

# **HIV/AIDS-related stigma and its associated prejudice and discrimination**

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## **Declaration**

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

25 November 2009

## **ABSTRACT**

### *“HIV/AIDS-related stigma and its associated prejudice and discrimination”*

From the moment scientist identified HIV and AIDS, social responses of fear, denial, stigma and discrimination have accompanied the epidemic. Many people who are HIV positive are too scared to tell others because they fear isolation and rejection. South Africa has reported a large number of incidents of stigma. These include, not allowing HIV positive children into schools (Sapa, 2002; Streak, 2001a), exclusions or attempted exclusions from the workplace (Ngqalaza, 2000a; Viol, 2000), within military services (Ngqalaza, 2000b) etc. On the other hand children orphaned by AIDS experience stigma and discrimination because they face verbal discrimination at schools and in the community (Streak 2001b). At an individual level stigma undermines the person's identity and capacity to cope with the disease.

Stigma and discrimination play significant roles in the development and maintenance of the HIV epidemic. It is well documented that people living with HIV/AIDS (PLWHA) experience stigma and discrimination on an ongoing basis. This impact goes beyond people infected with HIV to reach broadly into the society, both disrupting the functioning of communities and complicating prevention and treatment of HIV. While there are many instances for compassion and support towards PLWHA, there is a growing body of evidence of HIV related stigma and its associated prejudice and discrimination (Canadian HIV/AIDS Policy and Law 2002; Agglelilton & Parker, 2002; Aggleton 2000; Francis, 2004; Govender, Bhana & Pillay,1992; Mthembu, 1998; UNICEF, 2000; Webb, 1997;Kuhn, Steinburg & Mathews,1994) .These insidious impacts must be acknowledged, if the work to eradicate stigma is to be taken seriously.

This research reviews the available scientific literature on HIV/AIDS stigma and discrimination in the Mangaung Local Municipality (MLM). Analysis of this research indicates that stigma and discrimination drives HIV out of the public sight.

## OPSOMMING

*“MIV/VIGS-verwante stigma en die gepaardgaande vooroordeel en diskriminasie”*

Sedert die oomblik toe wetenskaplikes MIV en VIGS die eerste keer geïdentifiseer het, het sosiale teenkanting, gekenmerk deur vrees, ontkenning, skande en diskriminasie, die epidemie vergesel. Baie mense wat MIV-positief is, is uit vrees vir isolasie en verwerping, te bang om andere daarvan te vertel. In Suid-Afrika is talle gevalle van insidente wat met stigma verband hou, aangemeld. Voorbeelde hiervan sluit die volgende in:

- toelating tot skole aan MIV-positiewe leerders geweier (Sapa, 2002; Streak, 2001a)
- uitsluitings en voorgenome uitsluiting uit die werksplek (Ngqalaza, 2000a; Viol, 2000)
- uitsluiting van militêre diens (Ngqalaza, 2000b)

Terselfdertyd ondervind kinders, wat deur VIGS wees gelaat is, stigma en verbale diskriminasie in die skool en in die gemeenskap. Op individuele vlak ondermyn stigma die persoon se identiteit en vermoë om kop bo water te hou.

Stigma en diskriminasie speel beide 'n belangrike rol in die ontwikkeling en instandhouding van die MIV epidemie. Dit is alom bekend dat mense wat met MIV/VIGS lewe, langdurige stigma en diskriminasie ervaar. Die impak hiervan reik veel verder as slegs die mense wat met MIV/VIGS saamleef, tot in die breet samelewing, waar dit die funksionering van gemeenskappe ontwig, en die voorkoming en behandeling van MIV kompliseer. Alhoewel daar baie voorbeelde van meelewing bekend is, is daar ook toenemende bewys van MIV-verwante stigma en die gepaardgaande vooroordeel en diskriminasie (Canadian HIV/AIDS Policy and Law 2002; Agglelton & Parker, 2002; Agglelton 2000; Francis, 2004; Govender, Bhana & Pillay, 1992; Mthembu, 1998; UNICEF, 2000; Webb, 1997; Kuhn, Steinburg & Mathews, 1994).

Hierdie onaangename impakte moet in ag geneem word as ons die werk wat gedoen word om stigma te bekamp, ernstig wil opneem.

Hierdie navorsing ondersoek die beskikbare literatuur omtrent MIV/VIGS stigma en diskriminasie wat aan die Mangaung Plaaslike Munisipaliteit bekend is. `n Ontleding van hierdie navorsing dui daarop dat stigma en diskriminasie MIV uit die openbare oog dryf.

## **Acknowledgement**

I dedicate this work to Chris De Wet Clinic (Aids Unit) in the Mangaung Local Municipality and Lesedi La Setjhaba Welfare Organisation. I also want to express my sincere gratitude to my life partner, Tau Moiloa, my mother, sister Nozimanga and Thobeka, for their continued generous support and understanding. To them I say, “Mohale o tswa maroleng”.

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We are in one way or the other living with HIV.

“Ke tla busetsang ho Jehova hobane melemo yohle ya hae e ho nna”

I thank you

## **ACRONYMS**

AIDS	:	Aquired Immune Deficiency Syndrome
CBO	:	Community Based Organisation
CSEC	:	Commercial Sex Exploitation of Children
CSW	:	Commercial Sex Workers
FBO	:	Faith Based Organisation
HIV	:	Human Immunodeficiency Virus
LGBT	:	Lesbian, Gay, Bisexual, and Transgender
NGO	:	Non-Governmental Organisation
PLWHA	:	People Living With HIV/AIDS
S & D	:	Stigma and Discrimination
STI's	:	Sexually Transmitted Infections
TB	:	Tubecculosis
USAID	:	United State Aids International Donor
UNAIDS	:	United Nations Aids Programme

## EXPLANATION OF CONCEPTS

**AIDS** : *Acquired Immune Deficiency Syndrome*

- Acquired* - Obtained from another human being
- Immune* - The body's defence mechanism
- Deficiency* - Insufficient or malfunctioning of the immune System
- Syndrome* - Collection of different diseases or infections

**ATTITUDES:** Learned predisposition to respond in a favourable or unfavourable manner to a particular object or action. Attitudes are based on the beliefs and belief systems that an individual has developed.

**BEHAVIOUR:** The way in which one conduct oneself through one's actions and reactions.

**BELIEF** A feeling that something is real and true; trust or confidence in something

**DISCRIMINATION:** An unfavourable treatment based on prejudice, especially regarding race, colour or sex.

**HIV** *Human Immunodeficiency Virus*

- Human* Belongs to human beings
- Immunodeficiency* The malfunctioning of the immunity
- Virus* Belong to the family of Retroviral

**STIGMA:** Is defined as behaviour that unfairly and negatively impact upon the rights, life and opportunities of a person actually living with HIV or ill with AIDS; or a person associated (affected) with someone living with HIV or AIDS.

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## 1. INTRODUCTION

'If we are to address stigma, we must first understand it. We should focus our attention on understanding what causes us as a society to react in this way to people living with HIV/AIDS – people who are suffering enough, either physically or mentally to be challenged yet again by the judgment of others, by the people who yesterday were their neighbours and who should be reaching out to them today. Only when we understand the cause can we hope to help our fellow men and women react in a more compassionate and human way' – The Prime Minister of Tanzania, Hon. FT Sumaye in the Regional Consultation Report, 2001.

The potential impact of stigma and discrimination has been ongoing concern to those involved in addressing the HIV/AIDS epidemic. Goffman (1963) defined stigma as a deeply discrediting attribute that reduces person to some way tainted and can therefore be denigrated. It is a pervasive problem that affects health globally, threatening an individual's psychological and physical well-being (Cabe & Sorkin, 2002). Discrimination contributes acts or omissions in which the content of the stigma is applied, either at an individual or society/community level. Four components have been identified as being part of the stigma concept. These include distinguishing and labelling differences, associating human differences with negative attributes, separating 'us' from 'them', and status loss. Ultimately stigma is entirely dependent on social, economic, and political power, as power is required to be able to introduce stigmatisation.

Finally, stigma impacts on behaviour change as it limits the possibility of using certain safer sexual practices. Behaviour such as wanting to use condoms could be seen as a marker of HIV, leading to rejection and stigma. All interventions need to address stigma as part of their focus. However, the difficulty of the task should not be underestimated, as has been shown by the persistence of discrimination based on factors such as race, gender and sexual orientation.

## 1.1 AIMS AND OBJECTIVES OF THE RESEARCH

The aims and objectives of this research were to determine the impact that stigma and discrimination have on people living with HIV/AIDS (PLWHA) in Margaung Local Municipality

*Objectives include the following aspects:*

- Make people to speak openly about HIV/AIDS, attacking ignorance and prejudice and correcting wrong ideas about the disease.
- Awareness campaigns. These campaigns are important in helping PLWHA to know that there are people who are sympathetic and help and point them in the direction of support.
- Provide information about testing and counselling, the correct use of condoms, and following universal precautions.
- Eradication of myths and misconceptions.
- Acknowledge that individuals have the power to choose to refrain from discrimination, as opposed to placing all power to socialisation, and, thus removing individual responsibility.

## 1.2 STATEMENT OF THE PROBLEM AND OPERATIONALIZATION

The *research problem* to be discussed and analysed is:

***“How HIV/AIDS-related stigma and its associated prejudice and discrimination can be addressed?”***

Many people living with HIV/AIDS still live in fear of discovery because of the prevalent stigma and its associated prejudice and discrimination. It is true that stigma and discrimination(S&D) still exist in our communities, and it will continue to exist until something is done to mitigate it. This is seen when government and national authorities sometimes cover up and hide cases, or fail to maintain reliable reporting systems. Ignoring the existence of HIV/AIDS,

neglecting to respond to the needs of those living with HIV infection, and failing to recognise growing epidemics in the belief that HIV/AIDS '*can never happen to us*' are some of the most common forms of denial. This denial fuels the AIDS stigma by making those individuals who are infected *appear abnormal and exceptional*.

HIV and AIDS will therefore remain a problem in South Africa for a long time because of these factors that contribute to HIV/AIDS-related stigma and discrimination in our communities. In order to address HIV/AIDS-related stigma and its associated prejudice and discrimination, operationalisation of the following aspects need to be implemented in our communities:

- Encourage/challenge politicians and other leaders to be conscious of how they reinforce stigma through their words and actions, which contradict non-discriminatory policies and principles.
- A safe and nurturing environment where PLWHA can live freely.
- Work in partnership with others to fight the disease
- HIV/AIDS education programmes

### **1.3 METHODOLOGY / MODUS OPERANDI**

In order to achieve the problem statement, the following questions need to be addressed:

- What causes people to behave in a stigmatising and discriminatory manner?
- What causes people not to change stigmatising and discriminatory behaviour, even when they have knowledge about this?
- Why is S & D so widespread, regardless of social, educational and economic strata?
- How do individuals move beyond stigma to face the responsibility of having HIV within the current environment?

- What personal factors enable these people to seek testing, and what enables those who test HIV positive to deal openly with their status?
- How do the ones infected contribute to the perpetuation of S & D?
- What is the damage done to those experiencing stigma and discrimination?

#### 1.4 CONCEPTUALISATION

What exactly is stigma anyway? For the sake of this discussion, the researcher will define stigma as a behaviour or 'law/policy' that unfairly and negatively impact upon the rights, life and opportunities of a person actually living with an HIV or ill with AIDS; person associate (affected) with someone living with HIV or AIDS (for example, family and friends); a person, perceived to be infected with HIV or have AIDS; or a person perceived to be at risk of HIV infection or AIDS illness.

To distinguish this form of discrimination from other types, such as gender or racial discrimination it needs to be motivated primarily by the perpetrator (person or policy) of the stigma to have knowledge or a perception (true or false) that the other person is infected or affected by HIV/AIDS stigma is thus, essentially discrimination based upon HIV status. In other words, it is not stigma if, for example, you lose your job, because you did not do your job properly. It is, however, stigma if you did your job properly, but got fired, because your boss discovered that you are living with HIV.

Is HIV/AIDS stigma different from any other form of discrimination? This is a difficult question. Stigma is not exactly the same as discrimination, at least in terms of connotation. Stigma has an additional connotation to discrimination, namely, that of strong emotional rejection, over and above structural inequality. I would hazard a guess that '*stigma*' is characterised by overt fear, whereas '*discrimination*' is not always overt. I therefore, propose that stigma is the extreme end of discrimination continuum.

## 1.5 HYPOTHESIS

The hypothesis based on the researched statement and the operationalisation is that, the government does not have adequate plans and strategies at hand to deal with the HIV/AIDS-related stigma and discrimination (S&D). It is therefore up to the NGO's, FBO's, CBO's, PLWHA, Traditionalists, and the community at large to work together in the fight against HIV/AIDS-related S&D and make a difference in our communities.

The tentative idea or question that needs evidence to support or refute it is *"How HIV/AIDS-related stigma and its associated prejudice and discrimination can be addressed?"* in the Mangaung Local Municipality. We need to educate our communities about the impact/effect that stigma and discrimination have on a stigmatised individual.

## 1.6 RESEARCH METHODOLOGY IDENTIFIED

### a) *Survey Methodology*

#### ➤ Data collection

This is a descriptive study. The survey and data collection methods were used to collect the relevant needed information which was critically analysed and used for the purpose of mitigating HIV-related stigma and its associated prejudice and discrimination. The data was collected from different communities in Mangaung area in the Free State Province.

#### ➤ Survey technique

This is a research technique in which information was gathered from a sample of people using a questionnaire. (Zikmund, 2003: 66). In this study a questionnaire was used to solicit responses from the subjects, and questionnaires also had open-ended questions in order to probe the participants. The questionnaire was anonymous so that people could respond freely and honestly giving out their views on the researched topic.

## **Procedure**

Respondents who were exposed to this survey were members of the communities around Mangaung Local Municipality (MLM), for example, Bloemfontein, Botshabelo and Thaba-Nchu areas; they participated in and responded to the survey

A pre-survey workshop was held with the participants. The aim of this workshop was to familiarise all the stakeholders with HIV/AIDS-related S&D questionnaire contents, and with the procedures of distribution to ensure buy-in into the process, efficient survey delivery and to enlighten them about the importance of the survey to minimise all possible misunderstandings; and what is to happen in the whole process. Participants included: members of the communities, community leaders, NGO's, CBO's, FBO's, PLWHA, Senior officials from the MLM, elderly people within the communities, community leaders, traditional leaders, herbalists (Inyanga), Local Government Officials, Health care workers, commercial sex workers (CSW), providers of home-based care, people who are not necessarily HIV-positive, etc; were interviewed to determine their perceptions and attitudes towards HIV/AIDS and the stigma associated with it.

Surveys were distributed amongst all of the participating respondents. Participants were asked to place completed questionnaires in the collection boxes provided. Respondent were assured that the data collected would be kept confidential and anonymous.

### ➤ Literature study

A literature study was used to obtain background information. Reference has been given to Government documents, articles, newspapers, circulars, journals, etc. that deal with issues related to HIV/AIDS-related stigma and discrimination. The information gathered was used to critically analyse, and used for the purpose of combating stigma and discrimination in the Mangaung Local Municipality (MLM) area.

➤ Interviews

These were based on purposeful sampling, that is, searching for subjects or people who were expected in the selected problem and who were able to give rich and detailed information about the investigation.

Officials from MLM, elderly people within the community, community leaders, traditional leaders, herbalists (Inyanga), Local Government Officials, religious leaders, PLWHA, Health care workers, sex workers, injecting drug users, providers of home-based care, people who are not necessarily HIV-positive, etc; were interviewed to determine their perceptions and attitudes towards HIV/AIDS and the stigma associated with it.

➤ Observations

During data collection method, the researcher randomly selected a group of community members who are affected and infected to observe their behaviour and approach. The method was descriptive in nature, in explaining the mitigation of stigma and discrimination in the area.

➤ Questionnaires

Questionnaires were sent out to collect data from different communities around the Mangaung Local Municipality area. All questions were designed in such a way that they can probe the participants. The questionnaire were anonymous so that people could respond freely and honestly giving out their views on the researched topic. A check list was used to assess the level of stigma. This served as a diagnostic tool that assessed the level of HIV/AIDS-related S & D and sexually transmitted infections (STI's) within the community; which will be useful in counselling, disclosure, community organisation, advocacy, etc.

The questionnaires were later collected and critically analysed in order to get the views of the communities around Mangaung area. See the attached copy of the questionnaire as Addendum A.

### ***b) Sampling Design***

For the hypothesis to be tested, a sample of the communities where HIV/AIDS-related S & D occur was conducted. The selected members of this sample have been interviewed in order to determine how HIV/AIDS-related S & D can be mitigated. Members were selected randomly and the information was used with strictest confidentiality.

### ***c) Measuring Instrument***

Carefully selected and formulated questions were used to compile an interview instrument, for example, open-ended and agree, disagree, and uncertain questions were used in terms of operationalized approach.

### ***d) Statistical Analysis and Packaging***

The analysis intended to test the hypothesis depends on the independent and dependent variables in order for this research could be successful.

#### *Independent variable:*

The independent variable was based on the HIV/AIDS-related S & D as observed by the researcher more especially in the schools, workplaces, transport industry and within the communities because people observe a person, diagnose him/her by looking at his/her outward appearance and assume that the person is HIV-positive. The impact of HIV/AIDS on women is particularly acute because women are often economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education. In a number of societies, women are mistakenly perceived as the main transmitters of STI's. The above mentioned statement leads to women and young girls to opt for Commercial Sex Work (CSW) and Commercial Sex Exploitation of Children (CSEC) respectively.

*Dependent variable:*

Because of the stigma and discrimination that prevails among our communities, people are afraid to disclose their HIV status, because they fear that they will be stigmatised and discriminated against together with their family members, and because of this idea, stigma and discrimination will continue to prevail in our communities.

## **CHAPTER 1**

### ***LITERATURE REVIEW***

In 1987, the late Jonathan Mann, the director of the WHO Global Programme on AIDS, identified three phases of the HIV/AIDS epidemic: the epidemic of HIV, the epidemic of AIDS, and the epidemic of stigma, discrimination, and denial. He noted that the third phase is 'as central to the global of AIDS challenges as the disease itself' (Mann 1987). Despite international efforts to tackle HIV/AIDS since then, *stigma and discrimination(S&D) remain the most poorly understood aspects of the epidemic*. This poor understanding is due in part of the complexity and diversity of S&D, but also is part to limitations in current thinking within the field and the inadequacy of available theoretical and methodological tools(USAID 200).

Stigma is in essence one of two things. The onset of a Dark Age of fear, pain and social fragmentation, or the opportunity for a Renaissance, a revival of a new social order, based upon grater compassion and understanding. The only way to head off this potential 21st Century Dark Age is the open questioning of what we hold to be true in our cultures. In order for us to be effective, we must challenge people's core beliefs. We have spent more than 20 years trying to fix everything, except what really needs to be fixed. We are addressing everything, except our core beliefs, and yet, it is these very beliefs that are creating the problem we are facing today.

People are afraid of contracting HIV/AIDS because of the statements below:

- AIDS is a life-threatening disease.
- People are scared of contracting HIV because HIV/AIDS is believed to bring shame upon the family or/and that particular community.
- The disease's association with behaviours such as sex between men and injecting drug use – that are already stigmatised in many societies.
- PLWHA are often thought as being responsible for becoming infected.

- Religious or moral beliefs that lead some people to believe that having HIV and AIDS is the results of moral fault – promiscuity or “deviant sex” that deserve to be punished.

### *i. Analysing Stigma and Discrimination*

#### ❖ What are the sources of S&D?

We therefore need to understand the ways in which HIV/AIDS-related S&D appear and the contexts in which they occur, we first need to understand how they interact with pre-existing S&D associated with gender, sexuality, race and poverty (see figure 1). HIV/AIDS-related S&D also interact with pre-existing fears about contagion and disease. Early AIDS metaphors – as death, as horror, as punishment, as guilt, as shame, as otherness – have exacerbated these fears, reinforcing and legitimizing stigmatisation and discrimination.

#### ○ Sexuality

HIV/AIDS-related S&D is most closely related to sexual stigma. This is because HIV is mainly transmitted sexually and in most areas of the world, the epidemic initially affected populations whose sexual practices or identities are different from the “norm”. HIV/AIDS-related S&D has therefore appropriated and reinforced pre-existing sexual stigma associated with sexually transmitted disease, homosexual, promiscuity, prostitution, and sexual “deviance” (Gagnon and Simon 1973; Plummer 1975; Weeks 1981). The belief that homosexuals are to blame for the epidemic or that homosexuals are the only group at risk HIV is still common. Promiscuous sexual behaviour by women is also commonly believed to be responsible for the heterosexual epidemic, regardless of the epidemiological reality. In Brazil, for example, where surveillance data have shown high rates of HIV infection among monogamous married women, HIV-positive are still widely perceived to be sexually promiscuous (Parker and Gavao 1996).

- Gender

HIV/AIDS-related S&D is also linked to gender-related stigma. The impact of S&D on women reinforces pre-existing economic, educational, cultural, and social disadvantages and unequal access to information and services (Aggleton and Warwick 1999). In settings where heterosexual transmission is significant, the spread of HIV infection has been associated with female sexual behaviour that is not consistent with gender norms. For example, prostitution is widely perceived as non-normative female behaviour, the female sex workers are often identified as “vectors” of infection that put at risk their clients and their clients’ sexual partners. Equally, in sexual behaviour, such as men’s preference or need multiple sexual partners.

- Race and ethnicity

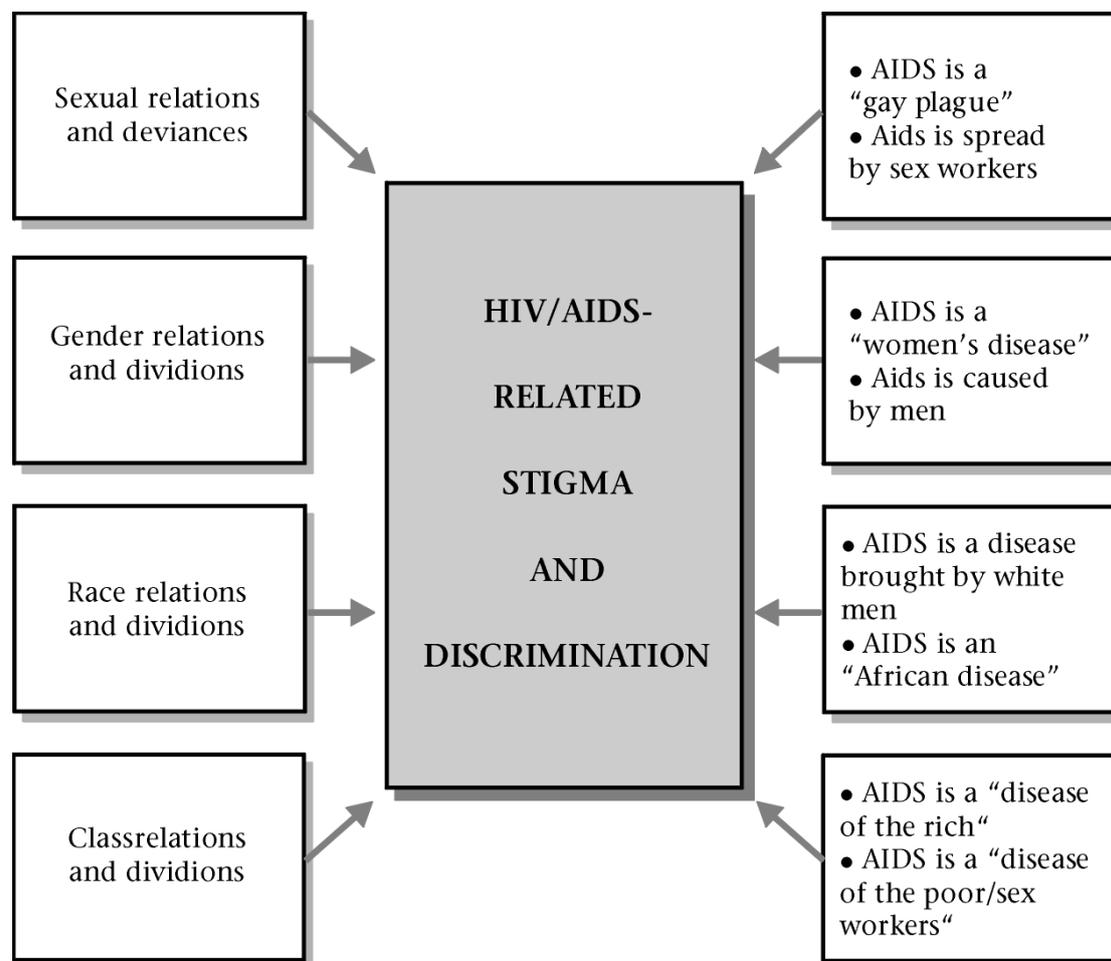
Racial and ethnic S&D also interacts with HIV/AIDS-related S&D, and the epidemic has been characterised both by racist assumptions about “African sexuality” and by perceptions in the developing world of the West’s “immoral behaviour”. Racial and ethnic S&D contribute to the marginalisation of minority population groups, increasing their vulnerability to HIV/AIDS, which in turn exacerbates stigmatisation and discrimination.

- Class

The HIV/AIDS epidemic has developed during a period of rapid globalisation and growing polarisation between rich and poor (Castells 1996, 1997, 1998). New forms of social exclusion associated with these global changes have reinforced pre-existing social inequalities and stigmatisation of the poor, homeless, landless, and jobless. As a result, poverty increases vulnerability to HIV/AIDS, and HIV/AIDS exacerbates poverty (Parker, Easton, and Klein 2000). HIV/AIDS-related S&D interact with pre-existing S&D associated with economic marginalisation.

In some contexts, the epidemic has been characterised by assumptions about the rich, and HIV/AIDS has been associated with affluent lifestyles

Figure 1: The link between HIV/AIDS and pre-existing sources of S&D (Figure taken from Horizons, 2004, p. 3)



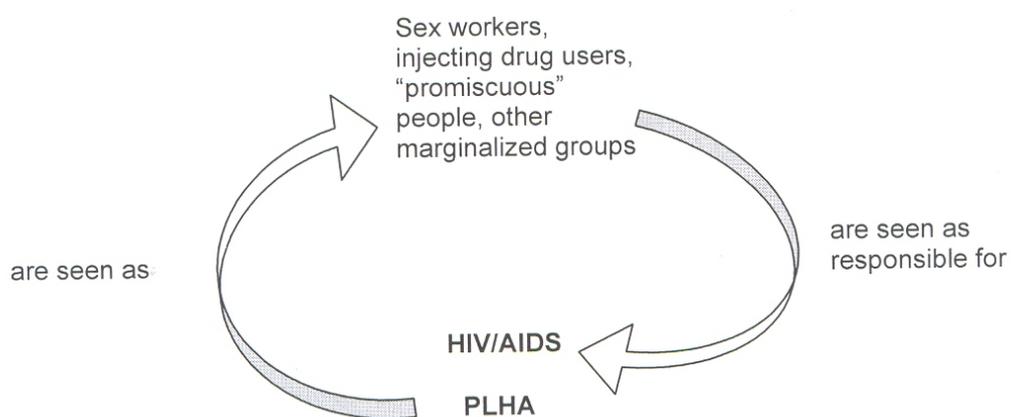
o Fear of contracting HIV/AIDS

HIV/AIDS is a life threatening illness that people are afraid of contracting. The virus metaphors associated with AIDS have also contributed to the perception of HIV/AIDS as a disease that affects “others”, especially those who are already stigmatised because of their sexual behaviour, gender, race, or socio-economic status, and have enabled some people to deny that they personally could be at risk or affected (UNAIDS 2000; Malcolm et al. 1998; Daniel and Parker 1993).

HIV/AIDS-related S&D is, therefore, the result of interaction between diverse pre-existing sources of S&D and fear of contagion and disease. The pre-existing sources, such as those related to gender, sexuality and class, often overlap and reinforce one another. This interaction has contributed to a deep-rooted nature of HIV/AIDS-related S&D, limiting our ability to develop effective responses. It has also created a vicious circle of S&D (see Figure 2), which works in two ways

Firstly, because HIV/AIDS is associated with marginalised behaviour and groups, all individuals with HIV/AIDS are assumed to be from marginalised groups and some may be stigmatised in a way that they were not before. For example, in some settings, men may fear to reveal their HIV status to their partners because it will be assumed that they are homosexual. Similarly, women may fear to reveal their serostatus because they may be labelled as “promiscuous” or sex workers and stigmatised as such. Secondly, HIV/AIDS exacerbates the stigmatisation of individuals and groups who are already stigmatised as oppressed and marginalised, which increases their vulnerability to HIV/AIDS, and which in turn causes them to be further stigmatised and marginalised.

*Figure 2: The vicious circle of S&D (Figure taken from Horizons, 2004, p. 4)*



- a) HIV/AIDS is associated with marginalised behaviours, and people living with HIV/AIDS (PLWHA) are stigmatised because they are assumed to be from marginalised groups
- b) Already marginalised groups are further marginalised because they are assumed to have HIV/AIDS

## ***ii. How is Stigma and Discrimination manifested?***

S&D takes many forms and are manifested in different levels – societal, community and individual – and in different contexts (INAIDS2000; Malcolm et al). The following examples highlight where HIV/AIDS-related S&D have been most frequently documented and where there is the greatest potential for intervention to reduce or mitigate S&D.

### ***❖ Institutional context***

#### ***○ S&D experienced at school***

The South African Constitution guarantees everyone the right to basic education. In addition the South African Schools Act (No 84 of 1996) based on constitutional principles and value, guides schools, governing bodies and principals towards adhering to the law. Sadly, even with this in place, lesbian, gay, bisexual and transgender (LGBT) scholar continue to be subjected to discrimination and stigmatisation at schools. Children with HIV/AIDS or associated with HIV through infected family members have been stigmatised and discriminated against in educational setting in many countries. Stigma has led to teasing by classmates of HIV positive school children or children associated with (Gilborn et al. 2001). Children who are HIV positive were expelled from their schools ones it was found that they were HIV positive. This puts these children at a higher risk of abuse and social exclusion, and they may be denied basic needs such as health care and housing. The resulting social exclusion cuts off individuals and communities from one another.

- S&D experienced in the workplace

The employment Equity Act (No 55 of 1998), including Equal Opportunities and Affirmative Action Policy, the Labour Relations Act (No 66 of 1995), the Basic Conditions of Employment Act (No 75 of 1997) and other labour legislation and policies are gear towards fair labour practices and equal benefits for all employees.

Reality is that employees are not treated equally nor with dignity and respect, despite the legislation. Such discriminatory practices as pre-employment screening, denial of employment to individuals who test HIV positive, termination of employment of PLWHA, and stigmatisation of PLWHA who are open about their serostatus (Gostin and Lazarrini 1997);Panos 1990; Barragan 1992; Gostin 1992;Panos 1992; Shisam 1993; Omangi 1997) have been reported from developed and developing countries. There have report of workers refusing to work next to those with HIV/AIDS or those perceived to be living with HIV/AIDS. Schemes providing medical assistance and pensions to employees have come under increasing pressure in countries seriously affected by HIV/AIDS, and some companies have used this as a reason to deny employment to PLWHA (Williams and Ray 1993; Whiteside 1993). Few companies have developed strategies to combat S&D or defined their responsibilities towards employees with HIV (Jackson and Pitts 1991; Bezmalinovic 1996)

- S&D experienced within the health profession

There have been many reports from health care settings of HIV testing without consent, breaches of confidentiality, and denial of treatment and care (AIDS Bhedbhav Virodhi Andolan 1993; Tirelli et al. 1991; Carvalho et al. 1993; Panebiaco et al. 1994; Ogola 1990; Masini and Mwampeta 1993). Failure to respect confidentiality by clearly identifying patient with HIV/AIDS, revealing serostatus to relatives without prior consent, or releasing information to the media or police appear to be problems in some health services (Panos 1990; Bharat et al. 2001; Singh 1991).

Factors contributing to these stigmatising and discriminatory responses include lack of knowledge, moral attitudes, and perceptions that caring for PLWHA is pointless because HIV/AIDS is incurable (Daniel and Parker 1993; Masini and Mwampeta 1993; Herek and Capitanio 1993; Herek et al. 1998; Blendon and Donelan 1998; Tesch, Simpson and Kirby 1990; Rosasco Dulanto 1992; Cole, Zhang, and Chen 1993).

On daily basis we see the extent to which HIV positive people are stigmatised and discriminated against by health care systems. In most instances some hospital staffs do not attend to PLWHA and these people may be turned away from health care services (that is, they are denied admission in government hospitals). Fear of discrimination may prevent people who are living with HIV and AIDS from seeking treatment for AIDS and/or acknowledging their HIV status publicly.

- *S&D experienced fro religious institutions*

In some context, HIV/AIDS-related S&D has been reinforced by religious leaders and organisations, which have used their power to maintain the status quo rather than to challenge negative attitudes toward marginalised groups and PLWHA. For example, at the international symposium *Religious Organisations Break the Silence on HIV/AIDS*, organised by the African Regional Forum of Religious Health Organisation during the 13<sup>th</sup> International AIDS Conference in July 2000 (Singh 2001), it was noted that religious doctrines, moral and ethnical positions regarding sexual behaviour, sexism and homophobia, and denial of the realities of HIV/AIDS have helped create the perception that those infected have sinned and deserve their 'punishment', increasing the stigma associated with HIV/AIDS. In other instances, PLWHA are refused entry to their places of worship and are denied access to other services that come with being a member of that religious institution or faith

- S&D experienced in the community

The South African constitution is one of the most liberal and comprehensive documents of protection in the world. It protects its people in many ways. In some communities people who are infected with the HI virus and those who are sick due to AIDS related illnesses are seen as shameful. Due to lack of knowledge and education among members of the society, they believe that people who are living with HIV and AIDS will bring shame and embarrassment into their communities. They also believe that being HIV positive is a punishment and/or curse from God for immoral behaviour; therefore these people should be excluded from their communities.

The societal rejection of certain social groups (for example, 'homosexuals, sex workers and injection drug users') may predate HIV/AIDS; the disease has, in many cases, reinforced discrimination and stigma. People tend to blame one another and because of this blaming, society can exclude itself from the responsibility of caring and looking after people who are living with HIV/AIDS

## CHAPTER 2

### ***WHAT POLICY SAYS ABOUT STIGMA AND DISCRIMINATION***

This chapter investigates how infected and affected people are protected by the HIV/AIDS policy and the implementation thereof, that is, whether the rights of PLWHA are included in the policy of different institutions as well as government sectors.

HIV/AIDS-related S&D in society is commonly manifested in the form of laws, policies, and administrative procedures, which are often justified as necessary to protect the “general population” (Kirp and Bayer 1992; Manuel et al. 1990). Examples of stigmatisation and discriminatory measures included compulsory screening and testing, compulsory notification of AIDS cases, restrictions of right to anonymity, prohibition of PLWHA from certain occupations, and medical examination, isolation, detention and compulsory treatment of infected persons (Tomasevski et al. 1992; Gostin and Lazzarini 1997).

One important example concerns limitations on international travel and migration. Despite widespread agreement that laws to prevent freedom of movement of PLWHA are ineffective public health measures, many countries have adopted policies restricting travelling and migration. Discriminatory practices include mandatory HIV testing for people seeking work permits (AIDS Bhedbhav Virodhi Andolan 1993; Solon and Barrazo 1993), the requirement that individuals seeking tourist visas declare their HIV serostatus, and denial of entry to PLWHA carrying medical drugs for HIV/AIDS treatment (Duckett and Orkin 1998). Foreigners have been deported from a diverse range of countries after the authorities have discovered they are HIV+ (Malcolm et al. 1998; AIDS Bhedbhav Virodhi Andolan 1993; Panos 1990).

S&D reinforces existing prejudice towards foreigners or marginalised groups. For example, travellers from countries most affected by the epidemic or whose appearance make others think they are gay men or commercial sex workers (CSW), may be subjected to additional questioning and physical searches.

Foreign nationals engaged in CSW may be deported because of the risk they are said to pose to local clients. This is the case in the Free State province where we have students coming from different places including our neighbouring countries (e.g. Lesotho, Malawi, Zimbabwe, etc).

Some governments, recognising that such measures are ineffective; they introduce legislations to protect the rights of PLWHA to education, employment, confidentiality, information and treatment (Kirp and Bayer 1992; Mann, Tarantola, and Netter 1996). *However, even when supportive legislation exists, it is not always enforced.* The failure of governments to protect the rights of PLWHA through legislation or to enforce existing legislation has been described as a form of discrimination by neglect (Daniel and Parker 1993; Watney 2000) as has the failure to provide effective prevention, treatment and care which is highly needed by those who are vulnerable to HIV/AIDS and for PLWHA.

Both Stigma and discrimination have a shameful history internationally. Discrimination arises out of many points of difference that can be consistently labelled: for example, physical deformity or disfigurement, racial differences, or any other factors that set up the person as different from the perceived norm. In this case the norm is generally defined in terms of who is powerful in the community (Goffman, 1963). The attachment of discrimination to illness has a long history, with it impacting on people with mental illness and physical disorders such as cancer, TB, STI's, and leprosy. The nature of stigma and discrimination is complex, varying across time, person and context, making analysis and especially intervention very difficult. Stigma and discrimination are cruel social processes that offer some feeling of protection to the powerful, while increasing the load on the individual or group who is victimised in the process. It is in turn constructed as impacting on directed recipients who are seen to be at blame anyway, so deserve this discrimination (Douglas, 1995).

### CHAPTER 3

## CAUSES, EFFECTS AND EXPERIENCES OF STIGMA AND DISCRIMINATION

The researcher suggests that stigma could be best understood from the perspective of four things, namely: (i) causes of stigma; (ii) context of stigma; (iii) experiences of stigma; and (iv) effect/impact of stigma on programmatic efforts. This macro-level framework is helpful to begin an understanding of the complexity of stigma.

#### i. *The causes and the effect of stigma*

The connection of stigma around HIV to historical racism and gender has developed a particular form of discrimination. Blame is often assigned to black people or to women. Men blame women for infecting them and spreading the virus. In couples, it can lead to violence against the woman or her exclusion from the household (Strebel, 1993). Stigma around disease often attaches itself to existing stigmatising frameworks (Sontag, 1988; van der Vliet, 1996), for example in South Africa AIDS has been associated mainly with black people and women.

Anger and fear contribute to the development of discrimination both in those who are HIV-positive or HIV-negative. A judgemental discourse has distinguished sharply between those 'innocents' who contracted HIV via organ or blood transfusions, the children of women with HIV, and women whose partners are unfaithful; and those who are considered guilty and almost 'deserve it'. On the other hand, religious groups may intentionally or inadvertently contribute to discrimination by making explicit or implicit judgements against those who are infected with HIV (Paterson, 1996). Attempts to label the epidemic as God's punishment for sinners, especially gays, prostitutes and drug users, have often been documented (Crawrod, Allison, Robinson, Hughes & Samaryk 1992; Johnson, 1995)

HIV/AIDS-related stigma is one of the most barriers affecting access to and provision of health services, particularly in South Africa. It is a well known fact that women refuse to be tested for HIV at antenatal clinics in the Mangaung Local Municipality, this is because of the fear they have, and the stigma associated with HIV/AIDS. It is therefore important that lines of communication be opened concerning the disease to improve adherence to treatment and facilitate patients' acceptance of the disease as well as coping skills with the stigma of being HIV positive.

To be able to blame others is psychologically reassuring as it divides the society into 'us' and 'them'. 'Others' are guilty as a result of their behaviour. They are guilty not only of getting themselves ill, but also of infecting 'innocents'. This among the members of a community increases the stigma load borne by those groups seen as responsible. The attachment of gender discrimination to HIV stigma has led to women being blamed for spreading the epidemic. Thus women are contradictorily expected to provide sexual services to men generally, be chaste and pure, and take on the responsibility of preventing pregnancy and disease.

In South Africa, we read about the story of Promise Mthembu (1998), the story highlights some of the challenges that women living with HIV face in this country. Mthembu' (1998) story also describes how she was subjected to daily beatings from her husband, who not only blamed her for contracting the disease, but also communicated this blame to his family. Furthermore, Mthembu was exposed to institutional discrimination after accidentally discovering that she was pregnant. The doctor only agreed to terminate her pregnancy on condition that she consented to being sterilized, giving her no choice in the matter directly related to her own reproductive health.

ii. Experience of Stigma

Understanding the attitudes of nurses and other health care workers toward AIDS patients is important in order to plan how to use health care workers to intervene against stigma. Health care workers themselves are the recipients of stigma because they care for people living with HIV/AIDS and are also often the source of stigma from the perspective of many people living with HIV/AIDS in the MLM. The health care workers say that they have a fear of becoming infected, their perceived rights in refusing to care for patients with HIV/AIDS, and the stresses they experienced in providing HIV care. Some health care workers feel reluctant or discomfort about having direct contact with AIDS patients and this lead to them being experiencing high levels of symptoms, such as depression and burnouts.

We have also read the report from the Law Project who reported that the Health Professions Council of SA did not act against 28 doctors who breached patient confidentiality. The patients were mostly domestic workers whose employers had been told of their diagnosis and many of whom were subsequently dismissed. Some health professionals have refused to treat people with AIDS, on the grounds of possible risk of infection (Krautkramer, 2000). Children orphaned or rendered vulnerable by AIDS are likely to experience increasing stigmatisation. Recently 90 children affected by HIV/AIDS spoke of their experiences of discrimination. They faced verbal and physical discrimination at schools and in the community (Streak, 2001b). Orphans have also been identified as a major security threat for the future (Schönteich, 2002). While this may be a rational call for resources and intervention; it does also lay the basis for them to be identified as a special group for discrimination. Stigma would clearly worsen the situation of orphaned and vulnerable children, excluding them even further from resources and support.

Another experience of stigma in South Africa is the example of the differential treatment meted out to people living with HIV was the death of Gugu Dlamini. Newspaper reports stated that Gugu Dlamini was stoned and beaten to death after she had spoken out about her HIV status. Neighbours accused her of shaming the community by revealing her HIV status (*Independent on Sunday*, August 14, 1999). Mpho Motloun is another example of a person killed because of her seropositive status (*Sowetan*, August 23, 1999).

In 2005, due to lack of knowledge/education, my cousin was treated unfairly by her community, friends and family when they found out that she was HIV positive. In her last stages of AIDS, no one could wash or feed her, including myself. I was even scared of looking her in the eye and talk to her although she was my friend and cousin. Even her sisters could not use the same eating utensils she used. They bought her a red plastic plate, a spoon, red bucket and a red basin for washing herself. When I asked why this kind of treatment, I was told that she was contagious. I could see the pain and hurt in her eyes, she was not killed by AIDS but she was killed by the stigma and discrimination she got from her friends, family, colleagues, and her community. I was sad to see her suffering the way she did. It was due to her illness that I saw the necessity of doing this research, so that I can make an impact in other peoples' lives who are suffering.

## **CHAPTER 4**

### **DISCRIMINATION IN THE FAMILY, COMMUNITY AND THE WORKPLACE**

The focus is based on the HIV/AIDS among members of the family, community around infected people as well as in the workplace situations. I assessed the situation whether the environment accommodate the infected people without labelling them as being HIV. I also assessed if there are facilities in the environment that can be used for support group purposes.

#### **4.1 Discrimination within the other families in the MLM**

The family is the main source of care and support for people living with HIV and AIDS. Discrimination has spread rapidly, causing anxiety, stress and prejudice against people living with HIV and AIDS. The disease is associated with stigma as people affected and infected by the HI virus have been rejected by their own families (in the Mangaung Local Municipality), their loved ones and their society and thus putting these people into more stressful situations. Sometimes family members think that members of their families who are living with HIV and AIDS will bring shame and embarrassment into their household. Due to lack of knowledge and ignorance, families think that the reason why their family members are infected with the HI virus is due to lack of personal responsibility.

In some instances their spouses divorce these people and suffer physical violence; and/or evict them out of their homes (more especially women) or even murdered (for example, Gugu Dhlamini who was stoned and beaten to death by the neighbours in her township near Durban, after speaking out openly on World AIDS Day about her HIV status). In most cases, HIV positive women are treated differently from men; in most instances, women whose husband have died because of AIDS related illnesses, are blamed by their in-laws for their husband's deaths because women are mistakenly perceived as the main transmitters of sexually transmitted disease (STD's) and HIV/AIDS.

Children orphaned by AIDS are taken by a new family and may be expected to work harder than other children, and may be the last to receive benefits such as having their school fees paid. In some communities, families will not take in orphans, because of the stigma of caring for non-related children, particularly those associated with AIDS.

Children, especially girls, normally drop out of school to care for ill parents, work to support the family and/or tend the household. Orphans may leave school because of discrimination or emotional distress or because they cannot pay school fees. Where there is steady income, much of it may be spent on medical bills in favour of basic commodities. Sometimes parents die without making financial provision for their children, or with unsettled financial debts. In some cases, relative or customary laws disregard wills, which result in loss of inheritance for the children. Sometimes children even lose the house they were living in.

People in the community may discriminate against children who have HIV positive, who have family members with HIV and/or who have been orphaned by AIDS. Children who are HIV positive were expelled from their schools ones it was found that they were HIV positive. This puts these children at a higher risk of abuse and social exclusion, and they may be denied basic needs such as health care and housing. The resulting social exclusion cuts off individuals and communities from one another.

#### **4.2 Discrimination in the communities around Mangaung**

The South African constitution is one of the most liberal and comprehensive documents of protection in the world. It protects its people in many ways. In some communities people who are infected with the HI virus and those who are sick due to AIDS related illnesses are seen as shameful.

Due to lack of knowledge and education among members of the community, they believe that people who are living with HIV and AIDS will bring shame and embarrassment into their community. They also believe that being HIV positive is a punishment and/or curse from God for immoral behaviour; therefore these people should be excluded from their community.

The societal rejection of certain social groups (for example, 'homosexuals, sex workers and injection drug users') may predate HIV and AIDS; the disease has, in many cases, reinforced discrimination and stigma.

Churches also discriminate against people who are living with HIV, they believe that their members will not be infected with the HI virus or get AIDS. These churches even expel member of their congregation who are HIV positive out of their churches because they say that these people are sinners and they deserve their punishment (that is, being HIV positive).Funeral parlours were also discriminating against people who have died due to AIDS related illnesses because they thought that they were contagious.

If an employee has been working for an organisation and declares his/her HIV status, it often happens that the employee is dismissed unfairly on the ground of his/her status. Sometimes an employee who is HIV positive may be refused sick leave or other benefits because of the status. Some friends and colleagues also discriminate against people who are living with HIV and AIDS.

The Bill of Rights indicates that one should not discriminate against people who are HIV positive, because an HIV positive person can live for many years and be productive if the right lifestyle is followed and medical care is given and taken properly. It further states that one cannot be discriminated against because of one's HIV status when applying for a job, unless the Labour Court has given the employer permission to do so. HIV is a disease and is nothing to be ashamed of.

### **4.3 Discrimination in the Clinics around Mangaung**

On daily basis we see the extent to which HIV positive people are stigmatised and discriminated against by health care systems. In most instances some hospital staff and particularly the clinic staff do not attend people who are living with HIV and AIDS and these people may be turned away from health care services (that is, they are denied admission in government hospitals). Fear of discrimination may prevent people who are living with HIV and AIDS from seeking treatment for AIDS and/or acknowledging their HIV status publicly in these areas. Due to the fact that people are blaming one another for bringing HI virus in their household and society, family members and members of the society tend to ignore and deny people who are infected with HI virus the health care services that they need.

Some health care professionals disclose patient's HIV status to other health care professionals without the patient's consent and thus breaking the person's right to confidentiality and privacy. At other clinics, some nurses are not properly trained on HIV and AIDS therefore they are unable to assist, support and care for people who are living with HIV and AIDS.

At some health care services, people who are HIV positive are made to queue separately so that everybody can see them that they are unique to other patients because of their HIV status (for example, my cousin who experienced this kind of treatment late in 2005 refused to go to the clinic to collect her treatment and she died in January the following year).

There is no proper pre-test and post-test counselling, for example, when I went for an HIV test late last year in one of the clinics in the Mangaung area I was never counselled before an HIV test. There have been many reports from health care settings of HIV testing without consent in this area.

Even though it is against the South African law, some medical aids do not accept people who are HIV positive even if the person can afford the contribution, we see this in the Clientel advertisement on TV, for example, they always say: *'pre-existing conditions are covered excluding HIV/AIDS but if you are diagnosed with HIV after you have taken the policy, it is covered like any other medical illness'*. This statement by Client shows how people living with HIV and Aids are still stigmatised and discriminated against in South Africa. As far as I am concern the media is still contributes to S & D because they condone such advertisements to be published. In some cases, if they accept PLWHA, these members will have to pay higher contribution as they are referred to as high-risk members.

Research in other parts of the country shows that to avoid stigma and discrimination, some HIV-positive people refuse to get information about HIV and sexually transmitted disease, staying away from health care professional and shining those suspected to risk behaviour in an effort to blend in with community norms (Lieber et al., 2005)

## **CHAPTER 5**

### **OBSERVATION**

From the findings it is evident that respondents are generally knowledgeable about the transmission and prevention of HIV/AIDS. The results of this study indicate that respondents are knowledgeable about the four main methods of HIV transmission, namely through sexual intercourse, through transfusion of contaminated blood, through sharing of contaminated needles among HIV drug users, from an infected mother to her baby during pregnancy and during the birth process. Results of the survey also suggest that the majority of respondents were clear that HIV cannot be transmitted through casual contact such as sharing of public toilets, sharing of cutlery and crockery and sharing of tools and equipment.

A greater uncertainty was expressed regarding whether HIV can be contracted via exposure to an infected person's bodily fluids such as saliva and whether mosquitoes could transmit the virus. Although all scientific data available leads to the conclusion that HIV cannot be transmitted through these modes, respondents appeared not to be convinced of this fact, as the above findings suggest.

Although respondents showed a high level of knowledge and awareness that HIV cannot be transmitted through the various means of casual contact some were not willing to or uncertain about using the same toilets as an infected person, others were not comfortable or uncertain about sharing crockery and cutlery and some few respondents were not comfortable or uncertain about sharing tools or equipment with an infected person. Although respondents indicated that they know that HIV cannot be transmitted through casual contact (as this is what they have been told) they may remain unconvinced of scientific findings because they worry that new evidence may come to light at a later date that points to the possibility of HIV transmission occurring through casual contact.

This study further highlighted that only 5% of respondents believed that their colleagues/friends would not avoid them if they found out that they had HIV or AIDS. The last-mentioned finding substantiates findings of Barrows et al. (1996) and Lau and Wong (2001) that individuals believe that they will be discriminated against or that others will resist working alongside or avoid them if they were found to be HIV positive.

Respondents' ages ranged from as young as 18 (N = 42) to age 50 and older (N = 90) with the majority of participants in the 25–29 year age category (N = 296); and those who ranged from 19 – 24 age category (N = 72). The sample indicated a leaning towards female respondents (N = 244), with male respondents accounting for (N = 136). The educational level of the sample varied between non-formal education, high school, college and university, with the majority of respondents reporting a high school education level (N = 244).

### ***EDUCATIONAL LEVELS***

<b><i>Highest educational level</i></b>	<b><i>Count</i></b>	<b><i>Percentage</i></b>
Non-formal education	33	6.6%
Primary school	87	17.8%
High school	244	48.8%
College/University	136	27.2%
<b><i>Total</i></b>	<b><i>500</i></b>	<b><i>100, 0%</i></b>

More than half of the respondents (52%) indicated that they were in a relationship with the remaining 48% indicating that they were single at the time.

## **MEASURING INSTRUMENT**

In the research, a questionnaire consisting of [36](#) items and comprising three sections was utilized. Section A recorded the demographic data of the various respondents. Section B ([21 items](#)) measured the level of knowledge of the respondents regarding HIV/AIDS and Section C ([7 items](#)) measured discriminatory practices regarding an HIV-positive individual, lastly, Section C comprising of open-ended questions ([8 items](#)). Various literature sources were used in the compilation of the questionnaire.

In this regard the ILO Code of Practice on HIV/AIDS and research done by the World Health Organisation refer. Following the study of HIV/AIDS, it appears that information regarding HIV/AIDS is cantered around the following themes:

- How is the virus contracted?
- What is the cause of HIV/AIDS?
- Communities' concerns, myths and fears;
- Prevention and control of the spread of the virus;
- Testing for HIV/AIDS;
- Discriminatory practices.

The abovementioned themes served as the researcher's point of departure in formulating the questions. Each of the items in the HIV/AIDS related S&D Questionnaire is presented in the form of a three point scale; namely Agree, Uncertain, and Disagree. This format is most appropriate, given the objective of the study, i.e. to address HIV/AIDS-related stigma and discrimination on the respondents. For the purpose of this study all questions answered as *Uncertain* were considered to be incorrect answers, which indicated a lack of knowledge. An example of the item construction is included.

“Do you believe HIV/AIDS can be cured?”

Agree	Uncertain	Disagree
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“Do you believe that you can prevent becoming infected by wearing a condom during intercourse?”

Agree	Uncertain	Disagree
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## RECOMMENDATIONS

- The provision of HIV/AIDS educational intervention programs are imperative in reducing discriminatory attitudes and behaviour towards people infected with HIV/AIDS.
- By reducing discriminatory attitudes and behaviour one contributes to a milieu of acceptance and understanding which in turn assists in reducing fear and denial and thereby indirectly reduces the risk of new infections.
- Current thinking regarding “at risk” groups such as younger age groups, should be reconsidered, since such “stereotyping of risk” can contribute to older individuals not perceiving themselves to be at risk when they may in fact be at higher risk due to their lower level of knowledge and past lack of exposure to sex and HIV/AIDS education.
- HIV/AIDS intervention programs should have the dual aim of providing information, according to Bellinger et al. (2004) information is data that has been given meaning by way of relational connection, this meaning can be useful, but does not have to be, and education (knowledge and understanding). People first need information i.e. the facts, which will help to lay the foundation for health education.
- Implementation of campaigns to help PLWHA to know that there are people who are sympathetic and help and point them in the direction of support.

- Find ways to care for the sick and the needy, especially when the family unit has broken down, and to establish a culture of caring and openness among our communities and to work towards creating a safe and nurturing environment where PLWHA can live freely, and to make PLWHA aware of the resources available to them in the community, for example: availability of antiretroviral treatment, etc.

While we educate people living with HIV and AIDS, while we tell them what is good for them, while we guide them, we often seem to forget to equip them with the necessary skills and knowledge to make responsible decisions. We need to change our attitudes toward PLWHA because, if **attitude** were to change with regard to HIV and AIDS, then the **trends in behaviour** would change too. This in turn would lead to more **positive changes** in the statistics of our country. Negative attitudes thus produce negative behaviour and positive attitude will result in positive behaviour and better relations.

People need to be educated, so that they are able to challenge the discrimination, stigma and denial that they meet in the society, family and in health care. A more enabling environment needs to be created to increase the visibility of people living with HIV and AIDS as a 'normal' part of any society. If we need to teach the ones infected how to live with the virus successfully, we need to ensure that they also believe that they have a future, and that there are good things to come that it is possible to live a good life. One aspect reducing discrimination is for people living with HIV and AIDS to earn the respect of others through engaging in a productive life, and not seeking for sympathy. At social and community level, it is critical that people hear and see that (a) it is possible to live well with HIV for many years if certain actions are taken; and (b) that the infected person can and will—add to the collective resource base for a long time if the support is given to stay healthy (in other words they should not expect people to care for them if they do not care about themselves).

## **CHAPTER 6**

### **SUMMARY**

Barnett and Whiteside (2002) argue that when there is openness and willingness to talk about HIV/AIDS, prevention has worked. The solution for HIV/AIDS-related S&D lies in our hands, we can challenge the attitudes towards people living with HIV/AIDS (PLWHA) and provide solidarity with those infected and affected. We can do this by implementing HIV/AIDS education programmes that explain how the virus is contracted, how it is spread, and how to ensure that HIV positive people are not discriminated against or stigmatised.

We must bear in mind that the fight against HIV and AIDS is not just government's concern. It is everybody's fight. We are morally obliged to know about the disease and be in a position to assist the sufferers. As South Africans, we must look at ways of fighting this disease and look at the problem from a holistic point of view, including scientific research, awareness programmes, changing the attitude of people in stigmatising the disease, treating those infected with ARV's, and providing support psychologically, socially, and spiritually.

We should take the lead in looking at the issue of caring for (Ubuntu) and supporting PLWHA. Working to reduce or end stigma and discrimination is not a short-term undertaking. As has been shown in attempts to end racism, stigma can be highly resistant to change (Foster, 1991). The popular notion that provision of information is sufficient to change stigma is clearly insufficient (Deacon, Prosalendis & Stephney, 2004). The link of information to beliefs and behaviour has been shown to be insufficient in changing sexual behaviour in relation to HIV, and has also proved insufficient in addressing racism and sexism.

It is not possible for us to influence any long term changes in discriminatory behaviour, unless we have the courage to *challenge people's core beliefs*. It is neither a comfortable – nor popular – process. All too often we are so busy worrying that we might offend a community's sensibilities that we do communities disservice, simply because we are too scared to take the risks of challenging these beliefs. If we do not challenge these core beliefs, we have failed in doing what needs to be done to serve our communities.

From the above discussion, I think that there is a clear need to establish a research agenda for stigma related to HIV/aids in South Africa. An initial priority is the development of a greater understanding of the nature and practice of discrimination and stigma against HIV positive people and those affected by this pandemic in South Africa. Stigma and discrimination are social phenomena so need to be understood at both individual and social levels. This is a real and centrally important challenge for harnessing the HIV/AIDS epidemic that needs to be taken seriously.

Lastly, I also think it is now time for us to act on this unjust discrimination against our fellow South Africans. I also think that there is only one solution, if we hope to make any difference at the social level. We must challenge people's beliefs. When we can do this, we can then make a real impact on stigma and discrimination, in our families, among our community and in our country (South Africa). What are the values we want to share? How do we want to live? Unlike past generations, we cannot say: *'For my children I want...'* If we wait and delay, it will be too late. This time we need to start with *'For me, and my children, I want...'*

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# Addendum A.

## AFRICA CENTRE FOR HIV/AIDS MANAGEMENT

### M.Phil in HIV/AIDS Management

#### RE: REQUEST TO COMPLETE A QUESTIONNAIRE

*Dear Respondent*

*My name is Funeka Mphumela. I would very much appreciate if you could participate in my research project for my M Phil in HIV/AIDS Management.*

*I am interviewing people around Bloemfontein, Botshabelo and Thaba-Nchu areas; in order to find out more about their **knowledge, attitudes and behaviour related to HIV/AIDS-related stigma and discrimination.***

*I would like to collect information that will help me to better understand HIV/AIDS-related stigma and discrimination in the Mangaung Local Municipality. I will appreciate it if you can answer all questions that asked as honestly as you can. I promise you that the data gathered from this survey will be treated with the **strictest confidentiality**, and presented only in a summary form without the name or affiliate of the respondent.*

#### **SECTION A: BACKGROUND INFORMATION**

**Q1. Gender:**

- Female  
 Male

**Q2. Population group:**

- African       White  
 Coloured

**Q3. Age in years:**

- 18-28       29-39  
 40-50       51 or more

**Q4. Home language:**

- Afrikaans       English       Isixhosa  
 Sesotho       Tswana       Sepedi  
 Ndebele       Other

**Q5. Highest education level:**

- No formal education  
 Primary education  
 Grade12       Tertiary education

**Q6. Marital status:**

- Single       Married

**SECTION B: KNOWLEDGE REGARDING HIV/AIDS**

<b>STATEMENTS</b>	<b>Agree</b>	<b>Uncertain</b>	<b>Disagree</b>
1. A blood test can show whether someone has HIV/AIDS			
2. An HIV-positive mother who is breast-feeding can pass the HIV virus on to her baby			
3. HIV/AIDS can be cured			
4. The presence of a sexually transmitted disease can increase the risk of HIV transmission			
5. A pregnant woman who has HIV/AIDS can pass the HIV virus on to her unborn baby			
6. TB can be cured if treatment is given early enough			
7. There is a difference between being HIV positive and having AIDS			
8. A person can be HIV-positive for many years without becoming ill			
9. Tuberculosis (TB) is often considered to be an AIDS related disease			
10. You can tell by looking at someone that they are infected			
11. You can become infected by sharing food or eating utensils with a person who has HIV/AIDS			
12. You can become infected by kissing a person who has HIV/AIDS			
13. You can become infected by touching the body of a person who has HIV/AIDS			
14. You can become infected by using syringes/needles .....previously used by a person who has HIV/AIDS			
15. One can become infected by having unprotected sex			
16. You can become infected by being bitten by a mosquito .....that previously bit an HIV-infected person			
17. You can become infected by using the same toilet seats .....as HIV-infected people			
18. You can become infected by being in contact with the perspiration (sweat) of a person who has HIV/AIDS			
19. You can prevent becoming infected if you wear a .....condom			
20. There are female condoms that are effective in the .....prevention of HIV transmission			
21. Contraceptive practices such as the pill etc. can also .....prevent HIV transmission			

**SECTION C: DISCRIMINATORY PRACTICES**

<b>QUESTIONS</b>	<b>Disagree</b>	<b>Uncertain</b>	<b>Agree</b>
1. If you were infected, do you believe that your colleagues would avoid you if they found out that you had HIV/AIDS?			
2. Would you feel comfortable working with a colleague if you knew that he/she was HIV positive?			
3. Would you feel comfortable sharing toilets with an HIV infected person?			
4. Would you feel comfortable sharing cutlery/crockery with an HIV-infected person?			
5. Do you believe that your boss would attempt to dismiss you if they found out that you were HIV positive?			
6. Should you become infected with HIV /AIDS would you tell someone?			
7. Should you become infected with HIV/AIDS would you tell your partner?			

**SECTION D: Open-ended questions**

- I. What causes people to display stigmatisation and discriminating behaviour towards their fellow human beings? \_\_\_\_\_
- II. What impact does stigma and discrimination have on people living with HIV/AIDS?  
\_\_\_\_\_
- III. What culturally acceptable approaches can be used carefully to reduce stigma and discrimination? \_\_\_\_\_
- IV. What factors work best in reducing HIV/AIDS-related stigma as it affects children?  
\_\_\_\_\_
- V. What factors have enabled some communities to overcome and move beyond stigmatising and discriminating responses to HIV/AIDS? \_\_\_\_\_
- VI. How do individuals move beyond stigma to face the responsibility of having HIV within the current environment? \_\_\_\_\_
- VII. What personal factors enable these people to seek testing, and what enables those who test positive to deal openly with their status? \_\_\_\_\_
- VIII. What 'best practice' models of stigma reduction are there that can influence intervention and programmes? \_\_\_\_\_  
\_\_\_\_\_

**Should you have any questions or comments with regard to this interview and my research, please feel free to contact me on 082 412 3811 or 051-432 2907(w).**

**Thank you for your time and inputs.**