RESISTING STIGMA: LIVING POSITIVELY WITH HIV/AIDS IN SOUTH AFRICA

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A dissertation submitted in partial fulfilment of the requirements for the degree of Master of Arts in Sociology to the Faculty of Humanities and Arts at the University of Johannesburg

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Johannesburg, July 2005
ACKNOWLEDGEMENTS AND DECLARATION

It seemed natural that I would do research on HIV/AIDS for my dissertation. After all, my mother has told me stories, almost daily, of the cases that she had seen in her workplace, and of the social and personal problems caused. Foremost, I would like to thank my parents; my mother for the inspiration and her passion for the topic, which I have borrowed for this dissertation. And my father, for supporting me throughout my crazed pursuit of higher education.

Ultimately, I must thank God, because He is the source of all my inspiration and energy, as well as, possibly, the one who has sacrificed my company more than anyone else for this work. Others, who have been relieved of my company by this research and can still be considered friends, I also wholeheartedly thank for understanding how poorly I multitask.

To James, truly my other half, for his unfailing support and care through frustration and exhaustion alike.

To Lindsey for her exact and pertinent criticisms, to Meera for her unfailing encouragement and to Tina for her methodological precision and patience. I have been very fortunate in having you as my supervisors. My thanks to Michael Burawoy, Peter Alexander and the rest of the GANSI project for helping to concretise my thoughts on the topic of AIDS and identity. Also, my thanks to the hospital for making this study possible and the AIDS activists interviewed.

Finally, in memory of Bongi, her words and spirit live on in the pages of this study. To Maria for filling very big shoes, and to every respondent who shared their life with me for this dissertation.

The financial assistant of the National Research Foundation (NRF) towards this research is gratefully acknowledged. Any opinions expressed and conclusions arrived at, are those of the author and not of the National Research Foundation.

I hereby declare that the mini-dissertation submitted for the partial fulfilment of the degree Master of Arts in Sociology at the University of Johannesburg, apart from the assistance recognised, is my own work, and has not been submitted to another university for any other degree.

Sandra Jane Roberts,
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This study emerged from the apparent contradiction posed by the frequent occurrence of stigma and the prevalent concept of ‘living positively with HIV/AIDS’ in South Africa. It was anchored in the need and commitment to resolve this paradox. This study contributes to filling a relative dearth of research which explores this phenomenon. Fieldwork consisted of observation, group interviews and in-depth interviews at two public hospitals in the greater Johannesburg area. People living with HIV/AIDS (PLHAs) experience stigma to differing extents in various contexts. In particular, PLHAs experience stigma in healthcare settings, from family, sexual partners and the community at large. Social identity is used in two significant ways as a defence mechanism against stigma in personal relationships. The first is to attempt to discredit stigmatising stereotypes as applied to the PLHA by emphasising how he/she is moral and valuable to those around HIV/her. By using this approach, termed ‘identity fixes’, the PLHA attempts to reduce the stigma which he/she is likely to experience in her/his social relationships. The second is to refuse to accept the ideology which underpins stigma. This denies that HIV/AIDS is an appropriate basis for stigma. The acceptance of this alternative ideology is marked by public disclosure. The goal of adopting this identity termed the ‘positive resistance identity’ is to challenge and oppose the stigma itself.
Hierdie studie het ontwikkel as gevolg van die oënskynlike teenstrydigheid ten opsigte van die hoë vlakke van stigma en die huidige uitgangspunt van ‘positief leef met MIV/VIGS’. Die studie was geanker in die behoefte en toewyding om hierdie paradoks uit die weg te ruim. Hierdie studie dra by om die leemte in die navorsing wat hierdie fenomeen verken, te vul. Die veldwerk het bestaan uit waarneming, groepsonderhoude en indiepte onderhoude by twee algemene hospitale in die groter Johannesburg-gebied. Mense wat saamleef met MIV/VIGS (MLHV) beleef verskillende grade van stigma in verskillende kontekste. Hulle beleef dit veral ten opsigte van gesondheidsdiensopsette, van familie en ook die bred gemeenskap. Sosiale indentiteit word op twee betekenisvolle wyses as ‘n verdedigingsmeganisme teen stigma in persoonlike verhoudings aangewend. Eerstens word daar gepoog om die stigmatiserende stereotipering waarmee die MLHV gekonfronteer word te diskrediteer, deur die beklemtoning van die feit dat hy/sy eintlik moreel en waardevol vir die mense om hom/haar is. Deur van hierdie benadering genaamd ‘identiteitsvestiging’ gebruik te maak, probeer die MSHVs om die stigma wat hulle heel waarskynlik in hulle sosiale verhoudings gaan ervaar, te verminder. Tweedens is daar die weiering om die ideologie wat die stigma ondersteun, te aanvaar. Hierdeur word die bewering dat MIV/VIGS ‘n geskikte basis vir stigma is, teegestaan. Die aanvaarding van hierdie alternatiewe ideologie word bewerkstellig deur openbare bekendmaking. Die aanvaarding van hierdie indentiteit, naamlik die ‘positiewe weerstandsindentiteit’ het ten doel om die stigma as sulks aan te spreek en teê te staan.
### ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
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<tr>
<td>CARE</td>
<td>Community AIDS Response</td>
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<td>NGO</td>
<td>Non Governmental Organisation</td>
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<td>PLHA</td>
<td>Person Living with HIV/AIDS</td>
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<td>RAU</td>
<td>Rand Afrikaans University</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<tr>
<td>TAC</td>
<td>Treatment Action Campaign</td>
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<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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<td>Wits</td>
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CHAPTER ONE
BACKGROUND TO THE STUDY

1.1. Background to the Problem

HIV/AIDS is a highly stigmatised infection. Yet, in South Africa, where HIV/AIDS tends to be most common amongst the black population, many HIV positive people appear to overcome this stigma associated with their HIV status and apparently live ‘positively’. Stigma has long been identified as the ‘third wave’ of the AIDS epidemic, leading to it spreading faster, as those who suspect they may be positive do not get tested and those infected do not disclose to their partners (Mann 1987). It often also means an early death of sufferers as they delay being tested or treated, and experience heightened stress which weakens the immune system. Therefore, evidence of an identity which is positive, despite the stigma associated with HIV/AIDS, may lead to people living with HIV/AIDS (PLHAs) to live longer and refrain from spreading the infection to others. The intention to address the mystery of some resisting stigma is reflected in the title of the dissertation; ‘Resisting Stigma: Living Positively with HIV/AIDS in South Africa.

Stigma is a problem in South Africa as it is around the globe. Certain groups are more likely to suffer stigma, such as gays, drug addicts and the poor. These groups share a vulnerability to stigma because of their devalued position in society. Homosexuals and drug addicts may face stigma because people feel that their behaviour is immoral, and they can be blamed for their own HIV infections. In developed countries, it is these populations who still form the majority of HIV infections, although heterosexual transmission is growing (Adudah and Hachonda 2004:149). The profile of those who are more likely to be infected with HIV/AIDS in developing countries differs, with heterosexual transmission being more likely. In such societies, economically disadvantaged women are more likely to be HIV positive because of a range of social and physical factors. Like gays and drug abusers, women are often unfairly blamed for their infection. However, they are less likely to have the networks of in-group support which homosexuals can claim. Women not only lack support but are also likely to be further victimised both in intimate relationships, in healthcare settings and by the
broader community. This victimisation may be of a violent nature. Stigma causes those already socio-economically marginalised to further lose access to resources, particularly financial. This loss may occur due to losing a job, being abandoned by a sexual partner or the withdrawal of familial support. Therefore, it is surprising that many of those who adopt a positive identity are from the same quarters of the population who experience so much stigma. This dissertation attempts to explain this apparent paradox.

The research explores and analyses the experiences of stigma that patients at a Johannesburg hospital encountered, and how this stigma could be dealt with to live ‘positively’. The study has three aims. Firstly, to explore the stigma to which respondents were exposed. Secondly, to discover the effects of stigma on participants’ identities. Thirdly, to explore how stigma was incorporated into PLHA’s sense of self or resisted to facilitate living positively with HIV. The theoretical assumption underlying this study is that women overcome social pressures and risks associated with HIV/AIDS through a social identity. While this identity is discernable in some men, it seems more common among women.

This research study falls broadly into HIV studies, as well as those dealing with HIV stigma and identity. Both HIV-related stigma and the vulnerability of women in Africa have received attention in the wake of HIV/AIDS (Sontag 1990; Alonzo & Reynolds 1995; Stanley 1998; Kelly 2001; LeClerc-Madlala 2001; Taylor 2001). Other studies have focused on how social and economic factors make black women susceptible to HIV and stigma (Walker and Gilbert 2000; LeClerc-Madlala 2001; Haram 2001; Nyblade et al. 2004). These studies also discuss the dire consequences which stigma can have for women, particularly subjecting them to abuse or loss of economic opportunities which are often linked to sexual relationships. Those with HIV/AIDS are conscious of the stigma and develop a stigmatised identity (Sontag 1990) as initially theorised by Goffman (1963). Yet, in the midst of all the stigma, poverty and desperation, some people are embracing a HIV ‘positive’ identity (Soskolne et al. 2003; Soskolne 2003). Theoretically, the positive identity is likened to Castells’ resistance identity.
1.2. Research Design

Given the aim of exploring the lives of those who are most likely to suffer from stigma - those who are disadvantaged by their socio-economic status, their sex and their race - an HIV clinic based at a public hospital was identified as the research site. Black women, in particular, were targeted by the research, since they are disadvantaged in terms of HIV/AIDS, but are also more frequently vocal than men, rallying around the issue of HIV/AIDS. In addition, the first national prevalence study found that more women than men were infected with HIV/AIDS (Shisana 2002: 46). The HIV positive women who have had the courage to disclose their seropositivity in a hostile environment, inspired this research. In addition, the selected research site lent itself to investigating women, because the majority of those who attended the HIV clinic at the public hospital were women. The study focussed on black respondents for similar reasons. Due to the injustices of the past, the majority of persons forced to make use of public hospitals for economic reasons, are black. Other races were not excluded from the study, but were rare at the research site. This intersection of race, class and gender is critical to consider in examining how HIV impacts on people’s lives (Sewpaul and Mahlalela 1998: 40).

This research study adopts a qualitative methodology to capture the lived experiences of women with HIV. Data was collected largely by means of group interviews, but also using one-on-one in depth interviews. Eight group interviews and seven interviews were conducted. In addition, before conducting interviews on this sensitive topic, four interviews with HIV workers and activists were carried out. The respondents were of different ages, marital and employment status, and had varied periods of seropositivity. The total number of respondents who participated in this study, aside from the expert interviews, was 47 people. Of these 47, 42 were women and five were men. All were black Africans, except for one coloured respondent.

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1 Seropositivity refers to being HIV positive
1.3. Structure of the Dissertation

Chapter Two, the literature review, is entitled ‘Contextualising HIV Stigma and Defensive Identities’ and canvasses the scientific background to HIV stigma and identity in the form of existing literature. Goffman’s writings on stigmatised identity and Castells’ notion of a resistance identity are explored as a theoretical background. HIV/AIDS and stigma are investigated in South African and African contexts. Support mechanisms are identified and analysed. The risks involving disclosure are surveyed, followed by potential mechanisms for defence against stigma.

Chapter Three is titled ‘Investigating Experiential and Interpretative Realities of those Living with HIV/AIDS’ and deals with the research design. Justification is provided for the qualitative methodology selected. The chapter considers the choice of site, respondents, the methods of collection and analysis of data, and ethical issues. The strengths and limitations of the study are also evaluated.

Chapter Four is entitled ‘Towards a Positive Identity’. It follows the respondents’ journeys from the suspicion that they may be HIV positive, to the point at which they disclose to friends and family. Stigma and support are examined as influences determining whether or not to disclose, and to whom. The consequences of disclosure are considered and the phenomenon of the positive identity examined.

The final chapter winds up the study where the findings are drawn together and conclusions extrapolated. Two significant reactions to stigma are explored; both attempt to address the identity which is marred by HIV/AIDS.

1.4. Significance of the Study

The significance of this study lies in attempting to describe the lives of a large and ever increasing population of PLHAs in South Africa; drawing linkages of key aspects in terms of HIV/AIDS from the viewpoints of those who have experienced it most intimately: the HIV positive. Whereas there is a large and increasing body of knowledge about the practical symptoms and impacts of stigma, there has been limited literature which describes the interaction of stigma with social identity in South Africa.
Evidence of a ‘Positive’ identity developing, has not yet been fully explored in this way. The study also has significance for the types of interventions which are aimed at reducing stigma.
CHAPTER TWO
CONTEXTUALISING HIV STIGMA AND DEFENSIVE IDENTITIES

The study is constructed theoretically within the milieu of studies of women, HIV stigma and identity. There is an increasing body of literature about how women are more vulnerable to infection and economic loss when it comes to AIDS (Travers and Bennett 1995; Talus 2000; Walker and Gilbert 2001; Limb 2003: 4-7, 22). Similarly, there has been considerable research about the stigma attached to HIV (Alonzo and Reynolds 1995; Stanley 1999; Haram 2001; LeClere-Madlala 2001; Taylor 2001; Nyblade et al. 2003; Brown 2004). The key finding about HIV/AIDS stigma is that it is associated with poverty and is structural in nature (Link and Phelan 2001; Parker and Aggleton 2003). Some literature has been written about the negative impact that HIV represents to an individual’s social identity (Sontag 1991; Joffe 2001; Sokolne 2003; Rohieder and Gibson 2005). In seeming contradiction, some literature refers to a positive or resistance identity which PLHAs may demonstrate (Fleischman 1995; Joffe 2001; Sokolne 2003). This chapter seeks to explore these findings.

The chapter begins by referring to the theories of Erving Goffman and Manuel Castells. Erving Goffman laid important groundwork in the social-psychology field which allows us to understand how stigma becomes a social identity. His concept of the ‘stigmatised identity’ is used to understand how stigma affects people’s identities. Castells is a part of the modern school of social theory, and theorises about social identity in the wake of globalisation. Both Goffman’s and Castells’ concepts are explained in this chapter and drawn on later in the dissertation. A brief portrait of the literature about black women’s lives in the wake of HIV/AIDS is then drawn. Thereafter, diagnosis is discussed, and the consequences for the PLHA’s life ambitions and identity are explored. Disclosure is an important step as it is necessary to disclose one’s status in order, hopefully, to gain support and understanding from others. Revealing one’s status is carefully considered and performed in an attempt to elicit a positive response from those to whom one discloses. The next section explains what stigma entails, as well as what strengthens it. Support groups are then presented as an arena where support can be received, but they may be risky. The literature discusses three ‘identity fixes’ which people employ in attempts to try lessening stigma. Finally, literature points to the HIV positive identity emerging amongst South African PLHAs.
2.1. Linking Stigma and Identity: The Theory

This section seeks to give the reader a definition of the theoretical concepts of ‘stigma’ and ‘identity’. Stigma can be broadly understood as associated with persons who are perceived as less than fully human (Goffman 1963: 15), that is, they have been socially discredited. A more detailed explanation of Goffman’s concept of stigma follows. Identity is the point at which the social and personal worlds of individuals meet. Goffman combines the two concepts with the stigmatised identity in which the stigmatised apply externally experienced sanction to themselves, incorporating the stigma into their self-concept. Castells’ theory allows people a reflexive freedom with identity, as social identity is manipulated to serve the individual’s or group’s purpose. One use that the identity can be applied to is resisting social domination, the ‘resistance identity’. This research makes use of both the stigmatised identity and the resistance identity to represent social reality, in which people both accept and resist stigma.

The dictionary definition of identity is ‘the characteristics, feelings or beliefs that distinguish people from others: a sense of national/ cultural/ personal/ group identity. Or the state of feeling, of being very similar to and able to understand somebody or something’ (Hornby 2000: 593). Of interest in this definition is that characteristics can be the basis of an identity, and that there is a sense of ‘feeling’ similar to others. Identity implies a sense of awareness of others, and an acknowledgment of interdependence (Thompson 1996: 65). This conception shows identity as a meeting point between the personal and social worlds. Identity is formed within a specific social environment and reflects back into that setting. ‘Identity is clearly seen to be socially bestowed, socially sustained and socially transformed’ in Berger’s conceptualisation (quoted in Outhwaithe 1993: 271). However, though this identity was previously viewed as relatively stable, it is now conceived as a ‘movable feast: formed and transformed continuously in relation to the ways we are represented or addressed in the cultural systems which surround us’ (Thompson 1996: 64). Roseneil and Seymour (1999: 8) agree, contending that ‘identities are never unitary or perfected, but are rather continually practiced.’
Stigma, on the other hand, has to do with people who have been socially discredited. The ancient Greeks saw stigma as a physical mark that demonstrated ‘something unusual and bad about the moral status of the signifier’ (Goffman 1963: 11). Stigma, according to Goffman (1963: 13) is ‘an attribute which is deeply discrediting’. Link and Phelan (2001: 3-5) identified five components of stigma. Firstly, differences must be distinguished and labelled; secondly, they must be linked with negative attributes. Thirdly, there must be a separation of ‘us’ and ‘them’. Fourthly, on the basis of separation, ‘them’ lose status and are discriminated against. Finally, those who wish to stigmatise, must have the power to do so. Stigma comprises of all of these. Goffman (1963: 13) would agree, since his conceptualisation of stigma was primarily social and relational, rather than a response too attributes.

The stigmatised identity, Goffman (1963: 12-13) argues, is marked by ‘a special discrepancy’ between the virtual (or expected) social identity and the actual (or the real) social identity, but the discrepancy must be discrediting in nature. Goffman also refers to stigma being assimilated into the social identity of he/she who bears the stigma (Goffman 1963: 21). Those who bear the possibility of encountering stigmatisation develop a stigmatised identity. Potentially stigmatising attributes are hidden by the person with the stigmatised identity, to protect the ‘self in various social environments that could lead to stigma. Interactions with those not similarly stigmatised or ‘normals’, are then inherently risky for the stigmatised (Goffman 1963: 25). The stigmatised are socialised into the ideologies created by ‘normals’ to regard themselves similar to how the stigmatisers do (Goffman 1963: 45). Goffman makes little allowance for an identity which does not adopt the norms of broader society, but rather dismisses the possibility, saying that ‘In America at present, however, separate systems of honour seem to be on the decline’ (Goffman 1963: 17).

Castells provides some balance to Goffman’s views as people are able, in his view, to go beyond managing information about the stigmatised identity, to opposing the logic behind stigma. In Castells’ view, oppressed persons have agency to resist repression. Castells (2000: 6) defines identity as ‘the construction of meaning, the meaning of actions by social actors on the basis of social attributes.’ In other words, identity is a shared interpretation of reality based on a common attribute which people share. For
some, Castells (1997: 8) asserts that those social attributes are marked by inequality, and an identity develops which is opposed to dominant ideologies. This resistance identity he defines as:

…generated by those actors that are in positions/conditions devalued and/or stigmatized by the logic of domination, thus building trenches of resistance and survival on the basis of principles different from, or opposed to, those permeating the institutions of society.

The resistance identity leads to the formation of communities, as those who perceive themselves to be similar are drawn together on the basis of those similar attributes. Groups also lead to identity formation as those in the group contrast themselves to those outside the group. Groups may construct ‘forms of collective resistance against otherwise unbearable oppression, usually on the basis of identities that were, apparently, clearly defined by history, geography, or biology making it easier to essentialise the boundaries of resistance’ (Castells 1997: 9). The individuals’ reflexive abilities allow them to build a ‘defensive identity in the terms of dominant institutions/ideologies, reversing the value judgment while reinforcing the boundary.’

Stigma combines with social identity to form the stigmatised identity. However, it seems possible to resist the stigmatised identity to some degree, and develop a ‘resistance identity’. The two identities seem oppositional by their nature. This ‘resistance identity’ along with the ‘stigmatised identity’ are key concepts in this dissertation. The study explores whether the resistance identity exists amongst those who are stigmatised by HIV/AIDS. The remainder of the chapter is devoted to exploring the literature. Most accounts agree that stigma is experienced, and the identity of PLHAs does become stigmatised, but a few also suggest that a resistance identity may exist for the HIV positive in the form of the positive identity.

2.2. Black Women and HIV/AIDS in South Africa

The purpose of this section is to demonstrate how poor black women are particularly vulnerable as a result of HIV/AIDS (Lawson 1999; Bujra 2000; Becker 2001:1;
Crothers 2001:13; LeClerc-Madlala 2001; Walker and Gilbert 2001). HIV further marginalises women who have already been made vulnerable by their economic position, gender and race. Poor black women face particular challenges when it comes to HIV infection. They have a high risk of infection, have limited chances to protect themselves from infection and bear most of the care responsibilities, as their families get sick. These challenges are compounded by stigma (Haram 2001; LeClerc-Madlala 2001; Nyblade et al. 2003). Poor black women are likely to suffer stigma to a much greater extent and the stigma may translate to abuse by a partner or family member(s). They may lose access to resources as their partners abandon them. Women may also have a lack of autonomy over what happens to their own bodies. Poor women have very few resources to defend or protect themselves.

Black women are most at risk for HIV, and HIV increases their social vulnerability. Walker and Gilbert note (2001: 3):

> It is these [young African] women who are most susceptible to infection, have the highest rate of infection, get the most inadequate and inferior access to treatment, take most of the responsibility for caring for the sick and dying and have the shortest survival rate.

Social and gender inequalities are the core problems that lead to the spreading of HIV/AIDS. This is due to the socio-economic inequalities where women rely on men for their access to necessary resources (Bujra 2000; Becker 2001: 1; Walker and Gilbert 2001). Women, more especially black women, are generally less educated, which further limits their access to economic empowerment (Walker and Gilbert 2001: 9). Additional factors relate to women’s lack of sexual decision-making power, experience pressures to form sexual relationships at a young age, and to accept violence in relationships as normal (LeClerc-Madlala 2001: 41). Poverty, in particular, is linked with sexually risky behaviour for women, as they need to survive (Ogden and Nyblade 2005: 14). In addition to this, women face increased challenges once they have children, as they may become sole caregivers and financial providers (Sewpaul and Mahlalela 1998: 36).

HIV stigma further increases their social vulnerability. Krabbendam et al. (1998: 2) clarify how stigma affects women at all stages of HIV infection:
Women . . . receive less support than men if they are ill and they have to take care of the ill, the husband and the children. An HIV-infected woman is more vulnerable to financial problems than an HIV-infected man . . . [and] might be abandoned by her husband or her family.

LeClerc-Madlala (2001) and Haram (2001) also note how women are blamed for AIDS and that female sexuality and promiscuity are ‘demonised’ as the cause of AIDS, while males are portrayed as innocent victims. This double standard is intimately linked to others, such as where men are allowed promiscuity and women not, and where women who attempt to assert their independence and choose not to marry, are portrayed as the source of the moral corruption that is AIDS (LeClerc-Madlala 2001: 41). Fox (2003: 15) reports that ‘the stigma attached to HIV/AIDS affects women in particularly adverse ways. Fear of violence, stigmatisation, exclusion and destitution dominates the lives of many women in South Africa.’ Women may be the victims of violence from their partners, if their status is known. ‘In an already abusive relationship, disclosure of HIV status poses a real threat’ of death or desertion (Fox 2003: 15). Abuse may be inescapable as women are often financially dependent on men (Fox 2003: 17). Public disclosure may result in mob violence, as in the case of the murder of Gugu Dlamini (UNAIDS 2003: 37). Women remain vulnerable to HIV stigma and the violence that may accompany it.

This section explored the weight of literary evidence demonstrating that women’s suffering is greatly increased by the stigma associated with the AIDS epidemic. Not only are women more likely to get HIV/AIDS, they are more likely to lose access to income as a result of the infection, thus further increasing their vulnerability to opportunistic diseases and stigma. Women’s options are limited due to four interrelated factors. These are race, class, gender and finally, seropositivity. Options to evade HIV include getting an education, delaying the sexual debut and avoiding abuse, all of which are limited by poor socio-economic conditions. The chances for poor black women to avoid being infected with HIV are smaller than for other groups. Similarly, once positive, black women are more likely to be subject to severe stigma. The stigma experienced by PLHAs comes to a head when they are diagnosed HIV positive. The discussion of the literature next turns to the way in which PLHAs are
likely to experience diagnosis.

2.3. Diagnosis

Diagnosis presents a right of passage into the stigmatised identity of the seropositive. For this reason, diagnosis is often avoided. Rohleder and Gibson (2005: 7) found that none of their 10 respondents was tested without an external compelling reason such as TB, the death of a child or spouse, or rape. This stigma is internalised and the HIV positive believe that they somehow deserve to be subjected to stigma.

Stigma does not remain outside the PLHA, but is adopted into the person’s identity or ‘internalised’, and the negative stereotypes may be attached to their social identity (Rohieder and Gibson 2005). Initially they are likely to feel shock and hopelessness. ‘Feelings of fear, depression, isolation and inability to cope, are common to people on initial receipt of an HIV diagnosis’ (Sewpaul and Mahlalela 1998: 36). Women may also experience guilt about the status of children infected through vertical transmission. Symptoms of this self-stigmatised identity are loss of hope, feelings of worthlessness and inferiority, believing that there is no future (Ogden and Nyblade 2005: 32). The phenomenon of internalising the stigma is not surprising, since ‘people living with HIV are, after all, members of the same cultural, social and moral communities as many of their “stigmatizers”.’ Whilst feeling depressed, the PLHAs may isolate themselves from others. Although, it seems that if supported, this time of depression passes, and hope is again felt (Ogden and Nyblade 2005: 32).

Soskolne (2003: 15, 16) in her narrative analysis of HIV positive women’s lives, found that diagnosis represented an end to the freedom that characterised the women’s experiences before. The PLHAs autonomy ended because of their intention to avoid stigma, and to look after themselves. Other perceptions involved the collapse of previous identities, hopes and dreams. Death was seen as eminent and they began to fear having to disclose. Stress related to the secrecy of the virus, was experienced. In addition to the fears and loss of identity which diagnosis can cause, it can happen simultaneously with other traumatic life experiences such as the death of a child, which further adds to the trauma of the diagnosis (Soskolne 2003: 17).
To be diagnosed HIV positive is difficult, even more so if it happens simultaneously with other traumatic life events. Those diagnosed find that they face a very different world from what they faced before the diagnosis. The negative perceptions of the community about those living with HIV/AIDS may be applied to the newly diagnosed person. The PLHA may abandon old previously cherished hopes and identities. Hopelessness and depression may take root. The PLHA may begin to look for support and information whilst fearing the disclosure needed to access these resources. The next section explores the risks, benefits and the process of disclosure.

2.4. Disclosure

PLHAs seem aware, from diagnosis of the danger represented by disclosure, however, they need to disclose in order to access support from others (Krabbe 1998: 8). Disclosure is often not immediate as, in order to be emotionally ready to disclose, people must pass through a process. Despite the psychological benefits of disclosing, it seems that even in the safest of disclosure contexts, the family, stigmatisation and isolation may result. In addition, it seems as though disclosing to partners is rare (Skogmar et al. 2004: 3).

Disclosure is required in order to access some services, such as counselling and informed medical treatment. Some PLHAs find it beneficial to discuss problems with those who are having similar experiences. The decision to disclose is a difficult one to make, particularly to those who are not similarly stigmatised. However, disclosing to fellow sufferers may help lead to further disclosure to significant others. The decision to disclose to significant others may be influenced by expected stigma which may be as real to the PLHA as existent stigma, influencing the PLHA’s decision to disclose (Green and Sobo 2000: 11, 12). Incentives for disclosure must be stronger than the potential negative effects at all points in the disclosure process. According to Kimberly’s theory of disclosure (Serovich, Kimberly et al. 1998: 12), there are six steps which the PLHA passes through when disclosing: 1) adjusting to the diagnosis, 2) evaluating personal disclosure skills, 3) taking inventory of whom to tell, 4) evaluating potential recipients’ circumstances, 5) anticipating reactions of the
recipient(s) and 6) having a motivation for disclosing. At any one of these steps the
disclosure may be obstructed and halted, particularly if the recipient is not likely to
respond well. In addition, it may be a minority who are prejudiced against PLHAs, but
it only takes a few in an environment of uncertainty to ensure that PLHAs do not
reveal their status in their communities (Kelly 2001: 39). PLHAs strategically choose
whom to disclose to, often to gain some benefit (Paxton 2002: 561). The benefits of
disclosure may include safer sex to avoid re-infection and infection with other sexually
transmitted infections (STIs), and understanding and support for when she does get
sick. It may also involve understanding the frequency of hospital or doctor’s visits for
treatment, or for taking up a better diet or healthier lifestyle and possibly just personal
and social support (Krabbendam 1998: 8).

Disclosure also offers psychological benefits, and non-disclosure poses health risks.
According to Paxton (2002: 560) ‘it is widely accepted that holding back one’s
feelings results in stress, which negatively impacts on physical health . . . inhibition
affects the immune system.’ Disclosure itself can be stressful; ‘Disclosure of some
disease-related information, such as an HIV-positive diagnosis can . . . be more stress
inducing than relieving.’ (Serovich et al. 1998: 1). PLHAs are likely to feel anxious
about the stigmatisation, rejection or abandonment that may accompany disclosure
(Soskolne 2003: 16). Kahn (2004) investigated disclosure in the family, peer group and
intimate relational contexts in the Cape Peninsula. She discovered that disclosure to
the family, although it was considered a safe option for initial disclosure, in practice,
was difficult and often led to rejection and isolation. Support was negotiated within the
family, not automatically bestowed. With friends, the women in her study formed
networks of support with their HIV positive friends, while, the men chose to associate
with other groups. For the men, this meant that they did not need to disclose their
status to their friends. Disclosure to a sexual partner was complex, with the women in
the study advocating for non-disclosure, due to their own negative experiences of
disclosure to partners. Stein (2003: 11) argues similarly, that choosing not to disclose
to some extent allows the person the right to enjoy romantic love. In addition, in
disclosing, the PLHA may have to confront other socially stigmatised identities about
such things as their own promiscuity or their partner’s infidelity. Disclosure forces the
PLHA to include increasing facets of being HIV positive that can be stigmatising into
her identity. This incorporation of stigma may be emotionally difficult (Green and
There are few motives for disclosure in the literature, and many reasons not to disclose. A sense of community or ‘calling’ can help the PLHA disclose, as she feels that she can help people in the same position or in prevention programmes (Stanley 1999: 111). A PLHA may disclose due to experiencing a ‘moral obligation’ emphasising her identity of a moral person, even as she shares socially and morally discrediting information (Green and Sobo 2000: 89, 91). Seemingly, the motivation is not always enough; recent research showed that more than 20 percent of patients at the two Johannesburg HIV clinics had not disclosed to their partners (Skogmar et al. 2004: 3). Disclosing is risky, and fear of rejection may lead the PLHA to increased depression and self-imposed isolation (Paxton 2002: 561). Paxton in her study of AIDS activists who had publicly disclosed, found that the fear of rejection was almost universal in PLHAs. The ‘African respondents were less likely to have strong support from family members than were speakers from other regions’ (2000: 563), and women often faced more discrimination.

Disclosure is difficult for PLHAs. It involves a process of coming to terms with their diagnosis, and then deciding how and whom to disclose to. Those who choose to disclose, while possibly improving their psychological situation, may face social stigma that may undermine their lifestyle. For many PLHAs, there seem little overriding motivation to disclose, and much fear of negative reactions. The limited disclosure to partners reflects that even protecting themselves from further infection with STIs or different strands of the virus, is often not a strong enough motivation for disclosing. Low disclosure rates also mean that HIV may lead to further infections. Next the discussion turns to as a lived experience of the PLHA, and what some, by not disclosing, try to avoid.

2.5. Stigma

This section discusses the characteristics of stigma. Firstly, poverty is linked with stigma. In fact, stigma and poverty form a self-perpetuating cycle, as the poor are subjected to an information divide that leads to their getting sicker faster and thus
increasing stigma. The stigma is also displayed in public healthcare settings. Secondly, Nyblade et al. (2003) explain their findings about what actions are stigmatic in Tanzania, Zambia and Ethiopia. These findings are relevant, because, in their comparative analysis of three African countries and Vietnam, Ogden and Nyblade (2005: 14) have found that stigma is similar across different countries, but there is a difference in expression and extent. Thirdly, Alonzo and Reynolds (1995) demonstrate how stigma fluctuates through the course of the illness, and increases as PLHAs get sicker. Finally, this information on stigma is supplemented by data on the extent of stigma in South Africa.

Parker and Aggleton (2003: 14) argue that stigma is more than an emotional reaction to difference, and that it serves to emphasise and maintain structural inequalities. That is, stigmatisation of those with HIV/AIDS is fundamentally a sociological phenomenon, discrimination based on power. Stigmatisers often stigmatise because they have power and resources to do so, and those stigmatised lack the capacity to defend themselves. PLHAs are stigmatised because they are regarded as weak, physically and morally. In South Africa there is also, however, a relationship between AIDS and material inequality, such that HIV/AIDS is associated with poverty. The practical problems of living with AIDS are much greater for those who are impoverished in terms of either resources or information, and the two are closely connected. It is more difficult for poor people to conceal their infection, and they tend to experience the impact of stigmatisation at an earlier stage. The structural disparity that underpins stigma is, then, directly related to illness, and indirectly linked to poverty. Parker and Aggleton (2003: 19) explain how global factors aggravate HIV/AIDS-related stigma. The epidemic is occurring in an era of escalating inequality, and this increases various types of exclusion, including informational. Polarisation also tends to reinforce all forms of discrimination, including those based on ‘race’, ethnicity and religion, but also HIV status. Stein (2003: 8) identifies a further reason why PLHAs are stigmatised in relation to resources, this being that PLHAs consume more than their fair share of resources in the household, in the public health sector and welfare system in resource-poor settings. Economic inequality causes discrimination including stigma for those who are HIV positive.

Stigma in healthcare settings leads to inadequate treatment, as the public healthcare
system is one arena in which stigmatisation of the poor is known to occur. HIV infection demands treatment, but accessing the treatment can lead to further stigma. Healthcare practitioners are known to stigmatise HIV positive patients. A study conducted in Durban pointed to intense stigmatisation of HIV positive people experienced at the hands of medical practitioners (Sewpaul and Mahlalela 1998: 40, 41). Patients ‘reported that the lack of care toward persons with HIV was reflected both verbally and non-verbally; some [medical practitioners] openly displayed anger.’ In addition, mothers found that their HIV positive babies were often denied treatment. Ogden and Nyblade (2005: 26) found, in their African-Asian comparative study that those with HIV were, in all countries studied, sometimes to be denied services, provided with substandard treatment and sent to other providers to avoid the HIV positive patient. Stigma in healthcare settings is thus particularly dangerous and can lead to an early death as PLHAs refuse to go to doctors or get incorrect or inadequate treatment. The mere act of accessing healthcare can expose PLHAs to the danger of stigma. This is due to the lack of resources the poor have to get treatment away from the community (in private settings) in order to ensure that their HIV status is not discovered by the community (Nyblade et al. 2003: 23).

Nyblade et al. (2003: 28) conducted research in Tanzania, Zambia and Ethiopia and found that stigma can manifest in different ways in different contexts. On a community level, PLHAs were often excluded from community events and isolated on public transport, in churches, bars and shops (Nyblade et al. 2003: 28, 29) and their children from schools (LeClerc-Madlala 2001: 44). Gossip and taunting could be a major problem, especially when it has economic consequences, as is often the case for women who are more likely to be dependent on local networks. Nyblade et al. (2003: 30) also report complaints about voyeurism, with people visiting bed-ridden PLHAs and then reporting to other members of the community. In the household, stigma was commonly manifested in differential treatment, including the separation of eating utensils and sleeping quarters. PLHAs also frequently lose power within their households; family members consider them incapable of activities such as housework or receiving visitors, and, effectively treat them like children (Nyblade et al. 2003: 31). In addition, once their positive status becomes known, women are sometimes the victims of violence or abandonment by partners (Fox 2003: 15). HIV is highly stigmatised in South Africa and sufferers can be driven out of communities. Stigma is
such that the virus increases isolation and many die alone (LeClerc-Madlala 2001: 44).

Levels of stigma are not consistent throughout the course of infection. Alonzo and Reynolds show how stigma is experienced differently as the course of the virus progresses. When there are few symptoms, HIV is concealable and is often hidden so that the PLHA is not stigmatised. At this stage, a PLHA engages in ‘information management’ so that she is not stigmatised, but begins to feel different from everyone else. PLHAs experience ‘isolation, alienation, denial and the building of an identity as a stigmatised person, despite opportunities for normalisation’ (Alonzo and Reynolds 1995: 309). At this stage, the complicated decision to disclose voluntarily is made and the PLHA may begin to seek social support. Identity challenges are brought to a head when symptoms are manifested and the AIDS becomes obvious to everybody. The PLHA may be discovered because of her choice of going on anti-retrovirals (ARVs), or as she gets progressively sicker. Along with the discovery of the PLHA’s status, the PLHA’s social identity is also altered, Alonzo and Reynolds (1995: 313):

The transition to an AIDS identity may be in the form of a ‘sharp rite of transition’ to AIDS as a ‘master status’. The ‘normal identity’ of the individual is essentially worn down and the stigmatic AIDS identity becomes fixed.

Stigma may be at its highest at this stage, due to the physical symptoms; ‘a plethora of disabling, disfiguring and humiliating symptoms makes the AIDS patient gradually more infirm, helpless, and unable to control or take care of basic functions and needs’ (Sontag 1990: 107). In addition, the physical symptoms subject people to stigma based on their moral behaviour (Sontag 1990: 110, 111). Both stigma and sympathy can be strongest for the PLHA and caregiver, friends and family at this stage (Alonzo and Reynolds 1995: 310; Taylor 1999: 2). Ironically, as the PLHAs are more obviously ill and the most stigmatised, they are also the most harmless, because they are least likely to pass the virus on through sexual contact (Alonzo and Reynolds 1995: 312).

HIV stigma is a definite feature of life in South Africa. In Brown’s recent study on HIV stigma in Cape Town, he found that the ‘most important factor in predicting stigma for all races, is knowledge about the virus’ (Brown 2004: 19). Thus, in communities with lower education levels and knowledge about HIV/AIDS, stigma is
likely to be worse. He also found that although some races were more stigmatising than others were, most people show some tendency to stigmatise (Brown 2004: 23). These findings were similar to Webb’s 1997 survey of Soweto which demonstrated very high levels of stigma. He found that 55.1 percent of people surveyed thought that PLHAs should be isolated and 6 percent said that they should be killed (Webb 1997: 166). Recent studies show less inclination to stigmatise HIV positive people, but these findings have been questioned. Stein (2003) disputes these findings, saying that stigma is not necessarily decreasing, but stigmatisers are less likely to acknowledge stigmatising behaviours or attitudes. This is due to the increase of information about HIV/AIDS which has also carried messages that it is not socially acceptable to stigmatise. These messages have guided responses on self-administered questionnaires. However, in the last ten years there has been an increase in voluntary counselling and testing (VCT) in South Africa. Greater levels of VCT are linked to a decrease in stigma (Hassim 2004: 220).

This section explained how stigma is structural in nature and associated, in particular, with poverty but also a lack of knowledge. The nature of stigmatising behaviours was examined, as well as the contexts in which they occur. The extent of stigmatisation was seen to vary together with the symptoms as the illness progresses. Stigmatising attitudes persist, despite messages that it is not socially acceptable to stigmatise, and are related to knowledge about the virus. Stigmatic perceptions are also internalised and the PLHA applies them to her/himself. However, despite the stigma associated with HIV, there is also support. The next section refers to the formalised support in the guise of support groups.

2.6. Support Groups

This section presents the current understandings of the dangers and benefits of support groups. In general, advantages include their linkage to greater emotional stability. They may help overcome the initial stress, which deeply affects the PLHA’s sense of self. They also offer the opportunity to feel normal in a group of their peers. Support groups also function to teach PLHAs how to live with HIV/AIDS and to provide emotional support. These factors all make support groups a good option for HIV
positive people, particularly women. However, support groups can be taxing as they may bring the PLHA into contact with others who are very ill. Other people’s stories of their suffering as a result of disclosure may function to prevent a PLHA from disclosing. Entering a support group also involves a PLHA having to disclose her status to others in the group, which lessens their privacy and can be emotionally trying. The details of the positive and negative effects of support groups follow.

There are many benefits to support groups which are run from AIDS clinics and some non-governmental organisations (NGOs) (Van Dyk 2001: 251). They have been linked to positive identity formation, and can cushion the PLHA from stigma, which when disclosing to other non-HIV positive people, might engender. Support groups offer the PLHA the opportunity to disclose to a group of their peers. Fellow sufferers are not likely to judge other PLHAs, and therefore, initially PLHAs may only disclose to them, and thereby gain entrance into the HIV community (Sewpaul and Mahlalela 1998: 38). Support groups can become a turning point in the life of PLHAs as they find the strength and support to disclose to others outside the support group (Sewpaul and Mahlalela 1998: 38). Support groups seem to assist women more than they help men. According to Krabbendam (1998: 3, 9) women most often attend support groups. In addition, women are likely to allow themselves to be supported by support groups to a greater degree than men (Green and Sobo 2000: 178). In such groups a stigmatised person can feel ‘normal’ (Alonzo and Reynolds 1995: 311). Support groups often emphasise the importance of positive living. In these groups, a PLHA can find a community of people in the same position, and can become a ‘hero of adjustment’ in that group. Providing counselling and making available a platform to share problems and advice, are key functions of support groups (Krabbendam et al. 1998: 9,10). The informational component of the support group is also critical for the PLHA who wishes to survive longer.

However, despite the positive effects which attending a support group can have on PLHAs, it can also be risky. It carries the danger of bringing the PLHA into contact with others whose health has deteriorated greatly due to AIDS, an experience which can be most upsetting (Green and Sobo 2000: 97). Support groups may sometimes not be safe, and the choice for the poor to disclose may be taken from them because of the non-private setting of public services. Disclosing HIV status to access these services
may make the poor more vulnerable to stigma (Nyblade et al. 2003: 39). In addition, becoming part of a group is not always easy, because the PLHAs may not know anyone in their position (who is HIV positive) or may wish to disguise their diagnosis, sometimes even from themselves. Alonzo and Reynolds (1995: 312) explain:

Individuals without ties to the gay and other communities where AIDS is more accepted, are more likely to continue to try to conceal their AIDS diagnosis as a means of coping with stigma and are less likely to associate with others or become involved in situations (e.g. support groups) where their HIV status may be identified or must be acknowledged. Support groups can therefore pose social risks and may be difficult to integrate into socially.

Some PLHAs, particularly women, seem to derive helpful support from support groups. Support derived by attendees is associated with positive identity formation and leaves attendees with more information and emotional fortitude. However, by their nature they exclude those who wish to mask their status, since, as an entrance requirement into the support group, the PLHA has to disclose to the group. Although disclosure may lead to the developing of a community-based identity, it can be emotionally difficult to accomplish.

2.7. Identity Fixes

There is recognition amongst several authors (Gilbert and Somerville 1994; Alonzo and Reynolds 1995; Taylor 1999) that the PLHA’s behaviour can, to some degree, control the stigma experienced. The literature reveals three general stigma defence mechanisms or identity fixes. To describe these defences together, the author coined the term ‘identity fix’. In general, these defences serve to try protecting PLHAs against stigma. The identity fix that is most widely described is an emphasis on the PLHA’s moral character. Stanley (1999) deals with this in depth. The second is to demonstrate that despite the infection, the PLHA remains a valued member of the family and in particular, is a good mother to her children. The third defence is to buy some ‘freedom’ or respect from stigmatisers by earning an income. These identity fixes are discussed in detail below.
The moral identity fix is used in order to deal with the stigma associated with HIV/AIDS. Sufferers develop a new moral identity or amend the one that they possess. For instance, HIV may be proof of ‘impurity’ and therefore the impurity can be embraced or rejected. Sufferers may see it as a ‘message from God’ and ‘a blessing’ (Stanley 1999: 108-114), or alternatively it can be used as an excuse to get as much pleasure from life as possible because it will be far shorter (Barnett and Whiteside 2002: 19). Stigma can be defused by aligning with a moral identity of self, as opposed to ‘other’ deviant perceptions of self. This realignment may take the form of ‘AIDS-inspired callings’ such as educating others about HIV/AIDS, or it could be realignment to moral or family-based identities (Stanley 1999: 109). An HIV infection may be felt to be a message from God, or a timely reminder of what is important. However, there were those who conceived AIDS as a punishment from God instead (Stanley 1999: 116). The tactic to distance identity from HIV/AIDS is influenced by social factors, for example, class and economic status can determine how successful that tactic can be. White, middle class women may be more successful in presenting themselves as ‘passive victims’ of AIDS (Stanley 1999: 106). It is clear that the moral identity fix is a reaction to the moral stigma that accompanies HIV/AIDS.

Another identity fix of the PLHA is to attempt to reduce stigma by aligning her identity to her role in the family. Despite the fact that the family is fragile in the wake of stigma, it may be the perfect place to reclaim her moral identity, and it may become the most important aspect of her life as she comes to terms with her shortened lifespan (Davies 1997: 562). Fertility and motherhood remain very important in various African cultures. Fertility ‘confirms [her] social identity as a woman, and also ensures care in old age’ (Barnett and Whiteside 2002: 21). Social pressure forms one reason why women may also choose to have children despite being HIV positive. Emphasising this adoption of greater societal norms, may protect one from some stigma. In addition, if the family is counselled properly, the family may be protected from breakdown. ‘If tested and post-test counselled together, husband and wife are more likely to proceed to a good relationship where both can share problems and support each other’ (Krabbendam et al. 1998: 1-2). Children may also be a reason to try to live longer (Davies 1997: 567), and may reduce a woman’s social isolation (Green and Sobo 2000:71). Whether still a part of a family, or cast from it, family remains an important
source of identity or possibly identity loss (Weigert and Hastings 1976: 1172). The family, then, is depended on by the PLHA, not only for material and emotional support, but to defend the self from outside stigma.

A third identity fix is also possible. If poverty is a great stigma-producer when it comes to HIV/AIDS, can income generation not lessen the stigma? For instance, a micro finance project operates in Thailand in order to reduce stigma and discrimination (Bodibe 2004a). Similarly, in South Africa, income-generating projects have been launched to prevent transmission through fostering women’s independence from income through sexual relationships (Bodibe 2004b; Fox 2003: 18). Income generation projects do not seem to share the problems associated with conventional work such as discrimination and dismissal due to incapacity (Fesko 2001). In addition, unemployment has been found to result in a shortened lifespan for the HIV positive (Davies 1997: 563). Could the power to earn an income increase the PLHAs social capital to the extent that they could use it to fend off stigma? Soskolne et al. (2003: 10) found in their study that employment ‘appeared to almost override the obvious disadvantages of being HIV positive’. The HIV positive person may also qualify for a disability grant of a maximum of R750 a month (Nattrass 2004: 6, 14), which may make up as much as 41-49 percent of the household income. This grant is valid upon reassessment by a medical officer as long as the PLHA remains too sick to work (Nattrass 2004: 7). The present welfare system, however, assumes that while someone is well enough to work, he/she should be able to join the labour force. This supposition is not always true with South Africa’s high unemployment rate (Nattrass 2004: 15). There is therefore an advantage to remaining with a high viral load\(^2\) and in imperfect health.

It seems that identity is manipulated and used to manage stigma strategically by the PLHA. This manipulation may take the form of making use of one of the identity fixes mentioned above; the use of morality, family and income generation, to demonstrate

\(^2\) The viral load refers to the amount of HI virus present in the blood. A high viral load is a good indicator that the patient will get sick soon.
value. The success of these tactics remains to be seen, but they may provide a little protection from stigma. There seem to be few other options for escaping stigma. It would seem that not only is poverty linked to increased stigma, but also relieving extreme poverty can provide the PLHA with more social capital to reduce stigma. The next section deals with an identity that presents HIV infection as an at least partly positive experience.

2.8. A ‘Positive’ Identity

This section deals with the positive or resistance identity that is referred to by a number of literature sources. This identity seems to be characterised by a positive outlook on life, and a realisation that the consequences of HIV/AIDS are not all negative. It may also be associated with a sense of ‘knowingness’, and a pride that those who possess this identity know their status, unlike those ‘outside’. This identity also serves as something to mobilise around, to challenge the systems that mean that some people are stigmatised, as well as, actively challenge the norms that lead to stigmatisation. For this reason, the positive identity is theorised as a resistance identity.

Morgan (2003: 2-3) hints at a positive identity forming in Khayelitsha just outside Cape Town, an area which is sometimes regarded as the home of the Treatment Action Campaign (TAC). A group of activists are involved in an ongoing struggle with the South African government to provide free ARVs to all the poor in South Africa. In Khayelitsha, ‘you can now see that the HIV positive people are often the ones dancing, laughing, toyi-toyiing, going to the clinics and getting on with their lives.’ He continued:

In one support group discussion, several women shocked me when they all said their HIV is not such a bad thing. They know their status, they have access to treatment, some of them receive disability grants, and many of them do HIV - and AIDS-related work where their insider knowledge gives them an edge of expertise out of which they earn an income.

Soskolne (2003: 19, 20) refers to the positive identity being marked by a sense of ‘knowingness’. PLHAs knew their HIV status, they knew what it meant and had
control of their lives. Knowingness also came with the responsibility to educate others about how best to care for their bodies and live longer with HIV. Along with knowing more, the women also differed from the ideas of the broader community about what HIV positive is, pointing out that it was better to know their status, unlike the ‘blind ignorance of persecuting community members.’ The positive identity is also connected with a network of support from friends, family and others with HIV.

Developing a sound social identity for the HIV positive, may lead to an extended lifespan as PLHAs are able to protect themselves better through diet and safe sex, and get support from people in the same position (Alonzo and Reynolds 1995: 311). Fleischman (1995) speaks about the Ugandan’s use of the HIV positive identity to confront practices that lead to women’s increased vulnerability to HIV/AIDS. A network of organisations supports HIV positive women, and an income generation project provides some money. Women are educated about how to enforce their legal rights and how to ‘live positively’ with HIV. With the help and support from this organisation, Ugandan women are empowered to challenge their husbands’ families who often seize their home when the husbands die and resist traditions of widow inheritance. Some women are even able to negotiate safer sex with their husbands, leaving them if they refuse to comply. Joffe (2001: 8, 9) speaks of how the gay men in her study resisted the stigma associated with homosexuality embodied in HIV/AIDS. Firstly, they would idealise their HIV infection, turning the idea of HIV as a punishment to ‘a gift from God’. It seemed that the immanence of death might lend a new joy to life. Secondly, they adopted conspiracy theories that excused homosexuals as the source of AIDS. Thirdly, gay groups organised against HIV/AIDS and created education campaigns which erotised homosexuality overthrowing stigmatising stereotypes. Klawiter (1998) refers to how women activists transformed the stigma associated with breast cancer and used the disease as a basis for activism. It is possible that HIV sufferers are doing the same through their use of the HIV positive resistance identity. Activism has played a key role in advances made towards the antiretroviral (ARV) rollout in South Africa (UNAIDS 2003).

The concept of the ‘positive identity’ remains largely undefined. This dissertation links it with Castells’ resistance identity as a basis for social action. However, the positive resistance identity may not be appropriate for all social situations. It is suitable to
challenge stigma and to advocate around rights for those who are HIV positive. However, Soskolne et al. (2003) note that the positive identity may impede progress in a counselling situation, by not allowing the PLHA to admit to the trials which they face. Soskolne et al. (2003) argue for a more resilient self through the incorporation of negative and positive aspects of HIV/AIDS into the personal identity.

2.9. Conclusion

This chapter presented what the literature has to say about stigma, support and identity formation with HIV/AIDS. Practical manifestations of stigma were explored in both the nature as well as sources of stigma. Support was examined in the form of formal support from support groups. Stigma negatively affects the PLHA’s social identity, whereas support from a support group has been linked to positive identity development. Identity is also used to protect the PLHA from stigma. The term ‘identity fixes’ was coined to refer to tactics found in the literature which attempt, in some way, to make up for being HIV positive. These tactics present the PLHA as valuable or virtuous despite the HIV infection by making use of morality, the family or income generation identities. Finally, evidence of the positive resistance identity is explored from literature which deals with both HIV and breast cancer.

Three research questions arise from this literature review. Firstly, it seems that there is a great deal of stigma experienced due to HIV positive status, in particular by women. Will it be similar for respondents from a Johannesburg or other big city hospitals? If so, what is experienced as stigmatising, and who are those who stigmatise? Secondly, it seems that stigma interacts with the social identity in a number of ways. How can stigma be internalised and resisted at the same time or increasingly resisted over time? The final question is directed at learning more about the resistance identity. What are the social dynamics and demographics that are associated with this phenomenon? The way in which evidence of this identity was collected, will be explored in the next chapter, the Research Design.
CHAPTER THREE
INVESTIGATING EXPERIENTIAL AND INTERPRETATIVE REALITIES OF LIVING WITH HIV/AIDS

This chapter looks at and provides justification for the methodological choices made in order to investigate the experiential and interpretative realities of living with HIV/AIDS. It begins by examining the problem statement that underpins the study. An explanation and justification is provided for the choice of a qualitative approach. The methodology is then explored, beginning with the preparatory phase of the study, where expert interviews and observation were conducted. Then, the choice of group and individual semi-structured interviews is examined and justification given. A discussion of the particular environment of the research site follows. The data collection process is then explained, looking at the target, sampling method as well as the characteristics of respondents. In addition, the ethical precautions taken to protect respondents as they share personal information on a sensitive topic are clarified and reasons for these measures are given. Finally, the strengths and limitations of the study are examined.

3.1. Problem statement

This study sought to explain how black South Africans, in particular women, who experience severe stigma, can talk about ‘living positively’ and mobilise around the very issue which brings so much stigma. In order to understand this it was important to answer three main questions. Firstly, do respondents feel that they are stigmatised? Related to this, the way in which they experience stigma, how they view stigmatisation and whom they experience as stigmatisers are investigated. This would confirm that the PLHAs experienced stigma and provide some descriptive information about it. Secondly, how does stigma affect the formation of identity? The final research question asks whether identity can be used to alleviate the effects of stigma and what factors work in favour of a strong, positive identity? In order to investigate this phenomenon, the theoretical assumption underlying this study is that PLHAs come to grips with social stigma associated with HIV/AIDS through a social identity. The research further postulates that it may be possible to use social identity to resist the
stigma and this is what the researcher set out to discover.

3.2. Approach

Broadly, the research made use of a qualitative research design. This approach was used in order to gain insight into the motivations and perspectives of people; this would not have been possible if a quantitative design were used. The approach also allows the reflections of respondents’ behaviour to be incorporated into the research. In addition, the qualitative design was selected to facilitate the assembling of in-depth information. It was important to explore the respondents’ perceptions of living with HIV. This methodology could search for contradictory information, which could indicate inconsistencies in the respondents’ portrayals of their lived experiences. The nature of this research is exploratory, since it sought to describe and explain the effects of stigma on the social identity, a phenomenon that had largely passed without academic comment in South African sociological research. In this sense, the research sought to discover and explain a trend, rather than gauge the extent of the existence of it.

3.3. Methods

In order to meet the aims of this exploratory study, the research had a number of general information sources. Firstly, the literature around stigma and HIV/AIDS, as well as identity theory and research, was drawn upon. Secondly, in the preparatory phase of the research, expert interviews were conducted and participatory observation of support group meetings took place. Finally, the interviews were conducted both in groups and individually with members of the support group at the clinic. For both group and individual interviews, a semi-structured format was used. This section discusses the methodology in detail.

As part of the preparatory phase of the study, the researcher interviewed four experts working with the potential target population. The purpose of these background interviews was to ensure that the research was correctly approached, bearing the
sensitive nature of the subject in mind. The comments from the expert interviews were incorporated into the planning phase and the research design was adjusted accordingly. The comments addressed, in particular, ethical considerations, in order not to further disadvantage this vulnerable population. The first interview was with a representative of an organisation that provides counsellors to both research sites of Community Aids Response (CARE). The second was with someone from the AIDS Law Project based at the University of the Witwatersrand that provides the law clinic to the main research site. The third interview was with a person from the AIDS Consortium, which is an umbrella organisation for Community AIDS Organisations. Finally, the clinic manager of the HIV clinic was interviewed and extensively consulted throughout the research.

As a result of the expert interviews and in order to understand the process of a support group, the researcher also observed three support group meetings. These took place at an HIV clinic run by a public hospital that was later not selected for the research. The site provided access to support group meetings, which could not take place at the main research site because only infected persons were allowed to attend the support group. The function of the observation was to provide supplementary information on what happened inside support groups. Aspects observed included, how they were run, what topics were discussed and how discussions took place. Access was negotiated to observe the support group with the convenor and counsellor from CARE who conducted the support group.

After the preparatory phase of the research, interviews on a group and individual basis were conducted. Group interviews had three distinct advantages for this study. Firstly, group interviews allowed for a large number of people to be canvassed and their experiences incorporated into the study. Secondly, they allowed for flexibility and for the respondents to speak on the topics they wished to discuss. This was important, given the exploratory nature of the research. Thirdly, the group interview simulated the support group situation and demonstrated how identities formed in the group setting. The use of group interviews was appropriate, since the intention was to capture a little of the culture associated within this community. Some errors were possible due to the presence of the other respondents during the group interviews who often offered advice such as to disclose, or to leave an abusive partner. It was also difficult to give attention to all group members and look for non-verbal cues.
Individual interviews, similarly, were used for their particular advantages. Most importantly, individual interviews allowed for more in-depth exploration of respondents’ experiences without the interruptions to which group interviews are prone. Secondly, because of the stigmatising nature of HIV, some interview respondents might not have participated in group interviews. Thirdly, it allowed for the noting of identity away from the peer pressure of the group, since group interviews tend to encourage normative responses (Alexander and Uys 2002: 303). The combination of the two approaches complemented each other and enriched the findings.

The methods chosen for this study included a preliminary study of expert interviews and participant observation of a support group. This was followed by a combination of in-depth personal interviews and group interviews. More details of the data collection process are given under the heading ‘Collection of Data’. Before that, the environment in which collection took place is explained.

3.4. The Research Site

The site of this research was selected after preliminary meetings with various expert respondents working with HIV organisations, and at the specific clinic itself. The decision was based on information that the clinic was a very busy one with support groups and other support mechanisms, as well as committed volunteers. The assumption was that it is in an environment of such positive energy, that a positive identity could grow. The site was a hive of activity. The HIV clinic was run on Thursdays, with the support group at 9:30 in the morning. The support group consisted of differing numbers of people as many attendees came irregularly, depending on when they came to see the doctor. Consequently, although the group was rather small (about six people) some weeks, at other times 30 people were present.

The HIV clinic had conceptualised, written and began to run a wellness course several years prior to the research. The ‘wellness’ course sought to address wellness as something greater than bodily health, and functioned to teach patients how to live
positively with HIV/AIDS. This course addressed topics such as nutrition and alternative remedies, as well as safe sex and how to avoid stress that can weaken the immune system. It ran on Tuesdays and Saturdays so that those who came to the clinic for medical treatment could also attend the wellness course. On Saturdays, those who worked weekdays could attend the course.

To provide more information to PLHAs and to complement the wellness course, the Wits Law Project ran a law clinic, one Thursday a month. This functioned to ensure that patients’ rights were protected and to provide the patients with legal advice on such issues as discrimination at the workplace and custody battles.

A well-organised volunteer system operated, and a volunteer manager from CARE worked to ensure that there was always somebody to counsel and conduct voluntary counselling and testing (VCT). In general, volunteers conducted pre- and post-test counselling and one of the nurses or the volunteer manager took a sample of blood from the patient’s fingertip to test for HIV. Results of the ‘finger prick’ test were ready in as little as ten minutes. In addition to counselling, volunteers assisted with the running of the clinic, doing filing and other administrative chores, or provided therapeutic treatments to patients. For instance, while the research was being conducted, patients could have a high frequency treatment, which was supposed to relax them and restore a sense of well-being. At other times, there were reflexology, massage therapy and other therapeutic treatments administered by volunteers.

A small public hospital in the greater Johannesburg area hosts the HIV clinic. Bordered by a lower middle class white population and further afield largely Indian, Coloured and Black communities, the hospital serves a diverse population, and the HIV clinic in particular, serves people of strikingly different demographics from the communities around it. The attendees of the clinic are mostly black and female. The people who came to this hospital paid R30 to see a doctor and get medication. In addition, they paid a minimum of R7 for transport to and from the hospital, if they lived close by and took a minibus taxi. These fees constituted a considerable expense for some of those who attended the clinic. While patients could go to facilities available nearer to their homes, they chose to travel further to consult this clinic because of its higher quality of care and geographical separation from stigmatising
community members. Similarly, organisations involved with PLHAs also frequently refer patients to this hospital because of its reputation.

Permission to conduct the study at this location needed to be negotiated at several levels. Firstly, the rules of the University of Johannesburg (at this stage RAU) required that permission for the studying of HIV/AIDS, due to its sensitive nature, be obtained from the university ethics committee. Therefore, a mini-proposal was written stating the specific measures to be taken to protect the respondents from any emotional harm resulting from the study. Secondly, permission was requested and obtained from the manager of the unit that houses the clinic. Furthermore, a letter requesting permission for research was written to the superintendent of the hospital, who agreed to the research request. Finally, the goals and risks associated with the study were explained to all the respondents and permission was requested from them to both conduct and record interviews. Respondents were asked to sign a consent form, stating that they understood the risks and participated voluntarily in the research.

3.5. Collection of Data

The target population for this study consisted of PLHAs attending the HIV clinic. The exact number of people seen by the clinic on any one day, or even over a month is documented by the hospital. However, the number of patients regularly seen by the clinic at the time of the research, amounted to about 1477 persons, in total. This number was obtained from the clinic’s regular patient database (accessed March 2004, four months after research was conducted). However, the patient base may not be fixed as some move around and attend a clinic in a new location, and other patients fall out of the health care system altogether. Additionally, the population grew as new patients were tested and/or grew ill from the virus. The clinic manager had noted a recent increase in the number of HIV positive patients both seen at the clinic, and admitted into the wards. Of the 1477 patients on the database, 70 percent were female. From observation and expert interviews, it seemed that women were the more frequent and more numerous attendees of the clinic. The database noted an age range for patients from 13 to 72. It was from this general population that respondents were drawn.
This research lent itself to a sample of female PLHAs with varying characteristics, and with a sample size large enough so that different combinations of characteristics were covered. In particular, age, length of seropositivity, marital and employment status, were explored to see the effects on social identity. The research made use of purposive sampling. This was the only possible sampling technique available, as the database of regular attendees of the HIV clinic was confidential and was only available for descriptive purposes. It would not have been possible to randomly sample even if the database were available, because the database and often the patient files lacked contact numbers. Potential respondents were chosen from those who had attended the support group that had taken place earlier in the day. The support group ran from 9:30 until 11:00 and the group interviews took place just after the session. From these potential respondents, a multi-lingual research assistant, who was familiar with the regular attendees of the research clinic, helped select the respondents. This further selection process was carried out in order to incorporate respondents with a range of personal characteristics. Such characteristics included marital status (single, married or having a stable partner), age and income generation (employed, unemployed, in an income generating project, or relying on other financial sources). Other characteristics would include family (does he/she have children?), disclosure (has she disclosed her status and to whom?) and the time since diagnosis. Secondly, it was important that selected respondents were emotionally ready to talk about their seropositivity to someone not similarly infected. This was one of the safeguards built into the research design in order to protect potential respondents.

During the interview process, the researcher worked along with a research assistant to collect data. This research assistant, who was also a volunteer for the clinic and regularly attended the support group, also acted as a translator when required. Eight group interviews, each lasting 35 to 45 minutes, resulted in responses from 40 people. These group interviews commenced on Thursday 31 July 2003, and continued, in most cases, on a weekly basis around a table in the counselling room of the clinic until October.

For both the group and individual interviews, questions were neutrally formulated, so as not to bias answers, with follow-up questions to clarify answers. The respondents’ level of English proficiency determined how simply the questions were expressed.
Some words were replaced by synonyms, for instance, ‘stigma’ was commonly replaced by ‘discrimination’ and ‘disclose’ was sometimes replaced by ‘tell somebody’, to enable comprehension. Questions were expressed and re-expressed if the respondent did not understand them, and if these attempts failed, they were translated into the respondent’s home language. In the rare occasion that the question was still not understood, it was abandoned. Unfortunately, due to the language barrier, a number of informal conversations could not be included in the study. A brief description of the group interviews and those who participated in them, follows.

The first group interview was held on 31 July 2003, and consisted of six participants who were all unmarried, and had had children. Three had partners, of whom two were partners and were interviewed as a couple, both being in the group interview. The man in the young couple was still studying and the woman had recently finished her studies. This couple and another woman in the group were in their twenties and had known about their status for a relatively short time (under two years). Two other women among the group of six were in their thirties and single. Both had had children, but one had lost her child to HIV/AIDS. The last participant had discovered her status a week previously after she had been sick. She earned money to support herself through gambling.

The second group interview was held on 7 August 2003 and had six female participants. Five of the women had had children, and one had lost both her two children due to HIV/AIDS. Four of the women were in their thirties and two in their forties. Two of the respondents were married, two single, one had a partner and one had been widowed. The woman who had lost her children, was single. Three of the women generated income through work they did, one had given up her job as she had become too ill.

Five female respondents participated in the next group interview held on 28 August 2003. All the women were between 24 and 34. Three had partners, one woman did not mention her romantic status, and one was married. One of the women was struggling to talk about the virus. Consequently, it was unclear how long she’d had it. The 24-year-old had known about the virus for eight years, but suspected that she had contracted it when she was raped eleven years earlier. She was gang raped at thirteen.
by a group of her friends. The 34-year-old had known that she was positive since she became pregnant, nine years before. Another participant was diagnosed two years earlier when pregnant. The other woman had known her status for eight months, after she had been tested by her GP. Her husband was with her at the clinic that day, waiting for the results of his second test.

The fourth group interview took place on 4 September 2003 and had five female participants. All the women were between 22 and 31 years old. The 22-year-old had known about her infection for a year, but suspected that she had acquired it years before when she was sexually abused as a child at the age of four. She was single at the time of the interview. Another participant had discovered her status the year before when she had gone for VCT as she had intended to fall pregnant. She was still studying and had a partner. A third respondent tested herself with a VCT kit from an organisation for which she volunteered. She had discovered her status four months prior to the interview. She had a partner at the time of the interview. Another woman had discovered her status six years before through her child’s status. She was likely to have been positive for at least fourteen years, as her eldest child was 14 years of age and also positive. She had been widowed and lost her youngest child to the virus. The last participant was diagnosed eight years before when she fell pregnant as a teenager. She had lost her child shortly after birth, but had had another one since, who was positive. She was married at the time of the interview, but was separated soon afterwards.

On 11 September 2003, the fifth group interview took place with four female participants. Of the four women in the group, two had partners, and two were single. One of the single women was in her thirties, and had been diagnosed fifteen years previously through VCT. She had been tested in order to encourage her friend to test who suspected that she was positive. She was single and had one child. The second single person tested positive after being ill, a year before. A third participant had known for less than a year, but had suspected for many years. She was tested when admitted to hospital. She was in her twenties with one child. The fifth respondent in her thirties had known her status for two years having been tested at the antenatal clinic.
The sixth group interview took place on 18 September, again with five respondents. Three of the respondents were in their twenties, two had partners, one was married and one single. The oldest woman, in her forties, was married and had had a child who had passed away due to AIDS. She had been aware of her status for sixteen years. Another woman in her thirties, was single with one child, and she found out when she was pregnant a year before. Two of the twenty-somethings discovered their status through their illness. Both had partners and one had a child. The other had known her status for less than a year and had no children.

On 25 September 2003, the seventh group interview took place. Four people participated; three females and one male. With the exception of one participant, all were in their early thirties. The exception was a 25-year-old female who had been aware of her status for one year through the status of her child, who later died. The two other women in the group had known for one and four years respectively, one had tested through VCT and the other after the suspicious death of her husband. The male of the group was the only one employed and he had discovered his status six months previously due to the status of his partner.

The final group interview was held on 9 October 2003 with five participants, two of whom were men. The ages of the participants varied between late twenties and late forties. The two men were 36, had both lost their jobs due to their failing health. One was married with two children, and one was with a partner and an unofficially adopted son. One had known about his status for eleven years, and the other one for fourteen years. The woman in her late forties had known her status for four years, after being tested at the hospital. She did not mention whether she had a partner at that time or not. A second female respondent in her thirties had known her status for one year, having been tested because of the symptoms she was experiencing. She had a partner and one child. The other woman in the group was in her late twenties, had known her status for 3 years, had a partner and a child. She was formally employed at the time of the interview in a professional capacity and so was less economically disadvantaged.

The in-depth interviews occurred at different times in vacant rooms at the HIV clinic with respondents who were chosen from the support group. Although initially ten interviews were conducted, two were mistakenly taped over, and one was recorded
with the microphone switched off. Unfortunately, because the interviews were done in quick succession, the transcriptions of these interviews were to be done quite some time after the interviews, not allowing them to be done from memory. Interviews lasted from 25 to 45 minutes. The first interviewee was in her thirties and an activist who was previously involved in a lawsuit compelling the government to pay for antiretrovirals. This interview was conducted prior to the group interviews. The rest of the interviews were held after the group interviews. The second interviewee was a male in his thirties, who was diagnosed ‘three or four years’ previously. A long-term non-progressive was the third interviewee, who was in her fifties and a grandmother. A fourth interview was conducted with a woman in her thirties who had known about her status for one year. The fifth interview was with a woman of 28 years who had known her status for five years. A 32-year-old was the sixth interviewee who had known her status for six years. The final interview was with a woman of 46 who had been diagnosed sixteen years previously. She was married with three children.

Over the course of eight group interviews and seven one-to-one in-depth interviews, 47 people participated in this research. Five of these people were men; one was a coloured man, the only non-black person to participate in the study. Most of the respondents were unemployed and lacked economic self-sufficiency; however, a few seemed to live rather well.

3.6. Analysis

The data was analysed by means of inductive thematic organisation, through the ‘scissors and tape’ method. This analysis was done based on the three broad research questions presented earlier. Analysis was done continuously throughout the data-gathering phase and later when transcribing and writing the dissertation. Themes that developed in the group interview discussions were noted and explored under the research questions. Linkages between the themes of the group interviews and between the accounts of the respondents were drawn. On this basis, quotations which captured the essence of the experiences of a number of respondents, were drawn out of transcriptions. The analysis made use of ‘grounded theory’ methodology, and in so doing to develop further the theory of HIV/AIDS stigma in the South African context.
In addition, the data was tested against results from other methods of data collection, observation, interviews and group interviews and examined for effects caused by the researcher.

3.7. Ethical Considerations

HIV/AIDS research is fraught with ethical issues due to the sensitivity of the subject. Measures were taken to address these issues. Firstly, the research assistant selected respondents who were able and prepared to talk about the virus. Secondly, potential respondents were clearly informed about the research so that they could give informed consent. As a requirement by the hospital, a form was used to confirm that they understood the risks of the research. Thirdly, confidentiality was offered through the use of pseudonyms and disguised personal details. Names and pseudonyms were later discarded in order to provide maximum protection for respondents. The name of the hospital and other identifying information were also left unmentioned. Fourthly, it was explained that should the potential respondent wish not to divulge information arising from a question, or wish for it not to appear in the research, that decision would be respected.

Considering the highly personal and emotional nature of the subject, further safeguards were put in place. Firstly, the volunteers at the clinic were approached both to act as key informants and provide support to women who participated in the study. Secondly, the risks of participating in the study were explained and councillors at the hospital were approached to do counselling after the interview, if the respondent chose it. Thirdly, a respondent had the option of discontinuing their participation at any point, should they wish to do so. Fourthly, an earnest effort was made to distribute the findings of this research. The preliminary findings of the research were presented to the participants and volunteers at the hospital, as well as the hospital psychologist who conducted the support group. The research will also be made available to those consulted about the study including CARE, TAC and the clinic staff. Other organisations later identified as being in a position to use the information for the improvement of PLHAs’ lives, will also be given copies of the research. Lastly, as a token to show appreciation and to empower the respondents, a half-day life skills
3.8. Limitations of this Study

Some bias may have been introduced as this study is limited by its methodology. Some respondents, for example, may have offered modified personal histories. A longitudinal study may have reduced this effect, but would have been beyond the scope of a mini-dissertation. Further difficulties could have arisen from respondents’ deaths and loss of contact in a longitudinal study. Secondly, no direct link can be proved from the methodology used in this study, between the culture found in this particular clinic, to the broader HIV culture. This connection could be established through content analysis of the language and specific words used in these interviews, and comparing it to that of the broader South African HIV positive community. Thirdly, because all respondents were drawn from a support group, it is possible that other potential respondents would have felt differently about the HIV/AIDS stigma. It is possible that other PLHAs experience greater support from family and friends or less stigma and therefore do not need to attend a support group. There is anecdotal evidence that some who avoid clinics do so because stigma is so strong as to keep them from leaving their homes, but there is no direct corroboration that this is the case.

A longitudinal study is suggested to understand how the different stages identified in the next chapter, develop. It would give a better idea of what impedes and what promotes the formation of a positive resistance identity, and how people’s views on this would change through the length of the infection. It is also recommended that people who do not attend support groups be included in future studies to establish if their support at home or other contexts can replace or even be more effective than support from a support group. It would also provide some evidence as to why people do not attend support groups. Is it due to possible stigma that PLHAs fear support groups, as was expressed by respondents in this research?
3.9. Conclusion

This chapter demonstrated how the perceptions and experiences of those living with HIV/AIDS were explored. This process began by expert interviews and support group observation to gain a broad understanding of the population under study. Then, of the population attending the HIV clinic, a sample was drawn on the basis of purposive sampling from the attendees of the support group. These respondents participated either in group or in individual interviews. These interviews were then transcribed and analysed. The methodology outlined in this chapter led to the findings presented in the next chapter, entitled ‘Towards a Positive Identity’.
CHAPTER FOUR
TOWARDS A POSITIVE IDENTITY

This chapter presents and discusses the findings of the research drawn in in-depth and group interviews with 42 women and five men attending a support group. It examines how the respondents negotiated the risky social terrain of seropositivity whilst endeavouring to make sure that their disclosure meets a positive response. There were a number of phases that most of the respondents underwent, and these are discussed in this chapter accordingly. The first was suspecting that they might be positive, and going for a test. The second phase involved diagnosis along with support from the HIV clinic. Simultaneously, outside of the HIV clinic, respondents faced some tough decisions around disclosure, and the reasons for disclosing and for nondisclosure were explored. Thirdly, stigma was experienced by most respondents and the nature and sources of this stigma are explained. Next, in reaction to this stigma and as a result of support gained at the HIV clinic, the respondents attempted normalising their stigmatised identities using various narratives and actions. Finally, a range of positive spin-offs from disclosure was examined. These phases are discussed in order to answer research questions relating to how stigma was experienced, how it affected respondents’ social identities and how stigma could potentially be resisted.

4.1. Suspecting HIV Infection

The journey towards disclosure often starts before diagnosis at the point where a person begins to suspect that he/she may be HIV positive. Fear of a positive result prevented many PLHAs from being tested early. This section explores why the PLHAs interviewed initially suspected that they might be HIV positive. It also shows how respondents dreaded being HIV positive so much that they waited, in some cases years, before being tested.

Respondents first suspected their status because of their symptoms. Tuberculosis particularly raised suspicions because of its association with HIV. Skin and stomach problems also led to qualms. Others guessed their possible positive status because of the sexual behaviour or symptoms of past or present sexual partners. Respondents
frequently remained in a state of uncertainty about their status for a lengthy time, the longest being four years. They looked back on this time of uncertainty as unsettling. It is not possible to plan in this uncertain state, and they lived in dread without information about HIV symptoms and treatments. A respondent explained how she ignored symptoms for three years before being tested.

I was diagnosed last year, but [before] then, I had symptoms from [19]99. I was afraid to come for a test. So last year after I give birth they told me I am HIV positive. Then my son, he is also HIV [positive] (Group interview 6).

Likewise, this woman suspected that she might be HIV positive and was tested but did not go to get the results:

I think [I’ve been positive] for a long time, even now I can’t count years. But I was just afraid ‘cos I used to go to a clinic [to] get the blood test. I would never go for the results, and I would go to another clinic and take the test and never go for the results. For a couple of years, until this year I knew, because I was admitted in this same hospital they told me this year that I’m HIV positive (Interview 5).

The interview with the clinic manager confirmed that this was a relatively common occurrence.

In general, PLHAs suspected that they might be positive for varying lengths of time before they went to be tested. For most respondents, diagnosis was avoided. Decisions that PLHAs often made around testing reflected both the desire not to accept the possibility that they could be positive and a reluctance to remove the doubt. This avoidance of getting tested is potentially dangerous, as it is likely to shorten one’s lifespan as correct treatment is not initiated early.

4.2. Diagnosis

Doubt about the HIV/AIDS status could not be indefinitely sustained, as the respondents were eventually tested under a number of circumstances. One of the cruellest consequences of avoiding acknowledgement of their status was infecting their children. Babies who are weak or sick at birth, may be tested for HIV. Once the status
of the baby is known, the parents are offered a test. A few respondents were tested as a result of their children’s status. Similarly, the death or status of a partner motivated a few respondents to be tested. Occasionally women are tested whilst pregnant, and some (27 percent) of the women in the sample found out in this way. Tests resulting from suspicious illnesses, revealed the status of several respondents (37 percent). Others were tested via voluntary counselling and testing (VCT) (30 percent). VCT obscures the reasons which compelled people to have a test. These could be because of illness, the death of a partner or other reasons.

Many respondents might have chosen to come to this particular hospital to avoid the communities close to them finding out their status. Others may have visited this particular clinic due to the esteem in which it is held by organisations that work with HIV/AIDS. However, diagnosis at a public hospital may not be preferable, compounding the perceived stigma and uncertainty experienced when the PLHA believes he/she may be positive. This section explains stigmatising experiences of respondents at the hospital. Stigma from those in healthcare settings acts as an introduction to broader societal stigma. A lack of knowledge of the virus and its progression exacerbates feelings of hopelessness.

An HIV positive diagnosis can be personally shattering. It can mean that one’s partner has been unfaithful, or that one has engaged in risky sexual behaviour. It impacts on the lives of one’s children, as they may be orphaned; or children one plans to have, as there is a risk of HIV infection. Diagnosis may happen simultaneously with a child or partner’s diagnosis or death. It also acts as a reminder of one’s own mortality and the perception of how long one might live. In addition, it challenges cherished life goals and perceptions. Respondents described all these reactions and most felt that life would not go on with the HIV. Many went home to wait to die and contemplated suicide. This male respondent spoke about the stress his diagnosis caused and his initial desire to kill himself:

And that was, like, stressing me, I couldn’t cope with the situation . . . all the stress I had before [when I was first diagnosed] because I even wanted to commit suicide (Group interview 8).

This depression and hopelessness were often due to the expectation of a highly
shortened lifespan. Expecting to die soon, a number of respondents put their things in order for their death.

The manner of diagnosis may compound the shock of seropositivity. The respondents had little chance with their limited means of going to a private hospital. As a public hospital, the site of the HIV clinic where the study was conducted, suffered from the over-crowding and shortage of staff, factors which are similarly experienced within many South African public hospitals. Overworked doctors were often tasked with telling patients about their status. Their behaviour in doing so attracted much anger from the patients. Patients felt that doctors’ words and actions were stigmatising when being diagnosed and treated. In addition, the clinic manager explained that treatment at other hospitals of some patients had been absent, leaving patients to find this hospital which eventually provided care. Some of her patients came from areas all around Gauteng and others from other provinces. This further added to the load at the hospital, but also indicated that care may be better at this hospital.

Doctors attracted anger due to a number of reasons. They were known, for instance to tell people that they had only a short time to live when, in fact, many survived for years. One woman related her experience and reaction to being told that she would die soon:

These doctors, they are so confused. There was a time I was so furious, one of the doctors told me that I was about to die. And you know, they are not God [they don’t know everything] (Group interview 1).

In a few cases, doctors had treated patients without explaining the treatment to them, and diagnosed a patient without explaining the consequences. A female respondent described her initial reaction:

It was not shocking or anything, he just told me I was positive. Just like that, he was in a hurry to go to the lunch. It doesn’t mean you are going to die, he said, ‘go to the [HIV clinic]’ (Group interview 1).

In addition, treatments given by doctors did not always solve the problem. The treatment of patients at the hands of various doctors, both at diagnosis and later when
receiving treatment, reflected negatively on doctors in general. Ineffective treatments had created a distrust of doctors coupled with desperation for treatment. This need for effective care was expressed in asking advice in the group interviews, from fellow participants and the researcher.

Particular experiences at diagnosis of PLHAs justified their long avoidance of discovering their status. The respondents in this study were, for the most part, socially and economically vulnerable. The infection itself compounded their marginality. Understaffed public hospitals combined with negative perceptions of HIV/AIDS from doctors can make this vulnerability fatal. The perceived stigma from medical practitioners can cause PLHAs to avoid medical treatment and to shun opportunities for gaining further knowledge of the virus. However, efforts have been made within the hospital to ensure that the attitude of medical offices during and after diagnosis was supportive rather than stigmatising. The next section deals with the spectrum of support needed by the respondents and the mechanisms at the hospital to meet that need.

4.3. Support Provided by the HIV Clinic

Despite the overcrowding and staff shortages, the HIV clinic boasted several support mechanisms, much of which is volunteer run. HIV clinics can provide support for a PLHA in many ways. The three main types of support found at this clinic were informational, emotional and normative. The delivery mechanism was primarily the support group, assisted by other initiatives at the clinic as well. It is shown that while there are many overall benefits of support systems, there are risks to participation such as a diminished sense of anonymity.

The support group that took place on a weekly basis at the HIV clinic, was the chief support mechanism discussed in this section. However, it was itself buttressed with other support mechanisms. In particular, the wellness course provided information on topics such as nutrition, stress avoidance and alternative remedies. Those who had been through the wiliness course were likely to be substantially more informed, were
more able to correctly judge others’ advice and cope with the illness better. A monthly visit by members of a legal project further made legal advice available to PLHAs. This legal assistance gave certain respondents a sense of empowerment as they learned their rights. Both the wellness course and legal project functioned to provide information which feed into the support group. Informal support was also made possible by a room at the clinic that had been attractively furnished with donated money, where those attending the clinic could visit to socialise, relax and watch television, as well as have a meal or a drink. Volunteer counsellors were also available for discussing problems, although the counsellors were chiefly involved in pre- and post-test counselling. In addition, other complementary therapies were available for patients from time to time. These various structures could be grouped into three main types of support; informational, emotional and normative. All three are important for the PLHA who wishes to live longer.

**Informational support** was in the form of advice on how to live in order to increase the period of survival. It was provided by the wellness course, and also within the support group in the form of sharing personal experiences of what worked. This type of support included diet-related information, alternative treatments for symptoms and/or ways to boost the immune system, safe sex practices, legal assistance, shelter for the night or other services which could, for the PLHA, mean living another day. As a respondent commented:

You don’t want to be under pressure always because you don’t have money, you don’t have something, like if you come to a support group, you’ll have some ideas, some help to survive (Group interview 5).

**Emotional support** was a further mode of help for the PLHA. This type of support from other PLHAs was helpful for respondents because, being in the same position, those who are also seropositive often understand the appropriate support needed. This is contrary to the home lives of PLHAs, where families and friends of PLHAs may, unknowingly, act in a stigmatising way. One woman explained her experiences. ‘It helps because at home you can’t talk to anyone, even those that understand [that you are HIV positive]’ (Group interview 3). It can also be a relief to PLHAs to know that others are having similar experiences. Another woman elaborated:
I was not handling it well, but when you come here and hear someone telling her story you realise that yours is better than hers. It’s helped me (Group interview 2).

Normative support taught PLHAS that they were not ‘strange’ or ‘different’ for having the virus. This type of support emphasised ‘positive living’, which entails living with hope in a community in which people deny being infected and affected by HIV/AIDS. Normative support provides space for PLHAs to question and resist the stigma accompanied with HIV/AIDS and can result in an in-group identity. A respondent expressed a common theme of HIV sufferers as caring people:

We need to love each other, and help each other. To tell people that if you are HIV positive, it is not the end of the world. Because most of the people with HIV are so in love, they love everybody (Group interview 5).

This support functions to show new PLHAs that they are valuable despite the HIV infection.

While there are many benefits that the clinic offers for PLHAs through the varied support mechanisms, it is important to note that the HIV clinic is not free from risk. A few people reported that support groups attracted voyeurs. A respondent noted how PLHAs were known to tell another’s status after attending support groups:

They come out of the support group and tell ‘Oo, so-and-so is also positive’. I think that is what makes it difficult for people to go to support groups and also for check-ups, like, at the clinics (Interview 5).

Another woman related that somebody from her community had told others about her status after finding out at the support group at the hospital. However, the fact that this clinic is located a distance away from where the majority of its attendees live, means that there is less chance of detection than at other clinics that are closer to the respondents’ homes. One woman explained:

Like here at [this hospital], most of the people come from Soweto and other places, so they run away from their communities because [if they attended a clinic in Soweto] everyone will know that they are positive. (Group interview 5).
There seems to be a little more chance to conceal attendance of this clinic, but the presence of others will always carry risks.

The support mechanisms attached to this clinic are safer than the support, largely in the form of support groups, which are close to spying neighbours. However, even the distance that separates them from the community, cannot promise anonymity to those who attend the support group.

PLHAs attempt to obtain a little more secrecy by paying more for travel. In the relative ‘security’ of this HIV clinic, newly diagnosed PLHAs or the person who has little information about HIV/AIDS can learn about the HIVirus. The PLHAs’ desire for secrecy indicates an awareness and fear of stigma from the broader society. In the following section, the PLHAs face their fears of disclosure as they weigh the benefits and costs of disclosure.

4.4. Disclosure

Outside the protected environment of the HIV clinic, respondents faced the challenge of disclosure. There were a number of different motivations for disclosure. A few disclosed because they were worried that they would die soon and wished to sort out potential practical difficulties. A sense of moral obligation to warn others about the consequences of unprotected sex was also a common motivator. Commonly, people disclosed to obtain support. PLHAs were encouraged by counsellors to disclose to avoid getting sicker, and a number did so. There is evidence of a time lag between diagnosis and disclosure for most interviewees. Seemingly, it is necessary to overcome internal emotional conflict to disclose.

Disclosure, particularly to intimate family members and partners who may be HIV negative, is difficult. The need to disclose is weighed against expected stigma that accompanies HIV/AIDS. It is difficult, if not impossible, to hide the presence of the HIV virus for the entire duration of infection. Moreover, because of the need for support and often the presence of stigma, an HIV diagnosis, ultimately, becomes a social issue. Most people understand the importance of disclosing, and are encouraged to disclose to significant others through the counselling process and support group. In disclosing
seropositivity, the PLHA is acknowledging his or her own spoiled identity to others and may sacrifice some privacy concerning her/his sexual activities. At this point, despite precautions, the PLHA is unsure about the way in which significant other(s) will react. Risk is minimised through investigating how significant others react to other PLHAs, and by demonstrating that the PLHA is a valuable person using one of the identity-fixing strategies of morality, family or income generation.

A number of respondents disclosed in preparation for their death. The HIV positive diagnosis, had caused frenzied panic and lead to them getting everything in order for their perceived imminent death, or incapacitating illness. Of particular concern to the PLHAs was that someone would be available and prepared to look after his or her children. This woman came to the realisation that no one would know about her status if she grew sick:

I realised that if I don’t tell anyone, what if I become very sick, there will be no one who will know. I have to tell one [person] (Group interview 2).

Fear of getting sick or dying was frequently the reason for immediate disclosure after diagnosis. Other motivations did not have this sense of urgency.

Many respondents felt that it was their moral obligation to tell people about their status. This moral obligation to disclose serostatus was felt in the desire to protect, particularly, younger people. A man explained why he had disclosed:

Ya, I disclosed by the hospice, schools and church, I disclosed and they know that I’m infected with the virus. I think before they sleep around as young adults they must be married first and they must go test first, because this is a very dangerous illness (Group interview 8).

Those who were warned could be strangers, friends or family. Various respondents were concerned about the risky behaviour of friends or family. This female respondent was concerned that her cousins might get the virus:

I disclosed because they must study, they are going with their boyfriends and not protecting themselves, they must protect
themselves (Interview 1).

PLHAs primarily wanted understanding from those to whom they disclosed. Practically, support could be consideration when they had to visit the doctor, or the inability to participate in the home or workplace due to ill health. One man in the study disclosed to his employer to obtain support, but most respondents who worked had not disclosed, fearing discrimination, ‘So I approached the management, with the intention that, oh, I might get the support from them’ (Group interview 8).

However, many of the women had not disclosed to their partners, as they feared stigma and abandonment, and felt no sense of moral obligation. Non-disclosure was despite the messages in the wellness course and support group that encouraged disclosure to partners. A woman told of her experience of mutual non-disclosure in a sexual relationship:

He knew that he was HIV positive and he didn’t tell me. So I was always stressing this thing of using a condom. Even me, I knew I was positive and I didn’t tell him (Group interview 3).

Another form of practical understanding of living with the virus needed by PLHAs was concerning the factors that could determine, to some extent, how long a PLHA can live with HIV/AIDS. These factors include condom usage and stress avoidance. Although these two reasons are critical for the continued survival of respondents, few had disclosed for these reasons. This is because admitting that you are HIV positive, particularly to a sexual partner, can jeopardise the relationship or encourage abuse. Despite the risks, those who had lived with HIV/AIDS for longer encouraged others to disclose so as to protect themselves. A female respondent, who had known her status for two years, encouraged others in the group interview to disclose to their partners:

If you tell your boyfriend and they don’t support you, leave him, leave and go

3 Unprotected sex between two infected persons is dangerous because it can potentially expose the partner to different strains of the virus and other STIs. Some respondents colloquially referred to this phenomenon as ‘doubling up’.
somewhere else. Because you are fighting for your life. This is your life (Group interview 6).

Most respondents waited before disclosing as many found it hard to talk about the virus initially. This was the experience of one woman:

I disclosed only to my family and a few friends. It is not so hard to talk about myself now, but I think time tells. There was a time when I couldn’t talk to anybody (Group interview 1).

Most often, the PLHAs had disclosed to a family member or sexual partner. However, four respondents (9 percent) had not disclosed to anyone outside the support group and group interview situation. It was clear that one woman could hardly talk about it in the group interview because of the emotions it evoked, others planned to disclose once they had themselves accepted their status.

Disclosure, although encouraged by the support group context, was not always practiced. It was difficult, particularly when the PLHA herself was not fully aware of all the consequences of an HIV positive diagnosis. It seems that most people needed some time to get used to the diagnosis before they felt that they could disclose. In order for disclosure to take place, the motivation to disclose had to be stronger than the fear of the consequences. Accordingly, those who had disclosed immediately out of fear for their immanent death might be in a better position than those who vacillate, doubt, and continue to hide their secret. Others had disclosed out of a sense of moral duty, though the duty was often to encourage others to protect themselves, and did not always extend to protecting sexual partners. There was a general desire to obtain some support from those to whom PLHAs disclosed. This support could be emotional, but practical support was also important. Both these types of support could lead to a longer life for the PLHA. However, in particular cases, secrecy may have been the best solution. Evidence for the benefits of secrecy can be seen from the losses and abuse suffered by some of the women. In the next section, these negative consequences of disclosure are explored.
4.5. Stigmatising Consequences of Disclosure or Symptoms

Stigmatising reactions might follow disclosure, or they might result from suspicions of others. Stigma was experienced in three contexts of PLHAs’ lives. These are the community, the family (including partners), and in money-related matters. There is a difference between the stigma experienced from the community and that from more intimate relationships. From the community, voyeurism, gossip and taunting were encountered. At home, PLHAs were subjected to neglect and fighting. Money also served to trigger stigma in the home and community, as family and communities suspected that PLHAs were being paid for their HIV status.

4.5.1. Stigma from the community

Stigma from the community was most commonly recognised as ‘stigma’ or ‘discrimination’. Other women from the community were often responsible for stigma. It arose from growing community suspicion about a particular person’s status, and it took the form of voyeurism, gossip and taunting. Respondents postulated that it stemmed from boredom and acted as a tactic of diversion for others with HIV, so that they could avoid personal stigma. Finally, stigma was not constant and decreased as symptoms did, so the PLHAs were occasionally granted a reprieve.

Women in the study commonly identified other women as their stigmatisers. This may be due to the high number of women in the research. Men, for instance, may possibly experience stigma from other men. A possible reason that women perpetuated stigma as identified by a female respondent, was a lack of entertainment. In the communities that many of the women came from, there was high unemployment, especially amongst women. The unemployment levels and boredom left a lot of opportunity for gossip. One woman observed how gossip originated from unemployment: ‘Now they are not working, you find that they are standing at the gate, looking for the people and gossiping’ (Group interview 2). Seemingly, the same boredom drove PLHAs to spend time with potential stigmatisers. This sometimes resulted in disclosure which then served as a basis for stigma.

Members of the communities began to suspect and talk about HIV infection when they
noticed conditions such as weight loss (or thinner people in general), tuberculosis, skin rashes and baldness or hair loss. One respondent reflected on the manner in which people deduced HIV status on the basis of physical stereotypes associated with the virus:

If you lose weight, they look at you, they can judge you, they say that you’ve got AIDS, even if you didn’t tell them. If you lose weight you’ve got AIDS (Group interview 3).

In addition to the gossip experienced by PLHAs, taunting was known to occur. A particular community member frequently harassed one of the female interviewees:

There’s a lot [of discrimination]. There is this woman that always calls me, tells me that I’ve got AIDS and I’m killing the community. Calling me all these names. Like, whenever she sees me, whenever she gets drunk, she knows where to go. She’s the only one who gives me a problem (Group interview 3).

Those who get sick and are confined to bed, are often suspected of having HIV/AIDS. Community members may even visit the invalid to ascertain her condition in order to tell the rest of the community. This respondent tells how she was stigmatised by a community member:

I was very sick in 2001. They would like to come to my room and say ‘how are you today?’ I say, ‘I’m fine.’ When they are coming outside, with their other friends they say, ‘we must come and look at her. She’s got Inculazi’ (Interview 3).

Respondents felt that the stigma, which PLHAs experienced, was intense and disturbing enough to keep PLHAs avoiding the community. Attempting to evade stigma from the community may result in a lack of medical care and an earlier death. As one woman explained:

You know why many people die; it’s because of those people [in the community]. Because when they hear you have this virus, ei, the way they will treat you. That’s why many people are dying, because the person with this virus, she will be or he will be afraid to go outside to

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4 Inculazi is the Zulu word for AIDS
the clinic to go [any]where. The other people they are afraid to walk in the street until they die (Group interview 6).

Stigma from the community is not constant, but varies in relation to physical symptoms. In fact, if somebody did not die soon after the symptoms were noticed, the initial supposition that they are HIV positive may be questioned. This doubt could lead to a decrease in stigma, as community members were no longer certain about whether the PLHA had HIV or not. This woman knew that she could hide her status behind her healthy weight:

When you lose the weight you are afraid that everybody’s going to see, but when you start gaining, like me, I’m gaining, even the one who said ‘this one has got this5 [HIV]’, now she’s confused, she doesn’t understand (Group interview 6).

Stigma from the community was intense, but was known to decrease or disappear altogether as symptoms did, and the community could be avoided to a certain extent. Community members were less stigmatising when there was little evidence of HIV, and in this case, turned their attention to someone else. Although stigma from the community can be invasive, it was possible, in some cases to limit contact with the stigmatising community, and thus evade enacted stigma. This, however, may result in a lack of medical treatment. In addition, the community is hard to avoid when PLHAs become bored and are in need for social contact.

4.5.2. Stigma on the home front

Although stigmatisation from the community is difficult, it can, at least temporarily, be avoided. This is not the case with stigmatisation by the family. Stigma from the family and sexual partners can be deeply hurtful and pre-eminently stressful. Thus these closer relationships were idealised by respondents. Pre-existing family problems may have been the reason for infection in the first place. Partners, in particular, were identified as causing stress by bringing up HIV status in fights.

Particular problems at home originated long before the HIV infection, but may have

5 HIV/AIDS was frequently referred to as ‘this’ or ‘this thing’ by respondents
had a role to play in the reason why the person was infected. In this woman’s case, the family problems led to infection:

    Even my mother, why did she leave me when I was 3 months old?
    But if ever there was a parent to just dump their child like that
    (Group interview 5).

Subsequent to the desertion by her mother, this respondent was abused by a friend of the family and ran away to become a street child, where she was repeatedly raped. With male partners, unequal gender relations can lead to rape by a partner, and ‘licence’ for male promiscuity can lead to HIV infection. The manner in which communication about status was absent between partners, could also indicate problems in the relationship, and lead to infection.

Subsequent to infection, most respondents emphasised their solid family relationships and seemed to receive support from their families and partners. Two women related their experiences of family support:

    I told my sister and her husband. I said ‘they told me that I’m positive’ and my brother-in-law said, ‘don’t worry, everybody has got this thing, everybody’s got this disease’. He said; ‘Don’t put it on your mind because you can’t live longer if you put it on your mind’
    (Group interview 3).

    My family is important me, so if they can accept me, I don’t mind what everybody else thinks (Group interview 1).

Partners were known to cause stress, particularly male partners. It is difficult to separate HIV stigma from normal relationship dynamics and unequal gender power relations in intimate sexual relationships. Many women reported arguments about their seropositivity. This woman was candid about the abuse she was suffering in her relationship:

    When we are fighting he says that ‘you are HIV positive and you are going to die’, but when we are not fighting, it’s fine, he says, ‘no, I love you’ and all these things (Group interview 3).

In addition, abandonment by partners was a realistic fear among female respondents. Her partner abandoned this respondent:
The father of my baby, when I told him that I was positive, he ran away, you know. He said, ‘hey, I don’t want to die with you, stay there and die alone’ (Group interview 5).

Two respondents, who were interviewed twice, had used tactics of misdirection to avoid speaking about negative aspects of their home lives. One female respondent had spoken very highly of her relationship with her grandmother. She was unable to live with her grandmother, however, and those at home were mistreating her. A male respondent shared what was happening:

She feels a little bit better while she’s getting her treatment from the hospital. At home [her family] neglect her, they are always fighting [with] her (Group interview 8).

The stress resulting from abuse and neglect taxed this PLHA’s immune system, contributing to her death a few weeks later. Another woman spoke at length about how her husband had courted her, despite the fact that she was HIV positive and of a different tribe. She underplayed the difficulties she was experiencing with her in-laws. Later, her husband took their child and they were separated.

In addition, it seems that PLHAs may expect to be stigmatised to a certain extent at home. Respondents mentioned how they or other PLHAs washed the dishes after they have used them or expected to be handled with gloves. This interviewee expected to be stigmatised from her aunts, but was not:

I think I was lucky, because, especially at home, my aunts they know, but they accept me. Even if I drink something, I want to wash the glass . . . and they say no, you are still the same person as we know. They just bring me this water and I drink it, but they don’t reject me (Interview 4).

Few respondents admitted to engaging in self-stigmatising behaviours, others only mentioned them in other PLHAs.

HIV stigma in intimate relationships may compound already existing family or relationship problems. As such, it may not be recognised as HIV stigma, because the problems were present prior to the HIV infection. In addition, it seems as though some
PLHAs expected differential treatment because of their HIV status. The emotional pain and identity needs of PLHAs caused them to avoid talking about stigma experienced at the hands of family and partners. Stigma from those at home could be very stressful and result in a loss of economic and other resources for the PLHA.

### 4.5.3. Money as a stigma-trigger

A crosscutting issue appeared in both distant and intimate relationships. This was money. Inaccurate knowledge concerning the financial benefits of public disclosure of seropositivity can increase levels of stigma.

PLHAs are often suspected of coming out openly about their status due to the financial and other rewards which may come with having HIV, such as attending conferences and educating people about HIV/AIDS (although this is often unpaid work and the suspicion is therefore unwarranted). This respondent was accused of lying to school children because they thought she was being paid:

> I was like doing a presentation and sometimes kids will just look at me. ‘You know what, we know that the headmaster paid you to come tell us that, you don’t look anything like a person who is HIV positive’ (Group interview 3).

The one financial benefit to being HIV positive is a disability grant. A disability grant is available for PLHAs as long as they remain too sick to work. This grant is up to R750 a month. In families with very low incomes, this money can be a crucial source of income, but also a source of conflict. Even small amounts of money can amplify disagreements when there is little to live on. A respondent mentioned how the loss of a house due to a shortage of money, caused arguments within the family of another respondent:

> I think that’s where the fight originated. I don’t know how these people are about money, really. I would conclude by saying that money is the root of devil. Really, where there is money there is devilish happenings (Group interview 8).

For a small number of the respondents, the HIV clinic itself was the only temporary escape from stigma. Neither the broader community nor the family provided an escape.
Desperate financial situations worsened stigma in both the home and community. In the next section, attempts to lessen stigma and challenge stigmatising stereotypes are explored.

4.6. Identity Fixes

Identity fixes represent one of two tactics used to lessen the impact of stigma. The second is the adoption of a positive identity. These approaches, although separated for analytic purposes, occur simultaneously, each fed by support groups and other support. A key difference between them is that the positive resistance identity requires disclosure, while identity fixes can be adopted in preparation for disclosure. Attempts at normalisation, as evidenced by identity fixes, also may not include a recognition that stigma based on sexual behaviour is hypocritical, the positive identity goes further in condemning ideologies which lead to stigma of those with HIV/AIDS. This section deals specifically with the identity fixes and positive identity is discussed after disclosure and its impacts are explored.

Respondents showed an awareness that their social identities were to some extent stigmatised by their attempts to present themselves as valuable, despite the HIV infection. These attempts to normalise the stigmatised identity are termed ‘identity fixes’. These are the strategic uses of morality, income generation or a family identity, which each demonstrate the value and/or virtue of the PLHA. These strategies attempt to present the PLHA as normal and valuable, like anyone else. A true ‘normal’ is someone who is not stigmatised. Attempts to ‘normalise’ the identity are attempts to appear normal using methods that the true normal does not need to use. For instance, one who is not considered immoral because of their HIV status does not feel the need to emphasise and prove that he/she is moral.

The symbolic blow which diagnosis into a stigmatised identity dealt to a person’s sense of self left the PLHA with little defence. Those who have experienced the support mechanisms of the HIV clinic or other support groups may be in a better position to defend themselves. These defences demonstrate a practical offshoot from the ‘normative support’ function of the support group. There were three principle
defences used by respondents. These three normalisation tactics represent the very little social capital that is left to PLHAs. Normalisation refers to making the stigmatised identity seem less so, and more ‘normal’. The first was to turn the stigma related to morality on its head to demonstrate that the person is good, pure and loving despite being HIV positive. The second was to use the family as a defence against stigma. This tactic emphasised close family relationships with the goal of demonstrating their value. The third and final tactic that was commonly practiced was to use income generation or work identities to prove their value to society. PLHAs practiced and acted out these narratives before diagnosis to minimise potential stigma, and after diagnosis to demonstrate positive characteristics.

*Morality* was one prominent discourse adopted by the women attending the HIV clinic, which functioned to challenge the association of HIV with immoral sexual values. Many respondents spoke about God in the interview, often aligning themselves with God and/or their church. Although HIV was presented as a form of personal, spiritual and emotional redemption, on society it was conceived as a curse. This contradiction was because God was punishing the society which commonly practiced sex outside of marriage, by sending HIV/AIDS. The virus itself bears the evidence of misconduct and seems to provide the crucial impetus needed to change behaviour; it therefore serves as a warning that led to redemption.

The theme of HIV/AIDS acting as a form of redemption was quite common. Many believed that HIV/AIDS made them realise the error of their ways, or gave them reason to reassess their lives. Commonly, HIV was presented as a test of faith. A male respondent explained his viewpoint:

> I say this thing it’s on me, thanks God, I’ll live with it, if you can give me some courage to live positively, get all the necessary things that will just keep me coping with this life, I will fight up till ends, then I will be alright (Group interview 8).

This ‘redemption’ was on a spiritual plane, but also in a personal way. Various respondents felt that HIV had made them more intensely aware of the value of life. One woman clarified how HIV had brought her life into focus:

> And it has changed us. You know I’m so happy, my life is so
focussed. I know what I’m doing and I get new hopes with everything that I’m doing (Group interview 1).

Redemption had emotional expressions, as some felt that HIV had given them insight into people, and made them more caring in general. One woman clarified how HIV had made her more emotionally responsive:

Like to help that person, because every time I see that person they wake up a little better. At the end of the day I say, ‘God, I’ve done something, I’ve done something’ (Group interview 5).

Others felt that they were not in need of repentance and denied fault in the first place. Some respondents did this by presenting their HIV positive status as being the result of rape (several of the women interviewed had been raped) and/or due to activities of their husbands or previous partners.

At an early stage, like, when I was very young I was abused, and probably I got HIV through that . . . So my mother doesn’t have the right to shout at me, because I was so small and I couldn’t do anything, I couldn’t defend myself (Group interview 4).

In general, people sought to appear blameless, whether it was in their infection or in their behaviour afterwards. This emphasises the symbolic power represented by moral stigma.

Family relationships were also used to demonstrate the PLHA’s value with HIV/AIDS. Family formed a big part of the respondents’ lives and identities with HIV. Respondents commonly presented the family as a place of relative safety from the stigma of the community. Families of origin and procreation were both presented in this way. Respondents demonstrated the pivotal role of motherhood. The significance of motherhood was demonstrated both in terms of the support that they received from a mother (sometimes other members of the family), and how the role of a mother was so important to them. This woman explained how only her family and the support she got from them made her not really care about other people’s stigmatising words or actions:

I don’t have any problem, I don’t mind, like, somebody knowing about my status. My family is important to me, so if they can accept
Moreover, children formed a core reason for the PLHAs to attempt to live longer, and were often a deciding factor in terms of whether or not to disclose. For instance, a child may experience social difficulties because of public disclosure. The milestones in their children’s lives, such as finishing school, getting married, having children, became objectives for which to live. This mother explained:

My worry is my son and my daughter. He is in standard 9 this year; my daughter is in standard 7, I’m worried for them. I pray God everyday for my child, ‘maybe they can pass matric, then You can do what you want to with me’ (Group interview 4).

In response to an HIV positive diagnosis, PLHAs may increasingly rely on family relationships. The family is also a place where the identity can be reformed. Intimate relationships are idealised in this context, and conflict in the family was understated or ignored in the interviews.

Income generation and work, even if voluntary, also formed social capital to ‘fix’ the social identity. Of the 47 people who were interviewed for this study, ten were employed, while a further four had an income from less formal work (such as an income generation project, or through a micro business). For the few people who were fortunate enough to have jobs, their employment formed a great source of pride and comfort. While boredom was a problem for several of the PLHAs, work was a source of identity even if menial and underpaid. A female respondent from a community confronted with high unemployment, demonstrated her pride in her business:

Me, what I’m doing, I’m HIV positive but they are healthy and I have a bit of a business . . . Now I’m better than them now, I’m sick, I’m not starving, I can do business now (Group interview 2).

Many of the female PLHAs believed that earning an income proved their value to their families, and allowed a certain amount of independence. This woman was freed from relying on relationships for income:
Like doing the beads⁶, where I am, at the end of the day you bring the beads, you know that little bit is enough, because it is from your own hands. You are proud, I have R50. Rather than wait for somebody else to give you R20 (Group interview 5).

Seemingly even small amounts of money constituted increased independence for women.

In contrast, the small number of male respondents in the study worked out of obligation, and felt no sense of pride in generating an income, possibly due to norms which dictate that men are financially responsible for their families. Two of the five male respondents who were similarly underemployed or with micro businesses, classified themselves as unemployed and did not speak with pride about their work. These two men had lost formal employment due to having HIV/AIDS. With their formal employment, they lost their economic security and that of their families. They were economically poorer for the change. Two men were never employed (one still a student), and only one was still formally employed.

Income generation was not necessary for those who used this identity fix. Volunteering also provides a distraction from the virus and a sense of purpose. It prevents boredom which leads to hopelessness or association with potential stigmatisers. For this reason, despite the limited budget available to pay for the transport of patients, the clinic was never short of volunteers. A respondent expressed her desire to volunteer:

What I want to do, as now, I want to volunteer, I want to do something. I want to do something, not sit down and moaning about the virus the whole day (Group interview 5).

Other women worked at the clinic or at other organisations as volunteers or desired to volunteer elsewhere.

Identity fixes function as a defence against stigma, but the success of such attempt is questionable. It depends, to a certain extent, on the social capital they have. In the case

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⁶ Doing the beads’ refers to beadwork done as part of an income generation project
of morality, a person must already have or be able to develop a reputation as a good person. For the family identity fix, at least one good family relationship is essential. For this reason, income generation or a work identity is the hardest to achieve because positions even to volunteer are rare, compared to the demand, and the informal sector too has limited opportunities.

4.7. Spin-offs of Disclosure

A PLHA can never be precisely sure what the reaction to disclosure will be before disclosing. In some cases, respondents lost a great deal as a result of disclosing. This loss is often reflected economically. For the women, abandonment was quite likely. One of the women interviewed who was economically stable with a medical aid under her husband’s name, was abandoned when her husband heard that she was HIV positive. He deserted her and their children. She is now employed, but prior to her status being revealed, she was a homemaker. Her honesty had cost her better medical attention, a home, her husband and, for a while, her financial stability. For her, as with many women, desertion also meant that she had to provide for her children alone. Men in the study also lost access to resources, but rather through the loss of their jobs.

Despite fears of disclosing, respondents often reported positive reactions. They reported that their relationships had improved after the revelation of seropositivity. It can also serve as an encouragement to others to be tested, and something to be proud of in an environment of denial and secrecy. Sometimes, disclosing seropositivity can result in positive changes in intimate sexual relationships. This respondent had a positive experience to relate:

The only thing that has changed, is that we are now using condoms at home. And my husband is a changed person, he is no longer sleeping around, he comes home (Group interview 6).

The family, too, can pull together to face the virus, as was this woman’s experience. ‘For me I think that it made my family to come closer and be there for me. Before, I didn’t have the relationship with my family that I do now’ (Interview 2). In addition, disclosing seropositivity can encourage others to be tested and to change sexual
behaviour. This woman became her cousin’s role model after disclosing:

Like my cousin [said], ‘I’m not afraid to take blood, but because you have been living with this thing for all these years, you are my role model. If I can find out that I’m HIV positive then I can say, “look at my cousin, she’s been living with this thing for a long time and she is not sick or anything”’ (Group interview 3).

Disclosure can protect family members as well as partners.

Even though PLHAs approach disclosure carefully, there is no way of ensuring that they will get the emotional, spiritual, and practical support which they need from those around them. For a few, non-disclosure may have been the correct choice, as disclosure may have attracted severe levels of stigma. Others who had disclosed and been deserted, successfully formed a life without their ex-partners, but the PLHA is frequently economically poorer for the change. Each new relationship also presents difficulties, as disclosure must be risked again.

Identity fixes to some extent provide justification for the positive identity. This can be seen by the positive assessments of the moral regeneration, family life and work life since the HIV infection. These all provide a logical foundation for viewing the experience of HIV/AIDS in a positive light. In addition, rejecting the moral basis of stigma is part of resisting the overall ideology that is associated with HIV/AIDS. The moral foundation of stigma can be seen as key to the irrationality of HIV/AIDS stigma, since the sexual behaviour of the HIV positive and HIV negative is considered identical. The moral identity may also provide the motivation to publicly disclose in order to encourage others to get tested and to use condoms.

The positive identity goes beyond identity fixes. It is an attempt to make the gap between ‘actual’ and ‘expected’ identities negligible by adopting a ‘positive’ or resistance identity. A PLHA can accomplish this by disclosing in a public forum, this closes the gap between the ‘actual’ and ‘expected’ identity by making them the same. In this way, people can expect the positive status of an HIV positive person. Otherwise, a PLHA can reject the logical basis of the ideology that deems that she/he is somehow less worthy than others. In this case, the stigmatised person develops alternative beliefs that reject the dominant views which stigmatisate those with HIV. The
positive identity constitutes a collective attempt at resistance against stigma.

Making use of a positive identity by public disclosure can be dangerous, because it carries the possibility of attracting a level of stigma that may prove unbearable, as reflected with the mob murder of Gugu Diamini. There are, however, a number of advantages. Firstly, it may reduce stigma for all PLHAs by putting a human face on the virus. Secondly, the PLHA gets to set the stage in which people find out his/her status. Thirdly, it becomes possible for the PLHA to socialise openly with other positive people. Finally, through the development of a community of positive people and the promotion of a positive identity, it becomes possible to challenge the structures upon which AIDS stigma rests. In this sense, the positive identity is also a resistance identity. By openly disclosing her status, a PLHA challenges not only her own stigmatisation, but that of others too, as it attacks the assumption that PLHAs should be ashamed of their status. In this study, two respondents had publicly disclosed in a setting which could cause social harm.

One respondent, a female, disclosed through a lawsuit against the government, and the other, a male, through television and at a sports stadium. Others had publicly disclosed in more socially innocuous settings such as schools and churches. Whatever the setting for the individual aspirations of disclosure, it might result in lessening stigma for all PLHAs.

The notion that being HIV positive is not necessarily a completely negative experience was reflected in a number of the interviews. For some respondents, being a PLHA had offered opportunities they would not otherwise have had. Two were provided with clothes for their families. One received shelter and income from an income generation project. Another woman found that her seropositivity enabled her to get a job, heading a company’s corporate HIV/AIDS programme. For others, adopting a positive identity was associated with engaging in AIDS-related voluntary work, such as counselling. From this, they derived personal satisfaction and purpose, but also opportunities for association with other PLHAs.

Some of the PLHAs reported that they had told as many people as they could about their infection - arguing that informing people helped lift a huge burden of pretence.
One of the respondents recalled how she had told people about her status during a journey in a minibus taxi. Her beauty and health made it difficult for people to believe that she was HIV positive, so she was able to present an alternative picture of HIV/AIDS from that common in the stigmatised stereotype. As somebody who had been HIV positive for a while, her seropositivity was no longer cause for shame, but something of which to be proud. Another woman explained:

> Like, I think I’m relieved when I talk to somebody, my heart becomes right, so I think I must tell everybody that. I think I’m relieved when I talk to somebody, so I must talk to everybody and get relieved (Group interview 3).

Disclosure of individual PLHAs brings the possibility of making the environment less stigmatising for others.

The idea of being a ‘positive person’ clearly involves a play on words. Having the confidence to be public about one’s status, requires a high level of self-assurance. This is not something that comes naturally for most people and the solidarity and advice gained from support group participation, sometimes provided necessary strength. Being positive was a process that often began with individuals being encouraged to feel positive about themselves. For many, HIV/AIDS was an awakening. It made them evaluate the state of their lives, reconsider their priorities, and put themselves first before others. This woman had learned that considering others first, was not always a viable solution with HIV:

> [You] just don’t think for another person - think for yourself first. Don’t make the next one happy, or the second person, you must be the first to be happy. Then you can make the other one happy (Interview 6).

This enforced ‘selfishness’ can provide a much-needed break from the demands of others.

The ‘positive’ identity provides an individual PLHA with psychological, social and sometimes economic benefits. In directly challenging societal stigma, they begin to take on a resistance identity that has broader implications. Whilst it takes some
courage to overcome the barrier that stops many PLHAs from becoming a positive person, there is some basis for cautious optimism. First, in disclosing their status to close family and other PLHAs, the PLHA gains the experience and often the base of support to allow wider circles of people to know that they are HIV positive. Secondly, as more people become infected, as awareness about HIV/AIDS grows greater, and as AIDS organisations and positive people become more prominent and numerous, it gets a little easier to challenge the stigma and adopt a resistance identity.

Spending time with others in a similar situation compelled PLHAs to take pride in the fact that they knew their status. Given that there is much denial about AIDS, this was often an important step. It removed the uncertainty about one’s status, and opened up possibilities for treatment. One female respondent related her view: ‘I don’t care. I just tell myself that I know my status, so whatever anybody can say, I don’t care.’ Another example is the comment of this respondent:

And you are better than the others because you know your status, the others they don’t know . . . sometimes some of the people point their finger at me. But I don’t care. I tell myself that they don’t know their status. So, I’m better, because I know my status. (Group interview 3)

Some of the respondents were understandably proud of having lived as long as they had and told stories about what it was like when they were first diagnosed. These women were veterans of the AIDS struggle, knew a great deal about the illness and were knowledgeable about their rights. A woman expressed her relationship with the HI virus: ‘You need to understand that it [HIV/AIDS] is your friend. It’s going everywhere with you; you can’t run away from it.’ This woman agreed, deeming HIV like other viruses, and not a death sentence:

HIV - it’s just a friend of mine. I don’t consider myself as a sick person. I just told myself I’m HIV [positive]. People now with HIV live longer, it’s just like other diseases (Group interview 4).

Another woman considered the positive changes that HIV had brought to her:

It [HIV/AIDS] has changed us. You know, I’m so happy - my life is so focussed. I know what I’m doing, and I got new hopes with everything that I’m doing. And I actually don’t care who says what.
And being here, helping other people, seeing other people getting better (Group interview 1).

It seems if some people consider HIV a blessing, as well as a source of happiness and hope.

Becoming a positive person is not the solution for everybody. Not all PLHAs were properly counselled, and many did not frequently participate in support groups. For others there were no rewards, perhaps because being positive did not open up opportunities for income generation (and with this, socialisation with other PLHAs). It is possible that the positive identity is associated with poverty, and so some lack the willingness to get involved with other PLHAs. Thus, middle-class PLHAs may be reluctant to disclose their status. Such people may find it easier than poorer people to conceal their status - partly because they have been able to afford medication. They could also fear a loss of social status if they become openly positive. Significantly, TAC is overwhelmingly an organisation of unemployed people, mostly black women.

The fact that PLHAs felt that they needed to demonstrate their own value points to their realisation that their identities were spoiled. The respondents’ portrayals of their own value may serve in changing the observers’ focus from the stigmatic stereotypes of HIV/AIDS. Gap closing tactics are not mutually exclusive. In fact, the first tactic, ‘normalisation’, can develop over time into ‘resistance’. Normalisation tactics may also serve to justify the resistance identity by proving that PLHAs are better than the non-infected. Resistance may be described as an attempt to win an end to stigma for others while risking stigma for oneself.

**4.9. Conclusion**

This chapter followed the respondents from when they suspected that they might be positive, through their diagnosis. The chapter argues that stigma and fear of stigma prevented respondents from going for an HIV test. The decision was made to go for a test, or quite commonly, PLHAs were tested because of their physical illnesses or that of their children. The treatment at the hands of hospital staff was found to be stigmatising, a factor that can be ascribed to the staff shortages in public hospitals.
However, the hospital also provided some much needed support. This support was broken down into the three functions, these being informational, emotional and normative. The informational function of support provides information and advice which can help PLHAs understand what HIV infection entails and how to prolong their lives. Emotional support is provided in support groups by counsellors and others facing similar problems. Finally, normative support provides a sense of group identity and encourages the formation of similar identity fixes. Support mechanisms encourage disclosure and prepare attendees for it, but seldom form a motivation for disclosing. Motivations to disclose include fear of death or incapacitating illness, a need for support from disclosees and a sense of moral imperative to protect others. Either disclosure or visible symptoms open the PLHA up to stigma. The source of stigma most readily identified was the community, but family and partners were also known to stigmatise. Financial factors played a role in worsening stigma but could also reduce stigma. In order to relieve or prevent stigma, identity fixes were used to demonstrate the PLHA’s value or moral sense. The three identity fixes identified are the moral identity, family identity and the income or won identities. Identity fixes are used together with and after disclosure. Disclosure could have positive or negative effects for the PLHA and sometimes played a role in improving persona relationships. The positive identity was then explored and expanded upon, demonstrating two characteristics. The first is a rejection of the logic that underpins HIV stigma and the second involves public disclosure of status.

The final chapter, the analysis and conclusions, draws together the findings and shows how they answered the three main research questions and the implications of the findings. The findings are compared with current literature, and similarities and differences noted. The findings are placed in the greater theoretical framework provided by Castells and Goffman. Finally, some implications of the research are documented.
CHAPTER FIVE
ANALYSIS AND CONCLUSIONS

The aim of this dissertation has been to contribute towards understanding the complexities of social identity in the context of HIV/AIDS stigma. To this end, the research adopted a qualitative approach to understand the lived experiences of People Living with HIV/AIDS (PLHAs). The result is presented as a journey that begins with the diagnosis of a highly stigmatising virus. The end of this journey is not necessarily increased stigma and death, but hope.

This chapter concludes the dissertation by providing answers to the three main research questions. The first question asks whether stigma is experienced by respondents, what they perceive as stigmatising and who the stigmatisers are. The second addresses the way in which stigma impacts on the social identity. The third question asks whether it is possible to alleviate the effects of stigma, and, if so, what are the factors that work in favour of a positive identity. How then is this identity recognised? Under each relevant section, the relation of this study to prior research is discussed. Finally, the theoretical and practical implications of the dissertation are explored.

Before the analysis, a brief summation of the approach is provided. The fieldwork for this research was conducted between June and November 2003. It consisted of observation, expert interviews, group interviews and in-depth interviews. Preliminary research consisted of interviews that were held with experts working with the target group and participant observation of three support group meetings. Data collation then commenced at a hospital in the greater Johannesburg area and consisted of group and individual interviews. Group interviews were then conducted at the main research site with attendees of the support group at the site. In addition, other people from the support group participated in one-to-one in-depth interviews. Individual interviews were carried out away from the consensual dynamics of group interviews which can distort responses. The combination of research techniques were chosen to give a good understanding of the experience of being HIV positive. In total 47 people were interviewed, five of which were men. Most of these respondents could be defined as economically disadvantaged, with the possible exception of a small number of
respondents. Hereafter, follows the discussion under each research question.

5.1. **How stigma is Experienced**

Stigma was experienced in different contexts and from different sources. This section begins by exploring these sources. It continues by examining the nature of stigma identified by the PLHAs interviewed. Finally, information relating to the degree of stigma is put in context and some analysis is provided to explain why respondents focussed on stigma experienced at the hands of relationally distant sources, whilst not relating closer stigmatic interactions.

PLHAs in this study had experienced stigma. This bears out findings in previous research; firstly that stigma is experienced by most disadvantaged PLHAs (Stanley 1999; Haram 2001; LeClerc-Madlala 2001; Taylor 2001; Barnett and Whiteside 2002; Nyblade et al. 2003: 29; Brown 2004). Most respondents mentioned various sources of stigma related to their immediate communities and the hospital. These sources included medical practitioners, the community at large, family and partners. Medical practitioners mentioned in particular, were doctors. Stigma on the part of medical practitioners is also noted by Sewpaul and Mahlalela (1998: 40, 41), as well as Ogden and Nyblade (2005). The community or members thereof were most commonly recognised as stigmatising. Women, in particular, mentioned experiencing stigma and identified other women as their stigmatisers. Previous research also indicates that women are likely to experience stigma to a greater extent (Haram 2001; LeClerc-Madlala 2001; Fox 2003; Nyblade et al. 2003). However, none of the sources reviewed noted the gender of the stigmatisers. Family and male partners were identified as being stigmatising, but there was also a tendency to try hiding the fact that this happened. This was evidenced by expressing the stigma experienced by past, rather than current partners. Family stigma was also underplayed and ignored in interviews, but there was evidence that it did occur. PLHAs expected to be stigmatised by their families to a degree, such as expecting to wash crockery after using it, or being handled with gloves. Stigmatisation by male partners was also experienced, and men were identified as prime stressors for women. Family and partners as perpetrators of stigma has been noted in earlier literature (Fox 2003: 7-10; Ogden et al. 2005: 27).
The nature of the stigma varied depending on who was stigmatising the PLHAs. PLHAs felt that medical practitioners stigmatised them by being insensitive to their emotions at discovering that they had a terminal illness, which in many cases had also infected their children. In addition, failed treatments led to distrust of doctors and fuelled desperation for effective care. The stigma reported by respondents was, if anything, less intense than had been reflected in prior research (Sewpaul and Mahlalela 1998: 40, 41; Ogden and Nyblade 2005). This is unlikely to be due to a drop in the level of stigma, but rather because the sample was drawn from the support group which indicates at least some trust in hospital staff, since the support group was run by a hospital psychologist. Community members would stigmatise PLHAs with gossip, voyeurism and taunting. Nyblade (2003: 30) had previously identified these three symptoms of stigma. This stigma was fuelled by boredom both in the community and on the part of the PLHA. Some interviewees mentioned exposing themselves to stigmatising community members due to boredom and others mentioned how other PLHAs participated in stigmatisation. At home, PLHAs were subjected to neglect, differential treatment and fighting by families and partners, physical abuse and rape was experienced by some women. It is difficult to ascribe this to stigma rather than unequal gender relations. In particular, male partners seemed to bring up the status of their partner in order to upset them. PLHAs were stigmatised by those with the power to do so, medical practitioners, community, family and male partners all had either the relational supremacy or the numbers, in the case of community members, to stigmatise.

The degree of stigma is difficult to gauge, although it seems to wax and wane together with the symptoms of the infection. This phenomenon is dangerous to PLHAs as they receive more stigma when their bodies are least able to cope. This finding lines up with Alonzo and Reynold’s (1995) trajectory, but also reflects that the course of the illness is not one-way, but allows for recovery from symptoms and even hospitalisations. However, the degree of stigma expressed had an inverse relationship to the relational distance of the stigmatisers. In other words, those with whom the PLHAs had distant relationships were more frequently accused of stigma, than those who were relatively close. Practically this meant that medical practitioners and the amorphous community were more frequently charged with stigma, whilst partners and family members were
not commonly implicated. Indeed, it seems as if diversionary tactics were used in close personal relationships. Respondents chose to dwell on relationships that were not stigmatising rather than those that were. Soskolne et al. (2003) refers to the underplaying of stigma in order to maintain a more positive outlook on life, but does not make the distinction as to de-emphasise some sources of stigma, rather than others. Another factor which obscures the degree of stigma in personal relationships, is whether it is difficult to tell which stigma is a result of the HIV/AIDS infection and which is as a result of pre-existing relationship dynamics, in particular, those related to gender relations and economic dependency. Other sources of stigma, for instance, those in the workplace, were not mentioned frequently. This is believed to be due to the mixed nature of the group interviews, often leaving only one or two people who worked in a group, and most of the individual interviewees did not work. However, considering the importance of work identity to the respondents, it is possible that they did not wish to dwell on this stigma.

Respondents demonstrated how identity influences their depictions of stigma. Identity and emotional needs are likely to have driven PLHAs to emphasise certain arenas of stigma and ignore others. The gender dynamics that underline sexual and familial relationships also serve to ‘hide’ the stigma experienced, possibly even from the PLHAs themselves.

5.2. How Stigma Impacts the Social Identity

Stigma experienced by respondents influenced the social identity in two specific ways. There is evidence that PLHAs adopted and internalised the stigma into their self-conceptions, and they consequently felt contaminated in a way that those around them presumably did not. In seeming contradiction to this, PLHAs used their social identity to defend themselves against stigma. In this case, PLHAs sought to normalise or fix their social identity through emphasising how they were valuable or moral despite stigmatic stereotypes of PLHAs. The three identity fixes are the moral, family and work or income generation identities. The two general impacts of stigma on the social identity are discussed next.
The first effect, that of internalisation, involved PLHAs feeling contaminated, or different in a negative way from those around them. This was shown in the desire to wash crockery after using it, or expectations of being handled with gloves. It is possible that the respondents will abandon such behaviours as they receive support and learn about the modes of transmission of the virus. The limited mentioning of these behaviours could indicate this, or could reflect a desire not to incorporate it into their broader social identity. Self-stigmatising behaviours could also have largely been ignored because of the interview situation in which PLHAs are normal, rather than different. The presence of other PLHAs may have had the effect of not making it socially appropriate to admit this behaviour. This is shown by group interviewees only mentioning other PLHAs engaging in such behaviour, while a small number of individual interviewees reflected personal employment of it. It is possible that stigmatisation by others, or the expectation of it, led PLHAs to feel that they deserve it in some way. This internalisation of stigma reflects that PLHAs social identity does become stigmatised (Goffman 1963), a conclusion that agrees with findings of Rohleder and Gibson (2005), as well as Ogden and Nyblade (2005: 43). Ogden and Nyblade explain that internalisation of stigma based on the norms PLHAs’ share with the community from which they originate.

Identity fixes are a more conscious strategy on the part of PLHAs, and constitute the second effect. It is based on an understanding that their social identity was in some way endangered or devalued. These are used in order to reduce stigma from others, and possibly to protect the stigmatised from internalising more stigma as the illness progresses. Seemingly, proving that one is valued and virtuous, is as important to fixing the social identity for those outside the PLHA, as for the PLHA her/himself. This effect requires agency on the part of the PLHA in order to resist stigmas associated with HIV/AIDS. The methodology adopted in this research could not gauge whether these fixes would reduce stigma, however, some literature sources suggest that behaviour can control stigma to a certain degree (Gilbert and Somerville 1994; Alonzo and Reynolds 1995; Taylor 1999).

The moral identity was used to demonstrate how the PLHAs were blameless in either their infection or their behaviour afterwards. Respondents did this by aligning their
identity with God and/or a church. In this context, HIV was considered as a blessing that had made them reconsider their lives. This agrees with Stanley’s (1999: 108-114) study in which sufferers saw HIV as a message from God, a blessing or something that made them reconsider what was important. Alternatively, it could be expressed in demonstrating how caring PLHAs were to each other, or others. This lovingness was contrasted to the brutal, stigmatising community. Some PLHAs long as the PLHA has symptoms (Nattrass 2004: 6). Volunteering, too, was beneficial as it gave women a sense of accomplishment and filled their days with something meaningful. In addition, those who worked and volunteered in HIV-related fields were given the chance to socialise with other PLHAs; a situation that was identified by respondents as beneficial. By conceptualising the income or work fix as an identity, the study goes beyond previous research largely focussing on income as a means of preventing the spread of HIV/AIDS as the Ugandan programme did (Fleischman 1995). In addition, voluntary work as an attempt to mend a social identity has also not been mentioned in sources that the researcher consulted.

These identity fixes were for the PLHAs, a chance to ‘normalise’ their identities despite the stigma associated with the HIV. The effectiveness of such strategies is unknown, but it seems to be connected with a group identity based on similar characteristics. However, normalisation also constitutes an acknowledgement that their social identities are stigmatised, and that the stigma must be addressed in some way. In this way internalising stigma and fixing the identity, both constitute recognition that those with HIV/AIDS have an identity which is stigmatised.

5.3. The Making of the Positive Identity

Although the ‘positive resistance identity’ and ‘identity fixes’ are analytically separated, together they form two parts of an overall strategy to close the gap between the stigmatised identity and the normal identity. Goffman (1963) conceptualised stigma as a gap between a person’s expected and actual identity. This study provides evidence of individual and collective attempts to close that gap. One way is to present a narrative that patches, but does not quite bridge the gap. This ‘patching’ is accomplished by using a facet of the social identity to ‘fix’ stigmatised identity. The
identity fix may work successfully in some circumstances because it challenges key areas where the stigma devalues the person. The positive resistance identity on the other hand, denies that the gap should exist. This identity questions the dominant idea that determines that some persons are stigmatised due to their HIV status. The identity fix can then be seen as an individual tactic to deal with stigma while the positive resistance identity is a collective effort.

The positive identity has two components. The first is the ideology that prompts the second - the action. Many respondents espoused the theory, turning the stigmatising viewpoints of the community on its head by asserting that HIV should not form a basis for discrimination. In particular, PLHAs argued that they are better than their stigmatisers because they know their status. The resistance identity adopted a positive attitude to the virus or some aspects thereof, in other words, seeing the HIV positive status as something good. The second practical aspect required a public acknowledgement of HIV positivity. Public disclosure could take place in a relatively low-risk environment, in front of strangers, but others risk public disclosure where important others would hear of it. Nonetheless, public disclosure, even in relatively low-risk situations, can be dangerous. As such, the adoption of a positive identity can encourage more social stigma. The mixed results of public disclosure can be seen in the admission of Gugu Dlamini of her HIV positive status. Although she was stoned to death, her death became an event to rally around, and resulted in the design of the purple HIV positive t-shirt. This t-shirt has been used to great affect by the TAC. Some respondents felt that because they knew their status, they had an obligation to disclose and educate others; similar sentiments were expressed in Soskolne’s report (2003: 20). The desire to disclose presupposes an understanding that disclosure will result in increased education. It is based on the acceptance of a positive ideology of living with HIV/AIDS.

The positive resistance identity arises to a large degree out of the support mechanisms provided by the hospital. These support mechanisms include a support group under the care of a psychologist, counselling by trained counsellors, legal advice and the
wellness course. Together, these support mechanisms provide PLHAs with three kinds of support - informational, emotional and normative. Informational support consists of the PLHA learning practical lessons about what HIV entails, and how best to live to survive longer with HIV/AIDS. Emotional support is delivered through counsellors, support groups and informal conversations, and helps the PLHA cope emotionally with the personal troubles that he/she is experiencing. Normative support helps the PLHA realise that she/he does not need to be stigmatised, and assists in the adoption of identity fixes. In particular, normative support functions to provide the basis of a positive group identity.

Evidence of the positive identity can be found in sentiments expressed in the interviews. Commonly, respondents expressed pride in the fact that they knew their status, implying that knowing that you are positive is better than not knowing your HIV status at all. The ‘knowingness’ of the group was compared to the ignorance of those in the broader society. The use of the term ‘knowingness’ is derived from Soskolne (2003: 19, 20). This sense of knowing freed respondents from the dread of being positive that they had experienced before. Knowing that one is positive and having information about HIV and treatment, meant that respondents could keep themselves healthier. This is similar to what Morgan (2003: 2) found in Khayelitsha, which is why HIV was perceived as ‘not such a bad thing’. Being HIV positive also caused some of the PLHAs to reassess their lives and make positive changes to them, which placed greater emphasis on the importance of looking after oneself rather than others all the time. Accepting that being HIV positive is not an entirely negative experience, implies a rejection on a broader societal viewpoint that links HIV with a short tragic life. PLHAs further linked this idea with the ignorance of broader society, showing how they were in a better position than their stigmatisers were.

Not only did a sense of knowingness give the PLHAs a chance at a longer life, but it had also provided, in some cases, chances to improve the quality of their lives. Some respondents received a disability grant (of up to R750). Others found that income

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7 The wellness course instructs PLHAs to live in such a way as to extend their lives. This is done through nutrition, stress avoidance and safe sex.
generation projects gave them a sense of independence as well as income. A few women had been hired for jobs based on their insider knowledge of HIV/AIDS. A number of respondents volunteered or lobbied around the issues related to HIV. Volunteering fills people’s days and gives them a sense of accomplishment. Those involved in income generation projects, HIV/AIDS-related employment, volunteerism and activism, had the opportunity to associate with those who were HIV positive. This association meant that they could further develop the positive identity and could help each other. Klawiter (1998) refers to how women activists transformed the stigma associated with breast cancer and used the disease as a basis for activism. It is possible that HIV sufferers are doing the same through their use of the HIV positive resistance identity. HIV/AIDS activism in South Africa presents a success story for local social movements by winning the antiretroviral (ARV) rollout (UNAIDS 2003).

The existence of the HIV positive identity constitutes resistance to the broader logic behind stigma. It is, in this sense, a resistance identity. This identity is, according to Castells (1997: 9) formed by opposition to dominant principles in society. In this case, the struggle is against the HIV/AIDS stigma. The HIV virus becomes something to advocate around and encourages action to reduce stigma. In this sense, the identity reverses the meaning of stigma while reinforcing the boundary between the HIV positive and those who stigmatise them. Similar mobilisation has taken place in opposition to the stigma associated with breast cancer, which likewise prevents early diagnosis and treatment. Support groups were fundamental to the taking of breast cancer from the realm of personal stigma, to global activism (Klawiter 1998). The similar strategy used with HIV/AIDS may succeed in destigmatising this emotive issue.

The *Positive identity* is based on an idealised view of the experience of being HIV positive. It is unlikely that a person can have a completely positive experience when infected with HIV/AIDS, due to the series of crises that are represented by HIV/AIDS. In addition, identities are neither unitary nor perfected, but are rather continually practiced (Roseneil and Seymour 1999: 8). Health or ignoring the suffering experienced due to ill health, is critical for the PLHAs to be successful in their adoption of the positive identity. Increasing stigmatisation can render a positive identity ineffective, as only so much stigma can be resisted. In fact, the positive
identity may deny or trivialise the suffering which people experience, according to Soskolne et al. (2003).

5.4. Implications of Research

One important strong point of this research is the departure from small samples of fewer than ten or fifteen respondents, commonly found in qualitative research projects on HIV/AIDS. Generalisation based on small samples is often the case with AIDS research, and this study tried to avoid this. In addition, the various respondents in the study lent substance to the findings that the research would not otherwise have had. Secondly, the research attempted to understand the complexities of social life with HIV/AIDS. The drawing together of various literature sources from different schools of thought and systematising them, contributed to the understanding of social identities with HIV/AIDS. This can be seen, for example, in the drawing together of the ‘identity fixes’. Thirdly, the research has firmly established the PLHA as the speaker. In this way, the findings are grounded in the perceptions of the respondents, addressing a key criticism about stigma research (Link and Phelan 2001: 2). Fourthly, this research grounded stigma in power, rather than considering stigma apart from community and family power relations. Parker and Aggleton (2003: 15) stated that most stigma research ignores these power relations. Finally, and most importantly, the dissertation problematised and explored the positive identity and other identity strategies which most previous literature had left fraught with assumptions.

A practical implication of the research is that stigma can be better resisted with more economic resources at the PLHAs’ disposal. Although the author supports a basic income grant that does not require that those with HIV remain ill in order to access it (unlike the current disability grant), this would only solve part of the problem. Rampant unemployment in South Africa leaves women vulnerable to HIV in order to access resources. It may also mean that women face more stigma from the family because they have little resources with which to negotiate more respect, but rather use more resources than the rest of the family due to their illness. The stigmatising community is difficult to avoid when unemployed, as boredom drives the need for social interaction. In addition, staying indoors and avoiding social interaction can lead
to hopelessness and loneliness. The author therefore appreciates the work done by income generation projects to avoid this situation, but recommends that the number of projects and their scale be increased.

5.5. Conclusion

The analysis presented here draws on and provides evidence for much of Goffman’s theory of stigmatisation and identity. It shows how stigma produces a stigmatised identity. An individual’s symptoms pose a danger of attracting stigma to the person, and this results in stress which can be detrimental to the health of the PLHA. It also demonstrates how PLHAs reduce the gap between their inner identity and their public identity by disclosing their status. This process of partially renormalizing an identity is crucially achieved through the solidarity of fellow PLHAs and through family support. The dissertation, therefore, emphasises the importance of the role of the private world of families and the safe support groups in developing a new identity. It is also proposed that Castells’s notion of a resistance identity helps us to comprehend the evolution of a positive identity - the birth of the ‘positive person’ - which constitutes such an important basis and mechanism for the fight against social stigma.

This dissertation has presented the words and perspectives of some inspiring people who have faced the difficulties of poverty and powerlessness to find themselves buffeted, but not defeated. Despite great adversity, their achievements are marked by the fact that they still live! Contrary to much research results on AIDS, it has been heartening to see how, despite receiving a death sentence diagnosis; PLHAs can live a happy, active and sometimes a ‘better’ life. This speaks well of interventions by HIV/AIDS organisations in supporting and improving quality of life, a process which contributes to the development of a new, positive collective identity; an ‘HIV positive’ identity with purpose, ambition and hope.
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APPENDIX I: INTERVIEW GUIDE FOR GROUP INTERVIEWS

1. Can we all introduce ourselves and say how long we have been positive?
2. Does anyone want to be known by another name for this research? What name would you like to be known by?
3. May I record our interview?
4. How old are you?
5. How did you find out that you were HIV positive?
6. Did you suspect that you were positive before the diagnosis? Why?
7. Have you disclosed your status to anybody?
8. To whom and how?
9. Why did you decide to disclose?
10. Have you ever publicly disclosed?
11. Do you attend the support group here? Why/why not?
12. What do you think of the HIV clinic here?
13. What does ‘living positively’ mean to you?
14. What do you think others think of HIV/AIDS?
15. Have you experienced any stigma or discrimination due to your status?
16. What did the stigma entail?
17. Are you still experiencing stigma?
18. How did your family react to your diagnosis?
19. Do you have a partner? Have you disclosed to him/her? How?
20. Do you have children?
21. Are they positive/negative?
22. Do you have a job?
23. What do you do? Did you have one before?
24. Do you volunteer? Why?
25. What would you tell someone who has just been diagnosed HIV positive?
APPENDIX II: INTERVIEW GUIDE FOR IN-DEPTH INTERVIEWS

1. What is your name?
2. What name would you like to be known as?
3. Can I record our interview?
4. How long have you known that you are HIV positive?
5. How did you find out that you were HIV positive?
6. Did you suspect that you were positive before the diagnosis?
7. Why?
8. Have you disclosed your status to anybody?
9. To whom and how?
10. Why did you decide to disclose?
11. Have you ever publicly disclosed?
12. Do you attend the support group here?
13. Why/ why not?
14. What do you think of the HIV clinic here?
15. What does ‘living positively’ mean to you?
16. What do you think others think of HIV/ AIDS?
17. Have you experienced any stigma or discrimination due to your status?
18. What did the stigma entail?
19. Are you still experiencing stigma?
20. How did your family react to your diagnosis?
21. Do you have a partner?
22. How did he/she react to your status?
23. Do you have children?
24. Are they positive/ negative?
25. Do you have a job?
26. What do you do? / Did you have one before?
27. Do you volunteer? Why?
28. What would you tell someone who has just been diagnosed HIV positive?