

**FACTORS CONTRIBUTING TO HIV AND AIDS  
STIGMA AMONG YOUNG ADULTS**

**BY**

**JABU PATRICK MOKWENA**

Submitted in fulfilment of the requirements for the degree of

**Doctor of Philosophy**

**in**

**Psychology**

in the

**FACULTY OF HUMANITIES**

**(School of Social Science)**

at the

**UNIVERSITY OF LIMPOPO**

**(Turfloop Campus)**

**Supervisor : Prof S. N. Madu**

**Co-Supervisor: Prof T-A. B. Mashego**

2012

**DECLARATION**

“I declare that the dissertation hereby submitted to the University of Limpopo for the degree of Doctor of Philosophy has not been previously submitted by me for a degree at this or any other university; that it is my own work in design and execution, and that all material contained therein has been duly acknowledged.”

MOKWENA, JP (MR)

2012/05/18



Signed at ..... on the .....2012

.....

JP MOKWENA

## **DEDICATION**

This work is dedicated to my wife, Refilwe, my daughter, Letlotlo, and my son, Thabo (Jabu Jnr), for their inspiration and their continuous support during my studies.

## ACKNOWLEDGEMENTS

I am extremely grateful to my supervisor, **Professor Ntomchukwu Sylvester Madu**, for his pearls of wisdom transferred to me throughout this study. Thank you for detailed comments and discussions on earlier drafts (humble beginnings) that helped me construct this study. I would like to show my greatest appreciation to **Professor T-A.B. Mashego, my co-supervisor**, for your assistance in the systematic and coherent organisation of this work. I can't say thank you enough for your tremendous support and help.

### **I owe a debt of gratitude to the following:**

- God for giving me the strength from the beginning to the end.
- My beloved parents (Johannah and Samuel), brothers (Buti, who is deceased, Fannie, Thato and Tshepo), and sisters (Sesi, Elsie and Salome). Thank you for your heartfelt support throughout my studies.
- I am also grateful to my in parents-in-law (Percy and Dorah), my brother-in-law (Meshack) and sisters-in-law (Confidence, Lebogang and Lerato) who have contributed to my life in many ways.
- The Department of Psychology, University of Limpopo, for academic guidance as well as personal enrichment.
- Young adults within the Polokwane municipality who served as participants in the study.

<b>TABLE OF CONTENTS</b>	<b>PAGE</b>
<b>Chapter One: General orientation to the study</b>	<b>1</b>
1.1 Introduction	1
1.2 Research of the problem	2
1.3 Background of the study	4
1.4 Aim of the study	5
1.5 Objectives of the study	5
1.6 Scope of the study	6
1.7 Significance of the study	7
<b>Chapter Two: Theoretical perspectives</b>	<b>8</b>
2.1 Introduction	8
2.2 Operational definition of concepts	8
2.3 Stigmatisation framework	10
2.3.1 Disease stigmatisation	10
2.3.2 Stigma and cultural variation	12
2.3.3 Stigma and self-identity	13
2.3.4 Stigma and the self-concept	13
2.3.5 Dimensions of stigma	14
2.4 Attribution theory	14
2.4.1 Correspondence bias	14

2.4.2 Actor-observer effect	15
2.4.3 The self-serving bias	16
2.5 Social structure perspectives	17
2.5.1 Racism, sexism and disability-related prejudice	17
2.5.2 Understanding functionality without functionalism	19
2.5.3 Understanding stigmatisation as a process	21
2.5.4 Stigma and power	23
2.6 Labelling theory	24
2.7 Blaming theory	25
2.8 Contact theory	26
2.9 Cultural perspective	27
2.9.1 Individualistic and communalistic cultures	28
2.9.2 Cultural beliefs and illness	29
2.9.3 Cultural norms and practice	30
2.10 Conclusion	31
<b>Chapter Three: Literature review</b>	<b>32</b>
3.1 Introduction	32
3.2 HIV and AIDS knowledge and stigma	32
3.3 Acquaintance and stigma	36
3.4 Gender and stigma	39

3.5 Knowledge of one's own status and stigma	42
3.6 Socio-economic status and stigma	49
3.7 Religion and stigma	51
3.8 Family communication and stigma	55
3.9 Perceived HIV and AIDS risk and stigma	57
3.10 Cultural background and stigma	60
3.11 Conclusion	62
<b>Chapter Four: Methodology</b>	<b>64</b>
4.1 Introduction	64
4.2 Research design	64
4.3 Sampling	64
4.4 Instruments	65
4.5 Procedure	67
4.6 Statistical methods	69
4.7 Ethical considerations	69
<b>Chapter Five: Analysis and interpretation of findings (results)</b>	<b>72</b>
5.1 Introduction	72
5.2 Biographical information of participants in the quantitative component of the study	72

5.3 Biographical information of participants in the qualitative component of the study	76
5.4 Results from qualitative data	78
5.5 Findings	80
5.6 Summary of quantitative results	88
5.7 Results from qualitative data	88
5.6 Summary of qualitative results	96
5.7 Conclusion	97
<b>Chapter Six: Discussion</b>	<b>98</b>
6.1 Introduction	98
6.2 Discussion of major findings	98
6.2.1 HIV and AIDS knowledge and stigma	98
6.2.2 Acquaintance and stigma	99
6.2.3 Gender and stigma	100
6.2.4 Knowledge of own status and stigma	101
6.2.5 Socio-economic status and stigma	103
6.2.6 Religion and stigma	104
6.2.7 Family communication and stigma	106
6.2.8 Perceived risk and stigma	107
6.2.9 Culture and stigma	108
6.3 Unique findings from the study	109

6.4 Recommendations	110
6.5 Conclusion	111
6.6 Limitations of the study	112
6.7 References	113
7. Appendices	129

## LISTS OF TABLES

Table 1: Demographic variables for the quantitative study	72
Table 2: Demographic variables for the qualitative study	77
Table 3: Regression model summary	79
Table 4: HIV and AIDS knowledge and stigma (derived from table 3)	80
Table 5: Acquaintance and stigma (derived from table 3)	81
Table 6: Regression analysis: gender and stigma (derived from table 3)	82
Table 7: T-test for gender and stigmatisation	82
Table 8: Knowledge of own status and stigma (derived from table 3)	83
Table 9: Socio-economic status and stigma (derived from table 3)	84
Table 10: Means scores on socio-economic status	84
Table 11: Religion and stigma (derived from table 3)	85
Table 12: Family communication and stigma (derived from table 3)	86
Table 13: Risk perception and stigma (derived from table 3)	86
Table 14: Culture and stigma (derived from table 3)	87

## **ABSTRACT**

The aim of the study is to determine factors contributing to HIV and AIDS stigma among young adults at Polokwane municipality in the Capricorn district of Limpopo Province, South Africa. A total number of 325 participants were involved in the survey and five focus groups were involved in the qualitative study.

The participants' ages were between 18 and 25 years. Biographical information entailing 14 items was used. Ten questions were used in five focus groups. For the survey, a nine-item stigma questionnaire was used as an independent variable. Dependent variables were the following scales: HIV knowledge, knowing a person with HIV and AIDS, family communication and perceived HIV and AIDS risk. The quantitative analysis shows that knowledge of HIV and AIDS, acquaintance with People Living with HIV and AIDS (PLWHA), gender and socio-economic status, as well as stigmatisation of people living with HIV and AIDS, significantly influence stigmatisation of PLWHA. On the other hand, knowledge of one's own status, affiliation to religion, family communication, perceived risk and cultural attachment played a limited role in the stigmatisation of people living with HIV and AIDS.

In view of the above findings, efforts need to be made to review programmes that are undertaken to create awareness about HIV and AIDS to improve HIV transmission knowledge. Constant interaction among PLWHA should be encouraged since this serves as a buffer to combat stigmatisation of PLWHA. There is a need for further research on gender, to explore in-depth reasons for stigmatisation of PLWHA, especially from females. Research also needs to be done in future to determine the factors that influence people from a high socio-economic level to stigmatise of PLWHA.

# CHAPTER 1

## GENERAL ORIENTATION TO THE STUDY

### 1.1. INTRODUCTION

Stigma has had particular implications for South Africa (SA), given a history of racism and other stigmatising beliefs. According to Skinner and Mfecane (2004) one needs to focus one's attention on understanding what causes people as a society to react in this way to people living with HIV and AIDS (PLWHA), people who are already suffering enough, either physically or mentally, to be challenged yet again by the judgment of others, by the very people who yesterday were their neighbours and who should be reaching out to them today. Only when one understands the cause, can one hope to help one's fellow men and women by reacting in a more compassionate and humane way.

The potential impact of stigma and discrimination has been of constant concern to those involved in addressing the HIV and AIDS epidemic. The implications of stigma go even deeper than the immediate problem to have an impact on multiple aspects of the lives of PLWHA and more broadly on members of society, creating disruptions in social functioning, increasing people's vulnerability to infection and reducing the overall caring capacity of communities (Skinner & Mfecane, 2004).

This is a qualitative and quantitative study of factors that contribute to HIV and AIDS stigma among young adults; thus, an attempt to discover any cultural factors that precipitate stigma and those factors in communities that could be useful in an endeavour to disentangle such stigma.

## **1.2. STATEMENT OF THE PROBLEM**

Stigmatisation of and discrimination against PLWHA are common worldwide problems and often occur in many cultures. South Africa is recorded to have the highest number of PLWHA in the world (Rehle & Shisana, 2003). Stigma has often been identified as a primary barrier to effective HIV prevention, as well as the provision of treatment, care and support (Deacon, Stephney & Prosalendis, 2005).

According to Skinner and Mfecane (2004), stigma goes beyond individuals infected with HIV to reach broadly into society, both disrupting the functioning of communities and complicating prevention and treatment of HIV. Stigma also introduces lack of desire to know one's own status, thus delaying testing and subsequent access to treatment. At an individual level stigma undermines the person's identity and capacity to cope with the disease. Fear of discrimination limits the possibility of disclosure even to potentially important sources of support such as family and friends. Finally, stigma influences behaviour change, with subsequent limitation towards the practice of safer sex.

In South Africa, HIV-related stigma and discrimination are associated with not disclosing HIV status to sex partners and non-disclosure is closely associated with HIV transmission risk behaviour (Simbayi, Kalichman, Strebel, Cloete, Henda & Mqeketo, 2007). On the other hand, the Botswana government recently implemented a policy of routine or “opt-out” HIV testing in response to the high prevalence of HIV infection, estimated at 37% of adults (Weiser, Heisler, Leiter, Korte, Tlou, DeMonner, Phaladze, Bangsberg & Iacopino, 2006). This holds significant promise for the prevention and treatment of HIV and AIDS in Botswana and elsewhere.

Effects of stigma can be psychological to someone infected with HIV and AIDS. Blame others is psychologically reassuring, and it divides 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’ (Skinner & Mfecane, 2004). Anger and fear contribute to

the development of discrimination in both those who are HIV-positive and those who are HIV-negative. 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 (Leclerc-Madlala, 2002).

In Botswana, Weiser et al. (2006) discovered that knowledge about HIV and AIDS, communication and paying more frequent visits to medical practitioners were associated with higher rates of testing, and less stigmatising attitudes towards PLWHA. On the other hand, high levels of stigma were associated with those with low levels of knowledge about HIV. In South Africa, perceptions of risk are likely to be linked to the social and cultural constructions and interpretations of risk, attitudes to sex, gender differences in sexual behaviour and a host of economic factors operating in the environment (Phaswana-Mafuya & Peltzer, 2006). A separate study in a black township in Cape Town by Kalichman and Simbayi (2003) showed that people who had not been tested had significantly higher levels of a tendency to AIDS-related stigma and negative attitudes towards testing than individuals who had been tested, even though two-thirds of the people who had not been tested reported having engaged in at least one behavioural risk factor.

Dissatisfaction with the health services related mainly to the provision of “inadequate and ineffective drugs”, poor staff attitudes and fear of discrimination and confidentiality being compromised by staff. To avoid having their HIV status discovered, patients sometimes sought care further away from home. Deetlefs, Greef and Koen (2003) found among a sample of South African nurses that their attitude towards the HIV positive patient was mostly negative.

Considerable research attention is now being focused on HIV and AIDS research in general in Africa because of the severity of the African epidemic, the politics of the HIV and AIDS issue, and the fact that HIV and AIDS seems to be highly stigmatised in the region (Deacon, Stephney & Prosalendis, 2005). In addition, Lorentzen and Morris (2003)

posit that the relative lack of scientific research on the manifestations of HIV and AIDS-related stigma [in sub-Saharan Africa] presents a serious challenge to the understanding, alleviation and prevention of HIV and AIDS-related stigma. Using the same intervention in different contexts has not worked very well in HIV and AIDS prevention programmes, as a result of different local issues and meanings associated with the disease (Rakotonanahary, Rafransoa & Bensaid, 2002).

The South African government has instituted national antiretroviral (ARV) programmes at every hospital for people infected with HIV and AIDS, thus strong social support is a prerequisite for infected persons to ensure that they get medication. If the infected are not open about their status because of fear of being stigmatised, this may lead to prolonged delay to access medication.

### **1.3 BACKGROUND OF THE STUDY**

Qualitative research on HIV and AIDS stigma draws mainly on psychological case-study models, anthropological models (using participant observation, grounded theory methods) and discourse analysis. These qualitative studies generally rely heavily on interviews and media analysis (Deacon et al., 2005). The problem of HIV and AIDS stigma in Africa has been raised in related research on barriers to voluntary counselling and testing (VCT), treatment, care and adherence (Brown, Macintyre, & Trujillo, 2001; Kamugisha, 2002; Mutembei, 2002; Nyblade & Field, 2000; Uys 2003), on quality of life (Mast, Kigozi, Wabwire-Mangen, Black, et al., 2004), and on social responses to HIV and AIDS (Adebajo, Bangbala, & Oyediran, 2003; Leclerc-Madlala, 2002).

Numerous studies on stigma and discrimination have been conducted in Southern Africa (Botswana) by Letamo (2003) and Muyinda, Seeley, Pickering and Barton (1997); and by Bond, Chase and Aggleton (2002) in other African countries. Important recent work on HIV and AIDS stigma in South Africa includes research by Kalichman and Simbayi (2003,

2004); however, no work on stigma specifically among young adults has been reported, especially in the Limpopo Province of South Africa.

The scope of the studies above was not specifically directed at young adults. Furthermore, the research designs were not triangulated; instead they were either qualitative or quantitative. Thus, the present research will be based on both qualitative and quantitative methods. Findings of this research will give new insight into the existing knowledge and additional information in the area of young adults and HIV and AIDS.

#### **1.4 AIM OF THE STUDY**

The aim of the study was to identify factors contributing to HIV and AIDS stigma among young adults living in Polokwane municipality within the Capricorn district in Limpopo Province, South Africa.

#### **1.5 OBJECTIVES OF THE STUDY**

The objectives of this study were:

To determine whether, and/or the extent to which the following aspects influence stigmatising behaviour in HIV and AIDS:

- Gender, socio-economic status, levels of religious affiliation of an individual, lack of knowledge about HIV and AIDS transmission, knowing someone with HIV and AIDS, Knowing one's status and family communication about HIV and AIDS
- Perceived HIV and AIDS risk
- Cultural attachment

## **1.6 HYPOTHESES**

- The level of knowledge about how HIV and AIDS is transmitted, has an influence on the level of stigmatisation of people living with HIV and AIDS
- Close association with someone living with HIV and AIDS has an indirect influence on the stigmatisation of people living with HIV and AIDS than being less associated with those people.
- Males stigmatise people living with HIV and AIDS more than females do.
- Lack of knowledge about ones HIV status leads to more tendency towards stigmatisation of people living with HIV and AIDS than when the status is known.
- Low socio-economic status leads to more tendency towards stigmatisation of people living with HIV and AIDS than when one is at middle or high socio-economic status.
- Commitment to religion is more influential on stigmatisation of people living with HIV and AIDS more than less commitment to religion.
- The more family communication there is about HIV and AIDS, the lower the level of stigmatisation of people living with HIV and AIDS will be.
- The higher the perceived risk of HIV and AIDS is, the lower the level of stigmatisation of people living with HIV and AIDS will be.
- The stronger the attachment to cultural beliefs is, the more stigmatisation of people living with HIV and AIDS will occur.

## **1.7 SCOPE OF THE STUDY**

The study was limited to young adults (aged between 18 and 25 years) of Capricorn district in Limpopo Province.

## **1.8 SIGNIFICANCE OF THE STUDY**

This study is significant in that it will reveal factors contributing to HIV and AIDS stigma, in particular cultural factors. This will assist with the future development of programmes designed to reduce HIV and AIDS stigma. One expects that this study will lead to a deepening understanding of factors that contribute to HIV and AIDS stigma. Consequently, it is expected that there will be reduced stigmatising behaviour, which will encourage people to go for testing voluntarily and will increase their willingness to accept antiretroviral treatment.

The researcher also hopes that, if youth and community members know what the factors contributing to stigma are, there will be enhanced social and spiritual support from peer groups, family and community members. Perceived and practical support will reduce stress and psychopathology associated with HIV and AIDS stigma, as well as increase disclosure. On a broader scale, the outcome of this study will also assist in the revision and development of policies that are relevant to the population.

## **CHAPTER 2**

### **THEORETICAL PERSPECTIVES**

#### **2.1 INTRODUCTION**

Theories that explain stigma have been drawn from a sociological and social psychology background. These theories are the attribution theory, social structure theories, deviance theories, blaming theory, contact theory and cultural perspective. However, the researcher will lay a foundation by defining key concepts and stigma concepts, such as the content of disease stigma, understanding variation, stigma and self-identity, stigma and self-concept and the dimensions of stigma.

#### **2.2 OPERATIONAL DEFINITION OF KEY CONCEPTS**

##### **2.2.1 HIV and AIDS**

HIV is a virus that is transmitted from person to person through the exchange of body fluids such as blood, semen, breast milk and vaginal secretions (Cichocki, 2010). Sexual contact is the most common way to spread HIV AIDS, but it can also be transmitted by sharing needles when injecting drugs, or during childbirth and breastfeeding.

Acquired immune deficiency syndrome, or (AIDS), is a condition that describes an advanced state of HIV infection. With AIDS, the virus has progressed, causing significant loss of white blood cells (CD4 cells) or any of the cancers or infections that result from immune system damage. Those illnesses and infections are said to be "AIDS-defining" because they mark the onset of AIDS.

## **2.2.2 Stigma**

Baron and Byrne (2003) define stigma as a personal characteristic that at least some other individuals perceive negatively. Stigma is most common with diseases associated with transgression of social norms, such as socially unsanctioned sexual activity. Stigma can be characterised as internal and external stigma as well as symbolic and instrumental. The definitions of these forms of stigma are given below; and, the present study will use the same definitions as outlined.

### **2.2.2.1 Internal stigma**

Internal stigma (felt or imagined stigma) is the shame associated with Human Immunodeficiency Virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS) and the fear of being discriminated against, which is felt by people living with HIV and AIDS. Internal stigma often causes refusal or reluctance to disclose one's status, or denial of HIV and AIDS (POLICY Project, Centre for the Study of AIDS, USAID & Department of Health, 2003).

### **2.2.2.2 External stigma**

External stigma (enacted stigma), on the other hand, refers to actual experiences of discrimination. These may include experiencing domination, oppression, the exercise of power or control, harassment, categorising, accusation, punishment, blame, devaluing, prejudice, silence, denial, ignorance, anger, a sense of inferiority, social inequality, exclusion, ridicule, resentment or confusion (POLICY Project, Centre for the Study of AIDS, USAID & Department of Health, 2003).

### **2.2.2.3 Symbolic stigma**

Symbolic stigma involves moral judgements, negative associations and symbolism around HIV and AIDS, such as blaming PLWHA for becoming infected (Maughan-Brown, 2004).

### **2.2.2.4 Instrumental stigma**

Instrumental stigma measures any attitudes or beliefs based primarily on fear of infection, such as not sharing eating utensils because of concern about catching HIV (Maughan-Brown, 2004).

### **2.2.2 Young adults**

For this study the term ‘young adults’ will refer to individuals whose ages fall between 18 and 25 years.

## **2.3 STIGMATISATION FRAMEWORK**

### **2.3.1 Disease stigmatisation**

Disease stigmas draw heavily on existing negative definitions of the ‘other’ and other social representations. In dominant group representations, which usually gain greater currency in society, these definitions often identify and blame existing marginalised groups in society, following existing lines of inequality. This association is often given credence by the fact that existing social inequalities can affect the epidemiology of disease, making marginalised groups more vulnerable to disease and less able to find (private) treatment. HIV and AIDS stigmatisation relies heavily on existing prejudice and social stereotypes.

The relationship between disease stigma and other forms of prejudice has been called multiple stigmatisation, double (or even triple) stigmatisation (Grossman 1991; Hergovich, Ratky & Stollreiter, 2003), following a trend in racism and gender studies in which it is argued that different kinds of prejudice are added together. But disease stigmatisation operates in a slightly different way. Disease stigmatisation does link diseases with negative meanings, but often by suggesting that already-defined out-groups are somehow responsible for the disease because of certain negatively valued traits or behaviour, rather than representing all people with a particular disease in the same way.

For example, some PLWHA are perceived as innocent victims (those who contracted HIV through blood transfusions or childbirth), while others are considered blameworthy because they contracted it through ‘deviant’ behaviour (sex that is considered immoral) that demonstrates their membership of already marginalised communities (such as commercial sex workers, gay men and so forth).

A more important, and perhaps controversial, question to ask would be whether one can include negative beliefs, such as 'HIV is easily transmitted by shaking hands' or 'HIV-positive people will consume more resources because they fall ill more easily' in the definition of stigma. If one is going to limit the content of stigma in this way, one needs to understand exactly how to categorise secondary stigmatisation associated with HIV and AIDS (Deacon, Stepney & Prosalendis, 2005). Secondary stigmatisation of various illnesses, treatments and forms of behaviour associated with HIV and AIDS widens the frame of reference for stigma and thus increases its potential impact.

In the case of HIV and AIDS, secondary stigmatisation has occurred with contraction of tuberculosis (TB), the use of formula feeding and the use of condoms. These are read as markers for HIV and AIDS and are thus stigmatised by association (Leclerc-Madlala, 1997). For example, a school-feeding scheme was recently placed in jeopardy because the cereal used was labelled 'AIDS-porridge' (owing to its use by AIDS patients), with the result that learners refused to eat it. Secondary stigmatisation can also involve people associated with PLWHA. Mental illness literature has coined the term 'courtesy stigma' to describe the stigmatisation of families of affected individuals (Angermeyer & Matschinger, 2003).

Stigma by association may also include people who care for those with HIV and AIDS (Deacon et al., 2005). Initially, then, HIV and AIDS was stigmatised in relation to existing out-groups, PLWHA were then stigmatised as a category in their own right (although some were excluded from this because they were 'innocent victims'), and a highly variable, but nevertheless distinctive, discursive field finally coalesced around the disease, stigmatising related diseases (such as TB) and activities (such as the use of formula milk) by association. Secondary stigmatisation does not always feed directly into the process of blaming PLWHA for the disease (which may justify discrimination): it may feed into the earlier process of identifying and differentiating PLWHA from other people. More work, as intended in this present study, needs to be done in this area to understand the way in

which the content of stigmatisation leads to differentiation and blaming, and what criteria can be used to identify stigmatising beliefs.

Biology is a vital factor in understanding variations in the strength and content of stigmatisation of a disease. Stigmatisation can change as an epidemic, or the disease itself, progresses through various biological stages. These changes can affect how stigma is experienced by PLWHA. Alonzo and Reynolds (1995) suggest that in different phases of HIV and AIDS, PLWHA experience stigma differently. They describe this changing experience of stigmatisation as a ‘stigma trajectory’ with four phases: ‘(1) at risk: pre-stigma and the worried well; (2) diagnosis: confronting an altered identity; (3) latent: living between illness and health; and (4) manifest: passage to social and physical death’.

Uncertainty in medical knowledge of a disease, and the lack of a cure, could thus both increase stigma by others and independently increase anxiety and fear among PLWHA in different phases of the disease. The successful introduction of ARV therapies since 1996 that have helped HIV and AIDS to be recast as a chronic illness in the West may have flattened the stigma trajectory and reduced uncertainty about treatment.

### **2.3.2 Stigma and cultural variation**

Stigma is influenced by a number of aspects that include social, political, historical and cultural factors which makes the understanding of the different cultural meanings associated with HIV and AIDS become essential in developing effective HIV and AIDS interventions (Deacon et al., 2005, Rakotonanahary, Rafransoa & Bensaid, 2002). This as it may be, there is scanty literature that actually investigates variation in the content of stigmatising beliefs about HIV and AIDS, or how specific local content is constructed (Campbell, Foulis, Maimane & Sibiyi, 2005; Leclerc-Madlala, 1997).

#### **2.3.2.1 *Specific cultural associations and disease stigmatisation***

People belonging to certain groupings tend to be stigmatised due to societal labelling emanating from those groups been seen as deviant. Such groupings would include gay

men, homosexuals, female promiscuity and unfaithfulness in marriages (Goffman ,1963; Katz ,2002; Alonzo and Reynolds,1995). Other cultural associations that lead to stigmatisation include associations with historically stigmatised diseases, such as syphilis, leprosy or TB; as well culturally mediated assessments of the role and responsibility of the individual in contracting the disease.

The biology of a disease is an important variable that influences the strength and nature of its stigmatisation, but the meanings associated with biological phenomena are always culturally mediated (Deacon, Stephney & Prosalendis, 2005). Changes in knowledge about biological processes are thus also of interest. Crandall and Glor (1997) suggest that knowledge about the severity, contagiousness and treatability of a disease are significant determinants of instrumental stigma.

### **2.3.3 Stigma and self-identity**

Central to any discussion of stigma is the powerful influence stigma exerts on a person's identity cause having an identity as a deviant, is extremely difficult to change, as the stigmatised label can be sticky (Goode, 1984). As Goode (1984) noted, there are many symbolic ceremonies involved in the labelling process, which include a diagnosis, being arrested or being admitted to a treatment centre or jail. Yet, there are no equally powerful ceremonies for the de-stigmatisation and reintegration of persons who choose to relinquish the deviant behaviour. It is thus clear that at the individual level, stigma can in line with the pressure it exerts on the individual, create profound changes in the identity of the stigmatised person as well as changing the way that person is perceived by others.

### **2.3.4 Stigma and the self-concept**

Symbolic interactionism proposes that either by taking the perspective of particular others, or by viewing oneself from the standpoint of the community and its values (the generalised other), one comes to see oneself as others do (Cooley, 1902; Mead, 1934; Blumer, 1969). Many theorists suggest that as a result of this process, possession of a stigmatised attribute

is likely to have negative effects on self-evaluation. "Given that the stigmatised individual in our society acquires identity standards which he applies to himself in spite of failing to conform to them, it is inevitable that he will feel some ambivalence about his own self" (Goffman, 1963, p. 130).

### **2.3.5 Dimensions of stigma**

Jones, Amerigo, Albert, Hazel, Dale, Robert and Rita de (1984) proposed that stigma has six "dimensions", which include:

- 1) The degree to which the stigmatising attribute/behaviour can be concealed,
- 2) The expected long-term result associated with the attribute/behaviour,
- 3) The degree to which activities of everyday life are impeded,
- 4) The physical appearance of the person who has the stigmatising attribute,
- 5) The degree to which the person is responsible for the attribute/behaviour, and
- 6) The degree to which the attribute/behaviour is dangerous to others.

## **2.4 ATTRIBUTION THEORY**

Attribution theory seeks to explain the cognitive process whereby individuals make explanatory inferences regarding the causes of events. For the purpose of understanding how stigma of HIV and AIDS develops, three phenomena that have been influential in attribution theory, namely, actor-observer bias, the fundamental attribution error, and the self-serving bias were found to be relevant among five classical ones, viz. correspondence inference and correspondence bias, casual attribution, actor-observer effect and self-serving bias (McLeod, 2010).

### **2.4.1 Correspondence bias**

This concept was coined by Ross (1977). Correspondence bias is used interchangeably with fundamental attribution error. It is the tendency to assume that people's character or personality is responsible for their behaviour, even when the situation is a clear constraint.

Whenever correspondence bias is made, the observer assumes that the actor intended to perform the action, had the ability to complete the intended action, and knew the ultimate consequence (Sonne, 2011). This is the tendency to explain others' actions as stemming from disposition even in the presence of clear situational causes.

Heider (1958) distinguished between two general categories of explanation namely, internal and external. Internal attributions implicate characteristics of the individual (such as ability, attitudes, personality, mood, and effort) for having caused a particular behaviour, whereas external attributions implicate external factors (such as the task, other people, or luck) for causing an event or outcome to occur. Our attributions are also significantly driven by our emotional and motivational drives. Blaming other people and avoiding personal recrimination are very real self-serving attributions. We will also make attributions to defend what we perceive as attacks.

The tendency to attribute others' actions to dispositional (internal) causes seems to occur most strongly in situations in which both consensus and distinctiveness are low, as predicted in by Kelley (1972). One possibility is that when one observes another person's behaviour, one tends to focus on his or her actions, the context in which the person behaves and hence potential situational causes of his or her behaviour often fades in the background. As a result, dispositional (internal) causes are easier to notice than situational ones. In other words, from one's personal perspective, the person one is observing is high in perceptual salience and is the focus of one's attention, while situational factors that might have influenced this person's behaviour are salient and so seem less important to one.

#### **2.4.2 Actor-observer effect**

The actor-observer effect was described by Jones and Nisbett (1971). The actor-observer bias first described by Jones and Nisbett in 1971 is typically thought of as the tendency for people to view their own actions as caused by the situation, while viewing others' actions as caused by those others' personalities. The tendency to attribute one's own behaviour to situational error involves attribution of one's own behaviour to situational (external)

causes. Thus, when one sees another person trips and fall, one tends to attribute this event to clumsiness. If one trips oneself, however, one is likely to attribute this event to situational causes, such as the possibility of having had ice cream spilt on the sidewalk. This tilt in people's attribution is known as actor-observer-effect. This occurs because people are quite aware of the many external factors affecting their own conduct, but less aware of such factors when they turn their attention to the conduct of others.

### **2.4.3 The self-serving bias**

The actor-observer bias is the phenomenon where the perceived cause of an event follows from the particular perspective of the explainer. An observer of an individual's behaviour displays a tendency to attribute the causes of that behaviour to internal characteristics of the actor whereas the person carrying out the act in question explains their own behaviour as having resulted from external circumstances (Jones & Nisbett 1971). The fundamental attribution error refers to a general bias on the part of an observer, whereby individuals tend to explain the behavior of others in terms of internal factors to a greater extent than situational factors. Most of these attributions fall into two categories, namely cognitive and motivational explanations. The cognitive model suggests that self-serving bias stems from certain tendencies in the way in which people process social information. Specifically it suggests that they tend to attribute positive outcomes to internal causes and negative outcomes to external causes because they expect to succeed.

The above mentioned concepts (correspondence bias, actor-observer bias and self-serving bias) of attribution theory can help us to understand how stigma develops. They help us to understand how internal and external perception and beliefs about such perceptions of situations influences interpretation of events. This can be understood in terms of how PLWHA develop internal stigma and how in turn the society reacts to PLWHA which leads to external stigma.

## **2.5 SOCIAL STRUCTURE PERSPECTIVES**

The entire society is considered to be the problem, including the total institutional network and dominant ideologies (Lauer, 1998). The fundamental problems may be narrowed to the capitalist system of production and the subsequent exploitation of people and alienation. The solution suggested is radical in that the social order must be restructured if the problem is to be resolved.

### **2.5.1 Racism, sexism and disability-related prejudice**

There is a relationship between HIV and AIDS stigma and other forms of prejudice, in the sense that different negative meanings associated with race, sexuality and so on are also used to stigmatise PLWHA. A number of commentators (Link & Phelan 2001; Stein, 2003) have pointed out the similarities between definitions of disease stigma and other forms of prejudice. Like HIV and AIDS stigma, racism, sexism and disability-related prejudice all involve the attribution of negative meanings to physical differences. Discrimination may occur on the basis of these prejudicial ideologies, and people may also internalise different forms of prejudice.

One difference between racism or sexism and HIV and AIDS stigma is that in the case of sexism or racism people are born with physical features that may mark them as 'black' or 'white', 'male' or 'female'; historical processes of cultural activity, discrimination or migration often create similar circumstances for groups of black or white families, men and women. In the case of HIV and AIDS, biological differentiation usually happens later in life (when HIV and AIDS is contracted) and people living in the same communities or families may not have the same HIV status.

Membership of existing out-groups (such as commercial sex workers) is sometimes considered to be revealed by the diagnosis rather than constructed by it. PLWHA may thus be differently stigmatised depending on how the virus was contracted: some HIV-positive people are considered 'innocent' because they contracted HIV through blood transfusions

rather than sex. This pattern of differential stigmatisation suggests that HIV and AIDS stigma revolves around the construction of blame and not simply the justification and continuation of existing inequalities between HIV-negative and HIV-positive people.

Racism, sexism and disability prejudice have been challenged by arguing that the physical differences used to mark race, disability or gender do not make a difference (in the case of race) or do not make as much of a difference as has been suggested (in the case of gender or disability). Skin colour, a primary marker of physical difference in racism, does not confer any significant advantage or disadvantage in itself (Stein, 2003). Most gender differences do not carry inherent disadvantages, except in so far as they are constructed as such within a sexist society. For example, the idea that one should not employ women because they might get pregnant is based on an over-estimation of the effects of physical difference: women can work if someone else looks after their babies, just as men have usually done.

Physical differences due to gender, and some kinds of disability, are not always disadvantageous in themselves, even in cases where their presence can justify differential treatment (such as the provision of separate sport teams or additional access facilities). The chief disadvantages experienced by women and some disabled people do not stem from physical differences, but from the way in which some societies interpret certain physical differences negatively and thus celebrate and accommodate only a narrow range of physical abilities. For example, many different people may experience problems with physical access.

At a social level, however, the 'invisibility' of HIV infection exacerbates stigmatisation and encourages people to use secondary markers (such as wasting or the onset of illnesses such as TB) to identify who has the condition (Deacon, Stephney & Prosalendis, 2005). The absence of visible evidence of how large the pool of infected people is, and of who is infected, encourages the idea that HIV and AIDS affects 'other' people.

Quite apart from any stigmatisation that might occur, the development of AIDS has undeniable and tangible negative effects on people's lives, including lowered fertility and life expectancy and higher morbidity. The contagious nature of HIV also makes some kinds of contact with PLWHA (for example, contact with bodily fluids) potentially disadvantageous to HIV-negative people, even if they do not stigmatise PLWHA (Stein, 2003).

As individuals and as societies, people legitimately associate negative meanings with disease syndromes such as HIV and AIDS, which have negative effects that they wish to avoid. However, a problem arises when prejudice against the disease becomes a prejudice against those who have contracted it (Deacon, Stephney & Prosalendis, 2005). This is especially likely, as discussed earlier, in cases where contracting a disease is perceived to be avoidable, where the contraction of a disease is linked to sex or other morally sensitive issues, and where the disease is serious or terminal. This suggests that if effective treatments are found and made widely available, stigma may decrease.

### **2.5.2 Understanding functionality without functionalism**

Drawing from sociological theory, which often has to explain why people act against their own interests, some researchers have suggested that stigma persists in spite of education programmes because it helps to maintain social control (Link & Phelan 2001; Parker & Aggleton 2003). Parker and Aggleton (2003) suggest that stigma and discrimination should be understood as part of the political economy of social exclusion present in the contemporary world. HIV and AIDS stigma exacerbates social divisions by stereotyping marginalised or disempowered groups (such as poor Africans, women and commercial sex workers) as responsible for the illness and its spread.

Heywood (2002) shows how, in South Africa, social inequality aids the spread of HIV, and how the pandemic widens the division between rich and poor, white and black, in society: Firstly, HIV takes advantage of entrenched fault lines in society, of the inequities and inequalities, in order to spread. Secondly, HIV makes these fault lines far, far wider. This

is clearly apparent in ‘post-apartheid’ South Africa, where the people who have access to advanced medical care (including ARVs) are predominantly white and where the people who have access to sub-standard care are black. Thus HIV and other causes of illness widen the divisions that already exist (Heywood, 2002).

The social control model focuses too much on the big picture, ignoring individual agency, imputing social functionality from the weak stigma-discrimination-inequality chain, and defining stigma as only that which leads to discrimination and fosters social inequality. Focusing on a very broad effect of stigmatisation (the maintenance of social inequality) as its *raison d’être* does not help one to understand the specific impacts of stigma on PLWHA, for example, in reducing access to treatment and care. Instead of explaining it away with a caveat, one should go back to the drawing board and avoid defining stigma as something that automatically leads to discrimination and therefore inequality. There is no denying that stigma may sometimes reinforce existing inequalities (Deacon, Stephney & Prosalendis, 2005).

But, because there is no direct, one-to-one relationship between stigma and discrimination, it may be better to speak of effects of stigma that are useful to the dominant class, rather than of functions which imply that discrimination and the exacerbation of inequalities are automatic, desired, or intended effects of stigmatisation. Of course, the functionality of stigma to individuals as a means of distancing risk is a short-term phenomenon, because feeling invulnerable to HIV infection reduces the incentive to protect oneself (for example, by practising safer sex with other members of the in-group) (Deacon, Stephney & Prosalendis, 2005).

Nevertheless, the benefits of anxiety reduction may be sufficient to reproduce stigmatising behaviour, along with the social processes of ‘anchoring’ – in which new events are explained within existing models – and ‘objectification’ and ‘symbolisation’ – in which new problems are represented by comparison with the tangible and the known, using shared symbolic representations (Joffe, 1999, p.75). Reasons to avoid conceptual inflation,

functionalism and individualism are the following: Firstly, it is not inevitable that stigma has to result in discrimination to reduce individual and group anxiety. Secondly, the individual-level effect of stigma is both (unconsciously) desired by the person who expresses it and universal, making it reasonable to term it a function rather than an effect. Thirdly, although Joffe (1999) focuses on the individual as the agent of stigma, she avoids excessive individualism by viewing individuals as social beings, who draw on social representations to formulate stigmatising beliefs. Those who stigmatise others on a specific issue are doing so not because they are isolated ‘splitters’, but because their reaction to that specific issue and its specific social circumstances awakens the splitting tendency that is latent in everyone.

### **2.5.3 Understanding stigmatisation as a process**

It is not sufficient to explain stigma simply as negative meanings associated with disease. This explanation avoids the problem of conceptual inflation but it fails to address why and how stigmatisation occurs, the relationship between stigmatisation, discrimination and social power relations, what the role of the individual is, and whether it matters who stigmatises whom (Deacon, Stephney & Prosalendis, 2005). Also, it seems to include any negative beliefs about disease.

Using a process model not only helps one to distinguish causes, functions and effects of stigma more easily, it also shows how significant variation in the content of stigma will occur. Miles (1989) argues that the articulation of racism involves signification of difference, then stacking of negative meanings. Miles’ (1989) model has influenced later work but his attempt to distinguish racism from discrimination has not been followed in process models of disease stigma. Gilmore and Somerville (1994) identified four features of stigmatisation: the problem, the identification of the person or group to be targeted, the assignment of stigma to that person or group, and the development of a response to the stigmatised person or group that tackles the problem. Taking a similar line, Link and Phelan (2001) define disease stigma as a convergence of four processes:

Stigma exists when the interrelated components mentioned below converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics – to negative stereotypes. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of ‘us’ from ‘them’. In the fourth, labelled persons experience loss of status and discrimination that lead to unequal outcomes.

Stigmatisation is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination. Thus one applies the term stigma when elements of labelling, stereotyping, separation, loss of status and discrimination co-occur in a power situation that allows them to unfold (Link & Phelan, 2001).

Sayce (2003) suggests that Link and Phelan (2001) should use ‘discrimination’ to describe the process ‘because of the confusion of using one term to describe both the act of discrimination and the personal experience of being labelled’ (p.628). Sayce (2003) contends that the term ‘discrimination’ is preferable because it directs attention to the power of perpetrators, which is essential to any effective change strategy. It can stand as the over-arching concept for all the processes that Link and Phelan (2001) outline – discrimination does involve distinguishing (‘discriminating’) between human differences, conferring negative value on some types of difference and treating people unjustly as a result by drawing on social and economic power.

Joffe (1999) goes on to argue that HIV and AIDS stigma is a process in which people use splitting of the ‘good’ and the ‘bad’ to forge ‘protected’ identities by projecting risk and deviance onto outgroups. This allows people to highlight characteristics which would increase risk of contracting the disease in representations of existing outgroups, and then subsequently blame outgroups for having those characteristics, and thus contracting or spreading the disease.

#### **2.5.4 Stigma and power**

As has been explained, the main aim of social control models of stigma is to understand the relationship between stigma and power. However, the blaming model of stigma explains the politics of stigma without resorting to a functionalist definition of stigma. The process of stigmatisation helps to create a sense of control and immunity from danger at an individual and group level, as it distances people (and their in-groups) emotionally from risk. The choice of who is identified as the out-group depends on personal identities and historical power relations, and is thus highly variable.

For example, Joffe's (1999) work has shown that some black South Africans blame Western scientists for HIV and AIDS, while some white heterosexual British men blame black Africans for it. These socially constructed representations are all functional to the individual in distancing themselves from risk and thus reducing anxiety, but that only result in discrimination and the reproduction of structural inequalities when other enabling circumstances (such as the power and opportunity to discriminate) come into play.

The loss of status that is ascribed to the stigmatised, in most cases lead to discrimination of stigmatised people, and, depending on the existence of power differentials and an enabling context this may also result in internalisation of stigma. When a particular group of stigmatising ideas is validated by a powerful person or group (in the media, in communities and so on) and deployed as part of broader power struggles, it becomes pervasive, entrenched and very difficult to shift. The powerful nature of dominant group 'othering' in a society can override other representations and even cause widespread self-stigmatisation (Klingemann, 1999).

In certain contexts, stigmatisation can actually be assessed in relation to how society and professionals perceive individuals with a history of stigma and how that varies from complete rejection to admiration or recognition of usefulness. This assessment would thus, depend on factors such as the degree of political and scientific interest in controlling, changing, and detecting hidden deviant populations, as well as public fascination with

'authentic' deviants, combined with increasing scepticism about conventional expert knowledge (Klingemann, 1999). It should be emphasised, however, that stigmatisation and loss of status result in discrimination far more often than they result in status gain.

## **2.6 LABELLING THEORY**

Labelling and incompetence are seen as a result of society's expectations or norms. Another society might not label the behaviour as deviant and thus the person would not be labelled as intellectually impaired. Once people have been labelled, this label influences their lives and they may never return to a normal existence. They must also behave in accordance with their new social role. Thus they may demonstrate further deviant or incompetent behaviour (secondary deviance) that is a function of their label and differentiated treatment and expectations.

This reinforces the label and removes the people further and further from normal social roles (Link, Cullen, Frank & Wozniak, 1987; Link, Streuning, Phelan & Nuttbrock, 1997). Being labelled is hypothesised to have a profound effect on people's identity. Goffman (1963) argues that people with demonstrable stigma are seen as "not quite human and reduced in our minds from a whole and unusual person to a tainted, discounted one".

His study of stigma among people who have been labelled indicates that this not only serves as a humiliating, frustrating and discrediting stigma in the conduct of one's life in the community, but also serves "to lower one's self-esteem to such a nadir of worthlessness that the life of the person is scarcely worth living". Although this evaluation might be overly pessimistic, there is substantial evidence that after individuals are labelled there is a decrease in expectations about behaviour and achievement and this leads to a self-fulfilling prophecy of lowered actual achievement and behavioural outcomes (Ashforth & Humphrey, 1997).

## 2.7 BLAMING THEORY

This model suggests that people often blame social groups other than their own for being affected by diseases and conditions such as HIV and AIDS, and for putting society at risk of infection (Joffe, 1999). This emotional (rather than cognitive), and often unconscious, response to danger helps people to feel they are less at risk of contracting serious diseases, but it has many negative effects (Deacon, Stephney & Prosalendis, 2005).

The association between disease, negatively defined behaviour or characteristics, and certain groups of people results in stigmatisation of the disease and most of the people infected by it (Deacon, Stephney & Prosalendis, 2005). Some stigmatising ideas have a very powerful hold on society because of the way in which they fit into existing prejudices and power alliances. The 'not me – others are to blame' phenomenon has become particularly prevalent in relation to disease threats in modern society (Deacon, Stephney & Prosalendis, 2005).

Crawford (1994) argues that, in America, good health re-emerged in the 1970s as a potent sign of the morally disciplined, conventional self as opposed to the 'unhealthy other', linking concepts of health to social and moral fitness and heightening the tendency to blame people for illness. Projecting of risk onto the 'other' has been particularly prevalent in modern society where one finds a high level of risk-awareness coupled with a lack of trust in the experts who might be relied on for protection, forcing people to fall back on their own resources (Joffe, 1999).

Many risks are perceived as predictable and therefore controllable because they are considered to be systematically caused and statistically describable (Douglas, 1990). The blaming model of stigma thus provides an alternative approach to the social control model. The main challenge lies in using this model to help understand the relationship between stigma, discrimination and power, and how to change the way people respond to risk (Deacon, Stephney & Prosalendis, 2005). If one can reduce the fear concerning the risk of

contracting HIV and AIDS, or its effects, one will be able to reduce stigma.

## **2.8 CONTACT THEORY**

The contact theory has been tested among several different groups, including the elderly, homosexuals, the mentally ill, disabled persons and AIDS victims (Pettigrew, 1998). This is important for the present study, as it is hypothesised that those with a higher level of contact with the mentally ill, or greater knowledge of mental illness, will be less likely to stigmatise the mentally ill based on the stereotypes they may have formed. Exposure to the mentally ill has been shown to reduce the stigma that people associate with them. The tendency to reduce stigma is directly related to the amount and quality of contact that one has with the mentally ill.

According to Baron and Byrne (2003), contact theory is the concept that more contact between members of different social groups can help reduce prejudice between the groups. These efforts only appear to work when the contact takes place under specific, favourable conditions (Baron & Byrne, 2003). Gordon W. Allport first expressed his contact theory in a book titled *The Nature of Prejudice*. Allport (1954) made it clear that prejudice is caused by many different things, and therefore to eliminate or reduce it is a multifaceted task.

At its bare bones, contact theory states that prejudice and discrimination against a minority group will be reduced when the contact between the individuals has the following qualities: the groups involved must feel that they are equals, the community supports the groups, the groups must be pursuing the same goals and the relationship between the groups must be deep, genuine and intimate. Furthermore, Allport claims that casual contacts are more likely to increase prejudice, rather than reduce it. Allport (1954) states

that the evidence shows that knowledge about and acquaintance with a minority group makes for more friendly and tolerant attitudes. He acknowledges that the relationship is not perfect, nor does he know if there is a reciprocal relationship between knowledge and friendliness. Nonetheless, there is a positive relationship.

There are many examples supporting this theory. One involves the military; the more contact white seamen had with black seamen, the more positive their attitudes to blacks became (Pettigrew, 1998). Desegregated projects in certain cities, when surveyed, showed that whites held blacks in higher esteem than those in segregated projects (Pettigrew, 1998). The actions of the whites in the desegregated and segregate projects were regulated by social norms. Those of desegregated projects expected approval from fellow tenants for their acceptance of blacks, while segregated whites feared ostracism from tenants for interacting with blacks (Pettigrew, 1998).

Pettigrew found that contact theory proves most operable over a period of time in which friendship may develop (Pettigrew, 1998). The repeated contact between the groups dispels the stereotypes because the groups see how similar they are to one another (Baron & Byrne, 2003). As a result of the contact between the groups, Pettigrew discovered there was less negative stereotyping, less prejudice and less discrimination (Pettigrew, 1998). Baron and Byrne (2003) report that sometimes it is enough to simply know a member of one's own group who has a friendship or high regard for a member of another group to lessen the prejudices between the groups (Baron & Byrne, 2003).

## **2.9 CULTURAL PERSPECTIVES**

It is important to look at the cultural factors that may influence perceptions of young people on HIV and AIDS. Culture is a pattern of beliefs and values reflected in behaviour (Van Dyk, 2005). Culture is shaped by these lasting values that one is given at an early

age. Smith and Cronje (2001) explain that culture can be manifested in many ways: dress, language, food, gestures, manners and various other forms, yet the bulk of the cultural component, such as beliefs, norms, values, standards, perceptions, attitudes and priorities, is visible and hence much harder to deal with successfully. The key assumption of the cultural framework is that senior family members are supposed to be the socialising agents of appropriate behaviour to children (Ramarumo, 2005).

All cultures change through time (O'Neal, 2005). No culture is static. However, most cultures are basically conservative in that they tend to resist change. O'Neal says some cultures resist more than others by enacting laws for the preservation and protection of traditional cultural patterns while putting up barriers to alien ideas and things.

### **2.9.1 Individualistic and communalistic cultures**

Some cultures value the individual while others place greater emphasis on the group (Adler, Rosenfelt & Towne, 1995). Individualistic cultures are characterised by self-reliance and competition. On the other hand, collectivistic cultures are more likely to define themselves in terms of membership of an in-group.

*The following are characteristics of an individualistic culture:*

- A high regard for the individual elevates it above the group
- Individual independence
- The opinion of the group is not particularly important
- Individual initiative is highly regarded - personal achievement is more important than attention to the community.
- Competition
- The rights of the individual are stressed
- Values such as formality, independence and self-sufficiency are highly regarded.

*The characteristic of communistic culture are as follows:*

- High regard for the group elevates it above the individual
- Dependence on people
- Strong group pressure
- Individual initiative is not appreciated - good human relations are a priority
- Cooperation
- Duties towards the community are emphasised
- Values such as friendliness, helpfulness, hospitality, patience and brotherhood are highly regarded.

Members of individualistic cultures see themselves as separate and autonomous individuals, whereas members of collectivistic cultures see themselves as fundamentally connected to one another (Van Dyk, 2005). Individualistic cultures, personal needs and goals take precedence over the needs of others, whereas in collectivistic cultures, individual needs are sacrificed to satisfy the group. This means that people from different cultures view the world, their environment, their workplace and by implication HIV and AIDS through their cultural filters.

## **2.9.2 Cultural beliefs and illness**

In all human societies, beliefs and practices relating to ill health are a central feature of the culture (Helman, 2001). Often these are linked to beliefs about the origin of a much wider range of misfortunes (including accidents, interpersonal conflicts, natural disasters, crop failures, theft and loss), of which illness is one form. In some cultures the whole range of these misfortunes is blamed on supernatural forces, or on divine retribution, or on the malevolence of a witch or sorcerer. The values of and customs associated with ill health are part of the wider culture and cannot be studied in isolation from it.

Helman (2001) is of the opinion that it is important to examine social organisation of health and illness in a society (the health care system), which includes the ways in which

people have become recognised as ill, the ways in which they present these illnesses to other people, the attributes of those they present their illnesses to, and the ways that the illness is dealt with. It is therefore important when studying how individuals in a particular society perceive and react to ill health and the types of health care that they turn to, to know something about both the cultural and social attributes of the society in which they live.

### **2.9.3 Cultural norms and practices**

According to Louw (2005) certain prevalent cultural norms and practices related to sexuality contribute to the risk of HIV infection, for example:

- Negative attitudes towards condoms, as well as difficulties negotiating and following through with their use. Men in Southern Africa often do not want to use condoms, because of beliefs such that “flesh to flesh” sex is equated with masculinity and is necessary for male health. Condoms also have strong associations of unfaithfulness, lack of trust and love, and disease.
- Certain sexual practices, such as dry sex (where the vagina is expected to be small and dry), and unprotected anal sex, carry a high risk of HIV because they cause abrasions to the lining of the vagina or anus.
- In cultures where virginity is a condition for marriage, girls may protect their virginity by engaging in unprotected anal sex.
- The importance of fertility in African communities may hinder the practice of safer sex. Young women under pressure to prove their fertility prior to marriage may try to fall pregnant, and therefore do not use condoms or abstain from sex. Fathering many children is also seen as a sign of virile masculinity.
- Polygamy is practised in some parts of Southern Africa. Even where traditional polygamy is no longer the norm, men tend to have more sexual partners than women and to use the services of sex workers. This is condoned by the widespread belief that males are biologically programmed to need sex with more than one woman.

- Urbanisation and migrant labour expose people to a variety of new cultural influences, with the result that traditional and modern values often co-exist. Certain traditional values that could serve to protect people from HIV infection, such as abstinence from sex before marriage, are being eroded by cultural modernisation.

## **2.10 CONCLUSION**

Work on HIV and AIDS stigma generally shows polarisation between psychological explanations that ignore the socially constructed nature of stigma and ‘social control’ explanations that downplay the role of the individual as an agent of stigma. Understanding stigma as a largely emotional process, in which people distance themselves from risk by projecting risk onto out-groups using existing social representations (Joffe, 1999), accommodates both individual and social levels of explanation and does not define stigma in terms of discrimination. It also explains why education has a limited effect on the reduction of stigma. Using the blaming model of stigma, one can develop a more sophisticated understanding of the relationship between stigma, discrimination and power that does not rely on social control theory.

## **CHAPTER 3**

### **LITERATURE REVIEW**

#### **3.1 INTRODUCTION**

The topic of HIV and AIDS stigma has been extensively researched worldwide and specifically in South Africa. For the purpose of this study, the literature review will be discussed in relation to the following subtopics: HIV and AIDS knowledge and stigma, acquaintance and stigma, gender and stigma, knowledge of own's status, disclosure and stigma, socio-economic status and stigma, religion and stigma, family communication and stigma, perceived HIV and AIDS risk and stigma, and cultural beliefs and stigma.

#### **3.2 HIV AND AIDS KNOWLEDGE AND STIGMA**

There are different views as to whether lack of knowledge about HIV and AIDS contributed to stigmatising behaviour. There are authors who found that lack of knowledge leads to stigmatisation towards people living with HIV and AIDS, whereas others found that knowledge about HIV and AIDS does not reduce stigmatisation behaviour towards PLWHA. In addition, there are other factors, such as cultural beliefs and denial that could be linked to stigma towards PLWHA.

According to the study by Nwezer (2008) in Nigeria, respondents demonstrated good knowledge of general belief, mode of transmission, and precautionary measures against HIV. However, about fifty percent of the respondents demonstrated intolerant attitudes towards people living with HIV and AIDS in response to various questions that reflected stigmatising attitudes. The study by Tung, Ding, and Farmer (2008) on Taiwanese college

students enrolled in two private universities also showed that fewer than half (48.5%) of the participants were aware that HIV could be spread through infected semen, and nearly a quarter of participants believed that HIV could be contracted through mosquito bites, toilet seats or swimming pools. The implication of their study shows that beliefs and attitudes to PLWHA were likely to be influenced by lack of knowledge and understanding about HIV transmission. Bastien (2008) conducted a structured face-to-face interview with 1007 young people between the ages of 13 and 18, in Northern Tanzania. Boys were found to have more knowledge about AIDS than girls, and those from urban areas are more knowledgeable than their rural counterparts.

In addition, Nyblade, Panda, Mathur, MacQuarrie, Kidd, Banteyerga, Kidanu, Kilonzo, Mbwambo and Bond (2003) conducted a study on HIV and AIDS stigma in three African countries (Ethiopia, Tanzania and Zambia). They discovered that stigma results from lack of in-depth and up-to-date knowledge about aspects of HIV and AIDS, such as the difference between HIV and AIDS, how the disease progresses, the life expectancy of the HIV-positive person, and the fact that opportunistic infections are curable in PLWHA. Kalichman, Simbayi, Cain, Jooste, Skinner and Cherry (2006) conducted a study where prospective path analyses were performed on measures collected from 131 men and 60 women with sexually transmitted infections in Cape Town, South Africa. They found that AIDS-related stigmas correlated inversely with knowledge about AIDS and there was a trend toward AIDS stigmas correlating inversely with behavioural intentions.

Letamo (2001) conducted a study on HIV and AIDS-related stigma and discrimination among adolescents in Botswana, Southern Africa. She found lack of knowledge of how HIV and AIDS is transmitted to be an important predictor of discriminatory attitudes among adolescents towards PLWHA. Bond, Chase and Aggleton (2002) conducted a study on stigma, HIV and AIDS and prevention of mother-to-child transmission in Zambia. They found that main causes of stigma were identified as ignorance and misinformation about how HIV is transmitted and what it means to be HIV-positive. The physical manifestations of HIV AND AIDS, feeling at risk of HIV infection and the shame of having a disease

were very strongly associated with promiscuity and prostitution.

In Jamaica, Norman, Carr and Uche (2006) conducted a study to investigate the role of sympathy on avoidance intention toward persons living with HIV and AIDS. The study shows that students who had inaccurate knowledge concerning HIV transmission, compared to those with accurate knowledge, were also less likely to express complete sympathy. These study findings indicate that much work is left to do in Jamaica with respect to improving attitudes toward PLWHA. The study by Apinundecha, Laohasiriwong, Cameron and Lim (2007) on community intervention found that increased knowledge about HIV and AIDS led to significant reduction in HIV and AIDS stigma.

In contrast, Goodman and Cohall (1989) found that knowledge about HIV and AIDS has not been shown to result in behaviour change by itself. In addition, Kaplan and Van der Worm (1993) conducted a study on the relationship between South African adolescents' knowledge and fear of AIDS and their attitudes to people who have AIDS. They found that there was no significant correlation between knowledge of AIDS and fear, and no significant correlation between knowledge and attitude to PLWHA.

Kalichman and Simbayi (2004) examined associations among the belief that AIDS is caused by spirits and supernatural forces, AIDS-related knowledge and AIDS-related stigmas. Multiple logistic regression analyses controlling for participant age, gender, years of education and survey venue showed that people who believed HIV and AIDS is caused by spirits and the supernatural demonstrated significantly more misinformation about AIDS and were significantly more likely to endorse repulsion and social sanction stigmatising beliefs against people living with HIV and AIDS. However, nearly all associations between beliefs that AIDS is caused by spirits and AIDS stigmas were non-significant when logistic regressions were repeated with AIDS-related knowledge included as a control variable. This finding suggests that relationships between traditional beliefs about the cause of HIV and AIDS stigmas are mediated by AIDS-related knowledge.

AIDS education efforts are urgently needed to reach people who hold traditional beliefs about AIDS to remedy AIDS stigmas.

In many parts of the world, one finds very high awareness about AIDS, HIV transmission and risk factors. However, one finds that in these settings, people still stigmatise. For example, research indicates that individuals who knew that HIV and AIDS was not transmitted through sharing eating utensils would in role-playing with individuals who they thought were HIV-positive still segregate utensils. There is a fear factor concerning AIDS that is very rational, but it has to be addressed (de Palomo, 2006).

### ***3.2.1 HIV and AIDS knowledge, denial and fear***

Denial takes place on at least three levels: denial by those *not affected* by HIV and AIDS, in other words, the healthy people who feel that this has nothing to do with them; denial by entire *countries* affected by HIV and AIDS that fear the consequences if the facts should become known, and denial by *individuals* affected by HIV and AIDS (Van Wyngaard, 2005). Stigma feeds on denial, but actually the one feeds the other: as long as people with HIV and AIDS are stigmatised, the problem will be denied and as long as the problem is denied, those with HIV and AIDS will be stigmatised.

Visser, Makin and Lehobye, (2006) found that on an interpersonal level, respondents believed that most people would feel uncomfortable around people with HIV (80%); afraid (80%) and not willing to date people with HIV (89%). The respondents' perception was that the community would favour coercive isolation (43%), that employers would not hire people with HIV (75%), that people would not allow someone with HIV to take care of their children (82%) and that free medication should not be provided (57%).

The majority of the respondents' first association with HIV and AIDS was that it is a deadly disease (50.8%), transmitted sexually (9%) and associated with moral issues (8.4%). They also perceived it to be accompanied by feelings of hopelessness and pity

(8.2%), pain and suffering (5%) and fear (4.9%). Interestingly, only 1.4% and 0.7% of the respondents associated HIV and AIDS with drug use and homosexuality, respectively. The main discourses that were found to underlie people's perceptions of HIV and AIDS are therefore related to death, sex, moral issues, pity and fear (Visser, Makin & Lehobye, 2006).

From the above it appears that there are differing views on whether knowledge or lack of knowledge about HIV and AIDS leads to stigmatising behaviour. In addition, most of these studies were conducted among the general population in countries outside South Africa and those that were done in South Africa did not include the young adults of Limpopo Province. Therefore, the researcher would like to explore those factors strictly among young adults.

### **3.3 ACQUAINTANCE AND STIGMA**

Acquaintance has been associated with less stigmatising behaviour. Thus, in this section most authors hold the view that indeed knowing someone living with HIV and AIDS, such as a relative or friend, lessens stigmatising behaviour. However, there are a few studies that contradict the above findings.

Norman and Gebre (2005) conducted a study to examine levels of HIV testing practices among a large sample of university students and the relationship among HIV testing, socio-demographic variables and HIV-related behaviour. They discovered that knowing someone who is HIV-infected or had died from AIDS was positively associated with a perceived risk of HIV and less stigma towards people living with HIV and AIDS.

In Kenya, females and males living in a community with a high proportion of residents who knew someone with HIV or someone who had died of AIDS were more likely to have accepting attitudes toward an infected vendor and infected female teacher (Chiao, Mishra & Sambisa, 2008). Visser, Makin, and Lehobye (2006) conducted an exploratory study on

stigma related to HIV and AIDS in a South African community. They found out that people who knew someone with HIV were less stigmatising than people who did not know someone who was infected.

This study is consistent with the one done by Hutchinson and Mahlalela (2006) in the Eastern Cape. They found that for both males and females in the full sample, knowing someone with HIV was associated with lower levels of measured stigma. In 2002 two studies considered ways to reduce stigma and discrimination through interventions among young people (Population Council, 2006). Regular visits by youth caregivers to homes of people living with HIV and AIDS were shown to lead to a better understanding of the needs of this group of people and greater support from family and community members, reducing stigma faced by PLWHA and their families.

In contrast, Palekar, Pettifor, Behets and MacPhail, (2008) conducted a study examining the association between knowing someone who had died of AIDS and self-reported behaviour change, condom use and attitudes towards HIV, among South African youth aged 15-24. They found no association between knowing someone who died of AIDS and other HIV prevention-related behaviour. The other study was done by Lam, Naar-King and Wright (2007) to describe mental health symptoms in a sample of 66 HIV-positive youth (16-25) and to evaluate social support, disclosure and physical status as predictors of symptoms. As measured by a brief symptom inventory, 50% of the youth scored above the cut-off for clinically significant mental health symptoms, thus highlighting the need for mental health services. Lower social support, higher viral load HIV-status, disclosure to acquaintances and being gay/lesbian/bisexual were all significantly correlated with more mental health symptoms, but disclosure to family and close friends and contact with the service provider were not.

### ***3.3.1 Experiences of stigma of PLWHA from families***

Furthermore, there are families that stigmatise people living with HIV and AIDS. Nyblade, Panda, Mathur, MacQuarrie, Kidd, Banteyerga, Kidanu, Kilonzo, Mbwambo and Bond (2003) posit that because people know that HIV is transmitted predominately through sexual contact, they distance themselves from those whom they believe are engaged in behaviour they disapprove of.

*“Families and relatives isolate their son who has AIDS because they think that he is promiscuous and he got infected while having sex with different people, and they assume that he doesn’t respect their instruction and order. Because they feel this way, they kick him out of their house and isolate him. Due to this, he may die”. (Participant in an FGD of urban men and women, Ethiopia) (Nyblade et al, 2003, p. 19).*

Paradath, Searle, Ntuli, Pennings, Sibiyi and Ntsike (2006) also discovered the following in South Africa:

*“I know of a case where cruel things happened where a TB/HIV patient was closed indoors and nobody went into that room because they said the individual will infect them. They even refused when visitors came into the room and they said visitors would depress the patient further.” (Padarath et al, 2006 p. 99).*

*“There is a woman who tested positive and she told her partner. Her partner left the house since that day and never came back. He left her with children. He didn’t even tell her where he was going.” (Padarath et .al., 2006, p. 100).*

Despite negative feedback, some people behaved positively to PLWHA. Elmore (2006) in South Carolina and Padarath et al., (2006) in South Africa discovered the following from one of their participants:

*“I know whose house to go into and ask for a bathroom, I know whose house to go into and ask for something to drink, and I feel within that person if they are sceptical.” (Elmore, 2006, p. 226).*

The aforementioned studies were showed that acquaintance with PLWHA reduces stigmatising behaviour. There was evidence of verbal abuse and rejection of PLWHA. Thus the researcher wants to determine whether the above trends still apply in South Africa, especially among the young adults of Limpopo Province. The use of both qualitative and quantitative methods will blend and complement results. The other reason is that communities have unique ways of reacting to and dealing with issues around them.

### **3.4 GENDER AND STIGMA**

Numerous studies on gender and HIV and AIDS stigma have been conducted in African countries such as Botswana, South Africa, Ethiopia, Tanzania and Zambia. Most researchers found that females are often blamed for having HIV and AIDS and males are mostly not blamed. Nevertheless, there are other studies with contrary findings were women were not blamed; instead men were blamed.

Entrenched ideas about suitably “masculine” or “feminine” behaviour enforce gender inequality and sexual double standards, and lead to unsafe sexual practices. Women’s respectability is derived from the traditional roles of wife, home-maker and mother. Childbearing and satisfying her husband, sexually and otherwise, are key expectations for a wife - even if she is aware that her husband is unfaithful. Refusing a husband sex can result in rejection and violence (Rose-Innes, 2006). The low status accorded to a woman without a male partner may be an additional reason for making women less likely to leave an abusive relationship.

Too much knowledge about sex in women is seen as a sign of immorality, thus insisting on condom use may make women appear distastefully well informed. Married women who

request safer sex may be suspected of having extra-marital affairs or of accusing their husbands of being unfaithful. The resulting unequal power relation between the sexes, particularly when negotiating sexual encounters, increases women's vulnerability to HIV infection and accelerates the epidemic.

Letamo (2003) in Botswana found that the prevalence of HIV and AIDS-related stigma was lower among females than among males. A comparison of findings for men and women showed that age and belief that a person could get HIV infection by sharing a meal with a person with HIV and AIDS were the only factors significantly associated with discriminatory attitudes to a family member with HIV and AIDS for both the sexes. Uys et al., (2005) also found out that male students are more likely (18.9%) than female students (10.3%) to believe that a student who has HIV or AIDS should not be allowed to continue living in residence.

Nyblade (2003) found that most severe blame and stigma are faced by women who are perceived as having brought on HIV infection through their "bad", "immoral" sexual behaviour, or their "immodest" behaviour, the way they dress or behave. Furthermore, women's unequal access to resources also means they have more difficulty in coping with stigma, are more dependent on networks and support systems and very fearful of gossip that could eventually destroy their safety nets. In addition, Bond, Chase and Aggleton (2002) found that participants felt that while men were likely to share their HIV status with their wives in the expectation of a supportive response, women were much less likely to disclose their HIV positive status to husbands for fear that this might precipitate divorce or violence.

A study carried out by a team of researchers at the Human Sciences Research Council's Social Aspects of HIV and AIDS and Health programme (Media releases, 2006). They found that because the disease is predominantly transmitted through heterosexual sex in South Africa, women are often blamed unfairly by society for being responsible for spreading the virus.

The other study was done in the Eastern Cape Province, South Africa, by Mafuya-Phaswana and Peltzer (2006). They found that people living with AIDS, especially women, have been found to be exposed to stigma and discrimination at community and family level. An intervention study conducted by Kalichman, Simbayi, Cloete, Cherry, Strebel, Kalichman, Shefer, Crawford, Tshabalala, Henda and Cain (2008) on reducing the risk of HIV AND AIDS and domestic violence among South African men, found that intentions to reduce risk-taking behaviour, self-efficacy for HIV risk reduction, and negative attitudes to women had changed in a positive direction. Negative attitudes to women were positively associated with a high level of HIV risk behaviour to a significant level, and endorsement of traditional male roles was negatively associated with HIV risk behaviour (Kaufman, Shefer, Crawford, Simbayi, & Kalichman, 2008).

#### ***4.4.1 Gender, stigma and psychological wellbeing***

Gielen, McDonnell, O'Campo and Burke (2005) conducted a study to examine the association between women's HIV serostatus, experience of intimate partner violence and risk of suicide and other mental health indicators. The results show that among HIV-positive women, thoughts of suicide occurred more frequently among those who were frequently diagnosed. The implication of this study is that health care providers who are interacting with HIV-positive people and/or those in abusive relationships should routinely assess them for mental health status, especially suicide risk, which may lead to crisis intervention. There was no relationship between sex and sexual behaviour (e.g., the number of sexual partners and frequency of condom use) and HIV knowledge and attitudes among Taiwanese students (Tung, Ding, & Farmer, 2008).

In contrast, the national survey from Kenya conducted by Chiao, Mishra and Sambisa (2008) shows that males were more likely than females to have more tolerant attitudes, and they were more likely to have tolerant attitudes to an infected household member, followed by tolerant attitudes to infected vendors, and then tolerant attitudes to letting female teachers living with HIV continue teaching. In addition, Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo (2007) in Cape Town, South Africa, found that a slight but

consistent pattern of gender differences in AIDS discrimination experiences and internalised stigma should be noted. Men were more likely never to have discussed AIDS with friends, were more likely to have been treated differently since testing HIV positive and were more likely to have suffered loss of a place to stay or job due to AIDS. In addition, men were more likely to report experiencing internalised AIDS stigma than women.

Consistent with the literature on gender differences in depression, they found that men reported less social support and less depression than women. Men therefore did not follow the pattern suggested by the correlation between internalised stigma and depression, which suggests that individuals with greater internalised stigma would report more depression.

A fair amount of literature addresses how women living with HIV and AIDS are being stigmatised by men in general throughout the world, especially in Africa. It is however, not clear how young adults react to people living with HIV and AIDS. Therefore, this study attempted to understand whether gender influences the stigmatisation of PLWHA among young adults.

### **3.5 KNOWLEDGE OF ONE'S OWN STATUS, DISCLOSURE AND STIGMA**

This subsection takes the point of view that people are scared of disclosing their status because of how the community treats them. However, there are studies that show that disclosure depends on particular factors, such as the nature of the relationship with the person to whom people who have HIV and AIDS disclose it. Emotional impact and mental health issues after becoming aware of one's status will also be discussed.

HIV and AIDS-related stigma affects issues related to HIV testing, including delays in testing, the effect of delay on further transmission of HIV and individuals' responses to testing positively (Chesney & Smith, 1999). Knowledge of one's HIV seropositivity can lead to earlier treatment and improved outcomes (Herek, 1990). Knowledge of

seropositivity can also lead to changes in risk behaviour that can reduce or eliminate the risk of HIV transmission. Pulerwitz, Michaelis, Lippman, Chinaglia and Di'az (2008) conducted a random sample of 1 775 truck drivers. Less stigma was to a significant level correlated with VCT use, knowing where to get tested and willingness to disclose HIV-positive test results. These findings indicate that stigma is an important barrier to HIV testing and disclosure among truck drivers in Southern Brazil.

A Kaiser Health Poll report (2000) suggested that fear of being stigmatised by HIV and AIDS has some influence on people's decisions about getting tested for HIV. One-third of survey respondents said that if they were tested for HIV, they would be "very" or "somewhat" concerned that people would think less of them if they discovered that they had been tested. In addition, eight percent of people who had never been tested for HIV said that worries about confidentiality played a part in their decision not to have the test. Vermeer, Bos, Mbwamboc, Kaaya and Schaalma (2009) conducted a study in which cross-sectional data were gathered from 186 Tanzanian medical students, using a self-administered questionnaire. They found that fear of being HIV-positive, self-efficacy, perceived susceptibility and fear of being stigmatised were associated with either intention to participate in VCT or previous participation. Many of these respondents admitted that the fear of HIV-related stigma and discrimination and fear of knowing their HIV status were the main reasons why they had not sought HIV VCT (Ulasi, Preko, Baidoo, Bayard, et al., 2009).

### ***3.5.1 Perceived fear at discovery of own status***

The study by Bond, Chase and Aggleton (2002) found that in those who know they are HIV-positive, the impact of stigma creates psychological 'pain'. People are worried about being condemned, about illness and about death, and it is believed that these negative thoughts shorten lives. Some people even contemplated suicide, reasoning that "It's better to be dead than alive and continue being bullied". Furthermore, people at substantial risk of HIV infection are not tested in time because they have previously experienced stigma or fear that they might come to experience-discounting, discrediting or judgemental attitudes

from health care providers and staff (Valdiserri, 2002). An intervention study by Mathews, Guttmacher, Flisher, Mtshizana, Nelson, McCarthy and Daries (2009) found that an adolescent-friendly initiative in clinics in Cape Town, South Africa, has improved the accessibility of HIV testing to adolescents.

In the United States, Bairan, Taylor, Blake, Akers, Sowell and Mendiola (2007) conducted a study on perceptions of HIV-positive persons regarding disclosure of their serostatus to others. Data analysis revealed that disclosure of one's HIV-positive serostatus depends on the type of social relationship, fear and stigma. Thus, HIV still remains a fearful and stigmatising disease and disclosure of HIV status is a complex phenomenon embedded in various types of relationships. In other countries, such as China, Cao, Sullivan, Xu, Wu and the China COPRA project 2 Team (2006) found that people living with HIV and AIDS experienced discrimination from health workers and as a result other people would not disclose their status to the doctors when they sought health care. The reason for discrimination was that health care workers who were discriminating were those without adequate knowledge of how to treat PLWHA.

Flowers, Davis, Hart, Rosengarten, Frankis and Imrie (2006) conducted an individual in-depth, semi-structured interview with 30 HIV positive black Africans in London, UK. They found that most participants viewed the impact of HIV diagnosis negatively. Most reported a period of shock at being told that they were HIV positive. This was followed by confusion, social withdrawal and depression. In receiving test results, people were faced with the difficulties of understanding the meaning.

They also found that the fear of stigma led to lack of disclosure and in turn non-disclosure was linked with social isolation and lack of social support. Furthermore, the study also showed that being known to be HIV positive was associated with being treated differently by family, friends and the community. The stigma associated with HIV prevented the participants from talking to other people and thus obtaining social support.

*“In this way, stigma itself serves as a barrier to coping successfully. For the participant below, HIV tests results have changed her life, and perhaps her own sense of self. Her description of her life revolves around her interaction with the very few with whom she can talk about HIV (Flower et, al, 2006, p115).”*

### **3.5.2 HIV and AIDS status, stigma and psychological experiences**

Nyblade (2003), in a three-countries study in Africa, discovered that youth are widely blamed for getting HIV through their bad behaviour. They are perceived to be lacking in control over sexual behaviour and to be moving away from the traditions of their elders. As a result many young people prefer not to know their status owing to fear of facing difficulties after determining their status, especially when they are HIV positive. Pulerrwitz, Greene, Esu-Williams and Steward (2004) conducted a study consisting of 69 in-depth interviews and eight focus groups with Eskom employees in South Africa. Ninety percent of the employees agreed with the statement, “If I have AIDS, people will avoid me”. Fear of social isolation and gossip in the workplace were also discussed in the focus group and in-depth interviews. These fears probably influenced workers’ opinion about disclosure of their HIV status. They concluded that stigma and discrimination and other interpersonal aspects, such as social isolation, must be addressed directly.

HIV-infected individuals are reported to experience a number of stressors that are associated with psychiatric disorders (Baillargoen, Ducate, Pulvino, Bradshaw, Murray & Olvera, 2003). These stressors have been classified into three categories: 1) medical stressors, such as hospitalisation, physical discomfort and medical procedures; 2) psychosocial stressors, such as fear of stigma and death, and social stressors, such as stigmatisation by one’s community. According to the AIDS Institute (2006), people with HIV and AIDS are more likely to experience emotional distress or mental health disorders. Depression, anxiety, post-traumatic stress disorder and cognitive impairment are among the common disorders.

Flower (2006) is also of the opinion that a variety of negative psychological reactions is associated with HIV infection, namely depression, suicide risk and anxiety. Depression is more likely in the early phases of HIV disease, less likely with the onset of the HIV-related symptoms. Depression was also complicated by the frequency of bereavement from AIDS-related deaths. Stein (2005) adds that the considerable amount of psychological distress reported among PLWHA in other studies in South Africa may be accounted for at least to some extent by internalised AIDS stigma.

### **3.5.3 Stigmatisation by health professionals**

Kohi, Makoe, Chirwa, Holzemer, Phetlu, Uys, Naidoo, Dlamini and Greeff (2006) conducted a study to explore the experience of stigma of HIV and AIDS of PLWHA and nurses. The study was conducted in five African countries: Lesotho, Malawi, South Africa, Swaziland and Tanzania. In Lesotho and Swaziland, focus groups involved people from all administrative regions of the country. Focus group discussions were held with respondents to capture an emic view of stigma and discrimination in PLWHA, and etic and emic views of stigma and discrimination in nurses.

*One nurse described the following incident: One day, the Medical Superintendent came to the ward and read his (an HIV-positive patient) chart. While he was still on oxygen, he then gave the instruction, which he even wrote down, to say the patient must not be given oxygen. (clinical nurse, urban). Please note that in many other settings blood transfusions are given to very debilitated patients to improve their quality of life and are not related to surgery. Before surgery the child was screened, and found to be positive. So the doctor saw it was of no use to operate on him because he would not live to adulthood (clinical nurse, rural).*

Discrimination and stigmatisation of PLWHA by health professionals makes it difficult for patients to disclose their status. These contribute to the expansion of the epidemic as many people become reluctant to disclose openly attributable to fear of stigmatisation. Although, discrimination and stigma are experienced by PLWHA little is known as to whether these health professionals know their HIV status.

Surlis and Hyde (2001) conducted a study to explore the experiences of patients in Ireland. A volunteer sample of 10 former inpatients of hospitals in Dublin was involved in the study, during which in-depth interviews were conducted. One participant describes the shame and humiliation she felt when she lost her anonymity:

*“When I had given birth to Ann, it was a shock birth. She came so fast, they could not have noticed a big red circle on my chart, that’s to say that I had HIV, and I was in the admission room . . . but she [the nurse] did not look at my chart and she had a cut. I’ll never forget this, never forget it and of course she mingled with my blood, my waters and then she discovered I had HIV. It was very, very degrading”*  
(Surlis & Hyde, 2001, p. 75).

Adebayo, Bamgbala and Oyediran (2003) conducted a study to assess attitudes of health care providers to persons living with HIV and AIDS in Lagos, Nigeria. Attitudes of respondents to PLWHA were generally poor. Information was received from 254 randomly selected nurses and laboratory technologists from 15 government-owned health facilities in Lagos State through the use of a structured questionnaire. They found that 202 respondents (79.5%) thought that PLWHA are dangerous to others and should therefore be isolated. Although the majority of the respondents were willing to treat HIV and AIDS patients, their reluctance to have any direct contact with them could be explained by the fear of contagion, indirectly expressed in their concerns and prejudicial attitudes towards AIDS patients.

Kohi, Makoe, Chirwa, Holtzemer, Phetlhu, Uys, Naidoo, Dlamini and Greeff (2006) conducted descriptive qualitative research in Lesotho, Malawi, South Africa, Swaziland and Tanzania. Participants were PLWHA and nurse managers and clinicians in rural and urban settings. The findings revealed that the human rights of people living with HIV and AIDS were violated in a variety of ways, including denial of access to adequate health care services or the absence of health care services and denial of home care, termination or refusal of employment and denial of the right to earn an income, produce food or obtain a

loan. The informants living with HIV and AIDS were also abused verbally and emotionally.

According to Kohi et al., (2006), breaching of confidentiality concerning the sero-status of PLWHA happened at community level and among families and friends, sometimes even health workers. Participants expressed their experiences in this way:

*I did not tell this friend since she would go around broadcasting about my status. (male PLWHA, urban). After testing I was informed of my results in the presence of grandma. (female PLWHA, rural)” (Kohi et al., 2006, p. 410).*

The results of the qualitative study conducted by Paradath, Searle, Ntuli, Pennings, Sibiya and Ntsike (2006) in Kwazulu-Natal and Limpopo Provinces reveal that at the clinic they were been treated badly; if they wanted something from the health officials they would be told that they did not give the patient the disease. They also found that in some instances lack of space is said to compromise the confidentiality of VCT and act as a deterrent to testing and counselling. There also appears to be reluctance among people to use services where local community members are employed for fear that the confidentiality of their status will be compromised.

*“There is no privacy as the VCT room is right in the middle of the clinic. It is very uncomfortable, as people in the clinic can see all the people who go into the VCT room after which they will gossip and say, ‘Did you see Mr. So and so coming from the VCT room?’” (Padarath et al., 2006, p. 98).*

Literature reflects qualitative and quantitative explorations of the emotional impact and the factors involved when discovering ones' status, including real and perceived threats, from countries including South Africa, except Limpopo Province. These findings discovered were unique to countries and to the province. Thus, exploring such factors among the young adults of the Limpopo Province will again unearth unique and original ideas that could benefit the community that is interested in this field of study.

### **3.6 SOCIO-ECONOMIC STATUS AND STIGMA**

Socio-economic status level is perceived to be linked to how people relate to PLWHA and their self-esteem. On the one hand there are those who found that PLWHA of high/middle socio-economic status are less stigmatised and show less stigmatising behaviour, whereas on the other hand those who have a low socio-economic status are stigmatised more and show more stigmatising behaviour. Other studies found no significant differences between people from low or middle/high socio-economic status.

A three-country (Ethiopia, Tanzania and Zambia) study by Nyblade, Panda, Mathur, MacQuarrie, Kidd, Banteyerga, Kidanu, Kilonzo, Mbwambo and Bond (2003) discovered that the poor experience more stigma. Respondents explained that this is because it is harder to hide HIV if one is poor. Rich people can afford nutritious food and good health care and can consequently live longer without showing physical signs of HIV. They can also afford private and discrete medical and other care, whereas the poor have to disclose their status in order to receive needed help.

Furthermore, Hamra, Ross, Orrs and D'Agostino (2006) conducted a household survey through which they created a stigma index and indices for other social and knowledge domains that influence HIV-related health care. They found that respondents who were younger, had never married, and had less education expressed greater stigma. Differences in stigma were associated with poor knowledge about AIDS and negative attitudes to testing. They also found no significant difference in stigma scale across income categories. They therefore suggested that associations between stigma and other domains need to inform interventions that improve HIV care and mitigate the spread of HIV.

Bird, Bogart and Delahanty (2004) conducted a study in the United States to examine perceptions of race-based and socio-economic status-based discrimination during interaction with HIV treatment providers. They found that the majority of participants had perceived discrimination in their interaction with providers when getting treatment for

HIV. More specifically, 71% reported having experienced discrimination when receiving treatment for HIV based on their race or colour, and 66% reported discrimination attributed to their socio-economic status, position, or social class.

Ramakrishna, Maslekar, Chandra, Darak, Pant, Kulkarni and Kulkarni (2004) conducted an exploratory study in India, Bangalore (this area was predominantly a low/poor class one) and the Pune (predominantly middle class area). This study was on perceptions and the experience of stigma among PLWHA. The Bangalore study (N=53; 22 men, 31 women) was carried out in a government HIV counselling clinic and the Pune study (N=79; 50 men, 29 women) was conducted in a private nongovernmental organisation's (NGO) counselling clinic where ARVs were available. They found that socio-economic and educational status modulates the experience of stigma to a great extent. The educated, middle class PLWHA interact with health care providers on a more equal footing and, most importantly, determine to whom they disclose their HIV status.

Hutchinson and Mahlalela (2006), in the Eastern Cape Province, South Africa, discovered the absence of stigma to be more common among more educated adults and adults in higher socio-economic quartiles. No differences were apparent across urban/rural areas or in the former Transkei. The study, conducted among middle class adolescents by Pramanik, Chartier and Koopman (2006), in New Delhi, India, found that adolescents' stigmatising attitudes were associated with knowledge. In addition, adolescents generally lacked accurate knowledge about the disease and related health resources. The implication of this study was a need for greater HIV and AIDS education and awareness of health resources, especially among female adolescents.

In contrast, Chen, Choe, Chen and Zhang (2005) conducted a study in China to examine the contextual effects of community environment on individual stigmatising attitudes to PLWHA. The regression model was used to analyse 5 658 respondents aged from 14 to 49 and 66 communities were involved in the study. They found that a high level of HIV and AIDS-related risk behaviour in the community and a low level of community development

are associated with increased HIV stigma. The study suggests that interventions to reduce stigma should take community development into account.

In Nigeria, in half of the study communities, including villages with medium or high prevalence of the disease, local leaders denied that people living with AIDS were present, for fear that their village would be stigmatised as an 'AIDS community' (Hilhorst, van Liere, Ode, & de Koning, 2006). The study of young adults in Botswana by Letamo (2003) reveals that no education or a low level of education and the belief that a person could get HIV infection by sharing a meal with a person with HIV and AIDS were associated with discriminatory attitudes towards a shopkeeper with HIV and AIDS. Although the level of education and the place of residence were associated with negative attitudes towards PLWHA to a significant degree among females, this association did not apply to males.

Stigmatisation was more often reported among people of high socio-economic status in Europe and America. In Eastern countries and Africa there seems to be a change in trends on how socio-economic status is linked to stigmatising behaviour. In addition, studies on this aspect were conducted on either a general population of adults and youth or PLWHA and little on empirical data is known about young adults exclusively.

### **3.7 RELIGION AND STIGMA**

This section describes how authors have determined and have perceived faith-based organisations' (FBOs) reactions and attitudes to PLWHA. Some authors are of the opinion that most PLWHA are being stigmatised by people from religious groups, whereas others have found that there is less stigma in countries where churches are engaged in HIV and AIDS-related activities.

Religion deals with morals, beliefs and values; stigma also deals with morals, beliefs and values (Patient & Orr, 2005). The report of Patient and Orr (2005) on research conducted in Johannesburg and Pretoria revealed that religious leaders can 'stigmatise' people by the

way in which they talk and refer to people living with and affected by HIV and that in their holy books (Bible, Qu'uran, etc) texts can be misrepresented or misinterpreted. In Ghana, Muslims were more likely than Christians to agree with identifying PLWHA (Ulası, Preko, Baidoo, Bayard, Ehiri, Jolly, & Jolly, 2009).

At first, many religious leaders interpreted HIV and AIDS as God's punishment of sinners and called for behavioural change or repentance (Tiendrebeogo, Buykx, & van Beelen, 2004). These authors are of the opinion that this generated defensive behaviour, fatalism and self-stigmatisation among followers and other stakeholders. A similar view is shared by Van Houten (2005), namely that churches have not been at the forefront in the fight against stigmatisation, whereas in some cases church leaders have denied the problem.

Hartwig (2003) conducted a case study in Tanzania in which seven male and eight female “grassroots” church leaders were involved. The results show that stigma exists because of fear. He also found that religious leaders were teaching congregants that AIDS is a punishment for sinning. Furthermore, participants perceived communities to have incomplete information on HIV transmission. The implications of the study were that church leaders at grassroots level need to be targeted. Cotton, Tsevat, Szaflarski, Kudel, Sherman, Feinberg, Leonard and Holmes (2006) conducted a study on changes in religiousness and spirituality attributed to HIV and AIDS in the United States. They found that one-fourth of participants used to belong to a religious community but felt alienated from it, perhaps because of the stigma associated with being HIV-positive and/or because of homosexuality, sexual promiscuity and injection drug use.

Hartwig, Kissioki and Hartwig (2006) conducted another study in Tanzania, where they found that HIV and AIDS stigma remains a major obstacle to prevention and care interventions in Sub-Saharan Africa. FBOs have been shown both to foster HIV stigma and to mitigate it. Many participants in the discussions and focus groups had moved from positions of silence and condemnation to one of teaching others about HIV and AIDS. Only 10 of the participants actively did some form of HIV education; they related how

their own actions influenced their church membership's attitude to HIV. However, others faced opposition from senior pastors.

Lau, Choi, Tsui and Su (2007) conducted a study in Hong Kong to investigate stigmatisation of PLWHA. Multivariate logistic regression indicated that those who were older, those who were married or in cohabitation, those who had a religious affiliation and those who perceived HIV and AIDS to be a severe problem in Hong Kong currently or in ten years' time were more likely than others to exhibit higher stigmatisation scores. Attitudes to PLWHA were associated with the belief that PLWHA are promiscuous and the belief that PLWHA are just receiving the punishment they deserve for making themselves vulnerable to contracting HIV. The implication of the study is that campaigns for removing stigmatisation of these vulnerable groups are required in order to reduce stigmatisation of PLWHA.

On the other hand, Asiimwe, Kibombo and Neema (2003) conducted a study on social cultural factors that have an impact on HIV and AIDS in Uganda. A total of 192 focus group discussions were conducted in the six selected districts and 12 key informant interviews were conducted with the people in mandated positions aged between 15-24 and 25-49 years. They found that the proliferation of Pentecostal Churches had further enhanced reduction of risk through continuous involvement of the youth and other community members in religious activities. People's attitudes to HIV and AIDS changed positively, as reflected by the growing demand for VCT and the integration of PLWHA in the community. This resulted in improved health-seeking behaviour among infected people and subsequent involvement in HIV and AIDS prevention. Dilger (2007) observed members of the of the Neo-Pentecostal church to be supportive of PLWHA in Tanzania.

In addition, many people, both the infected and non-infected, were reported to have become saved (Born-again Christians) and to have abandoned their old bad habits, which very often included alcoholism, multiple sexual relationships and adultery - factors frequently mentioned as key among those responsible for the spread of HIV (Asiimwe,

Kibombo & Neema, 2003). Sex outside marriage, polygamous relationships and alcoholism are anathema to Born-again Christian virtues (Islam is also against alcohol), implying that upholding those values promotes abstinence among the unmarried and faithfulness among married couples.

Bond, Chase and Aggleton (2002) conducted a study through focus groups of health care providers and two focus groups of service users in Zambia. The study was on stigma, HIV and AIDS and prevention of mother-to-child transmission. Their experience was that in attempting to assess the church in relation to HIV-related stigma, it was hard to get respondents to criticise the church openly. In the rural setting, it was only the pastor himself who felt able to be open about stigma within the church. Hilhorst, van Liere, Ode and de Koning (2006) conducted a study in Nigeria to assess the impact of HIV and AIDS on the livelihood of the rural inhabitants of Benue State. They found that the association of HIV and AIDS with multiple sexual partners was given in some FBO as a reason for rejection and disapproval, and had led to the withdrawal of assistance for PLWHA. 'If a person becomes infected with HIV, we simply don't help. This person has obviously lived a reckless life, running after worldly things, and so we don't want to associate with this kind of person.'(FBO Male youth, medium affected community), (Hilhorst, Liere, Ode, and de Koning, 2006, p 391).

Norman, Carr and Uche (2006) conducted a study in Jamaica in which on-probability sampling frames were used. The vast majority reported being moderately or very spiritual (78.1%) with slightly more than one-third attending a religious service at least weekly (37.3%). The majority of students (76.5%) had not attended any type of HIV education forum or lecture in the previous 12 months and about half (48.6%) reported knowing someone who was infected with HIV or who had died from AIDS. The researchers found that students who reported being very spiritual were more likely to express complete sympathy than those who were less spiritual.

The above studies showed how religious leaders were influential in the stigmatisation process. This was done in the form of spreading ideas that PLWHA were promiscuous and unfaithfulness. Furthermore, some religious leaders were reluctant to discuss about HIV and AIDS openly. However, there were also contrary findings as to whether commitment to religion influences stigmatisation of PLWHA. Thus, this research project attempted to find out how religious commitment influences the stigmatisation of PLWHA in South Africa, especially at Limpopo Province.

### **3.8 FAMILY COMMUNICATION AND STIGMA**

As far as family communication and HIV and AIDS stigma is concerned, most authors have found that it is difficult for parents to speak to their children about issues of sexuality and HIV and AIDS. Thus, in families where there are communication barriers, there were also high levels of stigmatisation of PLWHA. Some projects on reducing stigma in some communities proved to be effective, since families who were involved in such projects, compared to those who did not get involved in such projects, had much better attitudes with regard to stigmatising behaviour.

Campbell, Foulis, Maimane and Sibiyi, (2006) conducted a case study of a youth HIV prevention programme run by an international body, the Christian Youth Alliance (CYA), in the South African community of Ekuthuleni, a peri-urban area near Durban in KwaZulu-Natal Province. According to the findings of Campbell et al., (2005), families sometimes disowned dead relatives, refusing to collect their bodies from the mortuary, for example. Amidst stories of rejection and prejudice, there were a few stories of care and compassion among family members. However, even in such families it was not uncommon for both the dying person and his or her family members never to refer to the fact that the person had AIDS, even when everyone was fully aware of the situation. One woman reported that, even after her sister's death, no one in the family had ever strayed from the "official story" that she had died of tuberculosis, despite everyone secretly being aware that she had died as a result of AIDS-related illnesses.

According to findings by Michaud, Suris, Thomas, Kahlert, Rudin and Cheseaux (2008), some families did not want to share the information on HIV and AIDS with someone outside the family. In some instances the mother insisted on not disclosing a child's status, even if the adolescent was comfortable with disclosing his/her status. This shows reluctance to communicate about HIV and AIDS on the side of the parent because of the fear of stigma. A focused ethnographic case-study approach was employed by Paruk, Petersen, Bhana and Bell (2005) to understand better how families in a semi-rural area outside Durban, South Africa, could support youth to make healthy life choices, particularly with respect to HIV risk behaviour. The findings suggest that caregivers of youth feel disempowered and unsupported in a context of fractured and uncontained leadership structures, which works against social cohesion. The researchers suggested that implementation of programmes aimed at empowering parents or caregivers with knowledge about HIV and AIDS, as well as renegotiating parental practices to promote greater parental authority, would be important interventions at a family level.

As a result preliminary evaluation of a programme called the AmaQhawe (Champions) Family Project was adapted from a programme originally developed in the USA: the Collaborative HIV and AIDS Adolescent Mental Health Project (Peterson & Bhana, 2005). The same children were significantly less stigmatising of others with HIV and AIDS compared to those who were not taking part in the study (Peterson & Bhana, 2005).

Raizada, Somasundaram, Mehta and Pandya (2004) conducted an interventional study to determine the effectiveness of various forms of interpersonal communication in improving awareness and reducing HIV and AIDS-related stigma. They found that HIV-related stigma was indeed prevalent among adolescents and interpersonal communication emerged as the most effective method to reduce it. Frequent interpersonal communication and

sensitisation on stigma-related issues concerning HIV were recommended in school-going adolescents.

Almeleh (2006) conducted a study to explore the bio-psychosocial context of HIV and AIDS in which eleven HIV-positive women negotiated the process of disclosing their positive serostatus to significant others, specifically biological household members. Results show that 72% of the sample disclosed their HIV-positive status to a close biological household member (significant other) as significant others provided, or had the potential to provide, the necessary health-related social support. Fifty percent of the sample did not disclose their status until they were in the later stages of HIV-disease. When participants had never been ill, they disclosed their status in order to educate loved ones and challenge HIV and AIDS-stigma. The results suggest that the unique and changing biophysical nature of HIV and AIDS lends itself to possible social and individual confusion, which in turn facilitates false popular perceptions of HIV and AIDS. HIV-positive individuals have to negotiate through the disclosure process in this particular social context.

From the above factors, it has been established that family communication about HIV and AIDS is mainly avoided for fear of stigma of association. Usually communication about HIV and AIDS is forced by the progression of the PLWHA. Although families find it difficult to communicate about HIV and AIDS, very little is known on whether family communication about HIV and AIDS influences stigmatisation of PLWHA at Limpopo Province.

### **3.9 PERCEIVED HIV AND AIDS RISK AND STIGMA**

Researchers have found that perceived risk is mostly associated with knowledge about HIV and AIDS. There are those who found that perceived risk was associated with stigmatisation of people living with HIV and AIDS. On the contrary, in South Africa some

found that perceived risk was less often associated with stigmatisation of people living with HIV and AIDS.

The main barriers to HIV testing include perceiving oneself as low risk, fear of unsolicited disclosure and fear of stigma and discrimination that would result from taking the test (Ma, Detels, Feng, Shen, Li, Li, Chen, Wang & Liu, 2007). According to Mnyanda (2006), stigmatisation of others allows people to deny their own risk by projecting risk onto outgroups.

### ***3.9.1 Perceived HIV and AIDS risk and stigma among students***

In the United States, Burkenholder, Harlow and Washkwich (1999) conducted a study on social stigma, HIV and AIDS knowledge and risk among young adults aged between 18 and 20. They discovered that stigmatising and ways of gaining knowledge about HIV and AIDS were related to the perceived risk of HIV and AIDS and risky behaviour. They are of the view that more research, particularly on diverse populations, needs to be conducted to assess the nature of the relationships among stigmatising, ways of learning about HIV and AIDS, sexual behaviour risk, and relevant mediators more clearly.

The same study was conducted in by Duncan, Harrison, Malaka, Sithole and Toldson (2005). Although, South Africans were less likely to stigmatise people living with HIV and AIDS, the reported high-risk sexual behaviour among male respondents was similar. South African females differed significantly in reported risk behaviour, since it was reported that their behaviour could put them at greater risk. The implication of this study is that additional research is needed to fully elucidate the role that stigma may play in hampering HIV and AIDS prevention efforts.

Sikand, Fisher and Friedman (1996) conducted a study on knowledge about AIDS, attitudes to AIDS and condoms. Behavioural changes because of AIDS were studied in 771 students in Grades 9 to 12 (mean age, 16 years) who completed anonymous

questionnaires in gymnastics classes of a New York City high school. They found that students demonstrated good knowledge of AIDS, with some misconceptions, and significant concerns about AIDS, resulting in some behavioural changes, but most continued to engage in high-risk behaviour. These data indicate that efforts aimed at HIV and AIDS prevention in adolescents must translate knowledge and concerns into behavioural change.

### ***3.9.2 Perceived risk, stigma in communities***

Another study was done in the Eastern Cape Province, South Africa, by Phaswana-Mafuya and Peltzer (2006). The aim of the study was to examine AIDS knowledge, risk behaviour, risk perception, stigma and support. They found that risk perception was low among participants in the study, as only 14.8 percent were afraid of infecting other people. The study by Kalichman, Simbayi, Cain and Jooste (2008) on perceived HIV and AIDS prevalence, burden and risk determined that participants who perceived themselves to be at risk of HIV and AIDS believed that HIV and AIDS was more prevalent than those who believed they were at low risk of HIV and AIDS.

Gregson, Zhuwau, Anderson and Chandiwana (1998) conducted a study on behaviour change in response to AIDS among women in two rural areas of Manicaland Province, Zimbabwe. It examined self-reported data on two overlapping areas of behaviour: (1) action taken to avoid HIV infection, and (2) fertility practices. They found that differentials in fertility practices were associated with heightened risk perception, particularly when based on personal acquaintance with AIDS patients but not with greater knowledge of HIV and AIDS. Results from the study suggest that effective behaviour change in Manicaland is facilitated by greater knowledge, experience and personal risk perception, but obstructed by low female autonomy, marital status and economic status, and by male labour migration and alcohol consumption.

Furthermore, they found that better knowledge was associated with education, religion, and travel and media exposure. Personal risk perception was quite high (42%) and

correlated with not being married, media exposure and contact with medical services. Few respondents knew close relatives with HIV and AIDS (4%) but nearly a quarter of those who felt in danger of infection said this was because friends and relatives were dying of AIDS. The implication of this study is that intensified behaviour interventions are needed, which should include peer-education initiatives targeting men and individuals without access to modern media. The epidemic may accelerate fertility decline in rural Zimbabwe through behavioural as well as biological change.

On the contrary, Courtenay–Quirk, Wolitski, Parsons, Gómez and the Seropositive Urban Men’s Study Team (2006) conducted a study to document beliefs about HIV and AIDS stigma within the gay community and to measure its effects on sexual risk behaviour, substance use behaviour, serostatus disclosure and mental health. The study used quantitative data from 206 HIV–positive MSM and qualitative data from 250 participants. The results of the study showed that perceived HIV and AIDS stigma in the present sample was unrelated to sexual risk behaviour, including unprotected anal sex with partners of negative or unknown serostatus. The implication of the study was that more research is needed to determine which circumstances and sources of HIV and AIDS stigma have the greatest effect on serostatus disclosure.

In conclusion, the above studies demonstrated how perceived risk of HIV and AIDS was associated with fear of being stigmatised. Nevertheless, there is little or no empirical inquiry into whether perceived risk of HIV and AIDS influences stigmatisation of PLWHA.

### **3.10 CULTURAL BELIEFS AND STIGMA**

Studies done in South Africa compared racial groups to see how different groups reacted to stigma. Some found that whites exhibited stigmatisation as compared to other racial groups such as blacks, Indians and coloureds. On the other hand, some studies investigated other factors, not only race, which contributed to stigmatising behaviour.

HIV and AIDS stigmatisation and the meaning of HIV and AIDS may also vary by race. Maughan-Brown (2004) conducted a study on students in Cape Town and found that young whites and coloureds in Cape Town are more stigmatising than young blacks. Another study was conducted by Uys, Martin, Ichharam, Alexander, Els and Eiselen (2002) among RAU (Randse Afrikaanse Universiteit) students. Students were asked if they knew of a friend or relative who was HIV-positive or had died of AIDS. This specific knowledge may lead students to have higher levels of knowledge about HIV and AIDS and they could change their behaviour appropriately. Black students (43.2%) were more likely to have had a close relative or friend who had died of HIV and AIDS than students from other racial groups.

In addition, Uys et al., (2002) found that respondents displayed some stigmatisation in relation to living and/or studying with HIV-positive individuals and people living with AIDS, particularly with regard to whether these individuals should continue living in residences. Residence and non-residence students furthermore demonstrated the perception that greater risk tended to be located in the other. Although generally low, greater stigmatisation was therefore displayed with regard to the possibility of living with people who are HIV-positive or are living with AIDS. Some gender, racial and residence/non-residence differences in these beliefs were evidenced. Indian (19.75%) and white (18.3%) students were the least likely of all racial categories to believe that a student with HIV and AIDS should be allowed to continue living in residence.

A study by Visser, Makin, and Lehobye (2006) revealed that race, knowing someone with HIV, living area, gender and age were the most important variables in explaining the level of personal stigma. White respondents were more stigmatising than other groups, while black respondents, who were exposed to the HIV epidemic to a much greater extent, were least stigmatising.

The above studies were conducted among students and the general population. In addition, the attention was focused on racial differences among ethnic groups. Problems are unique to different settings, thus people in rural settings also have their unique ways of dealing with contentious matters. The researcher hopes to determine how ethnic differences and cultural attachment exacerbate and mediate stigmatisation behaviour.

### **3.11 CONCLUSION**

The literature review paid special attention to the manner in which stigma is influenced by the level of knowledge about how HIV and AIDS is spread, association with someone living with HIV and AIDS, gender, knowledge of one's own HIV-status, socio-economic status, commitment to religion, family communication, perceived risk and cultural beliefs.

From the studies, it appears that there were differing views on whether knowledge or lack of knowledge about HIV and AIDS leads to stigmatising behaviour. It was established that acquaintance with PLWHA reduces stigmatising behaviour, with evidence of verbal abuse and rejection of PLWHA. A fair amount of literature addresses how women living with HIV and AIDS are being stigmatised by men in general throughout the world, especially in Africa. It was discovered that people would rather not know about their status and others perceived themselves to be at risk of contracting HIV and AIDS but how is that linked to stigma it was not clear.

Stigmatisation was more often reported among people of high socio-economic status in Europe and America. In Eastern countries and Africa the situation is contrary. Numerous studies showed how religious leaders were influential in the stigmatisation process and family communication about HIV and AIDS was mainly avoided due to fear of stigma of

association. Little is known about the influence of cultural attachment and stigmatisation of PLWHA, instead was attention was focused on racial differences among ethnic groups.

Although stigma is widespread worldwide, it has become evident that the field young adults have not been sufficiently explored in the whole world, including South Africa. Most studies that have explored young adults have targeted students, where the main focus was on quantitative design. As a result salient existential cultural factors that can help one to understand stigma, especially in the rural setting, were simply overlooked.

## **CHAPTER 4**

### **RESEARCH METHODOLOGY**

#### **4.1 INTRODUCTION**

This chapter outlines the sampling methods and the number of participants in both the qualitative and the quantitative study. The procedure of data collection and statistical methods used to analyse data will be described and data captured outlined and summarised in tables of frequencies and statistical tests. Tables of frequencies of participants will also be outlined and described.

#### **4.2 RESEARCH DESIGN**

The study is exploratory in design using quantitative and qualitative methods of data collection. The quantitative approach entailed use of questionnaires to survey groups of young adults and the qualitative approach used the focus group discussion method of data collection.

#### **4.3 SAMPLING**

Five communities in the Polokwane municipality, in Capricorn district of the Limpopo Province were considered for involvement in the study. A simple random sampling method was used to select 370 young adults aged between 18 and 25 years from randomly selected schools and youth organisations in the communities. The schools and the participants were selected from their respective populations through the use of a paper list of random numbers to ensure that each participant gets the same chance of participating. . The researcher made sure that the principles of unbiasedness as well as independence were

adhered to.

Of the total number of 325 young adults who were involved in the survey, of the 325 questionnaires that were distributed, 301 questionnaires were considered, for study and 24 were not considered for use, since they were either incomplete or the participants who completed the questionnaire did not satisfy the criteria for participation.

For the qualitative study, five focus groups (45 participants) consisting of an average eight to nine participants per group, were involved in the study. The groups were drawn from the same communities from which the quantitative data were drawn. Thus the total number of participants who were involved in the study was 370 (325 for the survey and 45 for the qualitative study).

#### **4.4 INSTRUMENTS**

The following scales were selected for this study:

##### **4.4.1 Biographical data:**

The participants' biographical variables were determined by using a questionnaire with 14 items. This questionnaire enquired about the marital status, age, cultural background, total monthly income of parents and educational qualifications. Furthermore, other questions included commitment to religion, attachment to culture, whether participants use condoms during sexual intercourse and whether they knew a friend who had HIV and AIDS. Perceptions about the risk of contracting HIV and whether participations knew a person in the family with HIV and AIDS were explored.

#### **4.4.2 Guiding questions for the focus group:**

Focus groups enquired about participants' views about HIV and AIDS, factors that influenced them to hold such views, how people with HIV and AIDS are treated in the family and by the community. Gender issues were triggered by questions about changed attitudes because of knowing someone with HIV and AIDS or learning about the death of someone from HIV and AIDS. They were also asked about health-related issues and how a person becomes stigmatised.

#### **4.4.3 Stigma questionnaire**

For the survey, a nine-item stigma questionnaire developed by Kalingman, Simbayi, Jooste, Toefy, Cain, Cherry and Kagee (2005) was used to assess participants' stigma levels in relation to PLWHA. The respondents indicated whether they agreed or disagreed with statements on the questionnaire. The Cronbach's alpha for the scale among the participants was 0.407.

#### **4.4.4 HIV knowledge questionnaire**

Another questionnaire developed by Carey and Schroder (2002) was used to assess HIV knowledge among young adults (see Appendix D). The 20-item questionnaire was adapted to include 21 questions. Participants were requested to indicate the extent to which statements about HIV were true or not by answering "yes", "no", or "I don't know". The Cronbach's alpha for the participants for this scale was 0.758.

#### **4.4.5 Acquaintance questionnaire**

A health and lifestyle survey by Burkholder and Lang (1994) consisting of six independent factors was used for assessing the "Knowing a person with HIV and AIDS" variable (see

Appendix E). Participants were asked to indicate the extent to which they knew a person with HIV and AIDS. Responses were as follows: “definitely not true”, “not really true”, “somewhat true”, “mostly true”, and “definitely true”. The Cronbach’s alpha for the participants for this scale was 0.797.

#### **4.4.6 Family communication questionnaire**

Burkholder and Lang (1994) consisting of six independent factors will be used for assessing the ‘Family communication’ variable. Participants were requested to indicate the extent to which they communicate about HIV and AIDS in the family. Statements from which to choose were “definitely not true”, “not really true”, “somewhat true”, “mostly true”, “and definitely true”. The Cronbach’s alpha for the participants for this scale was 0.637.

#### **4.4.7 Perceived risk questionnaire**

A survey developed by Burkholder and Lang (1994), consisting of six independent factors, was used for assessing the “Perceived risk of HIV and AIDS” variable. Participants were requested to indicate the extent to which they perceived themselves to be at risk of HIV and AIDS as indicated by “not at all sure”, “a little sure”, “kind of sure”, “fairly sure” and “very sure”. The Cronbach’s alpha for the participants for this scale was 0.603.

### **4.5 PROCEDURE**

The researcher got permission from youth leaders to conduct research in their communities. On the dates agreed with the youth leaders, the researcher assisted in distributing questionnaires at some schools and others were distributed in a community hall.

Before the final version of the questionnaire was adopted for use in this study, a pilot study was conducted during which a questionnaire was administered to a group of 60 young people in one community. These results were not included in the main study. This was done to assess the questionnaire's level of understandability, participants' ability to complete it, the time it took to complete and its reliability.

Before administering the questionnaires, the participants were informed about the purpose of the research and were allowed to ask questions regarding the study. The participants were assured of confidentiality and anonymity in order to make them feel comfortable. The research assistant started administering the questionnaire by explaining the instructions for completion to the participants. The first part of the questionnaire, which was about the participants' biographical information, was done together, item by item, with the research assistant leading and reading out the questions to the participants.

From the second part of the questionnaire onwards, the participants were encouraged to work individually, quietly, honestly, and as quickly as they could. The questions that were challenging were explained to the youth, and they were encouraged to direct their questions at the researcher if they encountered problems. The questionnaires were collected on the same day and it took the participants an average of 15 minutes to complete.

For qualitative work, the researcher arranged to meet the participants who would be involved in the focus group prior to the day of the research. The aim of this was to answer any questions they might have about the research. On the agreed dates, focus groups were facilitated for about an hour. Each focus group consisted of eight to nine members.

In view of the fact that the questionnaire and focus groups may have aroused more questions and interest about the topic of study, the participants were given a further 20 minutes to talk about their experiences. They were further referred to psychologists and social workers, both in the private and public sector, for therapy and social intervention

respectively.

#### **4.6 STATISTICAL METHODS**

The Statistical Package for Social Sciences (SPSS) was used in analysing the quantitative data, with the linear regression method the method of choice. The t-test was used to compare the means of males and females. N-vivo version 2 was used to analyse the qualitative data.

The participants' responses were then coded. The stigma questionnaire was coded as follows: agree = 2 and disagree =1. The HIV knowledge questionnaire was coded as follows: don't know = 1, yes = 2, no = 3. Knowing a person with HIV and AIDS was coded as follows: definitely not true = 1, not really true = 2, somewhat true = 3, mostly true = 4, definitely true = 5. Family communication was coded as follows: definitely not true = 1, not really true =2, somewhat true = 3, mostly true = 4, definitely true = 5. Perceived HIV and AIDS risk was coded as follows: not at all sure = 1, a little sure = 2, kind of sure = 3, fairly sure = 4, very sure = 5. The coding for the negative statements in the stigma questionnaire, and the sections on HIV knowledge and perceived HIV and AIDS risk were reversed.

#### **4.7 ETHICAL CONSIDERATIONS**

According to Creswell (2003), researchers need to respect the participants and the sites for research. Thus, the researcher adhered to the following fundamental ethical issues: consent, no harm, privacy and no deception.

#### 4.7.1 Consent

This is the procedure by which research subjects choose whether or not they wish to participate in a research study. Consent involves three elements: capacity, information, and voluntary participation. All three elements were satisfied before consent was given.

- **Capacity** is defined as the ability to acquire or retain knowledge, and the authority, or legal qualification, to perform an act. Since the participants were above 18 years of age they all had the capacity to decide to participate in the study.
- **Information** consists of ensuring that the subjects were told, and understood, the purpose of the study and their roles as subjects. The purpose of the study was thus explained to all participants.
- **Voluntary participation** means that the subject chooses to take part in the study of his/her own free will and is free to withdraw from the study at any time. There must be no element of force, fraud, deceit, duress, ulterior form of constraint or coercion to get a subject to participate. According to Babbie, Mouton, Vorster and Prozesky (2001) voluntary participation is of importance because of the following reasons:  
Social research often, though not always, represents an intrusion into people's lives and it also often requires people to reveal personal information about themselves – information that may be unknown to their friends and their associates. Therefore the researcher made the participants aware of the above issues and they were also made aware that they were not obliged to participate in the study.

#### 4.7.2 No Harm

One of the most important issues in all of research ethics is that subjects may not be harmed by one's study. Avoiding physical harm is obvious, but other issues need to be avoided as well, namely psychological stress, personal embarrassment and humiliation. The dignity of the subject (be it human or animal) always needs to be a concern of the researcher. The study of HIV and AIDS provokes emotional issues; the researcher is qualified to deal with emotional issues and he also prepared the participants for emotional

discomfort that could be experienced in the process of data collection. The researcher referred those who felt uncomfortable to a psychologist and social worker for emotional and social support.

#### **4.7.3 Privacy**

Participants were made aware of their right to keep private the fact that they had participated in the study and the right that information given to the researcher would not be linked to them. They were also assured that information provided would not in any way be used in a way that compromised the individual's anonymity. Again, there is no rule about what is too private to ask about. The dignity of the individual was respected in all cases.

#### **4.7.4 No deception**

Deception in research involves the misrepresentation of facts related to the purpose, nature, or consequences of a research study. Babbie, Mouton, Vorster and Prozesky (2001) posit that it is useful and even necessary to identify oneself as a researcher to those one wants to study to avoid deception. Subjects were fully informed of the above issues before giving consent. The researcher also made participants aware of their legal rights if they were harmed or if their privacy was violated.

# CHAPTER 5

## FINDINGS

### 5.1 INTRODUCTION

This chapter focuses on the presentation of both quantitative and qualitative data. The biographic information about the participants will be displayed followed by the presentation of the quantitative data through the use of tables and the hypotheses will also be tested. Qualitative data will be presented through main themes and links between those themes.

### 5.2 BIOGRAPHICAL INFORMATION OF PARTICIPANTS IN THE QUANTITATIVE COMPONENT OF THE STUDY

The demographic variables for the quantitative study are shown in the following table:

**Table 1:**

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>Marital status</b>		
Married	8	2.7
Single	292	97.0
Divorced	1	.3
Total	301	100

The majority of the participants were single.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
-----------------------------	------------------	-------------------

**Ethnic groups**

N. Sotho	269	89.4
Tsonga	16	5.3
Venda	4	1.3
<u>Other</u>	<u>12</u>	<u>4.0</u>
Total	301	100.0

The majority of the participants were Northern Sotho speaking.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
-----------------------------	------------------	-------------------

**Age**

18	59	19.6
19	44	14.6
20	36	12.0
21	41	13.6
22	33	11.0
23	27	9.07
24	23	.61
<u>25</u>	<u>38</u>	<u>2.6</u>
Total	301	100

The largest group of participants was 18 years old.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
-----------------------------	------------------	-------------------

**Gender of participants**

Male	117	38.9
<u>Female</u>	<u>184</u>	<u>61.1</u>
Total	301	100.0

The majority of participants were females.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>Income</b>		
less than R 3000	208	69.1
R3 000 - R5 999	63	20.9
R9 000 - R11 000	15	5.0
<u>R12 000 and above</u>	<u>15</u>	<u>5.0</u>
Total	301	100.00

Most participants' household income was less than R3 000.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>Educational level</b>		
Primary school	5	1.7
High school	207	68.8
Tertiary	78	25.9
<u>No education</u>	<u>11</u>	<u>3.7</u>
Total	301	100

Most participants had completed their high school studies.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>HIV status</b>		
Positive	8	2.7
Negative	150	49.8
<u>Uncertain</u>	<u>143</u>	<u>47.5</u>
Total	301	100.0

Only a few participants were HIV-positive.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>Commitment to religion</b>		
Not committed	27	9.0
Less committed	31	10.3
Fairly committed	55	18.3
Committed	119	39.5
Very committed	69	22.9
<u>Total</u>	<u>301</u>	<u>100.0</u>

Most participants were committed to their religion.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>Cultural attachment</b>		
Not attached	68	22.6
Less attached	58	19.3
Fairly attached	52	17.3
Attached	89	29.6
<u>Highly attached</u>	<u>34</u>	<u>11.3</u>
Total	301	100

Most people were attached to their culture.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>Condom use</b>		
Yes	218	72.4
<u>No</u>	<u>83</u>	<u>27.6</u>
Total	301	100.0

Most participants used condoms during sexual intercourse

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>Know a friend</b>		
Yes	26	8.6
No	275	91.4
Total	301	100.0

Most of the participants do not know a friend who has HIV and AIDS.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>Family member</b>		
Yes	36	12.0
No	265	88.0
Total	301	100.0

Most participants do not have a family member who has HIV and AIDS.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>Risk of HIV and AIDS</b>		
Yes	85	28.2
No	216	71.8
Total	301	100.0

About 28% of participants perceive themselves to be at risk of contracting the disease.

### **5.3 BIOGRAPHICAL INFORMATION OF PARTICIPANTS IN THE QUALITATIVE COMPONENT OF THE STUDY**

The demographic variables for the qualitative study are shown in the following table:

**Table 2:**

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>Age of participants</b>		
18	5	11.1
19	10	22.2
20	3	6.7
21	5	11.1
22	1	2.2
23	4	8.9
24	5	11.1
25	12	26.7
Total	45	100

The largest group of participants was 25 years of age.

<u>Demographic variable</u>	<u>Frequency</u>	<u>Percentage</u>
<b>Gender</b>		
Male	22	48.9
Female	23	51.1
Total	45	100.0

Females outnumbered males by one participant.

## **5.4 RESULTS FROM THE QUANTITATIVE DATA**

### **5.4.1 Regression model summary**

Table 3 below shows a summary of the linear regression analysis of dependent variable (stigma) and independent variables, such as knowledge of HIV and AIDS transmission, knowing someone living with HIV and AIDS, gender, knowledge of one's own HIV and AIDS status, socio-economic status, religious beliefs, family communication, risk perception of one's own risk and cultural attachment.

#### **Table 3: Regression model summary**

Table 3 shows the regression model summary on the effect of the independent variables (knowledge of HIV and AIDS transmission, knowing someone living with HIV and AIDS, gender, knowledge of one's own HIV and AIDS status, socio-economic status, religious beliefs, family communication, risk perception of one's own risk and cultural attachment) and on a dependent variable (stigma).

**Model summary**

Model	R	R Square	Adjusted R Square	Std Error of the Estimate	
1	.260(a)	.068	.039	1.44781	

**Anova table**

Model	Sum of Squares	Df	Mean Square	F	Sig
Regression	44.061	9	4.896	2.336	0.015
Residual	607.886	290	2.096		
Total	651.947	299			

**Linear regression table:** Enter method was used.

	Standardised coefficients		Unstandardised coefficients	T	Sig
	B	Std error	Beta		
(Constant)	5.986	.780		7.674	.000
Knowledge of HIV and AIDS	.031	.013	.140	2.421	.016
Knowing someone	-.029	.014	-.121	-2.019	.044
Gender	.508	.180	.168	2.825	.005
HIV and AIDS status	.061	.157	.023	.392	.696
Income	.252	.108	.138	2.327	.021
Religion	-.058	.075	-.048	-.783	.434
Family	-.011	.020	-.032	-.546	.585
Perception	-.016	.015	-.061	-1.025	.306
Culture	.023	.064	.021	.362	.717

All the factors put together have a significant effect on stigmatisation ( $F = 2.336$ ,  $df = 9$ ,  $p < 0.05$ ). Since the R-square is 0.068, the factors contributed to 6.8 % on the variability of

stigmatisation. The effect of the individual stigmatisation will be used to test the different hypotheses, as shown below.

## 5.5 FINDINGS

The findings in this study will be discussed through the hypotheses tested in the study.

**5.5.1 Hypothesis 1: The level of knowledge about HIV and AIDS transmission, has an influence on the level of stigmatisation of people living with HIV and AIDS.**

Table 4 shows whether knowledge of HIV and AIDS significantly influences stigmatisation of PLWHA.

**Table 4: HIV and AIDS knowledge and stigma (derived from table 3)**

	Standardised coefficients		Unstandardised coefficients	T	Sig
	B	Std error	Beta		
(Constant)	5.986	.780		7.674	.000
Knowledge of HIV and AIDS	.031	.013	.140	2.421	.016

Regression analysis shows that knowledge of HIV and AIDS significantly influences stigmatisation of PLWHA ( $t = 2.421$ ,  $p < 0.05$ ). The less the knowledge of HIV and AIDS, the more stigmatisation of PLWHA. Thus, the higher the level of knowledge about how HIV and AIDS is spread is, the lower the level of stigmatisation of people living with HIV and AIDS.

**5.5.2 Hypothesis 2: Close association with someone living with HIV and AIDS has an indirect influence on the stigmatisation of people living with HIV and AIDS than being less associated with those people.**

Table 5 below shows whether association with someone living with HIV and AIDS significantly influences stigmatisation of PLWHA.

**Table 5: Acquaintance and stigma (derived from table 3)**

	Standardised coefficients		Unstandardised coefficients	T	Sig
	B	Std error	Beta		
(Constant)	5.986	.780		7.674	.000
Knowing someone	-.029	.014	-.121	-2.019	.044

Regression analysis shows that knowledge of someone with HIV and AIDS significantly influences stigmatisation of PLWHA ( $t = -2.019$ ,  $p < 0.05$ ). This means that there is an inverse relationship in that the more acquaintance with an affected persons, the less stigmatisation of PLWHA. Thus, those who are associated with someone living with HIV and AIDS will stigmatise people living with HIV and AIDS less than those who are not associated with them.

**5.5.3 Hypothesis 3: Males stigmatise people living with HIV and AIDS more than females do.**

Table 6 below shows whether gender influences stigmatisation of PLWHA.

**Table 6: Gender and stigma (derived from table 3)**

	Standardised coefficients		Unstandardised coefficients	T	Sig
	B	Std error	Beta		
(Constant)	5.986	.780		7.674	.000
Gender	.508	.180	.168	2.825	.005

Regression analysis shows that gender influences stigmatisation of PLWHA ( $t = 2.825$ ,  $p < 0.05$ ).

Table 7 below shows whether there is a significant difference between stigmatisation by males and by females.

**Table 7: t-test on gender and stigmatisation on PLWHA**

Gender	Means scores on stigma	t-test for Equality Means							
		t	Df	Sig (2-tailed)	Sig	Mean Difference	Std error Difference	Lower	Upper
								95% Confidence Interval	
Male	6.7436	-2.441	299	.015	.002	-.42489	.17409	-.76748	-.08230
Female	7.1685	-2.340	212.971	.020		-.42489	.18161	-.78288	-.06690

The table shows that there is a significant difference between stigmatisation of PLWHA by males and by females ( $t = -2.441$ ,  $p < 0.05$ ). Females stigmatise PLWHA more than males do. The test shows that the mean score for females is more than that of males (the mean score for males = 6.7436 and the mean score for females = 7.1685). Thus, females stigmatise people living with HIV and AIDS more than males do.

**5.5.4 Hypothesis 4: Lack of knowledge about ones HIV status leads to more tendency towards stigmatisation of people living with HIV and AIDS than when the status is known.**

Table 8 below shows whether knowing one’s status will significantly influence stigmatisation of PLWHA or not.

**Table 8: Knowledge of one’s own status and stigma (derived from table 3)**

	Standardised coefficients		Unstandardised coefficients	t	Sig
	B	Std error	Beta		
(Constant)	5.986	.780		7.674	.000
HIV and AIDS status	.061	.157	.023	.392	.696

The table shows that knowledge of one’s own status does not significantly influence stigmatisation of PLWHA ( $t = 0.392$ ,  $p > 0.05$ ). Thus, those who do not know their HIV-status will stigmatise people living with HIV and AIDS similar to those who know their status.

**5.5.5 Hypothesis 5: Low socio-economic status leads to more tendency towards stigmatisation of people living with HIV and AIDS than when one is at middle or high socio-economic status.**

Table 9 below shows whether socio-economic status will influence stigmatisation of PLWHA.

**Table 9: Socio-economic status and stigma (derived from table 3)**

	Standardised coefficients		Unstandardised coefficients	T	Sig
	B	Std error	Beta		
(Constant)	5.986	.780		7.674	.000
Income	.252	.108	.138	2.327	.021

The test shows that socio-economic status significantly influences stigmatisation of PLWHA ( $t = 0.327$ ,  $p < 0.05$ ). Thus, those with middle or high socio-economic status will stigmatise people living with HIV and AIDS more than those with low socio-economic status.

**Table 10: Mean scores on socio-economic status**

Gender	Mean scores	N	Standard deviation	Standard error mean
Low status	6.9853	272	1.477	.0891
High status	7.1724	29	1.559	0.289

The mean scores for people from a high socio-economic background is more than that of people from a low socio-economic background (mean score for those with high socio-economic status = 7.1724 and mean score for low socio-economic status = 6.9853). Thus, people from high socio-economic status stigmatise PLWHA than those from low socio-economic status.

**5.5.6 Hypothesis 6: Commitment to religion is more influential on stigmatisation of people living with HIV and AIDS more than less commitment to religion.**

Table 11 below shows whether more commitment to religion will influence stigmatisation of PLWHA more than less commitment to religion.

**Table 11: Religion and stigma (derived from table 3)**

	Standardised coefficients		Unstandardised coefficients	t	Sig
	B	Std error	Beta		
(Constant)	5.986	.780		7.674	.000
Religion	-.058	.075	-.048	-.783	.434

The table shows that commitment to religion does not influence stigmatisation of PLWHA ( $t = -0.783$ ,  $p > 0.05$ ). Therefore, those who are more committed to their religion will not stigmatise PLWHA more than those who are less committed to their religion.

**5.5.7 Hypothesis 7: The more family communication there is about HIV and AIDS, the lower the level of stigmatisation of people living with HIV and AIDS will be.**

Table 12 below shows whether family communication about HIV and AIDS significantly influences stigmatisation of PLWHA.

**Table 12: Family communication and stigma (derived from table 3)**

	Standardised coefficients		Unstandardised coefficients	t	Sig
	B	Std error	Beta		
(Constant)	5.986	.780		7.674	.000
Family	-.011	.020	-.032	-.546	.585

The table shows that family communication about HIV and AIDS does not influence stigmatisation of PLWHA ( $t = -0.546, p > 0.05$ ). Thus, family communication about HIV and AIDS, does not affect the level of stigmatisation of people living with HIV and AIDS.

**5.5.8 Hypothesis 8: The higher the perceived risk of HIV and AIDS is, the lower the level of stigmatisation of people living with HIV and AIDS will be.**

Table 13 below shows whether the perceived risk of HIV and AIDS significantly influences stigmatisation of PLWHA.

**Table 13: Risk perception and stigma (derived from table 3)**

	Standardised coefficients		Unstandardised coefficients	t	Sig
	B	Std error	Beta		
(Constant)	5.986	.780		7.674	.000
Perception	-.016	.015	-.061	-1.025	.306

The table shows that perceived risk of HIV and AIDS does not influence stigmatisation of PLWHA ( $t = -1.025$ ,  $p > 0.05$ ). Therefore, higher the perceived risk of HIV and AIDS is, does not necessarily the lower the level of stigmatisation of people living with HIV and AIDS.

**5.5.9 Hypothesis 9: The stronger the attachment to cultural beliefs is, the more stigmatisation of people living with HIV and AIDS will occur.**

Table 14 below shows whether attachment to cultural beliefs influences stigmatisation of PLWHA.

**Table 14: Culture and stigma (derived from table 3)**

	Standardised coefficients		Unstandardised coefficients	t	Sig
	B	Std error	Beta		
(Constant)	5.986	.780		7.674	.000
Culture	.023	.064	.021	.362	.717

In this instance regression analysis shows that attachment to cultural beliefs does not influence stigmatisation of PLWHA ( $t = 0.362$ ,  $p > 0.05$ ). Thus, stronger attachment to cultural beliefs has no influence on the more stigmatisation of people living with HIV and AIDS.

## **5.6 SUMMARY OF QUANTITATIVE RESULTS**

From the quantitative analysis it can be derived that knowledge of HIV and AIDS, acquaintance, gender, and socio-economic status significantly influence stigmatisation on PLWHA. On the other hand, knowledge of one's own status, religion, family communication, perceived risk and cultural attachment, which do not significantly influence stigmatisation of people living with HIV and AIDS.

## **5.7 RESULTS FROM THE QUALITATIVE DATA**

The N-Vivo computer program was used to code respondents' responses in relation to the themes in the hypotheses that were tested in the quantitative study. Other themes also emerged from the focus groups, such as reactions of community members to PLWHA, experiences and reactions of PLWHA, and protection and prevention HIV and AIDS.

### **5.7.1 HIV and AIDS knowledge and stigma**

One of the themes that emerged includes knowledge and information. Participants seemed to be knowledgeable about HIV and AIDS and how it spreads; however, there were participants in one community who indicated lack of knowledge about HIV and AIDS and this may influence their level of stigmatisation. They were also of the opinion that people in the rural areas need to be provided with information on HIV and AIDS transmission.

Female participants stated that HIV and AIDS are caused by sexual intercourse with more than five partners. Another one stated that one can contract the disease if one has more than 10 partners without using a condom.

*“I think AIDS is caused by sexual intercourse with people who are more than five or more and that you should use condoms that should not be infected.”*

*“I think the person gets AIDS when you sleep with more than ten people without using a condom and the person can infect the other one without using a condom”.*

A male participant was of the opinion that a mosquito bite could cause spread the infection of HIV and AIDS from one person to another. He phrased his views in this way:

*“They go sleeping around and after that mosquito will bite them and people become infected. I feel very bad to those people. You feel that people get HIV and AIDS through mosquitoes.*

Others were of the opinion that information is everywhere but the main issue is ignorance. Their views were expressed as follows:

*“Issue of ignorance because people can choose to ignore messages about HIV and AIDS. You start to see more see billboard, we see people who are dying of HIV we ignore them”.*

### **5.7.2 Acquaintance and stigma**

Most participants knew people who had died of AIDS; however, they were not sure if the death was as a result of AIDS. Some participants knew PLWHA but the relatives of these people did not want them to be known and seen. In addition, some acquaintances were not open to talk about their status because of fear of rejection. Their responses were phrased as follows:

*“There are few people and some are friends that I know. Because they do not talk about it, when they have it they won’t tell you straight that I have this thing, you will hear after, you are not 100 percent sure because people talk at the end of the day you will hear many myths about the death of somebody or the death of your friend so you will not be sure because you will take it as another disease. That is why it won’t bring any change. If you are told and you heard from the horses’ mouth it will bring change”*

The discovery of knowing the person died without knowing the cause made most respondents angry about lack of disclosure by the infected person. There were also respondents who felt they needed to change their behaviour and lifestyle to protect themselves, although others only changed their behaviour for a short period and then reverted to their old lifestyle. Their response was as follows:

*“I knew from 2001 but in 2004 people use to write things about a certain lady who was HIV positive. I ended up telling myself that I will not get involved but after few months.”*

### **5.7.3 Gender and stigma**

Most respondents highlighted that females are not well treated and there were a few respondents who felt that males are being stigmatised more. In most instances, men would abandon their wives/partners or they would take the wives their home to be taken care of by their own parents.

*“Females who have HIV and AIDS are treated differently. Men do not understand, if I’m pregnant and come back with test results that I have HIV and AIDS he will deny. He does not think that he could also be having it as well, you know he just bring it”.*

*“Men are nicely treated because if it is a woman will take care of him. If it a woman, he will take her home and tell them to take care of her. It is very rare to find a woman taking a man to his family for them to take care of him”.*

There were responses that highlighted whether negative or positive behaviour was influenced by perceived benefits and the nature of the relationship with PLWHA. These were as follows:

*“Men are not treated well, let’s take it say you are a rich man, your wife when sees you with AIDS, she will treat you well but with the intention that you are going to die. When you die she will possess all your monies and go to get another man. They always have plan B, women do not care for men.*

*They only care about money”.*

*“Yes, men can get support you will find him without friends. They will lock that person in the house without giving him support. There is no support they lock them inside the house so that their friends should not see them”.*

#### **5.7.4 Knowledge of one’s own’s status, disclosure and stigma**

Disclosure of one’s own status was faced with ambiguity. Most participants expressed feelings of fear and shame about people who had disclosed their HIV and AIDS status. One participant indicated that once one discloses one’s status, people will distance themselves from one. Consequently, people end up isolating themselves and predisposing themselves to stress.

*“As young people we know their friends and our parents are dying because of HIV and AIDS. Some of them are dying because of their pride because they do not want to tell others about this disease. Some of our friends are very ashamed to talk about this thing”.*

They mentioned an incident of a person who was allegedly diagnosed with HIV and AIDS, who was discriminated against and people were talking about her in the community until she isolated herself and eventually committed suicide. One participant’s views were phrased as follows:

*“I knew from 2001 but in 2004 people use to write things about a certain lady who was HIV positive. I ended up telling myself that I will not get involved but after few months I told myself that it is about my protection not status. She started being isolated and eventually the person committed suicide. They are scared and no one will want to stay with that person, to eat with that person and to isolate the person and this life is difficult to stay alone”.*

### **5.7.5 Socio-economic status and stigma**

Participants highlighted difference between people from a high socio-economic level and those from a low socio-economic level. This is because people from a low socio-economic level are predisposed to HIV and AIDS because of their financial situation and when they have HIV and AIDS they need medication and help from public health institutions.

Participants highlighted that health professionals often mistreat them and sometimes expel them from health institutions. On the other hand, those with a high socio-economic status are treated decently. However, there were participants who felt that stigma is the same for everybody. Those from a high socio-economic level show stigmatising behaviour and they face stigma if they live with HIV and AIDS, similar to those from a low socio-economic level.

*“I think this goes with classes. The services are not the same. The only best way is when people have access of money. The poor do not get good service. When you go to the clinics and hospital the nurses will say just go back. We know that you have HIV and AIDS. Then you do not have power to move from home to get medication. You will end up saying what is the reason for living because the community do not want me, even in the clinics where you hope to find help you will find people who have the knowledge and they cannot help you, they are using their knowledge uselessly. So they use their knowledge uselessly, I think my opinion, what about love”.*

### **5.7.6 Religion and stigma**

Although there were no direct questions about stigma and religion, the aspect of God was brought to light. Respondents in general believed that there was no link between stigma and religion.

*“We should know that God has called us in this world. We should know that everything comes because of the purpose of God”.*

*“Enjoy don’t forget God.”*

They stated that people should enjoy life but they should also remember God. The other aspect that was highlighted was that it is God who gives life and that one should be hopeful and take care of oneself. Respondents phrased their views in this way:

*“AIDS is a big disease people of God you need to take care of yourself. I want to say to people who do not know about this disease, they just hear many people talking about it.”*

*“Lets us be self-controlled because we are people because God has brought us to this world.”*

### **5.7.7 Family communication and stigma**

Participants were silent for some time. They felt that there is no supportive behaviour among family members. They feel that PLWHA are denied opportunities; others shame and isolate them. In addition, the situation reaches the stage where people in the community will peep to see the extent to which the PLWHA is affected. Some family members keep it a secret and sometimes they discriminate, not allowing PLWHA to touch their belongings and preventing other people from seeing the person who is infected if they are visited. Others expressed their views in this way:

*“Some families do not treat them like human beings. Like maybe for example, I’m HIV positive and they know at home, if they know at home when we are sitting like this they will say do not touch that thing because you will infect our children with the virus. That is why people do not want to disclose their status. May they are not 100 percent sure how the person gets infected. They think that if you have AIDS you should not live other people you should live alone”.*

### **5.7.8 Perceived HIV and AIDS risk and stigma**

There were no direct links between stigma and the risk of contracting HIV and AIDS. However, the risk was associated with anger after the person had contracted the disease. Some responses were phrased as follows:

*“The thing is if they find you positive they will say I don’t want to die alone they will say the best thing will be if I can spread it. Others will when he is positive like start changing”.*

Other forms of risk behaviour were associated with the number of partners that the individual envisaged to be involved with. The responses were as follows:

*“I have realised that you should condomise. You should not have more than five partners.”*

### **5.7.9 Cultural beliefs and stigma**

Cultural issues that emerged during the discussions were that they found it difficult to discuss HIV and AIDS-related issues between children and parents. Responses were phrased as follows:

*“We come from different family background. Is not easy to talk about issues of sex with parents, and I think there are guys out there who are like me who do not get to talk with elders and parents staff like that”*

In some communities HIV and AIDS is perceived to be “magoma” (this is a condition which one acquires after sleeping with an uncleansed widow); on the other hand perceptions of association of HIV and AIDS with witchcraft still exist. Participants phrased their views as follows:

*“Many people say it’s magoma. I don’t know where they got this from”.*

*“Elder people are not knowledgeable about this disease. Elder people seeing a person with HIV and AIDS will say the person is being bewitched”.*

Furthermore, the way in which people are socialised in their communities disadvantages them, for example, it is difficult for women to introduce the use of condoms during sexual intercourse. In addition, a woman who sleeps around is called a prostitute whereas a man who behaves similarly is called a player, thus encouraging men to have multiple relationships. Responses pointed out the following:

*“For me men get applauded for their behaviours and we discriminate women. We praise men and blame women.”*

*“I think what makes it difficult is when childhood young men growing up, like polygamy was practiced, they grew in that environment then it becomes difficult to change. It is difficult to change but if you start from young age.”*

#### **5.7.10 OTHER THEMES**

Additional themes that emerged from the focus groups were reactions of community members to PLWHA and experiences of PLWHA.

##### **5.7.10.1 Community reactions to PLWHA**

Some communities displayed supportive behaviour towards PLWHA, for example by being comfortable around PLWHA, sharing food and activities within the house and learning about HIV and AIDS.

Similarly there are also negative connotations to PLWHA, such as calling PLWHA different derogatory names, which are associated with fast cars and other people who have died from HIV-related conditions, whose names are as follows:

- *Z 3 (a fast car)*

- *Koloi ya Eliya (Chariot of prophet Eliyah)*
- *Magama a mararo (Three names)*
- *Nkosi Johnson (The boy who died of an HIV and AIDS-related disease)*

### **5.7.10.2 Experiences of PLWHA**

Although participants were not asked about their HIV status, they stated that PLWHA are prone to feelings of hopelessness (thinking that it is the end of the world). Others sometimes feel worthless and blame themselves.

*“We are scared of HIV and AIDS. Youth believe that AIDS is death. We think that if the person has HIV and AIDS will not live long. When you are infected now you will die. We take them for granted, we treat them not as people, and we are scared”*

Participants also expressed feelings of fear and concern for PLWHA. Association of HIV and AIDS with death and no future precipitated these feelings. One participant mentioned an acquaintance who eventually took her own life as a result of stigma. They expressed their feelings in this form:

*“I don’t understand, sometimes I’m even scared to visit him. He is alone I’m scared to visit him. I ask myself what will happen to me if somebody is infected at home”.*

## **5.8 SUMMARY OF QUALITATIVE RESULTS**

Participants seemed to be knowledgeable about HIV and AIDS and how it spreads; however, there were participants in one community who indicated lack of knowledge about HIV and AIDS and this may influence their level of stigmatisation. Some participants knew PLWHA but the relatives of these people did not want them to be known and seen. In addition, some acquaintances were reluctant to talk about their status because of fear of rejection. Most respondents highlighted that females are not treated well and there were a few respondents who felt that males are being stigmatised more often.

Most participants expressed feelings of fear and shame about people who had disclosed their HIV and AIDS status. They also highlighted differences between people from a high socio-economic level and those from a low socio-economic level. This is because people from a low socio-economic level are predisposed to HIV and AIDS because of their financial situation and when they have HIV and AIDS they need medication and help from public health institutions. Respondents in general believed that there was no link between stigma and religion. They felt that there is no supportive behaviour among family members. They were of the opinion that PLWHA are denied opportunities; others shame and isolate them.

There were no direct links between stigma and the risk of contracting HIV and AIDS. However, the risk was associated with anger after the person had contracted the disease. They found it difficult to discuss HIV and AIDS-related issues between children and parents. Some communities displayed supportive behaviour towards PLWHA, for example by being comfortable around PLWHA, sharing food and activities within the house and learning about HIV and AIDS. They stated that PLWHA are prone to feelings of hopelessness (thinking that it is the end of the world). Others sometimes feel worthless and they often blame themselves.

## **5.9 CONCLUSION**

Both quantitative and qualitative studies are complementary in that the quantitative study shows knowledge about HIV and AIDS, acquaintance with PLWHA, gender and socio-economic status significantly affect stigmatisation of PLWHA. The qualitative aspect provided deeper insights into why such variables were significant. Such insights include people distancing themselves, calling PLWHA derogatory names and depriving them of common human rights.

## **CHAPTER 6**

### **DISCUSSION**

#### **6.1 INTRODUCTION**

In this chapter the findings of the study will be discussed in relation to the literature review and other related factors. The chapter concludes by presenting the study's limitations, conclusion and recommendation.

#### **6.2 DISCUSSION OF MAJOR FINDINGS**

##### **6.2.1 HIV and AIDS Knowledge and stigma**

The findings of this study support reported findings by Nyblade et al., (2003) and Visser et al., (2006), which hold that lack of knowledge about HIV and AIDS is associated with stigmatisation of people living with HIV and AIDS. Nwezer (2008) also observed that respondents in this study demonstrated that knowledge of general belief, mode of transmission and precautionary measures against HIV correlated positively with intolerant attitudes to people living with HIV and AIDS.

With reference to the focus groups discussions in this study, most participants seemed to be knowledgeable about HIV and AIDS; however, there were participants in one community who showed lack of knowledge about HIV and AIDS. One participant mentioned that one could be protected from HIV and AIDS if one had sexual intercourse with fewer than five partners with a condom. Another one was of the opinion that a mosquito bite could spread the infection of HIV and AIDS from one person to another. This is similar to other findings by Tung et al., (2008) among Taiwanese students. They

found that a quarter of participants believed that HIV could be contracted through mosquito bites, toilet seats, or swimming pools.

The result of this study has prompted some concerns in the mind of the researcher with respect to knowledge and stigma, bearing in mind the HIV and AIDS education by the media and the engagement of various NGOs. This is because by now, (2009) it is expected that every person in South Africa should be knowledgeable about HIV and AIDS transmission and risky behaviour. However, the reason for the association between lack of knowledge and stigma could be explained by the fact that people in the rural areas have limited access to sources of information, such as the internet, clinics and television. In the rural areas, most of the information is transmitted through the radio. Moreover, in the rural areas, the availability of health professionals and HIV and AIDS organisations is often limited.

Campaigns that are undertaken by the government and NGOs seem not to be outcome-based. There are no assessment tools that can be used to determine the effectiveness of the knowledge transmitted and the gaps that need to be addressed. According to Ehrhardt and Exner (2000), interventions of longer duration are found to be more effective in reducing risky behaviour than shorter interventions. Most of the programmes in rural areas are short-term; for example, arrangements are made for a day and very seldom for a week. As a result information gathered tends to fade away easily.

### **6.2.2 Acquaintance and stigma**

Acquaintance was inversely associated with stigmatisation of people living with HIV and AIDS, in that the more association a person had with a person suffering from HIV and AIDS, the less likely the person would be to stigmatise people living with HIV and AIDS. This agrees with the contact theory proposed by Allport (1954), which conceptualises that more contact between members of different social groups can help reduce prejudice between the groups. The present study also agrees with Herek and Capitanio (1998), and

Hutchinson and Mahlalela (2006) who reported that contact with a person living with HIV disease reduced stigma.

Norman and Gebre (2005) also reported that knowing someone who is HIV-infected or had died from AIDS was associated positively with the perceived risk of HIV and less stigma being attached to people living with HIV and AIDS. In contrast, Palekar et al. (2008) found no association between knowing someone who died of AIDS and other HIV prevention-related behaviours. Furthermore, some families were reported to be stigmatising their members living with HIV and AIDS (Nyblade et al., 2003).

The results of this study can be explained by secrecy attached to HIV and AIDS. Lwihula, Dahlgren, Killewo and Sandstrom (1993) observed that families often lie about the illness of their relatives or the cause of death; they may shield a sick relative from the community for fear of rejection. On the other hand, those to whom the disease was disclosed will start to learn about HIV and AIDS.

Another reason that enhances knowledge about HIV and AIDS is the policy of the Department of Health, which requires PLWHA who wish to qualify for the rollout of antiretroviral treatment to have a person who will help them with treatment in order to improve compliance and adherence to treatment. This encourages people to be exposed to information about HIV and AIDS, for example, the mode of transmission, positive lifestyles and the role of medication. As a result most people who are close to PLWHA become empowered and the stigma attached to PLWHA is reduced.

### **6.2.3 Gender and stigma**

In this study it was found that females stigmatise people living with HIV and AIDS more often than males do. A similar finding was reported by Chiao et al. (2008) in Kenya. They found that males were more likely than females to have tolerant attitudes. They were more likely to have tolerant attitudes toward an infected household member, followed by tolerant

attitudes toward infected vendors, and then tolerant attitudes toward letting female teachers living with HIV continue teaching.

Furthermore, young adulthood is characterised by relationships that are perceived to be comfortable and marked by a sense of commitment, safety and care within a relationship. Therefore a person suffering from HIV and AIDS compromises these fantasies and expectations of young adults. This is because the disease affects the physical and emotional health of the individual and then the relationship. Consequently, young females would not want to be associated with a man whose health is perceived to be deteriorating.

In contrast to the findings of this study, many other authors, for example, in Europe, Bond, Chase and Aggleton (2002); Gielen, McDonnell et al., (2005), and in South Africa, Uys et al. (2005), media releases (2006) and Phaswana-Mafuya and Peltzer (2006), reported that men who were living with HIV and AIDS were stigmatising people with HIV and AIDS more often than females did. Similarly, from the focus group discussions conducted in the present study, most respondents highlighted that females are not treated well. In most instances, men will abandon their wives/partners or they will take the wives to their homes to be taken care of by their own parents.

#### **6.2.4 Knowledge of own status and stigma**

The study shows no significant influence of knowledge of one's own status on stigmatisation of people living with HIV and AIDS. Furthermore, Herek, (1990), Chesney and Smith, (1999), the Kaiser Health Poll report (2000), and Bond, Chase and Aggleton (2002) found a significant relationship between fear of being stigmatised because of HIV and AIDS and people's decisions about being tested for HIV, experience-discounting, discrediting, or a judgmental attitude from people and health care providers. Fear of being stigmatised (Vermeer, et al., 2009) and discriminated against (Ulası et al., 2009) were associated with VCT-participation intention. Kohi, et al. (2006) and Flowers, et al. (2006) have established that fear of stigma led to lack of disclosure and in turn non-disclosure was

linked with to social isolation and lack of social support. Other findings by Surlis and Hyde (2001), Nyblade et al., (2003), Baillargoen, et al., (2003), Pulerrwitz, et al. (2004) and Cao, Sullivan, Xu, Wu, and the China CIPRA project 2 Team (2006) revealed that fear of disclosure was associated with perceived maltreatment by community members and health professionals. Lack of knowledge and fear were also found on the side of health professionals (Adebayo, et al., 2003) and lack of privacy was experienced by people suffering from HIV and AIDS (Padarath, et al., 2006).

However, findings of the qualitative study on the disclosure of one's own status showed ambiguity in opinion. Participants mentioned an incident involving a person who was allegedly diagnosed with HIV and AIDS, who was discriminated against and people in the community were talking about her. The lady then isolated herself and she eventually committed suicide. There were some participants who were of the opinion that people are not disclosing their status not because of fear of stigma, but because of pride. On the other hand, there were those who felt that it is important to disclose one's status so that one can solicit help from friends and relatives.

Although there was no significant relationship between stigma and knowledge of one's own status, fear of knowing one's own status is prevalent among the youth. As a clinician, the researcher often comes across such situations where clients would prefer not to disclose their status to significant others for fear of stigma. In other instances relatives, friends and colleagues will be concerned about the well-being of people they suspect could have AIDS, but they are unable to assist because of the secrecy about HIV and AIDS. There are many people in the communities who will not solicit help from medical professionals and health institutions until they die because of fear of stigma. Furthermore, the belief that HIV and AIDS is a means by which white people try to control the black population still exists. Therefore health institutions are perceived to worsen their condition.

Active unequivocal involvement of the state president in the HIV and AIDS campaigns should be significant in affecting and changing behaviour. Botswana has succeeded in

reducing the rate of infection and increased access to VCT, and reduction of stigma due to its policies and the direct involvement by the state president. For example, Botswana was the first country in Africa to have a national policy of routinely offering an HIV test at clinics. However, in South Africa there were contradicting messages from a former state president, who said that HIV does not cause AIDS.

### **6.2.5 Socio-economic status and stigma**

This study found that people with high socio-economic status display more stigmatising behaviour to people living with HIV and AIDS than those with low socio-economic status. Contrary to this, studies by Hutchinson and Mahlalela (2006), in the Eastern Cape Province, South Africa, reported that the absence of stigma is more common among more educated adults and adults in higher socio-economic groups. This is also supported by a study done by Chiao, Mishra and Sambisa (2009), who found that respondents living in communities with higher economic status were more likely to have accepting attitudes to PLWHA than those living in communities with low socio-economic status. Low socio-economic status and lack of perceived risk barriers were related to lack of knowledge and lack of awareness of HIV (Bonjour et al., 2008).

Bonjour et al. (2008) also highlighted that health professionals often mistreat people whose socio-economic status is low and sometimes they expel them from institutions such as clinics. On the other hand, some participants mentioned that the treatment is the same. However, the difference was perceived to be with regard to access to information about HIV and AIDS and money, which the rich will use to enhance the quality of their lives and the lives of those in their families who have living with HIV and AIDS.

Bandura noted that people learn behaviours by perceiving the behaviour of other people who serve as their role models. One would think that stigma can be minimised by the involvement of people holding influential positions in society. Recently, very prominent people in the political and entertainment arena, such as Dr Mangosuthu Buthelezi (the

leader of the Inkatha Freedom Party) and Dr Irvin Khoza (the chairman of a big soccer team in South Africa) shared with the country their experiences of losing their children to AIDS.

In addition, one of the country's top musicians (DJ Sbu Masilela) is advocating anti-stigma campaigns and disclosure of one's status. These gentlemen are very influential and they are the role models for a great many people, regardless of their socio-economic status. However, their contribution seems not to have influenced the attitudes and behaviour of many South African young adults, especially, in Polokwane, with regard to HIV and AIDS stigma, as one would have thought.

According to Deacon, Stephney and Prosalendis (2005), HIV and AIDS stigmatisation relies heavily on existing prejudice and social stereotypes. Dominant groups, which usually gain greater currency in society often identify and blame existing marginalised groups in society. This emotional (rather than cognitive), and often unconscious, response to danger helps people to feel they are less at risk of contracting serious diseases (Deacon, et al., 2005).

#### **6.2.6 Religion and stigma**

This study found no significant influence of commitment to a religion on stigmatisation of people living with HIV and AIDS. This is not in line with current findings that have shown that stigmatisation in FBO is decreasing. Such studies were conducted by Asimwe et al. (2003), who found that religious community intervention resulted in lower stigmatisation in FBO. Norman et al. (2006) also discovered that people who regarded themselves as very spiritual were more likely to express complete sympathy with PLWHA than those who were less spiritual. Similarly, members of the Neo-Pentecostal church were supportive of PLWHA in Tanzania (Dilger, 2007). In some instances, Muslims were more likely than Christians to agree with identifying themselves with PLWHA (Ulasi et al., 2009).

In contrast to the above findings, there are documented findings of stigmatisation of people living with HIV and AIDS by FBO (Hartwig, 2003). The experience of Bond, Chase and Aggleton (2002) concerning church involvement in HIV-related stigma was that it was hard to get respondents to criticise the church openly. Hilhorst et al. (2006) and Cotton et al. (2006) also found that the association of HIV and AIDS with multiple sexual partners was given in some FBOs as a reason for rejection and disapproval, and had led to the withdrawal of assistance for PLWHA.

Although there were no direct questions about stigma and religion in the qualitative part of this research, the aspect of God was brought to light by participants in the focus group. Participants argued that people should enjoy themselves, but they should also remember God. The other aspect that was highlighted was that it is God who gives life and people need to be hopeful and take care of themselves.

Although the aspect of stigma and religion has not been sufficiently explored in Limpopo Province, it seems that the level of stigma in FBO is gradually decreasing. Efforts are being made in South Africa, especially in Cape Town, where one of the senior bishops of the Anglican Church is initiating anti-stigma campaigns. The researcher's observation is that most churches have slots for health education and in some instances the aspect of HIV and AIDS and stigma is being discussed.

Most research projects undertaken by universities and research institutions in the communities did not involve the church in the research projects. Nevertheless, the researcher has experienced reluctance from some FBOs to participate in some HIV and AIDS research projects. Therefore, eradication of stigma in FBOs depends entirely upon the availability and willingness of their authorities.

### **6.2.7 Family communication and stigma**

This study also found no significant influence brought about by family communication about HIV and AIDS and stigmatisation of people living with HIV and AIDS. A study by Lehmann and Zulu (2005) showed that it is difficult for health professionals to communicate issues on sexuality and HIV and AIDS to children and other family members.

In the focus groups, participants explained that it was difficult to communicate with parents about HIV and AIDS. They also felt that parents do not have enough information about HIV and AIDS; as a result of lack of knowledge, parents find it difficult to teach their children about HIV and AIDS. In addition, if parents talked to their children about HIV and AIDS-related issues, it was usually in the form of threats.

Participants felt that parents and their friends do not behave in a supportive manner. They feel that PLWHA will be denied opportunities and that others will shame and isolate them. At times, people in the communities peep to see the extent to which the PLWHA is affected. Other family members keep it a secret and sometimes they discriminate against PLWHA, not allowing them to touch their belongings and preventing visitors from seeing the person who is infected.

The qualitative and quantitative findings seem to differ. This can be explained by the findings by Raizada et al., (2004), who found that HIV-related stigma was indeed prevalent among adolescents and interpersonal communication emerged as the most effective method of reducing it. The observation of the researcher has been that young adults are being taught issues related to sexuality during initiation schools. It is also possible to talk to elderly people with whom young people are comfortable. Very often, parents' responsibility to communicate with young adults is shifted to educators and other elderly people in the family. This may not necessarily be a problem, because it seems to be

a way in which adults communicate with the youth about sexuality. This way of transmission of information will also raise the awareness of young adults.

### **6.2.8 Perceived risk and stigma**

Study findings indicate no significant influence of perceived risk of HIV and AIDS on stigmatisation of people living with HIV and AIDS. This is not in line with other authors, such as Mnyanda (2006), who is of the opinion that stigmatisation of others allows people to deny their own risk by projecting risk onto other groups. Burkenholder et al. (1999) reported that stigmatising and ways of knowing about HIV and AIDS were related to the perceived risk of HIV and AIDS and risky behaviour. Although males were more likely than females to have higher levels of tolerance towards PLWHA, most respondents perceived themselves at little or no risk of being infected by HIV (Chiao, et al. 2008).

The focus group discussions did not indicate any direct link between stigma and perceived risk. Nevertheless, risky behaviour was thought to be associated with anger, socio-economic status and lack of knowledge about HIV and AIDS. Risky behaviour was associated with the number of partners that the individual had. Respondents highlighted that the poor are prone to HIV and AIDS because some women engage in sexual activities for the sake of money, sometimes without a condom. Lastly, there are those who still believe that it is acceptable to have multiple partners as long as one uses a condom.

Consequently, there are more people who are infected with HIV and AIDS who have to deal with their status with respect to internal and external stigma. There is a belief that some of those who are infected are often angry and contemplate infecting others. The support of PLWHA by families is often inadequate; sometimes families do not know how to support those who are infected with HIV and AIDS. Recently, incidents have occurred in Limpopo Province of people who are infected with HIV and AIDS kidnapping people and raping them. There were also incidents of children being raped because of the belief that having sexual intercourse with a baby will destroy the virus.

### **6.2.9 Culture and stigma**

In this study, no significant influence of attachment to cultural beliefs on stigmatisation of people living with HIV and AIDS was found. Contrary to the above finding, Maughan-Brown (2004) found that young people from white and coloured cultures in Cape Town were more inclined to stigmatise people than young blacks.

Cultural issues that emerged during the focus group discussions were in relation to the way in which people are socialised. Young adults found it difficult to discuss HIV and AIDS-related issues with their parents. In some communities HIV and AIDS is regarded as “magoma” (this is a sickly condition that one acquires after sleeping with an uncleansed widow). Furthermore, perceptions of HIV and AIDS as witchcraft are prevalent. Moreover, the way people are socialised makes it difficult for women to introduce condoms. A woman who “sleeps around” is called a “prostitute” whereas a man who behaves similarly is called a “player”. Thus, the cultural milieu affects understanding and reactions to PLWHA.

In the researcher’s view, HIV and AIDS has an impact on all people and all cultures, including the Northern Sotho culture. Not that adherence to norms and cultural attachment are not important, but it seems as if HIV and AIDS has become part and parcel of the way of life. HIV and AIDS has affected societal strongholds and the way of life of most communities; for example, the number of child-headed families has increased (Hartell & Chabilall, 2005). In some instances, grandparents and relatives are taking care of the children of parents who have passed away because of AIDS.

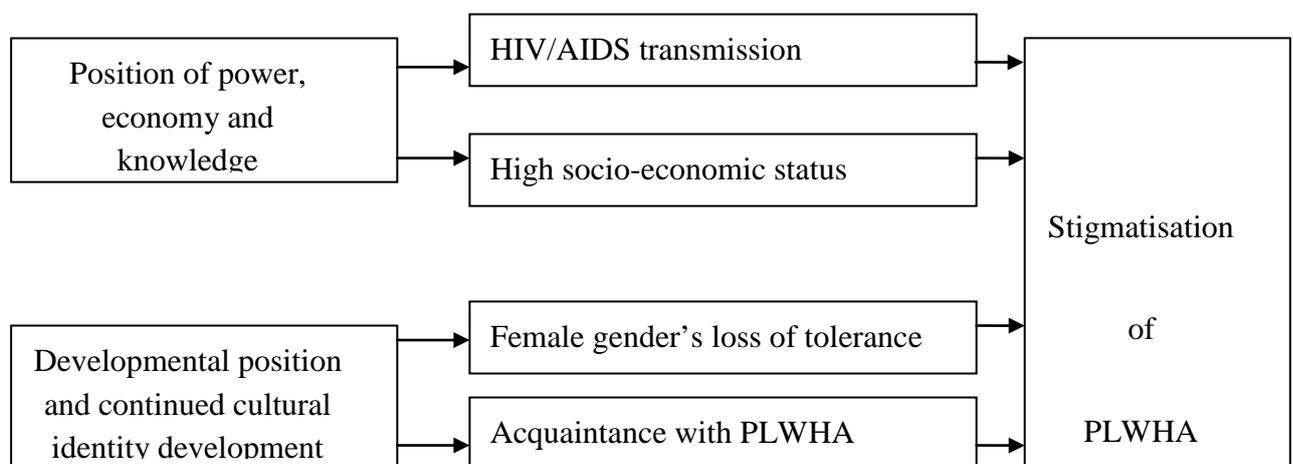
The other factor contributing to stigma is that in some communities people still associate HIV and AIDS with witchcraft. It is easier for communities to believe and accept that a person has been affected by witchcraft and “magoma”, than to accept and support people with HIV and AIDS. Thus, even if the person were suffering from HIV and AIDS, they would not disclose it but rather mention either “magoma” or “witchcraft” as the cause of

what the person is suffering from, in order to solicit support and sympathy from community members. Participants from the focus group also mentioned that lack of disclosure, particularly on the side of men, is due to fear of stigma, to protect the family from pain and stress.

### 6.3 UNIQUE FINDINGS FROM THE STUDY

The figure below (fig.1) presents the unique guidelines for determining stigmatisation derived from the results of the study.

*Fig. 1: Factors Influencing Stigmatisation of People Living with HIV and AIDS.*



HIV and AIDS transmission knowledge, gender, socio-economic status and acquaintance with PLWHA were found to be statistically significant to stigmatisation of people living with HIV/AIDS. These findings are unique in that position of power and transitional development from traditional to westernised position which indicate that stigma is embedded in issues of striving for who one is and the choice of group norms to guide our behaviour. Castro and Farmer (2005) view stigma to be embedded within the society which is shaped by social forces that define structural violence. These forces include racism, sexism, political violence, poverty, and other social inequalities that are rooted in

historical and economic processes that sculpt the distribution and outcome of HIV/AIDS. The highlighted factors of uniqueness from these findings are guided by the sample that consisted of Young Adults of the Capricorn District of the Limpopo Province, which picked on the developmental processes of the group with respect to continued cultural identity development and the influence of economic and knowledge power.

#### **6.4 RECOMMENDATIONS**

In the light of the findings of this study, the following recommendations are made as intervention strategies to reduce stigma:

- Efforts need to be made to review programmes that are undertaken to create awareness about HIV and AIDS to improve HIV transmission knowledge.
- Constant interaction with PLWHA should be encouraged, since this serves as a buffer to combat stigmatisation of PLWHA.
- There is a need for further research on gender, to explore in-depth reasons for stigmatisation of PLWHA, especially from females.
- Research also needs to be done in future to determine the factors that influence people with economic and knowledge power to stigmatise PLWHA.
- The community is to be made aware of the positive aspects of cultural factors that reduce stigma. At the same time caregivers need to be aware of negative aspects that can perpetuate the stigmatisation of PLWHA. The PEN-3 model, which was developed by Airhihenbuwa (1995), could be useful to deal with all issues at all levels in the community.
- Different religious groups react differently to stigma. There is a need to explore specific religions separately in order to be certain of factors contributing to HIV and AIDS in specific religious denominations.

- There is a need to conduct research strictly on young adults who do not have HIV and AIDS and those who have HIV and AIDS separately.
- There is a need to conduct further studies in the area of stigma among young adults, taking into account the limitations of the study.

## **6.5 CONCLUSION**

The results of this study suggest that lack of knowledge about HIV and AIDS transmission contributes to HIV and AIDS stigma. It also shows that females and people from a high socio-economic status were found to stigmatise people living with HIV and AIDS more often than males do. Acquaintance with someone living with HIV and AIDS was also found to be associated with reduced stigma towards PLWHA. On the other hand, factors such as knowledge of one's own status, religion, family communication, perceived risk and culture were found to be insignificant.

In addition, it was found that most people are still not comfortable to disclose their status. There are also members of communities who use derogatory names to address people who are suffering from HIV and AIDS. The above findings indicating gender differences in tolerance towards HIV and AIDS sufferers, possible elitist approach to the view of HIV and AIDS sufferers as well as the different views expressed depending on whether one is closely affected or not. These findings are unique in that the sample shows fluctuations in the expression of being completely African in their practice of 'ubuntu'. The less stigmatisation expressed by those affected is in line with the African culture of being collectivistic in nature with a tendency towards being shamed by not showing empathy to those close to you especially during suffering.

The same sample shows a sharp contradiction to the African culture on the deviation from the traditional expectations for female gender's general expression of tolerance and expected submissiveness. This shows that whilst on one hand there is some traditional way of responding to the environment on the other hand there is a tendency to move away

towards individualism typical of western cultural way of doing things. The sample showed tendencies to respond in a pattern that indicate cultural identity developmental process as well as economic and knowledge power as unique influential factors for stigmatisation towards HIV and AIDS sufferers.

## **6.6 LIMITATIONS OF THE STUDY**

It is important to understand the interpretation of the results of this study in the light of its limitations, which are as follows:

- This study relied upon the self-report method of data collection and focus groups, which are both subject to intentional distortion.
- The topic of HIV and AIDS is anxiety-provoking and arouses painful emotions, thus it might have been difficult for some participants to express themselves freely, making them give normative responses in an attempt to give a more favourable impression of their real self.
- Participants were mixed; those who were HIV and AIDS positive and those who were not HIV and AIDS positive were incorporated in the same focus groups. This could have led to participants not having the self-confidence to express themselves freely.
- The sample was homogeneous in terms of ethnicity. Because of this, the generalisability of the findings of this study to other ethnic groups is limited.

## 6.7 REFERENCE

- Adebajo, S. B., Bamgbala, O. A. & Oyediran, M. A. (2003). Attitudes of Health Care to Persons Living With HIV AND AIDS in Lagos State, Nigeria. *African Journal of Reproductive Health*, 7(1), 103–112.
- Adler, R. B., Rosenfelt, L. B & Towne, N. (1995). *Interplay: The process of interpersonal communication*. Harcourt Brace College Publishers: Florida.
- Aids Institute, (2006). HIV and AIDS among African Americans.  
<http://www.avert.org/hlv-african-american>. Retrieved on 2011/07/15.
- Airhihenbuwa, C. O. (1995). *Health and Culture: Beyond the western paradigm*. London: Sage Publications.
- Allport, G. W. (1954). *The Nature of Prejudice*, Addison-Wesley Publishing Company, Inc., Cambridge, MA.
- Almeleh, C. (2006). A qualitative study into the impact of HIV disease progression on initial HIV-serostatus disclosure to significant others, *AIDS and Society Research Unit, Centre for Social Science Research*, University of Cape Town, Cape Town, South Africa.
- Alonzo, A. A. & Reynolds, N. R. (1995) Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory, *Social Science & Medicine*, 41(3), 303–315.
- Angermeyer, M. C. & Matschinger, H. (2003). The stigma of mental illness: Effects of labeling on public attitudes towards people with mental disorder. *Acta Psychiatrica Scandinavica*, 108(4), 304- 309.

Apinundecha, C., Laohasiriwong, W., Camoron., M. P. & Lim, S. (2007). A Community Participation Intervetion to Reduce HIV/AIDS Stigma, Nakhon Ratchasima Province, Northeast Thailand, *AIDS Care*, 19(9), 1157-1165.

Asiimwe, D., Kibombo, R., and Neema, S., (2003). *Focus Group Discussion on Social Cultural Factors Impacting on HIV/AIDS in Uganda. Final Report.* Kampala: Uganda Ministry of Finance, Planning and Economic Development/UNDP.

Babbie, E., Mouton, J., Vorster, P. & Prozesky, B. (2001). *The Practice of Social Research*, Cape Town: Oxford University Press.

Baillargoen, J., Ducate, S., Pulvino, J., Bradshaw, P., Murray, O. & Olvera, R. (2003). The Association of Psychiatric Disorders and HIV Infection in the Correctional Setting. *Annals of Epidepmiology*, 13, 606 – 612.

Bairan, A., Taylor, G. A. J., Blake, B. J. Akers, T. Sowell, R. & Mendiola, R. (2007). A model of HIV disclosure: Disclosure and types of social relationships. *Journal of the American Academy of Nurse Practitioners* 19 (5), 242-250.

Bandura, A. (1965). Vicarious Process. A Case of no Trial Learning. In L. Berkowitz (Ed.). *Advances in Experiential Social Psychology*, 2, New York : Academic.

Baron, R. A. & Byrne, D. (2003). *Social Psychology*. Cape Town: Clyson Printers.

Bastein, S. (2008). Socio-demographic characteristics, AIDS Knowlwdge and Risk Perception Among Young people in Northern Tanzania, *International Journal of Educational Development*, 28, 393 – 404.

Bird, S. T., Bogart, L. M, & Delahanty, D. L. (2004). Health-Related Correlates of Perceived Discrimination in HIV Care. *AIDS Patient Care and STDs*, 18(1), 19-26.

Blumer, H., (1969). *Symbolic Interactionism: Perspectives and methods*, Prentice Hall, Englewood Cliffs, NJ.

- Bond, V., Chase, E. & Aggleton, P. (2002). HIV and AIDS and prevention of mother-child transmission in Zambia. *Evaluation and Programme Planning*, 25, 347-356.
- Bonjour, M. A., Montagne, M., & Zambrano, M. (2008). Determinants of late disease-stage presentation at diagnosis of HIV infection in Venezuela: A case-case comparison. *AIDS Research and Therapy*, 5 (6).
- Brown, L., Trujillo, L., & Macintyre, K. (2001) *Interventions to reduce HIV and AIDS stigma: What have we learned?* New Orleans: Horizons Program/Tulane School of Public Health and Tropical Medicine.
- Burkholder, G. J., Harlow, L. L., & Warskwich, J-L. (1999). Social Stigma, HIV-Knowledge and Sexual Risk, *Journal of Applied Biobehavioural Research*, 4(1), 27-44.
- Campbell, C., Foulis, C. A., Maimane, S. & Sibiyi, Z. (2005). 'I have an evil child at my house': Stigma and HIV and AIDS management in a South African community, *American Journal of Public Health*, 1-31.
- Cao, X., Sullivan, S. G., Xu, J., Wu, Z. & the China CIPRA project 2 Team. (2006). *Understanding HIV Related Stigma and Discrimination in a "Blameless" Population*, 18 (6), 518 -528.
- Castro, A., & Farmer, P. (2005). Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti, *American Journal of Public Health*. 95, 53-59.
- Chapman L (1998) Body image and HIV: Implications for support and care, *AIDS Care* 10(2): 179-187.
- Chen, J., Choe, M. K., Chen, S. & Zhang, S. (2005). Community Environment and HIV/AIDS Stigma in China, *AIDS Education and Prevention*, 17(1), 1-11.
- Chesney, M. A., & Smith, A. W. (1999). Critical delays in HIV testing and care: The potential role of stigma. *American Behavioral Scientist*, 42, 1162-1174.
- Chiao, C., Mishra, V. & Sambisa, W. (2008). Individual and community-level

determinants of social acceptance of people living with HIV in Kenya: Results from a national population-based survey, *Health & Place*.

Cichocki, M. (2010). What is HIV and How Does it Relate to AIDS? Understanding HIV and How it is Responsible for AIDS.

<http://www.aids.about.com/od/aids/aidsfactsheet>. Retrieved on 2011/07/18.

Cooley, C. H., 1902. *Human nature and the social order*, Scribners, NY. Corrigan, P.W., 1998. The impact of stigma on severe mental illness.

Cotton, S., Tsevat, S., Szaflarski, M., Kudel, I., Sherman, S. N., Feinberg, J., Leonard, A., C. & Holmes, W. C. (2006). Changes in Religiousness and Spirituality Attributed to HIV/AIDS: Are There Sex and Race Differences? HIV/AIDS and Religious/Spiritual Change. *Journal of General Internal Medicine*, 21, 531-520.

Courtenay-Quirk, C., Wolitski, C. R., Parsons, J. T., Gómez, C. A. & the Seropositive Urban Men's Study Team. (2006). Is HIV and AIDS Stigma Dividing The Gay Community? Perceptions of HIV-Positive Men who have sex with men. *AIDS Education and Prevention*, 18(1), 56-67.

Crandall, C. S., & Glor, J. (1997). AIDS-related stigmatisation: Instrumental and symbolic attitudes, *Journal of Applied Social Psychology*, 27(2), 95-123.

Crawford, R. (1994). The boundaries of the self and the unhealthy other: Reflections on health, culture and AIDS, *Social Science & Medicine* 38(10): 1347-1365.

Deacon, H., Stepney, I. & Prosalendis, S. (2005). *Understanding HIV and AIDS stigma:*

*A theoretical and methodological analysis*. Research programmes of Social Cohesion, Identity and the social aspect of HIV and AIDS and Health. [www.hsrc.hscrepress.ac.za](http://www.hsrc.hscrepress.ac.za) press, Retrieved on 18/03/2006.

- Deetlefs, E. M., Greeff, M. & Koen, M. P. (2003). The attitudes of nurses towards HIV positive patients, *African Journal online*, 8 (2) retrieved from, <http://ajol.info/index.php/hsa/article/view/10173>.
- de Palamo, F. B. (2006). *Confronting HIV and AIDS Community: Mobilization, Health, International Health*, <http://www.aed.org/Topics/HIVAIDS/International/CommunityMobilization.cfm>.
- Denzin, N. K. & Lincon, Y. S. (1998). *Collecting and interpreting qualitative material*. London: Sage.
- Duffy, L. (2005). Suffering, Shame and Silence: The stigma and HIV and AIDS. *Journal of the Association of Nursing in Aids Care*, 16 (1), 13-20.
- Duncan, C., Harrison, M. G., Malaka, D., Sithole, S. & Toldson, I. A. (2005). Social Stigma, HIV AND AIDS Knowledge, and Sexual Risk: A Cross-Cultural Analysis. *Journal of Applied Biobehavioural Research*, 10(1), 1–26.
- Ehrhardt, A. A., & Exner, T. M. (2000). Prevention of sexual risk behavior for HIV infection with women. *AIDS*, 14, 53-58
- Elmore, K. (2006) Southern Discomfort: AIDS Stigmatisation in Wilmington, North Carolina, *Academic Research Library*, (46), 2, 215 – 230.
- Flowers, P. (2006). Living with HIV: an overview of contemporary psychosocial issues among gay men. *AIDS and Hepatitis Digest*, 114, 1-6.
- Flowers, P., Davis, M., Hart, G., Rosengarten, M., Frankis, J. & Imrie, J. (2006). Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK. *Psychology and Health*, 21 (1), 109-122.
- Godfrey-Faussett, P., & Ayles, H. (2003). Can we control tuberculosis in high HIV prevalence settings?, *Tuberculosis* 83: 68–76.
- Gielen, A. C., McDonnell, K. A., O'Campo & Burke, J. G. (2005). Suicide risk and mental health indicators: Do they differ by abuse and HIV status?, *Women's Health Issues*, 15, 89-95.
- Gilmore, N. & Somerville, M.A. (1994). Stigmatization, scapegoating and discrimination in

- sexually transmitted diseases, overcoming 'them' and 'us', *Social Science Medicine*, 39:1339-1358.
- Goffman, E. (1963). *Stigma: Notes on the Management of a Spoiled Identity*. Englewood Cliffs: Prentice-Hall, Inc.
- Goode, R. (1984). *Jane Austen's Pride and prejudice*: New York: Barron's (Woodbury).
- Goodman, E. & Cohall, A. T. (1989). Acquired Immune Deficiency Syndrome and adolescence: Knowledge, attitudes, beliefs and behaviours in a New York City adolescent minority population. *Paediatrics*, 84, 36-42.
- Green E. C., & Ruark, A. H. (2008). *AIDS and the Churches: Getting the Story Right*. First Things.
- Gregson, S., Zhuwau, T., Anderson, R. M. & Chandiwana, S. K. (1998). Is there evidence for behaviour change in response to AIDS in rural Zimbabwe? *Social Science and Medicine*, (46), 321-330.
- Grossman, A. H. (1991). Gay men and HIV and AIDS: Understanding the double stigma, *Journal of the Association of Nurses in AIDS Care*, 2(4), 28–32.
- Hamra M., Ross, M. W., Karuri, K., Orrs, M., & D'Agostino, A. (2005). The relationship between expressed HIV/AIDS-related stigma and beliefs and knowledge about care and support of people living with AIDS in families caring for HIV infected children in Kenya. *AIDS Care*, 17(7), 911–922.
- Hartwig, K. A. (2003). *A Case Study from Tanzania on Church Leaders Confront HIV and AIDS Stigma: Global Health Division, Department of Epidemiology & Public Health*, <http://cira.med.yale.edu/events>, Retrieved on 09/05/2006.
- Hartwig, K. A., Kisioki, S. & Hartwig, C. D. (2006). Church leaders confront HIV/AIDS and stigma: a case study from Tanzania, *Journal of Community and Applied Social Psychology*, 16(6), 492-497.
- Heider, F. (1958). *The Psychology of Interpersonal Relations*. New York: Wiley.
- Helman, C. G. (2001). *Culture, Health and Illness*. New York: Oxford University Press.
- Herek, G. M. (1990). Homophobia. In W.R. Dynes (Ed.), *Encyclopedia of Homosexuality*. New York: Garland.

- Herek, G. M. (1997). The HIV epidemic and public attitudes toward lesbians and gay men. In M. P. Levine, P. Nardi, & J. Gagnon (Eds.) *In changing times: Gay men and lesbians encounter HIV/AIDS* (pp. 191-218). Chicago: University of Chicago Press.
- Herek, G. M. & Capitanio, J. P. (1998). Symbolic prejudice or fear of infection? A functional analysis of AIDS-related stigma among heterosexual adults, *Basic and Applied Social Psychology* 20(3): 230–241.
- Hergovich, A., Ratky, E., & Stollreiter, M. (2003). Attitudes toward HIV-positives in dependence on their sexual orientation, *Swiss Journal of Psychology*, 62(1), 37- 44.
- Heywood, M. (2002). ‘Chaffed and waxed sufficient’: Drug access, patents and global health, *Third World Quarterly, Journal of Emerging Areas*, 1-19.
- Hilhorst, T., van Liere, M. J., Ode, A. V. & de Koning, K. (2006). The impact of AIDS on rural livelihoods in Benue State, Nigeria. *The Social Aspects of HIV and AIDS*, 3 (1), 382 – 393.
- Hutchinson P. L., & Mahlalela, X. (2006). Utilization of voluntary counseling and testing services in the Eastern Cape, South Africa. *AIDS Care*, 18 (5), 446 – 455.
- Joffe, H. (1999). *Risk and ‘the other’*. Cambridge: Cambridge University Press.
- Jones, E. E., & Nisbett, R. E. (1972). The actor and the observer: Divergent perceptions of the causes of behavior. In E. E. Jones, D. E. Kanouse, H. H. Kelley, R. E. Nisbett, S. Valins, & B. Weiner (Eds.), *Attribution: Perceiving the causes of behavior* (pp. 79 - 94). Morristown, NJ: General Learning Press.
- Jones, E. E., Amerigo F, Albert H. H, Hazel M, Dale T., Robert A. S & Rita de S. F. (1984). *Social Stigma: The Psychology of Marked Relationships*. New York: W. H. Freeman and Company.
- Jones, E.E. & Davis, K.E. (1965). *From acts to dispositions: The attribution process in person perception*. In: L. Berkowitz (ed.), *Advances in experimental social psychology*, Vol. 2, 219-266. New York: Academic Press.
- Jones, E. E., Farina, A., Hastorf, A. H., Markus, H., Miller, D. T. & Scott R. A. (1984). *Social stigma: The psychology of marked relationships*. New York: WH Freeman.
- Kaiser Health Poll Report. (2000). *Relationship between stigma and HIV testing*: Geneva,

Switzerland.

- Kalichman, S. C. & Simbayi, L. C. (2003). HIV testing attitudes, AIDS stigma, and voluntary HIV counseling and testing in a black township in Cape Town, South Africa, *Sexually Transmitted Infections*, 79(6), 442–447.
- Kalichman, S. C. & Simbayi, L. (2004). Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa, *AIDS Care*, 16(5): 572–580.
- Kalichman, S. C., Simbayi, L. C., Cain, D., Jooste, S., Skinner., D., & Cherry, C. (2006). Generalising a Model of Health Behaviour Change and AIDS Stigma for the Use with Sexually Transmitted Infection Clinic Patients in Cape Town, South Africa, *AIDS Care*, 18(3), 178 – 182.
- Kalichman, S. C., Simbayi, L. C., Cain, D. & Jooste, S. (2008). Perceived HIV/AIDS Prevalence, Burden and Risk, Cape Town, South Africa. *American Journal of Health Behaviour*, 32(6), 689-700.
- Kalichman, S. C., Simbayi, L. C., Cloete, A., Cherry., C., Strebel., A Kalichman, M., Shefer, T., Crawford, M., Tshabalala, M., Henda, N. & Cain, D. (2008). HIV/AIDS Risk reduction and Domestic Violence Prevention Intervention for South African Men. *International Journal of Men's Health*.7, (3), 255-273.
- Kamugisha, C. A. (2002). *Culture-Based HIV AND AIDS Treatment and Management in Tanzania*. Language, Literature and the Discourse of HIV and AIDS in Africa University of Botswana English Department.  
[bwenglish.tripod.com/conf/abstract.htm](http://bwenglish.tripod.com/conf/abstract.htm). Retrieved on 07/02/2006.
- Kaplan, M. & Van Der Worm, Y. (1993). The relationship between South Africans' adolescents' knowledge and fear of AIDS and their attitudes toward people who have AIDS. *Journal of Social Psychology*, 133, 581-583.
- Katz, A. (2002). AIDS, individual behaviour and the unexplained remaining variation, *African Journal of AIDS Research*, 1(2): 125–142.
- Kaufman, M. R., Shefer, T., Crawford, M., Simbayi, L. C. & Kalichman, S. C. (2008). Gender, Attitudes, Sexual Power, HIV Risk: A Model for Understanding HIV Risk Behaviour of South African Men, *AIDS Care*, 20 (4), 404-441.

- Kelly, H. H. (1972). *Attribution in Social Interaction*. In E. E. Jones, A. Farina, A., H. Hastorf, H. Markus, D. T., Miller, & R. A. Scott (Eds.), *Attribution: Perceiving the causes of behaviour*. Morristown, NJ: General Learning Press.
- Klingemann, H. K., (1999) Addiction careers and careers in addiction, *Substance Use and Misuse*, 34(11), 1505–1526.
- Kohi, T.W., Makoae, L., Chirwa, M., Holtzemer, W. L., Phetlhu, D. R., Uys, L., Naidoo, J., Dlamini, P. S. & Greeff, M. (2006). HIV and AIDS Stigma Violates Human Rights in Five African Countries. *Nursing Ethics*, 13 (4), 404-415.
- Lam P. K, Naar-King, S. & Wright, K. (2007). Social Support and Disclosure as predictors of mental health in HIV-positive youth. *AIDS Patient Care and STDs*, 21(1), 20-29.
- Lau, J. T., Choi, K. C., Tsui, H. Y. & Su, X. (2007). Association Between Stigmatisation Towards HIV-related Vulnerable Groups and Similar Attitudes towards People Living with HIV/AIDS: Branches of the Same Tree? *AIDS Care*, 19 (10), 1230-1240.
- Lauer, R. (1996). *Social Problems and the Quality of Life*. California: Mc-Graw Hill.
- Leclerc-Madlala, S. (2002). On the virgin cleansing myth: Gendered bodies, AIDS and Ethnomedicine. *African Journal of AIDS Research*, 1(2), 87-95.
- Lehmann, U. & Zulu, J. (2005). How Nurses in Cape Town experience HIV epidemic. *AIDS Bulletin*, 14 (1), 1-8.
- Lemert, E. M. (1972). *Human Deviance, Social Problems and Social Control*. Englewood Cliffs: Prentice-Hall, Inc.
- Letamo, G. (2001). HIV/AIDS-Related Stigma and Discrimination among Adolescents in Botswana, *African Population Studies*, 19(2), 192-204.
- Letamo, G. (2003). Prevalence of, and Factors Associated with, HIV and AIDS-related Stigma and Discriminatory Attitudes in Botswana, *Journal of Health Population and Nutrition*, 21(4), 347-357.

- Link, B. G., & Phelan, J. C. (2001). On stigma and its public health implications, *Annual Review of Sociology*, 27, 363–85.
- Lorentzen, K. & Morris, S. (2003). *The enigma of HIV and AIDS-related stigma: A theoretical exploration of HIV and AIDS-related stigma in sub-Saharan Africa*, Unpublished Psychology thesis, Universitas Bergensis. Netherlands.
- Louw, P. E. (2005). *The Media and the Political Process*. London: Sage
- Lwihula, G., Dahlgren, I., Killewo, J., & Sandstrom, A. (1993). AIDS Epidemic in Kagera Region, Tanzania: The Experience of Local People, *AIDS Care*, 5, 347-357.
- Ma, W., Detels, R., Feng, Y., Shen, L., Li, Y., Li, Z., Chen, F., Wang, A. & Liu, T. (2007). Acceptance of Barriers to Voluntary HIV Counselling and Testing Among Adults in Guizhou Province, China, *AIDS*, 21(8), 129-135.
- Mast, T. C., Kigozi, G., Wabwire-Mangen, F., Black, R., Sewankambo, N., Serwadda, D., Gray, R., Wawer, M. & Wu, A. W. (2004). Measuring quality of life among HIV-infected women using a culturally adapted questionnaire in Rakai district, Uganda, *AIDS Care*, 16(1), 81–94.
- Mattews, C., Guttmacher, S. J., Flisher, A. J., Mtshizana, Y. Y., Nelson, T., McCarthy, J. & Daries, V. (2009). The Quality of HIV Testing Services in Cape Town, South Africa: Do Adolescent-Friendly Services make a Difference?, *Journal of Adolescent Health*, 44, 188-190.
- Maughan Brown, B. (2004). *Measuring HIV and AIDS Stigma*. Working Paper No. 74, Centre for Social Science Research, University of Cape Town.
- Mcleod, S. (2010). *Attribution Theory*. <http://www.simplypsychology.org/attribution-theory.html>. Retrived on 2011/07/18.
- Mead, M. (1934). *Sex and Temperament in Three Primitive Societies*. New York: Dell.
- Media Release (2006). *WHO launches new plan to confront HIV-related health worker shortages*. World Health Organisation. <http://www.who.int/entity/hiv/toronto2006/en/index.html>. Retrived on 2011/07/18.

Michaud, P. A., Suris, J. C., Thomas, L. R., Kahlert, C., Rudin, C & Cheseaux, J. J. (2009).

To Say or Not to Say: A Qualitative Study on the Disclosure of Their Condition by Human Immunodeficiency Virus–Positive Adolescents. *Journal of Adolescent Health*, 1 – 7.

Miles, R. (1989). *Racism*. London: Routledge.

Mnyanda, Y. N. (2006). *Managing HIV and AIDS in the Workplace Case Study of the Eastern Cape Department of Social Development*. Published masters Thesis: Department of Philosophy at Stellenbosch University.

Muyinda, H., Seeley, J., Pickering, H., & Barton, T. (1997) Social Aspects of AIDS-Related Stigma in Rural Uganda. *Health Place* 3(3), 143–147.

Norman, I. R. & Gebre, Y. (2005). Prevalence and Correlates of HIV Testing: An Analysis of University Students in Jamaica, *Journal of the International Society*, 7(1), 70.

Norman, L. R, Carr, R. & Uche. C. (2006) The role of sympathy on avoidance intentions toward persons living with HIV/AIDS in Jamaica. *AIDS Care*, 18(8), 1032-1039.

Nyblade, L. & Field, M. L. (2000). *Women, Communities, and the Prevention of Mother-to-Child Transmission of HIV: Issues and Findings from Community Research in Botswana and Zambia*. International Center for Research on Women (ICRW): Washington, DC:

Nyblade, L., Panda, P., Mathur, S., MacQuarrie, K., Kidd, R., Banteyerga, H., Kidanu, A., Kilonzo, G., Mbwambo, J. & Bond, V. (2003). *Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia*. International Center for Research on Women (ICRW): Washington DC.

Nwezer, C. M. T. (2008). A Survey of Information Sources Used by Secondary School Students in life Central and life East Local Government Areas of Osun State, Nigeria for Knowledge and Attitudes towards HIV/AIDS. *Journal of Librarianship*, 8 (4), 383-397.

O’Neil, D. (2005). Process of Change. Retrived from

<http://anthro.palomar.edu.change/credits.htm>.

- Palekar, R., Pettifor, A., Behets, F., & MacPhail, C. (2008). Association Between Knowing Someone who Died of AIDS and Behaviour Change Among South African Youth. *AIDS and Behaviour*, 12(6), 903-912.
- Paradath, A, Searle, C, Ntuli, A, Pennings, G, Sibiyi, Z. & Ntsike, M (2006). Community Participation in HIV and ARV Services. *Social Aspects of HIV and AIDS*, 95-104.
- Parker, R. & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action, *Social Science & Medicine*, 57: 13–24.
- Parker, W. & Birdsall, K. (2005). *HIV and AIDS, Stigma and Faith-Based Organisation, A review: A costella Company enhancing human health*. Washington DC: A Costella Company.
- Paruk, Z., Petersen, I., Bhana, A., Bell, C. & McKay, M. (2005). Containment and contagion: How to strengthen families to support youth HIV prevention in South Africa. *African Journal of AIDS Research*, 4(1): 57-63.
- Peterson, I. & Bhana, A. (2005). Championing families to fight AIDS. *HSRC Review*. 3, (3), [http://:www.hsrc.ac.za](http://www.hsrc.ac.za), Retrieved on 09/05/2006.
- Patient, D. R., & Orr, N. M. (2003). *Stigma: Beliefs determine behaviour, Unpublished paper. Nelspruit, South Africa: Empowerment Research*.
- Pettigrew, T, F. (1998). Intergroup Contact Theory. *Annual Review Psychology*, 49, 65-85.
- Phaswana-Mafuya, N. & Peltzer, C. (2006). HIV and AIDS Knowledge, Risk Perception, Stigma and Support among Staff in Tertiary Institutions in the Eastern Cape, *South African Journal for Physical, Health Education, Recreation and Dance (AJPHERD)*, 12( 4), 403-425.

- Policy Project, Centre for the Study of AIDS, USAID & Department of Health. (2003).  
*Siyam'kela: Measuring HIV and AIDS related stigma: A report on the fieldwork.*
- Posel, D. (2004). Sex, death and embodiment: Reflections on the stigma of AIDS in Agincourt, South Africa, Paper presented at the WISER 'Life and Death in a Time of AIDS' Symposium, Johannesburg, 14–16 October.
- Pramanik, S., Chartier, M. & Koopman, C. (2006). *HIV and AIDS stigma* and knowledge among predominantly middle-class high school students in New Delhi, India. *The Journal of Communicable Diseases*, 38 (1), 57-69.
- Pulerwitz, J., Michaelis, A., P., Lippman, S., A., Chinaglia, M. & Di'az, J. (2008). HIV-Related Stigma, Service Utilisation and Status Disclosure among Truck Drivers Crossing the Southern Borders in Brazil, *AIDS Care*, 20(2), 198-204.
- Raizada, N., Somasundaram, C., Mehta, J. P. & Pandya, V. P. (2004). Effectiveness Of Various IEC In Improving Awareness And Reducing Stigma Related To HIV and AIDS Among School Going Teenagers. *Indian Journal of Community Medicine*, 29 (1), <http://www.Indmedia.com>. Retrived on 09/05/2006.
- Ramakrishna, J., Maslekar, M., Chandra, P. S., Darak, R., Pant, V., Kulkarni, V. & Kulkarni, S. (2004). Perceptions and experience of stigma among people living with HIV and AIDS: Qualitative data from two Indian clinic populations, *International Conference on AIDS*, 15, 11-16.
- Ramarumo, M. (2005). *Attitudes of mothers towards their expected role of imparting sexual knowledge to their adolescent daughters in Limpopo Province*. Unpublished Psychology thesis. University of Limpopo. South Africa.
- Rakotonanahary, A., Rafransoa, Z. & Bensaid, K. (2002). Qualitative evaluation of HIV and AIDS IEC activities in Madagascar, *Evaluation and Program Planning* 25, 341-345.
- Rehle, T. M. & Shisana, O. (2003). Epidemiological and demographic HIV and AIDS projections: South Africa, *African Journal of AIDS Research*, 2(1), 1-8.

- Reiger, H. S. & Blignaut C. J. H. (1996). Individualiteit, kollektiwiteit en focus van beheer  
As mikroveranderlikes van diversitiet. *Journal of Psychology*.
- Rose-Innes, O., (2006). Socio-cultural aspects of HIV/AIDS. *Health 24*.  
[http://www.health24.com/news/HIV\\_AIDS/1-920,23100.asp](http://www.health24.com/news/HIV_AIDS/1-920,23100.asp).
- Ross, L. D. (1977). The intuitive psychologist and his shortcomings: Distortions in the  
attribution process. In L. Berkowitz (Ed.), *Advances in experimental social  
psychology* (Vol.10, pp. 173 – 220). New York: Academic Press.
- Sayce, L. (2003). Beyond good intentions: Making anti-discrimination strategies work,  
*Disability & Society*, 18, 625-642.
- Sikand, A., Fisher, M., Friedman, S., B. (1996). AIDS knowledge, concerns, and  
behavioural changes among inner-city high school students. *Journal of Adolescent  
Health*, 18(5), 325-328.
- Simbayi, L.C., Kalichman, S.C., Strebel, A., Cloete, A., Henda, N. & Mqeketo, A.  
(2007). HIV Status Disclosure to Sex Partners and Sexual Risk Behaviors among HIV  
Positive Men and Women in Cape Town, South Africa. *Sexually Transmitted  
Infections*, 83, 29-34.
- Skinner, D. & Mfecane, S. (2004). Stigma, discrimination and the implications for people  
living with HIV and AIDS in SA. *Journal of Social aspects of HIV and AIDS*. 1(3),  
157-164.
- Smith, P. J. & Cronje, G. J. (2001). *Management Principles: A Contemporary Edition for  
Africa*: Landsdowne: Juta
- Sonne, A. (2011). *The Fundamental Attribution Error and Correspondence Bias*.  
<http://www.examiner.co./mental-health>. Retrieved on 2011/07/19
- Stein, J. (2003). *HIV/AIDS stigma: The latest dirty secret*, Centre for Social Science Research  
Working Paper no. 46, University of Cape Town.
- Stockemer, D. & Lamontagne, B. (2008). HIV/AIDS in Africa: explaining the differences  
in HIV prevalence rates, *Contemporary Politics*, 13,(4).

- Surlis, S., & Hyde, A. (2001). HIV-positive patients' experiences of stigma during hospitalization. *Journal of the Association of Nurses in AIDS Care*, 12(6), 68-77.
- Surlis, S. & Hyde, A. (2001). HIV-positive patients' experiences of stigma during hospitalization. *Journal for the Association of AIDS Care*, 12(6), 68-77.
- Tiendrebeogo, G., Buykx, M. & van Beelen, N. (2004). Faith-based responses and opportunities for a multisectoral approach. *Sexual Health Exchange*, 1(1), 1-3.
- Tung, W, C., Ding, K. & Farmer, S. (2008). Knowledge, Attitudes, and Behaviours Related to HIV and AIDS Among College Students In Taiwan, *Journal of the Association of AIDS Care*, 19(5), 397-408.
- Ulasi, C., I., Preko, P. O., Baidoo, J. A., bayard, A., B., Ehiri, J. E., Jolly, C., M. & Jolly, P. E. (2009). HIV/AIDS-Related Stigma in Kumasi, *Health and Place*, 15, 255-262.
- Uys, T., Martin, L., Ichharam, M., Alexander, P., Els, R. & Eiselen R. (2002). *HIV and AIDS and Students at RAU Final Report*. Centre for Sociological Research, Rand Afrikaans University, Johannesburg.
- Uys, L. R. (2003). Aspects of the care of people with HIV and AIDS in South Africa. *Public Health Nursing*, 20(4), 271–280.
- Uys, L. R. (2005). *HIV/AIDS Stigma in Africa*, Sigma Theta Tau International Honour Society of Nursing, Hawaii, 14-16.
- Valdiserri, R. O. (2002). HIV and AIDS stigma: An impediment to Public Health. *American Journal of Public Health*, 92 (3), 341-342.
- Van Dyk, G. A. J. (2005). Individualistic-Collectivism (IC) in culturally diversity: A

- discussion in *Psychotherapy for Africa*. N. S. Madu & S. Govender (Eds.), *Mental Health and Psychotherapy in Africa*, (pp. 112-126). Polokwane: University of the Limpopo Press.
- Van Houten, R. L. (2005). HIV and AIDS: An Update, 5 (1), [http://www. Gospelcom.net](http://www.Gospelcom.net), Retrieved on 09/05/2006.
- Vermeer, W., Bos, A., E., R., Mbwamboc, J., Kaaya., S., & Schaalma, H. P. (2009). Social Cognitive Variables Predicting Voluntary Counselling and Testing Among Tanzanian Medical Students, Patient *Education and Counselling*, in Press.
- Visser, M. J., Makin, J. D. & Lehobye, K. P. (2006). Stigmatizing attitudes of the community towards people living with HIV/AIDS, *Journal of Community & Applied Social Psychology*, 16 (1), 42-58.
- Waarngard, A. (2006). Towards a Theology of HIV/AIDS. *Verbum Et Ecclesia*, IRG 27 (1), 265-290.
- Weinreich, N. K. (2003). *Integrating Quantitative and Qualitative Methods in Social Marketing Research*, <http://www.social-marketing.com/research.html>. Retrieved on 22/03/2006.
- Weiser, S. D., Leiter, K., Heisler, M., McFarland, W., Percy-de Korte, F., DeMonner, S. M., Tlou, S., Phaladze, N., Iacopino, V. & Bangsberg, D. R. (2006). A Population-Based Study on Alcohol and High-Risk Sexual Behaviors in Botswana. *Public Library of Science*, 3(10), 392.
- Wight, R. G. (2000). Precursive depression among HIV infected AIDS caregivers over time. *Social Science and Medicine*, 51, 759-770.

## 7. APPENDICES

### Appendix A: *Biographical Data*

Complete each question by writing an answer in the relevant space.

1.1 Marital status : Married ( ), Single ( ), Divorced ( ), Widowed ( )

1.2 Cultural Background :

N. Sotho	Tsonga	Venda	Other: specify
----------	--------	-------	----------------

1.3 Age : .....

1.4 Gender : Male ( ), Female ( )

1.5 Total monthly income of (father and mother) or your household is:

- a. Less than R3 000: -----
- b. R3 000.00 – R5 999.00: -----
- c. R9 000.00 - R 11 000.00:-----
- d. R12 000.00 and above: -----

1.6 My educational qualification falls within:

Primary School	High school	Tertiary	No education
----------------	-------------	----------	--------------

1.7 I reside in the:

Urban area	Rural area	Semi-rural area
------------	------------	-----------------

1.8 I am HIV

Positive	Negative	Uncertain
----------	----------	-----------

1.9 How committed are you to your religion?

Not	Less	Fairly	Committed	Very
-----	------	--------	-----------	------

committed	committed	committed		committed
-----------	-----------	-----------	--	-----------

1.10 How attached are you to your cultural values?

Not attached	Less attached	Fairly attached	Attached	Not attached
--------------	---------------	-----------------	----------	--------------

1.11 I use condoms during sexual intercourse. Yes: ----- No: -----

1.12 I have a friend who has HIV and AIDS. Yes: ----- No: -----

1.13 I have a family member who has HIV and AIDS. Yes: ----- No: -----

1.14 I consider myself to be at risk of contracting HIV and AIDS. Yes: ----- No: -----

**APPENDIX B: Focus group questions**

1. What are your views on HIV and AIDS?
2. What has influenced you to hold these views?
3. How would you say PLWHA are treated in the family?
4. Is your family supportive of PLWHA?
5. Are women living with HIV and AIDS treated differently?
6. Are men living with HIV and AIDS treated differently?
7. What about your views about health care in this matter?
8. Would knowing how people contracted the virus influence how they are treated?
9. What are major changes that have occurred in your life due to death or knowing someone living with HIV and AIDS?
10. When does the person become stigmatised?

### APPENDIX C: Stigma Questionnaire

*Please answer whether you agree or disagree with the following statements.*

	I AGREE	I DISAGREE
1. People who have AIDS are dirty.		
2. People who have AIDS are cursed.		
3. People who have AIDS should be ashamed.		
4. It is safe for people who have AIDS to work with children. (R)		
5. People who have AIDS must expect some restrictions on their freedom.		
6. A person with AIDS must have done something wrong and deserves to be punished.		
7. People who have HIV should be isolated.		
8. I do not want to be friends with someone who has AIDS.		
9. People who have AIDS should not be allowed to work.		

## APPENDIX D: HIV Knowledge Questionnaire

For each statement please tick Yes = 1, or No = 2, or 3 = I don't know. If you don't know please do not guess, instead please tick I don't know = 3

1 = Yes,                      2 = No,                      3 = I don't know

	1	2	3
1. Coughing does not spread HIV. (R)			
2. Sneezing does not spread HIV. (R)			
3. A person can get HIV by sharing a glass with someone who has HIV.			
4. Withdrawing the penis before the man climaxes/comes keeps a woman from getting HIV during sex.			
5. A woman cannot get HIV if she has anal sex with a man.			
6. Showering, or washing one's genitals/private parts after sex keeps a person from getting HIV.			
7. All pregnant women infected with HIV will have their babies infected with AIDS.			
8. People who have been infected with HIV quickly show signs of being infected.			
9. There is a vaccine that can stop people from getting HIV.			
10. People are likely to get HIV by deep kissing, putting their tongues in their partner's mouth if their partner has HIV.			
11. A woman cannot get HIV if she has sex during her period.			
12. There is a female condom that can help decrease a woman's chance of getting HIV.			
13. A natural skin condom works better against HIV than a latex condom.			
14. A person will not get HIV if he or she uses antibiotics.			
15. Having sex with more than one partner can increase the chance of being infected with HIV. (R)			

16. Taking a test for HIV one week after sex will tell a person if she or he has HIV.			
17. A person can get HIV by swimming in the same pool with a person who has HIV.			
18. A person can get HIV by sitting in a hot tub with a person who has HIV.			
19. A person can get HIV from oral sex. (R)			
20. Using vaseline or baby oil with condoms lowers the chance of getting HIV.			

**APPENDIX E: Knowing Someone with HIV and AIDS**

1= definitely not true,                      2= not really true,                      3= somewhat true,  
4= mostly true,                                      5= definitely true.

	1	2	3	4	5
1. I know a close friend who has HIV and AIDS.					
2. Someone in my family has HIV and AIDS.					
3. I know someone with HIV and AIDS who is not a close friend or a member of my family.					
4. I know a gay person who has HIV and AIDS.					
5. I know a person who is not gay who has HIV and AIDS.					
6. I know a woman who has HIV and AIDS.					
7. I know a person who injects drugs with a needle who has HIV and AIDS.					

## APPENDIX F: Family Communication

1 = definitely not true,

2 = not really true,

3 = somewhat true,

4 = mostly true,

5 = definitely true.

	1	2	3	4	5
1. It would be easy for me to talk to my mother or father (or guardian) about sex.					
2. It would be easy for me to talk to my brother or sister (if you do not have brothers or sisters, consider cousins, or other relatives).					
3. Most of what I know about HIV and AIDS I learned from my mother or father (or guardian).					
4. Most of what I know about HIV and AIDS I learned from my brother(s) and/or sister(s).					

**APPENDIX G: Perceived Risk of HIV and AIDS**

1 = not at all sure,

2 = a little sure,

3 = kind of sure,

4 = fairly sure,

5 = very sure

	1	2	3	4	5
1. I feel that I am at risk of getting AIDS at this time in my life.					
2. I sometimes think that I may have been exposed to AIDS.					
3. I have had sex with someone who could have given me AIDS.					
4. One of my close friends does things that could lead to him/her getting AIDS.					
5. How sure are you that you have not been exposed to AIDS? ( R)					
6. How sure are you that you that your sex partner (s) have not been exposed to AIDS? ( R)					
7. If you were to make a guess, how sure are you that you are at risk of getting HIV and AIDS at this time in your life?					

**SECTION A**

**Complete each question by writing an answer in the relevant space.**

1.1 Marital status: Married ( ), Single ( ), Divorced ( ), Widowed ( )

1.2 Cultural Background :

N. Sotho	Tsonga	Venda	Other: specify
-------------	--------	-------	----------------

1.3 Age : .....

1.4 Gender : Male ( ), Female ( )

1.5 Total monthly income of (father and mother) or your household is:

e. Less than R3 000: ----

f. R3 000.00 – R5 999.00: ----

g. R9 000.00 - R11 000.00: ----

h. R12 000.00 and above: ----

1.6 My educational qualification falls within:

Primary School	High school	Tertiary	No education
----------------	-------------	----------	--------------

1.7 I reside in the:

Urban area	Rural area	Semi-rural area
------------	------------	-----------------

1.8 I am HIV

Positive	Negative	Uncertain
----------	----------	-----------

1.9 How committed are you to your religion?

Not committed	Less committed	Fairly committed	Committed	Very committed
---------------	----------------	------------------	-----------	----------------

1.10 How attached are you to your cultural values?

Not attached	Less attached	Fairly attached	Attached	Not attached
--------------	---------------	-----------------	----------	--------------

- 1.11 I use condoms during sexual intercourse. Yes: ----- No: -----
- 1.12 I have a friend who has HIV and AIDS. Yes: ----- No: -----
- 1.13 I have a family member who has HIV and AIDS. Yes: ----- No: -----
- 1.14 I consider myself to be at risk of contracting HIV and AIDS. Yes: ----- No: -----

**SECTION B:** *Focus group questions*

1. What are your views on HIV and AIDS?
2. What has influenced you to hold these views?
3. How would you say PLWHA are treated in the family?
4. Is your family supportive of PLWHA?
5. Are women living with HIV and AIDS treated differently?
6. Are men living with HIV and AIDS treated differently?
7. What about your views about health care in this matter?
8. Would knowing how people contracted the virus influence how they are treated?
9. What are major changes that have occurred in your life due to death or knowing someone living with HIV and AIDS?
10. When does a person become stigmatised?

## SECTION C

Please answer whether you agree or disagree with the following statements.

	I AGREE	I DISAGREE
1. People who have AIDS are dirty.		
2. People who have AIDS are cursed.		
3. People who have AIDS should be ashamed.		
4. It is safe for people who have AIDS to work with children. (R)		
5. People who have AIDS must expect some restrictions on their freedom.		
6. A person with AIDS must have done something wrong and deserves to be punished.		
7. People who have HIV should be isolated.		
8. I do not want to be friends with someone who has AIDS.		
9. People who have AIDS should not be allowed to work.		

## SECTION D

For each statement please tick Yes =1, or No =2, or 3 = I don't know. If you don't know please do not guess, instead please tick I don't know = 3

1 = Yes,                      2 = No,                      3 = I don't know

	1	2	3
1. Coughing does not spread HIV. (R)			
2. Sneezing does not spread HIV. (R)			
3. A person can get HIV by sharing a glass with someone who has HIV.			
4. Withdrawing the penis before the man climaxes keeps a woman from getting HIV			

during sex.			
5. A woman cannot get HIV if she has anal sex with a man.			
6. Showering, or washing one's genitals/private parts after sex keeps a person from getting HIV.			
7. All pregnant women infected with HIV will have their babies infected with AIDS.			
8. People who have been infected with AIDS quickly show signs of being infected.			
9. There is a vaccine that can stop people from getting HIV.			
10. People are likely to get HIV by deep kissing, putting their tongues in their partner's mouth if their partner has HIV.			
11. A woman cannot get HIV if she has sex during her period.			
12. There is a female condom that can help decrease a woman's chance of getting HIV.			
13. A natural skin condom works better against HIV than a latex condom.			
14. A person will not get HIV if he or she uses antibiotics.			
15. Having sex with more than one partner can increase the chance of being infected with HIV. (R)			
16. Taking a test for HIV one week after sex will tell a person if she or he has HIV.			
17. A person can get HIV by swimming in the same pool with a person who has HIV.			
18. A person can get HIV by sitting in a hot tub with a person who has HIV.			
19. A person can get HIV from oral sex. (R)			
20. Using vaseline or baby oil with condoms lowers the chance of getting HIV.			

**SECTION E**

1 = definitely not true,

2 = not really true,

3 = somewhat true,

4 = mostly true,

5 = definitely true.

	1	2	3	4	5
1. I know a close friend who has HIV and AIDS.					
2. Someone in my family has HIV and AIDS.					
3. I know someone with HIV and AIDS who is not a close friend or a member of my family.					
4. I know a gay person who has HIV and AIDS.					
5. I know a person who is not gay who has HIV and AIDS.					
6. I know a woman who has HIV and AIDS.					
7. I know a person who injects drugs with a needle who has HIV and AIDS.					

## SECTION F

1 = definitely not true,      2 = not really true,      3 = somewhat true,  
4 = mostly true,      5 = definitely true.

	1	2	3	4	5
1. It would be easy for me to talk to my mother or father (or guardian) about sex.					
2. It would be easy for me to talk to my brother or sister (if you do not have brothers or sisters, consider cousins, or other relatives).					
3. Most of what I know about HIV and AIDS I learned from my mother or father (or guardian).					
4. Most of what I know about HIV and AIDS I learned from my brother(s) and/or sister(s).					

**SECTION G**

1 = not at all sure,  
sure,

2 = a little sure,

3 = kind of

4 = fairly sure,

5= very sure

	1	2	3	4	5
1. I feel that I am at risk of getting AIDS at this time in my life.					
2. I sometimes think that I may have been exposed to AIDS.					
3. I have had sex with someone who could have given me AIDS.					
4. One of my close friends does things that could lead to him/her getting AIDS.					
5. How sure are you that you have not been exposed to AIDS? (R)					
6. How sure are you that you that your sex partner (s) have not been exposed to AIDS? (R)					
7. If you were to make a guess, how sure are you that you are at risk of getting HIV and AIDS at this time in your life?					

## **UNIVERSITY OF LIMPOPO (Turffloop Campus)**

### **ETHICS COMMITTEE**

#### **APPLICATION FOR HUMAN EXPERIMENTATION**

(Completed forms, preferably typed, should reach the Chairperson of the Ethics Committee at least one month before the experimentation is due to start. Projects where the researcher only receives human material for analysis without actually being involved with collection from the experimental group must still register in the normal way. Researchers who are involved with projects which have been approved by Ethical Committees of other Institutions should provide this Committee with the necessary information and provide it with a shortened protocol for approval).

**PROJECT TITLE: Factors Contributing To HIV and AIDS Stigma among Young Adults**

**PROJECT LEADER: Mr. J. P. Mokwena**

#### **DECLARATION**

I, the signatory, hereby apply for approval to execute the experiments described in the attached protocol and declare that:

1. I am fully aware of the contents of the Guidelines on Ethics for Medical Research, Revised Edition (1993) and that I will abide by the guidelines as set out in that document (available from the Chairperson of the Ethics Committee); and

2. I undertake to provide every person who participates in any of the stipulated experiments with the information in Part II. Every participant will be requested to sign Part III.

**Name of Researcher:** Mr. J. P. Mokwena

**Signature:**

**Date:** 05/04/2007

-----  
---

**For Official use by the Ethics Committee:**

Approved/Not approved

Remarks:

Signature of Chairperson:

Date:

**PROJECT TITLE: Factors Contributing To HIV and AIDS Stigma among Young Adults**

**PROJECT LEADER:** Mr. J. P. Mokwena

**APPLICATION FOR HUMAN EXPERIMENTATION: PART II**

Protocol for the execution of experiments involving humans

1. Department: Psychology
2. Title of project: **Factors Contributing To HIV and AIDS Stigma among Young Adults**

3. Full name, surname and qualifications of project leader:

Mr. Jabu Patrick Mokwena, MA (Clinical Psychology) and PhD (Clinical Psychology) (Student)

4. List the name(s) of all persons (Researchers and Technical Staff) involved with the project and identify their role(s) in the conduct of the experiment:

Name:	Qualifications:	Responsible for:
Mr. J. P. Mokwena	MA (Clinical Psychology)	Student (Research)

5. Name and address of supervising physician: none
6. Procedures to be followed: Participants will fill in a questionnaire in a classroom setting and will also conduct focus groups.
7. Nature of discomfort: Emotional discomfort may arise among young adults who are HIV and AIDS positive and those who have relatives who are HIV and AIDS positive.
8. Description of the advantages that may be expected from the results of the experiment:

The study will assist to identify factors that contribute to HIV and AIDS stigma in order to implement appropriate and relevant intervention to reduce stigma and enhance voluntary counselling and testing.

Signature of Project Leader:

Date: 05/04/2007

**PROJECT TITLE: Factors Contributing To HIV and AIDS Stigma among Young Adults**

**PROJECT LEADER:** Mr J. P. Mokwena

**APPLICATION FOR HUMAN EXPERIMENTATION: PART II**

**INFORMATION FOR PARTICIPANTS**

1. You are invited to participate in the following research project/experiment:

**Factors Contributing To HIV and AIDS Stigma among Young Adults**

2. Participation in the project is completely voluntary and you are free to withdraw from the project/experiment (without providing any reasons) at any time. You are, however, requested not to withdraw without careful consideration since such action might negatively affect the project/experiment.
3. It is possible that you might not personally experience any advantages during the experiment/project, although the knowledge that may be accumulated through the project/experiment might prove advantageous to others.
4. You are encouraged to ask any questions that you might have in connection with this project/experiment at any stage. The project leader and her/his staff will gladly answer your question. They will also discuss the project/experiment in detail with you.
5. Your involvement in the project.

Participants will be expected to fill in a questionnaire in a classroom setting and focus groups will be conducted. Participation may arouse some uncomfortable emotions among young adults. However, participants who need counselling or psychotherapy thereafter will have the opportunity of receiving such attention from the project leader.

**UNIVERSITY OF LIMPOPO (Turfloop Campus)**  
**ETHICS COMMITTEE**

**PROJECT TITLE: Factors Contributing To HIV and AIDS Stigma among Young Adults**

**PROJECT LEADER: Mr J. P. Mokwena**

***CONSENT FORM***

I, \_\_\_\_\_ hereby voluntarily consent to participate in the following project: **Factors Contributing To HIV and AIDS Stigma among Young Adults.**

*(it is compulsory for the researcher to complete this field before submission to the ethics committee)*

I realise that:

1. The study deals with factors contributing to HIV and AIDS stigma among young adults.

2. The procedure or treatment envisaged may hold some risk for me that cannot be foreseen at this stage;
3. The Ethics Committee has approved that individuals may be approached to participate in the study.
4. The experimental protocol, i.e. the extent, aims and methods of the research, has been explained to me;
5. The protocol sets out the risks that can be reasonably expected as well as possible discomfort for persons participating in the research, an explanation of the anticipated advantages for myself or others that are reasonably expected from the research and alternative procedures that may be to my advantage;
6. I will be informed of any new information that may become available during the research that may influence my willingness to continue my participation;
7. Access to the records that pertain to my participation in the study will be restricted to persons directly involved in the research;
8. Any questions that I may have regarding the research, or related matters, will be answered by the researchers;
9. If I have any questions about, or problems regarding the study, or experience any undesirable effects, I may contact a member of the research team;
10. Participation in this research is voluntary and I can withdraw my participation at any stage;

11. If any medical problem is identified at any stage during the research, or when I am vetted for participation, a qualified person will discuss such condition with me in confidence and/or I will be referred to my doctor;

12. I indemnify the University of Limpopo and all persons involved with the above project from any liability that may arise from my participation in the above project or that may be related to it, for whatever reasons, including negligence on the part of the mentioned persons.

SIGNATURE OF RESEARCHED PERSON

SIGNATURE OF WITNESS

.....

SIGNATURE OF PERSON THAT INFORMED

.....

SIGNATURE OF PARENT/GUARDIAN THE RESEARCHED PERSON

.....