

Chapter 17

Experiences of people living with HIV

Lumka Daniel and Corinne Squire

17.1 Introduction

You are HIV Positive
YOU ARE – HIV POSITIVE
YOU ARE
YOU, HIV POSITIVE
YOU ARE POSITIVE
YOU ARE
YOU ARE
YOU ARE
HIV POSITIVE

I AM
I AM?
Nay, I am not
I am who I am
And
I am not HIV Positive

I may be living with HIV
That does not make me
HIV does not make me

I am who I am
And I still am who I am
And I live,
I live,
I live with HIV

HIV?
Humano
Immuno – def
Deficiency
V-Irus
HIV lives in me

I have not died
I am and HIV is within me
I am, I still am

There's no name for HIV
They can't find it
They can help me fight it
It is not detectable
It deteriorates,
Deteriorates my immunes

I was not born with it
God did not create me with it
Somebody got it
Somebody passed it on
Passed it on to me
Somebody whispered
You are HIV Positive

They cannot tell me, they cannot tell me
When I,
When I became, errr when I became HIV Positive
They cannot tell me
When I,
When I received the, errr the v-irus
They cannot tell me,
They cannot tell me who passed it on to me

The only thing they tell me
Is errr, my body's struggling
There's a battle in my immunes

Awakening my anti bodies
Ant-I bodies to battle with the v-irus
The trespassing curse
In my body
In my blood

They tell me,
They tell me,
You are HIV Positive

I feel like Judas in Passion of the Christ
Only that, only that I did not betray the Messiah
Only that, I did not sell the Messiah, nor my body
Only that, only that I have not killed myself
Maybe I have, maybe I did
By allowing them to change me
From who I am and who I am meant to be
To
You are HIV Positive

Who cursed me?
Why me?
Why now?
Why?

Should I kill?
Should I kill the cheater, the bastard, the moron?
If I was born with it, would I have to kill my parents?
Or would they have killed each other already by now?
Mhhh, errr should I kill the government?
Why wasn't there PMTCT?
Should we all die?
Am I?
Am I dead alive with the V-Irus?

I live
I am alive
And I,

I live with HIV!!!

(Lumka Daniel, 2008)

This chapter reviews research on experiences of people living with HIV in South Africa, and suggests that in addition, poetry, fiction, visual arts, music, autobiography and documentary are crucial to understanding HIV experiences (Cameron, 2005; Dangaremba, 1996; Health and Development Africa/Soul City, 2007). Research on HIV experience needs to include, not just statistical and qualitative studies, but also writing and images by and about people with faces and names whose lives have been changed by the epidemic.¹

The chapter adopts 'experience's broadest meaning: that of practical acquaintanceship with an object, event or phenomenon. It deals with the HIV experiences of two women researchers - one South African, black, and one British and white. Squire came to do research about people's support for living with HIV in South Africa through a combination of previous experiences: volunteering with US HIV support groups; researching UK understandings of HIV support; and interest in South African HIV services and activism, and South Africa's critical intellectual traditions in psychology and gender studies. In South Africa, everyone experiences HIV/AIDS, regardless of 'personal' HIV status. Efforts are made to make sure that everyone in the country engages in the battle against the pandemic. Daniel worked with various organized groups, in churches and schools, as well as with individuals, on HIV prevention campaigns. She collaborated with Squire on the HIV support study, conducted 2001-4 through semi-structured interviews in the Cape Town area with 37 participants (Squire, 2007). Through this work, a relationship with TAC emanated; as a result she co-founded the University of Cape Town branch of the Treatment Action Campaign (TAC). 'Voices' arose from this work. It includes, internal and external 'voices' that one often hears in connection with HIV positive status. The character that hears the voices could be anyone diagnosed with the virus.

17.2 Common experiences of living with HIV

Below, we describe four experiential fields that seem, 25 years after the start of the South African epidemic, to be 'common' in two senses: frequent, and held in common among people living with the virus. These fields can be described, using current terms of 'knowing your status;' 'othering' and depression; status acceptance and 'living

positively' with HIV; and 'speaking out'.

17.2.1 Recognising status

The moment of diagnosis is generally described as dramatic and deracinating (Abdool Kareem, 2005; Flowers et al., 2006). In Squire's (2007) and Daniel's interview study of support for HIV positive people in South Africa, participants repeatedly described the physical and emotional 'shock' of a positive result, even when, like Phumla (like all other names, this is a self-chosen pseudonym), who tested as part of a Prevention of Mother To Child Transmission (PMTCT) treatment programme, they were partly expecting it:

Phumla: Okay. Firstly, at that time when we were being told about doing blood tests, taking three blood tests, they told us about those three blood samples. I told myself that I should take the HIV test so that I could save my baby. Truly then, I did the test and then I was told that I have HIV. I thought, I was shocked I must say as a result when I got to the taxi {minibus}, I was crying, I did not know what to do.

'Voices' too starts with diagnosis: insistent, largely capitalised 'voices' – doctors, nurses, counsellors, and perhaps, an internal voice – repeating life-changing words 'You are *HIV* Positive/*YOU ARE-HIV POSITIVE/YOU ARE/YOU, HIV POSITIVE/YOU ARE HIV POSITIVE...*' As in many interviewees' accounts, 'HIV positive identity reverberates over and over, as if the ordinary world of life experiences is suspended and shifting into another shape.

17.2.2 'Othering' and depression

Experiences of accepting HIV and 'living positively' have particular salience in South Africa, where the HIV epidemic was contested and acknowledged late. There is considerable variation in the elements constituting such experiences, which makes a 'stage' account unreliable. However, on the resistant side, the elements often involve status disbelief or rejection; 'othering'; stigmatization; and post-diagnosis depression, suicidal ideation and anxiety (Olley et al., 2005).

Status disbelief can be helpful initially, diverting people from post-diagnosis despair. Phumla used a disbelief encouraged by her healthy appearance, alongside an avoidance of HIV's name and a displacement of her status to medical professionals'

diagnosis, to live with her status:

Phumla: I gave myself hope, 'no man, maybe {I am not HIV positive}, I cannot see this thing they say I have', then I handled it well.

Usually, however, respondents in the HIV support study connected status disbelief to neglecting their health and ignoring transmission issues, within a general climate of lack of education, treatment and care. Michael for instance did not believe his 1997 diagnosis, his sisters told him 'there is no such thing', and he continued being 'busy with girlfriends' and having undiagnosed, hard-to-treat illnesses:

Michael: I took it light and I ignore it just like that, 'no, this is not a truth that I'm HIV positive'. I just ignore it and the doctor didn't give me the guide lines, how to live with HIV, I must do this and this.

Michael's disbelief was enabled by a general climate of 'AIDS denialism' (Mbali, 2003) and 'othering' - locating HIV in other people or places – a response noted in a number of countries (Joffe, 1997; Joffe and Bettenga, 2003; Rohleder, 2007):

Michael: We had the problem of, of us the people in South Africa. We took, it, we took the HIV issue light and we compare it to the places like the countries like, like America...then we didn't compare it to in South Africa that HIV can be here you know.

Interviewees commented frequently on people's 'othering,' blaming and stigmatization of the HIV positive. Stigmatisation is associated with testing delay and with negative reactions, post-diagnosis, in many epidemics (see also chapter 8, this volume). Interviewees reported being stigmatised ubiquitously and relentlessly, on the basis of their own or partner's known status, their own, partner's or child's illnesses; how ill or thin they looked; what foods they cooked and ate; whether they took clinic-issued vitamins; whether they talked about HIV; and -as in other high-prevalence epidemics, and in African-origin communities in the developed world (Flowers, 2009) - whether they had caesareans –rare in South Africa – or formula-fed their babies. Mere fear of stigmatization can lead to isolation and alienation. But interviewees experienced stigmatisation even from those who claimed to accept them. Busisiwe's mother took her in, along with her HIV-positive child, but repeatedly positioned her as promiscuous and blameworthy:

Busisiwe: So, my mom embarrasses me with that {HIV} even in front of people because I'm HIV positive. It makes me feel not at home, as if I'm lost. It makes me want to stay outside. Even when I've made a minor mistake like spilling sugar, she would say, 'This is because you are thinking of guys and AIDS and all that'. So you see those things hurt me. They make me realise that I'm alone, there is no one who would tell me not to worry.

Where HIV is politically controversial; treatment, care and prevention under-resourced, and HIV reaches high, hard-to-comprehend prevalence, blaming, while not a rational or effective health strategy, makes some sense. With 1000 deaths a day (UNAIDS, 2008), every weekend in South Africa sees massive funerals of people dead from AIDS-related illnesses. We need to know who to blame for losing breadwinners, parents, children, colleagues, leaders and peers. We demand to know who is responsible for these massive killings, so we can stop them. For people like Busisiwe's mother, blaming renders it easier to deal with the emotional and economic crisis. This woman was contemplating the imminent deaths of all her children and some grandchildren, and decades of care for other grandchildren, in a low-employment rural village.

'Voices' acknowledges the blaming response, tracing it from passing-the-buck suspicion: 'Somebody passed it on to me....They cannot tell me who passed it on to me....' to formulate the virus as a 'trespassing curse' - the consequence of social hostility, an unknown transgression, or political neglect: 'Who cursed me?/Why me?...should I kill the government?/Why wasn't there PMTCT? Blaming can be, as 'Voices' shows, part of the process of internalizing the diagnosis, 'taking in' the news first by shutting it out. First, you blame the health practitioner who informs you, for sharing the sad truth and not having all the answers. Next, you blame the person that gave HIV to you - partly because people generally decide on whether to pity or blame you on the basis of how you contracted the virus. Thirdly, you blame whoever could have done something - government for not making or enforcing policies; NGOs for not effectively teaching prevention; religious institutions for not enforcing morality, abstinence and faithfulness; academic institution; pharmaceutical companies. After blaming and yet more blaming, you come to engage with HIV.

Another set of often-described responses translates blame inward into depression, withdrawal, self-disgust and suicidal feelings. *Sowetan* columnist, Lucky Mazibuko (2008a), openly HIV positive since 1999, records the self-punishing guilt of those who think they have 'killed' those they loved. Comedian and HIV activist Pieter-Dirk Uys (2003) says HIV has made fear and shame endemic in South Africa. Withdrawal and

reflection may be useful responses to the shock of diagnosis. But many interviewees in the HIV support study described self-destructive despair: incorrigible sadness; retreat from people, and the activities and pleasures of everyday life; recurring images of illness and death; a wish to 'disappear' -under a train, or by self-poisoning or drowning:

Nomazwe: When I first heard, I used to think a lot, I thought I would drown myself, I felt like disappearing, I did not want to be around but just that I didn't know how to do it. My heart was always aching even when I was trying to rest or relax. When I was alone I would cry, everytime when I was alone I'd cry.

HIV does not silence the 'voices' in Daniel's poem; but still the writer wonders whether s/he has indeed 'killed' her/himself, 'by allowing them to change me/from who I am and who I am meant to be/To/You are HIV Positive.' Secreted within the poem is HIV's potential social fatality. Diagnosis can turn you into a result, 'HIV Positive,' which suppresses your identity, making you lesser, incapable, even when there are no external signs of weakness.

17.2.3 Acceptance and 'living positively'

The positive experiences clustered around status acceptance are usually represented socially and often start with explicitly 'accepting' one's status, as many other studies have found. This generally happens in dialogue with a medical professional, community organization or relative. Linda, 'shocked' by her diagnosis, fled from the counsellor and got a minibus home, then came back to talk to her. But she needed more prolonged exchanges with her support group friends to 'accept' her status:

Linda: When I got home, I realised that I might have missed something by not listening to that lady {counsellor}, so I went back again. I went in and she told me to accept it because I am not alone there are many people with the virus. But I could not accept it, I only accepted it after joining the group, that was the only time I was able to accept it.

Interviewees often said that 'acceptance' involved gaining knowledge about the virus and how to live healthily with it. Again, they usually achieved this socially, in discussion with health professionals and support groups. The socio-emotional aspect of acceptance involves moving away from solitariness, the voice crying out in the poem,

'Why me?/Why now?/Why?,' and defining yourself as one of many living, not dying, with HIV. This experience shapes many fictional and documentary representations of the epidemic, for instance the annual television series *Siyanoqoba Beat It!* which since 1999 has been 'promoting and role modelling people living positively with HIV.' In everyday life, the collectivity of HIV acceptance disseminates powerfully through what Phumla called support group 'families,' in South African and other sub-Saharan epidemics. Support groups also operate as exemplars for wider family and community support (Keleeba et al., 1997; Squire, 2007).

A 'simple yet powerful philosophy' (Mazibuko, 2008a) of HIV acceptance does not indicate over-hasty or superficial responses, but rather, 'acceptance's contextual nature. Given other demands in their lives and HIV's ubiquity, interviewees described themselves moving quickly towards a degree of self-acceptance, even in the face of the negative representations of HIV around them, which let them continue living. As Siphon put it, 'It's a must that I accept it, as I have children in the house.' Acceptance has a strong connotation of active welcoming in Xhosa, carried into its usage in South African English, which renders its rapid achievement even more effective. Nevertheless, acceptance changes as you live with HIV, progressing from 'taking it in,' through trying to understand what HIV is, how you will function, what will change and what will stay the same; towards establishing a relationship with the virus – at its most explicit, perhaps, a kind of symbiosis, as Michael described at the end of his interview: '{I've} come in a long way with HIV... I take the HIV now as my friend, big friend... I talk to it, psychological.'

Experiences of 'living positively' were always represented by interviewees in the support study as involving sociality. HIV's 'interpretive communities' (Plummer, 1995), support groups, families and friendship networks, spread knowledge and acceptance; but they also enable 'positive' HIV identities. The experience of multiplicity is, Scott (1991) suggests, a kind of 'theory' of what is possible. Nomthandazo's support group's collectivity offers a powerful 'theory' of living as an HIV positive person, rather than dying.

Nomazwe: I was released by the support group from those suicidal thoughts. As a result now I don't even think about it.

What the group talks about becomes the basis for her own theory of self-care, how 'I think about my health.'

Alongside this sociality, the 'living positively' experience involves disclosure to partners, family, friends and work colleagues. Studies in different national contexts report good effects of disclosure. In the support study, interviewees rarely disclosed

freely, and spent considerable time and effort considering possible reactions. However, they reported mostly helpful reactions from partners, parents and siblings, indicating perhaps South Africa's expanding HIV 'interpretive communities' during 2001-4, the time of the research. Popular media and public health HIV education were building such communities, as were people's experiences of HIV diagnoses, illness and death amongst them. Disclosure was represented as a more immediate imperative than in much developed-world research (Flowers, 2009) partly because some treatment protocols, activism, and public HIV education were encouraging it, associating it with people being able to access resources and having better physical and psychological health; partly because of the paucity of biomedical support, which enhanced the value of openness as a kind of medicine in itself; but also because of strong familial psychological support and socioeconomic dependencies, and in response to the country's previous silence about the epidemic.

To disclose was to declare oneself, as many interviewees put it, 'the same person,' unchanged by HIV. Networks of HIV positive friends were said to 'live positively' by chatting about all kinds of things, constructing sociality in a way that was not HIV-determined. Some interviewees were moving away from HIV services; for them, as for people living long-term with HIV elsewhere, 'living positively' meant foregrounding other aspects of their lives (Squire, 1999; 2003). 'Minimising,' 'avoidant' representations of HIV status have long been accepted as valuable strategies, particularly when people are well (Carricaburu and Pierret, 1995; Ezzy, 2000). Within representations of 'living positively,' they operate strategically, to affirm the social personhood of someone living with the virus but not determined by it. 'Voices' writer similarly declares to us both her/his acceptance of living with HIV, and her/his continuity with a pre-HIV self: 'I am who I am/And I still am who I am/And I live,/I live,/I live with HIV.' The narrator's life-story settles with the epidemic's practical truths, without denying it or being taken over by it.

17.2.4 'Speaking out'

A final element among 'living positively' experiences is 'speaking out', telling about your HIV positive life to others. Interviewees' 'living positively' descriptions almost always ended with accounts or plans of not just disclosing, but educating. For Busisiwe, learning about her status and vanquishing HIV-related illness led quickly to this socio-moral speaking out. She takes responsibility for other people's ignorance and commits to positive transformation:

Busisiwe: I want to talk about that {HIV} with my friends. ‘I have a problem like this’, so I must take them to the clinic. But me, my sister, I am not ashamed. I have sacrificed myself {by being open} and I’m not ashamed even before my parents to come forward and be seen that Busiswe is talking, you see. What I’m saying is that I have accepted it. It’s not that now that I’m HIV positive I’m no longer a person. I can make a contribution in certain areas too, helping other people or else one would say ‘come and help me’, {and} talk saying that ‘you also have this’, because I’m also like a person who has this, it’s just that I’ve got it inside it hasn’t manifested on the outside.

It is not surprising that constructing yourself as an ethical, testifying HIV subject is a key element of ‘living positively’ experiences in South Africa, given the country's prolonged early silencing of the epidemic. However, ‘speaking out’ seems a key factor in other high-prevalence national epidemics: in the initial support and activist group activities of the Ugandan HIV positive community (Kaleeba et al., 1997); in that country’s commitment to making the epidemic speakable (Epstein, 2006); and in other African countries’ explicit declarations that HIV is indeed their problem (Ilfie, 2006). Unsurprisingly, ‘speaking out’ does figure so strongly in ‘living positively’ experiences when effective policy, treatment, care and education are in place, and prevalence is low.

Interviewees’ experiences of ‘living positively’ can thus be summarized as involving a continuing existence as the ‘same’ person, yet with HIV constituting a new sociality around you. HIV sociality involves being able to live, rather than die with HIV; and declaring this to others is an ethical and political necessity. Campbell et al.’s (2007) description of ‘HIV-competent’ communities converges with this description, identifying five highly social aspects out of six. If accounts of the pandemic in the developed world have left behind their socialized early incarnations for individualization seen as the consequence of HIV’s biomedical management, this has not yet happened in resource-poor countries, and still may not .

17.3 Heterogeneous HIV experiences

HIV experiences are mediated by many factors that shape, intensify or displace them. Material circumstances are perhaps the most powerful. Learning about HIV, or knowing people who are HIV positive but who are distressed about their status, does not generate positive experiences. Availability of resources, including income and

housing, as well as HIV medication, care and prevention, strongly affects how South Africans speak about being positive (Brandt, 2004; Squire, 2007). As has been found elsewhere, for instance Haiti (Farmer, 1999), improved resources help shift entrenched negative beliefs about HIV. Support groups have proved a valuable stimulus to 'living positively'; they also encourage treatment access. ART provision is key: it raises life expectancy, reduces vertical and horizontal HIV transmission, mitigates stigma, enables disclosure and – not least – improves job satisfaction of low-resource countries' medical professionals, already stressed, underpaid, overworked and migrating to richer countries

Other important shapers of HIV experiences are social formations that intersect with HIV identities: those of gender, generation, class, sexuality, ethnicity and religion. In South Africa, prevalence differences between historically and socially racialised groups generate large differences in everyday HIV experiences. The majority black South African group are much more likely than people historically described as 'coloured,' 'indian' or 'white' to be living with an HIV diagnosis. There are provincial and age differences in prevalence, rural-urban differences, and higher prevalence among women. Women seem from the support study and much other research to experience stigmatization most intensely and find disclosure most problematic. Women's greater HIV-related and other responsibilities around child and partner care, their economic dependence, social subordination, and susceptibility to gender-based violence, can impede them seeking diagnosis and treatment. South Africans' different sexual orientations also affect their HIV experiences; so do religious and 'ethnic' differences. Difficulties that people experience with other chronic health problems such as epilepsy or asthma, responsibilities for family care, refugee or migrant status, and histories of abuse and loss, may marginalize their HIV experiences – something that is also true for other chronic illnesses. Studies across several epidemics have suggested that HIV positive women, too, frequently shift focus after diagnosis towards other aspects of their lives (Brandt, 2004; Ciambone, 2001; Squire, 2003). Economic stratification is a particularly acute issue, partly because the legacy of apartheid is extreme inequality, but also because of black South Africans' uneven economic development over the past decade and the perception among many, including our interviewees, that people 'outside' poor neighbourhoods do not care about them. The experience of being HIV positive is thus always the experience of being other kinds of subjects, too. Not everyone is 'living with' HIV in the same way. What we see is something close to what Mouffe (2005) describes as 'equivalent' HIV identities, sharing some experiential fields on the basis of which common actions can be taken, but distinct in other areas.

Heteroin-homogeneities within the epidemic itself also structure HIV experiences.

How ill and incapacitated you are (Brandt, 2004; Flowers et al., 2006), length of time diagnosed and when diagnosed, affect your experiences. The extreme experiences associated with imminent fatality are attenuated in the 'treatment era', with varying, much-debated consequences for sexual practices. Younger people are reporting more HIV awareness across South Africa (Flisher et al., 2006); ART is reducing mortality and reaching and retaining more and more patients (Boulle et al., 2008).

To a degree, HIV citizenship is also shared across statuses. Our three interviewees of unknown or negative HIV status developed this equivalence through their political and work affiliations. Zanele, for instance, a lay counsellor, refused to test – a rational decision, since she was well and no treatment was available – because she did not want to distinguish herself from the people she worked with; she reported that this identification extended to her fellow counsellors:

Zanele: After we did that {HIV counseling training} course we take even us as, a HIV people. Even now I take I took myself as an HIV people because I don't know my status/mhm/that is why I told myself that maybe I've got this HIV. So I side I'm on the,s, on the side of HIV people. I don't say I'm not or I will not I took myself as an HIV people

This area of equivalent HIV citizenship has limits. People who are HIV positive often will not disclose to the 'affected' because they do not understand the latter to be 'living with' HIV as they are. However, several interviewees described this understanding being overturned by their experiences with people of all statuses working in HIV-oriented community-based organizations and NGOs. Experiences of HIV are thus heterogeneous in themselves, as well as across statuses; and are at the same time experiences of many other life contexts, of which in South Africa perhaps the most salient are poverty, gender, and lack of treatment and support (see Chapters 7, 3 and 4, and 11; this volume)

17.4 Signifying HIV

In phenomenological uses of the term, 'experience' signifies internal, personal phenomena that are best known by the person containing them, and that define the person. But we are writing about HIV 'experiences' more broadly. They need not have this 'interior' character, they may be expressed in objective, non-emotional terms; they may come from 'parasocial' experiences of TV soaps like *Soul City*, or radio talk

shows; they may refer to what others said or went through, as well as happening to you. When an interviewee described how 'some people's boyfriends leave them' after diagnosis, she was signifying a common experience, not just describing her own. When Michael declared that 'we' the people of South Africa 'took the HIV issue light' he was not displacing attention from himself, but describing an important, erasing representation in neighbourhood and nation. When 'Voices's narrator, realising that allowing her/himself to be crippled by the 'voices' is to live passively, as if sleeping, awakens, s/he affirms this awakening in a way which lets everyone engage imaginatively with it, as a collective as well as a personal declaration. The poem was, indeed, inspired by Daniel's appreciation of performances' ability to affect collectivities: expressing 'taboo' issues, allowing identifications, unlocking captivated mentalities and unleashing possibilities.

Poems can function as exemplary autobiographical representations that, like South American *testimonio* (Plummer, 2001) convey collective truths, condensing individual lives, and foregrounding instructive experiences within them. Songs, like the one accompanied by dancing that young women in the Western Cape who were campaigning for PMTCT made up in 2001 for rallies and demonstrations, complete with gestures and gait mimicking pregnancy, are also powerful collective expressions, working to express things that women, especially, cannot say. Songs have biblical precedents important in South Africa, and in traditional ceremonies, women often use them to express how they are oppressed by illnesses, spouses, in-laws or governing structures. Other women join in to sympathise and to encourage the initiator whose struggles they identify with (Guzuna, 2000). Youth 'open mic' poetry sessions and hip hop performances now work in similar ways around the epidemic.

Experience is made *by* and *within* representations, and these experience-representations work, have effects, and make a difference: That is, in several senses, they *signify*. Art and literature can therefore convey experiential knowledge, just like apparently more direct academic, documentary or autobiographical representations. And experience is always a specific form of culture, mediated by its significations. In the HIV support study, interviewees seemed to draw on a variety of cultural narratives to produce HIV story genres that, working together, yielded intertextualities of experience (Squire, 2007). As we have seen, one set of stories described 'living positively' as a progress towards moral and social 'speaking out, a ubiquitous genre in popular media and activist discourse at that time. Interviews also contained translations and appropriations of the medical lexicon, and stories of HIV citizenship that drew on the country's recent stories of political struggle, and its current imbrication in Truth and Reconciliation Commission testimony.

In addition, interviewees deployed South Africa's strong currency of Christian and

traditional faith narratives to talk about HIV life as a matter of ethical 'conversion' to acceptance and 'living positively', forgiveness, which allows the relinquishment of blame; hope that belief in the right way of life, despite suffering, will 'heal' metaphorically, if not literally; and witnessing. Linda ends a story about 'converting' her husband to living positively and striving for ethical openness about HIV, with the Biblical foreshadowing of HIV's difficulties:

Linda: I feel alright, most importantly I thank God. God said these things before, he said there will be these incurable diseases, so I believe in God truly. What he talked about, is happening today.

Linda's Messianic account of PMTCT, 'I was happy to save my baby,' echoed by many interviewees, implicitly constitutes her as an ethical subject who cannot be pilloried as sinful because of her HIV status. Part of knowing your status, is gaining means to protect those you care about. In the PMTCT and ART eras, testing enables not just responsible sex, healthy lifestyle and educating others, but also healthy babies and treatment-enabled longevity as partners and parents. At the same time, South African Christian discourse about HIV now emphasizes equivalence across statuses: as each is known and loved by Christ, so whole congregations must exercise reciprocal love and grace to each other.

'Voices' maps this ethical progress, starting from HIV's apparently contradictory moral character, punitive, yet directed at the 'innocent': 'I feel like Judas in Passion of the Christ.../Only that, I did not sell the Messiah, nor my body/Only that, only that I have not killed myself.' There is religious guilt and betrayal in the poem, as if the writer, a Judas-like backstabber, has killed the Messiah within. Like the writer, many interviewees scrutinised their life stories for moral answers, asking sangomas about witchcraft, asking pastors for prayers: 'who cursed me? /Why me? /Why now?' But some kind of redemption could be reached simply by staying the same, ethical person, not 'killed' by the label 'HIV,' overwriting Judas and winning lives through 'sacrificial' testimony, like Busiswe's, and salvational PMTCT programmes, like Linda's.

17.5 Problems of HIV experiences

In social research, we read participants' HIV experiences through the researcher, as we read 'Voices' through the poet's voice. Yet most HIV research originates in institutions that are socially, economically, culturally and in terms of 'race,' 'outside' the pandemic. We hear relatively little from the people living most intimately with HIV

epidemics. Paying attention to the intricate HIV significations that appear in art, literature and popular culture, helps address these omissions.

As Nkosi (in Lombardozi, 2006: 137-8) describes it, poetry 'lives on iron rations'; it is not 'omnivorous', in thrall to saying everything, like prose. But not all prose is omnivorous. Research writing, like poems, has the power to condense and generalise. The researcher's power lies in citing participants; the poet *becomes* the participant. Research translates people's experiences conceptually; poetry does this rhetorically. Nevertheless, research participants' and poetic subjects' signified experiences shape research and poetry in strong and enduring ways, claiming a place among the intertextualities of poetic and research 'voices'. Moreover, when research materials are archived, as with the HIV support study, a direct experience-representation will continue, and may be read differently, when the research itself is forgotten.

A considerable amount of HIV research suggests that the experiential patterns we have so far described are too simple. The virus itself remains hard to understand: physiological complexity and mutations compound treatment uncertainties. Even where treatment is accessible and effective, stigmatisation is persistent and widespread (Flowers, 2009). Women continue to be blamed for transmission; 'othering' and fear still shape many men's reactions to the epidemic. 'Living positively' can become a coercive signification, marginalizing experiences that do not fit. In the HIV support study, some experiences – the transgressiveness associated with a sexually-transmitted fatal disease, particularly for women; death, especially of children; status disclosure, especially to mothers – were replete with ambiguities, repetitions and silences. These representational elisions belong to the realm Kristeva calls the abject (1984), on the borders between subject and object, body and language; in the gaps between signification; characterised by a kind of inarticulate horror. For Kristeva, narratives provide a web within which abjection gains some expression, though it cannot really be represented. We propose that narrative genres provide a means of articulating parts of the self failed by symbolic language. This happens, Kristeva suggests it, *across* stories, though not within what we think of as stories themselves. Busisiwe for example, telling of her four-month-old child's stillbirth six months before, which led to her own diagnosis, spoke quickly and was hard to follow, comparing the baby to our voice recorder and seeming to declare the baby was born alive, though we asked later and found the child was indeed stillborn:

Interviewer: Why did you say 'I would have the test'?

Busisiwe: I was pregnant. I went to {hospital} and the baby came out when the child was four months old and s/he was as small as this radio {voice recorder} {gestures}. I discovered that I was HIV positive. I

accepted it in that way. I realised that I had to accept it since I had seen both the tummy and the baby and there is nothing I can dispute.

Interviewer: Was the child alive?

Busisiwe: Yes, I was also having nightmares at night and when I was dreaming, I saw people showing me {lifts beads into shape of AIDS ribbon} it's okay.

Busisiwe's story of accepting and learning to live with HIV finishes ambivalently and abruptly with the child's unspoken death. She turns immediately to another story genre: that of 'conversion' to faith in the right way to live with HIV, a narrative with particular resonance for her since she is in 'treatment,' or training, to be a sangoma, a traditional healer, as her beads signify. In the gap between the stories lie, perhaps, a struggle to communicate painful feelings for which words are lacking, but that find expression through striking analogy, incoherence, and the sudden narrative shift. Similarly, 'Voices''s affirmative ending is overhung by unanswered questions about the universality of death in this high-prevalence epidemic, and the liminal, abject place between death and life to which HIV consigns you: 'Should we all die?/Am I?/Am I dead alive with the V-Irus?'

The abject is constructed, *abjectified*, within social formations of discrimination and exclusion (Young, 1990). Like stigmatisation, to which it provides a foundation, abjection can be undone by changes in external circumstances, and worked against; but it has to be engaged with repeatedly because it reappears with different focuses. The recurrence of HIV's stigmatisation around different signifiers - at first weight loss; later, particular illnesses; today, ART side effects like lipodystrophy and its disturbing challenges to gendered bodies - exemplifies this persistence. Undoing HIV's abjection does not involve rejecting it, but rather tolerating ambiguities, contradictions and incompleteness within HIV experiences, and approaching them in diverse ways. In the HIV support study, participants sometimes dealt with emotional impasses by obvious routes, getting advice from nurses, counsellors, and support groups; but they also watched *Soul City*, listened to the radio, worked in local income-generation groups for HIV positive people, and talked about HIV in their churches, and with sisters, brothers and friends. Some HIV research suggests that dealing effectively with the epidemic involves people with new institutional practices. Counsellors go beyond their usual professional boundaries; social workers take a therapeutic role; neighbourhoods develop structures of 'HIV competence' (Campbell et al., 2007). In South Africa, HIV activism has invented itself out of transnational as well as local political histories, and from new and older local cultural formations (Mbali, 2005; Robins, 2004). These new formations, avoiding structural and procedural rigidity, mobilise abjection alongside

'living positively,' without being overwhelmed by it. Similarly, newly-developed HIV narrative genres of speaking out, testimony and political citizenship mediate people's difficult HIV experiences through deploying familiar but polysemic story forms. The poem achieves this too: declaring that many are living positively with HIV, while also asking, 'what it will take for me, for us, for the nation to wake up – and will we?'

17.6 Future experiences

One of the voices in 'Voices' is that of a child asking who to blame. There is relatively little research on how South African children live with being positive; such poetic versions of experience start to theorise this future. There are many other aspects of the epidemic, presently under-researched, of which knowledge will probably come first from experiential accounts. The strengths of HIV sociality in the support study interviews might lead us to ask whether this experiential element will continue as treatment becomes more accessible and the epidemic more openly addressed. The issues of a large, chronically ill population living on medication for the foreseeable future; dealing with side-effects; needing new generations of ARTs; developing conditions related to long-term infection and medication, balancing uncertain health with employment and domestic responsibilities; and facing long-term concerns, particularly around mental health issues and relationships – all these will need addressing. Death will not disappear from the epidemic: ART's will not always work, and some people will not access treatment. Experience of death as peaceful, dignified and in the midst of those who love you, is an important part of the epidemic's imagined future. There have been and will be, also, millions of deaths of people without treatment access, occasioning especially conflicted grief. The epidemic's multiple bereavements are an immense burden with largely unknown psychological and social effects. The overarching requirement for men's as well as women's economic empowerment is becoming more and more acknowledged as key to prevention work (see Chapter 7, this volume). Finally, HIV-positive and affected people are increasingly likely to identify and act as a political group, something Mazibuko (2008b) points out in the context of continuing treatment deficits:

There is absolutely no way in which any political leader can take for granted as emotive an issue...which has directly infected more than 6 million people in our country, excluding those who remain affected. This massive community of people affected and infected by this incurable disease forms a very critical and strategic constituency for any political leader.

17.7 Experience as theory

Experience is a form of knowledge, as we declared at the beginning of this chapter and as the examples gathered together throughout it have shown. We can, then, usefully understand HIV experiences as forms of theory. One of the etymological roots of 'experience' lies in the Latin verb *experio*, 'to try'. HIV experience, within art, culture, social research and everyday representations, is an attempt to generate knowledge about phenomena that mainstream HIV research has underinvestigated, misunderstood or ignored. Like the canonic medical, social, religious and political knowledges with which it negotiates, experiential HIV knowledge is historically and socially situated. But its differences from this canonic knowledge are marked and important.

'Voices' traces experiential knowledge-building, from the moment of diagnosis, 'YOU ARE HIV POSITIVE,' where a medical subject of HIV is constituted; through attempts at negotiating with medical, ethical and political understandings of HIV, to a final affirmation of 'living' with HIV that is also a wake-up call. It works like a performance, with one voice sounding out at a time amidst others. Some voices, though they have good intentions, bring harm and confusion; others are intentionally destructive. Through all this, the narrator comes to realize that the right choice is to live actively and positively. The poem describes a multiple, contradictory HIV subject, engaged in dialogue and contest with dominant HIV discourses and haunted by things that can hardly be said. This complexity appeared too in the HIV support study, and in other qualitative research on and popular representations of HIV experiences. It is a problematic but crucial element of efforts to understand the epidemic, and to plan and implement policy.

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¹ A longer version of the chapter can be found in the UEL depository: (insert URL which should be available in early 2009)