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**LIVING WITH A SPOILED IDENTITY:
HIV POSITIVE WOMEN TALK OF STIGMA**

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COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

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ABSTRACT

Women have been identified as being at greater risk in South Africa's growing HIV epidemic. Stigma contributes to the growing epidemic, as it creates a "spoiled identity"; making 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 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 the circumstances surrounding their diagnosis, their subsequent interaction with their family and community, and their experiences of living with a spoiled identity. The analysis suggested that the women drew on negative social discourses around HIV, which were then internalized, 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.

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LIST OF ABBREVIATIONS USED

AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
MSF	Médecins Sans Frontières
TB	Tuberculosis

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CHAPTER 1: LITERATURE REVIEW

1.1 Introduction

Sub-Saharan Africa is currently in the throes of a HIV/AIDS pandemic. In 2001, The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2001) stated that sub-Saharan Africa was the region most affected by HIV/AIDS in the world. Latest figures (UNAIDS, 2003) indicate that the HIV epidemic in sub-Saharan Africa, "remains rampant" (p.8), with an estimated 26.6 million people living with HIV in this region. The UNAIDS report further states that, unlike other women in the world, women in sub-Saharan Africa are more likely to be infected than men.

In South Africa, HIV/AIDS has grown to become one of the biggest challenges to development. A national survey of antenatal HIV infection conducted in October 2002 by South Africa's Department of Health (2003), indicates that the prevalence of HIV infection among pregnant women attending antenatal clinics in this country is 26.5%. This figure is used to calculate an estimated national prevalence rate of infection among the general population, which has been calculated at a total of 5.3 million South Africans being infected with HIV at the end of 2002 (Department of Health, 2003). According to this survey, women continue to be the group most infected, with an estimated 2.95 million women between the ages of 15 to 49 years being HIV positive, as opposed to 2.3 million men in the same age group (Department of Health, 2003).

A recent survey by the Human Sciences Research Council (Shisana & Simbayi, 2002) estimates the HIV prevalence in South Africa's general population at 11.4%. This survey also indicates that the prevalence among women is higher than that of men: 12.8% of women and 9.5% of men (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).

With the calculated figures of these two national surveys, it is clear that HIV infection is a major health problem. Furthermore it seems evident that women are at greater risk of HIV infection. Given the high prevalence of HIV infection, it is likely that the majority of South Africans have been personally affected by HIV and AIDS, either

through themselves being infected or knowing someone close to them who has been infected.

Stigma has been regarded as a primary obstacle to prevention and care when dealing with the HIV epidemic (Goldin, 1994). The Nelson Mandela / HSRC Study of HIV/AIDS (Shisana & Simbayi, 2002), however, suggest relatively low levels of HIV stigmatisation in the South African population. The study indicates, 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 of HIV/AIDS fail to measure stigma effectively. Stein (2003) 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. Despite reported lower level of stigmatisation, HIV and AIDS stigma is a very real issue in South Africa and public disclosure of one's HIV status can have dire consequences. This can be evidenced by the case of Gugu Dlamini, who was murdered by members of her community, after she publicly revealed her HIV-positive status ("Aids sufferer," 1998).

Stigma related to HIV and AIDS contributes greatly to the growing epidemic, in that HIV positive individuals are reluctant to become identified, thus making it difficult for them to seek appropriate care. This is made clear by UNAIDS (2003) when they state that

Stigma and discrimination both stymie efforts to control the global epidemic and create an ideal climate for further growth. Together, they constitute one of the greatest barriers to preventing further infections, providing adequate care, support and treatment, and alleviating the epidemic's impact.

Thus, combating stigma and associated discrimination is a crucial part of the fight against HIV and AIDS.

1.2 Aims and objectives of the study

The purpose of this study was to explore the experiences of women diagnosed with HIV/AIDS as well as to illuminate their attempts to manage a stigmatised identity. The study forms a small part of a broader research project into 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, which includes my supervisor, Kerry Gibson.

A previous study (Soskolne, Stein, & Gibson, in press) was conducted, exploring the experiences of living with HIV and stigma in a group of women who had been part of an intervention programme offered by The Memory Box Project. These women had been involved with The Memory Box Project for some time, and had subsequently become facilitators for this programme. The Memory Box Project invites HIV-positive women to create a memory box with stories and information about themselves, which serves as intimate reminders of their lives to leave for their children. It is found that the process of creating a memory box, is "able to help a great deal in relation to changing negative self image, as well as in relation to shifting self blame and shame" (Morgan, 2001; p.19). The women in the study (Soskolne, et al., in press) had to some extent been empowered by the support received from the Memory Box Project. In this research, the authors found that the women were actively involved in constructing a "positive identity around notions of health and strength" (p.144), 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. On the surface, the women were seen to have constructed a largely positive identity of themselves. The authors, however, found that on closer examination, there was some ambivalence between this positive view of themselves, and the more negative views of being HIV positive. The women at times struggled to "reconcile the more vulnerable parts of themselves with their desire to hold onto an unspoiled positive identity" (p.143).

In this study, I will adopt a similar approach to the analysis of material in a group of women who have not had the same access to support. The intention of this particular study is not to make overt comparisons, which will be explored at a later stage in the

research process, but to begin to explore how women experience and deal with AIDS stigma under conditions where they have little support.

This study aims to make a contribution towards further understanding the impact that stigma has on the psychology of the individual. It may provide some insight into the difficulties experienced by HIV positive individuals, which would aid in informing counselling needs for these individuals.

1.3 What is Stigma?

Goffman (1963) defines stigma as "an attribute that is deeply discrediting" (p.13). He argues that stigma is defined by society on the basis of what society constitutes as deviant or different. Goffman (1963) identifies three basic types of stigma:

- (1) "abominations of the body" (p.14), which refer to physical abnormalities or deformities;
- (2) "blemishes of individual character" (p.14) which refer to an individual's behaviour or character trait which is considered deviant, for example alcoholism or homosexuality;
- (3) "tribal stigma" (p.14) which refers to the stigma of race, religion and nationality, and can be attributed to all the members of a family.

Through these different types of stigma, a stigmatised person thus becomes labelled, as one who possesses some undesired deviance and difference, creating what Goffman (1963) terms a "spoiled identity". The stigmatised individual's family may also become stigmatised as a result of their affiliation with the stigmatised individual, through the mechanism of "tribal stigma". In an effort to conceal one's stigmatising status and thus avoid creating a "spoiled identity", many individuals attempt to 'pass as normal', concealing and avoiding any identifiers that may be attributed to a stigmatising identity (Goffman, 1963).

While Goffman conceptualizes stigma from a focus on the individual, others, such as Gilmore & Somerville (1994) and Alonzo & Reynolds (1995) conceptualize stigma with a focus on social constructions of inequality. In this case, stigma serves 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; p.1342). Similarly, Alonzo & Reynolds (1995) define the stigmatised as:

A category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse. (p. 304)

1.4 Stigma and HIV

Herek and Capitanio (1998), have defined AIDS stigma as “prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV” as well as their loved ones, friends, family and the social groups with which they are affiliated (p. 232).

Susan Sontag (1991) argues that following cancer, AIDS has emerged as a disease “whose charge of stigmatization, [and] whose capacity to create spoiled identity, is far greater” (p. 101). A meta-analysis of studies conducted by Crawford (1996) indeed indicates that there is a somewhat greater degree of stigma directed towards individuals with HIV and AIDS than towards individuals with comparable diseases.

Herek (1999; 2002) discusses four characteristics of HIV and AIDS that account for its ability to evoke great stigma. Firstly, it is a disease whose cause it is perceived to be the responsibility of the infected person, in that it is through behaviours that are considered voluntary that HIV is transmitted. Secondly, HIV/AIDS is a disease that is unalterable and results in death. Thirdly HIV is a contagious disease, and is thus perceived as posing a risk to others. Fourth, AIDS is visible in the advanced stages of illness, making it apparent to others. Using Goffman’s (1963) categories of stigma, we can see that HIV as a contagious disease, transmitted through voluntary behaviours of the individual, make it a disease that is stigmatised on the grounds that it is attached to “blemishes of individual character” (p.14). The disease’s visibility in the advanced stages of AIDS, results in stigma attached to “abominations of the body” (p.14). Herek (1999; 2002) further argues that there are two sources of AIDS stigma:

- (1) Instrumental stigma, which results from HIV being contagious and the associated fear and anxiety of becoming infected with HIV.
- (2) Symbolic stigma, which results from the socially constructed meanings associated with the disease.

Susan Sontag (1991) has elaborated on the socially constructed meanings associated with HIV and AIDS. She speaks of metaphors that have been constructed around AIDS as being a plague, evil, and sinful (Sontag, 1991). Gilmore and Somerville (1994) discuss seven metaphors, which are used in interpreting the meanings of HIV and AIDS. These are HIV/AIDS as death; as punishment; as crime; as war; as otherness; as horror; and as villain. These metaphors are socially constructed meanings, which are used by society to interpret and understand the disease and those infected with the disease. 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. These social representations of HIV and AIDS tend to be stable, and are difficult to change with information and education alone (Echabe & Rovira, 1989). 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. In light of this, receiving an HIV positive diagnosis may be traumatic for the individual, eliciting overwhelming feelings of despair and fear of the perceived threat to one's life and sense of self (Ciambrone, 2001; Soskolne, 2003; Stevens & Doerr, 1997; Squire, 1997). However, while HIV diagnosis in itself is a traumatic and disruptive event, in many cases it is not the only significant or even most devastating event in the lives of HIV positive persons (Ciambrone, 2001; Soskolne, 2003). Fife & Wright (2000) conclude that stigma is "a central force" in the lives of HIV positive individuals (p.63). 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. In a study by Kaleeba, et al. (1997), the majority of clients attending The AIDS Support Organisation (TASO) services in Uganda reported that fear of stigma was the primary reason why they did not disclose their status to others. HIV-positive individuals with high internalised stigma (that is individuals have internalised stigma associated with HIV and consequently hold a negative view of themselves) experienced increased levels of depression, anxiety and feelings of hopelessness (Lee, Kochman & Sikkema, 2002). Crandall and Coleman (1992) found that individuals who do feel stigmatised, experience anxiety and depression as well as social alienation. Perceived support from family contributes to a reduction in loneliness and presence of depressive symptoms (Serovich, Kimberly, Mosack & Lewis, 2001). It would thus seem that not disclosing ones status to family and friends out of fear of stigma and discrimination prevents the individual from getting the support needed for improved mental health. However, whether disclosure is beneficial or detrimental to the HIV positive individual, is not clear. Comer, Henker, Kemeny & Wyatt (2000) found that disclosure does not necessarily lead to improved mental health, and found that in some cases, disclosure may lead to poorer mental health as a result of stigma. On the other hand, Paxton (2002) found that public self-disclosure led to a decrease in discrimination and stigmatisation. She argued that "by facing AIDS-related stigma, one finds psychological release – liberation from the burden of secrecy and shame." (p. 559). However, she does not deny the risk of danger in going public, as evidenced by Gugu Dlamini's murder after going public with her diagnosis.

The experience of being stigmatised for one's HIV status may also depend on the individual's position in society. Grove, Kelly & Liu (1997) found in their study that women, having what they called "socially respected symbolic capital" (p.334) give them social power to manage their HIV status. They were not members of socially constructed 'deviant' or 'at risk' groups, and consequently were able to remain "blameless" and be portrayed as "innocent victims" of the disease.

As already detailed above, women are a group most affected by HIV and AIDS in South Africa. Walker, Reid & Cornell (2004) argue that 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 their subordinate role in gender relationships render them 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 socially transmitted diseases, are faced with the 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). Furthermore, in conditions of poverty, women's disclosure of their status, brings a risk of family rejection, with serious financial consequences as women are left to fend for themselves (Shabodien, 2003). Shabodien (2003) in a study in Khayelitsha, Cape Town, where this study was conducted, found that disclosure was met with an overwhelming response of rejection. She found that individuals disclose to predominantly the female members of families; the male members of the family, especially fathers, are not told, as they are often the main source of income.

1.5 Living with a "spoiled identity": A theoretical Framework

As this was an exploratory and descriptive study, qualitative research methods were used. The study aimed to explore the HIV positive person's lived experience of stigma, as well as their internalisation of stigma, and the mechanisms of defence used by the subjects in dealing with a "spoiled identity". For this reason a Social Constructionist framework was used to explore the individuals' construction of their "spoiled identity" in relation to the discourses about HIV and AIDS which are prevalent in the social environment. It has been indicated above, in the work of Susan Sontag (1991) for example, how metaphors are ascribed to HIV from socially constructed meanings and understandings of the disease. In Social Constructionism, language and discourse is regarded as the means by which knowledge and reality is

fabricated, and where the self is constructed (Bruner, 1991; Burr, 1995; Crossley, 2000; Wetherell & Maybin, 1996). Burr (1995) explains;

All the 'objects' of our consciousness, including our 'self', our notion of what it means to be a person, and our own identity, are all constructed through language, and that it is discourses as coherent systems of representation that produce these things for us (p.56).

Social discourses are incorporated into our constructions of our self-identity, and thus the 'self' is continuously shaped through the prevailing social discourses and construction of meanings. Thus, for an HIV positive person, the social discourses and meanings attached to the disease are incorporated into their construction of their self-identity, reshaping their 'self' as a result. The metaphors of HIV as 'evil', 'sinful' and 'deviant' (Sontag, 1991) are thus incorporated into the HIV positive individuals construction of their self-identity. Psychoanalytic theory helps us understand how these negative representations are defended against in an attempt to protect ourselves and maintain our positive self-identity.

Joffe (1999) uses psychoanalytic theory to show how the stigma of AIDS can be understood as a defence against threats to the self. Joffe (1999) shows how AIDS is represented as a disease which originates from the 'Other', by being represented as foreign, affecting out-groups, and being 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 the theory of Melanie Klein, and her concept of splitting objects into "good" and "bad" objects, to show how the "others - not me" argument functions as a mechanism of defence against anxiety. Anxiety of AIDS risk is split into AIDS being something that affects "others" (bad object) and "not me" (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) states that the split off 'unhealthy' aspects of the self "finds its projected physical location in the figure of the person with HIV-AIDS" (p.1347)

Klein (1959) talks of defensive positions, which originate in infancy. According to Klein, the infant's perception of its mother, is split into the good, nurturing mother that is loved, and the bad, frustrating mother that is hated. This splitting operates in what she called the 'paranoid schizoid position'. As the infant matures, the infant begins to perceive its mother as a whole, for whom it can feel both love and hate. Klein referred to this as the 'depressive position'. These defensive positions continue to be used throughout the individual's life, particularly in times of stress (Segal, 1992). When a person's self is under duress, it arouses the person's anxiety, and may result in a defence of splitting reality into good and bad, characteristic of the paranoid schizoid position.

When a person becomes HIV-positive, the individual has to incorporate the split-off aspects attributed to the "other", internalising the stigma attributed to the "other", creating 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; p. 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 a 'bad' identity, which is attached to the meanings surrounding HIV. In order to defend against the anxiety that this causes, it is possible that the individual will activate primitive defensive positions. Defensive mechanisms of splitting have been identified in a case study of HIV positive individuals (Cartwright & Cassidy, 2002).

Hollway and Jefferson (2000) draw on social constructionist theories of narrative and discourse analysis as well as psychoanalytic theory, to provide a framework of analysis of what is called the "psychosocial subject" (Hollway, 2001; Hollway & Jefferson, 2000). They refer to a 'psychosocial subject' as one that is both social and psychic. They argue that the theory of the socially constructed subject does not fully encapsulate differences and diversity in individuals' experiences in living in similar social contexts. Hollway & Jefferson (2000) have developed a theory of the 'defended subject' to explain this diversity between individuals. They argue that individuals position themselves and invest in particular social discourses in order to defend against threats to the self. Psychoanalysis argues that intrapsychic conflicts and threats

to the self, creates anxiety which precipitates unconscious defences against these threats. We have seen above (Joffe, 1999), how unconscious defences are activated to defend against the anxiety of threats to the self that exist around the concept of 'risk'. Thus there is an investment made in particular social discourses that place 'risk' onto others, so as to defend against the anxiety of being one who is at risk. Hollway & Jefferson (2000) state that the concept of a defended subject "shows how subjects invest in discourses when these offer positions which provide protection against anxiety and therefore supports to identity" (p.23). The authors draw on psychoanalytic Kleinian theory, already discussed above, and the defensive 'paranoid-schizoid' and 'depressive' position.

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CHAPTER 2: METHODOLOGY

2.1 Using a Qualitative Research design

As stated in the introduction, the purpose of this study was to explore HIV positive women's experiences of stigma, and living with stigma because of their HIV status. A previous study (Soskolne, Stein, & Gibson, in press) explored the experiences of living with HIV and stigma in a group of women who had been part of an intervention programme offered by The Memory Box Project, and had subsequently become facilitators for this programme. This study explores the stigma of living with HIV in a group who has not had the same access to support. The intention is to begin to explore how women experience and deal with AIDS stigma under conditions where they have little support.

As the study is an exploratory one, qualitative research methods were used. Qualitative research allows for data that is rich in its detail and is embedded in context. It attempts to make sense of issues in terms of the meanings that people bring to them (Denzin & Lincoln, 2000). Social Constructionism argues that reality is constructed through the interpretations that individuals offer to make sense of events. This provides a useful framework with which to explore individuals' construction of their HIV positive identity, and how they draw on shared constructions of the illness that are prevalent in social discourses. As discussed in the introduction, in Social Constructionism, language and discourse is regarded as the means by which knowledge and reality is fabricated, and where the self is constructed (Bruner, 1991; Burr, 1995; Crossley, 2000; Wetherell & Maybin, 1996). As it is through language and discourse that such knowledge is conveyed, it was decided to use the narrative interview as the method for data collection. The narrative interview, provides a useful tool 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 (Crossley, 2000). The narrative interview attempts to generate the interviewee's stories following their own structure, with as little interruption as possible from the interviewer (Hollway, 2001). Following Hollway & Jefferson's (2000) notion of the 'defended subject', in telling their stories, intrapsychic conflict is activated in the participants when talking of painful issues. Thus the interviewee's structure of the narrative, "may reflect an unconscious logic" (Hollway, 2001; 15). This method

provides a framework for exploring defensive structures and unconscious expressions in the interview subjects narrative when talking about themselves.

2.2 Participants

A sample of 10 women, between the ages of 16 and 47 (mean age of 31) were interviewed. All women were HIV positive, were currently receiving anti-retroviral treatment, and lived in Khayelitsha, a historically 'black' township created by the Apartheid South African government. The first language for all was Xhosa, although some of them agreed to be interviewed in English. 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). Table 1.1 (Addendum A) provides comparative data of all ten women.

The Memory Box Project was used as a resource to identify willing participants for this study. The participants were approached by a staff member of the Memory Box Project, who had links with other support groups in the area, particularly those connected to the anti-retroviral programmes managed by Médecins Sans Frontières. The sample of women are all members of these support groups, but at the time of the interviews had not yet been part of the intervention offered by the Memory Box Project.

All of the participants were paid for their time and reimbursed for transport expenses in getting to The Memory Box offices in Khayelitsha, where the interviews were conducted.

2.3 Data collection and method of analysis

The ten women were interviewed individually by myself. The interview took an unstructured approach, following the narrative of the participant. The participant was invited to talk of their experience of being HIV positive, starting when they were first diagnosed. An interview schedule was used as a tool to identify possible areas of exploration and possible questions to ask that explore further themes related to stigma (Addendum B). Using Hollway and Jefferson's (2000) notion of the defended subject, I allowed the research participants to narrativise their own experience. This narrative however is subject to interpretation within which I follow the nuances of emotion,

what is said and what is unsaid. My own feelings become important in co-constructing the experience of the participant. Psychoanalytic theory refers to the feelings elicited in the analyst (or interviewer) as countertransference, and is an important source of information. Using the psychoanalytic understanding of countertransference, Hollway and Jefferson (2000) argue that these feelings in the researcher also become important sources of information, and are used in interpreting emotional nuances in the interview narrative. They also inform my choice of where to ask probing questions to explore further areas that may be important.

Soskolne, Stein and Gibson (in press) also make use of their countertransference feelings to make sense of the contradictions in interpreting the narrative interviews in their study. This enabled them to uncover ambivalence in the participants as they struggle to incorporate the more vulnerable, negative parts of their identity to their unspoiled positive identity.

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) 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" (p.28). 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, is possibly lost. Consequently, my interpretation of the narrative follows the nuances of emotions as expressed by the interpreter as well as the interviewee. Secondly, as a non-Xhosa speaker, I 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, I took care to clarify responses and rephrase them so as to confirm that the narrative is understood. An example of this can be seen in an interview extract in Addendum C.

The interviews were transcribed verbatim by a student contacted through the Department of Psychology at UCT, who had been used many times before for transcribing work for the department. The transcripts were then analysed by means of thematic analysis, following the guidelines in Boyatzis (1998), and Denzin & Lincoln (2000). Themes were identified in the narrative, and common themes were identified among the ten interviews. Quotes from the interview texts were highlighted to represent these themes. Following the guidelines of Hollway and Jefferson (2000), a psychoanalytic framework was used to identify defensive structures and unconsciously communicated feelings in the individual narratives.

The data is presented in the results chapter, using selected quotes that present common themes throughout the women's narratives. This enables to identify constructions that are shared amongst all the women interviewed. I have also alternated between these quotes and case studies of two particular participants. This allows for a thicker description of individual experiences and a closer exploration of how these two women, as defended subjects, have constructed their subjective experience of their spoiled identity. The two participants were chosen because of the richness of their interview narrative. They also served as a useful comparison between women who lived in quite different social circumstances.

2.4 Ethical considerations

Before commencing with the study, a proposal was submitted to my supervisor, who was a member of the UCT Psychology Department ethics committee at the time, as well as to Jonathan Morgan, director of The Memory Box Project in Khayelitsha, who was to assist me with identifying a sample of women. The study was approved and I was given permission to proceed with the study.

Consent was asked of each of the women before being interviewed. The aims and purpose of the research was explained as an exploration into their experiences of stigma and living with HIV. All women signed a consent form agreeing to be interviewed, and for the interview to be tape-recorded (Addendum D). Confidentiality was assured, in that their names would not be divulged, the researcher would keep the tapes, and any details that would clearly identify the participants would be omitted. However, the study aimed to investigate how the subjects have internalised stigma,

and their mechanisms of defence against having a "spoiled identity". It is possible that the subjects may have declined the interview if this had been mentioned as an aim of the study. Or else, if they had consented, their responses in the interview, would in all probability have been constructed to portray a different experience to what was actually the case. This is one of the dilemmas of interviewing a "defended subject" (Hollway and Jefferson, 2000). Hollway and Jefferson (2000) argue that if a "defended subject" is forewarned about the possibility of discussing issues that are intimate, the subject is likely to back off. However, the authors view the giving of consent as following a process, rather than a once off statement. Hollway and Jefferson (2000) argue that a subject who has revealed intimate issues during the course of the interview has made the 'choice' to "reveal something as part of a continuing dynamic between two people" (p. 88). Thus, they argue that consent is given during the interviewing process. Furthermore, the nature of the topic suggests that intimate issues would be discussed. The subjects were informed of their right to terminate the interviews at any stage. None of the participants took this up.

As all the women are Xhosa speaking, and the interviewer was English speaking, the women were asked whether they were comfortable being interviewed in English, or whether they would prefer the use of a Xhosa-English interpreter. The staff member from the Memory Box project, who approached all the women for their participation in this study, also served as the interpreter. Five of the women agreed to be interviewed in English, and five gave their signed consent to be interviewed using the interpreter. In this case, the compromise to confidentiality was discussed.

When negotiating access to a sample of women with the Centre for Social Science Research and the Memory Box Project, it was suggested that the women be reimbursed for their time given to the interview and their transport costs. This was agreed to. All the women in the study are unemployed and living in conditions of poverty. It was felt that it was necessary to compensate them for their expense in taking part in the interview, that is the cost of getting there, and the cost of time spent at the interview.

The nature of the material discussed during the interview was often distressing for the participant, and at times during the interview I needed to use my clinical psychology

skills to help the participants talk through some of these distressing emotions. On two occasions, the participants were very upset, and I subsequently sat with them for about 15 minutes after the interview, allowing them an opportunity to talk about some of their distress. The participants were invited to contact me through the Memory Box Project if they needed to discuss issues raised during the interviews. It was felt that further support after the interviews could be managed within the support groups. At times, I realised that the interpreter was also affected by the nature of the interview material, and she needed to have an opportunity to talk about her feelings.

CHAPTER 3: ANALYSIS OF THE INTERVIEW MATERIAL

The results of the interviews will be discussed in four sections. The first section will examine the circumstances surrounding the diagnosis of HIV, and the impact that this had on the women's sense of self. The second section will look at the women's interaction with their family, following the HIV diagnosis, including their ability to disclose their status, and their family's reaction to their disclosure. The third section will examine the perceived reaction of the community to the HIV positive women. The term 'community' is here used to include others that are not members of the family, such as friends and neighbours. Within these sections, the role played by stigma, as well as the social construction of HIV/AIDS and the women's identities, will be examined. The final section will look at the women's experience of living with a spoiled identity, and their attempts to protect themselves against the pain that this evokes.

When quoting the ten women, they will be referred to as "Participant", rather than using personal names, to ensure anonymity. In the cases where an interpreter was used, this will be indicated in the quotes. During the chapter, there will be discussions of two case studies. In these studies, pseudonyms have been used to disguise the participants' identities. It is felt that the use of pseudonym names allows for a more personal telling of the case material. Quotes used may have been altered very slightly for ease of reading, or to disguise the participants' identity, but no significant meaning has been changed.

3.1. The Diagnosis

As can be seen from Table 1.2, the women received their diagnosis an average of approximately 3½ years before the time of the interviews. The longest duration since diagnosis was 9 years, and the shortest was 4 months.

Table 1.2: Time of Diagnosis

Participant	Age	Approximate time since diagnosis
A	43	3yrs
B	25	2yrs
C	22	5yrs
D	33	3yrs
E	38	7yrs
F	27	2yrs
G	29	3yrs
H	47	2yrs
I	16	4 months
J	30	9yrs

No women 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 was tested as a result of 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. Implicit in this is the reluctance of the women to be tested because they regard themselves to be "at risk". The women did not go to be tested in order to investigate their status and their potential risk, but rather arrived at a point where testing was necessary. For the women who were already ill and symptomatic, testing took place when they visited the clinic to treat their ailments, not because they explicitly went to be tested:

Participant C (translated): I went to the doctor only because of the boils, but when I arrived, the doctor told me to go for a test. Is my stepmother who said I must go for a test. Ja. And the doctor also asked me why I also wanted to go for a blood test, and I explained to him that my stepmother said I must go for a test

Participant J (translated): I went to a doctor because I was sick. I didn't really go for an HIV test but the doctor said that I must take it – an HIV test.

Although all the women eventually agreed to be tested for HIV, it is evident that their initial concern was not the possibility of being HIV positive. As discussed in the literature review, there is a tendency to defend against risk, by attributing risk onto 'others' (Joffe, 1999). In this case, HIV is often constructed as a disease that happens

to 'others' rather than the self. The women's narrative around their diagnosis reveals this construction of HIV as happening to 'others':

Participant C (translated): I thought people are getting HIV by sleeping with many partners or when they injected with the same needle.

Participant H: 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 some, their construction of themselves as 'not at risk' was so concrete, that there was disbelief around their diagnosis:

Participant F: Then I said hey I wanted to test again. I don't believe this. Why does this happen to me because I didn't have lots of boyfriends and all this?

One woman found it almost impossible to accept her HIV positive diagnosis. She was diagnosed on three separate occasions, before she accepted her diagnosis as true. Part of the reason for this is her use of the social construction of AIDS as a deviant disease (Sontag, 1991; Gilmore & Somerville, 1994), and thus placing herself outside of risk. Compounding her difficulty of accepting, is her fear of now being stigmatised by the community as such a deviant, and the struggle for her to prove otherwise:

Participant G: Yes it was very difficult because, it's because when I heard outside HIV it's about something - outside people they think it's when you just make a prostitute even if you are HIV. So I just feel guilty about that because I didn't want to tell that to disprove to people about that.

For many women, their understanding of HIV was that it meant death, and receiving an HIV positive diagnosis caused much distress as thoughts of death came immediately to mind:

Participant B (translated): I did not know anything about HIV. I only knew that a person with AIDS is going to die.

Interviewer (translated): So when you were told you were HIV positive is that what you thought or were thinking of?

Participant B (translated): Yes I thought about that. I thought about things. I was told I was HIV positive and I was going to die.

Participant H: Ooh I was so feeling, I was crying. And then when I coming back with a doctor and I go there in my room and then by the time I find my childrens and I'm crying. And she was asking me: What is wrong mommy? I can't talk it. I can't say nothing. What is wrong with you? I say: No the doctors is say I am HIV. And she say no don't worry, you are not died. From you must just keep it. I say, 'no I'm gonna died'. [...] Shew I was upsetting. I was upsetting. I was near to death. When I think I'd get up in the night I'm praying, I'm praying, I'm praying.

Interviewer: So you thought you were going to die?

Participant H: Ja, I think I'm gonna die.

HIV as death seems so entrenched an understanding for some, that for one participant the act of being tested and being diagnosed in itself would make her more sick than she already was:

Participant F: And then they wanted to tested me and I didn't want to. And then I got sick – I mean badly and they took me to hospital, to um Tygerberg Hospital and then there they ask me to take the blood test and then I resist again and then they phone my mother and they go my mother and my mother talk to me and say please let them take the blood because we don't know what is happening to you. And I said no I don't want to take it because maybe they say I am positive and then maybe I will be more sick. I don't want this sick [...] I thought maybe when I here that I'm HIV positive then I will be more sick.

Although the actual diagnosis is traumatic and causes much distress, it was often the case in many of the women's narratives that the diagnosis in itself was not what was

the most traumatic. For one woman, her distress was so great following being raped and being diagnosed positive, that she contemplated taking her own life:

Participant I (translated): It was very painful. I felt like I couldn't go home again and I also felt like I can just go and to play on the spoor, the tracks of the train or the cars. I was like dizzy.

Interviewer (translated): So it was very difficult and you were thinking of death?

Participant I (translated): Yes I thinking about killing myself.

While the women's initial thoughts upon receiving an HIV positive diagnosis were of death, it appears that the source of their pain very quickly became the responses of others. For another woman, her diagnosis brought about a betrayal from her only caregiver, and it was in talking about this betrayal that her pain was expressed:

Participant C (translated): I didn't get the results. And 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 - interviewer consoling*]

Case Study 1 provides a moving example of how the diagnosis uncovered the trauma of being lied to and betrayed by those least expected:

Case Study 1: Nonthembeko*

Nonthembeko was first diagnosed in January 2000, following the AIDS-related death of her estranged husband. She and her husband had been separated, however they had remained in contact. Her husband had been sick for some time, and she had suspected that it was HIV, as she had become familiar with some of the symptoms and opportunistic infections. Her husband had denied this, as did his family with whom he

* Nonthembeko is used as a pseudonym

stayed. They told her that he had fallen ill because of poisoned *muti* (that is poison contained in herbal medicine obtained from a traditional healer.) This reflects the common attempts to hide the disease from the community through alternative explanations for the illness, arising from the stigma associated with HIV. This can be thought of in terms of Goffman's (1963) concept of 'passing as normal'.

She had trusted that her husband and his family had told her the truth, so she laid her suspicions to rest. She relied on the assumption that figures of authority (in this case a parent and a family member who is a doctor) could be trusted to tell the truth. Later, upon finding out the truth, she realised that she had been lied to:

And then I said to his mother, "but those are HIV symptoms." And then she said. "No! No! No! It's that muti did that." Okay and then I didn't put it in my mind, because she can't lie to me, she's old enough to say that. And his sister is also a doctor, she can't lie to me, she should tell me. [...] But they were not honest to me

Some time later, Nonthembeko was informed by a member of her family that her husband was in hospital and was very ill. She went to visit him in hospital, and it was then that she learnt the truth of his HIV status from the nursing sister. This was a moment of emotional turmoil for her:

Oh! It was bad! And when the sister told me he's HIV, I was angry, hurt, sorry for him, because he didn't know if he told me the truth I would accept him.

What the diagnosis did for Nonthembeko, was reveal the lies and betrayal of her husband and his family. She was confronted with her husband's infidelity. She had never used condoms in her marriage, because she had trusted him. HIV prevention campaigns give the message that being faithful to your partner is preventative, thus Nonthembeko felt that her marriage was safe.

In Case Study 2, the diagnosis follows on from the trauma of loss because of HIV and AIDS. Here the narrative expresses the devastating impact that the disease has had on the family and the married couple:

Case Study 2: Neliswa*

Neliswa and her husband were first diagnosed in April 2001, following the death of their newborn baby from AIDS-related illness. At the time, the baby was sick, the doctors performed blood tests on the baby, and the tests showed that the baby was HIV positive. The doctors then asked Neliswa and her husband to be tested. They were both tested HIV positive. A year later, a second child died of AIDS. Neliswa's first-born child is HIV negative. Neliswa places these events firmly in the past, with a reluctance to talk about the emotions she felt at the time. She speaks of never thinking that her baby's persistent coughing could have been HIV. When asked about how she felt, she talks about resigning herself to the facts:

but we just accept because we are positive we can't do otherwise

Neliswa talks about what effect this experience had on her relationship with her husband. She speaks of how her husband immediately blamed her for bringing this disease into the marriage. This is a reflection on the prevailing idea that HIV is a woman's disease, like other sexually transmitted diseases (LeClerc-Madlala, 2001; Shefer, et al., 2002). Her narrative, when describing these events, seems to defend against the pain that this provoked for her. Her immediate response is to split the experience and place it firmly in a negative past, and to stress a positive present. This splitting, arising out of Klein's paranoid-schizoid position (Klein, 1959; Segal, 1992), enables her to place the 'bad' feelings separate from her current 'good', positive feelings, thus protecting her from their emotional pain. Further probing into her narrative revealed the abuse she suffered at the time:

Interviewer: And what happened with your relationship then?

Neliswa: It was wrong that man he say he asked who came with this disease and I say I don't know so he asked the doctors there to prove which one comes

* Neliswa is used as a pseudonym

with this disease. The doctors say no they can't do that but the relationship was wrong because we separate and there is a place there in [name], you know [name of place of safety]. I was there I think for two months, he was shout me so I came to the MSF clinic and I report there so they say I must go to the social workers so they find a place for me there at [name of place of safety] but you go there to the court in [name] so in my statement there I write all my problem and I told them I am HIV and my husband is HIV so he said it is me but now our relationship is all right. Because we stay together [...]

Interviewer: Was he hitting you?

Neliswa: Yes he was hitting me and shouting me and swearing me and I report him to the clinic. I report him.

Interviewer: What did you think of him?

Neliswa: I didn't think nothing because even if I say it is him I can't do nothing.

Interviewer: Hmm so you felt powerless?

Neliswa: [pause] he didn't want even me to go to the support group but I go there but even now he is also going to support group. He is the first one to go there.

Despite her insistence on 'everything being alright now', I was left with a feeling that things were not as positive as she was making it out to be. Hollway and Jefferson (2000) state that these countertransference feelings in the interviewer become important sources of information about the individual being interviewed. Most of Neliswa's narrative speaks of her having a supportive husband, and how this has helped her living HIV positively, however later in her narrative, she starts talking of problems in her marriage, with her husband drinking alcohol.

Case studies 1 and 2 reveal how it is in the family and in marriage where much of the pain surrounding HIV is located. In light of the meanings attached to HIV and AIDS, disclosing to the family becomes difficult and bears the risk of stigmatisation and rejection. Shabodien (2003) shows how in her study in Khayelitsha, disclosure to family was met with an overwhelming response of rejection.

3.2. Telling the Family

It was evident in the women's narratives how difficult it is to disclose their status to members of their family. Although at first the women in the interviews stated that they had disclosed to their families, and seemed relatively easy to do so, it was only after further probing that the difficulty of doing so emerged. It became evident in some interviews that some time had passed since the diagnosis, where the women were at a point of being able to disclose to their families. This is the case in Neliswa's story:

Case Study 2: Neliswa

Neliswa's narrative is that of having a family who know of her HIV status. The first impression is that it has been easy for her to disclose to her family. She mentions how her family did not throw her out. This refers to a common occurrence in the community where families do reject members who are HIV positive (Shabodien, 2003). Although she mentions that it did not happen to her, she defends against her fear that they might have:

Neliswa: And even my family knows; all my family and my husband's family know and they didn't take me out.

Interviewer: They didn't reject you?

Neliswa: No.

Interviewer: Did you, were you worried, did you fear that they would?

Neliswa: What?

Interviewer: Were you worried that they would?

Neliswa: *Silence.*

Interviewer: Were you scared that they would reject you?

Neliswa: No I am not scared.

However, she eventually reveals how difficult it was for her to reach a stage where she felt ready to disclose to her family. She told her family two years after her diagnosis. When asked why it was difficult for her, she reveals her fear of being rejected:

I am afraid of maybe they are not going to sit with me or eating food that I am making like if I cook they all eat.

Implicit in this statement is her sense of self as diseased, contagious and dangerous to others. She also felt unable to tell her family the truth about the death of her babies, choosing to inform them that they had died of TB. When she eventually told her sister her diagnosis, she asked whether her children had died of AIDS. Neliswa talks about how harbouring this knowledge was stressful for her:

Every time I visit them, I am coming sick. I have got stress headaches but when I came back to Cape Town, I am all right. So I think I have got the stress because I am afraid to tell them I am sick.

In some cases, the women have been unable to disclose their status to their families. They conceal their status by describing their illnesses in terms of other, less stigmatised diseases, like TB, in an effort to 'pass' as normal (Goffman, 1963).

Participant B (translated): As I am living with my sister, the treatment that I am taking I am telling her that it is TB treatment and then I was never sick since I living with her.

Participant G: ...I didn't disclose to family. I just ignore it because my mother had a heart attack. So I didn't want to disturb her. I went home. My mother said to me you know you better go to, my darling, to Cape Town because you are sick and you not working [...] I knew about my status but I didn't tell them. I just tell them no please can't you just leave me because I want to Cape Town because I know I am going to be all right there because I see many of the people which are struggling of my there. I just told them I had TB only and I didn't tell them about the other things. It's only TB.

The difficulty in disclosing to family is out of fear of rejection and stigmatisation. France (2001) states how the family, following the health care setting, is the place

with the most debilitating stigma. Women make use of commonly held public discourses of fear of HIV and rejection of HIV positive persons by others. It becomes the belief that the same would happen in their families. Some of the women also recall previous conversations and dialogues with their families, which would indicate the possibility of blame and rejection.

Participant I (translated): I was afraid of being HIV positive because in my family my father's sister was always talking about this HIV thing because me and my sisters like to go out to parties. So when we came back from the parties he was always talking about being HIV that we might get HIV from the parties, from going to the parties. Ok she was also telling us that if we can become HIV she can laugh at us

Participant E (translated): Ok I thought she [*sister*] was going to shout at me because every time they saw something on the TV [*television*] talking about HIV they were swear so I just thought she was going to shout at me but she didn't.

However, later in the interview, this woman's story pointed to some indirect rejection of her by her family:

Participant E (translated): Ok my whole family knows that I am positive.

Interviewer (translated): Was that difficult to tell some of them?

Participant E (translated): Ok no it wasn't difficult because I just told them now when I accepted it and as my kids are staying with them. As my kids are staying there, they said I mustn't take my kids. I must leave them with them.

Interviewer (translated): Why is that?

Participant E (translated): They say that I mustn't take the kids to come and be with her me because now that I am HIV positive. I must leave them there in Eastern Cape.

Here the implication seems to be that she is either too dangerous, or else too disabled, to look after her own children. Similarly, a woman spoke of her ex-husband not

wanting her to have their children because of her status:

Participant H: My children go there and then sometimes she [*he*] say, "ooh I don't want your mother because the people she told she's got AIDS."

Interviewer: So he doesn't want to have anything to do with you?

Participant H: Ja she [*he*] said me. I said "No she [*he*] must give it me the money for the children". She [*he*] say "No I can't. Bring my children here". And then my children say no I don't want to go there mamma with my father because he has got another wife now.

Interviewer: So he said that he wants your children to stay with him?

Participant H: Ja, with the other wife.

Interviewer: Because of ..?

Participant H: Because I'm got HIV, I've got AIDS. He say I've got AIDS.

Disclosing to their intimate partners and their children is perhaps more difficult. It is in these relationships that we often construct our sense of selves, in these cases as wives and mothers. The fear of being rejected may be overwhelming in these relationships.

Participant F: ...he was not here and then he came back and then he saw that I'm sick and then I didn't tell him at that time. I first think 'ooh how is he going to react?' And then I said I told myself I must told him because I know that he is already maybe suspecting some thing.

Interviewer: So you were afraid of how he was going to react?

Participant F: Yes.

Interviewer: What were you afraid of?

Participant F: I was afraid he was maybe going to say [*short pause*] maybe he is going to leave me, that's the first thing, or maybe he is going to say "ok you are the one who brought this thing", maybe he is also like that.

For some women, disclosing to their partners brings a possibility of violence:

Participant C (translated): He asked me why I had TB, and he ran away. And then he came back. And I ask him how he can react when he hear that I

am HIV positive. **(not translated):** And he said, "Yo, I'm going to kill you." He's going to kill me, and he going to kill me first and after he going to kill her. And what about my baby? And he said... "What I don't know, but I'm going to kill you if you are HIV positive." Going to kill me. Yo!

Only few relationships seemed to survive the trauma of disclosure. In many cases, the break up or demise of the relationship is not spoken about in relation to the disclosure, in an effort perhaps to defend against the pain that this has caused.

Interviewer (translated): And did your relationship change after that?

Participant B (translated): Ok no it didn't change I just took him to the clinic I attended.

Interviewer (translated): Are you still with him, in a relationship?

Participant B (translated): Yes we are still together but we are not staying together. He is living in his place and I am staying in my place.

Interviewer (translated): And was it always like that?

Participant B (translated): Ok the only thing that changed was that her parents are not working, I mean his parents are not working so he took all his family to stay with him and I also lost my mother so I also took my sisters and my brothers to live with me.

Interviewer (translated): But did you and your boyfriend live together before?

Participant B (translated): Yes we were living together.

In other cases, the demise of the relationship is clearly attributed to HIV status, and the loss of the relationship is spoken about with pain:

Participant E (translated): It was hurting to leave him but because he like he didn't give me the support after I was diagnosed and he didn't want to listen to what I was telling that you must use condoms because I was like telling him that the rules I have been told to the clinic that we must use condoms so he didn't want to and he also didn't want to accept this HIV thing so I just had to leave him.

Participant F: 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

Similarly, for some women, learning of their positive status, revealed their partner's status, and the knowledge that they had been lied to and deceived by their partner's disguising their status:

Participant G: At that time he didn't tell me about his status. He just said to me he's got Tuberculosis. But it was for the third time. But since then he come to me and tell me. In fact he disclosed to me now. He is living with HIV and AIDS.

What these narratives reveal is the break in trust in the relationships, which is brought about after an HIV diagnosis. The diagnosis reveals infidelity, betrayal, and the fact that one's partner has infected the other with the virus. If the relationship manages to survive, it is in the most intimate areas, sex, that the damage to the relationship is most felt.

Participant G: No. no. 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.

Where it seems difficult to face the impact of HIV on the intimate relationship, it becomes more difficult concerning one's children. Of the ten women, seven were mothers. Of these seven, three had babies who had died from AIDS. A fourth woman has a child who is HIV positive. For these mothers, talking about their losses and future loss was painful, and although it was seldom spoken of, one woman referred to her husband's sense of blame for having infected their child:

Participant G: Yes it was very painful. It was very difficult to me. But I do understand that I am going to keep his pictures to me so that I can - I've got

that feeling she is still alive with me although she passed away. It was very painful but now I do forget about that.

Interviewer: And what happened to your relationship with your boyfriend at that time?

Participant G: He just accept it because he said to me "I do understand that [name] is going to die". He just blame himself. And he said it's his stupidity because he didn't tell me about his status. So if he had already know he just told me so that we can get some Nevirapine to prevent our baby.

For the other women, disclosing their status to their children seemed very difficult. Stein (2004) indicates that there is often a significant delay in mothers' disclosure to their children. This was most evident in the case of Nonthembeko:

Case Study 1: Nonthembeko

For Nonthembeko, telling her children was painful and difficult. Her first thought after having received her diagnosis was to keep it a secret. This reflects the shameful nature of the disease, and the stigma associated with it. The first person she told was her oldest daughter. It appeared from the interview that Nonthembeko had told her daughter soon after her diagnosis. However, upon further probing, it was revealed that she was only able to come to a point of disclosing to her daughter two years after her diagnosis. Her daughter knew that her father had died of AIDS, when Nonthembeko had spoken about it the day after her death. Her daughter had not wanted this fact to be known, again pointing to the stigma associated with the disease. This had made Nonthembeko feel that she could not disclose her own status:

she knows that her father had AIDS, and then she said, "you mustn't talk about this." So now, when it comes, so I know I had AIDS, I didn't tell her I was also infected with this.

For two years, she felt unable to tell her family; for fear that she would be blamed and rejected by them. During this time, she was monitoring the safety of telling her children, by observing their attitudes and reactions to HIV and AIDS. She gave an

example of observing her son's negative reaction to talk about HIV on television. The prevailing attitudes led her to decide to hold off on telling her children.

Nonthembeko speaks about her daughter suspecting that she had HIV, when symptoms arose. However, it may also be that Nonthembeko was subconsciously trying to drop hints for her daughter, by calling attention to symptoms that she had in common with her husband. Nonthembeko spoke more overtly about dropping hints when trying to tell the rest of her children three years after her diagnosis:

So there was this thing, Memory, first Memory Book, and then was Memory Box. So, I write everything, everything, everything. So, one day I just put it on the table. [...] And then she [*youngest daughter*] opened this book one day after a little bit long time I'm writing this. And then she read this book, and then [*voice is hoarse and tearful*] I think she had a shock, you know, she - and then first question, "mama, did my father died of AIDS?...So you also have HIV?" I said, "Yes!"

As mentioned already, the first person that Nonthembeko disclosed to was her eldest daughter, two years after her diagnosis. At this time, she had become very sick with pneumonia. It was here that she decided that she could not keep the truth from her daughter any longer. Her daughter insisted that it be kept a secret between them, which was difficult for Nonthembeko, who wanted to relieve herself of the burden of harbouring this secret:

So, she asked me again, "please don't tell my brother and my sister for this. Let's keep this." And then I said, "But, I can't - until when I'm going to keep this?" I want them also to know about me, because sometimes they make me fed up and then they fight [...] They don't know I'm sick. They just talk, and then I'm getting furious and then I cry, because they don't know.

So, only the oldest daughter knew about her illness, until Nonthembeko eventually told all her children a year later. The children were supportive of her, and this was a huge relief for Nonthembeko. She has not been able to tell the rest of her family.

As can be seen in the case of Nonthembeke, the stigma associated with HIV and AIDS not only is seen to affect those infected, but also those related or associated with the stigmatised person. This is what Goffman (1963) refers to as 'tribal stigma'. For family members, like Nonthembeke's children, it becomes important to keep it a secret from others so that they, as a family, may not be stigmatised in the community. Telling friends and neighbours moves this into a public realm, rather than a private one.

3.3 Reaction from the Community

Despite the efforts of campaigns to raise awareness, like the Treatment Action Campaign, and LoveLife, HIV and AIDS remains a highly stigmatised disease in the community. 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). Very few of the women felt that there was stigma in the community. However, their narrative revealed that despite their conviction, they suggested that this was not entirely the case.

Participant E (translated): 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 [...] people who used to do that are only those people who are drunk otherwise yes some of the people like normal people do not say that to HIV positive people.

In this woman's explanation of stigma in the community, she splits the experience of stigma, locating the stigma onto deviant 'others'. This splitting serves as a defence against her own sense of being the 'deviant other', who is HIV positive (Joffe, 1999). This will be discussed further in the next section.

What was prominent in the narratives of the women, was that disclosure to others in the community was complicated. While support is needed from friends and neighbours, the HIV positive individual runs the risk of telling the "wrong" person,

and that person spreading gossip and rumours that would contaminate the individual's social identity. For many of the women, the decision of who to tell, is reached after some period of monitoring and assessing the character of the other, and watching for signs that that person would react negatively.

Interviewer (translated): How do you decide what person you can tell about your status and what person you can't tell?

Participant B (translated): Ok first look at the person who can give me support when I told her and I know who can maybe not talk about my status to like to the like the whole community. I know who is the right person and who is not right.

Participant J (translated): Some of my friends I didn't tell them because they – I think they didn't know much about HIV [...] I cannot tell them about my status but I am only telling them about what HIV is.

Interviewer (translated): What makes you feel that you can't tell them?

Participant J (translated): Maybe they can call me names. [*rest of answer lost in noise*]

[...] **Interviewer (translated):** How do you decide which friends you can tell and which friends you can't tell?

Participant J (translated): I just have a look at each of them and decide. I know their attitudes when I'm taking when we are, we are talking together.

Despite the care that Participant B above has in choosing who to disclose to and who not to, her continuing narrative reveals the danger of making the wrong choice. Her narrative contains her defence against the betrayal of her friends, who she describes as "supportive" yet are some of the ones who have publicly discredited her.

Participant B (translated): to those I disclosed to no one rejected me, but the others who had their rumours about me they have that attitude of, like, rejecting me, but not the ones I disclosed to that I told. But the other people who are hearing that I am HIV positive they have rejected me.

Interviewer (translated): Where do those rumours come from do you think?

Participant B (translated): I think they heard from those I told and those that I disclosed to.

Interviewer (translated): So, what is that like to know that somebody you have disclosed to has told somebody else?

Participant B (translated): I am glad to hear that they are like, um, I am glad to hear that they are telling the other people that I am HIV positive because they are helping me also to those I didn't disclose so they are disclosing for me.

Interviewer (translated): But yet some of the people who are being told react negatively to you?

Participant B (translated): The people I disclosed to didn't show anything to me but I know it is them who told the others, who gave the others the rumours that I am positive

A little later, she talks of the painful consequences of her disclosure to some of her friends:

Participant B (translated): It is just that it is upsetting because sometimes I hear these things about the people who are drunk. It seems as if the people I disclose to are telling everybody even the drunkards so when they are drunk they talk about the fact that I am HIV positive.

The possible consequences of some members of the community knowing is that they will then actively stigmatise the HIV positive individual, and some women talked of such experiences:

Participant A: 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

Nonthembeke spoke of a number of experiences where she felt actively stigmatised by others in her community. This contrasted with Neliswa who felt very supported and accepted by friends and neighbours:

Case Study 1 and 2: Nonthembeko and Neliswa

Neliswa and her husband have disclosed to close friends and neighbours in their community. They consult with each other about who they disclose to, and they do so together. Neliswa states that she tells people whom she has known for some time, who are respectful, and who will keep the knowledge confidential. Nonthembeko, on the other hand, felt that her community was not supportive. She presented two model scenes of being stigmatised as a result of her apparent ill condition:

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. 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.

Nonthembeko also spoke about the gossiping among people in the community, of which she is aware. This makes her to stay silent and not disclose her status. Despite this stigmatisation, Nonthembeko has not always remained silent and passive. She talks of occasions when she has confronted the one who has stigmatised her, in an attempt to defend herself:

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!"

Like this man who used to call "AIDS! AIDS!" I did go to him and told him, "You know you can also bury you, all from your wife to your grandchild they were affected with AIDS, what would you say? This is not nice. I didn't call

this disease. It came to me. No one wants to have AIDS."

Implicit in this last quote is the pain experienced by Nonthembeke of being the stigmatised 'other'. Her responses are an indication of her need to defend against the painful feelings she carries about her 'spoiled identity'. In the first quote is her projection of the disabling effects of her disease onto another, more 'disabled' person. In the last quote is her defence against shame of being the 'other', by positioning herself as the innocent victim.

For one woman, the public stigmatisation has even come from the people she thought least likely to be stigmatising. As with Participant E above, she splits off her sense of 'otherness' onto these 'deviant others':

Participant I (translated): It's like in my support group there are old people there who are drinking when they are attending the support group with me, when they drunk when they meeting on the way they just call you that you are HIV positive child and they call me names and they point at you. So that everybody can know that you are HIV positive. When they drunk they do that when they drunk.

The public stigmatisation for some has been very marked, and has resulted in their social isolation.

Participant G: 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. If you just enter that house [...] my house and my boyfriend's houses, we do live together, so we just hear if you go to that house you are going to be sick because the people that are living in that house are sick.

Participant I (translated): 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. [...] Like they didn't want to greet me back when I'm greeting them. They are not greeting me back.

It is the experience of stigma from others in their family and community that impact on the individual's sense of self, and gives that person her "spoiled identity". We have seen above that one way to defend against one's own sense of self as "spoiled" is to split off intolerable feelings and place them outside of oneself, for example placing the sense of self as deviant onto others. This is explored further in the following section.

3.4 Living with a Spoiled Identity

Throughout the women's narratives, and as shown in some of the above quotes, 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. The women have drawn on the constructions of HIV and AIDS as that of death; deviance; punishment; HIV as dirty, dangerous and highly contagious.

It was shown above when discussing the diagnosis, that all the women appeared to have placed themselves outside of those 'at risk'. HIV happens to those with many partners, prostitutes and other 'deviants'; it does not happen to them. Upon being diagnosed positive, these constructions are incorporated into the women's sense of self and construction of their own identity. Neliswa's narrative contains much of this sense of self as dangerous and contagious.

Case Study 2: Neliswa

Much of Neliswa's narrative speaks of the support she receives from her husband, family and friends, to whom she has disclosed. However, underlying this narrative, is the sense of a dangerous, contagious self, who feels isolated and lonely: This was acknowledged in the following piece of the interview transcript:

Interviewer: You are saying that there are some people who don't want to sit next you or don't want to eat with you. What is that like for you?

Neliswa: For me? It's bad.

Interviewer: It's bad explain that to me – bad?

Neliswa: Hmmm [*query*]

Interviewer: Bad what you feel? What do you mean bad – it's bad?

Neliswa: Feeling worried about that.

Interviewer: Ok. What are you worried about?

Neliswa: I am feeling lonely.

Interviewer: Lonely?

Neliswa: Mm [*affirmative*]

Interviewer: Ok. Do you feel lonely a lot of the times?

Neliswa: Hmm [*query*]

Interviewer: Do you feel lonely a lot of the times?

Neliswa: No I am not feeling lonely.

Interviewer: Sometimes you do?

Neliswa: Sometimes.

Interviewer: And that must be really difficult?

Neliswa: Mm [*affirmative*]

Interviewer: When do you feel lonely?

Neliswa: I am feeling lonely like for example I was got scabies right so even you are testing when it's hot you feel like scratching for somebody who is next to you and you are worried of that because they didn't get this scabies and it is a problem to me.

Interviewer: Ok. So you are like scratching and some body moves away from you and that hurts you?

Neliswa: Mm [*affirmative*]

It may be that Neliswa does not feel lonely much of the time. However, it may be difficult for her to acknowledge the loneliness and sense of isolation that she feels. She at first states that she feels lonely, but later is reluctant to answer further probing. She describes a scene where she perceives herself as been treated as dangerous and contagious. She goes on to talk about feeling guilty about being a contagious 'other', who is a danger to society:

Neliswa: 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?

Neliswa: 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?

Neliswa: It is that I know I am HIV.

Interviewer: How does that make you feel guilty?

Neliswa: 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?

Neliswa: Mmm [*affirmative*]

Interviewer: Ok. 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?

Neliswa: Yes I do something wrong.

Interviewer: What do you think you doing wrong?

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

When I acknowledge her sense of loneliness and isolation, she makes a free association to her husband, indicating that there are problems with her marriage, and that she does not have the close support that she purported to have:

Interviewer: It sounds to me you do feel very lonely with this sickness?

Neliswa: Sometimes even if I have got a problem in my house with my husband sometimes my family are telling me to go home, to leave him alone.

Interviewer: Hmm.

Neliswa: At the same time, I think I can't move there because the drugs are only there in Cape Town.

Her sense of self as dangerous is also contained in her discussion about sex. She speaks of not being interested in sex, and if she did not have a husband, she would not be involved in a sexual relationship:

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.

She explains that sex is unhealthy, and that she cannot have sex because of her HIV infection:

I can't have a boyfriend if I was not married because I am sick. I am sick with a disease of a sexual.

Other women also show their sense of being a dangerous 'other' when they speak of their sexual relationships. The overwhelming narrative is that sex is dangerous to have, and most of them no longer have sex, or else recognise the 'danger'.

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

Interviewer (translated): And sex with a condom?

Participant C (translated): 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 carrier and disseminator of the disease. As stated by Leclerc-Mandlala (2001), this makes women as dangerous. Women as diseased (and thus dangerous) is implied in the following quote:

Participant F: I think because we didn't have uh protected sex but maybe he is not because they said most men's are having strong immune system than us

Implicit in this is an expression of themselves as dangerous. This was expressed in other scenarios, for example in everyday chores, like preparing food.

Participant D: 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.

Participant F: the reason that make to them 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 stated by Participant F, these perceptions of self as dangerous is taken from lay beliefs about the nature of HIV contagion:

Participant F: I thought maybe you get HIV positive if you are maybe staying with somebody with HIV positive or if you are eating with the spoon that is using or even he is coughing or if you are kissing him or whatever

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 speak of their HIV infection as being a sort of punishment.

Participant I (translated): 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 Participant uses the word 'sentence' when referring to her diagnosis:

Participant B (translated): 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.

In five of the women's narratives, there was a sense of being publicly self-conscious about being HIV positive. Two of the Participants spoke of feeling like everyone around them is talking about them:

Participant B (translated): 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.

Participant H: 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) refers to "abominations of the body" (p.14), and are often interpreted as signs of HIV:

Participant E (translated): when you are very sick for a long time the people were saying you have AIDS, you have got AIDS.

Participant F: the people are looking at me because I did lose a lot of weight

Other 'stigmata' which were mentioned was having to go to the clinics, which are known for HIV, and the Treatment Action Campaign's "HIV Positive" T-shirts:

Participant F: 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 they just judge

To defend against this spoiled identity, and sense of self as 'bad', the women seemed to resort to splitting, where 'bad' feelings are placed outside of oneself and attributed to an 'other' (Joffe, 1999). Instances of splitting were contained in all the narratives. Most commonly was the splitting off of the sense of self as 'bad', 'deviant' and 'dangerous' onto others who came to hold these qualities. In many cases, the 'bad other' became those people who yet do not know their status:

Participant A: 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

Participant B (translated): 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 and they are laughing at us because they are not yet sick but when they are sick it's like it's bad for them

Participant G: I know about my status. I'm worried about the people who don't know about their status because in our generation it's very difficult and bad not to know about your status

Another common occurrence of splitting, was a splitting of self into a past, unhealthy self, and a present, healthy self. All of the women are being treated with anti-retrovirals. All the women, therefore, have experienced poor health before being placed on antiretroviral treatment, and have subsequently shown a marked improvement in health. This is then experienced 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 onto 'unhealthy others', enabling the women to hold on to a sense of a 'good', 'healthy' self (Crawford, 1994):

Participant B (translated): 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.

Participant E (translated): 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.

Coupled with this comes a feeling that HIV is not as dangerous as it is made out to be, and that it is 'just like any other disease'. This may function as a sort of denial of the seriousness of the disease, and the pain that this brings for the individual. This is evident in the following quote where, in the same response, the woman talks of HIV as not being 'bad', yet it has been 'bad' for her socially:

Participant G: 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 case of Nonthembeko provides further examples of what has been referred to above; that of internalising some of the social constructions around HIV and AIDS, and defending against the painful feelings by splitting off a sense of being a 'bad other' onto others:

Case Study 1: Nonthembeko

Much of Nonthembeko's narrative was split into a past when she was sick, thin and symptomatic and a present where she is 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 Nonthembeko when she is sick, and carries signs of her illness, like stigmata. When sick, attempts are made 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 me these stigmata, she was moderating their significance by stressing that they are much better now, thereby stressing her healthy present self in comparison to her unhealthy past self. This made me somewhat uncomfortable, as it showed that while her health may have improved dramatically, her health remains compromised. Nonthembeko's need to disguise her illness was also apparent when approaching the MSF clinic for the first time:

It was difficult first because I was shy, scared. Yeah, didn't want to be seen. And then, when I come there in the morning. First we came very early at six o'clock, and then the hospital was still closed that side. So, this people they don't want to stand this side, they want to stand at the back of the hospital. So, I also... you know, we are all shy about the people, not to be known I'm like this.

Nonthembeko relates a memory of seeing a familiar face at the MSF clinic, and the shame that this caused for the other woman who never returned. Nonthembeko explains the reason for this shame, and the stigma, as due to the sexual transmission of HIV:

So, that's why the people hide themselves from the other people, because this is coming, it's to sleep with the other. Maybe if it was a disease like you can just catch like a flu, should be better, but it's because you sleep with someone and then you get this disease.

HIV and AIDS has become a metaphor for deviance (Sontag, 1991; Gilmore & Somerville, 1994). Deviance becomes internalised as a spoiled identity for the HIV positive person. One can see in her narrative, that Nonthembeko struggles with this in terms of herself, where she identifies others at risk in terms of deviance, while stressing her own innocence:

How can you be so sure to say something like that to somebody else and then you don't know where are you standing, you know. 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."

Another myth of HIV and AIDS is that it is a disease that affects black people (Walker, et al., 2004). Nonthembeke marries this myth with the metaphor of deviance, where she splits the 'bad black us' from the 'good white you' in the interview with me. This carries also a historic 'othering' of black people in South Africa. It is as if Nonthembeke carries a double spoiled identity of being black and HIV positive:

Because, our children are not like you whites, you know. You whites, if you had a girlfriend, you do talk about with your parents, and children they don't hide anything. Our children are hiding things [...] We didn't talk about sex. If you talk about sex. If you're a mother, talk about sex, they say, "Yo! This women is like this and this". So, I am that mother who like always to talk to my children about those things, and tell them about the condom [...] I'm the one who like to speak with them. I want to be open with them. Because, it's a mess in my community. It's a mess.

One can see from the above quote that Nonthembeke defends against this spoiled identity by stressing her difference from this 'othered' group as good and responsible, unlike everyone else.

The metaphor of HIV and AIDS as dangerous is implicit in much of Nonthembeke's narrative. She defends against the danger of HIV, by splitting it from other, more dangerous diseases like cancer and diabetes. The reactions from others in the community instil this 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 condomize, 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 a sense of sex as dangerous, and having to repress her sexuality because of this danger. In other parts of this narrative around sex and sexuality, we can see how 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. Part of this 'danger to her health' contains the expectation of premature death because of the disease, and the need to preserve her health for as long as possible. This is expressed in her wish to be alive to see her grandchildren.

CHAPTER 4: CONCLUSION

4.1 Discussion of interview material

As mentioned in the Introduction chapter, a previous study (Soskolne, Stein, & Gibson, in press) explored the experiences of living with HIV and stigma in a group of women who had been part of an intervention programme offered by The Memory Box Project. 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" (p.143).

Using the framework of the psycho-social subject and the notion of the defended subject (Hollway & Jefferson, 2000), this study explored similar issues around being HIV positive, in a group of women who had not had the same access to support as those in the above mentioned study. The intention of this particular study is not to make overt comparisons, which will be explored at a later stage in the research process, but to begin to explore how women experience and deal with AIDS stigma under conditions where they have little support. However, what already seems clear, is that the 'positive identity' critiqued in the study by Soskolne et al. (in press), is much less present in the group of women in this study. 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.

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). Receiving the diagnosis was a shocking and traumatic experience as the women struggled to make sense of how they got to be infected, and what this meant to their lives. The shame of their diagnosis was evident in the women's struggle to

disclose to their partners, children and family. Many women harboured their status as a shameful secret, only disclosing to significant others once they started to fall ill, and "passing" (Goffman, 1963) became more difficult. Before this, however, many women explained their conditions in terms of other, less stigmatising, diseases, such as TB. Part of the difficulty in disclosing to their families, is the women's fear of rejection and stigmatisation, as the women incorporate into their sense of self, social discourses of HIV as dangerous, dirty and contagious. What became evident is that few relationships survived after disclosure. In some cases, this rupture in relationships was attributed to other factors, possibly in defence against the anxiety of being the dangerous, contagious 'other' that must be rejected. This was evident in other women's narratives, where the rupture of relationship was painfully attributed to their spoiled identity. This became even more painful and difficult to talk about when it came to mothers talking about their children.

For the women in the study, it was difficult to live with 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 minimising the presence of stigma, their narratives suggested otherwise. The women spoke of the difficulty of disclosing to members of the community, and the risk of telling the 'wrong' person, who would spread gossip that would contaminate the individual's social identity. Social discourses around HIV as dirty, devious, dangerous, and a punishment prevail, and the women in this study draw on these and internalized them to create a spoiled identity. Many women struggle with these notions of themselves, as they feel self-conscious of contaminating food, of being talked about in public, and feeling dangerous and dirty in the context of sexual relationships. Some of the women speak of being punished. They defend against the anxiety this causes, by splitting off these bad representations and projecting them outside of themselves, onto 'others' who are 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 'other' 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.

However, it is not only in the narrative itself that the emotional pain of having a spoiled identity is conveyed; in the words and unconscious defensive structure of the narrative, 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 myself, as I became aware of my own feelings of hopelessness and helplessness and despair. I often came away feeling very saddened and angry that these women had to struggle with being positive, in a social context that is already very difficult and deprived. I also came away from these interviews feeling guilty that I had nothing to give. As stated by Hollway and Jefferson (2000), my own countertransference feelings become important sources of information, and are used in co-constructing the narratives.

4.2 Limitations of the study

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. In addition, it is a small sample, which limits the ability to make these findings universal to the experiences of other women. Hollway (in press) states how it is the positivist mentality that only statistical analysis permits generalizability and has any universality. However, in psycho-social research, it is the interplay between the social and the psyche that is of interest. The narratives in this study gives 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. However, linking the interpretations of the narratives to particular theories of Social Construction and Psychoanalysis, enables one to recognise that there are universal aspects to telling a story.

In addition, as the researcher, I am actively placed in the construction of that narrative. I am guided by my own interpretations of emotional nuances, both in myself and the participant, to ask questions that probe and guide the telling of the story. It must be borne in mind that issues of gender, class and race play a role here. I am a middle-class, white South African male, interviewing poor, black South African women. This relationship contains all the internalized politics of power, products of an Apartheid past (Gibson, 2002). This imbalance of power may have influenced the way the stories are told. This was apparent, for example, in my interview with Participant H, who gave a grim picture of financial hardship. At the end of the interview, she asked me for a job. One can interpret this as a need for her to present a certain narrative to me, a person in a position of privilege and power, with a wish of getting some benefit from it. However, although her narrative may contain some bias, it does not detract from the fact that she does indeed come from a situation of poverty and underprivileged, and this shapes her construction of a social identity.

I have already discussed under ethical considerations in the Methodology chapter, the issue of language and translation. As a non-Xhosa speaker I remained somewhat distanced from the narratives of the participants. The interpretations of the narratives are likely to be different if I was a Xhosa-speaker.

However, true to the framework of a psycho-social subject, these differences in gender, class, race and language, contribute to the social construction of the participant's identity. They also reflect the broader context in South Africa, where race, class and language have marginalised groups in society, and gender has marginalised women. Thus the participants, as black women, represent a particularly marginalised group, and this is constructed in the interview situation, between myself as the researcher and the participant.

4.3 Conclusion

Although it is not the aim of this study to compare findings with the study by Soskolne et al. (in press), it can already be made apparent that differences exist in fending off a spoiled identity and constructing an unspoiled positive identity between the two groups of women studied. In this study, the women did not have the same access and form of support that the group of women in Soskolne et al's (in press)

study. It may be that supportive interventions make a difference in allowing women to construct more positive, unspoiled identities as HIV-positive individuals. This does need to be explored further, with more research.

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. It is these discourses that one draws on to place themselves outside of 'those at risk' in the first place. These discourses spoil the HIV-positive individual's identity. 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, it must be held in mind that the negative social discourses are very damning. Susan Sontag (1991) has argued that HIV and AIDS has emerged as a disease with the greatest capacity to stigmatize and create a spoiled identity. The consequences of this social stigmatisation can be dangerous. This was very painfully brought to reality, with the rape and murder of one of the participants in this study. It was some months after the interviews were conducted, and before writing up this thesis, that I learnt of the shocking rape and murder of one of the participants. She had started to become a public educator and AIDS activist with the Treatment Action Campaign, a short while after my interview with her. In December 2003, she was raped by a gang of five young men, in the toilets of an informal tavern (*shebeen*) 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). Treatment Action Campaign activist Zackie Achmat reportedly said "we want to remember her as a courageous fighter who lived openly with her condition." (quoted in Mtyala, 2003). His use of the word "fighter" seems apt. Not only is being HIV-positive a social fight against discrimination, stigmatisation and a social spoiled identity. It is also an intrapsychic fight, as shown in this study and that of Soskolne et al (in press), as the individual struggles to internalize the spoiled identity and reconstruct a more positive, unspoiled identity.

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ADDENDUM A: Details of Participants**TABLE 1.1: IDENTIFYING DATA OF WOMEN INTERVIEWED**

Partici- pants	Age	Marital Status	Children	Approximate time Since diagnosis	Months in ARV Support group	Language of interview
A	43	widow	yes	3yrs	Not known	English
B	25	single	Yes (deceased)	2yrs	12	Xhosa
C	22	single	yes	5yrs	8	Xhosa
D	33	married	yes	3yrs	8	English
E	38	single	yes	7yrs	24	Xhosa
F	27	single	yes	2yrs	5	English
G	29	single	yes	3yrs	7	English
H	47	divorced	yes	2yrs	12	English
I	16	single	no	4 months	3	Xhosa
J	30	single	no	9yrs	6	Xhosa
Means	31			3.5yrs	8.5	

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ADDENDUM B: Interview Schedule:

A. BRIEFING:

I am doing a research project into HIV and Stigma. The purpose of this interview is to explore with you how stigma has affected your life as an HIV-positive woman. I am going to ask you about your relationships and personal areas of your life, so we are not going to talk about just stigma. Some of the things we will talk about will be about the harder parts of being HIV positive. So, it won't be easy, but I just ask you to be as honest as you can. I will be tape-recording this interview, so that afterwards I may listen to the tape, and write down everything that you have told me. Only I will be listening to the tape, so what we talk about here is confidential. When I will write my research report, I may use some of your own words to talk about things, but no names will be mentioned, so you will remain anonymous. Is this okay with you? Have you got any questions before we start? Are you fine to begin?

POSSIBLE QUESTIONS:

Questions are only used as guidelines. The interview is to be free-flowing, following the material of the respondent. Areas are to be explored further by means of probing questions.

B. HIV TESTING:

- When were you first diagnosed as HIV positive?
- What made you want to go for an HIV test?
- How did you react to being told you were HIV positive?
- How do you feel about your HIV status now?

C. RELATIONSHIPS:

- GENERAL:
- If you think about your life since you were diagnosed, has the infection changed your relationships with other people? - Who? How?
- Who have you disclosed your status to?
- How do you decide whom you shall disclose to?
- Do you find it difficult to disclose your status to some people? - What makes it difficult?
- Who do you think you cannot tell about your status? - Why?
- PARTNER:
- Do you currently have a partner?
- Does your partner know your status?
- What is your relationship like now (with boyfriend or husband)?
- Does your HIV-positive status cause particular issues in your relationship? - Does your HIV-positive status make some things more difficult to cope with in your relationship?
- Has your HIV-positive status affected your sexuality? - How?
- FAMILY:
- Have you disclosed to your family?
- How has your family reacted to your HIV status?
- Has it changed your relationship to some members of your family?

D: STIGMA:

- What are the kinds of things that people who don't know you would think about someone that is HIV positive?

- Would you say that you have had any experiences of stigma? - What? Who? When?

E: FUTURE:

- What does it mean to you to be HIV positive now?
- How does this differ from when you were first diagnosed?
- What helps you to cope with your HIV-positive status?
- How do you see your future?

F: CLOSING:

- Thank you very much for sharing with me. I have no further questions of you. Is there anything else you would like to share, or any question you would like to ask?
- What was this interview like for you?
- How are you feeling now?

ADDENDUM C: Sample of interview transcript:

The following section of an interview transcript, provides an example of clarifying interpreted answers.

- Interviewer:** And this new partner – tell me about that?
- Participant J:** I stayed in love with him but before it was also difficult to tell him because I thought about my first partner.
- IN:** So you were afraid that he would run away as well?
- J:** Yes I was afraid of that.
- IN:** When did you tell him?
- J:** I told him in 1999 when I got TB.
- IN:** So was it about a year after you met?
- J:** Yes it was after a year.
- IN:** So during that year that you never told him anything were you thinking of it at all?
- J:** Yes I was thinking about telling him but I was also scared but when I was told that I had TB I got a chance to tell him.
- IN:** So with being sick with TB you had an opportunity to explain what was wrong with you?
- J:** Yes.
- IN:** And that must have been very difficult for you to do that? Yes?
- J:** It was difficult but I just told myself that I must use that opportunity.
- IN:** And what happened?
- J:** He accepted me and my status and he went for a test and his results came negative but then after some time he went for a test again and the results came positive.
- IN:** And what happened then?
- J:** There was nothing changed. We still staying the same like from when the, we are still staying. We are still in love. We still continue our relationship.
- IN:** So it sounds like a supportive relationship?
- J:** Yes it is a supportive relationship.
- IN:** But before you told him you were afraid that he would run away if he knew so it must have been a relief when he didn't?
- J:** Yes I was scared that but got relieved when I told him.
- IN:** Did it change your sexual relationship with him at all?
- J:** No we are using a condom.
- IN:** Did you always use a condom?
- J:** Before I told him we never used it.
- IN:** So that changed – that when you told him you started using condoms

ADDENDUM D: Consent Form

RESEARCH INTO HIV AND STIGMA.

I am conducting research into stigma, as experienced by HIV positive individuals. I am looking for people to be interviewed by myself. The interview will involve an exploration of how HIV might have affected your relationships, how it might have changed you as a person, and how you might have experienced stigma as a result of your HIV positive status. What will be spoken about might be difficult and personal to share. Participation is voluntary, and you will be compensated for your time and transport costs. We cannot tell you how much but it will neither be too much or too little. The interviews will be conducted individually, and will take between 1 and 1½ hours. These interviews are confidential, in that your name will not be made known. The research report will use the information and words as spoken by you, but no names will be mentioned in the report. The interviews will be tape-recorded, so that I can write down exactly what you said after the interview. Only I, or someone working with the research project will listen to the tape. Your name will not be on the tape, in order to ensure anonymity.

If you would like to participate in this study, and agree to be interviewed on this topic, and for the interview to be tape-recorded, please complete and sign the following form. This form will be used to help identify you for the purposes of arranging the interview.

NAME: _____.

AGE: _____.

AREA WHERE YOU LIVE: _____.

HOME LANGUAGE: _____.

GENDER: please tick: female male

CONSENT: Are you prepared to be interviewed and for the interview to be tape-recorded, on the condition that what you will remain anonymous?

Yes signature: _____.

No

Are you comfortable in being interviewed in English? Yes No

If no, would you be comfortable to be interviewed with the help of a translator? Yes No

Which telephone number may I use to contact you? _____.

What is the best time(s) to phone? _____.

THANK YOU FOR THE INFORMATION. I LOOK FORWARD TO SPEAKING WITH YOU!