ANTICIPATED AND ENACTED STIGMA

AMONG FEMALE OUTPATIENTS LIVING WITH HIV:

THE CASE OF CHRIS HANI BARAGWANATH HOSPITAL, SOUTH AFRICA

by

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"It is the men behind who make the men ahead." – Merle Crowell

Completing this dissertation involved passionate support and patience of several people, whom I owe much gratitude. First of all I would like to thank God for nurturing me from the poor background of being a double orphan to where He wanted me to be, and for bringing hope and courage in my life.

My fiancée Nontando Lukhele and my daughter Magdeline Lukhele persevered through the loneliness caused by this study, while my mother-in-law Ms Lindiwe Skhosana took care of our little Lerato when her mother and I were often not available for study-related reasons.

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Declaration

I, Maditobane Robert Lekganyane (student No: 3319-708-3), declare that ***Anticipated and enacted stigma among female outpatients living with HIV: the case of Chris Hani Baragwanath Hospital, South Africa*** is my own work, and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references, and that this work has not been submitted before for any other degree at any other institution.

                                                                                                                             MARCH 2010

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MADITOBANE ROBERT LEKGANYANE

Dedication

This dissertation is dedicated to the following people:

- My late parents, Mr Hitler Lekganyane and Mrs Magdeline Lekganyane, who passed on before they could witness the successes of their children;
- My fiancée Nontando Lukhele and my daughter Magdeline Lukhele, who never spent quality time with me due to the demand of time and effort required by this project;
- My cousin, who valiantly survived HIV- and AIDS-related stigma which left him with severe psycho-social scars;
- My grandmother and my siblings for their continuous love and support; and
- All people who are living with HIV/AIDS.

Abstract

Three years into the human territory, the fight against HIV/AIDS still prevails. According to Fuller (2008), it is estimated that by 2025, 80 million Africans will have been killed by this pandemic, while 90 million are estimated to be infected by HIV. Close to 3 thousand women are infected with HIV daily. In the beginning of 2008, some 22,5 million sub-Saharan Africans were living with HIV (Fuller 2008).

In South Africa, 5 million people are estimated to be infected with HIV, 250 thousand die each year due to AIDS-related deaths, while a thousand people die daily and 17 hundred get infected daily. South African women are the hardest hit population group, compared to their male counterparts (Fuller 2008; Zuberi 2004). In South Africa this epidemic crawled under the shadow of denial, fear, ignorance, stigma and discrimination, which disrupted efforts to prevent further spread and care for the infected and the affected individuals and groups. South African women are subjected to gender inequality, sexual violence and rape, and in the presence of HIV/AIDS their plight became exacerbated. They became subjected to blame and rejection because people do not want to associate themselves with this group, who possess the deadly infectious disease which is associated with commercial sex workers, intravenous drug users and homosexuals.

The aim of this research was to investigate the plight of anticipated and enacted stigma among the South African women who receive treatment as outpatients in the Chris Hani Baragwanath Hospital. The study was conducted among six women who are living with HIV/AIDS over a period of four weeks, with a qualitative research design adopted as research method. In-depth interviews were used as the primary tool for data collection. This study was conducted in order for the researcher to obtain insight into the subject of HIV- and AIDS-related stigma and to highlight the experiences of participants for policy and programme designing and development purposes.

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LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ANC	African National Congress
ANCYL	African National Congress Youth League
ART	Antiretroviral Therapy
ARV	Antiretroviral
CAS	Centre for AIDS Studies
DoH	Department of Health
HDN	Health and Development Network
HIV	Human Immunodeficiency Virus
KZN	KwaZulu-Natal
PLWHIV	People Living with HIV
RSA	Republic of South Africa
STI	Sexually Transmitted Infections
TB	Tuberculosis
UNAIDS	United Nations programme on AIDS
UNICEF	United Nations Children's Fund
UNIFEM	United Nations Development Fund for Women
UNGASS	United Nations' General Assembly Special Session on HIV/AIDS
UNISA	University of South Africa
USAID	United States Agency for International Development
WHO	World Health Organization

CHAPTER 1

ORIENTATION TO THE RESEARCH PROBLEM

1.1 INTRODUCTION

The impacts of HIV/AIDS are felt at every level of the human society. At the societal level the care burden created by this pandemic necessitates national budget revisions to accommodate the needs of people infected with HIV and affected by HIV/AIDS (Parker, Colvin & Birdsall 2006:22). At the community level, HIV- and AIDS-related stigma and discrimination lead to the violation of the human rights of the people living with HIV (PLWHIV). Unexpected burdens are placed on institutions such as schools, where educators are reported to be dying in large numbers, resulting in a reduction of skilled educators and the consequent poor HIV/AIDS educational programmes (Peltzer 2008:103).

At the familial level, the presence of HIV/AIDS often implies that the family will lose income because HIV-infection rates are highest among the economically active age groups. At the individual level, the decline in physical well-being often leads to an inability to work and to death (Parker *et al* 2006; Shisana, Rehle, Simbayi, Parker, Zuma & Connolly 2005). The psycho-social challenges associated with HIV/AIDS at the individual level range from PLWHIV being exposed to stigma and discrimination to dealing with their anger and fear of living with a stigmatised and serious health problem. According to Zuberi (2004:46), the stigma and discrimination surrounding HIV/AIDS can be as destructive as the disease itself.

HIV- and AIDS-related stigma has a particularly heavy impact on women because it is compounded by gender inequality, poverty and violations of women's rights (Fuller 2008; Kabwe 2006; UNAIDS 2000). HIV- and AIDS-related stigma tends to reinforce ignorance, denial and distortion and therefore interferes with treatment, care and support, as PLWHIV might shy away from seeking the relevant care, support and treatment due to their fear of being stigmatised. At the familial level, when PLWHIV interact with their significant family members the impact of HIV- and AIDS-related

stigma is assumed to be less painful, because the family is regarded as the first source to be mobilised when a person falls ill or encounters serious problems – but alas, this is not always the case (Aggleton 2000:14).

Unemployment can further perpetuate the stigma, as women living with HIV depend on the state's social grants for financial support. According to Viljoen (2005), research in South Africa has shown that high rates of unemployment are endemic and that African women are most likely to be unemployed. Many of these women rely on state grants and this drives the stigma by fostering the view that these women make themselves vulnerable to HIV-infection so that they can access grants (Viljoen 2005). Research by the Centre for AIDS Studies in Hammanskraal and Temba reveals that HIV-positive women living in these areas are stigmatised as *"prostitutes"* or *"loose women"* or as having *"invited"* HIV-infection in order to claim access to social grants (Viljoen 2005).

Denial and silence around HIV/AIDS remain some of the available coping mechanisms so that many women hide or deny their HIV-positive status out of their fear of being labelled as prostitutes or drug users. Overcoming this culture of denial and silence depends on a thorough understanding of the nature and dimensions of such stigma.

This study was an investigation into the anticipated and enacted stigma among female outpatients aged 18 years and older, who are living with HIV. It was conducted at the Chris Hani Baragwanath Hospital, one of the largest hospitals in South Africa and in the world. The hospital is situated in South Africa's Gauteng Province and the study was conducted at the hospital's Nthabiseng HIV/AIDS clinic.

1.2 BACKGROUND AND RATIONALE

In 1987 the late Jonathan Mann, then director of the Joint United Nations programme on AIDS (UNAIDS), identified three phases of HIV/AIDS, which are *the epidemic of HIV, the epidemic of AIDS* and *the epidemic of stigma, discrimination and denial.* He noted that the third phase – *the epidemic of stigma, discrimination and denial* – is as central to the global AIDS challenge as the disease itself (Parker & Aggleton 2002:1). The reality and severity of the third phase of the epidemic were also acknowledged by

the Declaration of Commitment adopted by the United Nations' General Assembly Special Session on HIV/AIDS (UNGASS) in June 2001, where it highlighted global concerns on the importance of tackling the stigma and discrimination triggered by HIV/AIDS.

In reaction to this commitment, the World AIDS Campaigns for the years 2002 and 2003 focused on stigma, discrimination and human rights with the main aim of preventing, reducing and ultimately eliminating stigma and discrimination whenever it occurs (Aggleton & Parker 2002:5). Despite this commitment and the efforts directed at fighting stigma and discrimination, people living with HIV (PLWHIV) continue to suffer stigma and discrimination because of their HIV-positive status. The report of the International AIDS Conference held in Toronto in 2006 provided evidence of the existence of stigma among PLWHIV (Health and Development Networks 2006). According to Aggleton and Parker (2002:5), in countries all over the world, there are well-documented cases of PLWHIV who are stigmatised due to their HIV-positive status.

Sub-Saharan Africa is the region worst affected by HIV/AIDS in the world. In 2007 it accounted for almost a third (32%) of all new HIV infections and AIDS-related deaths globally (UNAIDS 2008:1). According to Biriwasha (2006:9), being HIV-positive is often seen in Africa as a sign of promiscuity and as a curse, and naturally carries shame with it. Morris (2003) highlights some of the African ideologies and religious beliefs that seem to perpetuate the stigma, such as the belief that HIV is a punishment from God or that, if the graves of people who have died due to AIDS are not dug deep enough, there will be post-burial infections. Another example is the imposition of HIV testing before marriage in countries such as Zambia. Moreover, research conducted by Aggleton (2001) in Uganda and India reveals that stigma and discrimination exist even among the health care professionals who are supposed to act as models in the fight against HIV/AIDS.

Gender inequality remains common while the cultural and ideological constructs of gender reinforce the relatively powerless position that women find themselves in. In some of South Africa's communities women living with HIV are still stigmatised as prostitutes or loose women who have brought the epidemic upon themselves (Viljoen 2005:51). Their experiences are still characterised by blame, rejection, isolation and

even abuse. Stigma remains a barrier to prevention, treatment, care and support in South Africa, as it perpetuates the many misconceptions about PLWHIV.

The need to further explore the experiences of PLWHIV remains imperative so as to correct the misconceptions held about them, and also to understand the designing and development of programmes and policies aimed at promoting the human rights of PLWIHV. Special attention is needed to understand the gender dimension of HIV- and AIDS-related stigma and discrimination (Aggleton & Parker 2002:2).

This dissertation aimed at exploring the experiences of female outpatients aged 18 years and older that are living with HIV in respect of enacted and anticipated stigma. The study was conducted in the Chris Hani Baragwanath Hospital, and data was collected over a period of four weeks. The research orientation was qualitative in nature and data was collected through in-depth interviews.

1.3 THE GOAL AND OBJECTIVES OF THE STUDY

The overall goal of the study was to uncover, in the voices of women living with HIV, how they experience HIV- and AIDS-related stigma and the coping mechanisms they use to deal with the stigma.

The main objectives of this study were to obtain answers to the following questions:

- Do women living with HIV/AIDS accessing services at the Chris Hani Baragwanath Hospital experience HIV- and AIDS-related stigma?
- What are the dimensions and nature of the HIV- and AIDS-related stigma experienced by these women?
- What are the coping mechanisms used by these women in dealing with HIV- and AIDS-related stigma?

1.4 PROBLEM STATEMENT

According to Hofstee (2006:20), a well formulated problem statement allows the researcher to precisely define what he or she will investigate. Stigma is a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons (Alonzo & Reynolds 1995; Visser, Makin,

Vandormael, Sikkema & Forsyth 2009). Stigma can be felt (anticipated or be internal), leading to an unwillingness to seek help and access to resources, or it can be enacted (external stigma), leading to discrimination on the basis of an HIV-positive status or association with someone who is living with HIV (AIDS Law Project 1997:4). Stigma, like discrimination, interferes with support, care, treatment and prevention of the illness. PLWHIV who experience stigma tend to be reluctant to seek help out of fear of being discriminated against because of their HIV-positive status (USAID 2004). This implies a need to thoroughly understand the nature and dimensions of HIV- and AIDS-related stigma as well as the contexts in which it manifests itself. Moreover, those living with HIV and experiencing HIV- and AIDS-related stigma develop coping mechanisms which also need to be documented and analysed. Thus the central problem statement that guided this study was: How do women living with HIV experience and deal with HIV- and AIDS-related stigma and discrimination?

1.5 CHOSEN STUDY SITE

This study was conducted in the Chris Hani Baragwanath Hospital in South Africa. The hospital was erected in 1939 and officially opened in 1942. Since then the hospital has grown in size and scope, and like most hospitals in the region and in the country, it is seriously affected today by the impact of HIV/AIDS. According to Van den Heever (2006), most of the hospital's medical wards function on 95% to 100% bed occupancy due to HIV and AIDS and related diseases. The implication of this is that most of the hospital's in- and outpatients are PLWHIV. This study targeted six female patients aged 18 years and older, who were receiving the Chris Hani Baragwanath Hospital's services as outpatients.

1.6 DEFINITIONS OF CONCEPTS

According to Babbie (2005:129), operational definitions have the advantage of achieving maximum clarity about what a term really means in the context of a given study. Some of the key concepts used throughout this dissertation are defined below.

1.6.1 Anticipated stigma

Anticipated or felt (internalised) stigma refers to the feelings that an individual has about his or her condition and the fear of how others will react to this condition. Anticipated or felt stigma can be seen as fear of, or anticipation of, enacted stigma (Morris 2003; UNAIDS 2000). Another definition of anticipated or felt (internalised) stigma is provided by Ninda, Chimbwete, McGrath, Pool and Group (2007:93), who refer to it as an event which occurs when one living with HIV/AIDS imposes stigmatising beliefs and actions on themselves.

1.6.2 Enacted stigma

Enacted stigma refers to sanctions that are individually or collectively applied to people on the basis of their belonging or perceived belonging to a particular group. Enacted HIV- and AIDS-related stigma is therefore the discrimination and violation of human rights that PLWHIV or people assumed to be infected with HIV may experience (Green, as cited in Morris 2003:20).

1.6.3 Female outpatients living with HIV

For the purpose of this study, *female outpatients living with HIV* refers to the women who access services at the Chris Hani Baragwanath Hospital as outpatients, who have been diagnosed with HIV and who are 18 years and older.

1.7 CONCLUSION

This chapter has introduced the reader to the study by providing a background to and a rationale for the study. The goal and objectives of the study as well as the research problem statement were given. A brief outline of the study site was provided, and finally the definitions of terms used throughout this dissertation were provided.

1.8 OUTLINE OF CHAPTERS

The rest of the dissertation is organised in the following way:

Chapter two introduces a discussion of stigma from the reviewed literature. It provides a discussion of three humanistic theories of stigma and an in-depth

discussion of the nature of stigma, focusing on the definition, origin, progression, types, functions, impact and other factors of stigma. A specific discussion of HIV- and AIDS-related stigma is provided where an emphasis is placed on South Africa and South African women.

Chapter three outlines the research methodology adopted for this study. In this chapter an emphasis is placed on the research design, validity, sampling and sampling characteristics. Methods of data collection are discussed where attention is placed on qualitative interviews, while information on data analysis and interpretation are also provided. A discussion of ethical considerations is provided where the researcher shows how he observed the ethical principles and protocols during the study. Finally, a reflection on the researcher's role concludes the chapter.

Chapter four provides the findings and an analysis of the research results. In this chapter the researcher analyses the findings of the study in accordance with the research questions and the objectives, and provides an interpretation and summary of the findings.

In the last chapter (chapter five), the researcher provides a discussion of the general research conclusions. In this chapter attention is placed on a summary of the findings, conclusions, strengths of the study, limitations of the study, suggestions for further research and some recommendations are given for policy and practice.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Much of the literature on stigma has been developed by researchers from various disciplines in the human sciences such as psychology, sociology, criminology, anthropology, political science and others. With the rapid spreading of HIV infections in the early 1980s, many HIV- and AIDS-related stigma studies were conducted by international bodies such as the Joint United Nations Programme on AIDS (UNAIDS), the United Nations Children's Fund (UNICEF), the United Nations Development Fund for Women (UNIFEM), the Health and Development Networks (HDN), and many other local and international, governmental and non-governmental organisations. This led to a rapid expansion in the literature on the subject of HIV- and AIDS-related stigma. In the subsequent sections of this chapter, the researcher examines the problem of stigma by drawing on evidence of studies conducted by others.

The chapter is organised in such a way that the problem of HIV- and AIDS-related stigma is approached first by presenting a discussion of the three theoretical perspectives on the problem of stigma, specifically the bio-cultural framework, the attribution theories and the consensus theories of stigma. The nature of stigma is explored by paying attention to its definition, origin, types, progression and functions. The impact of stigma in general is also highlighted with an emphasis placed on prevention, treatment, care and support, family relations as well as the stigmatised person's human rights. This is followed by a discussion of HIV- and AIDS-related stigma in South Africa, specifically as it pertains to South African women. Finally, the coping mechanisms that people adopt when confronted with stigma are explored.

2.2 THEORIES OF STIGMA

Like other psycho-social problems, many theorists have developed frameworks for studying the problem of stigma (see Falk 2001; Goffman 1963; Herek, Capitanio & Widaman 2002; Link & Phelan 2001; Ogden & Nyblade 2006). In the following section, the researcher discusses stigma from the three humanistic theoretical points of view. The theories below are drawn from psychology, sociology, criminology, anthropology and related disciplines.

2.2.1 The bio-cultural framework

From a human ecology perspective, it can be argued that humans are preordained to belong to and live in groups. People are born into groups called families, are socialised in families and in peer groups, and when they die they need groups to pay them their last respects. It was this fundamental belief in humanity's innate desire to belong to effectively functional groups which led to the founding of the bio-cultural framework of stigma (Neuberg, Smith & Asher 2000:33).

Central to this framework is the interaction of biological and cultural processes. Biologically humans have the innate desire to belong to effective groups, and this desire is transmitted biologically from generation to generation through the genes and culturally through socialisation (Neuberg *et al* 2000). According to this framework, in order for groups to be effective and functional, they must successfully organise individual effort, share resources, create effective communication and protect individual members from predation, theft and the like. Norms of reciprocity, truth telling, and trust for creating a common identity and stable bonds between members are highly valued. The establishment of reliable mechanisms for group socialisation is regarded by the bio-cultural framework as a key requirement for effective group functioning (Morris 2003; Neuberg *et al* 2000).

Individuals are therefore expected to work hard to keep the group effective and functional through reciprocity, truth telling, and trust. Despite these expectations, there are those individuals and subgroups who present a threat to the group by not upholding the generally accepted norms. Neuberg *et al* (2000:38-47) include under such threats what they call the *"thieves"* and the *"free riders"* on the efforts of others,

the physically disabled, the treacherous who cheat and betray, those who counter-socialise as well as those with contagious diseases such as HIV/AIDS.

Bio-culturally individuals who work together and promote the values and norms of the group are more likely to transmit their genes and skills to the future generations, who will consequently transmit theirs to the upcoming generations to ensure effective group functioning (Neuberg *et al* 2000:35). Equally, those individuals who perform poorly are likely to transmit their genes to the upcoming generations, but can nonetheless if not stopped, threaten the group's effectiveness and functionality.

Because the group's effectiveness and functionality ought to be upheld, the threats to the norms need to be prevented and avoided. This is done through stigmatising those who pose a threat to the group. Individuals who threaten and hinder successful group functioning are therefore identified and labelled as such through stigmatisation. Group members are encouraged to withhold group benefits from the stigmatised and they are separated from the group if necessary, because they can potentially exploit the other members by unduly benefiting from their efforts. Exploitation in cooperative groups creates problems because, as individuals begin to exploit the efforts of others by not sharing, those who continue to behave pro-socially increasingly have to shoulder the burdens for fewer benefits (Neuberg *et al* 2000:36).

The bio-cultural framework can be applied to the problem of HIV- and AIDS-related stigma in the following way: Due to the fact that as a PLWHIV's viral load increases, his or her body's defence becomes weak and he or she eventually becomes unable to execute some of his or her daily tasks, he or she tends to become what Neuberg *et al* (2000:37) call *"free riders"* who unduly benefit from the group's efforts. They can no longer adhere to the group norm of reciprocity and are likely to develop a culture of counter-socialisation if they are not ostracised. The general group identity will be threatened in a sense that members will no longer claim to be effective and functional group members, because some of them are unable to reciprocate due to their worsening state, and they therefore benefit unduly from the efforts of others who provide support and care to them. Biologically the genes of these individuals and groups will be transmitted to the next generation and this will further threaten the integrity, functionality and effectiveness of the group. The bio-cultural framework accentuates that such individuals and groups should be identified as threats to the

group and be labelled as such, and be avoided so that the group's norms can be upheld (Neuberg *et al* 2000). HIV- and AIDS-related stigma therefore serves the exact function of identifying, labelling and separating out PLWHIV who are regarded as the *free riders* of the group. They are therefore prevented from unduly benefiting from the efforts of other members of the group via stigmatisation.

2.2.2 Attribution theories of stigma

Attribution theories of stigma are based on the notion that a stigmatised person is responsible for his or her own stigma. These theories accentuate that humans exist in a *just world* in which everyone gets what he or she deserves. People who are stigmatised are therefore viewed as deserving the conditions in which they find themselves. Attribution theory posits that uncontrollable behaviours are less likely to be stigmatised than controllable behaviours. This means that people tend to have more positive attitudes toward individuals with problems that are biologically caused and would therefore tend to stigmatise them less than people whose problems are regarded as behaviourally caused (Dijker & Koomen 2003)

The stigmatisers select, distort or even invent evidence to justify their blame of the stigmatised (Crandall 2000). A person who is seen in some way to be responsible for his or her victimhood is then subjected to anger and negative emotions such as rejection and avoidance, while a person who is viewed as not so much responsible for his or her own fate would receive pity, sympathy and help (Crandall 2000:129-133).

Attribution theories are relevant to the problem of HIV- and AIDS-related stigma. HIV transmission is preventable through the adoption of measures such as abstaining from sexual intercourse, using condoms, remaining faithful to one sexual partner and not sharing needles. Because these theories regard people as living in a just world with different choices available to everyone, everybody is able to choose the consequences of their choices. Applying these theories to PLWHIV means that they must have actively chosen to ignore available universal protection measures and must therefore be rejected and avoided to suffer the consequences of their choices. Those unfortunate enough to never have had a choice that contributed to their infection such as babies infected via mother-to-child transmission, or those accidentally infected through unsafe transfusions or accidental (nosocomial) infections, are according to the

attributional theories deserving of sympathy, pity and some form of support (Crandall 2000:133).

2.2.3 Consensus theories of stigma

According to the consensus theories of stigma, stereotypes (like all beliefs) are transferred throughout the society through communication, and individuals by and large tailor their options to conform to the opinions of others. Fundamental to the assumption of the consensus theory, as with other social-psychological theories, is the premise that individuals are motivated to be part of groups and that sharing beliefs allows them to be accepted in such groups (Morris 2003; Neuberg *et al* 2000; Stangor & Crandall 2000). In other words, according to the consensus theories of stigma, there are so-called "generally accepted beliefs" which are held by the majority, and most people merely conform to such normative beliefs due to their innate need to belong. Such beliefs (including stigmatising ones) are transmitted – both actively through communication and socialisation and passively through indirect exposure to such notions (Stangor & Crandall 2000:71).

Consensus theories posit that stigmatisation is not an individual act, but rather something which occurs at a more general societal and community level. Such stigma then becomes transmitted actively and passively through channels of communication and media to the individuals, who then conform to such beliefs due to their need to belong to the majority. Lawson (2008) shows how the South African apartheid government adopted this practice when they legislated the compulsory testing for Malawian migrant miners which led to a point where the Malawians were stigmatised as the group who brought the disease into South Africa. From the outset, HIV/AIDS was linked to marginalised groups such as homosexual men, commercial sex workers and injecting drug users, and the belief that such groups are responsible for the general spread of the disease to the population at large.

2.3 UNDERSTANDING STIGMA

The term *stigma* originates from the ancient Greek word *stigmata,* which described bodily signs designated to expose something unusual and bad about the moral status of the signifier (Goffman 1963; Shoham 1970; Sinha, Olutunji, & Babafemi, (2008).

The signifier of stigma was regarded as morally polluted and his or her body was cut or burned so that they could be identified and avoided, especially in public places (Goffman 1963:11). These individuals and groups were then reduced to subhuman beings and their full humanity was questioned by the stigmatisers.

Stigma manifests itself in various forms. According to Cao, Sullivan, Xu, Wu and the China CIPRA Project 2 Team (2006:519), stigma can be broadly grouped as *physical isolation or exclusion, verbal (gossip, insults, and voyeurism), loss of role (denied religious rites, loss of respect) and loss of resources (loss of job/customers/housing),* and even being given a poorer quality or no health care. All these forms of stigma are relevant to HIV/AIDS. In their studies in rural China for example, Cao *et al* (2006) found exclusion and isolation, loss of resources/service, verbal stigma, secondary stigma and self-discriminating behaviour to be common among their participants. PLWHIV were ignored and avoided by other villagers, who even avoided visiting, assisting or receiving services for PLWHIV. Some PLWHIV were reported in this study as being denied services due to their sero-status, while others experienced open gossip and were called names. In some instances, such stigma was even extended to their associates who suffered stigma on account of their associates who were living with HIV/AIDS. All these kinds of practices aim to reduce the PLWHIV in the eyes of others who see themselves as the normal ones, and who drive the PLWHIV away from any form of social intercourse.

Some individuals and groups of people are more likely to be stigmatised than others, because they possess characteristics or behaviours which are different from those of others. Goffman (1963:12) identifies a stigmatised person as someone who somehow is   reduced in the minds of others from a whole and usual person to a tainted, discounted one. Biernat and Dovidio (2000:58), Crocker and Quinn (2000:153) and Dovidio, Major and Crocker (2000:1) concur with Goffman's notion by pointing out that a stigmatised person is a person who is devalued, spoiled or flawed in the eyes of others. In this regard, Mathiti (2003:349) describes someone who is stigmatised as one whose social identity calls his or her full humanity into question.

The stigmatisers can be any of the associates of the stigmatised such as friends, lovers, family members, community members and others. In their investigation of HIV- and AIDS-related stigma and discrimination in China, Cao *et al* (2006:523)

found that PLWHIV felt stigma from community, family members and health care workers. Similar findings were reported in South Africa by Visser *et al* (2009:203), who went as far as to highlight that older people, less educated people and males are groups that are more likely to stigmatise than other groups.

Although some researchers tend to perceive stigma in the context of the stigmatiser and the stigmatised (Biernat & Dovidio 2000; Crocker & Quinn 2000; Dovidio *et al* 2000; Goffman 1963; and Shoham 1970), there is evidence that the victims of stigma can also become the stigmatisers. In other words, the stigmatised can internalise the perceptions of others towards him- or herself. Research by Lee, Kochman, and Sikkema (2002) found that 63% of HIV-positive persons were embarrassed by their HIV infection, and 74% stated that it was difficult to tell others that they were HIV-positive. The same point is made by studies conducted by Cao *et al* in China (2006:523), where they found that after having learnt that they were HIV-positive, some people reduced their contact with others.

2.4 DEFINING STIGMA

Various researchers and authors have developed different ways of defining the word *stigma*, but common to most of them is the *discrediting, reductive* or *devaluing* nature of the concept to the stigmatised. Goffman (1963:13) defines stigma as *an attribute that is discrediting*. He believes that this attribute manifests itself in a relationship context where there is a stigmatiser and the stigmatised. The attribute therefore serves as a two-way mechanism through which the usualness of the stigmatised becomes reduced, while at the same time the usualness of the stigmatiser becomes elevated. Justification of this is found in the downward-comparison theory which asserts that comparing oneself to less fortunate others (the stigmatised) can increase one's (the stigmatiser's) own subjective sense of well-being, and can therefore boost one's self-esteem, while motivating active discrimination against the less fortunate others (Dovidio *et al* 2000:7-8; Stangor & Crandall 2000:67).

A common perception of the discrediting nature of stigma is held by Shoham (1970:2), who understands the word *stigma* as *a derogatory attribute imputed to the social image of an individual or group*. In other words, stigma results in a reduced social image of the stigmatised. Crocker and Quinn (2000:156) concur with this view;

they believe that group oppression may destroy the integrity of the ego entirely, reverse its normal pride, and create a grovelling self-image.

Another definition of stigma which holds the common perception of its discrediting nature is the one provided by Blascovich, Mendes, Hunter and Lickel (2000:307), who refer to stigma as *some attribute or characteristic that conveys a social identity that is devalued in some particular social context.* All of the above definitions are relevant to HIV- and AIDS-related stigma in that PLWHIV find themselves in situations where they are discredited, imputed or derogated, so that their image is reduced mainly because of their HIV status.

However, a clearly HIV/AIDS accommodative definition of stigma is that which is provided by Dovidio *et al* (2000), who define stigma as *a process by which individuals with devalued physical, behavioural or medical attributes experience prejudice, discrimination, stereotyping and exclusion.* HIV/AIDS becomes a devalued physical, medical and behavioural attribute when the patient begins to develop some bodily symptoms which can clearly be seen. The physical and medical attributes of HIV/AIDS become apparent when the patient is devalued because he or she is suffering from the disease which is associated with death, and people therefore become afraid of being infected with this deadly disease for which there is no cure (O'Leary, Kennedy, Pappas-Deluca, Nkete, Beck, & Galavotti 2007:209). PLWHIV are therefore avoided and stigmatised because people do not want to risk being infected. Studies by Cao *et al* (2006:525) reveal that some uninfected participants believed that death from HIV infection was immediate and therefore a greatly feared infection. Some people were also scared by the physical appearance of PLWHIV.

2.5 THE ORIGIN OF STIGMA

In the seventeenth century, stigma was initially used as a group's reaction to norm violation. Crime and norm violation were perceived as offending the gods and causing pollution (Shoham 1970:11). The formal punishment (through stigmatising) was regarded as a cleansing mechanism to cleanse the offender and appease the gods. This kind of practice was later adopted by the ancient Greeks where the so-called morally polluted individuals and groups were marked and burned on their skins so that they

could be identified as such and be segregated from interpersonal benefits of association, especially in the public places (Goffman 1963; Shoham 1970).

In modern society the sanctioning of stigmatisation differs in kind and consequence from the mediaeval stigma, but the inherent nature of stigma itself is unchanged. Individuals and groups who in some or other way differ in personality or behaviour or are considered different in a way that infringes the group's normative system, are liable to stigma (Shoham 1970:15). In other words, unlike in the ancient times where stigma was seen as a mechanism to reform morally unacceptable behaviours, in modern times stigma is broadened to include things like the bodily characteristics of an individual, the general characteristics of the individual or group and the associates of the individual or group (what Goffman (1963) refers to as the tribal stigma).

With the emergence of HIV/AIDS, stigma found another angle to justify the above points raised by Shoham (1970); with the modern concept of stigma becoming broader than the mediaeval one, fear, denial, ignorance and rejection became common.

Justification of the rejection, fear and blaming of PLWHIV is mainly because HIV/AIDS has its roots among the marginalised groups in society who are regarded as morally polluted, and because HIV/AIDS is an incurable and contagious disease. They are therefore convinced out of ignorance and fear that the disease can be contagious even through a mere association with someone who is infected. Fear of losing associates also serves as one of the reasons why PLWHIV are continually marginalised and avoided because people are afraid of being identified as living with HIV. William F Buckley (cited in Lawson 2008) demonstrated this marginalisation in 1986 by suggesting in the *New York Times* that everyone detected with AIDS should be tattooed. In Tanzania HIV-infected children have repeatedly been requested to wear a red ribbon or red star on their school uniforms so that they can be identified as such (France 2001; Lawson 2008). In the mid-eighties in South Africa, the National Department of Health (DoH) blamed foreign migrant workers for the spread of HIV infections in the country (Lawson 2008:21).

2.6 THE PROCESS OF STIGMATISATION

Stigmatisation is described by Bond (2004) as a process which manifests itself when there is a convergence of the following four, interrelated components:

2.6.1 Distinguishing and labelling of differences

Stigmatisation has some significant function of visually and symbolically distinguishing between the normative and the non-normative (Shoham 1970:7). In similar fashion, Bond (2004) states that in order for stigma to manifest itself, there must be a process whereby people identify and label the differences possessed by the stigmatised. In other words, the stigmatised must be identified as someone who is different from others, because she or he possesses either different behaviour, attitudes or characteristics. In this case, if a person is known to have or is suspected to have a contagious disease such as HIV/AIDS, he or she will be identified as different and labels will then be attached to him or her.

In African countries such labels tend to take some form of metaphors as highlighted in Swahili, where people who has acquired AIDS are labelled as those who *"stepped on the electric fence"* (France 2001; Morris 2003). Jones, Farina, Hastorf, Markus, Miller and French (1984:13) believe that this phase, which they call the pre-interaction phase, is influenced by people's experiences from which they draw information in order to make such judgements. People tend to meet each other with certain expectations which are drawn from past experiences and which help define preliminary interaction goals linked to the individual's self-concept (Jones *et al* 1984:13). The issue raised by Jones *et al* above is supported by Dovidio *et al* (2000:7), who identify the enhancement of self-esteem of the stigmatisers as one of the functions of stigmatisation.

After this phase of identifying and distinguishing the normative from the non-normative and the consequential labelling, Bond (2004) believes that people then search for negative attributes which these people possess so as to justify the attachment of labels to them. This leads to the other component of stigma, which is the linking of identified and labelled differences with negative attributes.

2.6.2 Linking labelled differences to negative attributes

The identified and labelled differences in terms of the above component are now linked to certain attributes possessed by the stigmatised. From the attribution theoretical framework one might say during this component of stigma, the stigmatisers will select, distort or even invent evidence suggesting that the stigmatised individuals or groups deserve blame, because they possess certain attributes or because they behaved in a morally unacceptable way (Crandall 2000:129-130). Jones *et al* (1984:16) concur with this point in their assertion that people are selectively attuned to evidence that seems to confirm their expectancies or hypotheses, and they tend to retain it even if it disconfirms their perceptions. In other words, although people look for evidence to justify their perceptions, they end up stigmatising – regardless of available disconfirming evidence.

The differences that people identified between themselves and the PLWHIV are therefore linked with attributes of the morally polluted groups who are believed to be vectors of the spread of the infection. A person living with HIV might therefore be viewed as deserving his or her condition and so be stigmatised. From an attribution point of view, such an individual does not deserve any pity, sympathy or help because he or she is reaping the benefits of his or her efforts (Crandall 2000:129).

2.6.3 Separating the "us" and the "them"

According to Link & Phelan (cited in Bond 2004:36), once the differences have been identified, labelled and negative attributes assigned to them, the stigmatised person will begin to be isolated and rejected. They will then be deprived of certain benefits and association. In South Africa many such cases have been observed, for instance, the case of a cabin attendant that was denied appointment by the South African Airways on the grounds of his HIV status (Bond 2004:360). This separation in the case of HIV/AIDS is normally due to a fear of contamination with the disease which is associated with death, as well as a fear of being associated with someone who is infected by the disease which has its origin among the socially and morally polluted members of society.

2.6.4 Suffering loss and discrimination

The last component of stigma manifestation is when the stigmatised individual or group experiences the actual status of loss and discrimination. Because as social beings people are innately created to belong to groups (Neuberg *et al* 2000:35; Morris 2003:23), humanity itself suffers as a result of experiences of separation, isolation and rejection. Jones *et al* (1984:111) support this view by stating that the development of the self-concept is a distinctly social process which requires the involvement of other people in the effort to acquire knowledge about the self and to evaluate and interpret experiences. In other words, as people interact with their significant others, they develop a self-concept from such people's evaluations of themselves and of their own evaluations of themselves in comparison with them. Isolation and rejection therefore imply that people are denied such opportunities which are aimed at building a coherent and stable self-concept or full humanity. A person's social comparison needs that are concerned with evaluating the subtle nuances of self-referent feelings, beliefs and abilities can only be fulfilled through fairly extensive social contact that directly engages the relevant others in social interaction. The socially isolated, stigmatised person will therefore be denied the opportunity to construct and maintain such social contacts and he or she will therefore be further alienated (Jones *et al* 1984:142).

2.7 TYPES OF STIGMA

Just as there are various theoretical approaches to stigma, there are different types of stigma from the perspective of various researchers and theorists. Goffman (1963) for example identifies three types of stigma, namely *abomination of the body, blemishes of the individual character* and *tribal stigma*, while Bharat, Aggleton, and Tyrer (2001) believe stigma to be divided into self-stigma, perceived stigma and enacted stigma. On the other hand, Zuberi (2004:47) believes that stigma can be internal (or anticipated) and external (or enacted). For the purpose of this study, specific attention is placed on an in-depth discussion of Zuberi's types of stigma.

2.7.1 Anticipated stigma

Anticipated or self- (internalised) stigma is the shame associated with HIV/AIDS and the fear of being discriminated against, which are both felt by PLWHIV. Anticipated stigma causes refusal or reluctance to disclose one's HIV status, or denial of one's HIV/AIDS. This can lead for example to HIV-positive mothers who are aware of their HIV-positive status to continue breastfeeding, even though they know that breastfeeding might transmit the virus to their babies, because they fear that if they don't breastfeed, their HIV-positive status may automatically be revealed to others. Self-stigmatisation or anticipated stigma is a term for the shame that a person can feel over their own situation. Negative responses from people in their surroundings can be internalised by PLWHIV (Talja 2005:12). Bond (2004:47) believes that this internalisation of stigma is the impact of stigma on the stigmatised HIV-positive persons. In other words, PLWHIV opt to internalise stigma so that they can avoid being labelled and marginalised due to their status.

Anticipated or self-stigma is described by Morris (2003:20) as the feelings the individual has about his or her condition and the fear of how others will react to this condition. Anticipated stigma can therefore be chosen as a defence mechanism to protect PLWHIV from enacted stigma, which is the actual discrimination by their significant others (Morris 2003; Talja 2005; Zuberi 2004).

2.7.2 Enacted stigma

Enacted stigma refers to sanctions that are individually or collectively applied to people on the basis of their belonging or perceived belonging to a particular group. Enacted HIV- and AIDS-related stigma refers to the discrimination and violation of human rights that PLWHIV or people assumed to be infected with HIV/AIDS may experience (Morris 2003:20). Enacted stigma can take a form which Visser *et al* (2009:200) refer to as subtle discrimination, such as gossip, not treating PLWHIV with respect, keeping distance from PLWHIV, attempts to humiliate PLWHIV or physically harm them, and not taking care of them. Bunn, Solomon, Miller, and Forehand (2007:198) and Visser *et al* (2009) say that enacted stigma refers to the actual experiences of prejudice, stereotyping, discrimination, and exclusion described by the affected individual. These include both overt expressions such as loss of

friendships or social support after disclosing one's HIV-positive status, and more subtle expressions of stigma such as micro-insults, and daily hassles or macro-aggressions similar to those experienced by other marginalised groups.

2.8 FUNCTIONS OF STIGMATISATION

Stigmatisation serves certain functions to those who stigmatise (through norm sending and norm receiving) and to the society. However, just like the problem of stigma itself which is examined from various theoretical approaches, its functions are examined differently by different theorists. In the following section, the researcher examines the functions of stigma as described by Shoham (1970:7-23) and Dovidio *et al* (2000:7-8). According to Dovidio *et al* (2000:7), stigma serves three main functions to the stigmatisers, namely:

2.8.1 Stigmatisation enhances the self-esteem of the stigmatisers

Dovidio *et al* (2000:7) believe that stigmatisation serves the functional role of enhancing the self-esteem of the stigmatisers. By rejecting, avoiding and blaming the stigmatised, the stigmatisers' self-esteem becomes uplifted and enhanced. The downward-comparison theory concurs with this assertion. According to this theory, comparing oneself with less fortunate others can increase one's self-esteem (Dovidio *et al* 2000). The stigmatisers develop a sense of pride after their stigmatising attitudes and behaviours. This point is further supported by Turner , Hogg, Oakes, and Recker (1987:34), who assert that the favourable comparisons between the in-group and the out-group provide the in-group members (the stigmatisers) with high subjective status or prestige and thus a positive social identity, whereas the unfavourable comparisons provide the stigmatised with low prestige and negative social identity.

2.8.2 Stigmatisation buffers anxiety

Associating oneself with criminals or with PLWHIV poses a danger of being identified as a criminal or as someone who is infected by HIV. This is a risk to one's social identity because he or she might be rejected, isolated, stigmatised and denied the full benefits of being a group member of the stigmatisers (Neuberg *et al* 2000:36). Because rejection and isolation already cause anxiety to the sufferer, in order to

prevent such anxiety, people tend to resort to stigma in advance by simply rejecting and avoiding those people who might put them in a stigmatised position. This kind of practice is described by Jones *et al* (1984:71) as the peril of social rejection where people stigmatise others by avoiding any form of association with them, in order to avoid the risk of being stigmatised through association.

2.8.3 Stigmatisation enhances the control that stigmatisers have over others

According to Dovidio *et al* (2000), stigma rewards the stigmatisers with certain powers of being in charge of the stigmatised and their situations. In this case the stigmatisers engage in their stigmatising attitudes and behaviours so that they can control their victims and their situations. Motivation for labelling someone as deviant may arise from the desire to gain or maintain social position and power over them, as in the following statements made by a woman whose partner used her HIV-positive status to control her:

"I realised that he was using my [HIV-positive] *status to control me. Whenever we had a disagreement, he would say things like, No-one else would love you so you'd better stick around or else"* (Health and Development Networks 2004:11).

2.8.4 Stigmatisation separates the normative from the non-normative

The morally and socially acceptable practices should be clearly understood and known by every social being. Morally and socially acceptable behaviours and attitudes should be clearly distinguished from the morally and socially condemned ones. Stigma therefore serves as a norm which aims to contrast and distinguish the non-normative from the normative and to differentiate good from evil (Shoham 1970:7). In this way, stigma serves as a tool to ensure that those who transgress the norms are held accountable and responsible, because they would know what attitudes and behaviours are morally and socially accepted and what would be morally and socially condemned.

2.8.5 Stigmatisation encourages future conformity to the norm

Stigma aims to prevent future deviation from the norm by punishing those who deviate from the norms and making them recognisable so that people can learn from

them that a particular behaviour and attitude is unacceptable and therefore punishable. Physical branding, the pillory, the branks and the ducking stool were stigma penalties designed in the seventeenth and eighteenth centuries, not only to degrade the offenders, but also to deter any potential ones (Shoham 1970:9). This is the case with HIV/AIDS which is regarded by some, (especially religious authorities) as a punishment for sin (Mwondela-Katukula 2006). In this case, PLWHIV are stigmatised as sinners who deserve to suffer the consequences of their behaviour and from whom others should learn that norm violation is morally and socially unacceptable. The fear of stigma is much stronger than the fear of punishment for average law-abiding citizens. This function of stigma therefore means that people will be more likely to adhere to acceptable norms due to their fear of stigma but not of the punishment itself (Shoham 1970).

2.8.6 Stigmatisation measures the strength of the norm

According to Shoham (1970:9-10), the strength of the norm and the stigma are positively correlated: the graver the stigma, the harsher the group's reaction is to the breach of the norm, and the greater the inherent power of the norm. In other words, if the norm is believed to be important, the stigma will be very harsh. Shoham (1970:10) refers to the ancient Attica murderers who were ostracised and outlawed and whom anyone could injure or kill with impunity. They faced this extreme form of stigma because they have also violated a very important norm by committing murder. This function of stigma has been observed in most African countries including South Africa, for example in the brutal murder of Gugulethu Dlamini, who was stoned to death by members of her own community in 1998 for publicly disclosing her HIV-positive status on national television.

2.8.7 Stigmatisation internalises the norm

According to Shoham (1970:16), in its role as a deterrent mechanism, stigma makes the individual comply with socially and morally acceptable norms due to his or her fear of stigma. However, it also serves a function which facilitates the internalisation of compliance to norm as a personality element. In other words, the individual gets to a point where he or she does not comply simply because he or she is afraid of stigma, but rather because he or she feels compliance is part of his or her self. Compliance

therefore comes automatically to such an individual because it is incorporated into his or her self-concept. Such a person is referred to by Shoham (1970:17) as someone who has solidarity – the complete attachment of the individual to the goals and values of the group and his or her full internalisation of the relevant norms. Unlike the subjectivist who regards group solidarity as oppressing and suppressing, a solidarist has and enjoys his or her freedom (Shoham 1970:17). In other words, a person who has reached this level of solidarity regards adherence to norm as normal and as part of his or her being, and is likely to transmit this adherence to his or her children and grandchildren. In the case of HIV/AIDS, one finds those people would observe precautionary measures against HIV/AIDS in order to avoid infection – not because they fear the stigma. They therefore feel that observing precautionary measures is incorporated into their self-image. These are people who would feel that their small contribution has an impact in reducing and mitigating the spread and impacts of HIV/AIDS in a society.

2.9 THE IMPACTS OF STIGMA

Just like any other psycho-social problem, stigma has some serious impacts on the stigmatised and his or her context. Their interaction with other people cannot be ignored whenever the impacts of stigma on the stigmatised are considered. Because as social beings people are preordained to belong to groups (Morris 2003:23; Neuberg *et al* 2000:35; Stangor & Crandall 2000), the costs associated with stigma to the stigmatised will clearly be strenuous to his or her humanity, both on the interpersonal and intrapersonal levels.

On the interpersonal level such a person is likely to either directly correct what he or she sees as the objective basis of his or her failing, or do so indirectly by devoting much private effort to the mastery of areas of activity ordinarily felt to be closed on accidental and physical grounds to the one with the shortcoming (Goffman 1963:20). In other words, such a person is likely to hide away his or her stigma in order to survive the public. This kind of reaction to stigma is likely to lead to poor physical health. HIV infection studies show that HIV infection advances more rapidly in HIV-positive men who conceal their homosexual identity than in those who were open about their identity (Smart & Wegner 2000:229). Similarly, Crandall (2000) found that PLWHIV who did not disclose their status to significant others were likely to

become isolated, more depressed and more anxious than those who selectively confided in people whom they trusted. Clearly stigma destroys the bonds that had been established with significant others, while damaging the intrapersonal being of the stigmatised by destroying his or her health status and psychological well-being.

2.9.1 The impact of stigma on prevention

Given the long and unsuccessful efforts of the search for an HIV/AIDS cure, societies have resorted to prevention efforts as an alternative way of fighting this epidemic. Prevention therefore came to be regarded as better than cure, which is currently unavailable. Advocacy messages which encourage disclosure and the use of contraceptives such as condoms were adopted and are believed to be able to curb the spread of the epidemic by reducing new infection rates which eroded most of the families and left others unstable.

Prevention therefore remains effective if people openly come out, disclose their status and openly talk about their illness so that its reality and severity may be clearly understood. In other words, HIV/AIDS prevention measures can be clearly understood and taken seriously if such messages are from the PLWHIV themselves. This can take place in the form of disclosure, openness and being comfortable to talk about one's HIV-positive status. However, with the existence of stigma which forces people to hide their condition and to shy away from public places because of their fear of blame and rejection, this process of effective prevention becomes difficult if not impossible. PLWHIV's innate need for association therefore drives them to hide their status and to remain silent, because if they open up and talk about their condition they risk rejection and avoidance. Shefer (2003:299) says in this regard that the continued silencing and stigmatising of STIs (Sexually Transmitted Infections) including HIV/AIDS in South African communities perpetuate unsafe sex practices among men and women who are too afraid to reveal their status. The South African Department of Health (2007:33) acknowledges the impact of stigma on prevention when it states that one of the consequences of the problem of stigma, exclusion and discrimination against PLWHIV is that it forces people who are infected to hide their condition and to continue engaging in high-risk behaviours – which makes prevention efforts difficult. Stigma therefore remains a barrier to HIV/AIDS prevention through its perpetuation of fear, denial and silence.

2.9.2 The impact of stigma on treatment, care and support

Access to health care which include treatment, care and support is one of the basic human rights enshrined in the Constitution of the Republic of South Africa (Act 108 of 1996). Prevention, care and support therefore are components through which the impacts of HIV/AIDS (including stigma) can be mitigated. As people receive treatment such as ART (Antiretroviral treatment), their health status improves and they can avoid stigmatisation based on the abomination of the body, because their opportunistic infections will become controllable with treatment. Most countries, also South Africa, have specific targets of mitigating the impact of HIV/AIDS and its related stigma through treatment, care and support. In South Africa such target involves expansion of treatment, care and support to 80% of all PLWHIV and their families between 2007 and 2011 (South Africa, DoH 2007). Given all these targets, one may ask whether they will be at all attainable in the context where stigma and discrimination prevail. Although there is commitment on the part of the state to fight the impact of this epidemic, the existence and reality of stigma and discrimination which instil the very real fear of losing relationships and of being labelled can never be ignored as far as access to treatment, care and support are concerned.

Access to treatment in the case of HIV/AIDS is a process which begins with knowledge of one's HIV status through undergoing an HIV test. Given the fear, denial and silence accompanying the disease due to the stigma, this knowledge of one's HIV status becomes threatened because people become reluctant to be tested for HIV. People choose to live without any knowledge of their HIV status because they are afraid of being labelled and rejected if their results should be positive. This is supported by Hutchinson and Mahlalela (2006:446), who state that the stigma surrounding HIV/AIDS and PLWHIV serves as an additional barrier affecting the acceptability of testing and the extent of social support, because many people fear the psycho-social consequences of testing positive for HIV – particularly when it may lead to a loss of social status, discrimination and domestic violence.

Talja (2005:43) found in this regard that some people avoid testing because they fear dying and that this is because HIV/AIDS is strongly associated with death in popular perception. People therefore prefer not to know their status than to live with the death sentence. Another reason associated with people's reluctance to be tested is the fear of

being stigmatised and discriminated against. They know that going for a test would result with either a negative or a positive test result, and with the latter they would be called names, blamed, rejected and abandoned.

The South African survey conducted by Shisana *et al* (2005) found that stigma and discrimination against PLWHIV have often been identified as primary barriers to effective HIV prevention, treatment care and support. If one does not know one's status one can easily spread the virus further to others, and can deteriorate quickly because one could lose a couple of healthy years due to lack of medical treatment – something one might have received had one known one's status earlier (Shisana *et al* 2005). Equally one would not receive the relevant professional care and support such as counselling on how to practise a healthy lifestyle and how to protect oneself because one is afraid of being identified and stigmatised.

Fear of stigma is with those who decide to undergo a test and are then found to be HIV-positive. Such persons may then hide their status and shy away from accessing treatment and care due to their fear of being labelled and rejected. In their studies of barriers to acceptance and adherence to ART among rural Zambian women, Murray, Semrau, McCurley, Thea, Scott, Mwiya, Kankasa, Bass and Bolton (2009:78) found that 70,2% of their participants cited stigma-related responses as reasons for their non-adherence to treatment. For these people it was therefore better to suffer their conditions untreated in silence, rather than to receive treatment which comes with stigma attached to it.

2.9.3 The impact of stigma on family relations

The family is a source of support, a place where people seek help and support whenever they are confronted with problems. However, this is not always the case for all individuals. For some people the very source of support and care can be just as stigmatising as the broader society itself. Aggleton (2000:14) concurs with this point by saying that infected and affected family members may be stigmatised and discriminated against within their homes. The impact of stigma on the family members can therefore never be ignored. The family itself can be stigmatised, through what Jones *et al* (1984) call *genetic association*, which some families resolve by simply disowning and abandoning the stigmatised individual or through shielding the

individual from the wider community by protecting them from questioning (Aggleton 2000; Jones *et al* 1984).

The family is not only confronted with having to cope with stigma from the outside, but also from inside the family unit. Jones *et al* (1984:258) draw attention to the reactions and feelings which include shock, depression, guilt, denial, anger, sadness and anxiety. The stability of the family and its normal functioning are affected as members adjust to the stigmatised member and his or her condition. Dossier (1990:53) says that sometimes the family itself rejects the person with HIV/AIDS. Jones *et al* (1984: 261) cite the 1969 and 1970 study of Anthony into the effects of severe psychiatric illness and physical illness such as tuberculosis (TB) on the family, which revealed that different families respond to the situation in three ways, namely growth and differentiation, breakdown and rally, and rout and disintegration.

Jones *et al* (1984) referred the first category of family as those that are drawn closer together by the experience of serious illness. In other words, the family incorporates and shares the condition of the individual member into its identity. These are families which tend to protect their members from any form of maltreatment. Families in the second category, the breakdown and rally families are those that temporarily break down under the impact of severe illness and deal with issues of change, contagion and constriction (Jones *et al* 1984). In these families, one finds such members who are still separated and whose utensils are separated from those that are used by other family members, because they are afraid of being infected. Fear of physical contagion is common in such families and the individual is rejected in order to avoid any form of contagion. Families in the last category, those that respond to the situation in a rout and disintegration manner are those that deteriorate. Members in such a family lose contact with one another. This kind of family is characterised by massive denial of the condition, non-recognition of the condition and rationalisation of the symptoms. Isolation of the stigmatised individual becomes common. The sufferer is therefore left out to sort out his or her condition on his or her own (Jones *et al* 1984).

Jones *et al* (1984:271) believe that the feelings of ambivalence – conflicted feelings – which evolve from positive and negative feelings towards the stigmatised, are common within the families of stigmatised people. In other words, members of the family might have some feelings of pity and sympathy towards the stigmatised

individual, while on the other hand blaming and rejecting him or her for having been careless and irresponsible. Although ambivalence is common and normal among most families, within families of the stigmatised it is worsened by the presence of stigma. There is no openness about the condition and this perpetuates the lack of clarity about the emotional needs of the stigmatised member. This further leads to a point where either over-estimation or under-estimation of the needs of the stigmatised member occurs and he or she becomes further exposed to stigma.

Another problem which Jones *et al* (1984:275) believe is apparent within the families of the stigmatised is that of attributing every action of the stigmatised to his or her condition. In other words, the normal actions of the stigmatised person in the family may ignorantly be misattributed to be the result of his or her condition. The impact of stigma on the families of PLWHIV has clearly been observed in South Africa and most African countries, where PLWHIV who are mostly breadwinners quit their employment as their conditions deteriorate. The consequences of quitting employment imply that the family will start to depend on the goodwill of the community members and their relatives for basic necessities, and this in itself further subjects them to stigma.

2.9.4 The impact of stigma on the stigmatised person's human rights

The context in which HIV/AIDS and its impact prevail as well as the ways in which HIV is transmitted makes it to be treated as a human rights issue. According to Heywood (2004:17), unless the stigma is challenged, it translates into human rights violation of both the stigmatiser and the stigmatised. The stigmatisers tend to be afraid of contamination and therefore find discrimination, blaming and avoiding of the stigmatised to be the best coping mechanisms. In the work context this might take the form of unfair dismissal, unfair labour practices as well as the actual discrimination against PLWHIV, while in the family context it might translate into domestic abuse, violence and harassment. According to Fuller (2008:117), gender-based violence has been so prevalent in South Africa, with a woman being killed every six hours by her intimate partner.

To the stigmatised on the other hand, hiding one's HIV-positive status and continuing to lead a normal life might be an option in order to avoid stigma and discrimination.

These kinds of coping strategy tend to deprive them access to certain rights such as the right to health care and social services. They remain silent on issues relating to HIV/AIDS and might end up putting their significant others at risk of being infected, because they may not use protective measures for they fear that that would identify them as being infected. According to Ninda *et al* (2007:93), in Africa various human rights violations have been reported such as sexual abuse and coercion, discrimination in access to health, information, discrimination in property inheritance, rape and labour exploitation. South Africa is also not immune to these kinds of problems (Fuller 2008).

2.10 FACTORS PERPETUATING THE STIGMA

Jones *et al* (1984:24) believe that the manifestation of stigma is facilitated by the concealability of the condition, aesthetics, course of the condition, disruptiveness of the condition, origin of the condition and its peril. These factors are discussed as follows:

2.10.1 Concealability

Concealability of the condition refers to whether the condition is visible or hidden and to what extent its visibility is controllable (Jones *et al* 1984:27-28). In other words, whether the condition is hidden or obvious and one's ability to control it will determine whether one will be stigmatised or not. According to Smart and Wegner (2000:220), most people might prefer to keep their medical condition secret, but unfortunately for some such a choice is not feasible as their afflictions are visible and/or uncontrollable. Jones *et al* (1984:27) cite the case of President Franklin Delano Roosevelt, whose legs were paralysed by polio and who managed to present a public image of a reasonably able-bodied man by arranging to be seen publicly and to be photographed only when his handicap would not be evident. In other words, although he was physically handicapped, he executed some control over his condition to try and keep it concealed.

There is a lot of evidence available on the factor of concealability in terms of HIV/AIDS. Studies on HIV- and AIDS-related stigma and disclosure conducted by Ostrom, Serovich, Lim, and Mason (2006) show how people control or conceal their

conditions in order to avoid the stigma. In these studies, some of the reasons for women's non-disclosure were:

- mothers thought their diagnosis was personal and reported not disclosing because of the stress associated with disclosure;
- they feared that the child may tell others; and
- they did not want their children to be burdened by the stress of knowing that their mother was ill.

Jones *et al* (1984:33) highlight two other sub-factors under concealability, namely *long-term relationship* and *close relationship*. Because the stigma manifests itself in interpersonal relationships, its factors also emerge within interpersonal relationships. In other words, whether one is in a long-term relationship with the stigmatiser or the possible stigmatisers, may also perpetuate the stigma. Concealment is determined by whether the relationship is a long or a close one. In a close relationship the stigmatised or discreditable is in close encounters with his or her close people, who clearly know him or her. In this kind of relationship it may not always be possible to hide something from those who are close and in repeated contact with the afflicted person, because they will almost invariably become aware of the condition (Jones *et al* 1984).

Conversely, in long-term relationships, a debilitating condition would have an impact on day-to-day activities such as wheelchair access. This would mean that the affliction will be non-concealable and non-controllable. The more evident and non-concealable the affliction, the more it will interfere with normal life functions such as moving, working and caring for oneself (Jones *et al* 1984:35).

HIV- and AIDS-related stigma clearly fits in with this factor of concealability and its sub-factors. HIV/AIDS progresses through phases where initially the condition is concealable and controllable. Then the condition deteriorates, through the manifestation of opportunistic infections to the eventual manifestation of the final stage of AIDS, which would no longer be concealable and controllable. The nature of the relationship within which the stigmatised is with the stigmatiser will determine whether the stigmatised will be able to hide and control the condition or not. If one for

example stays with a life partner, one might find it difficult to conceal and control the condition, even during the early stages of manifestation (Jones *et al* 1984:33).

Alternatively, if one interacts with people in a long-term relationship such as in the work context, the condition might not be visible in its initial stages and the afflicted person may be able to conceal and control it during the initial stages, but this may not be the case during the last stages such as the full-blown AIDS stage. In the case of one who stays with a life partner, the partner might be able to identify the condition through things like emotional instability, certain attitudes and behavioural changes in the afflicted person. This might lead to curiosity in the matter and hiding it might prove to be difficult. In the case of a long-term relationship such as in the workplace, continuous abseentism, sick leave and under-performance may expose the condition to the stigmatisers.

2.10.2 Aesthetics

People's physical appearances affect the nature of their relationships. People tend to prefer to associate with other people of a certain height, skin colour and weight. *Aesthetics* – whether the disease manifests itself through bodily appearance is another factor which perpetuates the stigma. Disfigurements such as a missing limb, a twisted body, a club foot or distorted facial features can dramatically affect how attractive someone is to others. The bodily proportions resulting from the condition also serve as a factor to determine whether someone may be stigmatised or not (Jones *et al* 1984:49). Some researchers suggest that people's view of the world and themselves is coloured by their own appearance. They go as far as to link a lack of physical attractiveness with lower self-esteem and believe that those people who are satisfied with their faces are more self-confident (Jones *et al* 1984:54). The enduring nature of labelling and stigmatisation also means that some people can become completely defined by such labels, for example when people refer to someone as "the lady with one eye" or "the thin one".

Contagious diseases such as HIV/AIDS are subject to the aesthetic factor of stigma. As the condition deteriorates through its different stages, bodily attributes such as weight loss and manifestation of the opportunistic infections become common. All

these factors serve as some grounds for the perpetuation of the stigma, because such individuals are easily identified and recognised through such symptoms.

2.10.3 Course of the condition

Stigma is determined by the course of the condition – the degree to which the condition has either diminished or worsen over time. This factor refers to those features of the condition that determine the pattern followed by socially degrading conditions over time. Some conditions can be changed over time by the stigmatised persons themselves or by their significant others (Jones *et al* 1984:36-38). The course of the condition is clearly relevant in contagious diseases such as HIV/AIDS. Because HIV/AIDS is regarded as an incurable condition and because it deteriorates as it progresses through certain stages, this makes it to be a more stigmatisable condition. However, although it is not curable, some advances have been made, such as delaying the manifestation of the later stages and management of opportunistic infections through treatment programmes such as ART.

The above point is similar to what Jones *et al* (1984:40) call the efforts of the infected persons to change the condition through medical techniques in cases of HIV/AIDS, where total elimination is impossible. Physical exercises and a more balanced diet can be adopted by the stigmatised to boost the immune system and delay manifestation of opportunistic infections as well as death itself. In this regard the manifestation of opportunistic infections will be controlled and concealed, and the stigmatised can be able to minimise their stigma. The significant other plays an important role in changing and controlling the condition, and family members, doctors, counsellors and other professionals could play a pivotal role in ensuring that the stigmatised person complies with treatment so that the condition may be managed.

2.10.4 Disruptiveness of the condition

Disruptiveness refers to the condition's ability to be disruptive or to change what is normal in a relationship to non-normal. The more disruptive the condition is, the higher the likelihood that the stigmatised will be more stigmatised. The factor of disruptiveness has been researched mostly among mentally ill patients, but this does

not mean that it is only restricted to such groups (Jones *et al* 1984:47). It is also applicable to people living with contagious diseases such as HIV/AIDS.

HIV/AIDS deteriorates through certain stages, and with the fourth stage, which is more symptomatic and even critical, the stigmatised person requires all kinds of assistance even with basic things such as feeding and bathing. This might require someone to be there for him or her on a daily basis. This would mean that such a caregiver would have to abandon or suspend some of his or her other tasks in order to accommodate the needs of the stigmatised person. This practice has been observed in most African countries, for instance where children decided to drop out of school to look after their sick parents. Jones *et al* (1984) believe that such disruptiveness is likely to end up at a point where the caregiver will begin to stigmatise afflicted person. The fact that HIV/AIDS infect the most economically active populations of the society also provides a clear picture of the disruptive nature of the disease. As the condition deteriorates, the infected individuals might decide to leave their jobs and this would mean that their families would not have income. Such families might begin to depend on the goodwill of the community members and relatives, who would also have to re-adjust themselves in order to accommodate them. This practice makes the stigmatised person to be more prone to stigma because their dependence on the goodwill of their significant others causes a disruption – it forces the significant others to re-adjust themselves in order to help address the afflicted person's needs.

2.10.5 Origin of the condition

The origin of the condition is believed to be a factor which determines whether one will be stigmatised or not. By "origin" Jones *et al* (1984:57) refer to the question of how one contracted the condition. In the case of HIV/AIDS this might refer to whether it was heterosexually through rape, accidentally during blood transfusion, or voluntarily during unprotected sexual intercourse. One important aspect of origin as a factor of stigma is the responsibility of the stigmatised. Many theorists concerned with stigma hold that the afflicted person's role in bringing about the condition is an important factor in the stigmatising process. People who are believed not to have been responsible for the emergence of their conditions are less likely to be stigmatised than those who are believed to be responsible. Jones *et al* (1984:56-64) highlight three sub-

factors which influence origin as a factor of stigma, namely responsibility of the afflicted, intention of the afflicted and the rapidity of the onset of the condition.

The afflicted person's responsibility for the condition is believed to be either that of *causing the condition to emerge* or that of *maintaining the condition*. In the case of someone who is believed to have acquired HIV through commercial sex work as well as one who is believed to have been raped but who continues with unprotected sexual practices, the former might be viewed as responsible for the cause of his or her condition, while the latter may be stigmatised for maintaining the condition by continuing to behave irresponsibly and putting her life and the lives of others at risk.

Another sub-factor of origin which influences stigma is the *intention of the stigmatised*, that is, whether the condition was contracted accidentally or was it contracted intentionally. The sub-factor of intention is observable in many cases of HIV/AIDS, where PLWHIV who may have a history of commercial sex work, multiple sex partners or engaging in unprotected sex become more stigmatised, because it is believed to be their intention to acquire the condition, whereas someone who have been raped might be welcomed with pity and sympathy.

As far as the *rapidity of the onset of the condition* is concerned, Jones *et al* (1984:64) believe that when the condition manifests itself gradually it allows the person to adapt to it, but when it manifests itself rapidly within a short space of time, the person is suddenly confronted with the full-blown condition. Given the fact that HIV/AIDS manifests itself differently among different people, depending on the strength of their immune system, some PLWHIV find themselves not stigmatised because they do not rapidly progress into the later symptomatic phases of the condition, while others become victims because their condition manifests itself rapidly.

2.10.6 Peril

The last factor which determines whether one may be subjected to stigma is peril – the dangers posed by the stigmatised to the stigmatiser. People tend to reject and avoid people with certain conditions, mainly because such conditions pose a danger to them. Investigations reveal that the more dangerous the stigmatised is thought to be, the more he or she will be rejected (Jones *et al* 1984:65).

Jones *et al* (1984) distinguish the following eight kinds of peril:

2.10.6.1   *The peril of physical or verbal attack*

This kind of danger is posed particularly by some mentally ill patients who are violent. Such people tend to be feared and avoided because of the danger they pose to others. Physical or verbal attack is not applicable to most PLWHIV, because these people are mostly helpless and need support and care from their associates (Jones *et al* 1984:67).

2.10.6.2   *The peril of physical contamination*

The second form of peril is that of *physical contamination* where the stigmatisers avoid and reject the stigmatised person, because of the danger that he or she poses to them through physical contamination. HIV/AIDS fits clearly in this form of peril due to the fact that it is a contagious disease which can be transmitted if certain precautions are not observed. Its association with opportunistic diseases such as TB also makes it to be a feared condition because of its ability to be transmitted to the stigmatisers. The stigmatised are therefore rejected and avoided due to fear of contamination (Jones *et al* 1984:68).

2.10.6.3   *The peril of social rejection*

Another form of peril is the *peril of social rejection* (Jones *et al* 1984:67). Human beings are preordained to belong to social groups and form coalitions (Morris 2003:23; Neuberg *et al* 2000:35). The stigmatisers therefore tend to avoid and reject people who possess or who are suspected to possess a stigmatising condition, because if they associate themselves with such people they risk being rejected and avoided by their social groups and coalitions. This matter is explained better by the consensus theory, which states that people tend to live in the majority-rule world where they abide by the norms and values of the majority (Crandall 2000:129). Associating themselves with those who possess a condition or believed to possess a condition of the socially and

morally polluted groups of society, may leave them in a situation where they may also become stigmatised (Jones *et al* 1984:69).

2.10.6.4 *The peril of mere association with the stigmatised*

According to Jones *et al* (1984:71), mere association with the stigmatised in the form of an innocuous or casual walk down the street could make one subject to stigma. Such a person may be stigmatised because he or she may be believed to be hiding a similar problem. In order to avoid this kind of stigma, people tend to resort to stigmatising such people who pose a risk to them, and they avoid and reject mere association with PLWHIV due to their fear of being labelled as possessing suffering from the same condition but simply hiding it. In this regard Goffman (1963:64) states that to be seen to be interacting with someone can leave the social identity of the associates open to speculation, so that the only available coping strategy for such associates might be to resort to also stigmatising the already stigmatised.

2.10.6.5 *The peril of occupational association*

Some professionals are stigmatised for their involvement with stigmatised people such as PLWHIV, the mentally disabled and others. With HIV/AIDS, which caused the health care system in South Africa to be extremely overburdened, calls were made for community-based care programmes to be developed. This resulted in more informal para-professionals such as lay-counsellors and caregivers getting more involved with PLWHIV. Their professional involvement with PLWHIV therefore end up leaving them in stigmatising conditions. They are believed to possess the same condition but to be hiding it and pretending to be the helpers. It therefore appears to be this form of association peril which leads to a point where these para-professionals and the other professionals involved with people living with HIV, end up stigmatising the PLWHIV in order to avoid this stigma of occupational association (Jones *et al* 1984:72-73).

2.10.6.6   The peril of genetic association

Genetic association is believed by Jones *et al* (1984:73) to be the most severe form of peril. Here the individual who is genetically associated with the stigmatised becomes stigmatised because of such association. A coping strategy of the stigmatisers in this situation is through abandoning and disowning the stigmatised in order to be accepted in the larger group of society (Jones *et al* 1984:73). Because genetic association means that the associate may be a parent, a sibling or a child, disownment and abandonment is a hard step to take, because it might earn the stigmatiser another devaluation and the stigma of abandoning and disowning the genetic associate. The stigmatiser therefore becomes stuck in the middle of fear and finds it difficult to decide which stigma would be the easier one to bear. This practice has been observed in some families, where some members find themselves in a situation where they do not have a choice but to face the stigma of continuing to provide care and support for their stigmatised family member, while others decide to rather face the stigma of abandoning and disowning him or her.

2.10.6.7   The peril of moral contamination

As human beings we tend to have an attitude of rejecting and avoiding association with certain groups because their behaviour and attitudes are socially and morally unacceptable to us. The peril of moral contamination refers to the form of peril through which the stigmatisers stigmatise in order to avoid being viewed as morally contaminated (Jones *et al* 1984:75).

The reality of the peril of moral contamination is apparent especially among the religious and cultural groups. Mwondela-Katukula (2006:17) cites an example of Pastor Miriam Shinkongo, a Pentecostal preacher in Windhoek, Namibia who commented on the national radio that *"HIV was a curse from God and a punishment for man's iniquities"*.

Such experiences are common in South African religions and cultural groups, where PLWHIV are viewed as sinners who are cursed and who should ask for forgiveness from God so that their sins can be washed away. Consequently,

such experiences may be internalised by the stigmatised, who may start to view themselves as cursed sinners; they may begin to blame themselves and eventually see no value of living in the world of the morally and socially pure majority group members. Suicidal thoughts and negative feelings about life might emerge.

2.10.6.8   The peril of strong obligation

Another form of peril of social rejection is the stigmatisers' fear of a strong obligation that is likely to emerge as they interact with the stigmatised. This kind of fear becomes a serious threat when the relationship of the stigmatised and the stigmatisers is a continuous one, such as in the family or work setting (Jones *et al* 1984:75). With HIV/AIDS, as the condition deteriorates, the stigmatised may require more help and this might mean that they turn to their close associates for help and support. Because this kind of help might be permanent in nature, it becomes a strong obligation on the stigmatisers, who are then expected to continue providing care and support to the stigmatised. Because this kind of association end up leaving the stigmatisers themselves being strongly obliged to continue caring for the stigmatised, they tend to resort to stigmatising the stigmatised by simply avoiding and rejecting them. In this way, the stigmatisers try to keep the stigmatised away from them so that they cannot have any obligation attached in their relationship with the stigmatised.

2.11 HIV- AND AIDS-RELATED STIGMA

Negative labelling of certain groups and individuals who for some reason differ from the majority is not unique to HIV/AIDS. Certain categories of people have always been singled out as vectors for disease. According to Zuberi (2004:46), stigma is not unique to the HIV/AIDS epidemic – it has been well documented with other infectious diseases such as TB, syphilis and leprosy. The USAID (2004) expresses a similar view and states that social stigma and disease have been integral parts of human history, the classic example being the extreme stigma experienced by the persons with leprosy that has persisted long after the discovery of a cure. Because HIV infection is contagious, and spreads through socially and morally condemned

routes such as injecting drug use and unprotected sex, the problem of stigma became more complicated. According to Zuberi (2004), there are four reasons for people to stigmatise someone with HIV/AIDS:

- HIV/AIDS is a fatal disease and this causes fear of infection;
- HIV/AIDS is often associated with behaviour which is already stigmatised;
- Becoming infected with HIV is seen as the result of choices made by the individual; and
- Having HIV/AIDS is seen as a punishment for deviant behaviour.

Stigmatisation was therefore adopted in order to identify and separate PLWHIV because they were perceived as posing a threat to the general population. They became rejected and marginalised, because they were viewed as those who had committed sin and therefore deserve to suffer the consequences of their own fate; they have angered the Gods and need to be cleansed through punishment so that the Gods can be appeased (Shoham 1970).

2.12 HIV- AND AIDS-RELATED STIGMA, THE CASE OF SOUTH AFRICA

Just like in many countries of the globe, the South African HIV/AIDS was associated with stigma and discrimination. Lawson (2008:21) explains that the South African National Party government assured the general public that the virus could only be transmitted sexually between homosexuals or via needles of drug users. Moreover, the disease was left up to gay men to resolve (Lawson 2008). However, it soon became apparent that heterosexual transmission of HIV was prominent in Africa. This resulted in the shift of the stigma towards this group, and the disease was associated with Africa and being African. Later on, as the virus became widespread among this group, and the mining sector became widely affected, with 0,02 per cent of South Africans and 3,76 per cent of Malawian miners testing positive for HIV (Lawson 2008).

The shift of blame then became expanded to the African foreigners, who were accused of bringing the disease into South Africa, and in 1987 the government introduced new legislation requiring compulsory HIV testing for all foreign workers (Dossier 1990; Lawson 2008). This kind of shift in blame to certain groups spread with the disease until the so-called *bad behaviour* was blamed as the main reason for

the spread. With behavioural blame, PLWHIV are in a very difficult situation because it implies that they got infected because they engaged in unacceptable behaviours. Lawson (2008:65) quotes the South African Health Minister, who said in 1988, *"promiscuity is the greatest danger, whether one likes it or not. We have to say that. It is a fact. There is no way one can say I still want to sleep around but I don't want to get AIDS."* In another excerpt a Member of Parliament is quoted as asking *"when legislation would be introduced to authorise the Honourable Minister to remove* [PLWHIV] *from the community"*. This kind of perception of and reaction to the disease imply that PLWHIV had acquired the disease because they engaged in morally unacceptable behaviours. From Goffman's (1963) point of view one might say they were seen as "*not fully human beings"* and were therefore *"reduced"* in the minds of the general South Africans. They therefore had to be removed through legislation so that the society can avoid contamination.

This kind of practice overlapped into the democratic dispensation of the year 1994 where HIV- and AIDS-related stigma was treated with fear within communities and families. Because the stigma enables one to be viewed as guilty and to be blamed for acquiring this disease, South Africans who are living with HIV/AIDS feel that the only option to avoid being stigmatised, blamed and rejected is to keep quiet and pretend that the condition does not exist. Some tend to blame themselves because of the widely believed perception that they are sinners and are therefore responsible for their condition. They feel that they did something wrong which made them to deserve the condition. This is the kind of stigma which Zuberi (2004:47) calls *internal or felt (anticipated) stigm*a which is characterised by self-blame and self-denial.

Although the South African national survey conducted by Shisana *et al* (2005:xxiv) identifies low stigmatising attitudes among the South Africans, there is overwhelming evidence which highlights the fact that stigma is still a problem in this country (Daftary, Padayatchi, & Padilla 2007; South Africa, DoH 2007; Heywood 2004; Hutchinson & Mahlalela 2006; Visser *et al* 2009). The South African cultural beliefs perpetuate HIV- and AIDS-related stigma. PLWHIV are believed to be bewitched and therefore the reality of their condition is denied (Steinberg 2008). Studies by Visser *et al* (2009:200) reveal that – although only a small percentage (5,7%) – there are people who believe that PLWHIV have been bewitched, and others (15,7%) believe that

traditional doctors could cure HIV/AIDS completely. Steinberg's (2008) study reveals similar findings, with pills being regarded as toxic by some of his participants, who preferred herbs instead of pills.

2.13 HIV- AND AIDS-RELATED STIGMA,

THE CASE OF SOUTH AFRICAN WOMEN

South African women live in the legacy of the apartheid regime where race, gender and class determined what kind of life one should lead and where sexual violence and rape were rife (Lawson 2008). They live in the legacy of a patriarchical societal system which culturally and religiously dictated that they should remain caring, humbled and obedient towards their male counterparts, and this left many suffering violence and marital rape in silence.

In Africa and its countries such as South Africa, HIV/AIDS is a disease whose experience will mostly be told in terms of African girls and women whose lives it has (negatively) changed or taken (Commonwealth 2002; Lawson 2008; UNAIDS 2000). African women are the group worst hit by HIV/AIDS. They are vulnerable due to less education and cultural expectations of being married and having children. They are also expected to take care of their families, the aged and the ill (Commonwealth 2002). Because they have limited options for employment, they tend to be economically dependent on men – who all too often are unfaithful, migratory, violent and/or dismissive (Fuller 2008:2). Morris (2003:25-26) supports this by stating that stigmatisation requires power to do so. It is created and reinforced by social inequality. In other words, it is the economic and social power that most African and South African men have over women that perpetuates the stigma, because the women are compelled to depend economically and otherwise on their partners.

According to Talja (2005:28), when someone is already being badly treated, they are exposed to even harder situations. This is also the case with South African women, whose situations became more complicated as they became confronted with a sensitive disease which is associated with death, and with irresponsible and immoral behaviour, while they themselves are the most infected group (South Africa, DoH 2007). They are burdened with the role of caring for the sick and have become

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exposed to infections, due to misconceptions and the belief that the mode of transmission was through unacceptable behaviours such as promiscuity. Because they became the most infected group compared to their male counterparts, they are viewed as more irresponsible and they are blamed for having engaged in unacceptable, bad behaviours such as prostitution which left them infected.

According to Ostrom *et al* (2006:60), for women in particular, HIV- and AIDS-related stigma can cause them to be labelled as drug users, prostitutes or being sexually promiscuous. This has been observed in South Africa, where the African National Congress Youth (ANCYL) League President Mr Julius Malema publicly insulted an HIV-positive woman who accused the then President of the ANC (African National Congress) of raping her. In his statement, which later landed him in the Gender Equality Court, Malema told the cheering and appreciative crowd of students that:

"When a woman didn't enjoy it [the alleged rape]*, she leaves early in the morning. Those who had a nice time will wait until the sun comes out, request breakfast and ask for taxi money"* (Makhanya 2009:12).

The UNAIDS (2000) condemns such judgemental perceptions, and believes that stigma may have a certain impact on women, for instance in the following ways:

- Women in some regions of the world may not seek care out of fear that their children will be taken away from them if they are diagnosed with a severe illness (UNAIDS 2000:20).

- Women are often blamed for the spread of HIV-infection to their families (UNAIDS 2000:20). Findings of studies conducted by the Centre for AIDS Studies in Temba and Hammanskraal revealed that women living with HIV did not receive family support; instead their families thought it proper to punish them, especially if the victim's attitudes and behaviours before the disease were not desirable (Viljoen 2005:39).

- HIV/AIDS is incorrectly perceived as a woman's disease in many parts of the world, and this causes women to refrain from HIV testing and seeking out care in order to avoid being ostracised, abused, and viewed as promiscuous.

- In some parts of the world, stigma and discrimination against women living with HIV or other STIs may include refusal to treat them because of the widespread beliefs that these women are dirty or promiscuous.

The Commonwealth (2005:37) condemns this belief, and discourages the use of terms such as *"mother-to-child-transmission"* instead of *"parent-to-child-transmission"*, for it perpetuates the myth of women being the only carriers of the virus.

Heywood (2004:17) on the other hand perceives the virginity testing in KZN and many other parts of Africa as perpetuating the perception of women and their vaginas in particular as "dirty" and containers of the disease. These and many other practices perpetuate the stigma and discrimination against women living with HIV and leave them in worse conditions.

2.14 COPING WITH THE STIGMA

Coping mechanisms adopted by stigmatised persons are influenced or determined by factors perpetuating the stigma. Someone who has non-concealable symptoms may not cope in the same way as someone whose symptoms are concealable. To someone who has concealable symptoms, hiding them and avoiding situations where they may be revealed might be a good coping strategy, while to someone whose disease is more visible, displaying it more openly and making people feel more comfortable with it or avoiding stigmatising contexts might be a good coping strategy. According to Breitkopf (2004:5), individuals can manage stigma by secrecy, withdrawal, covering, informing or disclosing. These coping mechanisms are discussed below.

2.14.1 Secrecy

With secrecy the stigmatised person decides to keep the condition to him- or herself and to avoid situations where it can be recognised (Breitkopf 2004). These people make themselves appear healthy and without any problems in their social intercourse, even though they are suffering and are stressed by the condition. In this category one might find those individuals who possess concealable and controllable symptoms. Smart and Wegner (2000:220) acknowledge this kind of coping mechanism among those who possess concealable symptoms, and state that people with symptoms that

are not clearly visible to others have a choice of not telling. This is also the case with PLWHIV who are in their asymptomatic phase of infection and who often decide to keep their conditions to themselves due to their fear of being labelled and stigmatised.

2.14.2 Withdrawal

Withdrawal involves removing oneself from social situations in which the symptoms (concealable or visible) can become apparent (Breitkopf 2004). Individuals who engage in withdrawal as a coping strategy are those who avoid social associations and cut off friendships in order to avoid rejection and blame due to their HIV-positive status. In this category one finds those people who do not participate in support groups, those who avoid public treatment centres and avoid discussions about their condition.

2.14.3 Covering

People who adopt the third coping strategy, namely covering, are those who attempt to deflect the stigma and enable others to be more comfortable with it (Brietkopf 2004). Daftary *et al* (2007:374) describe covering as a strategy whereby a person with multiple discreditable attributes covers a dominant stigma with one that is less dominant. HIV- and AIDS-related stigma can be seen as the dominant stigma due to the fact that it is associated with personal blame and immoral behaviour; TB can instead be seen as a less dominant stigma; so someone who is co-infected by both diseases, is likely to cover the HIV/AIDS with TB, which is the less stigmatisable condition (Daftary *et al* 2007:574).

2.14.4 Informing

The fourth strategy for coping with stigma involves informing – when the individual disseminates the stigma widely by making themselves obvious over time (Breitkopf 2004). In other words, individuals in this category often find themselves in a situation where they do not use timing; they accidentally inform others about their condition and later regret it. Although individuals from all the different categories of stigma

may be found in this category, most people in this category are those who possess non-concealable and non-controllable as well as disruptive symptoms.

2.14.5 Disclosure

The last category for coping with stigma entails resorting to disclosure. According to Emlet (2006:351), PLWHIV may reduce potential infection of sexual partners and so diminish the spread of HIV by disclosure. Disclosure can provide a means to obtain social support and assistance in coping with the disease process. Disclosure is described by Makin, Forsyth, Visser, Sikkema, Neufeld and Jeffery (2008:908) as the process that involves decisions about timing, to whom, how, and under what conditions. Timing is therefore an important factor. In their study in France, Makin *et al* (2008:908) found that 42% of the subjects disclosed immediately after diagnosis, 21% in the month after diagnosis, and 24% waited for more than a year to disclose to someone.

According to Breitkopf (2004), disclosure may be *protective, spontaneous* or *preventative*. With protective disclosure, the person takes his or her time planning when, how, to whom, where and under what circumstances disclosure would take place. Spontaneous disclosure is when the person does not plan, it takes the person by a surprise and is sometimes characterised by emotional outbursts which can lead to regret. Preventative disclosure takes place when a person prevents the stigma by disclosing in advance. In others words, the person becomes sensitive to the danger of being discriminated against and quickly discloses before that can happen.

2.15 CONCLUSION

This chapter has shown that stigmatisation is a complex psycho-social process which is rooted in the seventeenth century and which may be understood from the perspective of various relevant psycho-social theories. As highlighted in this chapter, different researchers have different perceptions with regard to the definition of this concept. Like any other psycho-social problem, stigma serves certain functions to the stigmatisers and the maintenance of societal stability, while resulting in certain impacts on prevention treatment, care and support, family relationships and the

human rights of the stigmatised. As a psycho-social process, stigma manifests itself within a context where certain factors facilitate its emergence.

It was shown in this chapter how HIV- and AIDS-related stigma emerges and unfolds, as well as the nature of the South African HIV- and AIDS-related stigma, where specific emphasis was placed on women. The impacts of stigma on the stigmatised were discussed, and emphasis was placed on the stigmatised person's access to treatment, care and support, his or her family relations, and on his or her human rights. Finally, the coping mechanisms of stigmatised individuals were discussed, and attention was paid to secrecy, withdrawal, covering, informing and disclosure. In the next chapter the researcher discusses the background to the research methodology.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

In this chapter the researcher discusses the methodology utilised during the study. In doing so, he will first discuss the nature of an exploratory and descriptive qualitative research design, and will then demonstrate how it was applied throughout this study. This is followed by a discussion of how the sampling procedures were applied in the study. In the last section of the chapter, the ethical principles adhered to are discussed.

3.2 CHOSEN RESEARCH DESIGN

A research design is a kind of map which the researcher follows in order to achieve his or her goal and objectives. Babbie (2005:87) states that it is a process that involves a set of decisions regarding the topic, the population and the methods for gathering and analysing the data. Research can be conducted to serve exploratory, descriptive or explanatory purposes (Adler & Clark 2008; Babbie 2005). An exploratory study is research through which the researcher investigates a relatively unstudied topic or a new field of knowledge. A descriptive study is research through which the researcher aims to observe and describe a situation or topic (Adler & Clark 2008; Babbie 2005).

This study was exploratory and descriptive in nature, because the subject of anticipated and enacted stigma among female outpatients living with HIV at the Chris Hani Baragwanath Hospital is a new area of study. It was the aim of this study to explore, to gain insight into and describe the experiences of these women, and then to develop some recommendations for policy and practice.

According to Simelane (cited in Lekganyane 2008:37), the nature of qualitative research is oriented toward exploration. Qualitative research aims to capture the lived experiences of social actors and the meanings that people give to these experiences from their own perspectives. It is well suited to studying complex situations.

The fact that the researcher as a young and educated African male was conducting interviews on personal and emotionally overwhelming issues with female participants,

presented an ethical dilemma. Babbie (2008:317) points out that reactivity might occur in such studies, since research participants react to the characteristics of the researcher. However, the researcher guarded against this problem by approaching the study with great caution. He remained vigilant against harming the respondents in any way, while at the same time being cautious not to let that contaminate the quality of data. In doing so, the researcher struck a balance between getting in-depth information while remaining careful not to push the participants to reveal more than what they felt ready to divulge. He respected the decisions of the participants who did not answer certain questions for their own personal reasons. In cases where a participant got emotional, the researcher was always ready to immediately pause the interview to allow her to calm down, referred her to relevant practitioners like psychologists, and proceeded with the interview only with her permission. This practice is recommended by Dickson-Swift, James & Liamputtong (2008). In addition to the above, the researcher respected the participants who were not comfortable to answer certain questions by not forcing them in any way to provide answers.

3.3 VALIDITY

Different commentators suggest different validity criteria for qualitative research. For example, Lincoln and Guba (1985) stress truth value and credibility, Eisner (1991) refers to trustworthiness, and Guba and Lincoln (1989) emphasise authenticity. According to Neuman (2007:120), *"qualitative researchers are more interested in authenticity than validity. Authenticity means giving a fair, honest and balanced account of social life from the viewpoint of someone who lives it every day."* The researcher found it imperative to understand the experiences of the participants from their own point of view, as suggested by Neuman (2007) above.

The researcher enhanced and protected the credibility of the data gathered by allowing the research participants to tell him about their experiences of stigma and discrimination. In this regard Neuman (2007:249) explains *"field researchers depend on what members tell them. This makes the credibility of members and their statements part of reliability... field researchers take subjectivity and context into account as they evaluate credibility."*

The checks for validity in qualitative work as described by Whittemore, Chase, & Mandle (2001) were followed in this study. The researcher endeavoured to produce

research that is credible by presenting the results of the interviews in such a way that it reflected the experiences of the research participants and their social contexts in a believable way. In addition, authenticity of the results was emphasised by a representation of an academic perspective that showed convergence and divergence in the voices of the research participants. Observing the criterion of criticality, the researcher critically appraised the research design (see chapter 5 for a discussion of the limitations of the study). Mindful of the criterion of integrity, the researcher transcribed his interviews immediately after the interviews and checked and re-checked the transcriptions and coding. Taking the criterion of explicitness into account, the methodological decisions are detailed in this chapter. The researcher tried to adhere to the criterion of vividness by producing thick and faithful descriptions. Striving for thoroughness, the researcher reflected on the question of whether findings convincingly address the stated objectives of the study. The criterion of congruence was met by careful analysis so that the themes fit together and the findings fit into the context of the study situation. Finally, the researcher was mindful of the criterion of sensitivity by constantly keeping the ethical requirements of the study in mind, and by remaining sensitive to the nature of cultural and social contexts.

3.4 RECRUITMENT OF RESEARCH PARTICIPANTS AND SAMPLING

The population of this study consisted of women living with HIV aged 18 and older, and who received services as outpatients. Recruitment of the participants was made in the following manner: after the approval of his request to conduct the study by the hospital authorities, the researcher introduced himself to the Head of the Nthabiseng HIV/AIDS clinic, who later introduced him to the sister in charge of the clinic. After his meeting with the sister in charge, an announcement was made to all the patients who were waiting to access treatment, and a request was made for volunteers who met the researcher's criteria as provided below. The response to this announcement was positive and the researcher scheduled an appointment with the participants, where the details of the study were spelled out to them verbally and in writing. The actual data collection was then conducted, after the participants were informed about their roles, risks and benefits of participation and the researcher's obligations.

According to Adler and Clark (2008:121), for many exploratory studies and much qualitative research, purposive sampling is desirable. Babbie (2005:189) and Adler

and Clark (2008:121) describe the purposive sampling method as a method which is selected on the basis of the researcher's knowledge of a population and its elements that are similar to the purpose of the study. Participants of this study were selected in accordance with the following criteria:

- Participants were female outpatients of the Chris Hani Baragwanath Hospital.
- Participants had all been diagnosed as HIV-positive.
- Participants were all aged 18 years and older.
- Participants were all voluntarily willing to participate in the study, and to be interviewed and tape-recorded.

Although it was initially envisaged that at least 24 such women would be identified and contacted, following the criterion of saturation of themes, the researcher was able to recruit and interview only six research participants that suited the selection criteria. While all of the women were black, in terms of language, the group included one IsiZulu-speaking, one Northern Sotho-speaking, two Southern Sotho-speaking and two Setswana-speaking women.

Three of the research participants resided in Greater Soweto, one participant was from Westonaria, one was from Orange Farm and one from the Johannesburg CBD.

The participants' ages ranged from 28 to 54. One was 28 years old, one was 33 years old, one was 38 years old, one was 42 years old, one was 43 years old, and one was 54 years old.

Four participants reported that they were unemployed, while two reported that they did some part-time jobs. One participant was married, two cohabitated with their partners, one was a widow and two were single.

All of the research participants in this study had at least a secondary school level of education. One participant had an educational attainment level of Standard 8 (Grade 10), three had Standard 10 (Grade 12), and two had obtained tertiary qualifications at college level.

All of the research participants had at least one year of experience of living with HIV. One of them knew that she was HIV-positive for one year and a month, one had two

years' experience, and four had three years' experience of living with HIV. In terms of ARV experience, three participants had at least one year's experience, one had two years' experience and two had three years' experience of ARVs.

3.5 DATA COLLECTION METHODS

Face-to-face interviews were used as the primary data collection tool for this study. According to Warren and Karner (2010:2), qualitative interviewing involves present-time face-to-face interaction, telephone contact or mediated communication through the Internet. The most common format of interview is what is described by these researchers as a *dyad* (one interviewer and one respondent). This is the kind of qualitative interview that was used in this study.

The researcher had to interview the participants individually about their experiences, feelings, perceptions and coping mechanisms as PLWHIV. According to Adler and Clark (2008:271), qualitative interviews can vary from *unstructured* to *semi-structured* interactions. Semi-structured interviews are described by these researchers as interviews that are designed ahead of time but are modified as appropriate for each individual participant. *Unstructured interviews* are those interviews that are used by researchers who start a study with a sense of what information is needed and formulate questions as the interview unfolds. The semi-structured interviews were adopted for this study. In applying these interviews, an interview schedule comprising four main open-ended questions and 23 sub-questions was designed in advance, in accordance with the research goal and objectives in order to guide the flow of the interviews.

This study was undertaken in the Chris Hani Baragwanath Hospital's Nthabiseng HIV/AIDS clinic. Permission to conduct the study was granted by the hospital's Clinical Director prior to the study, participants were recruited in the following way: the researcher introduced himself to the Head of the Clinic, who orientated him to the general protocols, procedures and policies of the hospital and the clinic. The researcher was also familiarised with the hospital's ethical principles regarding PLWHIV.

During the second week the researcher attended a clinic for one day just to observe the procedures and the general atmosphere, and also to introduce himself to the clinic

staff. The following week the clinic staff introduced the researcher to the patients, showed him the boardroom where interviews were to take place, and made an announcement to all the patients about the study where six volunteers who would be willing to participate in the study, were requested. The response was positive, and six women immediately volunteered to participate. After this positive response, the researcher requested to see the participants in a private place where their names and cell phone numbers were taken and the formal invitation letters that specified the reasons for their participation in the study, the researcher's obligations as well as the risks and benefits for participation were provided to them. The researcher also signed a consent form that clarified the risks and benefits as well as his expectations with the participants (see Appendix A). During the fourth week the actual data gathering process began, where in-depth interviews of maximum duration of one hour were conducted. The interviews were tailored to fit each individual participant and their unique circumstances. In other words, the interviews were designed in such a way that the individual participants had the opportunity to tell their own stories in their own words without time or information restrictions. The interviews, which were recorded in the form of process notes and a tape recorder, were conducted in four African languages, namely Setswana, IsiZulu, Southern Sotho and Northern Sotho. Follow-up interviews were held and recorded in both audio form and in the form of process notes.

According to Adler and Clark (2008:285), it is vital to record through either audio or video when an interview covers a large number of topics. Babbie (2005:318) recommends that researchers make full and accurate notes of what goes on in both direct observation and interviewing. In this study, the researcher accurately recorded the interviews in the form of process notes into the journal immediately after each interview, for further analysis and interpretation. Follow-up interviews were later conducted and recorded in the form of audio tapes and process notes.

3.6 ANALYSIS AND INTERPRETATION OF DATA

Liamputtong and Ezzy (2005:257) describe analysis and interpretation as the process through which the researchers intentionally immerse themselves in data, and then in reading and rereading the data. The aim is to understand, through immersion in the data.

According to Seale and Kelly (1998:153), the initial stage when faced with an interview transcript, or with a set of notes describing observations or some other qualitative material, is to develop a set of codes that both reflect the initial aims of the research project, and to take into account any unexpected issues that have emerged during data collection. Du Plessis (2009:2) points out in this regard that researchers have to order and reduce data according to the objectives and the topics of discussion.

In this study a generalised inductive approach for qualitative data analysis was applied in analysing and interpreting the data. Thomas (2003:2) defines this approach as a systematic procedure for analysing qualitative data, where the analysis is guided by specific objectives. In his application of the generalised inductive approach to qualitative data analysis, the researcher aimed to achieve the following:

- to condense extensive and varied raw audio and text data into brief summary format;

- to establish clear links between the research objectives and the summary of findings derived from the raw data; and
- to develop a model or theory about the underlying structure of the experiences and processes of HIV- and AIDS-related stigma evident in the data.

Analysis of the findings of this study was sequential and was guided by its objectives. The researcher prepared the data in the following way: all the interviews were typed and formatted in Microsoft Arial, font size 11, with enough space in the left margin for the researcher's comments. He then read and reread the interviews several times in order to understand and highlight common comments, linkages and expressions, and these were later grouped into themes. Themes developed from this text derived from both the research objectives and the implied messages of the actual phrases made by the participants, which were identified from multiple readings of the raw data. A total of 36 themes emerged from the text, with some sub-themes. As this process unfolded, some of the themes overlapped into other themes, while others remained uncoded. Continuous revision and refinement of data was then made where uncoded themes became assigned to other identified themes. This process led to the eventual reduction of themes to six main themes, which were then linked to the research objectives. A

further detailed discussion of the findings and interpretation is provided in chapter four.

3.7 ETHICAL CONSIDERATIONS

According to Liamputtong and Ezzy (2005:42), one of the concerns of ethics committees is the potential of qualitative studies to cause distress to participants. In this study the researcher adhered to the relevant ethical principles. This research was cleared by UNISA's ethics committee, while permission to conduct the study was requested and granted by the Chris Hani Baragwanath Hospital authorities (see Appendices B, E and F). Following are some of the ethical principles that have been adhered to:

3.7.1 Anonymity and confidentiality

According to Liamputtong and Ezzy (2005), most ethical codes require that confidentiality of participants be maintained. According to Babbie (2005:65), anonymity has been achieved when the researcher cannot connect a given response with a given respondent. As Liamputtong and Ezzy (2005) put it: "*identities, locations of individuals and places are concealed in published results, data collected are held in anonymised form, and all data are kept securely confidential.*" This study was also sensitive to confidentiality and anonymity; the researcher signed a consent form in which he undertook to maintain confidentiality and anonymity throughout the project with the participants (see Appendix A). The consent forms were then locked into the researcher's confidential documents safe where no one can access them. After the process of data collection, pseudonyms (Mantwa, Mosetsanagape, Nomzamo, Mmamoroesi, Dineo and Mokgaetji) were used to protect the real identities of participants, while their respective locations were generalised in such a way that their specific locations are concealed in order to protect their identities. Collected data was password-protected into the researcher's personal computer to ensure that participants' identities remain protected.

3.7.2 Access

The researcher observed the hospital protocols in order to access data. He had to request permission from the office of the Chief Executive Officer of the Chris Hani Baragwanath Hospital in writing in order to conduct research at the hospital (see

Appendix B). Permission to conduct the research was granted in writing by the hospital's Clinical Director (see Appendix E).

3.7.3 Recruitment

Recruitment of the participants of this project was done in such a way that participants were well informed about the nature of the study. Their roles were clearly spelled out to them in writing (see Appendices A and C) and orally. They were also made aware of the fact that participation was voluntary, and of their right to withdraw during any stage of the project without fear.

3.7.4 Informed consent

Informed consent is a norm which means that participants must base their voluntary participation in a research project on a full understanding of the possible risks involved (Babbie 2005; Warren & Karner 2010). In this study, the researcher ensured that the participants understood the topic of this study, its purpose, objectives, risks and benefits, as well as their roles and expectations throughout this project. Participants were also informed about their right to withdraw from the study during any time if they should wish to do so. Informed consent was signed by both the researcher and the participants in order to obligate the former to ensure protection of any form of human rights violations during the study (see Appendix A).

3.7.5 No harm

Warren and Karner (2010:38) warn researchers against harming the participants in any way, for example, by asking questions that provoke emotional reactions such as shame, guilt or sorrow. During the process of the project, the researcher kept in mind some challenges which might arise, especially regarding the discussion of sensitive information which might be emotionally overwhelming to them. In order to guard against this, the researcher pre-tested the interview schedule with a sample of three women who met the criteria of the study sample, in order to check whether some questions did not provoke deep emotional reactions. He also identified relevant resources and their contact details within and outside the hospital for further intervention in cases where the participants might experience some problems due to their involvement in the study. In this regard a resource list was developed and a referral letter designed specifically for the project, so that participants with any

problems could be referred to the relevant resources. This practice is similar to what Babbie (2005:63) recommends in terms of avoidance of psychological harm in the course of a social research study, namely that the researcher must look for the subtlest dangers and guard against them.

3.8 REFLECTING ON THE ROLE OF THE RESEARCHER

The researcher was a young male social worker who worked at the Chris Hani Baragwanath Hospital during the beginning of the study, and later got transferred to the Hammanskraal community. His transfer changed some of the research plans including the role that he was supposed to play as the hospital's medical social worker during the study. Access to the participants became restricted after these changes; the researcher was compelled to revisit his plan and make a few adjustments such as reducing the number of participants and adjusting the data collection method. Given his professional status, the researcher endeavoured not to allow his professional capacity to interfere with his interaction with the participants. He ensured that he remained the investigator, not the helper or the counsellor. In addition to the challenge regarding the role of the researcher, language was another problem. Interviews were conducted in four African languages, of which the researcher was fluent in three only (Northern Sotho, Southern Sotho and Setswana). The researcher was a Northern Sotho speaker and he was not fluent in isiZulu. This often caused some interaction problems with the Zulu participant who was an isiZulu first language speaker, because the researcher had to continuously ask for clarification in certain statements. In doing so, he ensured that the research was conducted in a competent, trustworthy and professional manner.

3.9 CONCLUSION

This chapter has highlighted the background to the research methodology where exploratory qualitative research design was introduced. A brief discussion of population and sampling, data collection methods, data analysis and interpretation, validity and adherence to ethical principles was given, while the researcher reflection concluded the chapter. In the next chapter (chapter four), the researcher will be dealing with research findings and interpretations.

CHAPTER 4

FINDINGS AND INTERPRETATION

4.1 INTRODUCTION

In this chapter the researcher findings are given by first presenting a brief biographical profile for each participant. Pseudonyms were given to the participants and the reader is introduced to Mantoa, Mosetsanagape, Nomzamo, Mmamoroesi, Dineo and Mokgaetji. This is followed by a presentation of the research findings and interpretations in terms of dimensions and types of stigma, coping mechanisms adopted by the participants, synthesis of the research findings and conclusion.

4.2 BIOGRAPHICAL PROFILES OF PARTICIPANTS

The biographical profiles of the six women who participated in this study are presented below. Pseudonyms are used to protect the true identities of the interviewees.

4.2.1 Mantoa

Mantoa was born in 1955 (thus she was 54 years old at the time of data gathering) in Soweto, where she also grew up. She was a Southern Sotho speaker and she was a married mother of a 31-year-old daughter, who was due to get married. She completed her Grade 12 in 1978 and enrolled at a college for nursing. During the time of this study she was employed as a nurse at a nursing home in Johannesburg. She was diagnosed as HIV-positive in 2003 after she became concerned about symptoms such as weight loss and coughing. During the time of this study Mantoa had already completed three years of ART. She had disclosed her status to her husband only.

4.2.2 Mosetsanagape

Mosetsanagape was the 28-year-old third child in a family of five. She was born near Westonaria. She completed a Business management course at a college and was receiving ART at the Chris Hani Baragwanath Hospital during this study. She was a victim of rape and she lost her virginity due to this sexual assault. Apart from this

sexual trauma, Mosetsanagape also lost her sister in a car accident and her brother due to chronic illness shortly after being raped. Her father had deserted the family when she was still very young. She discovered that she was living with HIV in 2005 after having symptoms which forced her to consult a doctor. She had three years' experience of ARVs. Mosetsanagape was a single, underemployed Setswana speaker. Her household was dependent on an income earned through part-time work in a small cosmetics franchise that she and her mother ran. Apart from the researcher, Mosetsanagape disclosed her status also to her mother and her younger sister.

4.2.3 Nomzamo

Nomzamo was an isiZulu speaker. She is a first child from a family of five (with two sisters and two brothers), and was born in 1967. She was born in Soweto, where she also grew up. She completed her Grade 12 and later enrolled for a computer course, which she completed at a college. Like Mosetsanagape, she grew up without a father and her father's whereabouts was unknown. Nomzamo has two male children of her own and was living with her partner at the time of the data gathering. Nomzamo's eldest son, her husband and her brother were the income earners for the household. She was diagnosed as HIV-positive in 2004 after experiencing continuous coughing and weight loss. She had three years' experience of ARVs, and she disclosed her status to her husband and her mother, who passed away in 2006.

4.2.4 Mmamoroesi

Mmamoroesi was a 33-year-old Southern Sotho speaker. She was the unemployed single mother of three children. Mmamoroesi was born in Soweto, where she also grew up. She started school in Soweto but dropped out of school after completing Grade 10 due to financial difficulties in her family. Mmamoroesi had never been employed. She was diagnosed as HIV-positive in 2001 and she had three years' experience of ARVs. Mmamoroesi's main source of income was the government's Child Support Grant for her two sons, amounting to R480.00 per month. She had disclosed her status to her mother and her close friend, who is also living with HIV.

4.2.5 Dineo

Dineo was a 41-year-old mother of three children who lived with her male partner. She was a Setswana-speaking teacher qualified in Early Childhood Development. She

was diagnosed with cancer in 2001, and while she was receiving treatment for the cancer, she was also diagnosed as HIV-positive in 2005. Dineo had five years' experience of ARVs. Her diagnosis caused some confusion to her because she explained that her first HIV test returned a positive result, but subsequent test showed that she was HIV-negative. She then repeated the test, only to receive another sero-positive diagnosis.

4.2.6 Mokgaetji

Mokgaetji was a 38-year-old widow with three children. She was an unemployed Northern Sotho speaker who had lost her husband in 2005 due to illness. She used to live with her husband and three children in an informal structure in a squatter camp near Orange Farm, but after the death of her husband she decided to destroy the shack and to move back to her family of origin in Orange Farm. At the time of the interview, Mokgaetji resided with her mother, her younger brother, her deceased sister's two children, her two younger sisters, their children and her own in a backyard. Mokgaetji was the second child from a family of four, and her elder sister passed away in 2006 due to AIDS-related causes. Mokgaetji discovered that she was living with HIV in 2004, and she had one year's experience of ARVs during this study.

The following section of the chapter aims to present the reader with analysis and discussion of the research findings. Analysis will be conducted according to the research objectives.

4.3   DIMENSIONS AND TYPES OF HIV- AND AIDS-RELATED STIGMA EXPERIENCED BY PARTICIPANTS

One of the objectives of this study was, through the narratives of the participants, to describe the nature and dimensions of the experience of stigma among HIV-positive women. In this regard, three general themes emerged, namely stigma as related to loss, stigma as related to fear, and stigma as related to shame. Each of these sub-themes are explored below.

4.3.1 Loss

One of the themes emerging from the data, and which is in line with the first and second research objective stated above, was the sense of loss which manifested itself in the form of a loss of dignity and a loss of friendship because of the research participants' HIV-positive status.

Mantoa narrated her experiences of loss of dignity as follows:

"One day I came for treatment and I was referred to Glen Thomas [the Chris Hani Baragwanath Hospital pharmacy], *where I was going to collect medication.... The clerk who was helping me took my file and checked it and realised that I was referred from the Chris Hani Baragwanath Hospital ARV clinic. There was another clerk next to her. The one who took my file asked the other one what Chris Hani Baragwanath Hospital ARV clinic means, and I immediately responded by saying Ke ko* Nthabiseng [It means Nthabiseng clinic]. *The two clerks then looked at each other and laughed. This incident was very painful to me. I felt very bad."*

According to Cao *et al* (2006:519), stigma can broadly be grouped as physical isolation or exclusion, verbal (gossip, insults, and voyeurism), loss of role (denied religious rites, loss of respect) and loss of resources (loss of job/customers/housing), and given a poor quality or no health care. Mantoa's experiences clearly reflect gossip, loss of respect, loss of dignity, and loss of quality health care services due to her HIV-positive status. She has clearly received poor health care service as described by the above researchers, because her service was accompanied by stigmatisation in the form of gossip and violation of her right to dignity, and this is in contrast with the South African legislations such as the Constitution of the RSA and policies such as the HIV/AIDS and STI Strategic Plan 2007-2011, which advocate respect for human rights. Her experiences are similar to the attribution theories of stigma that hold the view that people tend to have more positive attitudes toward individuals whose problems are biologically caused and would therefore stigmatise them less, than those whose problems are behaviourally caused (Crandall 2000; Dijker & Koomen 2003). Mantoa was treated here as one of those whose behaviours are viewed as having contributed to her HIV-positive status.

Mantoa's experience of loss resonates with the findings by Visser *et al* (2009:200) that enacted stigma take the form of subtle discrimination such as gossip, not treating the PLWHIV with respect, keeping a distance from the PLWHIV, attempting to humiliate the PLWHIV or to physically harm them and not taking care of them.

In the following excerpt, Mmamoroesi reports how she lost her friendship because of her HIV-positive status:

"Some of my friends could see that I was sick and they decided to pull themselves away from me."

Mmamoroesi's experience confirms the saying which goes, "when days are dark friends are few". Just like Mantoa above, Mmamoroesi has also suffered prejudice, discrimination and exclusion due to her deteriorating condition. Friends began to realise that she was ill and they started to draw away from her because they themselves did not wish to be stigmatised by others because of their association with her. Visser *et al* (2009) identify this kind of behaviour as including both overt expressions such as loss of friendships or social support after disclosing one's HIV-positive status, and more subtle expressions of stigma such as micro-insults, and daily hassles or macro-aggressions similar to those experienced by other marginalised groups as enacted stigma. In this regard Bond (2004) states that stigma begins as a process whereby people identify and label differences that are possessed by the stigmatised, and later separate themselves from those who carry the stigma. In the case of Mmamoroesi, her illness was clearly visible to her friends and it was a difference which was identified by them and forced them to reject her. Because in their interaction with significant others such as friends people develop their self-concept, Mmamoroesi's experiences of rejection and isolation imply that she was denied the opportunity to develop her self-concept and therefore will remain further alienated (Jones *et al* 1984:142).

Nomzamo told the researcher how she lost neighbourhood associates because of her HIV-positive status in the following excerpt:

"…whenever I tried to associate myself with ladies around my street I would see them disappearing. I think they saw that I was losing weight and coughing. This was a bad treatment and I decided to spend my time indoors."

Nomzamo's experiences can be likened to the definition offered by Morris (2003:20) of enacted stigma, which refers to sanctions individually or collectively applied to people on the basis of their belonging or being perceived to belong to a particular group. She was being avoided because she was perceived to belong to a group of the sick. Nomzamo has clearly experienced prejudice and exclusion in line with what Bunn *et al* (2007:198) describe as enacted stigma in terms of the actual experiences of prejudice, stereotyping, discrimination and exclusion. She has therefore suffered a loss of friendship and association due to her HIV-positive status. Her experiences are similar to what Link and Phelan (cited in Bond 2004:36) assert as typically befalling the stigmatised person, namely to be isolated, rejected and deprived benefits of association.

4.3.2 Fear

Another theme that featured prominently in the analysis of the narrations (this also relates to the first two research objectives), was fear. Among the participants of this study, fear manifested itself as a fear of death, a fear of treatment, a fear of discrimination and a fear of traumatising the children.

Nomzamo shared her fear of death in the following manner:

"I then started to lose weight and began to cough, and I decided to go to the clinic because I could see that I was dying... When I arrived at Bara [Chris Hani Baragwanath Hospital], *nurses would shout at us like children. The situation was bad because people would even die in my presence… I was scared to go to church. When they see that you are sick and you are losing weight, they won't allow you to sit next to them. It did not happen to me but people do it even in the churches."*

In their studies of HIV- and AIDS-related stigma, Cao et al (2006:525) associated the fear of death with HIV- and AIDS-related stigma. Their studies revealed that some uninfected participants believed that death from HIV infection was immediate; it was therefore a greatly feared infection. The experiences of Nomzamo clearly reflect a fear of death. The implications of these experiences are that a fear of death may not be only among the uninfected people, as revealed by the above researcher; it can also be apparent among PLWHIV themselves.

Nomzamo's experiences can be likened to what Morris (2003) describes as the fear of how others will react to this condition. Her decision to quickly go to the clinic after she had started coughing and losing weight was an attempt to prevent the symptoms which might expose her to stigmatisation. In this regard Talja (2005:12) interprets anticipated or perceived stigma as the fear of how others would react and as the expected reactions from their surroundings.

In the following excerpt, Dineo shared her feelings of fearing death:

"During my first test I was very sick and I was afraid that I would die. I then consulted the Doctor and asked him to start me on treatment... I was very scared of death and I decided to consult the pharmacist for advice..."

Just like Nomzamo in the above excerpt, Dineo was also scared of death. Just like the uninfected participants from the study by Cao *et al* (2006), she thought that AIDS-related death was immediate and developed a fear of that. Dineo's experiences are similar to what Daftary *et al* (2007) describe as covering as a coping strategy to deal with stigma. According to these researchers, covering involves the coping strategy through which the stigmatised person who possesses multiple discreditable attributes covers the most dominant one with the less dominant one. Because she suffers from both HIV-infection and cancer, Dineo found it better to cover the HIV, which in her case is more dominant than the cancer, due to a fear of discrimination and of traumatising her daughter. Her reactions are similar to the description by Morris (2003) of anticipated stigma as the fear of how others will react to their condition.

In the following excerpt Mokgaetji expressed her fear, which manifested itself in the form of a fear of being discriminated against by her family members and a fear of traumatising her children:

"I did not tell anyone about my [HIV-positive] *status; even my children do not know my status. I am afraid to tell them because I think they will be traumatised. My elder sister passed away due to AIDS-related illnesses and she suffered a lot before she passed away. She was treated very badly and her children also suffered because of her HIV-positive status. They would do everything from fetching water to cleaning the house while my little sisters did nothing. She was separated from the whole family and no one was prepared to even assist financially during her funeral... If no one knew her*

status, I think the treatment would have been better... Yes, people talk too much, especially when they see some changes in your body. They will start asking questions and this might irritate you."

Mokgaetji's experiences demonstrate the ideas expressed by Jones *et al* (1984) and Aggleton (2000) regarding the perception of stigma in the family. According to these researchers, the family itself can acquire the stigma of one member through what Jones *et al* (1984) call genetic association, which some families resolve by simply disowning and abandoning the stigmatised member or through shielding the member from the wider community by protecting him or her from questioning. In the case of Mokgaetji, her sister's stigma was resolved through abandonment and disownment. As pointed out by Jones *et al* (1984), her family decided to avoid genetic stigma from the community by stigmatising her so that the general community could accept them. Consequently Mokgaetji developed a fear of falling into the same trap of being stigmatised by her family like her sister had been. This is what is described by Morris (2003:20) as anticipated stigma – the feeling that an individual has about his or her condition and the fear of how others will react to this condition.

Mokgaetji's above experiences are similar to how Morris (2003) interprets anticipated stigma as a kind of stigma which causes refusal to disclose one's HIV-positive status or denial of HIV/AIDS.

4.3.3 Shame

Being ashamed is one of the feelings that are experienced by PLHWIV because of the derogatory nature of the disease. As highlighted in the following excerpts, shame was a theme that was identified similar to the first two objectives of the study where some of the participants were found to be embarrassed by their HIV-positive status.

The following excerpts highlight how Mmamoroesi, Mosetsanagape, Mantoa and Dineo felt embarrassed by their HIV-positive status:

"Ha eba hona le ntho e nka e fetolang bophelong baka ke ho phela ka kokwana-hloko. Nkabe kele Modimo ke be ke tla ntsha kokwana-hloko ye eleng mo mmeleng waka." – Mmamoroesi

["If there is one thing that I would change in my life it is to live with HIV. If I was God, I would remove HIV from my body."]

"I do avoid situations which I think will hurt me and attend to those that create happiness in my life. I do have a boyfriend but I did not tell him about this [HIV-positive status]. *It is difficult for me but we are using condoms and we live a happy life."* – Mosetsanagape

"…the two clerks looked at each other and laughed. This incident was very painful to me. I felt very bad." – Mantoa

"The advice that I can give to people living with HIV is that they should go to the clinic earlier, because if you lose weight people will talk about you." – Dineo

The above participants' experiences are the reflection of HIV- and AIDS-related stigma. These are similar to findings from studies by Biernat and Dovidio (2000); Crocker and Quinn (2000); Dovidio *et al* (2000); Ogden and Nyblade (2006) and Shoham (1970), which all assert that victims of stigma can become stigmatisers through internalisation of the perceptions of others towards them and begin to view themselves as not fully human. They all felt embarrassed by their experiences of living with HIV. This is similar to what Lee *et al* (in Kalichman, Simbayi, Cloete, Mthembu, Mkhonta, & Ginindza 2009:87) have found regarding embarrassment among their participants. For Mmamoroesi the feeling of shame was so intense that she felt contaminated and wished to be purified by removing the virus from her body. This is similar to what Talja (2005) says about the perception of anticipated stigma, namely that a self-stigmatised person often blames himself or herself for his or her dilemma and this feeling can lead to depression, withdrawal and a sense of worthlessness.

4.4   COPING MECHANISMS ADOPTED BY PARTICIPANTS TO DEAL WITH HIV- AND AIDS-RELATED STIGMA

The third objective of the study was to obtain insight into the coping mechanisms used by these women in dealing with HIV- and AIDS-related stigma. In this regard, the following themes could be extracted from the narrations: isolation, silence or secrecy, and disclosure.

4.4.1 Isolation

Due to the nature and impact of the stigma surrounding HIV/AIDS, some PLWHIV prefer to remain isolated than to be confronted with stigma in most of their lives. They opt to withdraw from the support groups and other available structures. To them spending time indoors remains an active coping strategy to overcome HIV- and AIDS-related stigma. According to Breitkopf (2004:5), isolation refers to withdrawal. It involves removing oneself from social situations in which the stigma (or the condition) may be apparent. Breitkopf (2004) goes as far as to describe those people who engage in withdrawal as avoiding social associations and cutting friendships off in order to avoid rejection and blame because of their HIV-positive status. As highlighted in the following excerpts, isolation was also apparent in this research project; some of the participants were isolated by their associates or voluntarily isolated themselves form their associates due to their fear of the stigma.

The following excerpts highlight how Mosetsanagape suffered isolation after she tested positive for HIV:

"… I believe that what is personal is personal, it has nothing to do with them. I won't tell any friend about my status. Even le di support groups-nyana tse tsa bona ga ke di tsamaye…"

["I am not even a member of their so-called support groups…"]

"I was so stressed and repeatedly asked myself how long will I live?... I do avoid situations which I think will hurt me and attend to those that create happiness in my life."

Mosetsanagape's experiences are similar to the findings from studies by Cao *et al* (2006), Ogden and Nyblade (2006) and Lee *et al* (in Kalichman *et al* 2009). According to these researchers, PLWHIV can internalise their stigmas and begin to undermine themselves. In their studies, Lee *et al* (in Kalichman *et al* 2009:87) found that some of their participants (63%) were embarrassed by their HIV-positive status. Studies by Cao *et al* (2006) found that some PLWHIV reduced contact with their associates on their own initiative. Ogden & Nyblade (2006:32) explain that the loss of hope, and feelings of worthlessness and inferiority are some forms of internalised

stigma. Mosetsanagape clearly showed that she experienced HIV- and AIDS-related stigma as described by these researchers.

The following excerpts show how the majority of the participants (Mantoa, Mosetsanagape, Nomzamo and Mokgaetji) opted for isolation or withdrawal as their coping strategies when confronted with HIV- and AIDS-related stigma:

"I then decided to cut friends, stopped going out and spent most of my time indoors."– Mantoa

"I do avoid those situations which I think will hurt me and attend to those that create happiness in my life." – Mosetsanagape

"I was scared to go to church. When they see that you are sick and you are losing weight they won't allow you even to sit next to them... I used to attend a support group but after realising that I have recovered from stress I decided to quit." – Nomzamo

 "Ke ile ka kgaola ho tsamaya diparty mme ka qala ho tsamaya kereke."

["I then decided to stop going to parties and started to go to church."] – Mmamoroesi

"I used to have many friends but now I do not have any. I just think I should spend time alone these days." – Mokgaetji

The above excerpts highlight how participants decided to withdraw themselves from their respective social associations because of their fear of stigma. These findings are similar to what Cao *et al* (2006) found, namely that some of their participants reduced contact with other associates at their own initiative. This can result in their loss of resources or services such as spiritual counselling from the churches, group counselling from support groups and sharing of personal problems with their friends.

4.4.2 Silence/secrecy

Smart and Wegner (2000:220) state that most people might prefer to keep their medical conditions secret in order to avoid labelling and rejection. This is the coping strategy that is adopted by most PLWHIV to avoid the stigma that surrounds the disease. They prefer to keep quiet and hide any symptom that might expose them, and pretend that everything is fine in their lives. Secrecy is described by Breitkopf (2004)

as a choice that the afflicted person makes to keep the condition to himself or herself and to avoid situations where the affliction can be recognised. As shown in the following excerpts, secrecy was among the majority (four) of the participants of this study.

Mantoa says the following about her secrecy as a coping mechanism:

"It was difficult for me to talk about it until I decided to tell my husband..."

For Mantoa, secrecy assisted her to eventually have the courage to tell her husband. Initially it was difficult, and after keeping it to herself for a while, she later decided to tell her husband.

In the following excerpt, Mosetsanagape reported how secrecy assisted her to deal with her personal HIV-positive status:

"I do have three friends but I believe that what is personal is personal, it has nothing to do with them. I won't tell any friend about my status, even le di support group tse tsa bona ga ke di tsamaye."

["…I am not even a member of their so-called support groups."]

Mosetsanagape's coping strategy with friends is comparable to the findings of Ostrom *et al* (2006) that one of the reasons why women do not disclose their HIV-positive status is that they believe that their diagnosis is personal and should not be disclosed. For Mosetsanagape, living with the virus in silence remained an option rather than to face the stigma and discrimination which might follow disclosure.

Dineo's coping with the secrecy is illustrated in the following excerpt:

"You are the only person whom I confided to. The only person whom I confide most of my problems to is my 24-year-old daughter, but I did not tell her because I do not want her to get confused."

Dineo's coping strategy reflects her fear of her daughter's reaction to the condition. This is similar to the findings of Ostrom *et al* (2006:62) that some of their participants' inability to disclose was due to a fear that their children would be overwhelmed by the stress associated with their HIV-positive status.

Mokgaetji's secrecy was reported in the following way:

"I did not tell anyone about my status. Even my children do not know my status. I'm afraid to tell them because they will be traumatised."

Just like Dineo, Mokgaetji's coping strategy reflects the kind of secrecy that was found in the study by Ostrom *et al* (2006:62), where their respondents feared that their children might become burdened by the stress of knowing that their mother was ill. Although Mokgaetji never spoke about it, the fact that her family had treated her late sister, who had passed away due to AIDS-related illness, appallingly, may be another reason for her non-disclosure. Ostrom *et al* (2006) found that their participants feared disclosure to their children because they felt that the children might tell others, and this might have resulted in further stigma.

4.4.3 Disclosure

Disclosure is the gateway to access support and care. It is disclosure that enables PLWHIV to be accepted unconditionally and to receive the relevant support which will further enable them to fight the stigma through. In other words, if people have adequate support they can refrain from brooding on their HIV-positive status and move on with the business of life. However, disclosure does not always earn support for PLWHIV. Some become more stigmatised as a result of their disclosure. As already discussed in chapter two, disclosure is a process that involves decisions about time, the person to whom one discloses, the procedure that one would follow to disclose and conditions under which one would disclose (Makin *et al* 2008:908).

As was mentioned above (see par 2.14.5), Breitkopf (2004) categorises disclosure into three main categories, namely protective, spontaneous and preventative disclosure. With protective disclosure, the person takes his or her time planning when, how, to whom, where and under what circumstances disclosure is going to take place. Spontaneous disclosure is when the person does not plan; it takes the person by a surprise and is sometimes characterised by emotional outbursts which can lead to regret. Preventative disclosure takes place when a person prevents the stigma by disclosing in advance. In others words, the person becomes sensitive to the danger of being discriminated against and quickly discloses before that can happen. The excerpts that follow highlight how Mantoa, Mosetsanagape and Nomzamo opted for

disclosure as one of their coping mechanisms in fighting HIV- and AIDS-related stigma.

Mantoa told the researcher the following about her disclosure:

"It was difficult for me to talk about it until I decided to tell my husband, who also never believed until he observed that it was real."

Mantoa's comments highlight a protective disclosure. According to Breitkopf (2004), a protective disclosure is a type of disclosure where an individual plans how, to whom and when such condition is going to be revealed. Clearly Mantoa spent her time struggling to figure out how she was going to tell her husband until the right time to do so emerged.

In the following excerpt, Mosetsanagape told the researcher how she battled in silence until she decided to ask her sister to tell her mother:

"I did not know how to tell my mother and I decided to keep it secret. I kept it with me until I decided to ask my sister to tell my mother... I was not free to tell my mother..."

Just like Mantoa, Mosetsanagape also practiced protective disclosure as described by Breitkopf (2004), because she took her time to think about how, when and to whom she was going to disclose her status.

Nomzamo reported her disclosure in the following way:

"The first person whom I disclosed to was my mother and she was very supportive."

Nomzamo's coping strategy resonates with the conclusions drawn by Makin *et al* (2008:351), namely that disclosure provides a means for obtaining social support to assist in coping with the disease process. If she had not disclosed her HIV-positive status to her mother, she would not have received the support that she got, because her mother would not have known that she needed support because of her condition.

Dineo told the researcher the following about her disclosure:

"The person whom I confide in is my 24-year-old daughter. I did not tell her... I only told her about my cancer diagnosis... I attend the Universal church and I disclosed

only my breast cancer to the church; they do not know anything about my HIV-positive status…"

Dineo has decided to disclose her cancer status and to contain her HIV-positive status. As discussed in chapter two, covering is one of the coping strategies where the stigmatised person who possesses multiple discreditable attributes, covers the most dominant one with the less dominant one (Daftary *et al* 2007:574). Dineo was a cancer patient while she was at the same time living with HIV, and she has managed to conceal her HIV-positive status by means of her cancer.

4.4.4 Faith

Similar to many other problems that people believe can be resolved if they attend church regularly, pray and concentrate on the church activities, the problem of HIV- and AIDS-related stigma was also dealt with through faith. As the following excerpts show, one of the participants of this study (Mmamoroesi) never visited the church until she realised that she was living with HIV. By going to church her stigma became minimised because members of the congregation accepted her unconditionally. The theme of faith is justified by the voices of Mosetsanagape, Mmamoroesi, Dineo and Mokgaetji in the following excerpts:

"I do attend the church; when you are in a church you forget about all problems and focus on the church activities." – Mosetsanagape

"…Ke ile ka kgaola ho tsamaya di party mme ka qala ho tsamaya kereke e ke neng ke sa e tsamaye." – Mmamoroesi

["…I then stopped going to parties and began to attend the church that I didn't attend before."]

"I attend the universal church and I disclosed only my breast cancer to the church; they do not know anything about my HIV-positive status, but they are very supportive to me." – Dineo

"My condition is not stable; sometimes I am better and other times I find myself in a much worse condition… I think God is the one who knows." – Mokgaetji

4.4.5 Family members as the first sources of support

Whenever we need help the first people that we approach are mostly members of our own families. It is from the family where we get the care, love and support that we most need. The family is described by Aggleton (2000:14) as the first source of support to be mobilised when a person falls ill or encounters serious problems. This was the case among some participants of this study; the experiences of Mosetsanagape, Nomzamo and Dineo are highlighted in the following excerpts:

"...my mother was always very supportive to me...even le di support groups tse tsa bona ga ke di tsamaye, my family supports me." – Mosetsanagape
["…I do not even attend their so-called support groups…"]

"The first person whom I disclosed to was my mother and she was very supportive. My mother used to listen to the radio and heard when they advised people to treat and love PLWHIV just like any other person, so she understood and accepted me unconditionally." – Nomzamo

"I think my family and friends support me but sometimes I feel that they over-do it." – Dineo

As discussed in chapter two, Jones *et al* (1984:271) state that feelings among members of the families are often ambivalent – they are characterised by different reactions of members to their family members who are living with HIV. There are families like that of Mosetsanagape who are supportive to the extent that she even feels that support groups are superfluous, while there are of course also other families that see their HIV-positive member as deserving blame and rejection (Jones *et al* 1984:271).

4.5 SYNTHESIS OF RESEARCH FINDINGS

As the findings in this chapter have shown, this study has successfully addressed the research goal and objectives that were set out in chapter one. The researcher has successfully explored in the voices of the participants the types, dimensions and

nature of HIV- and AIDS-related stigma, and also the coping mechanisms that they adopted in fighting the stigma. The objectives of the study have been addressed, and the investigations confirmed that the participants did experience HIV- and AIDS-related stigma, which manifested itself in either anticipated or enacted form, or in both. The dimensions of the stigma were discussed and explained, and the mechanisms implemented by participants in fighting the stigma were also investigated, identified and described.

Implementation of the research process was also a success even though the research plan was affected by some changes which came into the researcher's life during the implementation process. Qualitative interviews have proven to be an appropriate research method for sensitive topics such as HIV- and AIDS-related stigma in that it enabled participants to feel free to express their feelings and experiences to the researcher. The generalised inductive approach for qualitative data analysis, which was applied to analyse the data, enabled the researcher to filter all available data according to the research goal and objectives.

From the analysis of the experiences of these women, it is apparent that there are commonalities in their experiences of living with HIV. Living with HIV/AIDS has always been approached with fear, shame, rejection and other negative attitudes and behaviours, and the experiences of these women were also characterised by these negative attitudes and behaviours. After being diagnosed with HIV, these women developed a fear of death. Due to the association of HIV/AIDS with death, some of them began to be scared of death, especially when their condition deteriorated. Fear of stigma and discrimination by associates was found to be apparent where most of them withdrew themselves from their existing associates and support structures at their own initiative after being rejected by their associates. These fears compelled most of them to hide their status, lose friendships and suffer their stress in silence. Their reputation and dignity fell as they began to internalise the negative perceptions and attitudes of their significant others by stigmatising themselves. Despite these negative reactions and their impacts, some participants identified other support structures such as their families, support groups and the churches as coping strategies (Nomzamo, Dineo, Mosetsanagape and Mantoa). To them going to church and spending time with

members of their families remained the only effective coping strategy to deal with their HIV- and AIDS-related stigma and to recover from the HIV- and AIDS-related stress.

4.6 CONCLUSION

From the analysis and interpretation of the participants' stories, it is clear that HIV- and AIDS-related stigma is still a problem. It is also apparent that HIV- and AIDS-related stigma manifested itself in various dimensions, where some participants demonstrated their experiences of self-stigmatising attitudes and behaviours as well as stigmatising and discriminatory attitudes and behaviours from their significant others. Like most of the South African women whose lives are characterised by silence, some also kept their voices arrested within themselves and their families, and avoided social intercourse due to the fear of being labelled through stigmatisation. Although this in turn has shown some complications such as lack of adequate social support structures in their condition, to them disclosing their status to their immediate significant others such as close family members, remaining silent and withdrawing themselves from the social arena, seemed to be better than facing stigmatisation from their outside significant others.

CHAPTER 5

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In chapter four the researcher provided a discussion of the research findings and interpretations. The aim of this chapter is to provide a discussion of a summary of the findings, the general conclusions and recommendations of the study, with specific emphasis on the summary of the major findings, the limitations of the study, suggestions for further research in the subject of HIV- and AIDS-related stigma, as well as recommendations for policy and practice.

5.2 SUMMARY OF THE FINDINGS

The following section provides a summary of the findings, with an emphasis on empirical research findings and the literature review findings.

5.2.1 Empirical research findings

Being diagnosed with HIV can clearly be an extremely stressful moment. The overall findings of this study reveal that HIV- and AIDS-related stigma was endemic among all the participants. The stigma they suffered manifested itself differently from both themselves and their significant others. Although they all reported experiences of HIV- and AIDS-related stigma, there were some differences in their sources and types of stigma. Mantoa and Nomzamo for example experienced enacted stigma from the hospital staff, while Mmamoroesi experienced it from her friends. In addition to the enacted stigma that was from the hospital, Nomzamo also suffered it from her neighbours. All the participants experienced anticipated stigma which was coloured by fear, embarrassment and isolation. They developed a fear of death, and the fear of their significant others' reactions, and felt that withdrawal from the social arena was an option. In other words, they all held negative and discrediting attitudes towards themselves.

The experiences of HIV- and AIDS-related stigma among these participants compelled them to adopt various coping strategies to deal with it. For Mantoa,

Mosetsanagape and Nomzamo disclosure was the appropriate strategy, while for Mokgaetji secrecy was effective, and Dineo adopted covering as a coping strategy. However, other coping strategies were also found to have been adopted as a combination in dealing with their HIV- and AIDS-related stigma. Mantoa and Mosetsanagape for example combined disclosure, secrecy and withdrawal, while Mokgaetji combined secrecy and withdrawal as coping mechanisms. For Nomzamo, a combination of disclosure and withdrawal was an appropriate way of dealing with the stigma, while Dineo combined secrecy and covering. Although all participants reported their experiences of HIV- and AIDS-related stigma, the majority of them mentioned that their families were the most available sources of support and their disclosure began within their families (Mantoa, Mosetsanagape, Nomzamo and Mmamoroesi). Only two of them (Dineo and Mokgaetji) reported fear of their family's reactions to their conditions, and therefore they decided to keep their HIV-positive status secret.

5.2.2 Literature review findings

The findings of this study are similar to those expressed in the reviewed literature. As explained in chapter two, Cao *et al* (2006:523) and Visser *et al* (2009:203) found that PLWHIV experienced stigma from the community, the family members and the health care workers. In this study the narrations of Mantoa, Mmamoroesi, Nomzamo and Mokgaetji show that they suffered stigmatisation at the hands of the health care workers (Mantoa), friends (Mmamoroesi) and the community (Nomzamo). All the participants reported the types of self-stigmatising experiences that are described in the literature (Biernat & Dovidio 2000; Crocker & Quinn 2000; Dovidio *et al* 2000; Goffman 1963; Ogden & Nyblade 2006; Shoham 1970).

Some of the elements of the theories of stigma are apparent in the findings of this study. The experiences of participants such as Mmamoroesi and Nomzamo, whose friends and neighbours isolated them after realising that they were ill, were found to be similar to the bio-cultural framework, which holds the view that humans have the innate desire to belong to effective groups that are characterised by norms of reciprocity, truth telling and trust for creating common identity and stable bonds between the members (Neuberg *et al* 2000). Participants such as Mmamoroesi and Nomzamo were viewed as threats to the normal and effective group functioning, as

explained by the bio-cultural framework, because they might deserve sympathy and support from the group (friends and neighbours) instead of adhering to the norm of reciprocity. They were rejected because the group felt that they were no longer identical to them (Neuberg *et al* 2000).

5.3 CONCLUSIONS OF THE STUDY

Based on the research findings, the researcher came to the conclusion that the lives of participants were deeply affected by HIV/AIDS in both enacted and anticipated forms. The same people (such as friends, family members, neighbours and health care workers) who are supposed to be their sources of support have turned out to be their stigmatisers. The participants' fear of being labelled and isolated has compelled them to adopt various coping mechanisms which mostly forced them to remain silent and hide themselves from the public domain. It is therefore imperative to realise that stigma is still a problem that complicates the living conditions of PLWHIV, and that needs to be addressed.

5.4 LIMITATIONS OF THE STUDY

According to Fisher, Foret, Laing, Stoeckel, & Townsend, (2002:117), there is no such a thing as a perfect study. This study was conducted among a small sample of six women living with HIV who were admitted at the Chris Hani Baragwanath Hospital's medical wards and who were receiving treatment at the hospital. The researcher identified the following limitations:

5.4.1 Study site

This study site was restricted to a specific hospital in South Africa, the Chris Hani Baragwanath Hospital. The results of this study can therefore not be fully representative of the other hospitals in the country.

5.4.2 Gender

All the participants in this study were black African women. Men were not part of the study and the interpretation of these findings should be limited to women. The researcher has included only women due to the women's vulnerability to most health and psycho-social problems such as HIV/AIDS. The vulnerable positions in which women find themselves are recognised by Cameron and Ritcher (2008:67), who assert

that it is important to highlight women's experiences of HIV/AIDS when considering the human security implications of the epidemic. Women are generally more at risk of contracting HIV for biological, social and economic reasons than their male counterparts. Unlike men, who are culturally ascribed to being assertive, physically strong, self-willed, rational and dominating, the social and economic inequalities that women face require more complex enquiry (Cameron & Ritcher 2008; Loffler 2008). In other words, although they find themselves confronted with challenges that are similar to women, men can cope more easily due to the traditional and cultural attributes that they possess. According to the Commonwealth (2005), the gender dimension of the epidemic (such as HIV- and AIDS-related stigma) has not fully been taken into consideration. Therefore, the need to thoroughly understand and highlight the experiences of women towards HIV- and AIDS-related stigma is still a priority in the battle against HIV/AIDS.

The fact that the researcher was a young African male presented a gender-related limitation as he could not delve deeper into all the aspects presented by the participants. This led to some of the answers being accepted without follow-ups, as the researcher often felt they might possibly be offended; this might have led to some valuable data having been lost.

5.4.3 Race

Other population groups were not represented in this study; all the participants were black women from the hospital and its surroundings. Interpretation of these findings should therefore not be generalised to other racial groups. The researcher selected African black women due to their vulnerability to most socio-economic challenges such as HIV/AIDS. During his initial visits to the study site, the researcher encountered Black men and Black women who came for treatment at the Nthabiseng HIV/AIDS clinic. He became concerned about the large numbers of Black women compared to the numbers of their male counterparts. This indicated the vulnerability of Black women and implied that it was their living conditions that needed to be highlighted in order to reduce their vulnerability to the impacts of HIV/AIDS.

5.4.4 Sample size

The sample of this study was very small; only six participants were interviewed. This implies that the findings of this study should be interpreted with caution because the general hospital population was not fully represented.

5.5 STRENGTHS OF THE STUDY

Although this study has not offered new insights into the issue of HIV- and AIDS-related stigma as the findings of this study are in line with those of the previous researchers, it reaffirmed the importance of HIV- and AIDS-related stigma at the individual and interpersonal levels. The implications are that HIV- and AIDS-related stigma is still a serious problem and therefore needs to be taken into account whenever efforts to address HIV/AIDS are undertaken. As the findings of this study have highlighted, the conditions in which women living with HIV find themselves are still characterised by stressful experiences, blame and rejection. The qualitative methodological process that was applied in this study has highlighted how PLWHIV can be empowered by creating a context in which they are listened to attentively while sharing their deepest pain and sorrows.

5.6 SUGGESTIONS FOR FURTHER RESEARCH

As this study has highlighted, HIV- and AIDS-related stigma remains a problem among women living with HIV. The researcher would like to propose that further studies be conducted in the following areas:

- The role of faith in fighting HIV-and AIDS-related stigma.
- Disclosure versus silence as coping mechanisms in fighting HIV- and AIDS-related stigma.

5.7 RECOMMENDATIONS FOR POLICY AND PRACTICE

Based on the above findings, the researcher would like to make recommendations to the following groups of people for policy and practice purposes:

5.7.1 Professionals working with PLWHIV/AIDS

It is imperative that professionals working with PLWHIV/AIDS keep the problem of HIV- and AIDS-related stigma in mind and remain as sensitive as possible whenever they interact with their clients or patients. Professionals should be trained on how to design and develop some advocacy programmes on the subject of HIV- and AIDS-related stigma in order to create an open and caring society in which PLWHIV can feel free and accepted. This in turn could foster a society wherein PLWHIV would feel free to access the available support, care and treatment. The silence surrounding HIV/AIDS issues will eventually come to an end.

5.7.2 People living with HIV

As this study has shown, support groups remain effective in helping PLWHIV accept their HIV-positive status and in overcoming HIV/AIDS stress. It is therefore recommended that PLWHIV be involved in some form of support groups in order to share their experiences with other people in similar circumstances.

5.7.3 Caregivers and family members of people living with HIV/AIDS

Care and support begins in the family. It is therefore important for the caregivers and family members of PLWHIV to support their family members and loved ones who are living with HIV/AIDS. By doing so, they will encourage them to live positively with their status and this will consequently reduce the risk of further infection under the culture of silence and fear.

5.7.4 Government and NGO officials involved in programmes and policies

targeting PLWHIV

For government and non-governmental officials involved in policies and programmes targeting PLWHIV, the need to sensitise the policies and programmes to address HIV- and AIDS-related stigma remains imperative. Policies and programmes should therefore be geared and widened towards addressing HIV- and AIDS-related stigma and its impacts in order to foster an HIV/AIDS-friendly society, where PLWHIV could feel free to disclose and discuss anything about their HIV-positive status within a caring and supportive society.

5.7.5 Funders involved in humanitarian programmes

It is imperative for funders who are involved in humanitarian programmes such as HIV/AIDS programmes, to make funds available for projects and programmes that are aimed at preventing and addressing the impacts of HIV- and AIDS-related stigma.

5.8 CONCLUSION

This study indicates that the conditions in which PLWHIV live are very stressful. These people are not only suffering from this painful and incurable disease, they are also confronted with negative attitudes, remarks, behaviours and treatment from the people with whom they interact on a daily basis. Given the challenges faced by this group, an understanding of the nature of the disease and its dimensions becomes difficult because they choose to remain silent and hidden due to their fear of these stigmatising attitudes. A successful battle against HIV/AIDS should begin by giving the PLWHIV a voice through the elimination of fear, shame, isolation and discriminatory attitudes and behaviours. This battle can only be won if all people can come together and create a society where unconditional love and acceptance of PLWHIV prevail.

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APPENDIX A

Informed consent

Dear research participant

This is an investigation of stigma as experienced by women living with HIV. This research is for a Master's degree at the University of South Africa (UNISA). I have contacted six women and asked them to please participate in this study. Participation is voluntary and this means that you may refuse participation or withdraw from this study at any time without any penalties. Participating in this study means that I shall interview you in the Chris Hani Baragwanath Hospital premises on a date and time agreed upon between us. More than one interview might be necessary for me to fully understand your experiences. Your real name and address will only be known to me as the researcher and I shall keep such information safe and treat it as highly confidential. In writing up the data, you will be assigned to a false name (pseudonym) so that your narration will never be traced back to you personally.

If you are willing to participate in this study, I need your signed consent below. These forms will only be seen by me and I shall keep them in a secure place. Signed consent forms and the tape recordings will be destroyed five years after the completion of this study.

INFORMED CONSENT DECLARATION

I agree to participate in this study. I have read this form and understand what participation in this study entails. I grant permission to be interviewed and for the interviews to be tape-recorded.

_____   _____

Signature of Participant   *Date*

_____   _____

Signature of Researcher   *Date*

Thank you,

Robert Lekganyane

APPENDIX B

LETTER TO THE HOSPITAL'S CEO

Enq: Mr Robert Lekganyane

Tel: 011-933 8857/8418

Cell: 071 493 5017

Email: robertlekganyane@yahoo.com

P.O BOX 1590

MABOLOKA

0197

03 FEBRUARY 2009

THE CHIEF EXECUTIVE OFFICER

CHRIS HANI BARAGWANATH HOSPITAL

PO BERTSHAM

2013

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I hereby request permission to access data of six female outpatients living with HIV who are 18 years and older. I am a final year Master's student in Social Behaviour Studies of HIV and AIDS at the University of South Africa. As part of my qualification, I am expected to conduct a research project under a topic relevant to HIV and AIDS. I therefore request permission to conduct a project in your Hospital under the topic of *"Anticipated and enacted stigma among female outpatients living with HIV: the case of Chris Hani Baragwanath Hospital, South Africa"*.

The project aims to explore whether participants experience HIV-related stigma and if

so what types of stigma and how do they cope with it. It will involve in-depth interviews with participants.

The study will be highly ethical. The research has been cleared by the UNISA's ethical Clearence Committee and the researcher will sign a consent form which will oblige him to ensure that the participants are protected and their rights are not compromised.

Yours sincerely

_____

M.R. Lekganyane

Principal investigator

APPENDIX C

INVITATION LETTER FOR PARTICIPANTS

P.O. BOX 1590

MABOLOKA

0197

03 October 2009

Dear Mmamoroesi Nnyeu

RE: REQUEST FOR PARTICIPATION IN A STUDY

The general announcement dated the 08th of August refers. Following the announcement made by the sister in charge of the clinic requesting volunteers who will participate in a study and your consequent positive response, you have been identified as a possible research participant. This study is about the experiences of women outpatients living with HIV. As a participant in this study, you will be interviewed by me, and I will ask you about your experiences and feelings as a woman living with HIV. I shall arrange a meeting date and time with you and visit you at the hospital where the interviews will be conducted. Participation in this study is voluntary and this means that you may refuse participation or withdraw from this study at any time without penalties. More than one interview might be necessary for me to fully understand your experiences. Your real name and address will be known only to me as the researcher, and I shall keep such information safe and treat it as highly confidential. In writing up the data, you will be assigned a false name (pseudonym) so that your narrations will never be traced back to you personally.

I am a postgraduate student at the University of South Africa (UNISA) and the proposal for this study has been submitted to the Ethics Subcommittee of the College of Human Sciences at UNISA. It has also been submitted to the hospital's clearance committee.

Before starting an interview, I shall ask you to sign an informed consent form. I shall contact you in a few days' time to hear whether you are willing to participate in this study.

Yours sincerely,

Robert Lekganyane

Tel: 012-717 1706

Cell: 071 493 5017

APPENDIX D

Interview schedule

1. In the first section of our discussion, I would like you to tell me your thoughts and experiences of how HIV/AIDS affects family members and loved ones.

1.1 In your experience, how does HIV/AIDS affect families and loved ones?

1.2 Do you think People Living With HIV are treated like any other person by their family members and loved ones?

      Probe: How are they treated differently?

      Probe: Is that a good or a bad thing?

1.3 How can families best support a family member living with HIV?

1.4 How does YOUR family support you?

      Probe: tangible support

      Probe: affectionate support

      Probe: positive social interaction

      Probe: emotional support

      Probe: informational support

1.5 Who is the person (or who are the persons) that you most confide in about your illness?

1.6. In your own view, what should happen to assist families to best help their loved ones who live with HIV?

2. I now want you to tell me more about yourself.

2.1 What is your age?

2.2 In what year were you diagnosed?

2.3 Are you using ARVs?

2.4 Are you employed?

    Probe: Did you lose your employment due to HIV?

2.5 What is your goal for yourself in the next five years?

2.6 Do you think your goal is attainable?

    Probe: Why or why not?

    Probe: Do you feel that you lower your expectations towards life because you are living with HIV?

2.7 If there was ONE thing that you could change about yourself, what would that be?

    Probe: Why?

3. Tell me more about yourself as a Person Living With HIV.

3.1 How did your HIV-positive diagnosis change your life?

3.2 Did people treat you differently after your diagnosis?

    Probe: What are the reasons?

    Probe: Did you ever feel discriminated against by someone else? Describe this.

    Probe: Did you ever feel let down by a family member or loved one after you had disclosed your status to them? Describe this.

3.3 Did your diagnosis change the way you think and feel about yourself?

    Probe for positive thoughts and feelings

    Probe for negative thoughts and feelings

3.4 Did you change your social habits after your diagnosis?

    Probe: For example, did you go out more?

    Probe: Did you stay away from people?

Probe: Did you lose friends?

Probe: Did you make new friends?

Probe: What is your relationship with the church or religious groups?

Probe: Did you join a support group?

4. For the final part of our discussion, I would like to find out more about your personal coping style when confronted with problems (mental health inventory).

4.1 How happy have you been with your personal life during the past month?

4.2 How often have you felt lonely during the past month?

4.3 Do you avoid unexpected situations (more now than before your diagnosis)?

4.4 Do you feel that the future looks hopeful and promising?

4.5 Do you feel nervous, anxious, worried or stressed when you think about your diagnosis?

4.6 Are you satisfied with your close personal relationships?

Probe: Are they rewarding? Do you feel accepted, loved, appreciated?

Thank you very much for your help

APPENDIX E

Unisa's Ethical Clearance letter

College of Human Sciences

30 April 2009

Proposed title: *Anticipated and enacted stigma among female outpatients living with HIV: the case of Chris Hani Baragwanath Hospital, South Africa*

Principal investigator: Robert Lekganyane

Reviewed and processed as: Class approval (see paragraph 10.7 of the UNISA Guidelines for Ethics Review)

Approval status recommended by reviewers: Approved

The Ethics Subcommittee of the College of Human Sciences has reviewed this proposal and considers the methodological, technical and ethical aspects of the proposal to be appropriate to the tasks proposed. Approval is hereby granted to the principal investigator to proceed with the study in strict accordance with the approved proposal and the ethics policy of the University of South Africa.

In addition, the principal investigator should heed the following guidelines:

- To only start this research study after obtaining informed consent

- To carry out the research according to good research practice and in an ethical manner

- To maintain the confidentiality of all data collected from or about research participants, and maintain security procedures for the protection of privacy

- To record the way in which the ethical guidelines as suggested in the proposal has been implemented in the research

- To work in close collaboration with your supervisor(s) and to notify the Subcommittee in writing immediately if any change to the study is proposed and await approval before proceeding with the proposed change

- To notify the Subcommittee in writing immediately if any adverse event occurs. Approvals are valid for ONE academic year after which a continuation must be submitted.

_____

Kuzvinetsa Peter Dzvimbo

Deputy Executive Dean: College of Human Sciences

Tel: 012 429 4067

E-mail: dzvimkp@unisa.ac.za

Distribution

Chair of Department

School Director

Executive Director (Research)

Executive Dean (CMC)

Ethics Committee File   83

APPENDIX F

PERMISSION TO CONDUCT THE RESEARCH

PERMISSION TO CONDUCT RESEARCH AT CHRIS HANI
BARAGWANATH HOSPITAL

PRINCIPAL RESEARCHER:

FULL NAME   MR. ROBERT LEKGANYANE

DESIGNATION   SOCIAL WORKER

CONTACT NUMBER   CH 933 8857/8415 CELL O71 493 5017

EMAIL   robertlekganyane@yahoo.com

DEPARTMENT/S   SOCIAL WORKER DEPARTMENT

HEAD/S OF DEPARTMENT/S   ACTING MRS MANKOPODI MAKABATE

TITLE OF RESEARCH   ANTICIPATED AND ENACTED STIGMA
AMONG FEMALE OUTPATIENTS LIVING WITH HIV:
THE CASE OF CHRIS HANI BARAGWANATH HOSPITAL, SOUTH AFRICA.

OBJECTIVES OF RESEARCH   1 DO FEMALE OUTPATIENTS LIVING WITH
HIV FROM CHBH EXPERIENCE HIV RELATED STIGMA IN
THEIR IMMEDIATE LIVING ENVIRONMENTS. 2 WHAT TYPES
OF RELATED STIGMA ARE EXPERIENCED BY FEMALE CLIEN
TS LIVING WITH HIV AND AIDS.

STUDY SITE/S   CHRIS HANI BARAGWANATH HOSPITAL   ↑ SEE ATTACHED

BRIEF OUTLINE OF METHODOLOGY   1. RESEARCH DESIGN 2. DATA
COLLECTION METHOD 3. DURATION OF THE STUDY
4. DATA ANALYSIS AND PRESENTATION

EXPECTED START DATE   JULY   EXPECTED DURATION   4 MONTHS

ETHICS CLEARANCE ?   Y   /   N   /   PENDING

CONFLICTS OF INTEREST ?   Y   /   N   DETAILS _____

COSTS TO HOSPITAL AND/OR PATIENTS ?   Y   /   N

SOURCE OF FUNDING   HE WILL PAY ON HIS OWN

PERMISSION GRANTED   Y   /   N

_____   _____   24.06.2017
SIGNATURE   NAME IN PRINT + DESIGNATION   OFFICIAL STAMP+DATE