

**SERO-POSITIVE STIGMA AND ITS IMPACT IN THE  
WORKPLACE**

by

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Submitted in fulfilment of the requirements for the degree of

**MASTER OF ARTS**

In the subject

**SOCIOLOGY**

at the

UNIVERSITY OF SOUTH AFRICA

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NOVEMBER 2003

## Acknowledgements

I have neither the power of expression nor the depth of vocabulary to do justice to this section. While I will single out a few people for acknowledgement, I would like to record the fact that there are a large number of unnamed people who have participated silently in the process, to whom I owe a debt of gratitude.

In her characteristically mild mannered and gentle way, **Ms. Gretchen du Plessis**, my dissertation supervisor has been a towering influence in my life, this last year. Her mentorship has been both razor sharp and nurturing. It could not have been easy for her to tutor a mature student revisiting academia after a break of two decades. She has done so with astuteness, sensitivity and dedication. She has risen beyond the call of duty and concerns for her own health to support me through this process.

**Dr. Derik Gelderblom**, has been a quiet, understated, yet nevertheless strong influence in my reconnection with academia. His calm and insightful guidance in the process has played a key role in the fructification of this dissertation.

The ethics of confidentiality prevent me from naming the **6 interviewees** who taught me that, a global response to HIV and AIDS is untenable without the leadership and sensitivity of people living with HIV and AIDS.

**Lopa Banerjee**, my wife and partner for 26 years has been my constant friend, philosopher and guide. More concretely, she has been my research advisor for this dissertation. Never one to shirk a challenge, she has stood beside me through thick and thin. May I never have to negotiate life without her.

I believe that every blessed person has one unconditional love in his or her life. **Disha Banerjee Bhattacharya**, my 10-year-old daughter, is that love in mine.

To all these architects in my life and career, I'd like to say a deeply felt and hugely inadequate, "Thank you".

**Title of dissertation****Sero-positive stigma and its impact in the workplace*****Scope of dissertation:***

The dissertation is an in-depth exploration of the stigmatisation of people living with HIV and AIDS (PLWHA) in the workplace. It attempts to understand the nature of stigma and its implications for the stigmatised.

**Title of dissertation****Sero-positive stigma and its impact in the workplace*****A summary of the dissertation***

With an estimated 500 infections everyday, the country is beset with a galloping HIV and AIDS epidemic. With these accelerating numbers, it is no longer possible to ignore people living with HIV and AIDS, as they will inevitably form a more and more significant volume of the workforce. A key aspect of this phenomenon, that needs dedicated attention, is the issue of their stigmatisation in the workplace.

The intent is to present the voice of the stigmatised. The dissertation attempts to understand how a stigmatised identity affects a productive member of society. It tries to capture the perspective of sero-positive persons as productive members of society and not as 'victims' or 'threats'.

The ultimate objective is to influence policy in the workplace in order to provide a nurturing and productive work environment.

The key thought emerging from the research is: driven by the inescapable structural stigma of the workplace, the virus fundamentally influences the self-definition of the sero-positive person.

**Title of dissertation****Sero-positive stigma and its impact in the workplace*****Key Terms for access:***

Sero-Positive, Stigma, Unspoken stigma, Discrimination, Workplace, Parastatal organisation, HIV and Commitment to work, HIV and feelings of being outcast, HIV and Sense of self, CAQDAS and qualitative data analysis for HIV, Finitude, Sublimation in work, PLWHA (People living with HIV and AIDS), GIPA (Greater Involvement of People living with HIV and AIDS) and Secondary Gains

**Title of dissertation****Sero-positive stigma and its impact in the workplace*****Key Glossary of Terminologies and Acronyms:***

The following glossary of terminologies and acronyms is used in the dissertation. Many of the terms are used particularly in the context of HIV and AIDS and do not constitute regular idiom. Some of the key phrases are explained in greater detail at the point at which they are first introduced in the dissertation.

They are:

- AIDS: Acquired Immunodeficiency Syndrome
- ARV: Anti-retroviral. A form of medical therapy that controls the viral load in the human body.
- Atlas.ti: A CAQDAS software used for data mining in qualitative research
- CAQDAS: Computer-Aided Qualitative data Analysis Software
- Data Mining: I use the term 'data mining' to mean, the structuring of raw data into easily accessible and rapidly useable form
- Eclectic: Deriving ideas from a broad canvas of sources
- Finitude: Used in the sense of mortality
- GIPA: Greater Involvement of People living with HIV and AIDS. It is a formal global movement.

- GIEPA: Greater involvement and empowerment of people living with HIV and AIDS. This is an informal suggestion of the researcher and some GIPA workers
- HAART: Highly Active Antiretroviral therapy. This regimen of treatment is capable of suppressing the virus for months or even years in many individuals.
- HIV: Human Immunodeficiency Virus
- KENWA: Kenya Network of Women with AIDS
- PLWHA<sup>1</sup>: People Living with HIV and AIDS
- SAA: South African Airlines
- Sero-positive: A person who has tested positive for HIV, the virus that may cause AIDS
- Somatic: Dealing with the body

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<sup>1</sup> I recognise and appreciate the importance of not referring to people as acronyms. It is critical for me to state my personal belief in the light of the fact that I will be using terms like PLWHA or GIPA merely to shorten the reading and ease the pressure on sentence construction.

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## Chapter 1: HIV and AIDS stigma in the workplace

In order to explore the issue of stigma related to HIV and AIDS, it is necessary to understand the HIV epidemic and its relation to stigma.

### Understanding HIV and AIDS

AIDS is the acronym for Acquired Immune Deficiency Syndrome. Each word in the nomenclature bears a meaning of significance.

**'Acquired'**, categorically means that the virus cannot be passed on through casual contact, like influenza or the recent SARS virus. It can only be acquired by the particular actions of people. I shall in subsequent paragraphs explain what these actions are.

This to my mind is a cause for hope. It means that reversing the epidemic is within our control as individuals and communities- it is about the choices we make in our lives. **'Immunodeficiency'**, highlights the fact that the virus affects the immune system of the person making it increasingly less capable of warding off

infections. **'Syndrome'**, is a very important statement of the fact that AIDS is not a disease in itself, but a syndrome that affects the immune system. The syndrome of the failing immune system makes the body vulnerable to secondary infections, like Pneumonia, Karposi's sarcoma, Tuberculosis etc (Whiteside & Sunter 2000:1).

Discovered only in 1979-80 as an unusual and inexplicable phenomenon (the outbreak of a rare "cluster of diseases" like pneumocystis carinii, which is normally spread by birds; and a rare form of skin cancer called Karposi's sarcoma), the virus was positively identified by scientists on either side of the Atlantic in 1983 (Whiteside & Sunter 2000:1).

There are broadly two strains of the virus, HIV-1 and HIV-2 with multiple sub-strains in each. The dominant strain globally and in South Africa is HIV-1, sub-strain-C. HIV-2 is found mainly in West Africa and is less virulent, which means that it is less easily transmitted and "slightly less harmful than HIV-1". However, given the migration and mobility of populations, the HIV strains are not geographically isolated (Whiteside & Sunter 2000:2; Barnett & Whiteside 2002:28).

People are said to be HIV positive or sero-positive, when HIV antibodies are detected in the blood. A person who is HIV positive does not necessarily have the condition of AIDS. When a person living with HIV starts to become ill with what we call AIDS-defining conditions such as severe thrush, brain conditions, severe pneumonia etc, we say that the person has AIDS. In places where sophisticated testing facilities are available, AIDS is defined by the CD4 count in the body. A person normally has about 1200 CD4 cells per micro-litre of

blood. In a person diagnosed with AIDS, the CD4 count falls below 200 (Barnett & Whiteside 2002:32-34).

The reduced CD4 count, compromises the immune system of the body rendering the person living with the virus vulnerable to infection from opportunistic infections and cancers that the body would normally be able to ward off. The following are the five **stages** (Barrett -Grant et al 2001:22-24) of HIV and the symptoms that go with them:

**Primary HIV- infection:** This is usually the first few weeks following infection, when the person sero-converts (changes from negative to HIV-positive) in their blood test. This stage is often accompanied by symptoms of flu-like illness, sore throat, swollen glands, headache, muscle aches and rashes. These symptoms usually last for a couple of weeks after which the person looks and feels well.

**Asymptomatic or silent stage:** After recovering from the primary phase, people living with the virus continue to feel well for long periods, often for many years. Sometimes people develop swollen glands, which is a physical manifestation of the virus. Blood tests are usually required to detect the virus at this stage.

**Early stage HIV- infection symptomatic:** Several years after infection, some people start developing mild symptoms such as: Shingles, swollen lymph glands, occasional fevers, mild skin irritations and rashes, fungal skin and nail infections, mouth ulcers, chest infections and weight loss.

**Medium stage HIV- infection:** At this stage people could become very ill without developing the AIDS-defining illnesses. Typically the illnesses during this period include: Tuberculosis,

recurrent oral or vaginal thrush (a fungal rash or spots), recurrent herpes blisters on the mouth (cold sore) or genital herpes, ongoing fevers, persistent diarrhoea, significant weight loss (more than 10% of body weight).

**Late stage HIV- infection or AIDS:** The lack of early and effective treatment can cause severe long-term damage to the body, affecting such vital organs as the brain. This stage is usually called AIDS and is defined by such illnesses as: severe diarrhoea, severe weight loss, severe pneumonia, brain infections, confusion and memory loss, severe skin rashes, pain and difficulty swallowing (Barrett -Grant et al 2001:22-24).

Though the **origin** of the virus is unknown, it is commonly believed to have crossed the species barrier into humankind from monkeys. It is related to a number of Simian Immunodeficiency Viruses (SIV) found in Africa (Barnett & Whiteside 2002: 34-35).

The following table shows the modes of transmission and the probability of HIV-1 infection per 1000 exposure:

| Mode of Transmission                    | Infection per 1000 exposure |
|---|-----------------------------|
| Male to Female, unprotected vaginal sex | 1-2                         |
| Female to Male, unprotected vaginal sex | 0.33 - 1                    |
| Male to Male, unprotected anal sex      | 5-30                        |

|   |            |
|---|------------|
| Intravenous use of Infected Needles     | 3          |
| Mother-to-child transmission            | 130 – 480  |
| Exposure to contaminated blood products | 900 - 1000 |

Table 1: Probability of HIV-1 infection per exposure (*Source: World Bank: 1997a:59 as quoted in Barnett & Whiteside 2002: 38*)

One interesting analysis of the above table is the fact that men are more likely to infect women than visa versa, exploding one of the myths, that women are the vectors of the virus. Further, “HIV and AIDS combines sex, death, fear and disease in ways that can be interpreted to suit the prejudices and agendas of those controlling particular historical narratives in any specific time or place. Fear of the infection all too easily translates into fear of the infected. The disease has been used to stigmatise various out-groups - gay people, women sex workers, foreigners etc -- people start using labels to identify targets for blame and stigmatisation” (Barnett & Whiteside 2002: 66). These are the prejudices and circumstances that identify people for stigma, “a mark of disgrace associated with a ... circumstance, quality or person” (New Oxford Dictionary 1998: 1826: Column 2). Stigma is viewed as a quality that “significantly discredits an individual in the eyes of others... within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable and unworthy” (Aggleton & Parker 2002: 8).

In this context it is also necessary to state the definitions of such terms as ‘prejudice’ and ‘discrimination’ as they are used in the dissertation. The word ‘prejudice’ is used to mean a “preconceived opinion that is not based on reason or actual

experience” (New Oxford Dictionary 1998: 1462: Column 1). In the research there have been examples of both positive and negative discriminatory behaviour. However, the overall discrimination has been a negative one based on a person’s HIV status and the physical characteristics that go with it. The word ‘discrimination’ is used to denote “the unjust or prejudicial treatment of different categories of people” (New Oxford Dictionary 1998: 526: Column 1), especially on grounds of their HIV positive sero-status. To underline the definition with an example in the context of this study, I would say that termination of a person’s job on account of his/her HIV status would be viewed as discrimination.

This would be a pertinent start to the discussion on the issue of HIV/AIDS-related stigma and its key manifestation – discrimination. Though the study is focussed on stigma, an understanding of discrimination is important to help contextualise some of the powerful emotions stirred up by the presence of HIV and AIDS in our society. Peter Piot, (Aggleton & Parker 2002: 7) the chief of UNAIDS, in a statement made at a world conference<sup>2</sup> says, “HIV/AIDS related stigma comes from the powerful combination of shame and fear [shame and fear are visceral emotions which I explore in the literature review and in my study] – shame because the sex or drug injecting that transmit HIV are surrounded by taboo and moral judgement, and fear because AIDS is relatively new, and considered deadly. Responding to AIDS with blame, or abuse towards people living with AIDS, simply forces the epidemic underground, creating the ideal conditions for HIV to spread. The only way of making progress against the epidemic is to replace shame with solidarity, and fear

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<sup>2</sup> “ Statement by Peter Piot to Plenary of the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance,

with hope". An important point that Aggleton and Parker (2002: 8) make is that stigmatisation is a "process". "The qualities", they say, "to which stigma adheres ... can be quite arbitrary. Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy.

Stigmatization therefore describes a process of devaluation rather than a thing". They affirm in the same document that, "Stigma and discrimination associated with HIV and AIDS are the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating impact" (Aggleton & Parker 2002: back cover).

HIV-related stigma, discrimination and denial<sup>3</sup> appear "in a variety of contexts" (Aggleton 2000: 14). Following Aggleton I discuss three major contexts in which one sees stigma. I elaborate more extensively on stigma in the workplace, which is the context of my study:

*The family and community:* As primary caregiver for the sick, the immediate family plays a key role in the management of stigma within the community. However, not all family members are either positively disposed, or neutral, to people living with the virus. Further, according to Aggleton (2000: 14), women are more likely to bear the brunt of this prejudice and stigma than either men or children (this is a relative comparison and in no way implies that men and children are free from HIV-related stigma). Also, "fear of rejection and stigmatization within the home and local community may prevent people living with HIV/AIDS revealing their serostatus to family members" (Aggleton 2000: 14-15).

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Durban South Africa, 5 September 2001" (Aggleton & Parker 2002: 7).

<sup>3</sup> I define 'denial' here as the inability to accept one's personal vulnerability to HIV and AIDS and of its existence in society.



*The health care system:* Breach of confidentiality vis-à-vis a person's HIV and AIDS sero-status is a problem faced in the health system. "In some settings signs have been placed near people living with HIV/AIDS with words such as 'HIV-positive' and 'AIDS' written on them. Elsewhere, registers of HIV-positive people have been compiled and their names released to media and police without permission" (Aggleton 2000: 16). Further complicating the problem of stigma in the health system is the issue of "ignorance and lack of knowledge about HIV/AIDS transmission" (Aggleton 2000: 15).

*Employment and the workplace:* In a majority of workplace settings, the World Health Organisation and the International Labour Organisation "confirm that there is no risk of acquiring or transmitting HIV – between workers, from worker to client, or from client to worker... yet despite the lack of risk of infection, people in many countries and particularly in the industrialised world, have been **dismissed from their jobs, ostracised by their workmates, or tormented at the workplace** because of fears about HIV and AIDS" (PANOS 1990:64). The dossier goes on to elaborate the ignorance and prejudice that drive people to stigmatise and discriminate against people living with the virus. In the UK, a "cinema projectionist lost his job because his 'life-style' – homosexuality – allegedly posed a risk" to his colleagues, while "the girlfriend of a man with haemophilia was sacked from her job in a laundrette because the owner thought that people wouldn't want to hand their trousers over the counter to someone whose boyfriend might be HIV-positive" (PANOS 1990: 64). In some cases prejudicial behaviour towards the employees was triggered when the employees told the employer of their sero-status and in other cases it was a factor of breached confidentiality (PANOS 1990: 64). The PANOS dossier also

elaborates on the arguments put forward by a number of employers who state that they “are under pressure from clients to keep the workplace ‘AIDS-free’” (PANOS 1990: 65).

I quote a verbatim case study from the PANOS dossier (1990: 67) which shows the stigmatisation and discrimination of people living with the virus in the workplace in South Africa. It also shows how the lack of counselling and the termination of jobs could indirectly lead to the spread of HIV in the community.

“Member organisations of the South African Chamber of Mines – an umbrella association of mining companies – employ several hundred thousand workers, many of whom are migrants from neighbouring countries. In 1986, the chamber began testing large numbers of employees for HIV antibodies. By 1989, a total of 2500 cases of seropositivity had been identified, the vast majority from Malawi, with the seroprevalence rate reportedly reaching 10% of Malawian mineworkers. However, one source within the industry claims that, by August 1998, the total was actually close to 4000”. The verbatim continues, “These miners subsequently returned to their home countries, according to some sources, involuntarily, although the South African Government denies that they were repatriated. Current policy of the Chamber is for migrant mine workers to be tested in their country of origin and refused a work permit if the result is positive. The Malawian Government has refused to condone what it sees as a discriminatory policy, and has denied the Chamber of Mines permission to set up testing facilities. As a result, the South African mines, which previously provided an important source of employment, are now a no-go area for Malawian workers, who have returned to their villages scattered through out the country. The impact on Malawi, already suffering the social and financial consequences of a severe AIDS

epidemic, could be considerable. There has been significant loss of income, on which whole families depend” (PANOS 1990: 67). While the laws in South Africa have changed with the introduction of the Employment Equity Act No 55 of 1998 (Whiteside & Sunter 2000:158-167), the PANOS verbatim gives us an idea of the nature of stigma and discrimination in the workplaces of South Africa. This thought is underlined in the dossier, which says that even where there are laws, “the difficulties in enforcing labour legislation mean that many people have little or no security” (PANOS 1990: 78).

The case study quoted above also demonstrates how discrimination based on stigmatisation is often used to bring order to society. In an effort to keep their work force uninfected by HIV, the Chamber of South African Mines undertook the discriminating policy of testing all migrant workers on the prejudiced assumption that they would be carriers of the virus. As Aggleton (2000: 9) states, “Stigma is a powerful means of social control applied by marginalizing, excluding and exercising power over individuals who display certain traits. It is a common response to perceived threat when escape from, or destruction of, this threat is impossible”.

Additionally, stigma intensifies the emotional strain and suffering of people living with the virus, their families and caregivers (Nyblade et al 2003: 34). This compromises the opportunity of early intervention to manage the infection and prolong a healthy life.

It is important at this stage to draw a distinction between **health** and **well-being**. ‘Health’ reflects the state of the body and its condition vis-à-vis disease and illness. ‘Well-being’ on the other hand, is a broader concept and “places emphasis on the social

and economic origins of ill-being” (Barnett & Whiteside 2002:349). In this definition, Barnett and Whiteside (2002:351) stress that social relations should be focussed on as a critical component of well-being. That being the case, the management of stigma plays a very critical role in the management of health and well-being in the response to HIV and AIDS, since stigma is a factor of unequal social interaction. I will at this juncture let this reference to stigma suffice and add layers to the explanation later in this section and again in the literature review.

A published study (Whiteside & Sunter 2000: 102-103) on the impact of HIV and AIDS in a sugar mill in South Africa shows that, “The total cost per worker per year for the period of the analysis was R 9543 with equal shares of 28 per cent for replacement worker costs, productivity losses and absenteeism”. With the combined replacement and absenteeism figure as high as 56%, it has become necessary to focus on studies that address the issue of stigmatisation of PLWHA in the workplace. With a replacement possibility of 28% of the workforce, employers will be faced with two possibilities:

- They could attempt to train surplus workers with the view to budgeting for the loss of employees due to AIDS-related illness and death. This, however, could result in an upward spiralling of overheads. This apart, attrition from among the workforce would also have to be additionally budgeted for (Barnett & Whiteside 2002: 242-243).

Despite all these measures, there would still be no way of accounting for the loss of productivity, due to the psychological trauma and low morale, caused by the deaths and the stigma.

- The second and in my understanding the more feasible option would be, to stimulate and foster an empowering work place -- free of stigma and supported by healthcare options to extend the productive years of PLWHA. This would enable employers to benefit from the continued presence of an existing and experienced workforce. This would also set a trend for the normalisation of PLWHA into society, which would lead the way for a just and equitable society, where the rights of all its citizens are honoured. This potential has brought stigma into the foreground of the issues associated with the epidemic.

What is slowly bringing the workplace into the foreground of the global response, is the fact that, “the majority of those likely to be affected by the virus are those who make up the bulk of the workforce at present (i.e. those aged between 20 and 40 years)” (Catalan et al 1997: 56).

Gadd & Goss have said (quoted in Catalan et al 1997: 56), “Economists can predict the average costs for services for people living with AIDS. However these direct expenses pale in comparison with the loss to society of the potential economic productivity of young people whose lives end prematurely. Add indirect costs generated by disruptions in social and economic activity caused by fear of contagion and the resulting price tag is astronomical”. The quote very subtly touches upon the hidden cost of stigma, which they refer to as, “disruptions in social ... activity”. Its validity has, in 13 years, stood the test of time.

This is the inspiration for my study. As such, the long-term objective of the dissertation is to influence policy to create a safe and productive work environment for PLWHA.

According to a PANOS handbook on HIV and AIDS entitled 'Men and HIV in Botswana' (SAfAIDS, PANOS & BNYC 2003: 8), a key step towards the removal of stigma is "creating a positive and supportive environment to encourage people living with HIV/AIDS to be open about their status without shame".

"Only when people refuse to be ashamed of their HIV status will stigma begin to disappear and the much-needed solidarity for people living with the disease begin to emerge" (SAfAIDS, PANOS & BNYC 2003: 8)

In 1987, the serving Director General of the World Health Organisation (WHO), the late Dr Jonathan Mann (Parker & Aggleton 2002: 1), predicted that the HIV and AIDS epidemic would go through three "phases":

- HIV epidemic
- AIDS epidemic
- Stigma and denial epidemic.

In this statement (Parker & Aggleton 2002: 1), Mann also observed that the third phase would be "as central to the global AIDS challenge as the disease itself". While, the three phases are not linear, but dwell and gather momentum together, the consequences of stigma are considerable and far reaching in their role in fuelling the epidemic. Not only did Mann recognise stigma, discrimination, silence and denial to be the most complex aspects of the HIV and AIDS epidemic, but he also highlighted the critical need to address them. While stigma related to HIV and AIDS still remains one of the most significant challenges faced by humankind, I attempt to contextualise it specifically to South Africa in the next section.

### **HIV and AIDS: The South Africa perspective**

South Africa has the dubious distinction of having stepped into the new millennium with the highest population of people living with HIV and AIDS. 4.7 million people, i.e. 1 in every 9 men, women and children in South Africa directly live with the virus in their body. In terms of percentage this is approximately 10% of the world population of people living with HIV and AIDS. With an estimated 500 infections everyday, the country is beset with a galloping HIV and AIDS epidemic (Barrett - Grant et al 2001: 11-12).

These accelerating numbers make it impossible to ignore people living with the virus, as they will inevitably form a more and more significant part of the workforce. While the civil society, along with various institutions of governance, is attempting to address the multiple facets of this epidemic, one of the singular aspects of this phenomenon that needs dedicated attention is the issue of the stigmatisation of people living with HIV and AIDS in the workplace. The extreme attitude towards PLWHA can be summed up in the following table:

| <b>Response</b>     | <b>Lebowa %</b> | <b>Soweto %</b> | <b>Natal %</b> |
|---------------------|-----------------|-----------------|----------------|
| Should be killed    | 23.0            | 6.5             | 22.3           |
| Should be isolated  | 45.0            | 55.1            | 65.3           |
| Should be cared for | 9.0             | 31.8            | 9.1            |

Table: 2: Attitude towards people living with AIDS (%): *Source Webb 1997: 166*

This table has been adapted from a chapter on 'Community Response to HIV/AIDS' in Douglas Webb's publication, 'HIV and AIDS in Africa' (Webb: 1997). It seeks to map community responses to AIDS by examining the attitudes of the lay population towards people living with the virus. The question asked was, "What should happen to people with AIDS?" The data was categorised into three clusters: "kill", "isolate" and "care" (Webb 1997:165). The response figures in the table do not, horizontally, add up to 100% for two reasons:

- The 3-column table has been extracted from a 6-column original, where the total responses in the horizontal rows exceed 100 (the following point explains the reason why).
- Some respondents wanted to isolate the patients while still caring for them and therefore featured in two rows, resulting in a total exceeding 100 in Webb's six column original table.

The data featured in the three geographical locations (Lebowa, Soweto, Natal) shown in the 3 columns of table 2 of this dissertation has been extracted to make a focussed observation. The responses bear testimony to the hostility and indeed violence that some people feel towards their fellow human beings living with the virus. The majority of respondents in this study demonstrate a greater inclination to subordinate the rights of the individual living with the virus in favour of the **perceived** rights of the community. The thinking being that it is permissible to kill or isolate a person living with the virus, in order to serve the community at large. No matter how one looks at the data, it is a cause for concern (Webb 1997:166).

This attitude of hostility bears itself out in action. On the 1<sup>st</sup> of December 1998 (the significance of which cannot be



overlooked, since it is the World AIDS Day), a young community worker, Ms Gugu Dlamini, was lynched by a mob in South Africa after she had revealed her sero-positive status (Barrett -Grant et al 2001: 1,37). The incident occurred in the township of Kwamashu, near Durban in the province of Kwa Zulu Natal.

In yet another instance, a South African Airlines cabin attendant, was denied employment based on his sero-status. This led to the landmark court trial, Hoffman vs. SAA 2000, where the employers stood adamant on the validity of their stand (Barrett - Grant et al 2001: 39). Fortunately, the courts supported the case of the employee and the airline's decision was overturned.

The Constitutional Court sent a clear message regarding the stigmatisation and vulnerability of PLWHA in the workplace: "They have been subjected to systematic disadvantage and discrimination. They have been stigmatised and marginalized... society's response to them has forced many of them not to reveal their HIV status for fear of prejudice. This in turn has deprived them of the help they would otherwise have received. People who are living with HIV/AIDS are one of the most vulnerable groups in our society" (Barrett-Grant et al 2001: 39). This ruling from the Constitutional Court helped set the vision for policy change in private sector organisations. These examples of stigma and discrimination made headlines, but countless other such cases may pass un-noticed. It is therefore critical, not just to understand the attitudes propelling stigma and marginalisation, but to generate studies that do so from the perspective of people living with the virus. This is important, since a rights-based policy needs to be based on the needs of all its citizens, regardless of their sero-status.

### **The aim of the study**

There is a paucity of in-depth studies that approach the epidemic from the perspective of the stigmatised person living with the virus. Seminal publications, such as, “AIDS in the Twenty-First Century” (Barnett & Whiteside 2002: 242- 270) and “HIV and AIDS in Africa” (Webb 1997: 165) have specific sections dealing with either HIV in the work context or stigma. However, these authors focus on the need to control the spread of the epidemic and the economic implications of HIV and AIDS, without elaborating on their analysis of stigma in the workplace. I therefore believe that it is very important to undertake an in-depth qualitative study from the intimate perspective of people living with the virus, exploring such emotional concepts as,

- Work and its relation to life
- Being HIV positive in the workplace
- Relationships with allies and others
- Issues of self and self-identity as they relate to pride and self esteem
- Risks and fears of expulsion from an in-group, both actual and implied.

Today, there are an estimated 4.7 million people living with HIV and AIDS, in South Africa (Barrett -Grant et al 2001:40).

Stigmatisation violates their constitutional right to equality, dignity and fair labour practices. As such, I believe that the time is ripe

for a study, which examines stigma from the point of view of the stigmatised.

The perspective of the marginalised is an important one in designing policy frameworks that attempt to counter such marginalisation. In this context, it is important to note that South Africa has a well-defined policy of rights, ranging from the architecture of the constitution to specific labour laws. However, both the epidemic and the Bill of Rights are relatively new and the laws have not yet been rigorously tested or exhaustively interpreted in the courts. As far as legislation is concerned, HIV and AIDS is only expressly referred to in the Employment Equity Act No 55 of 1998, but there are provisions in all other Acts which have relevance to HIV and AIDS (Whiteside & Sunter 2000: 158-167).

However, the Employment Act becomes the express point of reference here in South Africa, because of its specific protection for employees against unfair discrimination on the basis of their status. There are other items of policy, law and legislation that protect the rights of PLWHA though they are not specifically workplace-related. These are:

- The Medical Schemes Act No 131 of 1998
- The Proposed Notification of AIDS Disease and Death
- The Department of Health's draft National Policy of Testing for HIV
- Common Law Protection of the Right to Privacy and Dignity.

It is my belief however, that, the deep-seated nature of the stigma often results in people and organisations using their ingenuity, to stretch the interpretation of the law to a point where

it covers up for stigma. I deal with this observation in greater detail in the finding titled, "Careers- rituals of achievement". This is a pointed observation and I believe I need to substantiate it. I will analyse one loophole in the law and one unfavourable court decision.

In the Constitution Act No 108 of 1996, the Bill of Rights provides for every person to have the right to equality and non-discrimination (section 9), privacy (section 14), fair labour practices (section 23) and access to information (section 32) (Whiteside & Sunter 2000: 157-167).

The loophole lies in the fact that these rights are not absolute and may be limited to provisions such as reasonableness and justifiability (section 36) (Whiteside & Sunter 2000: 157-167). It is my belief that interpretation could provide acts of stigmatisation with potential legitimacy and therefore, escape from prosecution by the law.

The court decision I refer to is, the 1996 case of South African Airlines (SAA) vs. an HIV positive applicant for the job of the flight attendant, where SAA refused to employ the incumbent on the basis of his sero-status. SAA won the case in court by proving to the court that yellow fever inoculations were conclusively harmful for people living with the virus (a premise that has since been disproved for PLWHA with reasonably sound CD4 counts) and got away without exploring the option of employing the candidate as a cabin attendant and flying him within South Africa and/or non-yellow-fever-endemic countries (Whiteside & Sunter 2000: 157-167; Barrett-Grant et al 2001: 39).

A second and equally important reason for this particular study stems from my professional involvement with the issue of people living with HIV and AIDS in the workplace. As part of the GIPA (Greater Involvement of People Living with HIV and AIDS) initiative, I am, like all other staff members in the organisation, involved in a workplace programme. I look forward to the insights, gathered through the course of my research, to help me strengthen the delivery of the programme.

In other words, this study will contribute directly to an on-ground programme intervention. While the organisation in which the study is situated is not strictly a parastatal organisation (in the sense that it does not have any direct political authority), its mandate is to influence policy. It works with the state as a partner and influences it indirectly. As such, any influence that the study may have on policy in the workplace, will serve as a model for other organisations.

It would be pertinent to state at this juncture, that the prime focus of this study will be the sociological understanding of stigma in the workplace through the perspective of working persons, living with and aware of their sero-positive status.

My attempt will be to move the focus away from the bio-medical approach and towards a sociological understanding. As Hyatt (as quoted in Hyatt and Pollard 1999: 94) opines in this context, "Medicalisation has become one of the primary metaphors through which many contemporary social phenomena are understood and addressed. By medicalisation I mean the translation of the appearances, behaviours, or lifestyles of individuals occupying particular niches defined as socially problematic into the language of medicine. Through this process, troublesome populations become transformed from living

testimonials to the possible deficiencies inherent in the political economy of contemporary life, into patients in need of therapeutic treatment”.

The endeavour of this dissertation is to add one more study to the cause of strengthening the case for the prevention of this medicalisation. I show that my research participants, living with the virus, are indeed “living testimonials to the deficiencies” (Hyatt and Pollard 1999: 94) inherent in a society ill-equipped and unwilling to deal with people who are different. I demonstrate, through the case of one of my participants (Mary), how policy alone cannot address this unwillingness in society. In this context I explore how my participants deal with the stigma they are faced with in the workplace. I attempt to understand the extent to which people living with the virus have internalised the somatisation<sup>4</sup> of their own lives and how this affects their ability to cope with their sero-status.

The study needs a benchmark for evaluation. I have therefore, attempted to put down the purpose of my search in the form of key questions. I believe that these questions anchor the findings and summarise the queries that surface in chapters one and two of the dissertation. They are:

- *How does a person living with HIV and AIDS perceive Stigma? Does this perception shape his or her **worldview**?*
- *What is the manifestation of this perception in the workplace? How does this perception influence the activities of the workplace?*

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<sup>4</sup> Somatisation here refers to making the physical body the focus of interest. Turner (1992: 12-13) refers to the somatic society as, “crucially, perhaps critically structured around regulating bodies” .

The study findings will answer the various aspects of these questions, individually, and as a whole. The dissertation has been structured to unfold in the following manner:

- The purpose of Chapter 1 was to make the case for a study on HIV and AIDS in the workplace and set the context for the study.
- Chapter 2 provides for a sociological overview of HIV-positive stigma and its various facets. It explores not just the writings of social theorists, but also those of field practitioners living with the virus and working in the arena of HIV and AIDS.
- Chapter 3 lays out the fundamental methodology of the research study, the sampling, the data collection and analysis. It also outlines the strengths and weaknesses of the methods used.
- In Chapter 4, the findings of the study are clustered in subsections that record the experiences and responses of the interviewees (who are all people living with the virus), to the stigma and discrimination faced by them in the workplace.
- Chapter 5, provides an overview of the study, covers some key findings, the strengths and weaknesses of the study and a way forward for future research and policy.

## **Chapter 2: A sociological overview of sero-positive stigma and its facets**

HIV-related stigma remains poorly understood, particularly in developing countries (Nylabade et al 2003: 4). A review of my list of sources as well as the bibliographies of the authors named in my mine, will clearly demonstrate that studies investigating stigma are more voluminous in the West. However, the focus of most of the studies is directed towards being able to list the different types of stigma and discrimination, as a practical base to recommend remedial action. Useful as that is, I believe that (for a more intimate and sensitive understanding of the subject), it is necessary to undertake studies that view the issue from the perspective of PLWHA.

My research study was prefaced by a review of scholarship on the subject. I shall discuss the literature review in two sections. In the first section, I shall outline the broad areas of search. In the second section I shall discuss select concepts that I encountered and relate them to the subject of the dissertation.



## Areas of search

The desk research can be classified into three broad areas of search:

- **Structural framework:** My first search was for a theoretical framework to my study: to explore any meta-theory that might comprehensively situate the findings of the research. For this I read broad theories, from the classicists to the modern and post-modern theorists - Durkheim to Simmel and Parsons to Habermas (Craib 1997 & 1992; Handel 1993; Turner 1997). I did so with an analytical perspective but without partiality to any particular theory.

This area of search yielded for me the simple understanding that there were no meta-narratives that could explain a complex issue such as stigma in the workplace. For this, I re-visited some books on classical and modern theory, the names of which appear in the list of sources.

- **Interpretive framework:** Second, I studied interpretive works to understand, “the situation of the individual who is disqualified from full social acceptance” (Goffman 1986: Preface).

This scope of search directed me to a line of inquiry that helped me to glimpse into the minds of those living with the virus. For this section I studied authors writing on the issues of identity. I read authors such as Goffman (1986) (who specifically wrote about spoiled identity, and was to my mind the first to have done so in detail). Craib (1998) and Giddens (1984 & 1991), as also Sontag (1990), (who wrote an article, later converted to a book on AIDS and its metaphors). The titles are detailed in the list of

sources and some of the key concepts are discussed in the next section of the literature review.

- **Contextual framework:** Third, I reviewed some documentary sources focussing on HIV and AIDS (Among them Webb1997; Catalan et al 1997; Barnett & Whiteside 2002; Whiteside & Sunter 2000; Nyblade et al 2003). This enabled me to locate my study directly in the context of the epidemic. It helped me understand the situation in Africa and explore moral and rights-based issues.

This area of search deepened my commitment to the study and validated the criticality of my selection. Apart from books on the impact of HIV and AIDS and its various dimensions (which I name in the list of sources), I accessed articles written first hand by people living with the virus, such as Neil Patient, David Orr and Asunta Wagura. These authors have been quoted as field practitioners, to highlight and underline the concepts propounded by established social theorists, not to disprove a theory or establish a controversial perspective. They also played a part in helping me prepare for the interviews and analyse the responses of my participants who, like the authors, are living with the virus. I took every opportunity to get close to the perspective of people living with the virus. While Wagura, does not have the background of a theorist, I have included her quotations at key junctures of the dissertation in order to provide me with a first hand perspective of people living with the virus. I found that the views of non-academic authors living with the virus helped vivify, through actual experience, the views of theorists such as Goffman. I also sought out documentation from development agencies such as ICRW and UNDP and UNAIDS (the UN body that serves as a secretariat for HIV and AIDS in the UN system).

I have variously detailed the organisations, authors and dates as and when I have quoted them, as also in the list of sources.

I have, in this subsection, outlined my areas of search to provide the reader with a broad road map of my progress through the literature review. In the following section, I dwell on the substantial aspect of the literature review.

### **Theoretical concepts and their links to the study**

In this section of the literature review, I present a few of the concepts I came across. I attempt to show how these concepts relate to my understanding of the issues and how they influenced my line of inquiry.

#### **The unfulfilled search for a meta-narrative**

In the first phase of my literature review I attempted to find a meta-theory. I did this because, on the surface of things, it appeared to me that the tidal wave of the HIV epidemic had a volition and momentum all its own. It appeared to be bound on a course human beings as individual agents were unable to control or steer. Against the backdrop of this perception I was influenced by Durkheim's (as quoted in Craib 1997: 33) insistence that "there is such a thing as society and there are ways in which it imposes itself upon us; it is there and it works upon us whatever we may think about it".

Craib's (1997: 25-33) interpretations of Durkheim seemed to be even-handed and flexible. He is careful not to view Durkheim's "social facts" as "general laws in a rigorous way". He interprets

Durkheim in the broadest possible sense, as “looking for underlying causes of surface phenomena”. Craib (1997: 25-33) goes on to explain that a “social fact” is imposed upon us from the outside and “there is a large degree of compulsion about it”. He expands his argument with an example. He says that people can hardly resist the force of a “patriotic war”, nor do people knowingly render themselves unemployed, except in the context of a few specific situations (Craib 1997: 25-33).

This compulsion, Durkheim (as quoted in Craib 1997: 25-33) believes, brings about cohesion and integration in society. In Turner’s (1984: 210) language, “Society is experienced through common rituals as a sacred entity which has a life and character which stand[s] over the individual; the sacred is experienced and apprehended as massive and extensive”. Even with its limitations, it is true that Durkheim’s “social fact” did attempt to interpret phenomena beyond our control. Irving Zeitlin (1968: 5) sums up the basis of the classicist’s thought with this observation, “By knowing, understanding and recognising the main forces and tendencies of their epoch, men could determine the direction and control the consequences of these forces”.

Before I accepted the argument that there is no generalising theory of society, given its layering, intricacy and complexity, I revisited the classicists and progressed through to the structural functionalists without finding a theory that would serve as an over-arching umbrella to the study. Parsons was a progression on the fatalistic inclinations of classicists like Durkheim, who propounded the rigid meta-theory of the, “social fact” (Craib 1997: 25-33). Parsons recognised the multidimensionality of social theory and acknowledged that, “there are multiple causal processes at work in social life” (Craib 1992: 61). He first

introduced the role of the “human actor” in making choices and the importance of “goals”, “values” and “norms”, weakening Durkheim’s omnipotent concept of the “collective conscience” (Craib 1992: 37-67).

Parsons’s (as quoted in Craib 1992: 37-67) theory went beyond attempting to understand individual human action, to understanding “systems of action”. To him, the interactions of various actors constituted “systems of action” (Craib 1992: 40), bound together by, what Turner (1984: 210) refers to as, “reciprocal obligations”. Parsons’s theory takes cognisance of the role of human actors and the complexity of choices and decision-making. It does not however, as Craib (1992: 50) reiterates, “generate testable propositions about the world”. With its focus on synergy and cohesion, Parsons’s theory seemed ill-equipped to explain change and conflict in a society dealing with the manifestations of sero-positive stigma and discrimination. The bias is overtly on balance and synergy, with no focus on the structural conflict, “malintegration”, “hostility” and divisiveness society generates at a time of crisis (Craib 1992: 58). Besides, while Parsons did write about important transformations in his time, he did not address the issue that events of global proportions transform society on a historic scale, which is a fundamental flaw, for a sociologist working today, on HIV and AIDS. HIV and AIDS started as a health issue and is now directly changing laws, structures of governance, interpersonal relations in society and concepts of mortality or finitude. I deal with it in more detail later in the literature review.

The Conflict theorists addressed some of the flaws in Parsons’s argument and provided perspectives that I found useful in the

analysis of HIV and AIDS stigma. But these still didn't provide me with a meta-theory.

Lewis Coser (as quoted in Handel 1993: 74-81), a transitional theorist of Conflict, filled in some of the much-needed gaps. He brought in the issue of conflict in society and attempted to specify its role vis-à-vis change and stability. His understanding of the conflict of interests and values corroborates the principles of a preceding theorist, John Dewey (as quoted in Handel 1993: 87) and presents the perspective that conflict "prevent[s] stagnation and preserves vitality" through the "human creativity" it "provokes", resulting in "new norms and institutions". His theory differentiates the "slow" and "perpetual... change *within* a system" from the "profound... change *of* the system" (Handel 1993: 74-81).

According to Coser (as quoted in Handel 1993: 74-81), changes *of* a system are "deep" and "profound", resulting in the demise of an old order, giving way to new. Changes *within* a system are inevitable and often imperceptible. Despite the fact that Coser (as quoted in Handel 1993: 74-81) predates HIV and AIDS, the relevance of his theory lies in the fact that HIV has resulted in conflicts within organisations and communities within society. It has, as Coser points out, prevented stagnation of any sort. But, his theory has only part full-filled its prophecy in the real world of sero-positive stigma. While the sample of my study doesn't have the robustness to propound any finding as a universal truism, it shows (as discussed in the finding, "Structural perpetuation of stigma") that, change brought about by the phenomena of stigma is, after over two decades of living with the pandemic, seriously affecting the governance and management of the institution in which the study was located. But this change has not resulted in the emergence of a new system. Coser's (as quoted in Handel 1993:

74-81) premise does however validate the principle that conflict induces “human creativity”, which in turn induces positive “vitality”. The findings of this area of search are recorded in my finding, “The silver lining of progress”.

In hindsight I realise that it only served as an intellectual short cut. A rigorous journey through the literature review very rapidly disabused me of that possibility. As postmodernists like Francois Lyotard (as quoted in Craib 1997: 4) argue, “all knowledge comes in the form of a narrative”. However, I have found no meta-narrative or mother-of-all-narrative, with an absolute explanation for every phenomenon in society. While this is feasible in the world of science and mathematics, it doesn’t realistically explain society, as we know it.

This brought my early search for an umbrella theory to an end, opening up the need to understand various facets of society and human reaction to stigma. From here on, my reading threw up concepts, which I felt I could use, and I analyse them in the context of my dissertation and the views of different authors.

### **Stigma and the marginalised<sup>5</sup> other**

Having given up the search for a meta-theorist, my focus first settled on an understanding of stigma, the core concept in my study. I reviewed it through the writings of various authors, seeking out and discovering various facets of the concept as I progressed.

According to the New Oxford Dictionary (1998: 1826), the primary

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<sup>5</sup> I use the word marginalised in the context of people (person or group), who, for reasons of being different from a larger majority are treated as “ insignificant or peripheral” (*New Oxford: 1998: 1131: Col 2*).

definition of the word stigma is, “A mark of disgrace associated with a particular circumstance, quality or person”. The word dates back to the mid 19<sup>th</sup> Century and originates from the Greek work stigma that meant, “a mark made by a pointed instrument” (New Oxford Dictionary of English 1998:1826: Col 2). According to Goffman (1986: 1-2), the word is used today more specifically in the context of the “disgrace” than in the context of the “bodily evidence”.

Though Erving Goffman’s (1986: Preface & 1-5) seminal study on stigma pre-dates the HIV and AIDS epidemic by four decades, it still bears direct relevance to this dissertation. The fundamental issue is the same -- the situation of the individual who has been disqualified from full social acceptance. The drivers for this disqualification are the attributes that make people “different” and “less desirable” from others in a category, based on their “incongruity” with a set of “normative expectations”.

To explain the argument in the context of HIV and AIDS, we could say that sexual fidelity and morality is a possible “normative expectation” in some societies. The “incongruity” could be (to take an example) the utilisation of the services of a commercial sex worker. Since the transmission of the virus is often linked to immorality and illicit sexual relationships (however unjustifiable<sup>6</sup> the term may be) in some people’s cognitive maps, the person living with the virus is often disqualified from “full social acceptance” (Goffman 1986: Preface) based on this prejudice. One important observation pertaining to this disqualification of PLWHA from “full social acceptance” is that human relationships are based on perceptions, not always on facts. I discuss this in my findings.

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<sup>6</sup> It is my understanding that morality is not the issue in the sexual transmission of HIV; it is the practice of unsafe sex that is the issue.



It would be in place at this juncture to briefly sketch the historical evolution of morality as a normative expectation. This would help us appreciate the deep-rooted nature of the attitudes we are dealing with. According to Herzlich and Pierret (1987: 152-168), illness had ceased to be perceived as retribution or an act of God, well before the turn of the 20<sup>th</sup> Century. This resulted in physicians superseding the hegemony of the priests and divine retribution being replaced by treatment and therapy. “Yet”, to quote Herzlich and Pierret (1987: 52), “when the notion of illness supplanted sin, it took on its moral connotations and the body became the locus of norms par excellence”. They validate this with a quote from a letter written in 1905 by Proust to Robert de Montesquiou underlining the shift in the notion of illness. “You are, Monsieur, more cruel than the most cruel Catholic theologians, who wanted us to take our illness for punishments of our sins. You want us to consider them as faults in themselves; you want us not only to suffer physically from our ills but also think that we should feel remorse for them, that our illness[es], inevitable and painful enough though they are, should make us feel guilty as well” (Herzlich & Pierret 1987: 52-53). This perceptual shift to illness being regarded as a “social scourge” (Herzlich & Pierret 1987: 161) resulted in “a new identity of the sick” (Herzlich & Pierret 1987: 161) beginning to take shape. The ill were no longer defined by their mortality, but by a “special form of life”... a form of life that made them feel “rotten”, “tainted” and “damaged” (Herzlich & Pierret 1987: 152-168).

AIDS is today viewed as the fallout of a “morally rotten” (Herzlich & Pierret 1987: 168) social deviance. As Aggleton and Parker (2002: 8) describe it, “People with HIV/AIDS are often believed to have deserved what has happened by doing something wrong... often these wrongdoings are linked to sex or ... socially frowned upon

activities, such as injecting drug use". While it is being managed and treated medically at one level, it is also being treated morally and judgementally. It is on this perception that Goffman (1986: 7) bases his premise of stigma and the split between 'self demand' and 'self'. I expand on this split later, at a more relevant moment in this subsection.

I'd like to, at this point, get back and complete Goffman's (1986: 3) perspective on stigmatising "attributes", with which I had opened the argument in this section. Goffman (1986: 3) observes that an, "attribute that stigmatises one type of possessor can confirm the usualness of another". While this definition of his links stigma to an attribute (in the context of my study, this would be the virus or the sero-positive status of an individual), he is quite clear and unequivocal in his contention that a "language of relationships, not attributes, is really needed". He believes that stigma is not about the attribute or characteristic of the possessor, but the relationships people develop based on perceptions vis-à-vis the attribute. An important extrapolation I would make, based on this statement, is that the focus should very concretely lie in the jurisdiction of society and human relationships, rather than in a bio-medical domain. This is a very important aspect of my study, since the bulk of my interviews were discussions about relationships and how stigma affects them.

While isolating individuals from one another, the stigma also brings people together in an effort to deal with the pressures of stigma. This to my knowledge is the fundamental premise on which people distance themselves from their colleagues in the workplace as well as come together in mutually reassuring groups (Goffman 1986: 24-25). Lobby groups, such as GIPA

(Greater Involvement of People Living with HIV and AIDS), are thus formed. This perspective has been explored by me in the study, where I have attempted to find out if the sero-positive status of a person living with the virus, dominates his or her position as a human being... rendering irrelevant other qualities and attributes. I will show in my study how deeply stigma affects the self-definition of an individual. The discussion of this issue is central to my research findings.

A key aspect of Goffman's (1986:7) work, which I have touched upon earlier in this section and would like to return to, is his concept of the split between 'self demand' and 'self'. He propounds the theory that, "the standards he [the marginalized person] has incorporated from the wider society equips him to be intimately alive to what others see as his failing... causing him to... agree that he indeed falls short of what he really ought to be". This makes "shame" a "central possibility" (Goffman 1986:7), since the marginalized person's "actual social identity" (Goffman 1986:2) (attributes that the person can be proved to possess) and his/her "virtual social identity" (Goffman 1986:2) (the normative expectations of society) diverges. The person is left feeling "discredited" and "discounted" (Goffman 1986: 2-7, 34, 77).

Rose Weitz (1989: 271), who focussed on the illness experience of sero-positive people, corroborates Goffman's premise and takes it to a more complex level of analysis. According to her, the sero-positive person attempts to simulate a "sense of control", in an effort to deal with the stress of stigma. She writes about people both seeking and avoiding blood tests (that would determine their status) with the express purpose of being able to "explain their situation to themselves" thereby "making the world

seem predictable” (Weitz 1989: 271). The word “seem” in Weitz’s quote, for me, underlines the point that the whole issue of self-demand and self is perceptual. It is not, so much, about the presence of the virus in the body, as it is about the interpretations associated with the virus being there. Like for example, a person’s lack of sexual drive or deterioration of physical appearances leads the person to interpret that he/she is no more who he/she was.

David Patient and Neil Orr (2003: Email) dub these interpretations “beliefs”. “Stigma”, they say, “cannot be understood as a simple or largely conscious behaviour. If we examine and seek to understand the beliefs behind stigma, we stand a chance of doing something about it. Just like any other apparently irrational behaviour, at the core of stigma is a set of beliefs, presented as facts, that is creating discriminatory behaviour” (Patient & Orr 2003: Email). As I see it, in order to empathise with a person, we should be able to, in a metaphoric sense, step into that person’s shoes. As corroboration, I would like to refer to an exercise I have seen simulated with groups, to sensitise them to the issues of HIV and AIDS. The objective of the exercise is to help participants point the lens inwards, at their own beliefs. It is called the “Losses exercise” (Source: UNDP Video of Losses exercise, titled, “The Answer Lies Within”). While this explanation is not strictly a literature review, I am taking the liberty of narrating it as a relevant personal experience of working with the subject of sero-positive stigma.

The exercise is carried out early in the workshop with the objective of creating empathy. It simulates, among sero-negative people (or people who are oblivious of their status), an understanding of what it feels like to be living with the virus.

Participants are given ten cards each and asked to pair up for the exercise. Each card has a vital aspect of daily life written on it. Like for example 'Bodily Functions' or 'Physical Appearance' or 'Finances'. Each card has a short elaboration for explanation purposes (*Cards detailed in Annexure B*). Each participant is then asked to, at the first level, remove 5 of the 10 cards that they have in their hands and talk with their partner about how they felt giving up key aspects of their life.

Following the discussion, the exercise deepens the emotion further by asking the pairs to remove three cards from their partners' pack leaving them with only two. On this second occasion the person does not have a say in the cards that are taken away by their partner. They are once again asked to discuss with one another, and in plenary, their personal feelings about losing the three cards. The emphasis of both discussions is on what the participant feels rather than a rationalisation of the choices they have made.

My observation has been that most people are reluctant to give up any card. Since the loss constitutes key aspects of people's lives, the trauma of the loss is acute and participants grapple with the perceived consequences. When discussing the issue with their partners, the common thread in the conversation is the ***perceived loss of control*** and ***one's self-identity***. This compounded sense of loss (simulated by the participants) can be explained in the light of Bury (1988) and Shilling's (1993) argument, that chronic illness is viewed as a "social disadvantage" (Bury 1988: 91) and a "decline in the symbolic value of the body" (Shilling 1993: 186). Also, the general sense I got from the exercise corroborates Rose Weitz's (1989: 271) finding that self control and the attempted control of one's

environment is an important aspect of managing the circumstances that one finds oneself in. My observation of the participants' reluctance to part with any of their bodily functions (by way of the cards in the sensitivity exercise) can be explained by Rose Weitz's (1989) perspective that a sero-positive person attempts to simulate a "sense of control" over the situation. The exercise was a vivid demonstration of the participants attempt at dealing with the complex consequences of living with the virus, such as stigmatisation, discrimination, isolation and also finitude. Later in the literature review, I establish how this trauma of body failure manifests itself in withdrawal and isolation and the dependence on others around for "self definition".

Interestingly, another perspective to the management of one's environment and one's self-identity, comes from an unlikely source dating back four decades. Anthony Wallace (Handel 1993: 85) propounds the concept of maintaining "rituals". He states that "cognitive consensus" is not required for societal integration. Wallace analyses "ritualised and routinised" exchanges among people. He attempts to understand whether each person needed to be cognisant of the same things in order to participate in the routine. He shows quite categorically in his publication that they do not need to. All it requires, he propounds, is enough knowledge of the elements of the "ritual" to "generate the sequence" that all parties are comfortable with. A variety of different cognitive maps can co-exist to adequately "maintain rituals". He believes that people often play out roles more for the expediency of the outcome, than for any particular belief in it. As such, "organised diversity" is just as manageable as "consensus" (Handel 1993: 85). Despite the fact that the theory pre-dates HIV and AIDS by two decades, the concepts are very relevant and have been used to support my research

study. In the finding titled, "Careers: Rituals of achievement", I demonstrate the rituals of stigma in the workplace and where people stand on it. I distinguish those aspects of the sequence that were cognitively accepted and those that were ritualised.

Nyblade et al (2003: 32) in a research study for ICRW look at the phenomena from the perspective of "internal stigma". They elaborate the point to explain the manifestation of this form of stigma, "This is a complex process that involves internalising the devaluation from people around them. Internalised stigma is further complicated by the despondency and feeling of utter helplessness that comes with a condition that is believed to be a sentence of death without any possibility of reprieve". The authors go on to quote one of their interviewees as saying, "Because I have the virus in my blood, I came to understand that my father does not see me equally like his other daughters. I became sad. I felt inferiority and I realised that I am below any person" (Nyblade et al 2003: 32). Three broad themes emerge in the Nyblade et al study, showing how people internalise stigma: "They internalise guilt and blame for being HIV positive and accept their inferior status in society; they are psychologically affected by stigma and become despondent and lose hope; and they tend to isolate or separate themselves and even give up on previous aspirations" (Nyblade et al 2003: 32). Since my study probes stigma through the intimate lens of persons living with the virus, much of my findings show how people living with the virus judge themselves in the context of the virus. The study also shows the demands and consequences of this perceptual map on the workplace.

Another concept tabled by Goffman (1986: 10), is that of "secondary gains". It explores the issue of people with

disabilities using their status as a “hook” to hang “inadequacies, dissatisfactions, procrastinations and unpleasant duties of social life”. He propounds that the stigmatised often “depend on it (the disability), not only as a reasonable escape from competition, but as a protection from social responsibility”.... viewing the “trial he has suffered as a blessing in disguise” (Goffman 1986:10).

This argument was, in later years, reinforced by Giddens’s (Giddens 1984: 15; Handel: 1993: 92-93) view, that people, no matter how disadvantaged, always have choices to make and manoeuvre to exercise them. This is part of Giddens’s theory of “agency, power and mutual influence”, where he refers to “power” as the ability of agents to influence the course of events. Each agent will attempt to “influence” others to act in a manner suitable to his/her purpose (Giddens 1984: 15; Handel: 1993: 92-93). My conclusions in this regard are confirmatory. I discuss it in my finding pertaining to, “Secondary gains –subtle dynamics of assertion”.

Two areas of search that provide a different perspective to the issue of stigma are the areas of ***AIDS metaphors*** and the ***somatic bio-politics of our time***.

Susan Sontag (1990) in her treatise, ‘AIDS and Its Metaphors’ brings a certain linguistic sensitivity to the analysis. She explores the language of stigma from personal experience when she says, “Of course one cannot think without metaphors. But you must admit that there are some metaphors we might.... try to retire”. Descriptors like “scourge”, “disaster” and “punishment” applied to the virus, very naturally start applying to the person carrying the virus (Sontag 1990: 93). The purpose of her book therefore was to “calm the imagination” and “not to incite”. She paradoxically set out on her literary endeavour with the sole



purpose of depriving the language of negative meaning rather than attempting to interpret it (Sontag 1990: 102). Richard Parker and Peter Aggleton (2002: 1) in their paper on stigma underline this point, when they say, “Early metaphors- as death, as horror, as punishment, as guilt, as shame, as otherness— have exacerbated these fears, reinforcing and legitimising stigmatisation and discrimination”.

Sontag (1990: 102) talks about the very real consequence of stigma, “the metaphoric trappings that deform the experience... inhibit people from seeking treatment early enough”. She sheds critical light on the stresses and pressures people living with the virus experience, and on the restorative and therapeutic qualities of hope. Our metaphors of disorder reflect our beliefs that “death visits our bodies, not through any act of overt violence, but secretly through cancerous growth, silent viruses and humiliating strokes” (Turner 1992: 12). This belief prompts Turner (1992:12) to define the somatic society<sup>7</sup> as a social system in which the body is the “principal field of political and cultural activity. The body is the dominant means by which the tensions and crises of society are thematised”. “Feminist movement[s], pensioners’ lobbies, AIDS campaigns, pro and anti-abortion cases... safe sex campaigns, are all major manifestations of the bio-politics of the somatic society”. Turner goes so far as to propound that: we are no longer as concerned about “increasing production” as “controlling reproduction” (Turner 1992:12). While it appears to me that Turner’s perspective over-emphasises the somatic interpretation of society, my research did bring out some somatic concerns and the linked issue of mortality. The somatisation of human decisions is a key area of exploration in my literature

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<sup>7</sup> Somatic Society: A society that is predominantly pre-occupied with the body, as opposed to the mind. The word ‘Somatic’ has a Greek origin and dates back to the 18<sup>th</sup> century.

review and research. I discuss it in greater detail, under “HIV, finitude and the body stigma nexus” later in this chapter.

I would like to close the literature review on ‘stigma and the marginalised other’ with a quote that summarises the alienation and marginalisation that the shame of stigma can cause and underline once again the vital importance of this study:

***“He was not born to shame: Upon his brow shame is ashamed to sit.”*** Shakespeare, Romeo and Juliet, Act III, Scene 2

### **Stepping out of the shadow of stigma**

As is clear from the literature review pertaining to stigma, marginalisation, isolation and stigmatisation, generates stress on the individual. One manifestation of this stress is an effort to alleviate the pressure through some form of action, an effort at ***stepping out of the shadow of stigma***, if you will. The literature review shows that this effort to mitigate the stress, broadly, takes three forms,

- The secret quest for a cure
- A dependence on faith and religion
- Earning the respect of others in the workplace.

I attempt to analyse each of the three based on the perspectives of the authors who have commented on it. Among the authors, I quote, is included a person living with the virus. I do so to be able to bring the perspective of a person living with HIV.

***The secret quest for a cure:*** Goffman (1986:9) points out that marginalised people often try to make direct attempts to correct

what they see “as the objective basis of his failing”. A silent and unobtrusive “quest for a cure”, this action often renders the marginalised person prone to victimisation and exploitation by people cashing in on the vulnerability. It demonstrates the extremes to which the stigmatised are willing to go and “the painfulness of the situation that leads to these extremes” (Goffman 1986:9).

Bringing Goffman’s concept directly into the realm of HIV and AIDS, in today’s context, is Asunta Wagura, a columnist, a person living with the virus and the Executive Director of the Kenya Network of Women with AIDS (KENWA). She validates this first hand, in an article released in ‘The Profile’ section of the publication, East African Standard<sup>8</sup>. She says, “I know of a couple of so-called healers who are hawking old ropes in the name of a cure. And some of us – out of ignorance and desperation – did hang on to such ropes without much success. They gave in like worn out cotton threads by an enormous weight and brought us tumbling down faster than a falling star”. The key word in her quote, to my mind, is the word, “desperate”, because it provides us with a hook to hang Goffman’s (1986:9) theory of victimisation. Ignorance and desperation, to my mind, increases the vulnerability of a person living with the virus.

If one views the “secret quest for a cure” (Goffman 1986: 9) as being based on hope, it opens up a whole area of analysis regarding the very complex role of hope in human beings’ efforts at dealing with the epidemic. The thread of hope weaves through

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<sup>8</sup> Wagura, A: Ten Things HIV/AIDS has taught me: The Profile: East African Standard: Oct 25-31, I have quoted Wagura in different sections of the study with the sole purpose of being able to find resonance between the views of some of the theorists and everyday life.

this subsection on “Stepping out of the shadow of stigma”. I shall therefore unpack the concept at the end of the subsection.

***Sublimation through faith and religion:*** Rory Williams (as quoted in Radley 1993: 71-91) in his article, “Religion and illness” argues, religion is both a “creator” and by-product of “social experience”. The experience a person has in life, influences the importance (or lack) of religion in her or his life. According to him, parallel to the process of medical diagnosis, consultation and treatment, there is often a “moral discourse” going on. The invocation of religion at a time of illness is an effort to interpret the world in a manner in which it helps to sustain the person.

Asunta Wagura, in her article in ‘The Profile’ section of East African Standard, dwells on the role of hope and religion. In the column, ‘Asunta’s Diary’ (*dated 25<sup>th</sup> - 31<sup>st</sup> Oct 2003*), she tells the reader how AIDS, “does not kill me, and only makes me stronger”. In her self-sustaining interpretation of her own situation Wagura continues, “God [here she refers to a Christian God] has tailor made this pain just for me... He designed what I am going through. It’s up to me to decide how I will go through it”.

Wagura’s views on the calming effects of faith, are echoed and explained by the historical perspective of Herzlich and Pierret (1987: 139), who propound that, “...some of the early Christians – and this is sometimes seen as one of the reasons for the spread of Christianity in times of calamity, such as the great plague – looked upon illness more as an opportunity for redemption and salvation than as a punishment” (Herzlich & Pierret 1987: 139).

Further search on the subject took me to Littlewood (as quoted in Pollard & Hyatt 1999: 151), who talks about the prescriptive power of religion in determining the social order. “Religion” he says, “is an ideology: it both describes and prescribes, allocating the individual into the natural order. Through its otherworldly authority it legitimises personal experience and the social order” (Littlewood as quoted in Pollard & Hyatt 1999: 151). The succour that one finds in religion was visible not just in the writings of Asunta Wagura, “it is comforting to know that God is in the mix” but also in the responses of, Mary, one of my interviewees, who said, “I was the happiest person after talking to the priest”.

***Earning the respect of others in the workplace:*** Another key aspect of dealing with stigma is the effort of stepping out of its shadow, by proving oneself and earning respect in one’s place of work. This is a relatively new thought and surfaces only in recent articles and public presentations.

David Patient and Neil Orr (2003: Email), who live with the virus, write, “One aspect of reducing stigma is for PLWHA to earn the respect of others through engaging in a productive life, and not wallowing in ‘sufferer’ or ‘victim’ sympathy-seeking roles”. While this point is corroborated by some of my interviewees, my study argues the point a step further. It shows how this attempt at stepping out of the shadow of the victim role, could quite easily lead to a tendency to over-correct, often resulting in workaholism. Wagura (1-7 Nov 2003:1) reiterates Patient and Orr’s point by using vivid metaphors, when she says, “Don’t let opportunities pass you by. Opportunities are like manna from heaven – waiting to be picked. Get out of your tent and gather as much manna as you can. Despite your status, stigma and whatever baggage you are carrying around, get out and explore

the opportunities available to you. You only need to look at me to know that it is possible". A point to note is that both the commentaries I have located on this subject come from people living with the virus and both underline the importance of striving to earn the respect of the community. This effort to earn the respect of colleagues and associates, by working harder was visible in three of the participants in my interview.

### **Self and self-identity in the context of stigma**

While 'self' has been briefly dwelt with in a previous section of the literature review, entitled, "Stigma and the marginalized other", in this section I dwell in greater detail on the theoretical aspect of 'self' and 'identity'. I attempt to draw a demarcation between the identities of men and women, and show how the nuances are dealt with in the study.

Ian Craib's (1998: 75) publication, "Experiencing Identity" brings the element of psychoanalysis to social theories. He explores GH Mead's concept of "Self" and the ongoing conversation between "Me" and "I". As I understand it, "Me" is the conception of myself that I receive as a feedback from the world around me. "I", on the other hand is a more creative perspective, and constitutes my response to the world around me (Craib 1998:75). To my mind, the interplay of "Me" and "I" helps individuals form their own self-portrait. This self-portrait is a virtual one that changes with the change in variables. I show, in my study, how the portrait of "Me" is significantly affected by the effect of stigma and how it influences the self-definition of the person living with the virus. I demonstrate how the language (both verbal and body language) used to describe and deal with the epidemic and

those living with the virus, strongly influences the 'Me' and consequently the 'I'. I further show how determination and human creativity, enable some of the people living with virus, to positivise 'I' or their personal identification in response to the world.

Nyla Branscombe et al (1999: 35-58) investigate a very important niche of identity. They touch upon, not just the issue of social expulsion (as did Goffman, in his section on in-group alignment), but people's response to the ***perceived risk of expulsion***. They bring to their analysis, the element of anticipation. They say that, "when people who currently belong to the group are faced with the risk of exclusion from the in-group", facing either actual or implied rejection... the reaction of people with low self esteems (or what they call "low identifications") is to dis-identify from the group in anticipation of the rejection. In some cases the threat is not even one of expulsion but merely a "lack of full recognition", but this alone is enough to trigger the response of dis-identification (Branscombe et al 1999: 35-58). This theory intensifies the implication of what Nyblade et al (2003) call "Internal Stigma". One of my interviewees, Peter, displayed this pattern of behaviour very strongly. His frame of mind summed up in his own words, was, "...so I behave like any normal human being" - the implication is that in spite of not *feeling* like a "normal" human being, he *behaved* like one. He was, however, alone in this mindset pattern. The others had defined identities and positive perspectives to life and, despite testimonies of isolation and loneliness, did not feel driven to reject the environment and relationships.

This ability to deal with the threat to self-esteem is a factor of pride on the one hand and the complex emotions of shame and guilt on the other. Giddens's (1991: 63-69) explanations of these emotions may help us understand the drivers fuelling people's threat perceptions and inclinations to dis-identify. According to my interpretation of Giddens, "guilt and shame" (1991: 65) are part of a continuum, beginning at motivation and leading to self-identity. However, before dealing with the continuum, it is important to understand Giddens's (1991: 64-65) views on the terminologies, "motivation", "guilt" and "shame". Giddens (1991: 63) refers to "motives" as the "well-springs of action", meaning the first and primary stimulus to action. He goes on to describe it as "an underlying 'feeling state' of the individual, involving unconscious forms of affect as well as more consciously experienced pangs and promptings" (Giddens 1991: 64). In his assessment, motives are "essentially born of anxiety ... whereby a sense of ontological security is engendered" (Giddens 1991: 64). If there is a transgression, or "fear of transgression" (Giddens 1991: 64), by which a person may be concerned about things "done or not done", it results in "guilt" which in turn triggers "shame". By Giddens's (1991: 65) definition, the subtle difference between guilt and shame is that, "Guilt is a private anxiety state" while "shame is a public one". It is not germane to my argument to go into Helen Lewis's (as quoted in Giddens 1991: 65) distinctions between "overt shame" (open and directly stated, as children often do) and "by-passed shame" ("unacknowledged" and "repressed") (Giddens 1991: 65). The important point is that "shame eats at the roots of trust more corrosively than guilt, because shame is involved in a fundamental way with the fear of abandonment" (Giddens 1991: 65). On the positive end of the motivation continuum is "pride" or



“self esteem”, which enables a person to hold his/her self-identity intact as one “justified and unitary” self-biography (Giddens 1991: 66). This is an important discourse to explore because of its direct links to HIV and AIDS. The transmission of the virus is largely linked to perceptions of illicit sex, guilt and shame, and the consequent judgements of society affect the self-identity of people living with the virus. The participants of my study (all of whom were living with the virus), experienced a feeling of anxiety, which directly affected answers to the questions, “Who am I now?” and “Where do I fit in now?”

Exploring the manifestations and effects of stigma is a chapter by Lea MacDonald (as quoted in Anderson & Bury 1988: 177-202) called, “The experience of stigma: living with rectal cancer”. I believe that this is an important study to take cognisance of in my literature review, because it deals with stigma related to colostomy. Both AIDS (in its later stages) and colostomy are chronic conditions with visible outwardly signs of identification which is often used as a hook for stigma. In her study, MacDonald (as quoted in Anderson & Bury 1988: 196) explores some other correlations of stigma (i.e. other than illicit sex). Her study reveals two other correlations. The first was the correlation between “stigma and poor health”<sup>9</sup>. The second was that the, “feelings of stigma were also significantly correlated with the inability to carry out routine domestic tasks” (MacDonald as quoted in Anderson & Bury 1988: 196-197). The observation that I found echoed in my study by the participants was MacDonald’s (as quoted in Anderson & Bury 1988: 197) finding, “Those who felt stigmatised were ... likely to leave the house less frequently

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<sup>9</sup> I explore this in greater detail in the next subsection of the literature review, “ HIV, finitude and the body-stigma nexus” , through the works of Shilling (1993); Featherstone (1997) and Anderson-Bury (1988).

... [and] to be less interested in customary social activities". My study shows that the stigmatised feel a sense of isolation and some tend to withdraw into themselves and away from society.

Taking a closer look at gender differences in the context of identity, through the perspectives of different authors, I find that men and women have been socialised differently and therefore respond differently to external stimuli. "The facts of female physiology are transformed in almost all societies into a cultural rationale which assigns women to nature and the domestic sphere and thus ensures their inferiority to me [male]" (La Fontein 1981: 347 as quoted in Pollard & Hyatt 1999:153). Roland Littlewood (as quoted in Pollard & Hyatt 1999: 153) goes on to extrapolate that there is an expectation that women will "emphasise nurturance and a life dedicated to and lived for others". He emphasises the discrepancy in power and opportunity between the "dominant" and the "subdominant" groups within a community, highlighting the inequality of access and orientation between the genders. He says that women are, in most cultures, excluded from participation in the "highest powers of society" (as quoted in Pollard & Hyatt 1999: 153).

My view, extrapolating from the views of La Fontein and Littlewood (as quoted in Pollard & Hyatt 1999: 153), is that this inequality of access and opportunity leads to different orientations of the genders, resulting in different responses to similar stimuli. Let me articulate the point further. In a generalised sense the response of each gender will be similar in its own category but different from the opposite gender. A necessary rider to this generalisation is that every individual is different, and will therefore respond differently, in the same situation. My observation and those of the authors I quote

attempt to seek out and map trends to help understand the place of the human agent in the context of society. In the context of this study, these views provide for a deeper understanding of gender differences, as they relate to the issue of identity in the context of stigma. While my study was not large enough to propound a universal truth on the issue of gender differences, it was clear to me that the two genders did respond differently from one another and similar in themselves.

Craib (1998: 94), in a brief summary of Chodorow, further develops the explanation of this point, when he says that woman's "comparatively weak ego boundaries... allow them to empathise readily with the needs of others". While on the surface it would appear that Chodorow's implication is that women are thus rendered vulnerable, it is my understanding that the constant adjustment to meet the needs of others fortifies the woman better than her male counterpart, whose relatively more "defined" and "inflexible egos" haven't been oriented to come to terms with this adjustment. In my study the women demonstrated a strength and resilience that, I believe, could at one level be explained by their social orientation. Living through and for others, demands a suppression of one's own needs and wants. My analysis is that the routine enactment of this phenomenon (unjust as it is) makes the woman more resilient to the vicissitudes of the situation.

Shilling (1993: 182) provides an interesting, if somewhat esoteric, perspective to isolation. He says that the body provides individuals with a "last retreat", an "entity that appears to be a solid basis on which a reliable sense of self can be built". My perspective therefore is that if the physical body is a last bastion of retreat, it is important enough to be a fundamental axis of

definition. My finding titled, “Isolation and the physical manifestation of revulsion and pity” shows how illness and health have been perceived by physical definitions and interpretations.

### **HIV, finitude and the body-stigma nexus**

The literature review has, up to this point dealt with stigma largely at a perceptual level. I have introduced this short subsection to deepen the link between the perceptual aspects of sero-positive stigma and the body. I will attempt to put a theoretical base to the issues of the somatisation of human decisions in the context of illness.

In this section I explore Bryan Turner’s (1992: 8) concept of the “lived body”, which is an essential departure from the “disembodied consciousness” of Giddens’s “social actor” (as quoted in Turner 1992: 7). While Giddens (as quoted in Turner 1992: 7) has on “a number of occasions recognised the importance of the body... his social actor is still primarily a living, choosing actor”. In his book, “The Regulating body”, Turner (1992: 7-8) propounds the theory that the body of the social actor cannot be separated from the choices and decisions of the actor. We therefore need a theory that transcends the mind-body divide, bringing them together as one living, thinking and decision-making unit. This aspect of the theory is very critical in the light of the corporeal basis of HIV and its related stigma. In itself this argument appears esoteric; however, through the works of other authors like Shilling (1993) and Featherstone (1991), it develops a practical and usable form.

Following Mike Featherstone (1991: 52), I would suggest that the body becomes most conscious of itself when it comes into a

process of interaction with others. It manifests itself in two interactive modes: **The monadic mode**, where it is closed in on itself. This is a mode in which the body deals with itself within the confines of its surface. This mode merits understanding because, as I have observed in my study, persons living with the virus are often propelled to isolate themselves and attempt to deal with what society views as the sin of their body. **The dyadic mode**, on the other hand, is a polarised concept to the monadic mode. It exists in, what Featherstone (1991: 52) succinctly refers to as a, “relation of mutual constitution with others”. The Dyadic body, according to Knauff (quoted in Featherstone et al 1991: 52), “understands itself as a medium through which self and other are connected”. The dyadic relation is a critical concept to take cognisance of, because it can be one of “domination and force” as also one of openness and “communication”. It helps to contextualise the power interactions of, and towards, people living with the virus at one level. It also underlines the importance of openness and communication as a *modus operandi* to address stigma in the workplace, and indeed the society, at another level (Featherstone et al 1991: 51-54).

Having addressed the concept of the “lived body” (Turner 1992: 8), I will now turn to the issues of value as it relates to the body. According to Shilling (1993: 186), “Social systems incorporate within them a variety of social fields which attach values to different types of bodies”. Human beings attach significant value to the “living, acting body”. Illness and old age bring with them a “decline in the symbolic value of the body” and death constitutes the “ultimate end of the self... Consequently, it should not be surprising if the prospect of dying makes individuals particularly anxious. For individuals whose self-identity has become closely connected to their body, death [or debilitation, I argue] is

disturbing because it represents an [erosion and] end to value in a world geared towards the accumulation of value” (Shilling 1993: 186). Mike Featherstone (as quoted in Shilling 1993: 186) further argues that the values attached to particular bodily forms differ, often making people uncomfortable about their embodied selves. This discomfort is not without its consequences. As Michael Bury (as quoted in Anderson & Bury 1988: 89) interprets it, “Suffering the onset of symptoms involves changes in the body and in the social relationships which are already likely to be complex”. In the quote Bury takes interpretations of the body from its “instrumental capacities” to the “symbolic domain”. He shows how chronic illness can “create both activity restriction ... and social disadvantages”. The “social disadvantage” comes from stigma; the fear of which derives “not so much from the disability as from the significance accorded to the conditions by others”. This is significant in the light of the “Losses exercise”, which I described in an earlier section. In the exercise, participants in an HIV and AIDS role-playing and simulation process were extremely uncomfortable with the thought of having to lose their appearance and bodily functions. This compounded sense of loss (simulated by them) can be explained in the light of Bury (1988) and Shilling’s (1993) argument, that chronic illness is viewed as a “social disadvantage” (Bury 1988: 91) and a “decline in the symbolic value of the body” (Shilling 1993: 186). Going a step further and linking it to stigma, my understanding is that people view HIV as being responsible for an irreversible slide towards debilitation and death... a final loss of all value. This attitude, consciously or otherwise affects perspectives about people living with the virus; equally the views of PLWHA about themselves as also the views of the general population.

Kathy Charmaz, in her 1983 publication, “Loss of self: A fundamental form of suffering in the chronically ill”, focuses on the trauma of body failure. She deals with it, not just from the angle of the direct consequences of body failure, but also from the perspective of the social consequences. She shows how this manifests itself in the person believing that she or he becomes a burden to society and the family, resulting in withdrawal and isolation. She shows how illness propels the person to depend on others around for “self-definition”, which simultaneously strains the relationships (Charmaz 1983: 190; Rinken 2000: 71). The relationship dependence on one hand and withdrawal and isolation on the other is a complex phenomenon. While I did perceive withdrawal and isolation among most of my interviewees, in some form or other<sup>10</sup>, I was in no way able to link it to Charmaz’s phenomenon of “body failure” (Rinken 2000: 71).

Shilling (1993: 2) propounds that, the modern age has desacralised social life. Yet it has failed to replace “religious certainties” with “scientific certainties” of the same magnitude. He continues to argue that science may have increased our control over life, yet it has failed to provide us with the values that would enable us to guide our lives. There is instead, what Shilling (1993: 2) calls, a “privatization of meaning”, leaving “individuals alone with the task of establishing and maintaining values to make sense out of daily lives”. Consequently, it is my understanding that this lack of a strong and sustainable value base has resulted in human being’s inability to withstand the interpretations and pressures of stigma.

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<sup>10</sup> Peter, one of the participants in my interview said, “ ... I just want to be all by myself” .

Sebastian Rinken in his publication (2000), “The AIDS Crisis and the Modern Self”, takes the issue of ‘self’ and ‘identity’ more specifically into the terrain of HIV and AIDS, focussing on finitude and “the intense awareness of being mortal” (Rinken 2000: Preface). It is important to state that Rinken’s (2000: Preface) pre-occupation was not on the rates of mortality or the time of death. His focus was “exclusively on the patterns of thought” that the prospect of death generated among people living with the virus. He talks about the “biographical disruption” experienced at the time of diagnosis (Rinken 2000: Preface). It is Rinken’s (2000: Preface) premise that the disruption of a person’s “biographical self-construction” disrupts in turn a person’s pursuit of “self-actualization”. To me it meant, ‘who I am’ will determine ‘what I am able to make of myself in life’. As such, if I believe that my life expectancy is to be shorter than I had earlier planned for, I will be forced to reset my goals and the journey to it.

Despite its relative chronological recency, Rinken’s (2000) testimonials on finitude vis-à-vis HIV and AIDS are already losing some of their relevance, since it pre-dates the discovery of anti-retroviral (ARV) treatment. I believe that the life enhancing capabilities of ARVs will, increasingly in the future, influence the perspectives of people living with the virus, tempering and modifying their feelings of mortality. As Robert Anderson and Michael Bury (1988) say in the conclusions to their book ‘Living with Chronic Illness: The experience of families’, “What were once life-threatening conditions have now, in many instances, been turned into chronic ones. An ‘extension of morbidity’ occurs often involving the unintended consequences of treatment” (1988: 250). While the shift (of HIV and AIDS) to becoming a chronic illness has far from begun in Africa, it is possible that finitude will in the years to come play a diminished role in the



context of the “self construction” of people living with the virus. My study, however for now, assumes Rinken’s (2000: 204-215) observation of finitude and disruption as given, and attempts to build on aspects of disruption in the context of stigma in the workplace.

### **Myth of incompetence and the denial of resources**

I have introduced this subsection because it is, in my understanding, one of the most important physical manifestations of stigma in the workplace. It is also a form of stigma that people living with the virus are very apprehensive about, because it could lead to job loss and impact upon the livelihood of persons living with the virus. To quote Ruth (one of my interview participants), “I am supposed to be communicating policies to staff, whereas the policy does not even cover me, the person who is preaching it to the staff members. So I feel grief and pain about that”.

I have placed this subsection last in the literature review because I believe it is best understood against the backdrop of the various cognitive maps and processes dealing with stigma that have preceded it.

Obvious as it may seem, it is important to state that, managers, supervisors and heads of offices and departments are just as human and just as much products of the socialisation process as the staff they lead. As a result of this, it is reasonable to expect that, they could, in some cases be forming, interpreting or executing office policy that is contradictory to their personal beliefs.

This observation echoes Gadd and Goss (as quoted in Catalan et al 1997: 56), who in their paper state what they believe to be the

predominant interpretations of the managers. To quote them directly, “confronting HIV/AIDS pro-actively in the workplace is often problematic. For example, many managers and personnel specialists dismiss AIDS as a non-issue for companies or as someone else’s problem. They refuse to regard the issue as part of their problem”. The credibility of this particular observation lies in the robust nature of the sample size<sup>11</sup> it is based on. This makes the denial of personal responsibility an important perspective to explore. My finding in this regard, details, confirms and emphasises Gadd and Goss’s observation. It also shows the lengths to which people go to perpetuate the stigma in the workplace (Gadd & Goss as quoted in Catalan et al 1997: 52).

Irene Jillson-Boostrom (as quoted in Ahmed 1992: 123-135) in a chapter entitled, “Workplace Issues and Strategies Concerning HIV” (published in Paul Ahmed’s book, *Living and Dying with AIDS*), highlights three myths that she believes fuels stigma in the workplace:

- Myth1: AIDS is a contagious disease that can be spread by casual, nonsexual contact
- Myth2: Those who are HIV-positive are as sick as those who have progressed to having symptoms of the disease
- Myth3: Once someone has the disease, he or she cannot really function at work.

Patient and Orr (2003: Email) have also echoed, Jillson-Boostrom’s 3<sup>rd</sup> Myth in their paper on stigma. They dig deeper into the underlying cause of the myth. According to them this myth essentially implies the “withdrawal of support from those who are

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<sup>11</sup> The Centre for AIDS and Employment Research (CAER) conducted an in-depth study on attitudes, definitions and values in the workplace, both managerial and workforce. It covered a total of 106

perceived as no longer able to contribute to the survival of the group". This is the instinctive outcome of "a group survival strategy, which has been a survival strategy used throughout human history, namely utilitarianism". It is, according to Patient and Orr (2003: Email), more predominant in resource poor societies, as it is directly linked to the unequal distribution of wealth. As such decision-makers at all levels (through the sheer force of orientation), use yardsticks to judge who merits or deserves resources and who doesn't, resulting in the possible denial of resources and rights to people living with the virus.

Nyblade et al (2003) in a study that has synergies with the theory of the previously quoted authors Jillson-Boostrom (as quoted in Ahmed 1992) and Gadd and Goss (as quoted in Catalan et al 1997), through their findings on the ground, have tracked stigma and discrimination in three countries of southern and eastern Africa. The study shows, in sheer numbers, the consequences of the myth of incompetence, on the livelihood of people. The authors have documented a large number of cases where resources and livelihood are denied to people living with the virus. In Ethiopia alone, for example, 61% of the respondents said they would shun vendors with HIV or AIDS.

Patient and Orr (2003: Email) have an explanation for the reason why this form of stigma happens. "For two decades", they say, "we have been drumming the same death and fear message into communities concerning HIV and AIDS, and we act surprised and outraged at the stigma that emerges? We try to motivate through fear – terrifying all and sundry about HIV/AIDS - and we don't understand why people respond with irrational rejection of

those infected? Why is it so strange that people act from terror when we have told them to be terrified?” It is an explanation that corroborates Sontag’s (1990: 102) opinion that there are “some metaphors we might ... try to retire” and Parker and Aggleton’s (2002: 1) view that there has been language in use that has, “exacerbate[d] these fears, reinforcing and legitimizing stigmatization and discrimination”... and lends credence to this aspect of my study.

I have in my study gleaned material that directly dispels the myth of the dysfunctionality of people living with the virus. I demonstrate in my findings how, contrary to common belief, people living with the virus often step up their output to earn the respect of the system that they have to survive in.

To end this subsection on a note of hope, the CAER (Centre for AIDS and Employment Research) programme has emphasised the notion that “obligations to humanity and the organisation are not in fact mutually exclusive, but are reconcilable” (as quoted in Catalan et al 1997: 57). It is my belief that more studies like mine would help stimulate a deeper understanding of the issues of people living with the virus and mobilise positive change in society.

### **Conclusions to the review of scholarship**

I have deliberately dealt with concepts emanating from my readings, largely as inquiries, in the section on literature review. Addressing these inquiries conclusively in this section, I believe, would dilute the focus of the section on findings. I feel that this approach will give the reader a contextualised insight to my thinking before I embarked on the fieldwork. I have left the

focussed analysis of the concepts for the section on findings, where I draw upon the relevant aspects of my learning from the literature review.

At this juncture I briefly summarise the focus areas of the six sections of the literature review:

- **The unfulfilled search for a meta-narrative:** There are no meta-narratives that would help understand or frame the situation of stigma in the workplace. The interpretive works were the most beneficial, as vehicles of analysis. While none were able to embrace the subject in its entirety, they did offer key areas of search.
- **Stigma and the marginalised other:** This section deals with the normative expectations of society and the attributes that make people different and less desirable from others in a category.
- **Stepping out of the shadow of stigma:** This section covers the efforts of individuals to alleviate the stresses and pressures of marginalisation, isolation and stigmatisation.
- **Self and self-identity in the context of stigma:** This section analyses how stigmatisation and marginalisation causes feelings of shame and guilt which affect the self-identity and self-esteem of people living with the virus. Over and above the theoretical aspect of the definitions of self and identity, this section also draws attention to gender differences in the context of identity.
- **HIV, finitude and the body-stigma nexus:** This section deepens the link between the perceptual aspects of sero-positive stigma and the body. It shows how the body becomes conscious

of itself when it comes into a process of interaction and unpacks the value system that contextualises this interaction.

- **Myth of incompetence and the denial of resources:**

This deals with the physical manifestations of stigma in the workplace. It analyses the myth that people living with the virus cannot function effectively in the workplace.

Some of the broad conclusions of the literature review:

- While studies in the social sciences and the development sector have covered stigma, discrimination, finitude and the issues of self-construction, they have left out its ***first hand biographical manifestations in the workplace.***

- Given Goffman's location in time, and the seminal nature of his work, most of the authors working in the area of stigma, use Goffman as a frame of reference. I as a researcher have been no different. Authors variously corroborate, expand and contradict his concepts; as such he finds mention at numerous junctures of my literature review. However, I have attempted to avoid the trap of ***presentism vis-à-vis Goffman.*** My view is that Goffman's relevance lies in the understanding that, the imposition of a stigmatised identity can cause severe "biographical disruption", robbing individuals of their selfhood, thus allowing for their marginalisation.

- HIV and AIDS being a relatively new and constantly evolving phenomenon, there is scope for intense research in the area. The focussed need is for ***depth studies that attempt to understand issues,*** rather than validity research. This is particularly so in the southern hemisphere and developing countries, which have a smaller body of scholarly work than the northern hemisphere. While I was able to locate literature on

stigma, I was not able to locate significant material on stigma in the workplace, and none on stigma in the workplace from the first-hand perspective of a person living with the virus. This I believe underlines the criticality of my study and the need for more studies exploring stigma in the workplace from different angles.

- “At least 60 million Africans have been directly impacted by AIDS: 30 million people are living with the ... virus, more than 15 million have died from AIDS, and more than 11 million have lost at least one parent to the epidemic” (UNAIDS 2003: 7). This propels a different sociological phenomenon than in parts of Europe and North America where the HIV and AIDS populations are less than 1%, further underlining the ***need for sociological studies in countries like South Africa.***

The most important conclusion of my literature review was that I was most comfortable following an **inclusive strategy of analysis**, rather than one in which I adopt a particular paradigm, concept or genre as either an umbrella or a motherhood precept. I have taken a pot pourri of concepts, from a range of writers (representing different genres and paradigms) and brought them together to understand, explain and contextualise my findings.

This strategy for analysis has been, at once, both enriching and constructive as it has borrowed from the arguments of each author, without being confined by the boundaries or obsessions of any one of them.

On a more personal note, I would like to say that the literature review has been an exciting exercise in discovery...

materialising from unexpected quarters of my life, not merely libraries.

Asunta Wagura, for instance, came into my research providentially on two flights in and out of Nairobi's Jomo Kenyatta International Airport en route to Addis Ababa. By a sheer stroke of luck, both flights were on Saturdays -- the day on which the Eastern African Standard, published out of Nairobi, carried the profile feature, 'Asunta's Diary'.

David Patient and Neil Orr came into my paper unsolicited, through an article emailed to me by a colleague.



### Chapter 3: Methodological considerations

The nature of the topic demanded a qualitative research approach focussed on exploring and understanding attitudes at the workplace. The research was therefore qualitative in nature and based on personal in-depth interviews and observation.

The paucity of research on the subject determined the nature of this study. The research has been conducted as a **knowledge building exercise**. I have viewed the study as a **learner** rather than an interpreter. It is important to state that the study was not an exercise in information generation or a commentary on known and well-researched social situations. The research design was structured to be **exploratory**. It was descriptive in nature and captured individual emotional discourses. The purpose of the design was to discover concepts and ideas, which would later support mechanisms that address the issue. As a result, some of the testimonies are quoted exhaustively to give the reader an idea of the emotional landscape of the interviewee.

The significance of this study is its attention to the little represented PLWHA experience. It attempts to be coherent in its singular focus on the integrity of the PLWHA voice.

**Data collection format:**

The *primary sources of data* were **personal interviews** using the principles of Appreciative Inquiry. I have used the principles of **Appreciative Inquiry** in my approach to the interviews because I believe that it provides a safe space (psychologically speaking, for the person being interviewed) for dialogue. As a principle it attempts to build on what already exists in a system or in a person's mind, instead of being interrogative in nature. To quote Joe Hall and Sue Hammond<sup>12</sup>, "Appreciative Inquiry works on the assumption that whatever you want more of, already exists in all organisations". As such, the line of questioning appreciates that there are "multiple realities" and that it is therefore "important to value differences". The data captures personal histories, through personal narratives and individual, intimate anecdotal evidence.

It is important to state here, the reason for the selection of personal in-depth interviews rather than another valid qualitative technique, focus group discussions. Qualitative studies are judgemental to a large extent and often tend to follow the instinct of the researcher. My personal reasons for the selection of in-depth interviews are as follows:

- Focus groups tend to highlight common patterns of attitude rather than significant individual emotions. We are already aware of the attitude patterns of stigma and discrimination - what this study is attempting to do, is probe individual responses.
- Second, discourses of stigma, shame and otherness, no matter how sensitively handled, are difficult to probe in the public setting of focus groups.

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<sup>12</sup> (Hall & Hammond:  
<http://lib1.store.vip.sc5.yahoo.com/lib/thinbook/whatisai.pdf> : 1-3).

- Finally, focus group discussions require the introduction of external stimuli to lead the conversation. These external stimuli are, by their very design, self-referential. They tend to restrict thought processes within the boundaries of the stimulus and are therefore too limiting and close-ended for the quality of conversation that this study requires.

**Interview sample:**

The selection of the sample permitted me, the researcher, to view the universe as a coherent one. The universe is a single organisation and the interviewees are agents (past and present) within this universe.

The selection of interviewees was based on pre-selected criteria:

- They were all directly working with or closely associated with the organisation selected for the study. One interviewee had recently lost her job with the same organisation.
- They were all living with the virus and had disclosed their status, either partially or completely (partially because, some had informed only their office and were phasing the process of disclosing their status socially).
- All interviewees volunteered for the interview. They were informed that it was for a dissertation on stigma in the workplace and that their names would not be disclosed in the study.
- They all agreed to one-on-one, private and first-hand interviews.

- This constituted a complete universe of six. While we can assume that there were larger numbers of people living with the virus, only six matched the criteria. The interviewees had to have disclosed their status and had to be willing to participate in the study.

As a result of these criteria, six was the maximum number of interviewees available within the homogeneous context of the sampling criteria.

- It is important at this juncture to weigh the strengths and weaknesses of my total sample of six. The weakness lies in the fact that it is not feasible to come to any universally applicable conclusions with a sample of six. The sample is not large and robust enough for that. Also, it is not a large enough sample to naturally acquire a robust representation of both genders. The strength however lies in the fact that they were all part of one homogeneous work ethos and one over-all management structure. This makes the universe a contained one and therefore representative, despite the small numbers interviewed. If the research had been carried out across 2 or more organisations, it would have lacked homogeneity due to different structures and varying HIV and AIDS policies. As such, even with a sample of six, my study constituted a realistic universe of a kind. The manageable sample size permitted very detailed in-depth interviews, providing a rich data source of exploratory findings. These explorations provide suitable material for future research possibilities.

While the methodology is designed to explore stigma in the workplace through the perspective of people living with the virus, it is inadequate as a methodology to validate the

findings and universalise it. That will need to be the task of larger research initiatives undertaken in the future.

**Note on the selection of interviewees:**

- A total of five interviews were concretely usable, though six interviews are processed in the study. The exercise began with six interviewees in all. Two men and four women. The third interviewee, a man, was interviewed but the quality of the recording was inferior hence the transcription could not be completed. The interviewee was not accessible for a second interview, as he had taken ill and was not attending work. As such, there were only five data rich interviews for analysis.
- The premise of confidentiality made the location and accessibility to the PLWHA who have not disclosed their status, restrictive; as such we were looking at a very small sample for the survey. This is a reality that the study has respected and worked with.
- The names and contact details of the interviewees are available with the researcher and retained for reasons of confidentiality.
- I have, for reasons of convenience and empathy, given the interviewees, pseudonyms for this study, instead of the de-humanising option of referring to them as 'Male Interviewee 1' or 'Female Interviewee 2'.

The names have **not** been selected randomly. I have picked names from the **Bible** for all the interviewees. The reason is simple. I found a very strong reconnection with faith among the interviewees. It has given a number of them a reason to live and a belief in the future. As, my fourth interviewee, whom

I shall name Mary, said, “I am a born again Christian”. So, my interviewees, are:

- Interviewee 1: **Peter**: Age 34
- Interviewee 2: **Ruth**: Age 39
- Interviewee 3: **Paul**: Age 28
- Interviewee 4: **Mary**: Age 28
- Interview 5: **Naomi**: Age 46
- Interviewee 6: **Judith**: Age 42.

#### **Data collection method and fieldwork practice:**

The complexity of the situation of people living with the virus and the issues of confidentiality demanded a sensitive approach to the process and a phased access to the interviewees. I couldn't for instance go directly up to a potential candidate whom I did not know and approach him or her for an interview. The subject matter was too sensitive for that. Also, and more importantly, it would have been a gross violation of the person's Right to Privacy and Confidentiality<sup>13</sup>. As such, the following phased procedure of access, based on confidentiality and trust was to my mind the best course of action:

The interviewees were identified with the help of the organisation's co-ordinator for HIV and AIDS in the workplace, who was briefed about the above-mentioned criteria. She (as a

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<sup>13</sup> I refer to section 14 of the Bill of Rights in the Constitution Act No. 108 of 1996 (*Whiteside & Sunter 2000:157-167*).

person who had their implicit trust) then approached each person individually. Her task was to,

- obtain their consent for the interview
- secure their availability for the interviews
- provide them with a brief of the objective and outline of the initiative, so that they could feel comfortable with the process.

I asked to be given access to the names only after they had consented to the interview. I also asked not to be told of any name or occasion where a person had refused to be interviewed. This respected the Right of Privacy under Section 14 of the Bill of Rights. The Right provides privacy for all. This means that, “If you have HIV or AIDS, you have the right to keep that information to yourself” (Barrett-Grant 2001:83). The six interviewees had disclosed their status earlier and had all given the coordinator and the researcher (me), their consent for the interview.

The coordinator sought a suitable time from the interviewees, which matched my availability and then typed out a list of contact details and interview times (after consulting all parties concerned). Some preferred to be interviewed at lunch time, others preferred to be interviewed after work.

Each interview took between 1.5 hours and 2.5 hours. One interview took three hours in two separate instalments, since the interviewee re-contacted me and expressed her inclination to extend the interview as she had more to say on the subject. This request was honoured.

The interviews were conducted in the privacy of an office room and recorded using a dictaphone (with the permission of the interviewee). The door was shut, to avoid the carriage of voices speaking in normal tones, but not locked. The interviewees were advised that they could conclude the interview at any stage they chose to, without the need to give the researcher a reason for doing so.

I was careful to maintain a relaxed atmosphere and provide a comfortable and non-judgemental space for the discussion. We sat together at a round table, on two separate and identical chairs, to avoid the intimidation of power seating. My opinion is that, in the intimidating construct of a power seating arrangement the interviewer would have sat at the head of a rectangular table with all the signals and trappings of power, such as telephones, special chairs etc. on the side of the interviewer, to demonstrate who was in charge of the conversation. I also checked with them about the room temperature and adjusted it to their comfort. I offered tea and in one case, lunch. The person who was offered lunch accepted the offer and asked to carry the food away after the interview. This was arranged. I was also careful not to register any judgemental reactions to the interviewee responses. I felt that it was important for me to signal to the interviewees that anything they had to say was fine and acceptable to me. This, I felt, was important to induce spontaneity. Comfort with the environment lead to the spontaneous display of emotion and often, candid conversation.

While the questionnaire was pre-planned, it was used largely as a guideline for discussion and expression, rather than a rigid sequence of questions. The questionnaire is attached as an annexure to this document.



The interviews were recorded on tapes, which were then handed over to an independent and professional transcription organisation called Datafer. Datafer professionally transcribe court proceedings for courts and law depositions as also transcribe medical proceedings. They transcribed the interviews on an urgent basis in one week and provided the outputs on A4 size sheets in double spacing format. The transcriptions were then electronically transferred to me on email. I commented on them and sent them back for a final copy in electronic form. The transcriptions were then ready for use in 'data mining' (a term I have explained in the section on terminologies, at the beginning of the document). The electronic copy was then sent to the Psychology Department of UNISA for an analysis on the emerging trends and thoughts, using the Atlas.ti software. The software was first used to codify the text for easy access. It was codified by interviewee and then by concepts.

The data mining process, using CAQDAS software, and the methodology, is outlined in the following section on 'Data analysis'.

#### **Data analysis method:**

The analysis of the data is based on some of the dominant themes emerging from the study. In an effort to do a thorough mining of the data, I used a Computer-Aided Qualitative Data Analysis Software (or CAQDAS) called Atlas.ti.

More than a mere retrieval package, it served as a code based theory builder for my qualitative research. It provided me with the opportunity to codify every aspect of the interview on the basis of search guidelines set by me. Having been both the interviewer

and the researcher, I fed the CAQDAS software with a set of key concepts to codify the data. The software then arranged the data, giving me clusters of quotes to review and use. The interviews were coded by participant and by the concepts (elaborated in the next section).

While the software cannot replace the researcher's own analytical input and considered judgement, it enables the user to be thorough and exhaustive with the analysis. It also clusters and arranges the transcripts for quick and easy access to data.

#### **Selection of concepts for codification:**

The concepts were selected on the basis of:

- the context of the subject -stigma in the workplace
- the emotions that accompany stigma
- the intuition of the researcher
- manageability.

The entire study on stigma was situated in a work environment, with its related associations, such as **career**, **achievement**, **commitment** and **failure**. These four codifying concepts helped me to contextualise the study to the work environment.

In order to capture the cues that accommodated some of the associated emotional responses, I selected codifying concepts that were both positive and negative, such as, the feeling of being **outcast**, **loneliness**, and **isolation** were selected as negative concepts. For positive concepts I used the broader

ambit of, **positive emotions**. For neutral concepts, I selected concepts that could go either way depending on the interviewee's mindset, such as **future driven**. The concept, **combination of emotion** was suggested by the software analyst, as there were some statements that were neither positive nor wholly negative, but a mixture of the two. To directly capture a key aspect of my study, personal identity, I selected the concept, **sense of self**. The concepts were restricted to a total of twelve so as to keep it manageable.

It is important to note that these were not questionnaire guides, nor did they lead the interviews or influence them in anyway. They were post facto structures designed to provide easy access to the data. They served as a filing mechanism, which enabled me to access the data on the basis of the research needs. While the theory still has to be developed by the researcher, the software makes access and structuring easier.

The broad concepts I used to codify the interviews generated 400 quotes for analysis. Below is a table showing the concepts and the cluster of quotes, CAQDAS generated, against each code:

| Concepts                | Quotes |
|-------------------------|--------|
| Achievements            | 12     |
| Career                  | 44     |
| Combination of Emotions | 13     |
| Commitment to Work      | 23     |

|                       |            |
|-----------------------|------------|
| Failures              | 13         |
| Feeling Cast Out      | 79         |
| Feeling Lonely        | 8          |
| Future Driven Emotion | 30         |
| Isolation             | 26         |
| Negative Emotions     | 58         |
| Positive Emotions     | 52         |
| Sense of Self         | 42         |
| <b>Total</b>          | <b>400</b> |

Table: 3: Number of quotes generated by Concept using the Atlas.ti software

The table shows that the data has generated 400 quotations in all, across all the concepts. The single largest majority of quotes (79) were generated under the feeling of being outcast. Given the fact that stigma was the focus of the discussion, it was natural that it was concentrated in this fashion. The numbers themselves are of no real significance, for a few reasons:

- My study is not a trend analysis.
- The questionnaire is not rigidly structured to ensure that each interviewee was asked the same questions. Hence generalised comparisons are not feasible in this study.
- The sample size is not robust enough for such a study.

- It is also important to note that the questionnaire guidelines were designed to be exploratory and to stimulate the interviewee to open up and explore new areas of thought.
- I feel that it is inadvisable to force the emerging thoughts into the structure of predetermined concepts. That will result in the loss of spontaneity in its articulation.

For the expediency of analysis, therefore, I shall not be using these concepts to structure the findings. The findings will be structured around emerging themes. They will be advised by the literature review for contextualisation and analysis. The Atlas.ti computer run will have served the purpose of making the data manageable and easily accessible, in homogenous categories.

**Sample: A psychographic profile:**

Interviewee 1: **Peter:** Age 34: Peter holds a lower ranking administrative job. He has a simple desk like the other staff at his level. He is a frail, slightly built man of nervous disposition. His speech was unclear and he tended to trail off at the end of his sentences. This was particularly so, when he said something he felt might meet with censure if his supervisor found out.

He did not appear to have fully come to terms with his sero-status, despite being the only one of the interviewees on ARV medication. As a result, the underlying tone of his testimony was that of a complaint. For example, the tenor of his conversation is reflected in these typical statements, “So far there are very few good days in the office, because I am really under pressure” or “I wake up very sad. And I find it very difficult to come to office”.

This view however needs to be contextualised to his situation in life. He has lost his partner and child to the epidemic and tends to live a reclusive life. He has moved away from his parents and siblings. He lives on his own despite the inconvenience of doing so. While he has a good relationship with his family and goes to them if he needs help, he prefers to live separately. When I asked him if he had friends, he said, “Well, I do not have friends”. And then as an afterthought added, “The colleagues are, you can say, are my friends... because I sometimes... need to share my pain”.

Interviewee 2: **Ruth:** Age 39: Ruth is a middle-management person. She has her own room, to provide her with the

opportunity to interact with people in private. She is confident, articulate and seemed very comfortable with her sero-status. She called back the day after her interview, asking for more time. She did her interview in two parts. She talked about being “drawn” into her work and “feeling the fruits” of her efforts. In a moment of candid insight she even told me, “I have grown”... learning from other people who are living with HIV, “because they come in with completely different angles... to what you experienced”.

She was also my focal point for access to the other interviewees.

Interviewee 3: **Paul**: Age 28: Paul, whose interview wasn't transcribed properly, is a low ranking staff member. He has no workstation, in the traditional sense of the concept. He works with his colleagues in the same conditions they do. The conditions are physically demanding and entail long hours. No special concessions are made for Paul.

He was mild mannered and talked about a mentor within the organisation, whom he went to for succour. The mentor was an older woman, who was like a caring mother figure. She treated him like her son and he was drawn towards the comfort this provided. He also went to the church on sundays. He seemed concerned about being able to continue the long hours at work, without the aid of ARVs.

Interviewee 4: **Mary**: Age 28: Mary, when she was working, had a similar workstation to other staff carrying out secretarial duties.

Discrimination against her was verbal and subtle and neither space nor location driven.

She was in the toughest situation, having lost her job and given up ARV medication. She was however, calm, composed and articulate. She has made every effort to sustain herself with affordable home remedies and depends on the church for her strength and support.

Hope is the emotion underpinning Mary's life, "I went to a church and got counselled by a preacher. And he told me that I can defeat this. You know, I am the happiest person after talking to the priest".

Interview 5: **Naomi**: Age 46: Naomi, shares a room with another consultant (whose sero-status is understood to be negative) and the sharing is mutually comfortable and supportive.

Naomi is well paid. She is however not on ARVs and chose to steer clear of it till it becomes imperative for her to take it.

She is soft-spoken, but confident and articulate; she was also open and frank in her discussions and did not steer away from sensitive questions. She spoke about her sexual relationships and the manner in which she contracted the virus, with a great deal of composure.

Interviewee 6: **Judith**: Age 42: Judith was the most energetic and vivacious of all my interviewees. A middle management person, she demonstrated the greatest confidence in the



manner in which she occupied her portfolio in office. She appeared focussed on her assignment and very hard working.

She negotiates her rights within the organisation with a great deal of courage and fortitude.

She controls her viral load through positive living and good eating and steers clear of ARVs. She doesn't believe she could sustain the expenses of ARVs. However, she also believes that positive living and a nutritious diet is sufficient for her health.

One interesting fact about Ruth, Naomi and Judith is that they were all (at the time of the interview) living with sero-negative partners, whom they met after coming out with their status. None of them lost their partners to prejudice.

### **Setting: A profile of the workplace**

I am, on principle, concealing not just the identity of the interviewees, but also that of the organisation. I am doing so for two reasons. First, I believe that identifying the organisation will make it easier to identify the interviewees. Second, I believe that some of the findings may be better accepted if they provide the objectivity of unfamiliarity. Directly identifiable examples are often viewed as accusations and demand a defence. As such, I shall refrain from identifying the organisation.

The organisation is a global parastatal organisation, with a defined policy for HIV and AIDS and an HIV and AIDS workplace programme for the staff and their families.

A value-based organisation working in the development sector, it is structured to be politically correct and non-discriminatory. As

such, there are no obvious and visible signs of stigma in the day-to-day management of the organisation. The stigma is therefore silent and usually driven by individuals, often ill informed and personally prejudiced.

While the organisation is an old and established one, with long-term systems in place, the HIV and AIDS policy is relatively recent. Though egalitarian and well meant, the policies are, like most policies, open to interpretation by the staff. The sense that I got from the interviews was that the implementation of the policies at various levels was based more on benevolence than belief. My study findings under “Structural perpetuation of stigma” elaborate this point.

These are the salient features useful in the analysis of the data.

## Chapter 4: A discussion of the study findings

### **An introduction to the study findings**

While I will be making some factual recommendations leading from the research findings, the research findings themselves are not about facts. They are about people, constructs and contextual emotions.

As a researcher, I am aware of the subjectivity that accompanies the production of emotional narrative evidence. Nevertheless, I have related to my interviewees as people, and I believe that it has been my involvement with the subject, which has allowed me to be introspective about the issues.

Dorinne Kondo (1990:43), comments on the need for anthropological research narratives to focus on, “the ways people construct themselves and their lives – in all their contradiction, and irony - within discursive fields of power and meaning, in specific situations, at specific historical moments”. She further goes on to say that it is the role of the reflective researcher to “trace the parameters, the limits, and the possibilities of our located understandings... animated by an openness to otherness” (1990: 86).

Ruth Behar (1996: 165-167) believes that the researcher should be able to, “respond vulnerably” to others and should be able to look upon the self (researcher) in relation to the other (subject).

It is this importance of the awareness of subjectivity that I have brought to my role of researcher, as learner.

As I have concluded in my literature review, my strategic approach has been inclusive, rather than uni-focussed. As such, the research study is an **eclectic** one. It brings together a broad spectrum of findings. My understanding is that an eclectic approach is ideal for exploratory research, because it broadens the base of the search and analysis. It is my hope that the width of the findings will provide material for introspection, more in-depth research and directions for policy.

I have, for reasons of analytical convenience, organised the findings under separate sub-heads that capture both the sensitivity of the responses and the implications of the findings.

### **Structural perpetuation of stigma**

The structural perpetuation that I found in my study was more a factor of interpretations and implementations of policy, rather than a weak policy framework per se. Given the fact that it is an organisation working in the area of development, the policies themselves were strong and founded on the sound framework outlined by the International Labour Organisation (ILO).

However, interpretations and implementations, by some of the staff members, reflected inequity. For example, despite the fact that the organisation has an egalitarian workplace policy on HIV and AIDS, none of the interviewees held permanent jobs with the organisations. Each one was on a short-term contract<sup>14</sup> with

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<sup>14</sup> It is important to state that this is not a discriminatory action focused on any specific person or group. It is a routine part of the organisation's work process. Staffs are often hired for short assignments to help complete specific projects or to bring specialized inputs to it.

limited benefits. Some contracts held by the interviewees were more accommodating of medical benefits than others; but the fact of the matter is that all the contracts held by the participants were temporary in nature. While there were sero-negative staff members on short term contracts, in the case of my interviewees, all of them were on it, without exception. Living with this transience created acute stress for the interviewees.

One of the interviewees, Mary, having completed her contract found that it was not renewed. It merely lapsed without a particular clearance. The recommendation neither cleared Mary nor failed her. It never came. As Mary put it, "... maybe somewhere along the line, someone was throwing my papers". The rules of the organisation had the flexibility to renew Mary's contract. However, my reading of the situation is that human action, based on the fundamental myth that once a person is sero-positive, he or she cannot really function at work, took over the process and the contract "was not cleared". Being an organisation working within an ILO-based workplace policy framework, the decision-makers may have felt disinclined to fail Mary outright. However, their personal "beliefs", to use it in the sense in which Patient and Orr do (2003: Email), did not permit them to clear her either. So, they took what seemed to them an expedient course of action. They let the case hang undecided, till it expired naturally and no one in particular had to answer for it. In terms of attitude and mindset, Mary's ex-employers joined the ranks of (in a figurative sense) the 61% of respondents in the Nylabla et al (2003: 32) study that said they would shun a vendor with HIV.

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This is not the only occasion when managers have demonstrated a disinclination to invest in sero-positive staff. Judith was fully qualified for a six month international training programme in eastern Europe, but someone else was sent in her place. Someone with fewer qualifications, but whose sero-status was presumed to be negative, prompting Judith to say, "I do not have a future in the department". Judith felt that her presence in the department was, in her own words, a "politically correct" gesture, but a gesture nevertheless. She said in the interview, "... they never thought that I would give them more than what they were expecting from me". The overwhelming feeling was one of being under-valued: "There is a career path, but then I think my status could be an obstacle" (Judith, transcript notes).

Elaborating on the issue of a poor career path, Judith makes a very strong case that supports my finding of the structural perpetuation of stigma. She says, "In the department there are opportunities. It is like when I was appointed on a full time basis, I had to apply for a..." (inaudible)... "I had three options as far as the papers were saying. But when I submitted the papers, they came back, I had no option. They gave me just one option, it was that or nothing, you know. Why, because maybe of them, the years that it was going to take me to achieve that goal of that degree or whatever. So now ... when you talk to people ... [in] these monthly meetings. Then you speak of ... [doing things] in five years time from now, you can see that people do not really believe you, you know. So it is so difficult for them, because at the end of the day you still need their signatures to qualify for anything. So, it is very subtle, you do not see it. You know it is not something that you can touch, but it is there and you feel it.

Even when you talk... to them, you feel it. This is not going to be approved<sup>15</sup>.

What is most difficult to underpin in the structural perpetuation of stigma is the fact that it is interpretive in nature. Senior staff judge subordinate employees and the circumstances before them and interpret the policy as they see fit. In my understanding, it amounts to the subtle hegemony of dominant groups. As Featherstone et al (1991: 66) say, "The capacity of dominant groups to reproduce themselves, and to legitimise this reproduction, depends on their capacity to define what a society holds in distinction".

The structural perpetuation of stigma is very subtle in Peter's case. He is given restricted types of assignments that do not provide him with an end-of-the-day satisfaction of achievement. In his own words (Peter was very soft and often inaudible; hence the quote does not flow easily. However, I have kept it close to the original with only marginal editing to give the reader a flavour of the trauma, he is experiencing). "Well, being a ... [description of his job, which I have concealed for confidentiality] is not been approved for me, there is no post, it does not exist... Some of the smaller things that I am doing and I cannot change the situation. I would love to be in an office where I am given one, two, three things whereby I at the end of the day I can say this is what I am working for and I have done one, two, three. But with the type of work that I am doing it is difficult for me to say I have done one, two, three..." (Inaudible) "...so it is very difficult for me to say. I can say maybe I do not always live up to the office's expectation. They are always complaining about me not doing my duties, not performing my duties and I always try to perform

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<sup>15</sup> Some sections of the interview may seem incoherent, but I have left it

my duties to the best I can". In Peter's case, it appears that the job description has deliberately been kept vague (a set of random tasks that do not add up to a coherent assignment), as such it is difficult for him to turn to specific terms of reference to show achievement.

The sero-negative staffs often interpret the presence of PLWHA as an act of charity. Peter's supervisor has on occasion used the organisation's medical scheme (which includes ARVs) as leverage to counter Peter's inability to meet deadlines. "...We are doing this for you and you also in return should do this for the office". This form of negotiated benevolence naturally forces people living with the virus to view their work and environment entirely in the context of their sero-status, much as Goffman (1986) predicted they would (in another context), four decades ago. The possible solution to this lies in Patient and Orr's (2003: Email) recommendation, that it is important for people living with the virus to engage in a productive life, which is seen as valuable.

My assessment as a researcher is that, equity-based policies alone are insufficient. The need is to mainstream and normalise the presence of people living with the virus in organisations. Otherwise the subtle perpetuation of structural stigma, as experienced by Judith and Peter, will remain. This would imply a deeper understanding of PLWHA among staff members presumed to be sero-negative. This would also necessitate the retiring of negative and disempowering innuendo that encourages images of sero-positive transience. To put it into Peter's own words, "Like, if they come in there and find you sitting, he will come and say hey, what are you doing? Do you



not have work to do? As if I am just sitting there, doing nothing. Do you understand that kind of discrimination that I am talking about? It is not visible, but it exists". Let me corroborate the point with a quote from, Sontag's (1990) paraphrase of Lucretius. I add my commentary on the quote in parenthesis, to help underline my observation. She says, "Give it [the violent metaphors that describe the epidemic] back to the war-makers [as it exacerbates the stigma]" (Sontag 1990: 183).

### **Quest for legitimacy**

The structural perpetuation of stigma, as shown in the last section, results in two reactions: A quest to establish oneself in the environment or a withdrawal from it. Let me elaborate this point using authors from the literature review.

For people with a "low identification" and self esteem, as explained by Nyla Branscombe et al (1999: 35-58), there is a feeling of rejection leading to dis-identification from the larger group when facing a real or perceived threat of "expulsion". For the "dyadic" and confident person who is in a "relation of mutual constitution with other" there is a greater sense of openness and inclination to communicate with society and respond to it (Featherstone et al 1991: 52). This openness of the dyadic person leads to an effort to overcome the stigma and discrimination by trying harder to establish oneself... a quest for legitimacy. However, the tacit pressures of **enforced indebtedness** (seen in Peter's interview in the last section, where Peter's supervisor used the organisation's health plan as a leverage to make Peter feel guilty about his work), **transient contracts** (all six of the interviewees had temporary contracts

and Mary even lost her job, which underlines the transience of the agreement) and organisational **disinclination to invest** in people living with the virus (as seen in Judith's case where she missed a training programme because of her status), have sent the signal that people living with the virus are not viewed as long term or legitimate members of the organisation. As Peter says, "It is like the offices are doing me a favour by keeping me in the office". This leaves sero-positive persons feeling the painful burden of proving themselves, as productive members of the organisation, at every juncture and as Patient and Orr (2003: email) state it, "earn the respect of others"... on a continuing basis.

Among some interviewees, as in the case of Peter, the quest for legitimacy has manifested itself in a **victim self image**, where he views himself as powerless and at the mercy of others. "So it is difficult for me to say hey, but you are putting so much pressure on me. Because, I want to achieve something. I want to move up ... It becomes difficult for me". Peter's lifestyle is one of isolation. As Kathy Charmaz (1983:168-195) predicts, living with the virus results in the phenomenon of withdrawal. Peter goes back home (where he lives alone), as soon as he can and stays closed within himself in what Featherstone et al (1991) refer to as the "**monadic** mode" of being. Peter's interview is rich in material that underlines the phenomenon of withdrawal and isolation. He says, "Sometimes I wake up very sad. And I find it very difficult to come to the office. Sometimes I will stay away, because, I can say that some days are not as good as always, or as I expect them to be". I pursued the conversation further to ask him, "What are the things that you do outside work that give you joy?" and he replied, "I think, normally I rent movies to the house, I bring that to my house. This way I find all the comfort, you

know. I can eat whenever I want to eat when I am at home; I rent my movies so that I do not get bored when I am all by myself... Because I can spend time with some friends, but I am not always happy, you know. During that period I just want to be all by myself. I do not want friends around me, that is when I refuse them to go back to the house. I lock myself in and then watch the movies". This behaviour emanates from a low sense of esteem. It is signified by the inclination of the person to walk away (metaphorically speaking) from a situation.

The other side of the response came from the reactions of **dyadic** personalities of Ruth and Judith, who were more adjusted to their sero-positive status. In them the quest for legitimacy was a positive striving for acceptance and recognition. Their effort to correct the imbalance of stigma and discrimination has, I believe, been taken to the other extreme. It has manifested itself in **workaholism**. Both work long hours and take work home. As Ruth said in her interview, "My work, to be frank, means the world to me right now. I cannot see myself staying away from work for no apparent reason...I even take my work with me to bed... my work is like 24 hours". Judith goes on to underline the same point in the following conversation, "But for me, for the past four years, I have never had a holiday exactly. INTERVIEWER: How do you feel about that? Judith: I feel great ... and what else can I do...?"

It would be pertinent at this stage, to draw attention to my observation that there is, I believe, a common thread running between the monadically constructed Peter and the dyadically constructed Judith-Ruth. Both Peter's **complaints** and Judith-Ruth's **workaholism** are manifestations of the burden of proving oneself constantly. The resultant fallout is that it affects the

person's sense of self. Ruth underlines the point when she says, "... I got pushed to do things I didn't want to do... because I could not cope". This sense of feeling pressured into doing things that one would not normally do, affects a person's self definition. I explored this perception in greater detail with Ruth and quote it at length to give the reader a direct feel of the emotion. Ruth says, "I do not know if I can speak of this. But you see what happened, I was suppose to come and ask [a colleague] ... to help me. You get pushed to do things you do not want to do. Remember, I came to ask [a colleague] ... for help for my daughter, because I could not cope. Those are some of the pressures... you are forced to do something that you do not want to do, you know". This, to my mind, places people living with the virus in a close-ended cycle of work-stress leading to illness, thus encouraging the myth that PLWHA are unable to perform at work.

*NB: I have quoted conversations extensively because, I believe that it is necessary to experience at first hand the sense of isolation that people living with the virus often experience. I feel that it helps to understand and empathise better with their painful quest for legitimacy.*

### **Emotional and moral stigma**

Another factor that precipitates the marginalisation of people living with the virus is the overt emotional and moral stigma that they deal with routinely. An analysis of the incidents that each interviewee has articulated helped me trace the emotional and moral stigma to two origins:

- Ignorance of the facts of transmission

- The perceived link between heterosexual transmission and promiscuity.

Prior to the disclosure of her status, Mary and her colleagues would eat lunch together as a community. Once her status was known, however, her colleagues stopped eating lunch with her, leaving Mary with a deep sense of emotional rejection. Here is the incident as it unfolded in Mary's own words, "You know we were ... four ladies the same age as I am, different [sections], because we were on the same floor, we had..." (inaudible) "...and the others. We used to at lunchtime stand together, buy food and you know we were going to eat like. But then it was different, because everybody will eat separately. Maybe they did not want me to see, because if they were eating together and I was alone, I will see it. So we were no longer eating as a group. Maybe they decided to discuss that when I was not in. Because when we would eat, everybody would like eat alone. Even when we talk you will hear them talking you know, people are dying of AIDS. In a way you know, not telling me straight, [Mary] you know we know that you have AIDS. You know the discussions that we had, I could feel that they are trying to tell me something, which they are not, they cannot just say it. So I could just figure it out". The stigma in this episode is silent and unstated, leaving Mary with the pain of rejection.

Ruth talked about her experience in elevators, "... you will find people will just take-off on a topic and completely leave you out", leaving her with the feeling, "where do I fit in here now". The point to note here is the notion that Ruth has been rendered completely invisible to her colleagues, who do not feel it necessary to include her as one of them.

Ruth articulated a strong feeling of emotional rejection from the stigma she faced in the workplace because it made her feel dirty. To quote the verbatim in Ruth's words, "It is fear of the stigma. It is fear of the unknown as well. Fear [that] people are going to stigmatise and also because it is ... a virus that is sexually transmitted. It is like you have been promiscuous, it is like you are **dirty**, [and] it is like you have been sleeping around. It is associated with so many wrong things. So people are just not ready to talk about it because of all those factors". Ruth's comment echoes Herzlich and Pierret's (1987: 152-168) chapter ('The Damaged Individual'), where they draw attention to illness being regarded as a "social scourge". They point out how this results in "a new identity of the sick" beginning to take shape. The ill are no longer defined by their mortality, but by a "special form of life"... that makes them feel "rotten, tainted and damaged" (1987:161). The phraseology of my participant Ruth resembles the choice of words used by the theorists Herzlich and Pierret (1987:161) sixteen years ago. Ruth describes as "**dirty**" what the authors describe as, "**rotten, tainted and damaged**".

A benign, though insidious attitude towards people living with the virus is the indifferent patronising of them, by the well-meaning sero-negative population: Ruth, "Sometimes they overreact. **They will be over nice**, trying at the **same time to avoid you**. Trying at the same time to make you not see that they avoid, the overreaction. And they will be over kind ... and the fear of the unknown is something also that makes people, I think, that I see, they do not know. It is because they are not well informed, some of these people, that they act this way. Like for instance also about TB, we know TB is contagious, but HIV and AIDS is not contagious through a cup. Like with TB you can get through a

cup. So there is those misconceptions you know. Mis-interpretation of these people are not clear. Even though we say HIV is sexually transmitted to them, it is not just only that, for those who are not well informed. They think even just by standing next to a person with HIV positive I can be dirty, ***it can make me dirty***, you know”.

This is further compounded by a feeling of moral rejection. Ruth tells the story of “a particular person” who “was actually chased out of the church, because of ‘her’ status, by the priest”. To quote the tale in detail, “Deep down it does make you feel isolated, it makes you feel not wanted, it makes you feel dirty. You do actually feel that way. You feel like an outcast. You feel you do not belong. You feel like you have sinned. Like for instance even in the church where a particular person was actually chased out of the church, because of their status, by the priest. She was actually asked to leave and not come in, because she is now seen as she is going to...” (inaudible) “...because she is seen as a dirty person, you know, she is now dirty”. This incident had a deep and moving impact on her. The moral rejection further manifested itself in the use of phrases with overt religious overtones, like, “***You feel like you have sinned***”.

Sontag (1990: 113) underpins the source of this judgemental attitude towards people living with the virus, as the “price one pays for ... excesses of lifestyle... The unsafe behaviour that produces AIDS is judged to be more than just weakness. It is indulgence, delinquency – addictions to chemicals that are illegal and to sex regarded as deviant”.

According to Ruth, “I am a person who is trained and I am able to deal with it. Even though deep down it does make you feel

isolated...like an outcast". Ruth is herself a person who has helped a number of people through stable counselling support. She has people coming to her not just at work but also at home for help. In her own words, "they know that they can access my service even if I am at home and over the telephone". She was in fact the person who provided me with the support of co-ordination. She had the trust of the staff members and balanced the ethics of confidentiality with the need to access the views of people.

In spite of the courage demonstrated by the interviewees, the implications of dealing with stigma, which has become so routine, cannot but be debilitating.

### **Isolation and the physical manifestations of revulsion and pity**

People's impressions of the ill and the healthy are definite and distinct. The need to separate the other physically from oneself is an urgent one. The argument as outlined by Featherstone et al (1991:5) is that the body (its health) is taken as substantial evidence of the spiritual soul. "The skin becomes the window of the soul".

Even among the, so-called, well-meaning, Ruth senses that people need a physical reassurance for pity. She says "...because of the way the message was passed initially on television broadcasts, showing a very sick person in their last stages, so people, it is in their mind that, that is the picture they want to see". Ruth continues, "Because the stigma is so much, if you are healthy, you are fine. They do not suspect that you could also be having the HIV virus. They do not want to accept that it is



there, because of stigma". It is my understanding that as long as some illnesses, in this case HIV and AIDS, are regarded as a "social scourge" and those who carry the virus in their bodies feel, "rotten, tainted and damaged" (Herzlich & Pierret 1987:161), there will be this denial in people's perspectives to the epidemic. Furthermore, the value system that Ruth has "incorporated from the wider society equip[s] ... [her] to be intimately alive to what others see as ... [her] failing.... Shame becomes a central possibility, arising from the individual's perception of his own attributes" (Goffman 1986:7).

Goffman's (1986: 7) concept about the split between "self demand" and "self" plays out in the fact that people living with the virus have been so engrained in the majority world view of the "normal" self, that they often find themselves acting out the cycle of discrimination. Mary, "I even started avoiding people... I was no longer interacting the way I used to, because I tried and I did not like the way they treated me. So I was trying to be alone." As Goffman (1986:7) very poignantly states, "self hate and self derogation can also occur when he [the stigmatised] and a mirror [the other] are about..."

Ruth, when asked if she had "ever been a party to any discrimination willingly or unwillingly", responded: "Yes. Yes, it happens especially when you go visit someone in hospital, when maybe they are ill. You feel scared, even to touch their clothing". Ruth's revulsion reflects the value systems that surface when judging "different types of bodies" and show with clarity how illness brings "decline" to the "symbolic value of the body" in a somatic society (Shilling 1993: 186).

The interviews demonstrate that discrimination takes place at various levels. It exists, not just in the employment contracts

PLWHA receive, but also in colleagues' acts of distancing themselves from the stigmatised other, physically and emotionally. The sense I got from the interviews was, that this shame and distancing of colleagues, throws the person living with the virus into a cycle of self-defeating negativism. People like Ruth and Naomi took many years and a lot of counselling to come out of it and Peter was still stuck in the cycle.

### **The price of integration**

As is clear in the literature review, people need to feel a part of an "in-group" (Branscombe et al 1999: 35-58). This need results in two reactions. A person either adjusts to fit in or if threatened, walks away or "dis-identifies" (Branscombe et al 1999: 35-58). The primary effort is to identify with a group (Branscombe et al 1999: 35-58). If successful it reduces stresses, increases commitment and strengthens ties. But process of fitting in is not an easy one for people living openly with the virus. For my interviewees, satisfying the urge to belong to the workplace community meant the ability to compromise, and accept such unthinking discriminatory behaviour as jokes and innuendo.

Ruth says, "... earlier back in 1999, posters in the lift used to be vandalised in the UN. They shift now, they no longer do that. I was just jotting down. You know it used to hurt me, when I used to walk into the lift and I see my posters, you know I used to put posters, HIV and AIDS posters in the lift, and I see that happen, with a pen they have been made ... funny marks there. I used to say, my goodness, I am sure they are somebody who is HIV-positive, but they cannot deal with it". She goes on to say, "... people come to visit me at my place, they respect me... but here

at work, I leave my respect at home and make myself approachable to people". Peter's experience has been, "... it happens sometimes, as if it is a joke, you know. Sometimes it happens, it is something that we should all laugh about, you know. But, sometimes you find that at the end of the day it does not go down well with me, you know".

On this subject Goffman (1986: 110) warns the marginalised person against "minstrelization", or playing a caricatured role to relieve social stress. "He is encouraged to have distaste for those of his fellows who, without actually making a secret of their stigma, engage in careful covering, being very careful to show that ... they are sane, very generous, very sober, ... in spite of the reputation of their kind". Neither Ruth nor Peter was party to any "minstrelization" in their respective situations. However, it neither reduced the trauma of stigma, nor gave them a clue on how to manage the situation. This was a situation where neither the literature review nor my interviews provided me with answers on how to manage such situations.

It is quite clear from both Ruth and Peter's quotation how painful, demeaning and stressful the situation can be. So strong were the emotions, that Peter asked for the tape to be turned off so that he could compose himself when talking about people joking at him, rather than with him. Ruth on the other hand was more composed and didn't break down. Instead, she adjusted herself in her seat and straightened her dress, when telling the story about the posters. This emotion ran through the conversations of most of the interviewees. If one were to briefly revisit Table: 3: *Number of quotes generated by Concept using the Atlas.ti software*, one would see that of the 400 quotes generated for this study, 79 were directly related to feelings of being outcast. This

was doubtlessly the most common thread that ran through interviews. It is my understanding, therefore that the snowballing effect of the stigma goes beyond the pain of marginalisation into the stress of constantly trying to integrate and prove oneself.

### **Careers -- rituals of achievement**

The rituals of achievement, I discovered from the interviews, comprise two steps. In the first, I will first outline the manifestations of achievement and then link it to the element of ritualisation.

The probes on **achievement** lead to two clear findings:

The first finding was that, just being alive, and **feeling alive** was a big achievement, as it transcended earlier feelings of revulsion of self. Naomi explains this very well, when she says, "I have been able to love myself in order to love others. Despite what I have gone through, I find it easy to live my life with other people, because I know what it means to love myself". Mary echoes the same sentiment, when she says, "To me to be still living today, I look at it as a miracle".

The second one was that most achievements are **related to work**. Ruth said, "When I am talking to communities, I feel I am imparting my knowledge there... and coming to work means... it is part of me, my life" Judith said, "You know, my greatest achievement so far is to be able to dream about something and realise that dream...which is the project that I am trying".

However, there appeared to be another side to the work-related achievement. Ruth, for example, was excited by the fact that heads of units attended a presentation that she made and that a

particular senior person took interest and asked questions about her work when she met Ruth in the corridor. This was viewed as the legitimisation of her portfolio. When I place this legitimisation, in the context of the fact that these same senior colleagues are responsible (for reasons I would not presume to judge them by) for providing Ruth with her temporary contracts, I see Anthony Wallace's (as quoted in Handel 1993) theory of "rituals" playing itself out. Wallace propounded that, "**cognitive consensus is not required for societal integration**... all that is required for successful participation is knowledge of enough contingencies of the ritual to generate the sequence" (as quoted in Handel 1993: 85). Let me explain Wallace's concept in the context of Ruth's experience.

On her part, Ruth is happy that the senior colleagues have legitimised her presence in the workforce by talking interestedly with her in the corridor and by attending her presentation. The senior colleagues, on the other hand, are comfortable in the thought that these actions justify them as politically correct supervisors. Neither believes entirely in their role in the situation, but both have enough knowledge of the steps that make for a suitable sequence to perpetuate the ritual. Both parties stay within the boundaries of a status quo they may or may not agree with, but feel they can live with. The senior person by following this interaction could feel that she/he has provided what is necessary to ensure a rights-based work environment. The interviewee, on the other hand, feels that her output at work is acknowledged. This maintains a balance of rituals. The consequence of this ritual, as far as the careers of PLWHA are concerned, is that they do not appear to have a demonstrable career charted out for them. Judith underlines this point when

she says, “There is a career path, but then I think my status could be an obstacle”.

The subtle fact of each person’s work is that they are all doing task-oriented jobs with renewable contracts, not following careers. This is so, in spite of the fact that the PLWHA’s sense of self is so critically linked to achievement at work. As such, the feeling of being undervalued never abates significantly and feelings of value stem from small gestures of recognition (such as attendance of senior colleagues at presentations).

### **Dealing with finitude**

The world of illness is like a bookend, bounded on one side by normal health and on another by death; some never enter it and some pass through it so rapidly that there is no question of controlling it (Williams as quoted in Radley 1993: 79). However, for people living with the virus the “world of illness” is usually a long and complex journey. To me this indicates the significance of, what Bryan Turner (1992: 7-8) calls the “lived body”. As a progression on Giddens’s (as quoted in Turner 1992: 7) “disembodied consciousness” of the “social actor” both Dennis Wrong and Bryan Turner (as quoted in Turner 1992: 7-8) propound the theory of the “embodied” social actor. Their fundamental premise, which is a transcendence of the “Cartesian division of mind and body”, is that the body cannot be separated from the decisions and choices of the actors. To my mind the corporeal rootedness of AIDS links the state of the body to the decisions and actions of social agents. Turner’s (1992: 7-8) theory transcends the mind-body divide, bringing them together as one living, thinking and decision-making unit. So, the

perceived implications of mortality link directly to the temporary nature of work assignments given to sero-positive employees, and investment decisions made about them.

The biographical self-construction of PLWHA is severely compromised by perceptions of finitude, and they need coping mechanisms to deal with it. In Judith's words, "At these monthly meetings... when I speak of goals and achievements in 5 years time from now, you can see that people do not believe me".

I found interviewees deal with **finitude** (I use the word interchangeably with the word mortality) in three ways:

- **Sublimation in work:** Work was, for a number of interviewees, an escape, a coping mechanism and a point of reference for relationships. Success is measured by work that is accepted and failure is when illness prevents acceptance. A number of participants, particularly Ruth, Naomi and Judith deal with the issues of finitude through sublimation in work.

As Ruth said in her interview, "My work, to be frank, means the world to me *right now*. I cannot see myself staying away from work for no apparent reason...I even take my work with me to bed... my work is like 24 hours". The phrase "right now" draws subtle attention to the implication that it was not always so.

Judith goes on to underline the same point in the following conversation, "But for me, for the past four years, I have never had a holiday. INTERVIEWER: How do you feel about that? Judith: I feel great, because ... what else can I do...?"

The subtext of her statement, "...what else can I do?".... draws attention to the fact that this workaholism, is induced by her present condition.

- **Turning to religion and faith:** Others, like Mary (who lost her job following detection and ill health), immerse themselves in religion to find strength. Religion, for some, provides the pathway that eases the journey. This reliance on religion involves "non-dominant individuals" like Mary, who take shelter in the "mystical pressures" and stand by "other worldly authority" to explain and legitimise their lives (Littlewood as quoted in Pollard & Hyatt 1999: 153). To quote Mary's experience, "After I, it was I think a month or two months after I got my results from the doctor I was a very depressed person. But then I went to a church and I got counselled by a preacher. And he told me that I can defeat this. You know I was the happiest person after talking to that priest. You know I felt that I am above everyone, because I can believe. You know I was, I felt so miserable all the time. I felt that I know I am not going to live long, I had all these things, so I was always depressed. But after that day I was the happiest. That day changed the whole of my life, because my attitude was like totally different. And I am happy, I am always happy. I do not let little things get me down also. I am always happy".

This section of Ruth's testimony finds synergy with a statement made by Asunta Wagura (25-31 Oct 2003:1), the Executive Director of KENWA, "I have learnt that God has not promised that things will be easy. Rather, he has promised to stand by me when the going gets rough.



Healing or no healing, God will always be there. Even as we deal with all the stress we are going through, it is comforting to know God is in the mix”.

Therefore in spite of a committed and positive outlook towards work, fatalism (and the lack of control this implies) rules the mindset of the person living with the virus.

- **A quest for treatment and cure:** All the interviewees brought up various conversations of treatment and management of the virus in the body. Judith and Mary recommended various products that would either reduce stress or increase CD4 counts.

This conversation with Mary is quoted in detail but it builds not just on the search for a cure, but also on the role of marketing organisations that use the situation. Mary, “Food. C-e-l-l-f-o-o-d.” INTERVIEWER: “Okay”. Mary, “It, is a medication. They are saying it enhances maybe the bloodstream. The person who told me about it was a nurse. Last week I had a sore throat, so I went to the hospital. She told me that it will help me with my cervical count; because they said my cervical count was very, very low. So you buy distilled water, you pour a few drops inside that water and you drink it three times a day. It depending on how your cervical count, how low it is. Or I do not know for how long. I thought I was going to come with it, I just forgot it. So it is, something, it is R200. I never bought it, because I just find out last week about it. I wanted to buy it, so that I could try it and see. Because the person said it also helps with stress. That person has a problem with stress. So it manages stress. When you

are drinking it, I do not know, you feel more relaxed and all that. There is a lot of diseases that it helps, cancer... (intervenes): INTERVIEWER: Was it recommended by a user or? Mary, "A user". INTERVIEWER: Who has found that it works? Mary, "Ja, because the distributor is somebody here in town who also holds workshops and all that. She is going to call me when there is a workshop on that I could see people and hear from other people, because she was telling me. There is a big leaflet of it. It tells you what it helps, cancer, HIV and AIDS, all this other, heart attacks, and it tells you the lot of. There is, the main thing that it does, when I read the paper it says, it helps to bring more oxygen into your bloodstream. So that is maybe and your cells multiply more with that and when you are positive your white or red blood cells I think can be less and less. So I think it will really help me. INTERVIEWER: And you are going for this? You are not dismissive about it? So any time where somebody gives you an opportunity do you seek it out with hope? Mary, "Ja. No, I am not dismissive. You know what I believe HIV and AIDS some years soon, they will get the cure. That is what I believe. I do not think I am going to die like, people will be dying. No, I might die because of my own worry, I do not know. But I believe, because of HIV and AIDS, those people who has it and who are living positively and who are taking care of themselves, eating healthy and everything. They are going to live until there is going to be a cure. I believe there is going to be, there is so many research". Mary demonstrates vulnerability when considering the issues of finitude. This "proneness to victimisation", as Goffman (1986: 9) phrases it, is

understandably an area of concern and focus, because it signals “the extremes to which the stigmatised are willing to go, and hence the painfulness of the situation that leads them to these extremes”.

I did, however, get the sense that the search for medication rendered some of the interviewees potentially vulnerable to the suggestions of marketers, who package their products in the context of **hope**. These marketers seem to use promotional vehicles like workshops and credible sources like nurses, to promote their products.

Asunta Wagura (25-31 Oct 2003:1), the Executive Director of KENWA and a person living with HIV, in a first-hand testimony states, “Even as I write, I know of a couple of so-called healers who are hawking old ropes in the name of a cure. And some of us – out of ignorance and desperation – did hang on to such ropes without much success. They gave in like worn out cotton threads strained by an enormous weight and brought us tumbling down faster than a falling star”.

It is my understanding, that the desperate quest for a cure would assume less importance, if other factors in the workplace provided more hope and optimism to the PLWHA.

### **Secondary gains -- subtle dynamics of assertion**

On the flip side of the coin, to vulnerability and victimisation, lies assertion and domination. To my knowledge, this aspect has never been researched. I decided, in the interviews, to search for

occasions where the interviewees manoeuvred to assert themselves.

I pursued the inquiry based on Goffman's (1986: 10) concept of "**Secondary gain**... as an excuse for ill-success that has come his way... as the hook on which that patient has hung all inadequacies, all dissatisfactions, all procrastinations and all unpleasant duties of social life... and has come to depend on it, not only, as a reasonable escape from competition, but as a protection from social responsibility".

This yielded interesting testimonies. The more proactive interviewees did indeed use their status to get work done faster. Though this verbatim is lengthy, I quote it exhaustively for the reader to get a sense of the both the subtlety and the determination of the assertion.

I asked Judith, "So, have there ever been advantages that you have ever been able to get out of your status?" She promptly came back with an answer in the affirmative. She said, "Yes, yes, several times. I was summoned to the [Boss's Boss] twice for not observing protocol. I am a very impatient person. I want to do things and finish it. So there is this routine where you have to take this document from here to here to here and they just waste time, you know. So, I just took the document straight to the [Boss] and he asked, why [Mr XX] did not sign? Then I said ... I cannot wait, I do not have time to wait. You know I am HIV positive, you are wasting my time. And he was saying, oh, and then he signed. Even when I was summoned to the [Boss's Boss] because of not observing the protocol, I did not hesitate. Mr [Boss's Boss], these people they do not understand, you know they do not. I have got this work plan, which is for one year. For me to reach my goal ... I cannot wait. If I have got a

document that needs to be signed, I just feel that it needs to be signed immediately. Because I do not know, anything can happen to me any day. And he wrote a letter, so I do not have to go through this, entire stepladder; I go straight to the [Boss's Boss] office then he signs for my documents. And nobody you know, questions it, because I do not have time to wait”.

Judith's quote demonstrates that when confident and motivated, people living with the virus can not merely work effectively within a system, but lead programmes and processes creatively. It also confirms Giddens's (as quoted in Handel 1993: 90-91) view that people, no matter how disadvantaged, have **choices** to make and manoeuvre to make them to their own advantage.

My inference is that, if the work environment is nurturing and confidence inspiring for people living with the virus, it will stimulate **innovation** and creativity among them. It could therefore improve productivity in the workplace.

### **Self esteem -- a manifestation of the virus**

A key finding of the research was that the sero-status of the interviewees was the most dominant definer of their identity, rendering other qualities and attributes secondary.

Goffman's (1986:7) observation that, “the standards he [the marginalised person] has incorporated from the wider society equips him to be intimately alive to what others see as his failing... causing him to... agree that he indeed falls short of what he really ought to be”. “Having been stigmatised late in life... such an individual... will have... a special likelihood of

disapproval of self". This phenomenon is evident in all my interviews.

For Mary, "It [the virus] does define who I am, because it is there". And then the most telling sentence in her testimony:

***"I have the virus, I am the virus"***

Ruth dislikes being talked about in hushed tones because she assumes it is about her sero-status, "Do you see that one, she is positive". She therefore prefers to get her status out into the open as soon as she can, in an introduction.

Even when a person refrains from stating his or her sero-status, as in the cases of Peter and Judith, the whole argument for doing so is predicated on the context of their status. Peter puts it very succinctly, "It is easy for me to create an impression, because HIV is not written on my face".

Judith's introduction was a self confident and powerful one, but the subtext of her logic clearly bore traces of the virus. I will quote the entire introduction to give the reader an idea of what I mean. "I am a proud African woman. I am a mother to three beautiful kids. I am a sister to somebody; I am a cousin to somebody. And I am very proud to be me. *I will not exchange anything in my body, you know. I would not replace anything in fact*".

Despite the machinations of Peter's introduction, the confidence of Judith's introduction or even the frankness of Ruth and Mary's introduction, the context of the virus clearly centres itself in the PLWHA's self-definition and influences the person's self esteem. Even when a person is not making an emotional statement pertaining to the pain he or she suffers, the language very clearly

indicates this. Peter's innocuously used sentence, "... so I behave like any normal human being", is a case in point. I asked Peter that if he were to introduce himself to a person, how he would do it. I am quoting the entire conversation verbatim. In the introduction he breaks down and starts to cry, underlining the basic premise of my study... that the virus defines the self-identity of people living with the virus. Peter, "I am [Peter] working for [unit name]. I am very pleased to meet the people around. I get along fine with everybody. When they talk to me they cannot resist getting along with me. I do not have a problem" ... (Inaudible... he breaks down and cries) "...but sometimes then I did not cry, I am going to cry. I try to be strong and I try not to cry, but unfortunately that also crosses me first. Because there are times whereby I just feel like breaking down and cry and I just do not..." (inaudible) "...There are times where I feel why me? Why this is happening during this time, during my lifetime, why has it not been happening..." (inaudible) "... It is easy for me to create an impression and say, because HIV is not written on my face, you know. People do not know that I am HIV. So I behave like any ordinary human being, I can make impressions, I can do anything that any other person can do". From the conversation quoted, my understanding is that disclosure seems to imply giving-in to the manner in which the virus defines life, interpreting it for oneself and then living alongside those constraints. Those who do it seem to feel a sense of achievement and those who do not demonstrate the trauma of it, as Peter did when asked how he would introduce himself to a person he had never met. Peter's breaking down and crying was, for me, a strong non-verbal clue to his emotion as he dealt with feelings of shame.

I would also like to make an observation based on my small sample of interviewees and the literature review (particularly Chodorow as quoted in Craib 1998: 94). It is my understanding that women with their “comparatively weaker ego boundaries” seem better equipped to deal with the stress of stigma than the men. To reiterate a point mentioned earlier, living through the lives of others and for others, demands a suppression of one’s own needs and wants, making the women more resilient to the vicissitudes of the situation. Let me take an example from the research. The bottom line of Peter’s testimony was, “So far there are very few good days in the office”, while Naomi’s bottom line thought was, “I see a very bright future. A fulfilling future”.

I would like to underline the point that, I am making this observation, not as a universal truth or even as a confirmed finding of the study (the limitations of my sample do not permit this), but only as a point for future researchers to watch out for and either prove or disprove.

### **The silver lining of progress**

The silver lining lies in the fact that, though there is silent stigma and discrimination in the workplace, the interviewees believed that society has come a long way. Even if it is on a limited scale, the stress and conflict of the epidemic has induced human creativity, as Coser (as quoted in Handel 1993: 75) predicted it would. My dialogue with Judith underscores this point. Judith: “Yes it has changed... I am looking at myself in the government department, living openly with my status and still being treated the way they treat me. And you know that this is acceptance of some sort”. Judith’s commentary is hopeful and yet realistic



about the scope, “I am there and I am able *to propose some things and make suggestions*”. As Giddens (1984: 9) propounds, the “free will” of social agents, or the ability “to do otherwise” plays a significant role in a person’s life, no matter how difficult the circumstances. In Judith’s case, she rises above the difficulty of her situation to continue making “suggestions”. The importance of the “human mind in social life” is undeniable.

It is clear that positive change is taking place in the workplace. People are more enlightened and proactive than they have been in the past two decades. However, the question is, “Is the change fast enough to address a galloping epidemic?” I believe that it is necessary to accelerate the process, from what Lewis Coser (as quoted in Handel 1993: 75) refers to as the gradual “change **within** a system” to his concept of the more rapid transformational “changes **of** the system”... these “changes of the system” are, “deep changes that result in the emergence of new systems following the destruction of the old” (Handel 1993: 74). The answer for organisations will be to find out what actions will precipitate that rapid change.

Before I move into the summary of my findings in the context of the key questions I had set out to answer, I would like to observe that I started out on the analysis with 400 quotes compiled by the Atlas.ti software. Though the single largest cluster of quotes was the ‘feeling of being outcast’ (79), overall, the quotes were more or less evenly balanced. Half were negative emotions and half, positive. An exact count is difficult to obtain since there were a number of quotes that were neutral, or in part both positive and negative. But broadly speaking, the quotes generated were evenly positive and negative. I would attribute this to the

balanced and non-judgemental approach I had attempted to take in my line of questioning.

I do believe that I have done justice to and dealt, in a balanced fashion, with the positive aspects of hope and the negative aspects of stigma at the workplace. One cannot dispute the fact that the epidemic is stigmatising and isolating of people and that the tendency is to dwell on the negative aspects of the situation, on the things that are going wrong. I have, however, attempted to balance the silver lining of hope with the dark clouds of stigma, in my analysis.

### **A researcher's perspective on the findings**

In this chapter, the effectiveness of the research methodology as a process of inquiry is tested through the findings. While the findings must speak for themselves and through the test of time, it would be pertinent at this juncture to attempt an explanation of my position as a researcher.

In a Socratic parable, I came across in John and Jean Comaroff's book (1992: 49) on ethnography, Socrates gives a few of his students two magnifying glasses, inviting them to look at the one through the other. After the students told him what they had seen, the sage delivers a telling lesson with his question, "Of what have you told me," he asks, "the thing that you have seen or the thing through which you have seen it?"

For me the magnifying glasses were my interviewees, what the Comaroffs' call (if somewhat detachedly) the "analytic object". And, the stigma that they experienced in the workplace was the

“conceptual subject”... which opened up the silent and complex world of pain and prejudice, joy and success.

For me the interviewees were more than just “analytic objects”, they were my partners in a process. The nature of the study required me to spend substantial time with them, forming relationships, building bonds, sharing their sorrows and their mirth, listening and learning from their intimate insights....

In the process, I became their student and friend.

***As their student***, I feel it is my responsibility to learn from their experiences and cogently document, analyse and report on their thoughts.

***As their friend*** I feel it my responsibility to take the results of the study beyond the archives of a library to the tables of the policy maker.

This hasn't been easy. As a qualitative researcher I have attempted to, at one level, be objective about the analysis and at another level, treat the very subjective content with empathy. As a researcher, I am acutely aware of the tendency to let my own prejudices, pre-conceived notions and perspectives colour the research from questionnaire to analysis. I had to check myself time and time again, not to put together a sequence of quotes just to help me make a predetermined point. I have resisted the temptation to tie up the findings in one simple and conclusively explained bundle. The study is therefore eclectic in nature and the pieces have been allowed to fall as they have been inclined to. There are many findings that could do with greater research and larger sample sizes. The role of religion and hope, the rituals of stigma, are just two of many. I hope that the findings will spark a greater body of research.

Personally speaking, this study has broadened my perspective on the subject of stigma and HIV in the workplace and deepened my commitment to act upon my findings and do my part in bringing about a reversal in the marching progression of the epidemic.

***I hope I have been able to do justice to both the magnifying glasses and the world I saw through them.***

## **Chapter 5: Conclusions and the way forward**

At the conclusion of the dissertation it is necessary to look back and take stock of the study. This exercise provides a learning opportunity and helps determine a potential way forward for future research and policy.

A review of the chapters:

- Chapter 1: The purpose of this chapter is to make the case for a study on HIV and AIDS in the workplace. It has laid the ground for the study by providing an understanding of the definitions and issues related to HIV-positive stigma. It has ventured basic definitions of stigma and discrimination and attempted to understand the various forms of stigma, especially in the workplace. It has done so on the basis of key reports, studies, manuals and publications on the subject. To strengthen the relevance of the study, the chapter contextualises the issues of stigma to the laws, communities and workplaces of South Africa.
- Chapter 2 provides for a sociological overview of HIV-positive stigma and its various facets. It does so through the writings of social theorists and those of field practitioners,

living with the virus and working in the area of HIV and AIDS. In this chapter the various perspectives, theoretical and practical, work in synergy to provide a rich basis for both questioning and analysis. The chapter is divided into two parts. The first part deals with the broad areas of search, providing a road map of the literature review. The second part discusses select concepts, relating them to the study. This section provides a theoretical framework for the analysis of the findings.

- Chapter 3 lays out the fundamental methodology of the in-depth qualitative research carried out in the study. It underlines its relevance as an exploratory tool to understand attitudes in the workplace. The chapter explains the sampling technique and the criteria for selection as also the data collection and analysis process. It also outlines the strengths and weaknesses of the methods used. For example, it shows that while the sample was too small and inadequate to generalise any finding, it did provide a homogeneous universe and the opportunity for in-depth probes.
- Chapter 4 brings to fruition the efforts of the first three chapters through the presentation of the research findings. The in-depth qualitative research provides the findings with rich quotes that enable the reader to get a first hand perspective of the thought process and emotions of the participants. The literature reviewed in chapter 2 provides a framework for analysis and presentation. It facilitates a deeper understanding of stigma and the pain of rejection, of isolation and its effect on the self-esteem of PLWHA. It shows how discrimination is evident even in a parastatal organisation, due to the interpretive nature of policies and

laws. The strength of this chapter lies in the directions the studies provide for future researchers, like for example the finding that people living with the virus sometimes compensate for their situation and negative image by working harder and taking work home. The weakness of this chapter lies in the fact that the findings are not robust enough to serve as generalised findings.

- Chapter 5 has attempted to provide a chapter wise overview of the study. It proceeds from here to cover the key response of the study and the implications of some important findings. It will also attempt to revisit the strengths and weaknesses of the methodology and offer ideas for a way forward for future research and policy.

The key response of the study is that: **Driven by stigma, the virus visibly influences the self-definition of the person living with HIV and AIDS.** This directly addresses the set of questions tabled in chapter one of my study.

According to the findings, the stigmatisation of sero-positive people is an unequivocal reality in the workplace. However, it is important to note, that the violence of the community's response to people living with the virus (as seen in table 2 of the dissertation) is absent in the workplace. I believe that the value based orientation and policy of the parastatal organisation tempers the stigma. The stigma reflected by the interviewees was of a subtle and silent variety, making the person feel, ***"Where do I fit in now?"*** Due to the interpretive nature of anti-discriminatory measures in the workplace, this stigmatisation is often unconscious or covert. However, it exists structurally, and the PLWHA's perception of this stigma is absolute. This results in feelings of profound alienation and isolation – such that, the

interviewees define themselves in the context of the virus. To quote Mary again, ***"I have the virus, I am the virus"***.

While some of the interviewees are more adjusted to their status and cope with it better, all of them seek legitimacy for their presence in the workplace. Due to the routine emotional and moral stigma that they face, both tangible and abstract, the price of integration is painful and often demoralising.

This self-definition directly affected the interviewee's **self esteem and worldview**. Some were adjusted to their status and hence positive about it, while others manifested the pressure of the stigma in their daily life. This then resulted in a quest for legitimacy among the interviewees and the price of integration was high, painful and often demoralising.

Stigma manifests itself numerous and significantly in the workplace. The perceptions of the general population are so strong, that the stigma perpetuates itself in the decisions of managers and their interpretations of systems. This often leads to tokenism (as is visible in the cases of Ruth and Judith) and devaluation of people living with the virus. This fundamentally affects identity issues such as self-esteem, of PLWHA, making their view of themselves and the world around them virus centric.

On a positive note, the outcomes of stigma are not only about trauma. The interviewees have worked out coping mechanisms, to various degrees of success -- sublimation in religion, immersion in work and quests for cure, are some of them. In fact the more adjusted and enterprising interviewees even manoeuvred the situation to salvage some gains and advantages from their status.

In an effort to put these findings to tangible use and to build from here, I believe that a larger study needs to be conducted covering the known sero-positive group, the perceived sero-negative group and the decision makers across the organisation to get a more comprehensive picture of the three-way dynamics of discrimination.

Like for instance, the section on rituals is a depiction of subtle realities based on people's interpretations of policy, in the context of their pre-conceived notions. This will require more than just validation, it will need a deeper understand of the drivers fuelling the actions. More substantially, in the long run it will also need to go beyond the modification of policy frameworks into areas of policy implementation.

There was evidence of two unusual findings that demand further research and analysis. First the finding that PLWHA sometimes manoeuvre to assert themselves and negotiate for secondary gains from their status, such as a quick approval on a report or a lighter work schedule. The second finding is that people living with the virus often sublimate themselves in their work in an attempt to deal with their status. A deeper tracking of both these findings could help strengthen policies at work. Policies that nurture staff members and optimise their output. A greater understanding of the phenomenon could help table a counter point to some of the prejudicial views of sero-negative staff members, like the perspective that there is no merit in investing in staff members living with the virus.

Since this dissertation has been viewed from the intimate lens of the marginalised person, its findings would serve as an excellent reference point for the framing of insightful questions for all three groups. This dissertation would help develop a line of



questioning based on a deeper understanding of the perspectives of PLWHA and the sensitivities of the issues involved.

I also believe, that the key finding of this study: 'Driven by stigma, the virus visibly influences the self-definition of the person living with HIV', has the potential to mould sensitive attitude and behaviour enhancement material for a scaled-up media and information campaign. The objective of the information campaign would be to dispel the "myth" that, Irene Jillson-Boostrom (as quoted in Ahmed 1992: 123-135) talks about in her article. "Once someone has the disease, he or she cannot really function at work". If validated, the finding that people living with HIV, often stretch themselves to work harder, because they have a point to prove — making them a better accepted and more important part of the workforce. The cognition of this fact and its scaled up presence in media could go a long way in addressing the myth.

I believe (as a person working in the field of HIV and AIDS) that it is not enough to merely provide for the greater **involvement** of people living with HIV and AIDS (Commonly referred to as GIPA). As this study shows, this could be reduced to tokenism. I believe that I echo the opinion of my participants and other people living with HIV and AIDS, when I suggest that we need to ratchet-up the response to ensure greater **involvement, empowerment and leadership** of people living with HIV and AIDS. Scaled up, this response could make the work environment less stressful and more integrated leading to a potentially more harmonious and productive workforce. While no miracles are envisaged, it is likely that this perspective (being vastly different from the commonly held view that investment on

PLWHA is an unwarranted expense) will stimulate both discussion and further research. This perspective, along with information pertaining to the life-prolonging effects of ARVs and HAART could prove to be a substantial argument in favour of mainstreaming, normalising and empowering PLWHA in the workplace.

It is my recommendation that the findings of this research be converted into an article for publication in journals and magazines to provide the findings with greater visibility, so that it may stimulate conversation, dialogue and a larger body of research.

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# Annexure



## A: Guidelines for QUESTIONNAIRE: Sero-positive persons in the workplace

Though the guidelines have been developed like a questionnaire, they were not used rigidly. They were used as guidelines to steer the conversation.

### Personal Details

- Name
- Age
- Profession (a qualitative description – what work does the person do?). This may later be co-related with concepts such as person's self worth/ area of influence/ significance to organization, etc
- Living status – single/ with partner/ with children. This will relate to notions of isolation/ intimacy/ etc
- Type of accommodation – township/ city apartment/ detached/ semi-detached/ house. This will relate to community notions of support or discrimination/ alienation or integration/ discrimination or indifference
- Place of birth – migrant worker/ immigrant/. This will relate to concepts of alienation/ integration

### Professional Details

- Type of job – permanent/contractual/ part-time/ full-time
- Clerical/management/administrative
- Creative/technical/routine

- It is important to get the person's perspective of the job and compare it to the interviewer's personal assessment of it.
- Level of job – junior/senior/middle
- This will reflect how professional networks deal with stigma
- Description of the job – responsibilities/duties
- Describe a daily work day – who are the people that the person interacts with/does he/she work within the office or outside/ what constitutes a good workday/ what does the person do during breaks and with whom?
- Salary – what level is it at? (Close to the highest that he or she can go/ how far away from it?) Is it a fair salary? If not why? Who gets a fair salary?

(Analysis instructions and Questioner flags: Relate all this to the person's sero+ status and constantly probe how it has affected all of the above issues.)

### **Career details**

- Trace the person's career – achievements, failures
- What were these due to?
- Were they affected by any factors? How
- What is the future? What is it dependant on? How does the person feel about it?

(Analysis instructions and Questioner flags: Relate to person's sense of self)

**Emotional concepts: Work and its relation to life**

- What does your work mean to you? What would life be without it? Has your response changed after your + status? How?
- Describe your life before your sero+ knowledge. What were the highlights? Would they have been different if you had already known of your + status? How?
- What are your joys today? How do they compare with before?
- What are your griefs today? How do they compare with before?
- What do you feel in the morning when you wake up on a workday? Was it different before? How?
- What is a good workday? A bad workday? What makes them different?
- Compare a workday and a holiday – feelings, people you meet, activities
- Describe your office (note the language that the respondent uses to do this)
- Describe your colleagues (note the language that the respondent uses to do this)
- Is this where you want to be? Why/why not?
- Describe your ideal office (note the distance from present)
- Is this where you worked before you tested positive? If so, are things different today and how? If not, describe your previous place of work and what led you to change?
- How long do you see yourself here? Why?

- Where do you see yourself next? Why?

### **Emotional concepts: Being + in the workplace**

- When did you discover your status? How long ago?
- Who knows of it? How and why?
- Who does not know of it? Why not?
- Do people at work know? Who?
- How do they feel about it? Have they changed towards you? Why and how?
- How do you feel about yourself at work? Do you feel you are different at work today than before? How?
- Do you believe that you have to behave differently today? Why?
- Do you think your status is an issue at work? Do you want it to be?
- What is expected of you today? How is it different from before? Why do you think this is?
- What do you expect from yourself at work today? Has this changed? How and why?
- How would you change things if you could?
- Do you think people would accept your changes? Why?
- What means would you use to change?
- Who would be your allies?

- Are your career ambitions the same as they always were? What has changed? Why?

**Emotional concepts: Allies and others**

- Whom do you depend on at work? For what?
- Do you have friends at work? If not, why? If yes, are they new friends or old? Do they know of your status or not? Why?
- Do you like your colleagues? Why/Why not? What distinguishes a colleague from a friend at work?
- Would you spend leisure time with a work colleague? A work friend? Is this different from before? How and why? How do you feel about this difference? Do you want it?
- If you had a health emergency at work what would you do?
- Would this be different from any other kind of emergency? How?
- Do you have a mentor? At work? Describe your relationship with him/her
- Has your relationship with your colleagues changed after your positive status? How?
- Would it change if they knew about it? How?
- What if you had a different type of life-threatening disease? Do you think your relationship with your colleagues would be different? How and why?

**Issues of self**

- Define yourself. Who are you? How would you introduce yourself to a stranger?
- How would you introduce yourself to someone that you wanted to impress?
- How has your introduction changed over the years?
- How do people/ your friends/colleagues introduce you? Is this their perception of you? Is it correct? How has this changed over the years?
- Do you like the way you introduce yourself? Would you like it to be different? How?
- Do you like the way you are introduced/ perceived? Would you like it to be different? How?
- In general, how do people behave towards you? Does it differ from place to place? How?
- Have you ever encountered hostility? When?
- Have you ever felt hostile? When?
- What do you believe an example of stigma is?
- An example of discrimination?
- Do you believe that you are stigmatized?
- Do you believe that you are discriminated against? Give examples
- Do you believe that this can change? How?

- Would you discriminate against others in similar circumstances?  
Why/why not?
- What are some other instances of discrimination that you have seen?
- Have you ever been party to instances of discrimination?  
Willingly or unwillingly?
- Is this different? How?
- Do you believe that some instances of stigma are justified?  
Which?

## B: Losses exercise

These are the 10 **cards** used in the “Losses exercise” outlined in the sub-section of the literature review, “Stigma and the marginalized other”. The exercise is explained in detail in the main body of the dissertation.

|  |   |
|--|---|
| <b>Loved one:</b> partner, lover, spouse, best friend, family  | <b>Residence:</b> house, apartment, condo   |
| <b>Bodily Functions:</b> sight, hearing, taste, sex, bowel and bladder control                                 | <b>Physical Appearance:</b><br>weight loss, skin condition (Kaposi's sarcoma)<br>overall physical condition |
| <b>Mental reasoning:</b> sanity, memory, coherence, speech   | <b>Independence:</b><br>privacy, ability to make decisions, self-determination                              |
| <b>Physical mobility:</b> ability to run/walk, ability to operate a bike, car or other means of transportation | <b>Future plans:</b><br>vacations, travel, holidays, career, children                                       |
| <b>Favourite activity:</b> art, music, dancing, sports, hiking, pets   | <b>Finances:</b> money, bank account balance, credit cards, savings, job                                    |

My observation of the participants’ reluctance to part with any of their bodily functions (by way of the cards in the sensitivity exercise) was for me, as a



researcher, a vivid and real life echo of Rose Weitz's (1989) perspective that a sero-positive person attempts to simulate a "sense of control" over the situation in an effort to deal with the complex consequences of HIV and AIDS, such as stigmatisation, discrimination, social isolation and also the finitude.