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# **“WE ARE NOT FRESH”: HIV-POSITIVE WOMEN TALK OF THEIR EXPERIENCE OF LIVING WITH THEIR SPOILED IDENTITY**

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# **“We are not Fresh”: HIV-Positive Women talk of their Experience of living with their Spoiled Identity**

## **Abstract**

*Women have been identified as being at greater risk in South Africa's growing HIV epidemic. Stigma contributes to the epidemic, as it makes HIV positive individuals reluctant to become identified and seek appropriate care. The purpose of this study is to begin to explore how women experience and deal with AIDS stigma under conditions where they have little formal support. In-depth, narrative interviews were conducted with ten HIV-positive women, living in a poor, black township in Cape Town. The study used both Social Constructionist and Psychoanalytic theory to understand the impact that their 'spoiled identity' had on the emotional lives of these women. The study elicited women's narratives as they talked about their experience of living with a 'spoiled identity'. The analysis suggested that the women drew on negative social discourses around HIV, which were then internalised, to become part of the self. However, the narratives also indicated the women's resistance to their stigmatised identity. The narratives illustrated their attempts to fend off the 'spoiled identity' by splitting off these bad representations and projecting them outside of themselves.*

## **Introduction**

In South Africa, HIV/AIDS has become one of the biggest challenges to development, with an estimated 11.4% of the population being HIV positive (Shisana & Simbayi, 2002). Two national HIV prevalence surveys indicate that the prevalence among women is higher than that of men (Department of Health, 2003; Shisana & Simbayi, 2002). In the Western Cape Province, which is where

this study was conducted, an estimated 18.5% of women aged 15-49 years are HIV positive (Shisana & Simbayi, 2002).

Stigma has been regarded as a primary obstacle to prevention and care when dealing with the HIV epidemic (Goldin, 1994; UNAIDS, 2003). The *Nelson Mandela / HSRC Study of HIV/AIDS* (Shisana & Simbayi, 2002), however, suggested relatively low levels of HIV stigmatisation in the South African population. The study indicated, for example, that a large majority of respondents would share a meal with someone who is HIV positive (74.1%), and would talk to someone with HIV (94.3%). However, Stein (2003) suggests that surveys such as the *Nelson Mandela / HSRC Study* fail to measure stigma effectively. She argues that in such surveys, stigma is measured by assessing individuals' reported attitudes, beliefs and behavioural intentions; they do not measure actual incidences of discrimination and stigmatisation. Such surveys generally make use of quantitative instruments to measure levels of stigma, taking the subjects responses at face value. Anecdotal reports, in contrast, suggest that the experience of stigma may be a far more significant part of the experience of those living with HIV/AIDS. For example, in South Africa, Gugu Dlamini was murdered after she publicly revealed her HIV-positive status ("Aids Sufferer", 1998).

Goffman (1963: 13) defines stigma as "an attribute that is deeply discrediting". He argues that stigma is defined by society on the basis of what society constitutes as deviant or different. A stigmatised person becomes labelled, as one who possesses some undesired deviance and difference, creating what Goffman (1963) terms a 'spoiled identity'. Later theorists such as Alonzo & Reynolds (1995) and Gilmore & Somerville (1994) have argued that stigma serves as an "exercise of power" to reinforce socially constructed norms for what is acceptable and desirable, by defining what is deviant, and excluding those that are found to be deviant (Gilmore & Somerville, 1994: 1342).

Susan Sontag (1991: 101) has argued that AIDS has emerged as a disease "whose charge of stigmatization, [and] whose capacity to create spoiled identity, is far greater" than that of other diseases. She elaborates on the socially constructed meanings associated with HIV and AIDS, noting the metaphors that have been constructed around AIDS as being a plague, evil, and sinful (*ibid*). Gilmore and Somerville (1994) also discuss the powerful metaphors, which are used in interpreting the meanings of HIV and AIDS. These metaphors are socially constructed meanings, which are used by society to interpret and understand the disease and those infected with the disease. They note seven interacting metaphors including HIV/AIDS as death; as punishment; as crime; as

war; as otherness; as horror; and the HIV sufferer as a villain. These metaphors become part of the language used to discuss and understand HIV and are used to make representations of 'others' who are infected, and the 'self' who is not infected. Joffe (1995) show us that the social discourses of South Africa's AIDS campaign has largely portrayed AIDS as resulting from deviance.

Receiving an HIV positive diagnosis puts into the foreground the stigma of HIV and AIDS. Fife & Wright (2000: 63) conclude that stigma is "a central force" in the lives of HIV positive individuals. As a consequence of stigma and fear of discrimination, many individuals with HIV attempt to 'pass as normal' rather than HIV-positive (Alonzo & Reynolds, 1995; Alubo, Zwandor, Jolayemi, & Omudo, 2002; Grove, Kelly, & Liu, 1997; Ingram & Hutchinson, 1999; Nack, 2000; Paxton, 2002; Stein, 1996). Many HIV-positive individuals do not disclose their statuses to others, resulting in the patient being unable to find social and family support, aggravating their sense of helplessness and loneliness (Hackl, Somlai, Kelly, & Kalichman, 1997; Meursing & Sibindi, 2000). France (2001) outlines how the health care setting and the family are the two most cited contexts where stigma is experienced in South Africa.

Parker & Aggleton (2003: 13) further show that "stigma feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality". In South Africa, Black women generally occupy the lowest rungs on the hierarchy of social, economic and political power. Women are also the group most affected by HIV and AIDS. As Walker, Reid & Cornell (2004) argue, in order to understand South Africa's spiralling HIV/AIDS epidemic, we must examine the role of gender, sex and power. Women's experience of living with HIV and the stigma of HIV is "intensified because of their subordinate role in society" (Soskolne, 2003; 1). Women are a group at risk, as they are often powerless to negotiate safe sex (Strebel, 1995; Strebel & Lindegger, 1998). Gender differences also play a role in the construction of promiscuity and deviance; many sexual partners are a testament to a man's manhood, whereas women with many sexual partners are regarded as dirty (Shefer, *et al.*, 2002). HIV positive women and women with sexually transmitted diseases face additional stigma of being perceived as deviant, dirty and damaged (Lawless, Kippax, & Crawford, 1996; Nack, 2000, 2002; Shefer, *et al.*, 2002), and having "departed from the socially prescribed behaviour worthy of 'good women'" (Lawless, Kippax, & Crawford, 1996; 1375). In South Africa, women in some communities tend to be regarded as dirty and diseased, and are seen as the source and infectors of HIV and other sexually transmitted diseases (LeClerc-Madlala, 2001; Shefer, *et al.*, 2002). Black South African women with HIV/AIDS are likely to be subject to multiple forms of stigmatisation that create for them, a 'spoiled identity'.

The results discussed in this paper are taken from a study (Rohleder, 2004), which was part of a broader research project on stigma and HIV/AIDS in South Africa, which is being conducted by a team at the University of Cape Town's Centre for Social Science Research and the Psychology Department. An earlier research study from this same team suggested that women who had received considerable support through the *Memory Box Project*<sup>1</sup> in dealing with their HIV diagnosis had, to some extent, been able to resist elements of the 'spoiled identity' that had been thrust upon them (Soskolne, Stein & Gibson, 2004). The study reported here was intended to explore how women, who had had little formal support since receiving their diagnosis, experienced and managed a stigmatised identity.

## **Living with a 'Spoiled Identity': A Theoretical Framework**

Social Constructionism provides a useful framework for understanding how an individual's own identity may resonate with the discourses about HIV and AIDS which are prevalent in the broader social environment. In Social Constructionism, language and discourse are regarded as the means by which not only external reality but also one's own identity is constructed (Bruner, 1991; Burr, 1995; Crossley, 2000; Wetherell & Maybin, 1996). The 'self' is continuously shaped through the prevailing social discourses and construction of meanings. Thus, for an HIV positive person the metaphors of HIV as 'evil', 'sinful' and 'deviant' (Sontag, 1991) may be incorporated into the HIV positive individuals' construction of their self-identity.

Psychoanalytic theory may be a useful addition to the constructionist framework, providing an understanding of how these negative representations are experienced emotionally and also how people attempt to protect themselves from the anxiety associated with a stigmatised identity.

Psychoanalytic ideas have been used to elucidate the way in which people protect themselves against threat of AIDS. Joffe (1999), for example, uses psychoanalytic theory to show how the stigma of AIDS can be understood as a defence against threats to the self. She shows how AIDS is represented as a

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<sup>1</sup> The *Memory Box Project* provides support for women with HIV/AIDS by helping them tell their life stories, and create a memory box, which serves as intimate reminders of their lives to leave for their children.

disease which originates from the 'Other'. It is constructed as foreign, affecting out-groups, and associated with deviant and perverse practices. Representing AIDS as a disease that originates from and affects 'others', functions as a defence against the anxiety of being at risk of infection; thus AIDS is a disease that affects 'others', 'not me'. Joffe (1999) uses Melanie Klein's theoretical concept of splitting objects into 'good' and 'bad', to show how the 'others - not me' argument functions as a mechanism of defence against anxiety. Anxiety about AIDS is reduced with AIDS being something that affects 'others' (the bad object) and 'not me' (the good object). Similarly, Crawford (1994) argues that when talking of 'health' and 'healthy', 'bad' aspects of the self with regards to deviance and self-control are split off and projected onto the 'unhealthy' other. Crawford (1994: 1347) states that the split off 'unhealthy' aspects of the self "finds its projected physical location in the figure of the person with HIV-AIDS".

The process does not, however, end with this projection of the bad onto the 'other'. When a person becomes HIV-positive, the individual becomes the recipient of these social projections. They are forced to incorporate the split-off aspects attributed to the 'other', internalising the stigma attributed to them. It is this, which creates a 'spoiled identity'. The infected individual becomes bound to "a deviant identity which is seen as offensive and repellent in the broader society" (Joffe, 1999: 47). A strong feeling of shame may manifest as a result of this identification. Squire (1997) notes how respondents experience shame, despair, fear, and felt dirty and visibly contaminated, soon after being diagnosed HIV-positive. This is a time of threat to the self, where the individual is faced with incorporating the 'bad' identity, which is attached to the disease.

Hollway & Jefferson (2000), however, argue that the theory of the socially constructed subject does not fully encapsulate differences and diversity in individuals' experiences with living in similar social contexts. They provide an additional layer of theory to account for the way in which social experience is not simply internalised but is also subject to psychic processes aimed at managing and minimising its effects on the individual. They use the notion of the 'defended subject' to explain how social experience interacts with personal and emotional experience resulting in a more complex process of identity construction. They argue that individuals are not passively created through discourse, but rather that they position themselves and invest in particular social discourses in order to defend against threats to the self. Borrowing from psychoanalysis, they suggest that threats to the self, creates anxiety which precipitates unconscious defences against these threats. From this perspective, those diagnosed with HIV/AIDS are subject to the powerful stigmatising discourses around them, but are also active emotional participants in their

experience. They internalise stigmatising views of themselves, but are also dynamically engaged in managing their identity and trying to protect themselves against the anxieties associated with a 'spoiled identity'. As Hollway & Jefferson (2000: 23) suggest through their notion of a 'defended subject', people are not simply subject to discourses, rather they actively invest in discourses when these "provide protection against anxiety and therefore supports to identity". For those on the receiving end of AIDS stigma, it is important to understand how social discourses around the diseases interact with their own emotional investments to construct their experienced identity.

## **The Study**

A sample of 10 women, between the ages of 16 and 47 (mean age of 31) were individually interviewed to explore their experience of a stigmatised identity. All women were HIV positive, were currently receiving anti-retroviral treatment, and lived in Khayelitsha. Khayelitsha is the area with the highest prevalence of poverty and HIV infection in the Western Cape, with 22% of women attending antenatal clinics being HIV-positive (Shabodien, 2003).

Following Hollway & Jefferson's (2000) method, the narrative interview was used to explore the way that social discourses seep into the subjects telling of their stories, while still eliciting the personal, subjective experience of the narrator. Within this approach, intrapsychic conflict is understood to be activated in the participants when they talk of painful issues. Thus the interviewee's structure of the narrative, "may reflect an unconscious logic" (Hollway, 2001; 15). This narrative however is subject to interpretation within which the interviewer follows the nuances of emotion in both what is said and what is left unsaid. The researchers' own emotional responses may also help to inform their choice of where to ask probing questions to explore further areas that may be important. This method provides a framework for exploring defensive structures and unconscious expressions in the participants' narratives when talking about themselves.

The first language for all the women was Xhosa. Of the ten interviews, five were conducted in English, and five in Xhosa. In the case of the five women who chose to be interviewed in Xhosa, an interpreter was used. The use of an interpreter creates a number of possible problems. Firstly, the quality of the interview is compromised to a certain extent. As the interview was largely

unstructured, many nuances in the narrative may have become lost to interpretation and further probing. Swartz (1998: 28) argues how in a constructionist approach to language, "our feelings are affected and shaped by the words we use and the vocabulary and sentence structure we have available to us". He goes on to argue that when using a translator in the psychiatric setting, these semantic constructions are changed. Words and their meaning are ultimately altered in translation, and subtle contradictions in the narrative or subtle indications of possible issues that are defended against, are possibly lost. Secondly, as a non-Xhosa speaker, the interviewer could not be certain that the narrative was interpreted closely, and thus validity of the data may be compromised. In order to minimise this as much as possible, care was taken to clarify responses and rephrase them so as to confirm that the narrative was understood.

The interviews were transcribed verbatim and analysed to illuminate the participants' experience of stigmatisation, the extent to which they had internalised stigmatising discourses and their attempts to manage these discourses intrapsychically. Following the guidelines of Hollway & Jefferson (2000), an attempt was made to identify the women's attempts to protect themselves against anxiety and the unconsciously communicated feelings in the individual narratives.

## **Receiving a Diagnosis**

The women in this study received their diagnosis an average of approximately three and a half years before the time of the interviews. The longest time between the diagnosis and the interview was nine years, and the shortest was four months. No woman in the study had gone for an HIV test for the purposes of finding out their status. Seven of the women were tested and diagnosed once they were symptomatic or were very sick with TB. One had been asked to be tested following the death of her baby from AIDS, another following the AIDS-related death of her estranged husband. One of the participants was tested and diagnosed after she had been raped.

What was clear from these accounts is the reluctance of the women to be tested. The women did not proactively seek testing in order to investigate their status and their potential risk, but rather arrived at a point where testing was unavoidable. Although all the women eventually agreed to be tested for HIV, it seemed that they were reluctant to confront their own susceptibility, even when

there were clear signs, for some, that they were at risk. This response fits with recognised defences against risk.

To create further distance between the self and the potential risk, the danger may be projected onto 'others' (Joffe, 1999). In this case, HIV is often constructed as a disease that happens to other people rather than one's self. The women's narratives seemed also to correspond to this pattern. Within their accounts of the diagnosis some recalled their initial belief that HIV would happen to deviant 'others', for example persons who have many sexual partners, or who share infected needles. In the words of one participant:

I thought people are getting HIV by sleeping with many partners or when they injected with the same needle

Another said:

I didn't think I can get the HIV [...] No I didn't think; I'm feeling I can't get the HIV cause I think I'm TB [...] Because I think HIV is getting the other people who's got a lot of boyfriend or she is drunk or what, you know?

For many women, receiving an HIV positive diagnosis caused much distress as thoughts of death came immediately to mind. However, while the women's initial concerns on receiving an HIV positive diagnosis were the possibility of their own mortality, it appeared that the source of their pain very quickly became the responses of others.

## **Reactions from Others**

Reactions from the community affect the individual's sense of self as a social being and as a member of a group, as the individual constructs their identity from prevailing social discourses (Bruner, 1991; Burr, 1995; Crossley, 2000; Wetherell & Maybin, 1996). Some of the women seemed initially reluctant to acknowledge that there was stigma directed against those with HIV/AIDS in the community. This acknowledgement in itself may have served as a painful reminder of their stigmatised identity. But in spite of their initial statements to

the contrary, the women's narratives provided a number of examples of their direct experience of stigma. The words of one woman seemed to capture some of her initial reluctance to recognise stigma and her recognition that it did indeed exist:

I cannot say that stigma exists or doesn't exist because there in my community people there do not have a problem with HIV and HIV positive people. But there are others who, when they see people wearing the HIV positive T-shirts, who are like saying some things, some bad things

Other women gave examples of overt incidences of being stigmatised:

then in my church, when we, after the church we all greet with hands. So, the others, they were so, so, you know, they were scared for me, maybe I'm going to give them this HIV

there in our place, if you get thin, you already AIDS. Whatever they know, they don't know, because they didn't know me, but when I was sick, and then I was thin, thin, thin. And then the other said, when the children come to play in my yard, and then they said, "(name) why don't you take your children, because she's going to, your children are going to be affected to that AIDS! Can't you see she's got AIDS!" So, those things hurt me, you know.

This woman, goes on to talk of another incident of being stigmatised by a man, who had suffered a stroke, and how she defended herself against this public attack:

And the other man is got a stroke by the, in my little corner at my back, the street, and then when he saw me coming from the clinic he called, "AIDS! AIDS!" So, I was hurt that time. So, one day I said to him, "you know, you had stroke, I had AIDS. So, I can go to toilet, I can go do my washing. I can do everything!"

Implicit in this quote is the pain of being the stigmatised 'other'. Her response is an indication of her need to defend against the painful feelings she carries about

her 'spoiled identity'. Here she projects the disabling effects of her disease onto another, more 'disabled' person and in the process resists her own identity as stigmatised.

The public stigmatisation for some has been very marked, and has resulted in their social isolation. As one woman put it:

I do disclose to the people of my community about my status, but they just put me from their stigma [...] They does discriminate most of them, they just discriminate me. They said, “no you mustn’t go to that house because all the people of that house are positive so you can get diseases”.

Another participant spoke about how her relationships with others had been affected:

What is happening is that the people I used to greet, like, I’m not greeting them now because they became funny when I’m greeting them because of what they heard about me.

It is the experience of stigma from others that impacts on the individual's sense of self.

## **Internalising the ‘Spoiled Identity’**

Throughout the women's narratives, the meanings attached to their HIV status, and thus their sense of identity as HIV positive, is largely drawn from the social constructions of HIV and AIDS. Although before their diagnosis, all the women appeared to have placed themselves outside of those 'at risk'; that it could not happen to them. Once diagnosed HIV positive, however, the negative constructions of HIV previously projected onto ‘deviants’ were then incorporated into the women's sense of self and construction of their own identity. One woman’s narrative seemed to capture this internalised sense of herself as dirty, dangerous and contagious. In the interview she describes a time when she had scabies, and was scratching herself while sitting next to someone. That person moves a little away from her, leaving her feeling hurt and feeling

that she is treated as contagious. She goes on to talk about feeling guilty about being a contagious 'other', who is a danger to society:

**Participant:** Ja you are feeling guilty because the person they know the symptoms of HIV so you have got a guilty conscience of yourself.

**Interviewer:** Guilty?

**Participant:** That guilty of yourself because you know I am sick, maybe this person thinking of this HIV.

**Interviewer:** And why does that make you guilty?

**Participant:** It is that I know I am HIV.

**Interviewer:** How does that make you feel guilty?

**Participant:** I am guilty of that that I know I'm sick. I am guilty of that person thinking of this maybe.

**Interviewer:** Ok. So this person is suspecting and you know?

**Participant:** Mmm [*affirmative*]

**Interviewer:** Okay. But um you guilty it sounds almost like you think you are doing something wrong? Is that what you feel like – that you are doing something wrong?

**Participant:** Yes I do something wrong.

**Interviewer:** What do you think you doing wrong?

**Participant:** I am going to scratch myself so the blood is going to come out.

Some women also show their sense of being a dangerous 'other' when they speak of their sexual relationships. The overwhelming narrative is that in sex, they become dangerous to others. One woman spoke of how she had given up the possibility of having sex with her partner:

**Participant:** that if I can have sex with him, all the dirty things that came from me can make him very sick.

**Interviewer:** And sex with a condom?

**Participant :** No, I decided not to sleep with him again, but I still love him

Popular beliefs about HIV infection state that it is women that are the carriers and disseminators of the disease. As Leclerc-Mandlala (2001) suggests, women become perceived as dangerous. This idea of their dangerousness was expressed in other scenarios, for example in everyday chores, like preparing food. As one woman said:

When I make food, I know the things I mustn't do so they cannot affect it. Like for instance if I have got a cut I can't touch food with that cut.

Another women shows how the sense of dangerousness spreads even to family members:

the reason that make to them [aware] is that they like to take my kid maybe for weekend or something like that. So when I hear that my kid is also positive and I decided to disclose to them, because I was thinking that maybe he is gonna have an accident when he is there and then they maybe gonna have a cut or something like that. I didn't want some body else to get affected, to get infected because of me.

As with the sense of HIV as dangerous, the construction of HIV as resulting from deviance (Sontag, 1991; Gilmore & Somerville, 1994) is also internalised by some of the women interviewed. During their interviews, three women spoke of their HIV infection as being a kind of punishment.

I think that it means that it is something that I deserved.

The above Participant expressed a conscious feeling of being punished for being 'deviant'. For others, this sense of punishment seems more unconscious, as is shown in the following quote, when the woman uses the word 'sentence' when referring to her diagnosis:

I can also tell the other people now, but before I heard about my sentence I shouldn't; before I didn't because I didn't accept it and I wasn't able to tell any one and, but now I can tell any one because I accept it.

This feeling of internal badness seems to be translated into concerns that others will judge them for their condition. Two of the Participants spoke of feeling like everyone around them was talking about them:

they are not coming straight to me and talk anything straight to me but I can hear when they are passing by me, they are talking about HIV and that.

Because it makes me worry all the time. Because maybe sometimes she's not talking about me, you know. Now I think ooh she is talking about me you know.

Implied in this is a feeling of being 'marked', of having stigmata. The idea of stigmata was made more explicit in other narratives, when women referred to physical symptoms like skin rashes, weight loss, and being constantly ill. These become what Goffman (1963: 14) refers to "abominations of the body", and are often interpreted as signs of HIV. For example, one woman said:

the people are looking at me because I did lose a lot of weight.

Another women spoke about how signs of illness were feared as people would begin to say "you have AIDS, you have got AIDS."

Other 'stigmata', which could be observed by others, included visits to clinics, which are known for HIV services, and the wearing of the Treatment Action Campaign's "HIV Positive" T-shirts:

Like they have got this attitude, like, if you are wearing an HIV T-shirt – people in the community they are telling themselves that you are HIV positive, that's what they know. If you are wearing a T-shirt they told themselves that you are HIV positive. Even if you lose

weight or you got sick, whatever, maybe it is one of the opportunistic infections. Then they thought...with this one [stigmata] they just judge

## **Resisting the 'Spoiled Identity'**

Although the women interviewed seemed to incorporate elements of the stigmatised identity, it was clear from the interviews that they also tried to protect themselves from the anxiety that this identity evoked in them. To defend against this spoiled identity, and sense of themselves as 'bad', the women seemed to resort to the kind of splitting that is ironically also used in the process of stigmatisation. In this process, the women's own 'bad' feelings were placed and attributed to an 'other' (Joffe, 1999). Instances of this kind of splitting were contained in all the narratives. In many cases, the 'bad other' became those people who yet did not know their HIV status. In each of the examples below the woman position these people as the one's deserving of pity or derision

those who doesn't know, they think they are better, because they think they don't have this, and then now, they get. When they know they got this and then they don't accept it, and then now they end up dying.

Another women 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.

Although these comments may in some way reflect the reality of a situation in which many people may not be aware of their HIV status, these women seem to use this discourse to assert their own situation as more admirable.

Another common strategy the women used to protect themselves, was a splitting of self into a past, unhealthy self, and a present, healthy self, a strategy also noted by Soskolne, Stein & Gibson (2004). In this way the women attempted to distance themselves from the threat of illness but also from the physical stigmata

of AIDS. All of the women are being treated with anti-retrovirals. All the women, therefore, can be assumed to have experienced poor health before being placed on antiretroviral treatment. Since receiving the medication, most had shown a marked improvement in their health. Their current state presented in their narrative as a 'good' present self that is 'not sick' versus a 'bad' past self that was 'sick'. In this way, the undesirable aspects of their illness and of being 'unhealthy' are located safely in their past or with others who are visibly ill, enabling the women to hold on to a sense of a 'good', 'healthy' self (Crawford, 1994). One woman clearly asserts her current 'wellness' as opposed to her previous 'sickness':

I was confident to tell them because I wasn't sick any more and I also told them that I am living with HIV because where ever they talk about HIV so I wanted them to know that I am also living with HIV [...] I wanted to tell them that I am HIV and I am not sick.

Another illustrates the distance she had created between her present state of health and the earlier illness:

there is nothing like HIV; doesn't mean anything to me now. I just take it as other diseases because I am just feeling fine.

In order to protect themselves against the stigma of AIDS the women also attempted to normalise it as 'just like any other disease'. In the following example, however, it is possible to see how this wishful idea that AIDS is no different to any other illness breaks down in the face of stigmatisation:

HIV is something like any diseases. You can get Tuberculosis. You can get anything. It's not, um, a bad diseases. It is an accepted diseases so they do what we did. But now I haven't got a friend since then I disclosed to them.

## **The Dynamics of Internalisation and Defence against the ‘Spoiled Identity’**

A more detailed case example taken from the narrative of one of the participants, whom we shall call Nonthembeke, provides further examples of the dynamic process of internalising the ‘spoiled identity’ and strategies aimed at protecting against the painful feelings evoked by this. Much of Nonthembeke's narrative seemed to reflect a split between a past in which she was sick, thin and symptomatic and a present where she was relatively healthy as a result of her anti-retroviral treatment. The past self is a pained and struggling self, while the present self is an empowered, healthy and 'normal' self:

That time I was not free, but now I feel free. I feel I can just tell them.  
And, because, you know, I'm healthy now

Feelings of shame, fear, being damaged and dangerous becomes more unbearable for Nonthembeke when she is sick, and she carries signs of her illness, like stigmata. When sick, she makes attempts to disguise her illness as being another disease, like TB, which becomes used as a euphemism for HIV. This attempt to hide her illness became apparent during the interview, when she revealed her hidden ailments, which represent stigmata. She took off her hat to reveal her marked hair loss. She also pulled up her long sleeves to reveal the marks of a skin rash. While showing these stigmata, she was moderating their significance by stressing that they were much better now, once again asserting her healthy present self in comparison to her unhealthy past self.

HIV and AIDS has become a metaphor for deviance (Sontag, 1991; Gilmore & Somerville, 1994), and this deviance becomes the basis for an internalised ‘spoiled identity’ for the HIV positive person. In her narrative, Nonthembeke shows her internalised struggle with deviance as she identifies others who are “deviant’ in an attempt to assert her own normality. Describing how she might react to someone who ‘accuses’ another of having AIDS:

And then I said to her, "you see, she's got a lot of boyfriends too! And you know yourself, so where is she standing to tell you your mother has got AIDS!"

The metaphor of HIV and AIDS as dangerous is implicit in much of Nonthembeko's narrative. The reactions from others in the community instil Nonthembeko's sense of being dangerous and contagious. This sense of a dangerous self is present when talking of intimate relationships:

No, I don't want a lover anymore. I... You know I can say condomise, but now I say 'stay away from men'. I'm only with my children. I don't have feelings for a man. [...] I mean I don't talk about sex, because on the sex side, I have to control myself, whatever I want happens to my body, but then I have to control myself

Implied in this narrative is the representation of sex as dangerous. Nonthembeko feels she had to repress her sexuality because of this danger. In other parts of this narrative around sex and sexuality, it seems that she defends against unbearable feelings of being dangerous, by projecting the danger onto the man, who then becomes dangerous for her and her health:

So, as I also hear on the group, they got difficulties of the boyfriends who doesn't want to condomize. So, that will be another problem with me, because I don't want to put my life in danger to sleep with a man without a condom.

When sex is the vehicle by which she became infected, it may be that she continues to view sex as a vehicle of further transmission and infection leading to deteriorating health. In this way, her sexual identity, a very personal aspect of identity, becomes bound to stigmatisation. Her attempts to protect herself against taking sole 'blame' for sexual danger however have the effect of reinforcing her social isolation.

## **Living with a 'Spoiled Identity'**

Although they attempt to manage the 'spoiled identity', the effects are just too powerful. When talking about the impact that HIV has had on their lives and their relationships, the overwhelming feeling was one of sadness. When talking about the time of diagnosis, some women recalled with much pain and sadness the traumas surrounding their newly 'spoiled identity'. One woman in particular found this a painful part of her story to tell:

my stepmother told my family that I'm HIV positive [...] I heard the results in a very bad way, because I just heard it from other people, and it was all over my family. My stepmother told everybody. [*crying*] [...] As I have no parents, no mother, no father, is only my stepmother. So, when I went back to Eastern Cape, I found out that there was that card, the card which has my results. So, it was shown to everybody who's coming to read that [*crying heavily*]

Other women, expressed their sadness when speaking of the losses that their 'spoiled identity' has brought for them:

the worst thing is I thought maybe this year or last year I could have go back to school, and then I didn't. And then what else, is me and my boyfriend, that the new one that I was with, we planned to get married and all this stuff. Now there is nothing. I was going on about that and [pause] it's only that I was planning. So I have lost to go back to school. I've lost to get married

As the above quote also refers to, much of the experience of loss is in the area of relationships, damaged by their 'spoiled identity':

There is no sex because by that time. Nothing. Yes. Because everything was very broken, nothing, no feelings, there is nothing we just go sleep one and next one another.

we are not fresh, some people are always in the mood for sex making. No mood when you are HIV even when decide to stay alone. Even if I was not married I was not thinking I was got a boyfriend after that news. I feel like sitting alone, but I'm married.

However, it is not only in the words and unconscious defensive structure of the narrative itself that the emotional pain of having a spoiled identity is conveyed, but in the fact that the telling of the stories was distressing. Both distressing for the participant, who in many cases was in tears, and had to be supported afterwards, but also for the interviewer, who became aware of his own feelings of hopelessness, despair and anger that these women had to struggle with being positive, in a social context that is already very difficult and deprived. Not only do the women have to struggle with spoiled notions of themselves, but they have

to face the many social losses that their 'spoiled identity' generates for them. The social response can also be a dangerous one. This was very painfully brought to reality, with the rape and murder of one of the participants in this study. She had started to become a public educator and AIDS activist with the Treatment Action Campaign, a short while after the interview with her. In December 2003, she was raped by a gang of five young men, in the toilets of an informal tavern in Khayelitsha, where she lived. After she reportedly disclosed her HIV-positive status to the attackers, they beat her to death. This was witnessed by a friend who was assaulted when she tried to intervene. Her death caused a public outcry, with public marches and media reporting (eg. Gophe, 2003; Mtyala, 2003).

## Discussion

In the previous study by Soskolne *et al.* (2004: 143), the authors explored the experiences of living with HIV and stigma in a group of women who had been part of a therapeutic intervention programme. In this research, the authors found that the women were actively involved in constructing a positive identity about themselves as 'healthy' and 'strong', through the selection of particular positive social discourses which were available to them. The selection of these discourses was seen to be motivated by a need to defend against the anxieties that their stigmatised identity raises. However, the authors found that on closer examination, the women at times struggled to "reconcile the more vulnerable parts of themselves with their desire to hold onto an unspoiled positive identity".

Using the framework of the psycho-social subject and the notion of the defended subject (Hollway & Jefferson, 2000), this study explored similar issues around the effects of stigma, in a group of women who had not had the same access to support as those in the above mentioned study. What emerged from this study, is that the 'positive identity' critiqued in the study by Soskolne *et al.* (2004), is much less present in this group of women. While there is some attempt to reject the stigmatisation and fend off the spoiled identity, this is much less effective, and overall there is much less optimism among the women.

As women in South Africa, the participants are probably in the category most vulnerable to risk (Shisana & Simbayi, 2002). Despite this however, all the women in the study initially placed themselves outside of risk, as they drew on the social construction of HIV risk as affecting deviants (Sontag, 1991; Gilmore

& Somerville, 1994). Once receiving a HIV-positive diagnosis, the women incorporate into their sense of self, social discourses of HIV as dangerous, dirty and contagious. While more positive, and empowering, social discourses around HIV and AIDS do exist, it is perhaps the negative, more damning, social discourses that individuals drew on when first diagnosed. The women's inability to find more positive discourses in their initial experience of the disease is not surprising, partly because of the power that these discourses hold socially, but also because they would already have had some prior investment in these discourses in order to place themselves outside of 'those at risk'.

These discourses spoil the HIV-positive individual's identity. For the women in the study, it was difficult to manage their spoiled identity in the social context in which they live. Despite extensive public awareness campaigns, HIV remains a highly stigmatised disease that affects deviant 'others'. Despite the women's attempt to fend off this stigmatisation, and minimise the effects of stigma, their narratives revealed social discourses around HIV as dirty, devious, dangerous, and a punishment. The women in this study drew on these and internalised them to create a 'spoiled identity'.

Many women struggle with these notions of themselves, and they resisted the anxiety this caused, by splitting off these bad representations and projecting them outside of themselves, onto 'others' who were then represented as 'bad'. Most commonly, it is those that have not tested, and thus do not know their statuses, who come to represent the 'bad', deviant 'other'. Another means of defence is to split their experience of themselves into a 'bad', sick past self, and a 'good' healthy present self on anti-retrovirals. The deviant 'others' becomes those that do not take care of their health. In this way, the undesirable aspects of illness and being 'unhealthy' are located onto 'others' who do not take care of their health, enabling the women to hold on to a sense of a 'good', 'healthy' self.

## **Conclusion**

This study took as participants ten HIV-positive Black women living in a poor suburb in Cape Town. The data extrapolated from their narratives reflect their particular experiences, which cannot be generalised to the experiences of others, but the processes identified as being involved here might represent a useful addition to the AIDS stigma research. The narratives in this study give voice to the alternative experience of HIV-positive women, "who have been otherwise

marginalised" (Soskolne, 2003). The narratives are interpreted from a particular framework, and are a constructed reality, true to the ideas of Social Constructionism. It reflects the experience of having a 'spoiled identity' from the perspective of marginalised women, and is certain to be different from the experiences of having a 'spoiled identity' from the perspective of men, who are positioned differently in society.

Although it is widely accepted that stigma is a primary obstacle to prevention and care when dealing with the HIV epidemic (Goldin, 1994; UNAIDS, 2003), little is known about exactly how stigma is experienced by individuals in the local South African contexts. Very often research into stigma uses quantitative measures for stigma, which take at face value people's responses about stigma. Using qualitative research methods, and the notion of a 'defended subject' allows a deeper, richer exploration into HIV-positive individual's experience of being the stigmatised 'other'. While on the surface, many of the women in this study felt that there was little stigma in their community, the analysis of how they narrativise their experience reveals a highly stigmatised individual, struggling to defend against the negative notions they have constructed of themselves.

Such knowledge is important when considering supportive counselling which could be offered for HIV-positive individuals. As argued by Soskolne *et al.* (2004) in their critique of the 'positive' HIV/AIDS identity, the negative, more damaging notions that are disavowed are not effectively worked through, and become a continued source of anxiety for the individual. Counselling might allow the women in this study, for example, to work through the damage created by the stigmatised identity.

But while this study paints a very bleak picture of the effects of AIDS stigma on this group of women, there are also some areas of hope suggested. The women interviewed here were not passive receivers of their stigmatised identity and there were clear signs that they challenged and tried to fend off some of the ideas that people had about them. Their attempts were not always successful, and in some cases may either have had further negative consequences for them or others, but that they resisted at all is significant. This tendency for people to try to protect themselves against the worst effects of stigma may provide a foundation on which to develop 'stigma resisters' who will not passively accept society's representations of them. It is possible that with effective interventions, like the *Memory Box Project*, that individuals can be helped to construct new, more positive, unspoiled identities about themselves.

However, those on the receiving end of stigma cannot be made responsible for protecting themselves. The real challenge is to alter the powerful, negative social discourses that surround HIV/AIDS.

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The CSSR is an umbrella organisation comprising five units:

The Aids and Society Research Unit (ASRU) supports quantitative and qualitative research into the social and economic impact of the HIV pandemic in Southern Africa. Focus areas include: the economics of reducing mother to child transmission of HIV, the impact of HIV on firms and households; and psychological aspects of HIV infection and prevention. ASRU operates an outreach programme in Khayelitsha (the Memory Box Project) which provides training and counselling for HIV positive people

The Data First Resource Unit ('Data First') provides training and resources for research. Its main functions are: 1) to provide access to digital data resources and specialised published material; 2) to facilitate the collection, exchange and use of data sets on a collaborative basis; 3) to provide basic and advanced training in data analysis; 4) the ongoing development of a web site to disseminate data and research output.

The Democracy in Africa Research Unit (DARU) supports students and scholars who conduct systematic research in the following three areas: 1) public opinion and political culture in Africa and its role in democratisation and consolidation; 2) elections and voting in Africa; and 3) the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has developed close working relationships with projects such as the Afrobarometer (a cross national survey of public opinion in fifteen African countries), the Comparative National Elections Project, and the Health Economics and AIDS Research Unit at the University of Natal.

The Social Surveys Unit (SSU) promotes critical analysis of the methodology, ethics and results of South African social science research. One core activity is the Cape Area Panel Study of young adults in Cape Town. This study follows 4800 young people as they move from school into the labour market and adulthood. The SSU is also planning a survey for 2004 on aspects of social capital, crime, and attitudes toward inequality.

The Southern Africa Labour and Development Research Unit (SALDRU) was established in 1975 as part of the School of Economics and joined the CSSR in 2002. SALDRU conducted the first national household survey in 1993 (the Project for Statistics on Living Standards and Development). More recently, SALDRU ran the Langeberg Integrated Family survey (1999) and the Khayelitsha/Mitchell's Plain Survey (2000). Current projects include research on public works programmes, poverty and inequality.

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