their HIV-test results.

#### **Excerpt 4**

*How did you feel about the hospital phoning your mother?*

They asked me if there's someone they can tell, then I said, "Yes."

*And what did the counsellor say to you?*

She said I must be strong.

*After you left the hospital what did you do?*

I went home and slept.

*And your mother?*

She didn't say anything.

*And when did you discuss it with her?*

We didn't discuss about it...even now.

*So that day of the test, did you discuss your status with anybody?*

When I got the HIV result it was September... 2006. Maybe about one week later I found Nomawethu then I talked with her about my status. My aunty found Nomawethu. She [Nomawethu] was talking on the radio. So my aunt called me and she told that there's somebody I must talk to. So I went there with my aunty and then we talked to Nomawethu because she [my aunt] knew that place from before.

*And who told your aunt, was it your mother?*

Ja.

*And did you discuss anything about your status with your aunt?*

No.

(Noloyiso T: pp. 4-5, 178-212)

At this point in the interview, her responses signal to me that she is reluctant to offer any in-depth answers about her relationships with her mother and her aunt. Having reached a dead-end line of questioning, I am left no option but to return once again to the questions of the interview schedule. From this point onwards, the tone of the interview is characterized by her reluctance to give lengthy storied answers and this, in turn, undermined the extent to which narrative-rich material could be obtained. From a Foucauldian point of view of 'resistance' (Foucault, 1984), she could be interpreted as withholding her precious 'data' from the 'researcher' since she, in all likelihood, experienced my 'therapist' as ineffectual in containing or ameliorating her lived experience. In this way her 'silence' served as an act of resistance (Foucault, 1984), one that readdressed the balance of power within the narrative interview. From the excerpts above what is apparent is that I was sliding between different voice positions and their forms of power. These were not only contributing to the shaping of the account being produced, but also to how the respondent may have come to experience herself thereafter.

## **5.2 Whose story is it after all? - The multi-voicedness of narratives**

While stories serve to connect individuals to the interpersonal, social and moral context in which their lives are lived, they "do not 'emerge' from 'within' the isolated individual; rather they develop in the context of specific interactive episodes and contexts" (Crossley, 2000a, p. 59). What this means is that the listener/audience are collaborators who co-construct the story. The three excerpts below, which come from the interview with Phumzile, illustrate how stories become co-produced and multi-voiced. In this interview there are at least four voices or inter-texts immediately present: my own voice, the voice of the facilitator, the voice of the interviewee and the 'voice' of her body map. It is these voices in combination that co-produce a specific account within a specific context.

In the first excerpt below, Phumzile tells of how she came to know that the woman she'd believed to be her mother was actually her grandmother and that her biological mother had abandoned her when she was three months old. The narrative tone characterizing Phumzile's early years is here intensified by the facilitator who 'dramatizes' the moment of Phumzile's realization by drawing on images of nasty sibling rivalry. In speaking for Phumzile, as she does here, she gives voice to the incomprehensibility and disorientation Phumzile is surely likely to have experienced as a child coming to this realization. However, while this normalizing gesture serves to give voice to Phumzile's experience, it simultaneously constructs her as someone who continues to be spoken for:

### Excerpt 1:

*Facilitator: She was staying with her granny. Her parents abandoned her when she was very young. She had to stay somewhere else with different people. And from Grade 7...*

*Interviewee: Kusho ukuthi ngifunda u-std. 5 ila engazikhona ukuthi uma wangishiya ngisemncane nginezinyanga ezintathu.  
[It was when I was doing standard 5 that I discovered that my mother had abandoned me when I was three months old.]*

*Facilitator: When she was doing grade 7 it's when she knew that her mother abandoned her when she was 3 months old.*

*Researcher: So she found that out when she was in grade 7?*

*Facilitator: Wakutshela ugogo wakho? [Your granny told you?]*

*Interviewee: Ngatshelwa ingane ezalwa ugogo ngoba ngangazi ukuthi imina owokugcina kuyena encane yase iyangitshela ukuthi akuyena uma wami lo.  
[I was told by my granny's child (i.e. aunt) because I had believed that it was me who was her (my granny's) last-born until she (my aunt) told me that she (my granny) is not my mother.]*

*Facilitator: What happened was her mum's sister (i.e. Phumzile's aunt), the last born to her mum, because they (i.e. the aunt and Phumzile) were like the same age, she told her, "You are not my sister. Your mother left you when you were 3 months. I'm the last-born. You are not the last-born." It's how she found out.*

*Researcher: And after that, how did you see your life?*

*Facilitator: Impilo yakho yaba njani emva kokuthi usewazi lokho? [How was your life after you came to know that?]*

*Interviewee: Akuphindanga nje ngaba right isimo sami asiphindango saba sesimenwi. Ayizange isaba right impilo emva kokwazi ukuthi angisiyena owakhona kulomndeni.  
[Things were not the same for me as before. My life wasn't the same after finding out that I did not belong in that family.]*

*Facilitator: Things were not the same anymore. (Phumzile T: pp. 1-2, 33-76)*

In presenting the interview transcript as above, I acknowledge that I digress from the conventional interview format in which the 'third' person, be it facilitator or translator, is rendered a background figure. Choosing to present the interview in this way highlights the constructedness of transcripts themselves, in this case, even more so by my decision to insert, where relevant, references from the person's body map. These intrusions, which 'speak' at different levels, produce the overall polyphonic texture of the narrative. Because, in this case, the facilitator personally knows Phumzile, she functions as a meaning-broker whose comments add more weight to the production of the narrative than those an outsider might make. In the excerpt below the facilitator provides extensive commentary on how Phumzile sought to mend the disruptions caused to her sense of belonging and place in the world, vis-à-vis her knowledge of her abandonment, by attempting to find her biological mother. As the story unfolds it becomes apparent how the disruptions to her childhood overshadow the disruptions caused by HIV. It is these formative experiences of hers that ultimately characterize the difficulties of her present life circumstances (McAdams, 1993).

### **Excerpt 2:**

*Interviewee: Kwabanzima ngoba ngahamba ngamfuna uma. Ngabhalela kuthemba alibulali ngase ngiyamthola esesibhedlela eMshiyeni.  
[Things were difficult because I went searching for my mother. I wrote to Hoping Doesn't Kill (a radio program) and then I found her at Prince Mshiyeni hospital]*

*Facilitator: What happened was she tried by all means to get her mum. She had to go to Radio Zulu. She wrote some letters to Radio Zulu and luckily they responded to her. She heard that her mum is in hospital. She was thinking her mum was a nurse or sister or something else, only to find out that her*

*mum was a patient there and she was finished with HIV/AIDS. She was bed-ridden. So she went to see her mum and her mum didn't recognize her. Her mind was not well, it was not clear, as if she had forgotten everything. Maybe she had meningitis. So, after that her mother was discharged to one of the places where she used to stay at Kwa-Makhutha. It's where she went to stay with her mum.*

**(Phumzile BM: lower right)**

“Kwapatha kahle ngoba ngimtholile umama wami ngamthola 2001”

[It was good for me when I found my mother. I found her in 2001.]

*Facilitator: Wahlala isikhathi esingakanani no ma? [For how long did you stay there?]*

*Interviewee: Kwaba amasonto amathathu washona ngelesine isonto.  
[It was three weeks and she died in the fourth week].*

*Facilitator: Only 3 weeks and she died after 4 weeks. After that she started to cope with her life badly after her mother's death because it was not going to be easy for her to go back to her grandmother's home because they were saying, "You went to look for your mum and what did you gain? You didn't gain anything and you want to come back?" So it was very difficult for her. She started to live her life like that. What happened was she got involved with someone because she needed love and support. She thought maybe she would get love from that person and then she gave birth to a son, a baby boy. She came with him to the support group and then the father of that boy passed away so it was difficult for her to cope with life again. She lost the only person who gave her support. After that she got involved again with the dating scene. Then she got pregnant again and had a girl. She's getting the grant although the grant is R200, it's very little and the boy is schooling now.*

*Researcher: How is she coping with having little money for the children?*

**(Phumzile BM: central right)**

“NGihlala EMQASHWE[NI] NEZINGANE ZAMI ezimbili uma nkinga ngino mgani wami anginalo ikhaya.”

[I am living in a rented place with my two children. When I have a problem I take it to my friend. I don't have a home.]

*Facilitator: What she normally do now is she comes to me for washing and ironing and I give her what I have. Sometimes I get someone from my friends to give her work for her to be supported. And luckily she joined the support group. It's where she gets support. We are like her family, all of us. (Phumzile T: pp. 2-3, 83-131)*



From the above excerpt it can be seen how the facilitator's voice functions as a 'voice-over' that connects and weaves together the unfolding story. Her voice dominates the storytelling here and draws our attention to the 'miracle' of radio and how a potentially happy story (in Phumzile finding her mother) ends in the tragedy of Phumzile being forever denied the parental love she so desperately craves. The tragic tone of the voice-over differs from Phumzile's tone of resignation and fatalism and may be accounted for, in part, by the interviewing process itself which set her up to be 'spoken for' and 'spoken about' by the facilitator and researcher (e.g. "How is *she* coping with...?", my emphasis). This may have led to Phumzile experiencing herself as alienated from the interviewing process. Hence, the research process and setting sets 'subjects' up to experience themselves in a particular way and determines the narratives they produce as a result.

Interpretations of narratives must therefore recognize how the processes involved in gathering them are what also, in part, produce them. In this case, it must be acknowledged that the interpretation of Phumzile as 'helpless' and 'alienated' may be a reflection of the research processes themselves in action. Thus, the way in which multiple voices contribute to the construction of a narrative is determined by how and in what context it is done. It is the combination of these elements that gives rise to a narrative as being an ensemble of voice positionings. In the final extract below we see how the facilitator appropriates Phumzile's own story by over-layering it with her own experiences, thus contributing to the construction of an account of even wider applicability:

### **Excerpt 3:**

*Facilitator:* Yini eyenza ukuthi utshele ugogo wakho e-status sakho? [What made you tell your granny about your status?]

*Interviewee:* Ngangibatshela ngoba ngangizitshela ukuthi uma usu-positive usuke usuzoshona kufanele bazi uma ngifa kufanele kube yibona abazokwazi ukungincwaba.

[I told them because I thought that becoming positive means you're going to die and they should know so that, when I do die, they will have prepared for my funeral.]

*Facilitator:* She told them because she thought if you tell someone about your status it is good for them to give you support. But for her it didn't help.

*Researcher: Does she still see her grandmother sometimes?*

*Facilitator: Yes, she does. She goes there... but the relationship is not good.*

*Researcher: What does her grandmother think she should do now?*

*Facilitator: All our grandmothers, all our families, they think if you have this HIV you have to go and die where you got it. It's like you're cursed. They don't care. It's as if you are the only person in the family who's got it. While some people do take ARVs, it's because they didn't tell their families. (Phumzile T: pp. 4-5, 170-193)*

The facilitator, by referencing Phumzile's account to "all our families", takes a personal story and elevates it to a meta-narrative. This universalizing of the story ties it to archetypal themes of abandonment, rejection, loss and hope. In addition to the themes of Phumzile's childhood years, there are HIV-related themes and its metaphors of disruption, contagion and loss. These themes, which are experienced at the personal level by Phumzile and which intersect with dominant social constructions at the collective level, are mediated through acts of storytelling. What the above extracts illustrate is how the polyphonic texture of narratives implicitly refute any claim to singular authorship. Rather, it is the embellishments to Phumzile's story by the facilitator, together with my 'interruptions' in the transcript by way of questions and/or references from the body map, that contribute to the construction of her account as multi-layered or polyphonic. It is through the interaction of these different voice contributions that her 'narrative identity' emerges.

## Chapter 6: Conclusion

The emphasis social constructionism places on open-ended and ongoing reflection, discussion and debate resists the foreclosure of meaning as implied by a 'conclusion' (Zaina, 2005). Seeing the conclusion in this way, not as an 'ending', but rather as a space in which to raise questions and stimulate further discussion acknowledges the fluidity, contextuality and constructedness of 'knowledge'. In attempting to derive findings that reflect the macro context of post-apartheid South Africa, I am compelled to acknowledge that what I offer here is a function of my own socio-cultural and political lenses as much as it purports to express the participants' own socio-cultural 'embeddedness'. In this regard the work of Foucault (1977; 1981; 1984) is instructive because it alerts us to the ways in which the practices of social science simultaneously produces its subjects and the findings out of which 'reality' is constructed. From this I draw a corollary about how my own discursive positioning may have predisposed me towards what I have looked for and how my findings may have been used to construct a particular version of 'reality'. However, while Foucault exposes the dangerous ways in which the practices of knowledge uphold the practices of power, his view denies the possibility of deconstructing or resisting the dominant discourses in which people are embedded.

The decisions taken in this research, while acknowledging how the Foucauldian dimensions of knowledge and power operate to produce subjects, were also theoretically informed by the more liberating outlook of narrative therapists such as White and Epston (1989). While these authors recognize that individuals are constrained by dominant discourses, it is these selfsame constraints that allow for the generation of meaningful counter-narratives through 'deconstruction' and 'externalization'. In the context of research, their approach acknowledges that it is not only narratives that are socially, culturally, historically and politically embedded, but research practices too. Their approach is deemed highly relevant in a cross-cultural, post-colonial, post-apartheid context where dominant discourses about HIV/AIDS have functioned to 'silence' those who are ill. In my own case, these 'silences' could be observed in the formidable obstacles I encountered when trying to locate a group of participants.

My decision to use a narrative theory approach in conjunction with body mapping arose from the recognition that, in working with African HIV-positive women, there would be several barriers pertaining to health-status, language, gender, race and culture and that these carried the potential for power imbalances and 'othering' to occur. These differences demanded from me a rigorously critical and self-aware approach, not just in how proceedings were conducted, but also in my willingness to deconstruct my own empowered and privileged position as the 'researcher' and the lenses through which I would be making interpretations. The use of body mapping actively involved the participants in externalizing their experiences of HIV and its impact on their bodies. In this way they were able to give 'voice' to the silences imposed on their HIV-positive bodies by dominant discourses. Because body maps remain open to multiple interpretations they stand as a meaningful counterpoint that resists the imposition of a singular interpretation of the women's narratives.

While the non-verbal medium of body mapping afforded me entry into the participants' worlds in a way that served to minimize the obstacles above, language differences undoubtedly shaped narratives by constraining the linguistic resources the women might have otherwise appealed to in constructing versions of their lives. While I was willingly accepted into the group, I entered as an 'outsider' and this may have led some to construct their stories to fit a perceived audience, one outside of the one they are familiar with. Hence, while the research was envisaged to offer a facilitative 'space', one in which the women could construct versions of their identities in their own terms, it is important to recognize that the narratives they produced represent one of a number of possible sets of narratives that *might* have emerged. This is in keeping with the social constructionist outlook that views all knowledge as co-constructed, contextually dependent and non-finalisable. In this regard I have attempted to show that my own interpretations do not purport to represent empirical truth, but are rather derived from the multiple subject positions of my own situatedness. This deliberate decentring of the 'authorial' voice on my part represents a powerful way of deconstructing the practices of knowledge and their agendas. In short, it represents a conscientious way of conducting social research.

In interpreting the women's narratives what emerges is that, inasmuch as their identities are embedded within dominant discourses of HIV/AIDS, they also engaged in forms of 'resistance' whereby they attempted to produce self-defining counter-narratives. This ongoing dialectic, in

which individuals struggle to free themselves from dominant discourses and are, in turn, shaped by their 'resistance', is what gives rise to the lived experience of HIV as embodied subjectivity. In the case of South Africa, the rapid transitional shift from apartheid to democracy in 1994 brought with it a proliferation of alternative and competing discourses within which the identities of individuals must be negotiated. These discourses, insofar as the prevailing denialism over HIV/AIDS has been concerned, have highlighted the continuation of the racial practices of the past in that it is the materially disadvantaged who are the most affected by HIV/AIDS and are the ones most in need of effective treatment (Walker, Reid & Cornell, 2004). It is against this backdrop that the research question, by tapping into HIV-positive African women's narratives, sought to consider in what ways their investments in particular discourses gives rise to their lived experiences of HIV as embodied subjectivities. In attempting to answer this question several theoretical constructs about living with a chronic illness were drawn on (Bury, 1982; Davies, 1997; Frank, 1995; Crossley, 1999a; 1999b; 2000a; 2000b).

The stories that were generated showed up an incongruity with narrative models such as those put forward by McAdams (1993) and Crossley (2000a). Working in a developing context with African women exposed the heavily Western theoretical basis driving some of the questions used on McAdams' (1993) narrative interview protocol (see Appendix 4). Concepts such as 'life chapters' and 'life themes' (questions 1 and 7 respectively) were experienced by the participants as alien concepts and could not be translated directly. These concepts betray a Western propensity to organize time (in the case of 'life chapters) and its meanings (in the case of life themes') in a way that differs from how the African women in this study 'organised' meanings associated with time. Furthermore, the construction of HIV as a 'biographical disruption' (Bury, 1982) carries very different connotations for women in developing countries who are subject to multiple and often ongoing disruptions where threats to their very livelihood do not only come from HIV/AIDS.

A particularly strong theme to emerge from the women's narratives in this study was how, for many of them, their formative years were characterized by the absence of a father or both parents. This strongly influenced the narrative tone of their stories and their perceived degree of agency and familial support. For the mothers in this study, their children represented a strong reinforcing factor in contending with the uncertainty of the future. Another strong theme to emerge was how the women engaged in managing their identities so as to maintain their sense of 'embeddedness'

(Josselson, 1996). This had implications not only for how they constructed their responsibilities and morality, but how they managed their bodies also. By investing in particular subject positions they were able to resist some of the discrediting and damaging proponents implicit in dominant discourses of HIV/AIDS. However, their 'investments', while opening up certain discursive possibilities, also bring about the foreclosure of others. The position of 'silence' for instance, while preserving 'credibility' in the eyes of others in certain contexts, contributes to a social atmosphere that denies those with HIV the realities of their lived experiences. For those who do speak out and disclose their HIV-positive status, they must find a way of maintaining moral coherence in the onslaught of stigmatizing attitudes about HIV/AIDS. This shows how different individuals can take up particular discourses depending on how they intersect and compete with other discourses in their own discursive repertoire.

Also informing the present enquiry was a consideration of how research practices themselves are implicated in shaping the accounts participants produce. Seeing accounts as co-constructed and multiply-voiced allows them to remain open to the possibility of different interpretations. Approaching them in this way, as heading not towards closure, but rather towards the opening up of spaces for ongoing discussion and debate, represents the point of entry whereby transformational learning can begin to occur. In this regard, it is important for research not only to attempt to answer questions, but to be able to generate them too. To this end the body maps were instrumental in provoking not only self-reflexive inquiry for the HIV-positive women who made them, but also in the questions they pose to the reader. By including the body maps with the narratives these women are given 'voice' at multiple levels in a way that begins to acknowledge the plurality of meanings associated with HIV/AIDS and self-making. Hence future directions, as suggested by the present inquiry, point to the need to create research contexts that allow for the emergence of a plurality of voices, rather than privileging one voice over the others.

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## **Appendices**

## Appendix 1: Ethical clearance letter



RESEARCH OFFICE (GOVAN MBEKI CENTRE)  
WESTVILLE CAMPUS  
TELEPHONE NO.: 031 – 2603587  
EMAIL : ximbap@ukzn.ac.za

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13 SEPTEMBER 2006

MR. J OLMESDAHL (941362524)  
PSYCHOLOGY

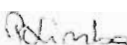
Dear Mr. Olmesdahl

**ETHICAL CLEARANCE APPROVAL NUMBER: HSS/06472A**

I wish to confirm that ethical clearance has been granted for the following project:

**"Positive HIV stories: Body mapping as a therapeutic tool for a narrative exploration of the lives of black HIV-women"**

Yours faithfully

  
.....  
MS. PHUMELELE XIMBA  
RESEARCH OFFICE

**PS: The following general condition is applicable to all projects that have been granted ethical clearance:**

**THE RELEVANT AUTHORITIES SHOULD BE CONTACTED IN ORDER TO OBTAIN THE NECESSARY APPROVAL SHOULD THE RESEARCH INVOLVE UTILIZATION OF SPACE AND/OR FACILITIES AT OTHER INSTITUTIONS/ORGANISATIONS. WHERE QUESTIONNAIRES ARE USED IN THE PROJECT, THE RESEARCHER SHOULD ENSURE THAT THE QUESTIONNAIRE INCLUDES A SECTION AT THE END WHICH SHOULD BE COMPLETED BY THE PARTICIPANT (PRIOR TO THE COMPLETION OF THE QUESTIONNAIRE) INDICATING THAT HE/SHE WAS INFORMED OF THE NATURE AND PURPOSE OF THE PROJECT AND THAT THE INFORMATION GIVEN WILL BE KEPT CONFIDENTIAL.**

cc. Faculty Officer (Post-Graduate Studies)  
cc. Supervisor (Prof. L Wilbraham, Bren Brophy)



## Appendix 2: Consent form



### CONSENT

I, \_\_\_\_\_ hereby agree to participate in an art-making body mapping workshop for the purposes of research to be conducted by University of KwaZulu Natal Psychology Masters (Counselling) student, James Olmesdahl (Reg. no. 941362524).

I give permission to be interviewed about my artwork and for the interview to be tape-recorded and for my artwork to be photographed for research purposes, but that my names and place of residence will be kept strictly anonymous, and that all material will be treated with confidentiality.

I understand that should the occasion arise where I need to receive further counselling support, I may do so at the Psychology Clinic of the Centre for Applied Psychology, University of KwaZulu Natal.

I further understand that participation is voluntary and that I may withdraw my participation at any time.

Signed:

Date:

### IMVUME

Mina \_\_\_\_\_ ngiyavuma ukuthi ngibambe iqhaza kwinhlanganyela (body mapping) emayelana nocwaningo olwenziwa ngumfundi waseNyuvesi yakwa Zulu Natali oqogoda imfundo yakhe yezengqondo. Igama lomfundi ngu James Olmesdahl (Inombolo yakhe yasesikoleni 941362524).

Nginikeza imvume yokuphendula imibuzo nokuthi baluqophe phansi kanye nokuthi umsebenzi wami womdwebo bawuthathe izithombe ukwenzela ucwaningo, kodwa igame lami nendawo engihlala kuyona, nokuthi konke loku abazokusebenzisa kugcinwe kuyimfihlo.

Nginyaqonda ukuthi uma kuvela isidingo sokuthi ngidinge usizo lwengqondo, ngingakwazi ukuluthola ngokuvakashela esizindeni salolusizo eNyuvesi yakwa Zulu Natali – Centre for Applied Psychology.

Nginyaqonda futhi ukuthi ukubamba iqhaza kulolucwaningo akunampoqo nokuthi ngingaphuma kulona noma yingasiphi isikhathi.

Isayinwe:

Usuku:

Researcher: **James Olmesdahl**  
tel: 464 3931  
cell: 072 778 5377

Research supervisor: **Lindy Wilbraham**  
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Founding Campuses:

█ Edgewood

█ Howard College

█ Medical School

█ Pietermaritzburg

█ Westville

## **Appendix 3: Body mapping workshop instructions**

### **Part I: Supportive others**

1. Choose a partner.
2. Draw carefully around your partner's body with a black khoki on a big piece of cardboard.
3. Ask your partner to draw around your body on the same piece of cardboard.
4. **Repeat** the exercise on another piece of cardboard so that your partner has his/her own body map to work on with you as the shadow.
5. Name the **date** and **place** where you were **born** on the cardboard. Write this nice and big in a place outside of your outline. Name the **important places** you have lived.
6. Choose a colour that represents you and paint it around your body outline.
7. Choose another colour and fill in your partner's figure everywhere where it is outside the outline of your body.

### **Facilitator to ask these questions:**

- What is the significance of the shadow?
  - Has there ever been somebody in your life that has consistently given you support through good and bad times?
  - Which of your ancestors might this shadow be?
8. Write the name(s) of who this shadow person/people is/are some way next to the shadow and write something about how they have influenced your life.
  9. Draw in any other people (e.g. family, friends) who are important to you and write in next to them how they are important to you.
  10. Draw a symbol of your clan and write the name next to it (e.g. family, church, country). Write in why you chose that symbol and how you belong to it.
  11. Now ink up your hands and feet and stand them where you have drawn your hands and feet on your body map.

### **Part II: Personal power**

12. Fill in on your body map your facial features: your mouth, nose, eyes etc.

13. When you are feeling down or depressed where inside your body do you feel emotional pain? Draw/paint it onto your body map.
14. What part of your body gives you strength to overcome difficult times? Feel where your place of personal power is located on your body and mark the place.
15. Choose a symbol that represents you. The symbol should represent your strengths and weaknesses. It can be a plant, an animal, an object, or anything, or combination of a few symbols. Some people have drawn Table Mountain representing their ties to southern Africa. Others have drawn a fruit or vegetable and some have drawn farm animals.
16. Choose a phrase or a slogan that represents how you live your life and/or what you believe.

### **Part III: Personal experience**

17. Close your eyes for one minute and try remembering your first memory. Somewhere on your body map paint or draw a picture of your first memory and describe it in a few words next to the picture.
18. Draw and write about an important high point/good experience in your life.
19. Draw and write about an important low point/bad experience in your life.
20. Close your eyes and imagine your future. Draw or paint this future somewhere on your body map.

### **Part IV: HIV**

21. Choose a colour and/or pattern (e.g. dots, stripes) to represent the HIV virus. Ask yourself how HIV or HIV medicine has affected your body on the ***outside***, specifically your skin. What has happened to your skin? Has HIV left scars? Have you had rashes? Mark those places on your skin where HIV has affected you. Next to these places describe how you dealt with the problems.
22. Using this same colour/pattern draw/paint the parts of your body that have been most affected by HIV-related illnesses on the *inside* of your body (e.g. your hear, lungs, blood). Write next to each illness, side-effect or opportunistic infection what you did to control the symptoms or to heal yourself?
23. Write in what beliefs have helped you to cope with the disease.
24. Complete your body map by decorating it with any other details, colours or patterns of your choice that have special meaning to you.

## **Appendix 4: Semi-structured interview schedule**

This semi-structured interview covers the following narrative aspects: (1) life chapters; (2) key events; (3) significant people; (4) future script; (5) stresses and problems; (6) fundamental beliefs and values; and (7) discerning a life theme.

1. 1.1 Looking back over your life how would you divide it into different stages or phases?  
**Uma ubheka emuva eminyakeni yakho oyiphilile ungayihlukanisa kanjani ngezigaba ezahlukene?**
2. 2.1 What life events have been high and low points for you?  
**Yiziphi izinto ebeziphansi phezulu empilweni yakho?**  
2.2 What life events have been turning points for you?  
**Yiziphi izinto ezithathe ijika noma ezijikile empilweni yakho?**  
2.3 What are your earliest childhood memories?  
**Yiziphi izinto ozikhumbulayo ebunganeni bakho?**  
2.4 What adolescent memories stand out for you?  
**Yiziphi izinto ozikhumbulayo esigabeni sokukhula kwakho?**  
2.5 What adult memories stand out for you?  
**Yiziphi izinto ozikhumbulayo ebudaleni bakho?**
3. 3.1 Who are the people who have been important to you in your life?  
**Obani abantu abebesemqoka kuwena empilweni yakho?**  
3.2 Do you have any heroes/heroines?  
**Bakhona abantu obubathatha njengamaqhawe akho?**
4. 4.1 Can you describe for me how you see your future?  
**Ungangichazela ukuthi ikusasa ulibona linjani?**  
4.2 What are your hopes and fears?  
**Yimaphi amathemba nezinto ozisabelayo?**

- 4.3 What plans do you have for yourself?  
**Unaziphi izinqumo ozibekela wena zona?**
5. 5.1 What problems do you currently face?  
**Yiziphi izinkinga obhekene nazo njengamanje?**
- 5.2 How do you think you will deal with these?  
**Ucabanga ukuthi uzobhekana kanjani nalezinkinga?**
- 5.3 Can you tell me about the day you received your HIV-positive diagnosis?  
**Chaza ngosuku owathola ngalo ukuthi unegciwane leHIV-positive?**
- 5.4 In what ways has HIV affected your body?  
**Ingabe isandulela ngculazi siwuhlukumeze kanjani umzimba wakho?**
- 5.5 How have you dealt with these problems?  
**Uzixazulele kanjani lezinkinga?**
- 5.6 How has your life changed since you were diagnosed HIV-positive?  
**Impilo yakho yashintshe kanjani emveni kokuba usutholile ukuthi uneHIV-positive?**
6. 6.1 What are the values and beliefs that are important to you?  
**Yiziphi izinto ozixabisayo nokholelwa kuzona ezisemqoka kuwena?**
- 6.2 How do you feel your beliefs differ from those around you?  
**Uzizwa kanjani ngokuthi izinkolelo zakho zihlukile kwabanye abaseduze nawe?**
- 6.3 In what ways have these values and beliefs changed over time?  
**Zishintshe kanjani lezinto ozixabisayo nokholelwa kuzona ekuhambeni kwesikhathi?**
- 6.4 Describe how you have viewed your life since you became HIV-positive?  
**Chaza ukuthi uyibona kanjani impilo yakho njengoba usuthole ukuthi uHIV?**
- 6.5 In what ways have your views of others changed since the day you were diagnosed HIV-positive?  
**Zishintshe kanjani izindlela obabuka ngayo abantu kusukela ngosuku owathola ngalo ukuthi uHIV-positive?**

6.6 What opinions do you hold about politics or the government?

**Yini imibono yakho onayo ngepolitiki noma ngezombusazwe noma ngohulumeni?**

6.7 What do you believe about God?

**Umkholelwa njengani uNkulunkulu?**

7. 7.1 Looking back over your life are there any patterns or themes that stand out?

**Uma ubheka emuva nempilo yakho zikhona izinto indlela ophila ngayo ezivukayo ngokushesha emqondweni wakho?**

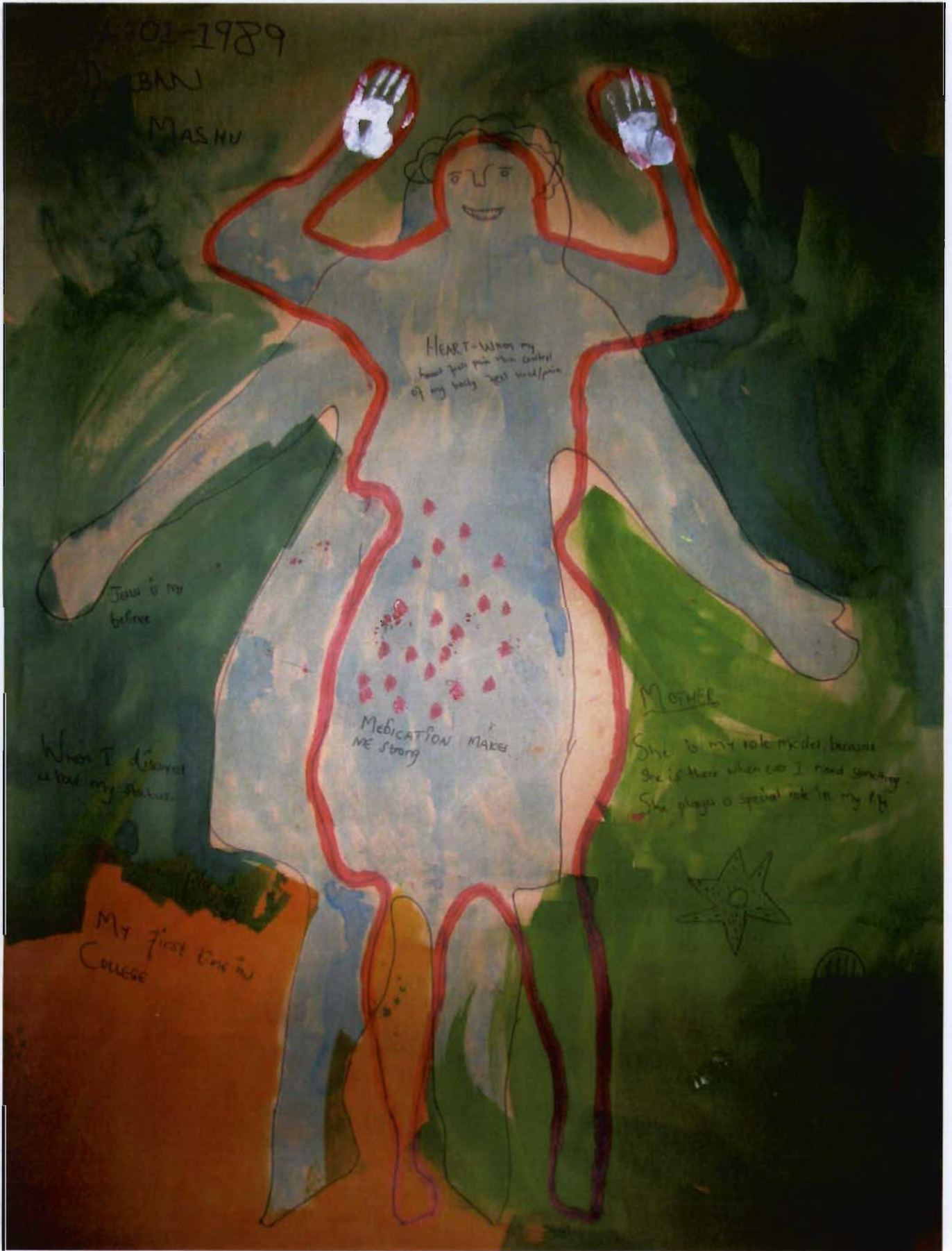
## **Appendix 5: Body maps**



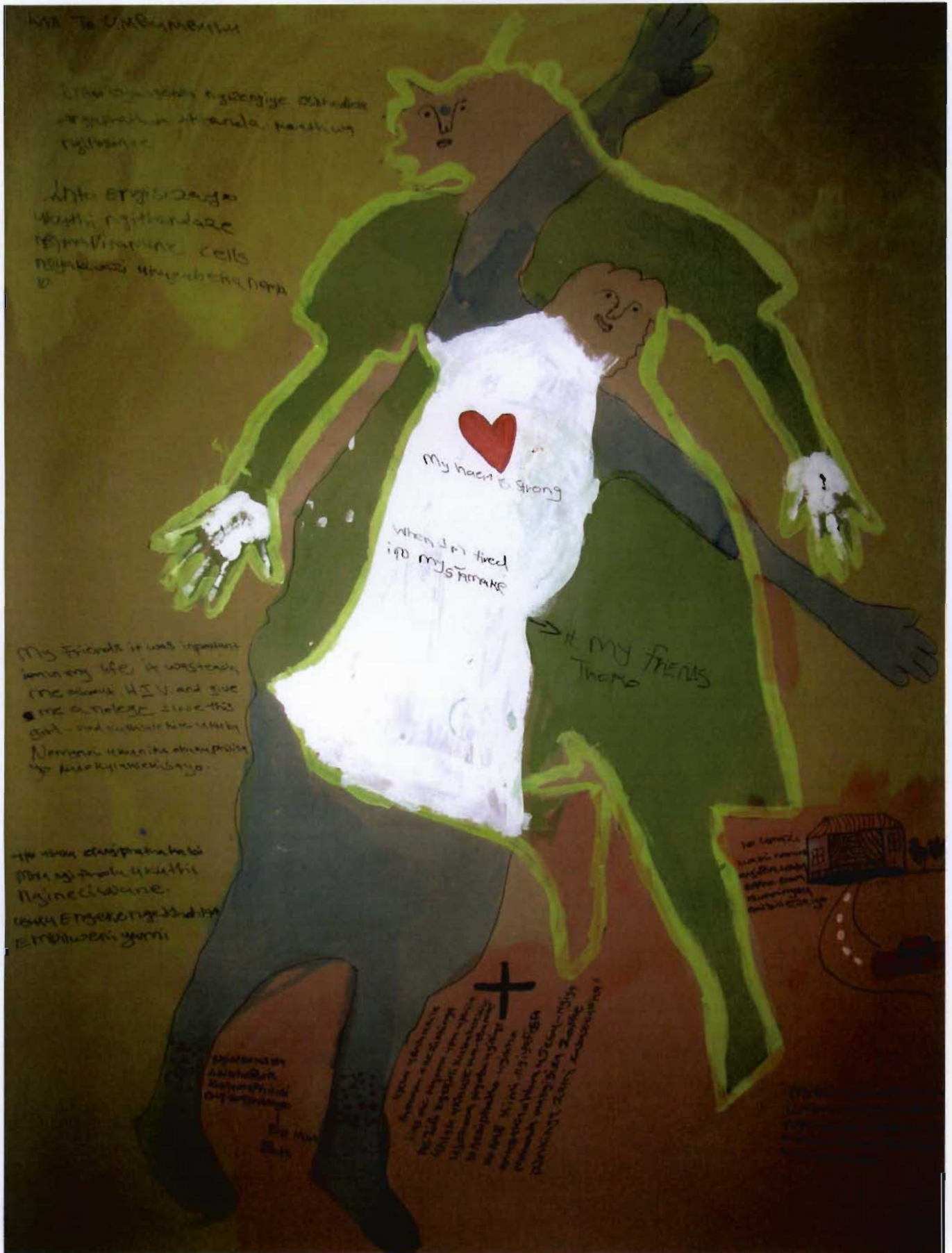








Noloyiso



Nondumiso





Phumzile



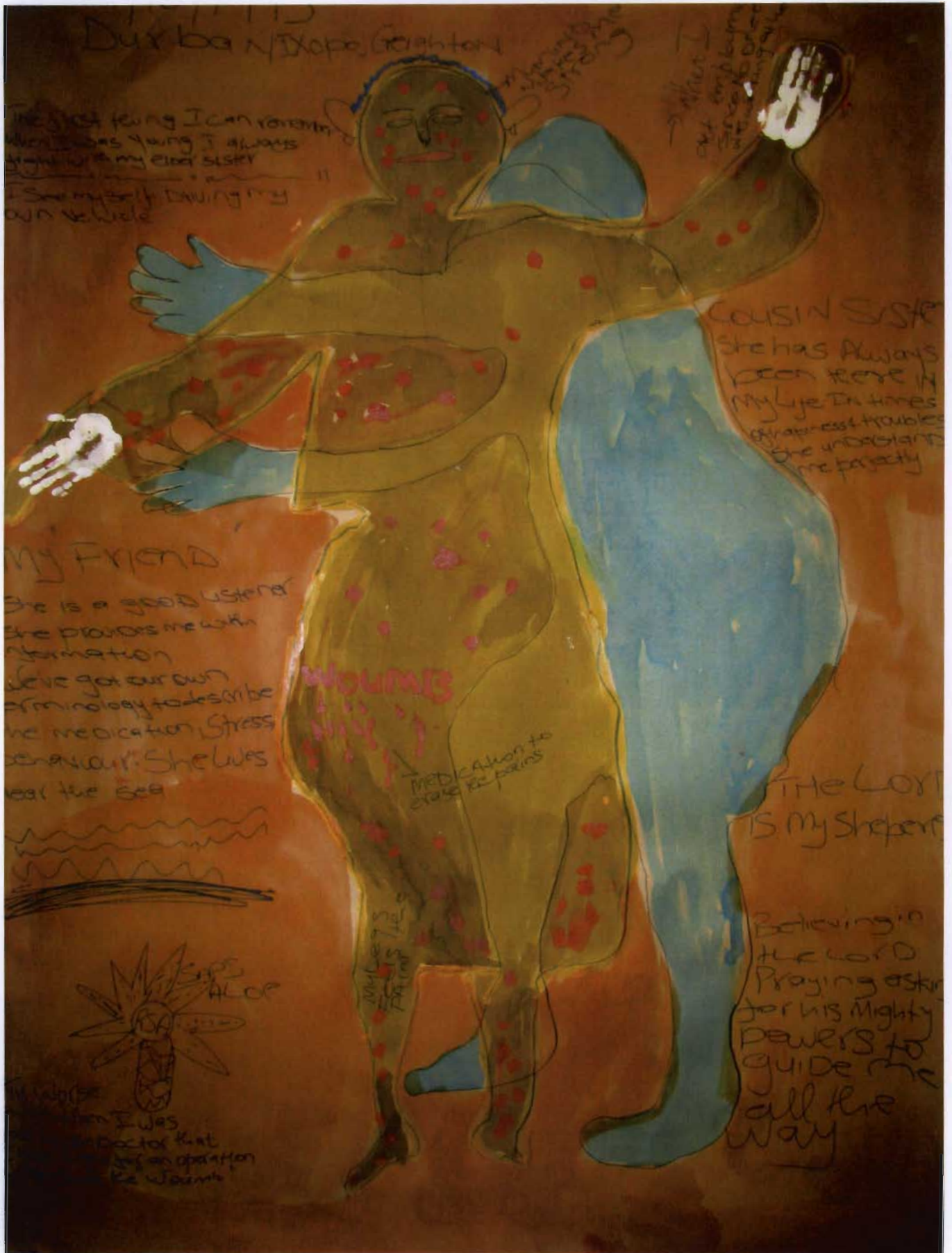
Thandeka





Zanele





Zinhle