STIGMA WITHIN HEALTH CARE SETTINGS: AN EXPLORATION OF THE
EXPERIENCES OF PEOPLE LIVING WITH HIV AND AIDS

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KEYWORDS

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ABSTRACT

South Africa has one of the highest HIV and AIDS prevalence rates and the pandemic shows no signs of abating. Challenges facing South Africa in combating this pandemic include the social responses of fear, denial, stigma and discrimination. Stigma related to HIV and AIDS poses a major barrier to treating and managing HIV and AIDS. Stigma is defined as involving an attribute which significantly discredits an individual in the eyes of others or society. This attribute is therefore seen by others as being negative, something which devalues, spoils or flaws an individual. Perceived or felt stigma is described as being the anticipation of rejection and the shame of having the stigma, whereas enacted stigma refers to actual incidents of discrimination. The aim of this study was to determine, from the experiences of people living with HIV and AIDS, whether stigma manifests within the South African primary health care system. A qualitative study using a phenomenological approach was conducted. Semi-structured interviews were conducted with ten HIV positive participants. The interviews were transcribed and analysed using an interpretive phenomenological approach. The results indicated that the participants have experienced the health care setting as having undergone a positive change in terms of how people with HIV and AIDS are managed. They do not feel stigmatised in the primary health care centres they attend, but experience stigma related to their HIV status within their community and families. Further research is needed to determine 1) what initiated the positive changes in these health care centres and 2) the experiences of stigma in the community and family by those who are HIV positive.

September 2006
DECLARATION

I declare that *STIGMA WITHIN HEALTH CARE SETTINGS: AN EXPLORATION OF THE EXPERIENCES OF PEOPLE LIVING WITH HIV AND AIDS* is my own work, that it has not been submitted before for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged as complete references.

Heidi Sandra Wichman

September 2006

Signed:
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PREFACE

The Human Sciences Research Council together with Penn State University and University of the Western Cape embarked on a five year study of stigma relating to HIV and AIDS. The overall goal of this project is to strengthen infrastructure and capacity building at University of Western Cape and to sustain and develop cultural and gender-based interventions for eliminating stigma associated with HIV and AIDS prevention, care and support in South Africa. My research study forms part of this broader project. The project specified certain aspects of the research such as: it had to be a qualitative study; it had to be conducted in the Mitchell’s Plain area with a previously disadvantaged community and it had to be in the health care setting. This project also provided the Atlas TI as a means to assist with analysis of the data and funded the research study. The following thesis is a separate document and compilation of research results to the project. I would like to express my appreciation to those involved with this project.
CHAPTER 1
INTRODUCTION

1.1 Introduction

The enormity of the HIV and AIDS\(^1\) pandemic is probably best expressed through the statistics being compiled on a regular basis by various organizations. The recent statistics indicate that the number of people living with HIV globally, in 2005, was 40.3 million, while the number of people newly infected with HIV was 4.9 million and the number of deaths 3.1 million (AIDS epidemic update, 2005). These statistics seem to confirm that the HIV and AIDS pandemic entered its third decade with no signs of abating. The impact of the pandemic is felt throughout the world and no society has been unaffected by its consequences (Dorrington \textit{et al.}, 2001; Greene, Frey & Derlega, 2002). The challenges that this pandemic brings to modern society present itself in all facets of life.

One of the recent challenges facing this illness is the introduction of medication for the management of the illness. The introduction of anti retroviral medication has changed the status of HIV and AIDS to that of a chronic illness. Life expectancy for someone with HIV and AIDS can therefore be expected to increase (Greene \textit{et al.}, 2002; The Global Health Council, 2005). Management of this illness will thus have to be adapted. The increase in life expectancy implies that a greater emphasis must now be placed on

\(^1\) According to Greene, Frey and Derlega (2002) those who study HIV and AIDS should be aware of not contributing to stigmatisation through their discourse. They therefore use person-first language when referring to people living with HIV and AIDS. They also use the ‘and’ between HIV and AIDS since people with AIDS have HIV but people with HIV don’t necessarily have AIDS. This practice has been employed in this study for the same reasons.
the personal and social life of an individual who is living with HIV and AIDS (Greene et al., 2002).

Sub-Saharan Africa experiences these challenges on an enormous scale and appears to be the region where the impact of HIV and AIDS is greatest. Sub-Saharan Africa constitutes just over 10% of the world’s population but has 60% of all people living with HIV and AIDS (25.8 million) making it the epicentre of the global AIDS pandemic (AIDS epidemic update, 2005). HIV and AIDS are therefore exerting a dramatic impact in sub-Saharan Africa.

Van Rensburg (2004) mentions that HIV and AIDS has become a major source of disease burden in South Africa, and suggest that it might be the single most important phenomenon that will shape future demographic, health and development trends in the country. South Africa further faces a huge challenge in dealing with HIV and AIDS and is not only said to be the country with the largest number of people living with HIV and AIDS (PLHAs) in the world but is also reported to have the fastest growing epidemic in the world (Dorrington et al., 2001; Kaslow & Francis, 1989, Love Life, 2001; Rehle & Shisana, 2003). According to Berry (2004), 600 people die of HIV related illnesses each day in South Africa. A further challenge faced by South Africa is that of its society not being a homogenous one in terms of economics, culture, gender and religion. The result is that South Africa experiences HIV and AIDS along a continuum of prevention, care, support and rights (Nelson Mandela study, 2002). When one combines the
aforementioned with the present statistics and rate of infection occurring in South Africa, the picture of the illness in South Africa represents one of great concern.

The challenges facing South Africa, as a result of the HIV and AIDS pandemic, are therefore not only limited to the epidemiology of the illness. It reaches across many dimensions including economic growth, political stability, health care, family and community. One factor which would assist in alleviating the negative impact of this illness on all spheres is the eradication of stigma related to the illness. The focus of this study is therefore on stigma and specifically the stigma that people living with HIV and AIDS (PLHAs) might experience in the health care setting.

Poverty and health are inextricably linked to one another and together has a determining effect on the development of a country. Three of the eight goals of the Millennium development Goals (MDG’s) as determined by the UN Millennium Declaration, concerns health, one of which is the halt to the spread of HIV and AIDS, malaria and tuberculosis (DAC guidelines and Reference guide, 2003). South Africa’s poverty levels are high and one would therefore expect that there would be a strong relationship between poverty and the increase in prevalence of HIV infection. Poor people have less education, less access to health care facilities, are more vulnerable to diseases and have poor living conditions (DAC guidelines and reference guide, 2003; Fitzpatrick, McCray & Smith, 2004). If actions are taken to decrease the HIV and AIDS prevalence rate in South Africa one would have to keep in mind the impact of poverty on the illness.
1.2 Statement of the problem

Stigma has been identified as a key reason why PLHAs don’t access voluntary counselling and testing and healthcare, as well as a significant cause of non-adherence to treatments (Deacon et al., 2005; Brown, Macintyre & Trujillo, 2003). Recent reports confirm that stigma and discrimination towards people with HIV and AIDS remain pervasive and are probably the most difficult obstacles to prevention efforts (Global Health Council report, 2005; UNAIDS, 2006). According to Shisana (2004), stigma and discrimination represent key barriers to the provision of prevention, treatment and mitigation of impact of HIV and AIDS in South Africa. The eradication of stigma is therefore a key factor in any attempts aimed at the treatment and prevention of HIV and AIDS.

Although no part of the population is unaffected by HIV and AIDS, it is often the poorest that are the most vulnerable to the illness and for whom the consequences are most severe. Health care services face different levels of strain, depending on the number of people who seek services, the nature of their need, and the capacity to deliver that care (Fredricksson & Kannabus, 2005). In South Africa an individual’s socio-economic status is a mediating factor in their experience of HIV and AIDS as a chronic or terminal illness (Deacon et al., 2005). Thus, an individual who has more economic resources can access better healthcare. An individual that can pay for his/her own antiretrovirals would therefore be able to access this medication sooner. It is imperative that every effort is made to ensure that the process of accessing health care, at the level of the public health system, is one that does not disadvantage any person.
Within the context of health care, various studies reported that health care workers display stigmatising behaviour and attitudes towards PLHAs (Bond, *et al.*, 2002; Brown, *et al.*, 2003; Knussen & Niven, 1999; Niang *et al.*, 2003; Shabalala, *et al.*, 2002; South African Department of Health, 2002). If the primary health care centres are not accessed by PLHAs then the pandemic will grow and the impact on the country will be devastating. It is therefore imperative to determine the extent to which PLHAs experience stigma in the health care sector so that a deeper understanding can be acquired and more focused work can be conducted to eradicate the stigma.

1.3 Aim of the thesis

The primary aim of this study was to explore, through the experiences of PLHAs, whether stigma manifests within the primary health care centres. The secondary aim was to explore whether stigma is experienced in any other spheres of their lives.

1.4 Rationale and significance of the study

Given that South Africa has recently emerged from a history of discrimination, it appears to be facing a major challenge in the form of HIV and AIDS. Stigma has been listed by various researchers as a major challenge to addressing this problem. Research on HIV and AIDS stigma in the health care setting in South Africa, is limited. The public health care system faces an enormous burden of addressing the health care problem associated with HIV and AIDS, due to the stigma and discrimination which accompanies the illness. The findings derived from this particular study would therefore be relevant to all those who are interested in gaining an understanding of the manner in which PLHAs
experience stigma. By gaining insight into the world of PLHAs, the researcher hopes to assist health care workers, counsellors and lay counsellors to gain a deeper understanding of PLHAs experiences in the health care setting. It is hoped that as a result more effective use of treatment available at health care settings would be facilitated. The study will specifically allow those in the public health care system to understand what types of behaviours and attitudes are considered by PLHAs to be stigmatizing, as well as how this affects them and their use of health care facilities. For those involved with counselling PLHAs, it is hoped that a deeper understanding will be gained with regard to what feelings, fears and challenges are experienced by PLHAs so that these can be addressed in the counselling process. For researchers it is hoped that this study will illuminate further areas where research is a necessity in order to address the problem of HIV and AIDS related stigma.

1.5 Overview of the thesis

The thesis comprises five chapters. Chapter one is a brief introduction to the main considerations of this thesis. The problem being addressed through this research is discussed and the purpose expressed. Chapter two focuses on literature related to the topic. It broadly covers various aspects related to this thesis including: the prevalence of HIV and AIDS, HIV and AIDS in South Africa, the phenomenon of stigma (includes a theoretical understanding of stigma), the South African Health Care System and HIV and AIDS related stigma in the health care system. Chapter three introduces the methodology used in the study. It describes the methodology used to collect and analyse the data, the selection of participants and the ethical considerations. Chapter four is a
presentation of the results of the information that was collected. An interpretative phenomenological approach was used in analyzing the data. Chapter five covers a discussion of the results, the implications of the findings, as well as a brief look at the limitations of the study and recommendations for future research.
CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

Research over the past decade, have had a strong focus on the study of HIV and AIDS and related aspects. In scrutinizing studies related to this topic, it appears that there is still much to be learnt about HIV and AIDS, although a vast array of aspects have already been covered extensively. The research indicates that two of the biggest challenges related to HIV and AIDS are that the health care system has to provide for an increase in HIV infected people and the issue of stigma related to HIV and AIDS (Shisana, 2002).

The following literature review will focus specifically on studies and literature relating to the issue of stigma, the health care profession, as well as HIV and AIDS related stigma. The review would however be incomplete without an initial discussion on the general aspects relating to HIV and AIDS internationally, as well as nationally.

The HIV and AIDS pandemic pose a specific challenge to the African and specifically the South Africa context. Research studies conducted in Southern Africa and Africa generally are limited, resulting in a huge gap in information related to HIV and AIDS in this region (Deacon, Stephney & Prosalendis, 2005). The review will cover some of the available research and literature related to HIV and AIDS in South Africa. Stigma is the central issue being studied and consequently a theoretical discussion of this issue will be undertaken.
2.2 The prevalence of HIV and AIDS

Statistics relating to the prevalence rates associated with the HIV and AIDS pandemic seem to be plentiful (AIDS epidemic update, 2005; Kalipeni et al., 2004; UNAIDS Fact sheet, 2004). These statistics consistently manage not only to cause a shock reaction amongst lay people but also those who work in fields where they are faced with the pandemic on a daily basis, such as in the health care system.

Researchers appear to differ from each other on certain aspects relating to HIV and AIDS, specifically with regard to the origin and prevalence of the illness (Nord, 1997). AIDS was first recognised as a new condition in 1981, and homosexual men and intravenous drug users constituted the majority of cases at that point (Cogan and Herek, 1998; Green and Mc Creaner, 1996; Nord, 1997; Stroebe, 2000). This referred to cases reported in America, as well as other Western countries. According to Berry (2004), the first cases of HIV were diagnosed in South Africa in 1982 and were mainly amongst white homosexual men. At present however, as in the rest of Africa, heterosexual people face the biggest risk of becoming infected. Nokes (1996) says that the time taken to diagnose influences the ability to treat the illness. If the time is shortened then access to treatment will be quicker and the psychological impact of the illness will be addressed sooner.

The HIV diagnosis requires techniques not widely available in developing countries and is further affected by a medical infrastructure which has been and is currently limited in Africa (Green & Mc Creaner, 1996). Due to the differences between Western Countries
and Africa one has to be cautious when generalising research results from western countries to African countries.

The social, economic, cultural, political and ideological contexts in Africa have resulted in different manifestations of the pandemic within the African context. Kalipendi et al. (2004) and Fitzpatrick et al. (2004) suggest that deepening poverty experienced in African countries over the past twenty years have exacerbated the HIV and AIDS pandemic. It is further suggested that vulnerability to HIV is impacted on by chronic overcrowding, movement into urban areas and the lack of resources for addressing issues of sanitation, health care and employment. Although these conditions increase vulnerability to HIV and AIDS, the illness simultaneously impacts on these factors resulting in an increase in poverty, deteriorating medical conditions and further movement towards urbanization. This is supported by Ndlovu (2003) who indicated that in South Africa, specifically, the HIV and AIDS pandemic has contributed to poverty, damaged public health and is reversing and undermining gains in development.

According to available statistics, Sub-Saharan Africa is said to have close to 60% of the global total of HIV positive people in the world and bears the brunt of the effects of this pandemic. From 2004 to 2005 the number of newly infected people in this region increased from 3.1 million to 4.9 million people (Berry, 2005; Fitzpatrick, McCray & Smith, 2004; UNAIDS Fact sheet, 2004). A similar increase was seen regarding the number of deaths due to AIDS which increased from 2.3 million in 2004 to 2.4 million in 2005 (AIDS epidemic update, 2005; UNAIDS Fact Sheet, 2004). The AIDS epidemic
update (2005) further reported that in 2005 adults and children living with HIV totaled 25.8 million compared to 24.9 million in 2003 in Sub-Saharan Africa. In 1999 mother to child transmission was estimated to be at 90% of cases in Africa (Kalipeni et al., 2004). The prevalence rate amongst pregnant women reached its highest levels to date at 29.5% in 2004 (AIDS epidemic update, 2005). These statistics indicates that South Africa, as a part of Southern Africa therefore faces a major challenge in combating this illness (AIDS epidemic update, 2005; Fitzpatrick et al., 2004).

2.3 HIV and AIDS in South Africa
According to the Nelson Mandela study (2002), Sub-Saharan Africa is the most severely affected by the pandemic. Fredriksson and Kannabus (2005), mention that AIDS is the leading cause of deaths in Africa. According to Berry (2005), 3.2 million of the 4.9 million new infections occurred in Sub-Saharan Africa. Berry further indicates that in 2004, 28% of the 40 million people in South Africa were affected by HIV and AIDS and 13% of all the people in the world living with HIV, at that time, could be found in South Africa. The UNAIDS Epidemic update (2004) indicates that South Africa has the highest number of people living with HIV in the world and show no sign of decline in the epidemic.

Fredriksson and Kanabus (2004) indicate that social responses of fear, denial, stigma and discrimination are prevalent regarding HIV and AIDS. Stigma and discrimination, actual or feared, are amongst the most difficult obstacles to the prevention of HIV (The Global health council, 2005). As a result of these responses people do not access medical care and testing. In this manner the management of the pandemic becomes complicated since
it makes it difficult to know the full extent of the problem and how to manage it in the best possible manner.

The South African scenario presents unique challenges to fighting the pandemic which include the following: unsafe sexual behaviour, stigma and denial, gender related issues, migration, poverty, incarceration in overcrowded prisons, male circumcision, rites of marriage and indigenous healing practices (Nelson Mandela study, 2002).

South Africa’s diverse demographical composition further constitutes unique challenges in addressing the HIV and AIDS pandemic. HIV and AIDS affect all ages, sexes and races in the South African population but differ in terms of severity and prevalence amongst groups. The disparity appears to be the result of the difference in social and behavioural determinants across the groups (Dorrington et al., 2001; Nelson Mandela Study, 2002). Females have a higher rate of infection than males, Africans have a higher rate of infection than other population groups, and people living in urban informal settlements have a higher rate than people living in urban formal settlements and rural areas (Kalipeni et al., 2004; Love Life Report, 2001; Rehle & Shisana, 2003; Shisana, 2002). Young girls and women have been found to be more vulnerable to HIV and AIDS. Amongst the reasons offered for this is the manner in which poverty, resource allocation and community norms impact on gender and generational lines (Stock, 1995 in Kalipeni et al., 2004). Rehle and Shisana (2003) suggest that since there is insufficient data related to these socio-demographic factors, it is consequently difficult to determine its actual impact on prevalence rates in South Africa. It is therefore important that further
studies look at the impact of these demographic differences on the HIV and AIDS pandemic in South Africa.

The South African scenario is further complicated by the issue of culture. People belonging to the same culture will share beliefs and norms. In South Africa there are many different cultures resulting in different world views. Macheke (1998) conducted a study which focused on mine workers and their perceptions of health, HIV and AIDS, and sexuality. The study found that although many traditional information-based HIV and AIDS education programmes were conducted with the mineworkers, and their knowledge of the facts were fairly accurate, programmes seem not to take into account the beliefs, norms and contexts within which these facts are embedded. The result was that people did not appear to see this information as relevant for themselves and consequently the programme’s impact was limited. Certainly, within the South African context, which is diverse in many ways, the issue of beliefs, norms and context are of primary importance when addressing issues relating to HIV and AIDS.

The manner in which prevalence rates are determined can significantly influence the data gathered. In the initial stages of the pandemic in South Africa statistics related to the prevalence of HIV and AIDS were limited to those gained from antenatal clinics (Macheke, 1998; Rehle & Shisana, 2003). Prevalence rates for South Africa were therefore based on a limited portion of the population, which results in limited information with regard to aspects of behaviour related to infection or prevention. This had an impact on programmes aimed at prevention and education. The Nelson Mandela
study (2002) represented a shift to household surveys to determine prevalence of HIV and AIDS. According to the UNAIDS/WHO Update (2005), both methods for determining prevalence rates should be considered together since both have potential weaknesses in their method. It is therefore imperative that one is aware of how statistics were arrived at before using them in addressing issues related to HIV and AIDS.

South Africa is thus faced with a specific combination of challenges to addressing the problem of HIV and AIDS. These challenges include amongst others: the prevailing economic conditions, social and behavioural determinants within a diverse population, limited information with regard to prevalence and differences in culture. To address the HIV and AIDS pandemic in South Africa it is imperative that these challenges either be dealt with, or be taken cognisance of, when efforts are made to address the pandemic.

2.4 The phenomenon of stigma

Stigma undoubtedly represents one of the biggest challenges to dealing with HIV and AIDS in South Africa. The following discussion of stigma will cover the nature of stigma, stigma related to disease, a theoretical understanding of stigma and aspects of HIV and AIDS related stigma.

2.4.1 The nature of stigma

Stigma appears to be a multifaceted phenomenon. If an understanding of stigma is sought it is necessary to consider definitions which are already proposed for this
phenomenon. In addition it would be necessary to understand how stigma is experienced and how it is responded to.

2.4.1.1 Defining Stigma

Views differ with regard to whether or not stigma should be seen as a social, cognitive phenomenon, or whether it should be considered as a social, cultural phenomenon within a certain context. Research focusing on the issue of stigma appears to differ vastly in terms of where the emphasis is placed. The result is that though research is abundant in this field, it however does not provide one specific theory or model delineating the boundaries of stigma and stigmatization (Deacon et al., 2005).

Goffman (1963) is cited most often by researchers as a point of departure for discussions on stigma. Various researchers agree that stigma is defined as involving an attribute which significantly discredits an individual in the eyes of others or society. This attribute is therefore seen by others as being negative, something which devalues, spoils or flaws an individual (Bond, et al., 2002; Goffman, 1968; Kent, 1999; Parker & Aggleton, 2003; Pryor, Reeder, Yeadon & Hesson-McInnis, 2004). The stigmatised individual is seen as possessing an undesirable difference. This judgement is made on the basis of what constitutes the difference or deviance by society who then applies rules and sanctions resulting, in what Goffman (1963) refers to as the ‘spoiled identity’ of the individual. Parker and Aggleton (2003) suggest that stigma and discrimination produce and reproduce relations of power and control resulting in some groups being devalued and others feeling superior. They further suggest that in highly individualized cultures,
stigma and discrimination can be viewed as individual processes. In cultures, where bonds and allegiances to family, village, neighbourhood and community are focused on, stigma and discrimination are better understood as social and cultural phenomena linked to the actions of whole groups of people (Parker & Aggleton, 2003).

Bond et al. (2002) and Herek, Capitanio and Wildaman (2003) mention that stigma is socially constructed and therefore arises from cultural norms. These norms determine what people should be and what is considered a deviation. Goffman (1963) suggests that stigma arises in social interaction when an individual’s actual social identity does not meet society’s normative expectation of the attributes the individual should possess, while stigmatisation is a process of global devaluation of an individual who possesses a deviant attribute. Kurzban and Leary (2001) suggest that stigmatisation is based on the shared values and preferences of a particular group’s members and this becomes the basis for disassociating from individuals who are perceived as being part of the group. Stigmatisation is considered a dynamic process which arises from the perception that there has been a violation of a set of shared attitudes, beliefs and values. It can lead to prejudicial thoughts, behaviours, and/or actions by friends and families (Cameron, 1993; Goffman, 1963; Jayaraman, 1998; Ziegler et al., 2000 cited in Brown et al., 2003; Nord, 1997).

According to Crocker and Major (1989), stigmatized groups are different to out-groups. They view a stigmatized group as being an out-group relative to the dominant group in a culture or society. An out-group is usually viewed as being defined by reference to any
particular in-group, regardless of which group holds the dominant position in the social hierarchy. They also suggest that a stigmatized group can be devalued by the broader society or culture, as well as specific in-groups. The significant difference between an out-group and a stigmatized group therefore appears to relate to the issue of power, with the stigmatized group being the one that does not hold the power.

Weiner, Perry and Magnusson (1988) examined the perceived controllability and stability of causes of various stigmas. They found that physically based stigmas are distinguished from those perceived as mental in origin or based on untoward behaviour. Responsibility for the onset (the problem) and offset (the solution) of a stigma was also found to be significant in this study. This study further investigated the onset uncontrollable and onset controllable perception of a stigma. It was found that physically based stigmas were seen as onset-uncontrollable whereas mental-behavioural problems were perceived as onset-controllable. Responses to the stigmas varied. Onset-uncontrollable stigmas illicits responses of pity, liking, no anger and help-giving behaviours. Onset-controllable stigmas illicits responses of no pity, little liking, anger and judgements not to help.

2.4.1.2 The experience of stigma

Stigma is experienced by the stigmatised in various ways. The literature indicates a distinction between perceived stigma (internal) and enacted stigma (Brown, Macintyre & Trujillo, 2003; Kent, 1999; Policy Project, 2003). Perceived or felt stigma is described as being the anticipation of rejection and the shame of having the stigma, whereas enacted stigma refers to actual incidents of discrimination. According to the Policy Project
enacted stigma can, at times, lead to actual incidences of violence against a person. Perceived stigma is described as being more disabling since it leads to anxiety and avoidance of social activities and contact. Kent (1999) found, in a study looking at stigma attached to dermatological conditions, that respondents were more likely to report incidents related to felt stigma than enacted stigma. Both types of incidents were related to reports of distress and disability.

The primary focus of the Siyam’kela project, conducted in South Africa, in 2003, was the study of HIV and AIDS related stigma. Their aim was to identify well researched indicators of stigma which would pave the way for stigma mitigation. Proposed indicators of external stigma were identified as including avoidance, rejection, moral judgement, stigma by association, unwillingness to invest in PLHAs, discrimination and abuse. Proposed indicators of internal stigma (perceived) were identified as including self exclusion from services and opportunities, negative perception of self, social withdrawal, overcompensation and fear of disclosure (Policy project, 2003).

In their study Lee et al. (2002) focused on internalised stigma among HIV positive individuals and found that individuals reported varying degrees of internalised stigma. Internalised stigma refers to the process whereby individuals have internalised the stigma associated with their disease and consequently views both themselves and their disease as negative. Internalised stigma causes an individual to be more sensitive to both actual and anticipated rejection and stigmatisation by others (Lee et al., 2002). This can impact on
an individual by leading to self doubt, lowered self esteem, depression, immuno-suppression and even premature death (Deacon et al., 2005).

Mickelson (2001) in her study questioned whether all individuals with a stigmatised stressor feel equally stigmatised, and suggest that at times those individuals who are most socially stigmatised perceive the least stigma. Her study focused on the effect of perceived stigma on perceived support availability, negative interactions and depression. This study found that not all individuals experienced the same level of stigma even though they shared the same socially stigmatised stressor.

2.4.1.3 Responses to stigma

Various responses to the stigmatised individuals have been identified. PLHAs experience stigma differently and in the same way responses to PLHAs differ between individuals. Responses to stigma include avoidance of the stigmatised individuals, fear of contaminations, increased physical distance, interactions which are cut short and the treatment of inanimate objects used by the stigmatised as if it has been contaminated (Pryor et al., 2004; Nord, 1997). According to Kalipeni et al. (2004) & Nord (1997), once individuals are placed in a risk category they are separated from other sources of identity, stigmatised and degraded by definition. The creation of alterity or “otherness”, allows those in power to dehumanize, scapegoat and blame, and thus to avoid responsibility for sufferers. The struggles of people with HIV and AIDS to resist this “othering” process were charted from the beginning of ethnographic research on Aids (Kalipeni et al., 2004). Labelling as promiscuous, denial of access to housing, dismissal
from jobs, mob killings all constitute some of the initial responses of individuals, groups and organizations to HIV and AIDS (Kalipeni et al., 2004; Nord, 1997). Weiner et al. (1988) refer to attribution theory when suggesting that the perceived cause of the stigma determines the affective reactions toward the stigmatized person, future expectations regarding that individual and a variety of behavioural responses. Chin and Kroesen (1999) conclude that negative reactions to individuals with HIV and AIDS, i.e. enacted stigma, appear to stem from a combination of stigma and ignorance about HIV and AIDS.

2.4.2 Stigma and disease

The relationship between stigma and disease, whether physical or mental, is one which has interested many researchers. It appears that stigma has accompanied illnesses throughout history especially diseases which are sexually transmitted or terminal (Deacon et al., 2005). The result of this stigma has held negative consequences for those who have been unfortunate enough to have contracted the disease or stigmatised condition. Crocker and Major (1989) mention that the members of stigmatised groups face substantial negative social, economic, political and psychological consequences.

Deacon et al. (2005) define disease stigma as an ideology that claim that people with a specific disease are different from ‘normal’ society, more than simply through their infection with a disease agent. This ideology links the presence of a biological disease agent (or any physical signs of a disease) to negatively-defined behaviours or groups in
society. Disease stigma is therefore viewed as negative social baggage associated with a disease.

Frable, Platt and Hoey (1998) and Greig and Bell (2000) distinguish between people, who have an illness, physical or mental, which is concealable versus one which is visible or conspicuous. Frable et al. (1998) found that people with concealable stigmas are more vulnerable to negative self perceptions due to the absence of similar others in the individual’s environment. They further found that individuals with a concealable stigma experienced lower self esteem and more negative affect than an individual with a conspicuous stigma.

Deacon et al. (2005) suggest that discourse around disease stigma has resulted in what Joffe (1999) has termed the ‘not me – others are to blame’ phenomenon. Blame is attributed to out-groups who are considered or, as in the case of HIV and AIDS, have been identified as risk groups.

### 2.4.3 A theoretical understanding of stigma

Various theories and models have contributed to developing and understanding stigmatisation and stigma in general. The attribution theory, social representation theory and phenomenological theory will be discussed in this regard. The phenomenological theoretical approach, seem to be the most appropriate for this study to explain the experiences of stigma by the PLHAs.
a. Attribution Theory

According to Joffe (1999), attribution theory is seen as one of the most established approaches in social psychology. At the basis of this theory is the presumption that people actively search for meaning in the world around them (Shaver, 1975). Foster and Louw-Potgieter (1991) and Glassman and Hadad (2004), mention that attribution theory is not a coherent theory but rather a set of models which has a unifying feature. Attribution theory is one that seeks causal explanations with regard to our own behaviour and that of other people. These interpretations we make are called attributions. Attributions are considered to be social judgements and serve to give coherence and organization to the individual’s behaviour (Jaspars, Fincham & Hewstone, 1983).

Fritz Heider is considered to be the founding father of attribution theory (Glassman & Hadad, 2004; Jaspars, et al., 1983). Heider’s view was that we tend to interpret behaviour in terms of internal (personal) and/or external (situational) factors. An error can occur in this attribution which is referred to as fundamental attribution error. This error is understood as being the tendency to underestimate the importance of situational influences and overestimate the importance of internal factors in interpreting the behaviour of other people. In the same manner that errors can occur in the way we perceive others, errors can occur in the way we perceive ourselves. This error is referred to as the self serving bias. It involves a desire to see ourselves in the best possible light, the tendency to attribute our successes to personal factors (our ability), but blame our failures on situational factors (distraction, lack of time), which results in a distortion of
the individual’s self-image in a favourable way (Foster & Louw-Potgieter, 1991; Galssman & Hadad, 2004; Jaspars et al., 1983).

These attributions are derived through two broad steps which will be highlighted here. Firstly, the individual searches for hypotheses that could provide answers to finding an explanation for the observed behaviour. The individual’s cognitive repertoires will determine the hypothesis. Secondly, once one or more hypotheses have been formulated the observer will look for additional information or evidence to evaluate the validity of the hypothesis being considered. An attributional judgement is arrived at by evaluating the extent to which the relevant evidence is consistent or inconsistent with the hypothesis. The process of attribution therefore involves the generation and validation of hypotheses concerning human behaviour (Jaspars et al., 1983).

Jones et al. (1984) suggest that a “mark” becomes discrediting when it is linked through the attributional processes to causal dispositions and these dispositions are seen as deviant. To understand stigma it would therefore be necessary to understand the attributions which have preceded it. These attributions would be made by a group or individual with regard to the behaviour or specific attributes of the stigmatised group or individual. In the case of PLHAs one would expect that certain attributions have been made by those who are HIV negative with regard to those who are HIV positive. An in-group out-group dynamic is established in this manner. Judgements of in-and out-groups are therefore seen as the outcome of an attribution process and not simply as distorted perception. The starting point of an attributional judgement is a behaviour or a
behavioural episode. Jaspars et al. (1983) identified three key concepts relevant to attributions, namely causation, moral responsibility and punishment reward. Causations refer to the event generation, responsibility to the moral evaluation of an actor and punishment/reward to the recommended consequences for the actor. The fundamental attribution error and self-serving bias then results in the out-group being stigmatised since they are considered to be responsible for acquiring the illness which separates them from the in-group. These are some of the concepts used in attribution theory to explain stigma and what causes people to stigmatise others who are seen as different or belonging to a different group.

b. Social Representation theory

The concept of social representations was developed by the French social psychologist Moscovici in early 1960’s. A social representation is a socially shared and interactively produced process whereby a common understanding of objects and processes can occur, as well as a way to communicate about them. In this way realities are constructed within a group and consequently meaning is created within a group (Foster & Louw-Potgieter, 1991; Smith, Harre & Van Langenhove, 1995). Social representation theory therefore explains how groups come to have a common understanding of phenomena and how meaning around specific phenomena is created and shared. According to Jones et al. (1984), stigma is a socially developed phenomenon and this theory provides a way of understanding this process. According to this theory HIV and AIDS stigma would therefore develop as a result of the process of social representation.
According to Foster and Louw-Potgieter (1991), two processes are responsible for generating social representations, namely anchoring and objectifying. Stigma would therefore develop as a result of these two processes occurring in a group. Anchoring refers to the process of classifying, labeling or naming. In this way the person/object acquires certain characteristics, becomes distinct from other things and becomes an object of convention among those who share such conventions. A social identity is thus given. The information for labeling could be acquired through various sources and might be genuine or not. In the example of an individual who is HIV positive, by naming that person as HIV positive the individual, through the naming/labeling process, is seen to possess certain characteristics. This labeling process would be assisted by the medical labeling that accompanies HIV and AIDS in terms of symptoms of the illness. These could be communicated through the media or any other available sources.

During the objectifying process words are transformed into objects with specific contents and thereby made sense of in a collective manner. This transformation would occur with the core values and social norms of the culture and take on meaning specific to that group (Joffé, 1999). Through these social representations collective processes are able to penetrate into individual thought. It is through this process then that groups will come to share meaning and create meaning. According to Smith et al. (1995), it is through this process of social representations that an individual is able to make sense of their own life and environment since the goal is to make the unfamiliar familiar. What therefore becomes stigmatised in a specific group would be determined by that group’s values and norms together with the information which is received.
Applying this theory to gain an understanding of stigma would certainly help one in understanding how stigma is shared in a group and how groups come to share meaning around the specific stigma being looked at. It could also assist one in understanding how the stigmatised come to understand and communicate with regard to the stigma attributed to their condition/situation.

c. **Phenomenological theory**

Phenomenology is a philosophy that was initiated by Edmund Husserl at the start of the 20th century (Giorgio, 1997; Groenewald, 2004; Smith *et al.*, 2003). This philosophy thematises consciousness and all of the objects, events, and processes that we become aware of by means of consciousness. It is also a method for accessing all of the objects and events that consciousness refers us to (Giorgio, 1997; Smith *et al.*, 1995). Giorgio (1995) further mentions that it offers a method for accessing the difficult phenomenon of human experience. It does not take the world for granted but wants to understand what motivates a conscious creature to say that something is. If an individual who is HIV positive talks about being stigmatised, this approach would want to understand what motivates that individual to say this. In this way it provides a means of understanding the natural attitude better. The biases, errors and prejudices that we carry with us everyday can consequently be understood.

According to Giorgio (1995), this approach centers on the fact that the world appears to us through our stream of consciousness as a configuration of meaning. Acts of consciousness include perceiving, willing, thinking, remembering and anticipating, and
are modalities of the self – world relationship. Consciousness is intentional and always directed toward something. Smith et al. (1995) mention that knowledge is always correlated with consciousness (that is, someone must be aware of it) and knowledge is always of or about some thing or event. We are presented with all sorts of objects, entities and events through the stream of consciousness. These objects and events are complexly related both simultaneously and sequentially. Since it is difficult to grasp completely even a segment of the stream, we tend to make distinctions with respect to it in order to have at least partial access to it. Smith et al. (1995) further say that phenomenologists do this by distinguishing between the acts of consciousness and the objects that are correlated by such acts. The word act refers to both the fact that by means of consciousness events and objects outside consciousness can be actualised for us and to the fact they endure in time. By means of consciousness the presence of things, objects and events are possible. The way phenomenology deals with the uninterrupted stream that consciousness presents, is by attempting to distinguish moments or aspects of the stream by correlating them either with time or with presentations of objects, events or processes (Smith et al., 1995).

According to Smith et al. (1995), for every perception of a real thing, the real thing is accessed, but only in a partial, perspectival way that he calls an adumbration or profile. Each grasp is partial and one is therefore motivated to acquire many perspectives and the perceived thing would be the synthesis of many profiles of the same real thing. The number of perspectives one brings to the apprehension of a thing is infinite and so the synthesis that one calls the “thing” is really presumptive and less than all of the possible
perspectives that could be brought to it. For this reason one would have to distinguish the “thing” itself from the perceived awareness of it.

An individual’s subjective meaning is therefore considered not as something haphazard but rather as something which is structured and accessible. A phenomenon is therefore the external world perceived in a particular way and not something inaccessible in the inner world. It is seen as the manner in which a human subject attributes meaning to certain aspects of the world and is available through expressions (Lester, 1999; Smith et al., 1995). Therefore if an individual says that he/she experienced a particular situation as stigmatising then this reflects how the individual perceived that situation and might be the same or different to how others in the same situation perceived it.

The experiences of PLHAs have a subjective meaning for the individual. Every experience this individual has would be perceived by him/her in a certain manner. It is this meaning which would determine whether or not an individual experiences the event or action or behaviour as stigmatising. If an individual, for example, is asked to move out of his/her home after disclosing his/her HIV status, the meaning the individual attributes to this event will determine if the individual feels this is due to the stigma attached to the illness. By accessing the experiences of individuals in this study it is hoped that subjective meaning relating to the phenomenon being explored (stigma) would be accessed.
The phenomenological theory has been chosen for this study because it describes phenomena as they occur which allows one to gain an in-depth understanding of how these phenomena are experienced. It does not propose an explanation for stigma but allows one to ascertain how stigma is experienced. This research study aims to gain an understanding of how PLHAs experience stigma. It is therefore necessary to consider a theory which assists in gaining access to the individuals experience as it is experienced. Both attribution theory and social representation theory on the other hand attempts to explain stigma in terms of the causes and therefore have not been considered appropriate for this study (Jaspars, Hewstone & Fincham, 1983).

2.4.4 Stigma and HIV and AIDS

Corrigan (2004), in his article on stigma and mental health care, suggests that stigma prevents people from seeking care or fully participating in care. Researchers are in agreement that HIV and AIDS related stigma negatively impacts on prevention, diagnosis, treatment and care (Bond, Chase & Aggleton, 2002; Deacon et al., 2005; Reidpath & Chan, 2005). According to Herek and Glunt (1988), negative reactions to HIV infected individuals have shaped the behaviour of infected individuals and have also limited effectiveness of prevention efforts. The reduction of HIV and AIDS related stigma can therefore be seen as playing a vital part in stemming the pandemic by making health care more accessible (Brown, Macintyre & Trujillo, 2003; Reipath & Chan, 2005).
2.4.4.1 Stigma and discrimination

Stigma and discrimination are two concepts which are often used interchangeably by most lay people. Researchers however draw definite distinctions between the two concepts (Deacon et al., 2005). Stigma refers to negative things people believe about individuals living with HIV and AIDS, whereas discrimination refers to what people do to unfairly disadvantage people living with HIV and AIDS. The one does not necessarily result in the other.

Herek and Glunt (1988) suggest that AIDS – related stigma include all stigma directed at persons perceived to be infected with HIV regardless if they are or whether they manifest symptoms of AIDS. According to Herek and Glunt (1988), AIDS – related stigma is viewed as a socially constructed reaction to a lethal illness most prevalent among groups that already were targets of prejudice.

2.4.4.2 The impact of pre-existing stigma

Deacon et al. (2005) proposes a pattern of differential stigmatization which refers to HIV and AIDS stigma being constructed around blame. They suggest that PLHAs are stigmatised as a result of belonging to a group or community which has already being defined in a negative manner, i.e. a stigmatised group as described earlier (Alonzo and Reynolds, 1995 cited in Bond et al., 2002). Lee, Kochman and Sikkeman (2002) and Reidpath and Chan (2005) further suggest that stigma related to HIV and AIDS is layered on pre-existing stigma of sexual conduct, drug use and homosexuality. Herek and Glunt (1988) agree that stigma related to AIDS is layered on pre-existing stigma and
consequently reactions to AIDS are reactions to gay men, drug users, racial minorities and outsiders in general.

A study conducted by Bond et al. (2002) found that women in bars and clubs were blamed for their love of money, flirting and spreading HIV and AIDS. In this study blame was also directed at sex workers. A study conducted by Niang et al. (2003) found that there was pre-existing stigma directed at men who have sex with men. This act is seen as unacceptable in terms of their religion and people are therefore stigmatised if they partake in this activity. Consequently men refrain from indicating any symptom of diseases related to homosexuality, since it is considered to be shameful. It is imperative to understand and address the layered nature of stigma and understand how the different layers intertwine in order to develop programmes and interventions which would address this complex relationship (Reidpath & Chan, 2005).

2.4.4.3 The impact of stigma on disclosure of HIV status

According to Leary and Schreindorfer (1998) in Greene et al. (2002), stigma impacts on an individual’s decision to disclose his/her status, social support received, coping, as well as identity.

A study conducted by Chin and Kroesen (1999) investigated disclosure of HIV status by Asian/Pacific Islander American Women. The results of this study indicated that fear of stigmatisation, concern about burdening or disappointing others and concerns about discrimination, influenced the individual’s decision to disclose his/her status. This study
also found culture to have a significant impact on decision to disclose. Within this specific culture, the topics of death, disease, sex and drugs are considered to be taboo and disclosing one’s HIV status is therefore considered openly associating oneself with a topic (i.e. HIV and AIDS) which should remain unspoken. Consequently women in this study reported finding it difficult to disclose their status within this environment.

An individual who is not willing to disclose his or her HIV status due to stigma would not have access to social support, needed medical and social services and may also delay in seeking medical care and might not be as committed to treatment regimes if they have entered one (Herek et al., 1996).

2.4.4.4 The impact of stigma on coping

Heckman et al. (2004) study which focused on emotional distress in non-metropolitan persons living with HIV, found that social support plays a prominent role in quality of life and adjustment efforts of men and women living with HIV. This study used Smith and Crystal’s (2000) model which is an AIDS-specific model of emotional distress that identifies emotional distress as being related to HIV-symptom severity, HIV-related stigma, family rejection, social support, and active avoidant coping. The Heckman et al. (2004) study found that Smith and Crystal’s model applies to their non-metropolitan sample and could explain up to three quarters of the variance in emotional distress in their study’s participants. It further found that greater HIV related stigma and rejection by family led to more emotional distress and that social support and avoidant coping,
mediated the effects of stigma and rejection. The stigma related to HIV and AIDS can therefore be seen as having an impact on an individual’s ability to cope with the illness.

2.5 The South African health care system

In a country where a big disparity exists between the rich and the poor, the evidence of the disparity will not only be seen in the lifestyles of the people, but will also be reflected in their illness profiles. South African society reflects these vastly different lifestyles and social conditions amongst the poor and the rich (Van Rensburg, 2004). As a result of this disparity South Africa has implemented a pro-poor health approach in an attempt to address the disparity.

The DAC guideline and reference series (2003) describes a pro–poor health approach as being one which gives priority to promoting, protecting and improving the health of poor people. This includes the provision of quality services in public health and personal care, with equitable financing mechanisms essential to improve health and prevent the spiral from ill health to poverty.

South Africa’s health sector has a history of being racially divided and unequal. This has resulted in inequitable resource allocation with poor people living in poorer socio-economic areas suffering the most as a result. Pick (1995) cited in Van Rensburg (2004) concludes that the South African health care system is one in which human resources for health care have developed in an ad hoc and fragmented manner. The apartheid system compounded the inequality in the provision of health care along racial, gender and class
lines, and entrenched the development of human resources along these lines. The result is a health care system with an inequitable distribution of human resources. The change to a pro-poor system is an attempt to change this situation.

The transformation within the South Africa society, post 1990, paved the way for changes to be introduced within the health care system. The South African health care sector is made up of private, as well as public sectors. The public health care system in South Africa is further divided into primary health care, secondary, tertiary and academic state hospitals (South African Department of Health, 2002).

The new government introduced a district based primary health care system which forms the cornerstone of the health reform in South Africa. Primary health care in South Africa is a public service that is delivered in various ways, for example stationary or fixed clinics, mobile clinics, satellite clinics, community health centres and outpatient departments (Van Rensburg, 2004). Disparities exist between the private and public sector in terms of remuneration of employees and medical facilities available. Within the private health care sector personnel are highly paid and medical facilities are advanced. In the public sector, where 80% of the population seek care, only 20% of health care expenditure takes place (Love life, 2001; TAC Fact sheet, not dated). This is an indication of the level of need which the public health sector has to attend to and especially with the impact of increased HIV and AIDS related cases the burden is huge.
It is estimated that 51.5% of all people in South Africa use the public health care sector, and with the increase of 30% expected over the period 2002-2007 for HIV related cases, one can expect the burden on the state to be immense (Shisana, 2002). The Department of Health receives a large amount of money for HIV and AIDS. In the Western Cape for 2004/05, R66,818 million was allocated (Ndlovu, 2003). When one considers this huge allocation of resources being made in managing HIV and AIDS at a public health care level, it is apparent that to gain the benefit of this allocation of resources one has to understand and manage the barriers to the use of these resources.

Health workers at primary health care facilities face major challenges. These include the following: inappropriate training, multiple roles, heavy workload, infrequent and inadequate supervision, inequitable distribution of resources, poor facilities, infrastructure and transport (Van Rensburg, 2004). In addition, the HIV and AIDS pandemic have multiplied the burden with additional and urgent demands (Van Rensburg, 2004).

An efficient health care system is a vital requirement in the response to HIV and AIDS. This would reduce the spread and impact of HIV and AIDS through improved diagnosis and treatment of sexually transmitted illnesses (STIs), voluntary counselling and testing, treatment for opportunistic infections, reduction in mother to child transmission (DAC guidelines & reference series, 2003). It is predicted that the anti-retroviral programme in South Africa will be the largest public health intervention the world has ever seen, since it is estimated that in South Africa 1.4 million people will be on the programme by 2007.
(Strode & Barrett Grant, 2004). The implication for the health care system is enormous as this has implication for all other care required by individuals who are HIV positive.

### 2.6 HIV and AIDS related stigma in the health care system

One expects that health care workers would fulfill a role of support for individuals who have a stigmatised disease since their knowledge about the disease would give them insight that a lay person would not have. It appears however that there has been mixed reactions in terms of responses to PLHAs amongst health workers (Bond, et al., 2002; Brown, et al., 2003; Knussen & Niven, 1999; Niang et al., 2003; Shabalala, et al., 2002; South African Department of Health, 2002).

The health care system is faced with the challenge of stigma and discrimination within the system. Some behaviours and attitudes towards PLHAs which have been found to be stigmatizing in this setting include the following: staff treat PLHAs differently to other patients, staff speak in a different manner, staff gossip about patients and staff are at times reluctant to provide proper care (South African Department of Health, 2002). The study also found that as a result of this stigma, PLHAs reported to the clinics at a stage when there was little that could be done for them. The delay in reporting to the clinic places a further burden on the system since the care needed at a later stage of the infection requires more resources.

Bond et al. (2002) in their study with service providers and service users of health care facilities found that amongst the forms of stigmatisation reported were denial of drugs and treatment, being dealt with last, being labeled and called names, breaches of
confidentiality and being left in the corridor. Providers also reported that HIV positive patients were more difficult to work with; they displayed hysteria and attention seeking behaviour; and their need for both psychological and medical help contributed to them being difficult to work with.

According to the Nelson Mandela study (2002), people living with HIV and AIDS, especially women, have been found to be exposed to stigma and discrimination at community and family level, as well as by health personnel. According to Berry (2005), one of the major challenges South Africa faces is that of the roll-out of Neviropine to pregnant women through the health care system. Berry further says that the stigma of being HIV positive stops women from taking a test. Further, if they are pregnant and they know that they are HIV positive the stigma keeps individuals from admitting their positive status to midwives.

A study conducted by Shabalala et al. (2002) investigated the quality of care for STIs at primary health care centres in four provinces in South Africa. The results indicated inconsistencies in participants’ experiences at health care centers with some indicating experiencing negative attitudes and behaviour, as well as stigma relating to their illness and others experiencing positive attitudes. In this study participants described health care providers as being disrespectful, rude, judgemental and stigmatising.

The extra burden which has fallen on health care workers to care for these individuals has also taken its toll. Fredriksson and Annabel (2004) mention that as HIV and AIDS
matures, the demand for care for those living with HIV and AIDS rises and simultaneously the toll on health workers increases. Furthermore, it is reported that 43.9% of health workers felt that the prevalence of HIV and AIDS impacted on their work. These health workers further indicate that they experience stress, fear, frustration and depression due to their work with patients living with HIV and AIDS. The burden on health care staff is therefore enormous since prevalence rates are on the increase resulting in the problem becoming bigger (South African Department of Health, 2002). Not only have health care workers been guilty of stigmatising individuals who are HIV positive but they themselves have also suffered as a result of the stigma which is assigned to HIV positive individuals due to their work with such individuals. In the study by Brown et al. (2003) this is referred to as secondary stigma.

A study conducted by Knussen and Niven (1999) with health care workers in Scotland found that where staff did not receive in-service training relating to HIV and AIDS they displayed more negative attitudes to PLHA. Training in HIV and AIDS appears to be an important aspect in the eradication of negative attitudes that health care workers hold. This training should ideally address the fears and concerns of health care personnel and should provide for personal contact with PLHAs. The Knussen and Niven study (1999) also found that staff who had predominantly more social contact with HIV positive patients had more positive attitudes towards them.

In their study Green and Platt (1997) found that fear of contagion was identified as the principal source of negative reactions towards people with HIV in health care settings in
Scotland. Their results further indicate that as health care professionals become familiar with treating people with HIV, the stigma related to the disease appears to be declining.

Chin and Kroesen (1999) noted that medical providers, therapists and counsellors are most likely to be the first people to whom HIV positive individuals disclosed their status. They further concluded that this suggests that health and mental health care providers become important in the lives of HIV positive individuals. The attitude and behaviour of health care providers to PLHAs are therefore crucial elements in determining whether people will make use of health care services.

Deacon et al. (2005) suggest that the response of PLHAs does not directly relate to a measure of stigma. Consequently if PLHAs do not attend health care centres it is not a direct measure of the level of stigma presently enacted by health care workers. It follows then that one would need to determine in some way whether PLHAs experience stigma in health care centres.

According to the National Survey of the Health Sector (2002), the presence of stigma in health care settings results in HIV infected people hiding their status and only reporting to centres when they were very ill. It also resulted in individuals visiting a new hospital each time they fell ill. In turn resulting in both more work for health care personnel and impacting on personnel emotionally. Stigma in the health care setting will therefore only have negative results for staff since they would have to work harder and more money would be wasted in this manner as well. To improve this scenario, it is therefore
imperative that health care personnel understand the impact that their behaviour and attitudes have on PLHAs.

2.7 Conclusion

This chapter focused on literature relating to stigma and more specifically stigma related to HIV and AIDS. It further discussed the South African scenario and took an in-depth look at the South African health care system and its response to the challenge of dealing with HIV and AIDS.

HIV and AIDS is a pandemic which is posing various challenges worldwide. The nature of the disease is such that its impact is felt in all spheres in society. The disease presents a challenge not only from a biological standpoint but also on a social and cultural level. South Africa and Sub-Saharan Africa have been found to be the worse hit by the HIV and AIDS pandemic. Studies indicate that stigma is one of the biggest challenges to dealing with HIV and AIDS.

Literature reflects that stigma within the health care setting poses a barrier in the treatment of PLHAs. Health care workers are not only responsible for displaying stigmatising behaviours and attitudes but also face stigmatisation themselves as a result of their work with HIV positive people. Limited research studies have been found which focus on the perspective of the person living with HIV and AIDS. Research focusing on the issue of stigma related to HIV and AIDS within the health care setting is also limited and is an area which is in need of research.
CHAPTER 3
RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction
To assist in reducing the impact of the HIV and AIDS pandemic on the health care system, as well as the negative impact it has on PLHA, it is imperative that the nature of stigma be explored and understood. The focus on health care facilities is important since this often represents the first point at which people are faced with their HIV status.

The primary purpose of this study was to explore PLHAs’ experiences of treatment received in public health care facilities to ascertain whether PLHAs experience stigmatising behaviour and attitudes by health-care workers. This could inform the development of interventions aimed at eliminating HIV and AIDS related stigma.

3.2 Research Method
The study employed a qualitative methodological framework. According to Creswell (2003), qualitative research collects participant meaning, focuses on a single concept or phenomenon, studies the context or setting of participants, makes an interpretation of the data and creates an agenda for change or reform. According to Terre Blanche and Durrheim (1999), when the aim is to study phenomena as they occur in real world situations without manipulation of variables to determine a cause-effect relationship, then the appropriate approach to use is that of qualitative research. As the aim of this study is to access the experiences of PLHAs as they occur, it follows that the qualitative approach is most suited to this study. In addition the qualitative approach is well suited to the theoretical framework used in this study, i.e. phenomenology, in terms of the methods
used for data collection, namely interviewing. According to Giorgi (1997), the phenomenological approach offers a method for accessing the difficult phenomena of human experience. Giorgi further explains that phenomenology does not take the world and experience for granted but rather wants to understand what motivates a conscious creature to say that something “is”. Phenomenological method therefore refers to the totality of lived experiences belonging to a single person. The phenomenological approach does not suggest one explicit theoretical orientation for understanding the phenomenon being studied, rather the researcher attempts to build the essence of experience from participants (Creswell, 2003).

The following three aspects of phenomenology are important to highlight: (1) it focuses on the totality of lived experiences that belong to a single person, (2) it gives a more precise meaning to the word experience, and (3) it attempts to understand the given as it is given and experienced precisely. Phenomenological research attempts to obtain descriptions of situations from the participants and these descriptions refer to how the participant construed the situation and not whether or not the situation really was the way the participant took it (Giorgi, 1997)).

As qualitative research allows one to access these phenomena through the interview process, it was therefore a suitable approach to adopt. By using individual semi-structured interviews it was possible to gain access into the participant’s world (Terre Blanche & Durrheim, 1999). Interviews also assist in building rapport and empathy, it allows for flexibility in the direction of the interview and as a result produces richer data
(Smith & Osborn, 2003) it was therefore decided that interviews would be appropriate for accessing the information wanted. An interview schedule was drawn up to assist in this process. This will be discussed later.

3.3 Selection of Participants
HIV and AIDS present challenges for research in that, individuals are not always willing to disclose their HIV status. By accessing participants through support groups it was therefore possible to access PLHAs in a manner which ensured that individuals would be able to volunteer in a relatively “safe” manner.

The target population for this proposed study was PLHAs in the Mitchell’s Plain area. Mitchell’s Plain is perceived to be a largely “coloured” suburb, a previously disadvantaged community. Mitchell’s Plain itself is not a homogenous group, since there are also differences between the different regions within Mitchell’s Plain, specifically in terms of socio-economic levels. Van Rensburg (2004) suggests that within South African society the poor households carry the greatest burden of disease, experiences the greatest negative impact and have the least resources to cope with the illness. The participants in this study were in the lower socio-economic bracket.

An enquiry was made as to possible support groups in the designated suburb, i.e. Mitchell’s Plain. It was established that the Treatment Action Campaign (TAC) had established support groups in this area. The TAC is a pressure group which started in 1998 in response to the claims/unwillingness of the South African government to
provide antiretroviral treatment for people with AIDS (Berry, 2005). The TAC, since its establishment, had erected offices in various parts of the country.

Permission was obtained from the TAC Head Office to approach their support groups in the Mitchell’s Plain area. By accessing participants who are involved in support groups, it was possible to ensure that support would be available after the interview if needed. The support group leaders, as well as the support group itself, were available for this purpose. Contact was established with the TAC’s coordinator in Mitchell’s Plain. This contact was followed up with a letter from the HSRC/PENN STATE project requesting assistance from the co-ordinator (see Appendix i).

An initial contact meeting was set up where the requirements for the study were discussed, as well as some concerns dealt with. The researcher was then asked to attend a weekly meeting held with all support group leaders in the Mitchell’s Plain area. During this meeting the purpose of the study was discussed, as well as concerns the support group leaders had. Concerns around confidentiality were raised and the researcher was given the opportunity to address these concerns. Support group leaders then went back to their groups and asked for volunteers for the interviews. According to Terre Blanche and Durrheim (1999), the sampling employed here would be considered to be “convenience” or “opportunistic” sampling since cases were taken on their availability.
Participants were all HIV positive “coloured”\(^2\) adults who used health care facilities and reside in the Mitchell’s Plain community. Ten participants volunteered to participate in the study. The volunteering process was managed by the support group leaders since they felt that this would provide anonymity for the support group members. Interviews were arranged to take place over four days. Four males and six females were interviewed. Participants ranged in age from 24 to 41. All participants attended health care facilities in Mitchell’s Plain. Three participants were Muslim and seven were Christian. Four participants were employed and six were unemployed.

3.4 Data collection

Interviews were held at a primary health care centre in Mitchell’s Plain. The venue was made available by the primary health care centre since it would be more convenient for the participants to travel to the venue. This was arranged by the TAC co-ordinator. The venue was quiet and private. The duration of the semi-structured interviews was between 45 – 60 minutes. The researcher used the interview schedule to guide the interview process. The interview schedule consisted of five main questions (see Appendix ii). The questions were open-ended since within phenomenological research it is important for the data to emerge in the form of rich descriptions (Groenewald, 2004). All interviews were conducted by the researcher herself. Three interviews were conducted in English and seven in Afrikaans, based on the preferred language of the participants. The interviews were recorded on audio tape with the permission of the participants and transcribed.

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\(^2\) The racial category of “coloured” in this mini-thesis refers to South Africans of mixed origins. This manner of categorising groups of people formed part of the South African apartheid history and was deemed necessary for this study.
verbatim. The interviews were translated from Afrikaans to English to obtain uniformity in the transcripts.

Interviewees were asked to sign informed consent forms which informed them about the aims of the research. The procedure, which would be followed during the interview, was explained to the participants before the start. It also reinforced the fact that participation in the interviews was voluntary and that the participant could stop the interview at any point. When the interview was concluded the researcher enquired from the participant if there was assistance required from the support group leader. None of the participants indicated a need for counselling. The participants were also compensated for their traveling costs.

3.5 Data Analysis
An interpretative phenomenological analysis (IPA) was used to analyse the data. This approach accepts the impossibility of gaining direct access to the participants’ life worlds. It therefore aims to explore the participant’s experience from his/her perspective but recognizes that this exploration necessarily implicates the researcher’s own view of the world, as well as the nature of interaction between the researcher and the participant. The analysis is therefore an interpretation of the participant’s experience (Smith & Osbourne, 2003).

The Atlas TI, a qualitative data analysis software package, was used to assist with the analysis. This program allows one to code the material, as well as to explore the material by using various functions available.
The procedure followed in an IPA consists of various stages. The first stage was to read and reread the transcripts. Atlas TI allows one to enter the transcripts onto the system. This was done and the transcripts were then read and reread so that the researcher could become as familiar as possible with the account.

The second stage involved the transforming of initial notes made in stage 1 to themes. By using the Atlas TI system the researcher was able to firstly code the data, then organize it into themes. The Atlas TI system assisted in making this stage simpler and more manageable.

The third stage involved the listing of emergent themes and the researcher then looked for connections between them. Some themes formed clusters and others emerged as superordinate concepts. Atlas TI, through its various functions, again made this stage more manageable.

3.6 Ethical Considerations

Ethical clearance was received from the University of the Western Cape. During selection of the participants the use of the support groups assisted in ensuring that participation was voluntary. Participants had the opportunity to enquire from their support group leaders what the study entailed before meeting the researcher. Support group leaders also had the opportunity to approach the researcher with regard to any part of the study they had queries about before the study commenced.
Prior to the data gathering phase an informed consent letter was prepared for the participants to sign. The letter explained the purpose of the study and addressed issues of confidentiality and anonymity. During the introductory phase of the interview the researcher went through the letter with each participant to explain and clarify the content of the letter. The concept of voluntary participation was explained to the participant and the fact that he/she could end their participation in the study at any point was reinforced. Once the researcher was sure that the participant understood the details of the letter, the participant signed the letter.

To ensure anonymity and confidentiality neither the participants name nor any other means of identifying the individual was used by the researcher. The labeling of the interview tapes was done by assigning a code for each participant.

At the end of the interview the researcher discussed with the participant whether or not he/she needed further support as a result of the interview and informed them that the support group leaders would be available if needed.

### 3.7 Reflexivity

According to Creswell (2003, p182), “…the qualitative researcher systematically reflects on who he or she is in the inquiry and is sensitive to his or her personal biography and how it shapes the study”. At the start of this research I became aware of my own conflicting feelings and position with regard to the public health care system, specifically the clinics. My own mother worked in these clinics in previously disadvantaged communities for most of my life. I therefore have many stories from the perspective of
the health care workers which relate to the difficulties of being a health care worker in South Africa. On the other hand I have my own experiences of attending such clinics, many of them negative experiences relating specifically to the attitudes and behaviour of the health care workers. My expectation, I realized at the start of the interviews, was that I would be encountering individuals who are sick and have possibly been treated badly at clinics with resultant negative feelings about the health care system. These views were dramatically challenged from the first interviewee to the last.

My interviews with the ten participants evoked in me feelings of admiration for the manner in which most of the participants have risen to the challenge that this illness presented to them. I also found myself becoming angry at the manner in which the community, as they reported, treated these individuals. I was saddened by their individual life circumstances and became aware of the differences in my own circumstances resulting in some feelings of guilt.

Although some interviews were conducted in Afrikaans and I am able to speak Afrikaans fluently, it is however my second language and consequently I was aware of how this could influence my understanding of what was being discussed. I was also aware of the fact that my being English speaking might be a barrier in establishing rapport with the participants. This however did not appear to have any real influence in achieving rapport with any of the participants or on the flow of the interview.
CHAPTER 4
RESULTS

4.1 Introduction
The purpose of this chapter is to present the results obtained from the interviews held with the ten PLHAs. A description of the demographics of the participants will be given. Thereafter a brief explanation of the interpretative phenomenological approach to the analysis of the data will be given. The identified themes and sub-themes which emerged from the analysis will then be focused on. The quotes used are presented verbatim including the grammatical errors where they occur. Finally, a brief summary of the main findings will be given.

4.2 Demographic information
The participants were asked limited demographic information at the start of the interview. In order to participate in the study, the participants had to meet the following criteria: the participants had to be “coloured”; they had to be adults i.e. over the age of 18 years; they had to live in the Mitchell’s plain area, and they had to be a primary health care user.

All the participants were “coloured” individuals living in Mitchell’s Plain. Their ages ranged from 20 – 45 years. They further indicated that they have lived in this region for at least one year. All the participants indicated that they use the primary health care centre in their suburb whenever necessary, at least once a month. All participants further indicated that they have used a primary health care centre in determining their HIV status.
During the interviews additional demographic information emerged as part of the discussion. The additional demographic information covered religious affiliation, marital status, knowledge of HIV status and economic status. Three participants indicated that they were Muslim and seven indicated they were Christian. Two participants were married, two were living with a partner and one participant indicated that he lost his wife as a result of AIDS. With regard to how they found out about their HIV status, four participants indicated that they found out during a pregnancy, one found out after her husband tested positive and one found out after contracting a sexually transmitted infection. Eight participants indicated that they were unemployed and two were employed. Three participants indicated that they receive an income from talks/workshops they conduct. Two participants are unemployed by choice since their husbands are the breadwinners.

4.3 The analysis

An interpretative phenomenological analysis was conducted using the transcripts of the 10 participants. The analysis aims to explore how participants in a study make sense of their personal and social world. The focus is placed on the meanings that experiences, events or states hold for the participants. The participant’s personal perception or account is the focus rather than attempting to produce an objective statement (Smith & Osborn, 2004). This particular type of analysis has been chosen since the researcher aims to understand how PLHAs experience the health care setting by looking at their experiences in this setting. The analysis provided access to the experiences of PLHAs within health care centres. In terms of the secondary aim it provided access to other
experiences which were stigmatising for the participants. A broader understanding of how PLHAs experience their positive status, as well as some of the challenges that are faced by PLHAs was also gained.

Seven themes emerged from the data analysis and four of the seven were divided into sub-themes. The themes cover the perceptions participants’ have of their positive status, participants’ perceptions of HIV and AIDS, experiences relating to the response of family and community to their status, participants’ perceptions of the responses of health care workers and the health care setting, labelling, disclosure and suggestions for the elimination of stigma. These themes and sub-themes will be presented below.

4.4 Perception of positive status.

This theme refers to the manner in which participants experience and perceive their positive status. Four sub-themes were identified and will be discussed. All the participants mentioned that they have accepted their status and eight indicated that they felt positive about being HIV positive. All the participants appeared to have reached the stage of acceptance. Three of the participants indicated that they see their lives as having a higher purpose at present as a result of their HIV status and that they can cope with the illness.

“...I myself felt, for myself, I can cope well with myself the way I live”

(Participant 1)

“...it is a kind of a challenge...” (Participant 2)

“...okay the virus is there...I need to deal with it” (Participant 3)
"No man, I have a mission to complete...” (Participant 5)

“But like I said I am very satisfied with my life now” (Participant 8)

Six participants indicated that their initial response was to consider suicide and four indicated that they had attempted suicide.

“I just felt that I wanted to die...I was in hospital already. I tried to commit suicide and it didn’t happen. ...” (Participant 5)

“I thought in the beginning about death. Because I wanted to kill myself so many times already” (Participant 8)

4.4.1 Religion (God). Five of the participants indicated a belief in God as being integral in their understanding of their illness, as well as in how they cope with their illness.

“...and only God can tell when the time will be for a cure,...” (Participant 3)

“...I have a mission to complete that God does not want me yet. He wants me to fulfill my mission” (Participant 5)

Two participants indicated that they experienced their religious affiliation as being important in understanding the response of their family to their HIV status.

“...I know it’s because of me being Moslem and they are also Moslem, religion wise now I am getting rejected...” (Participant 3)
It appears that a belief in God as being there for “them” is prevalent amongst the participants.

“...I think God has really kept me going for the past fourteen years...” (Participant 4)

“But I say there is just one God and God will help us. It is all in the hands of God...” (Participant 8)

“I did not look for it; it is God’s illness” (Participant 9)

4.4.2 Marital status. Four participants indicated that they were infected by their husbands. Two participants indicated that their husbands were aware of their status but failed to tell them (the participants) about it.

“...my husband had it but he didn’t tell me. We were already married and he still didn’t tell me” (Participant 8)

“... because my husband got it...I got it through him” (Participant 7)

One participant indicated that her HIV status is used against her during times when she and her partner have arguments.

“I am not married. When my boyfriend and I fight then he scolds me about my HIV but I got it from him” (Participant 9)

4.4.3 Knowledge of HIV status. Participants indicated that knowledge of their HIV
status was gained subsequent to presenting at the primary health care centre for other complaints. Four of the female participants indicated that they found out about their status during a pregnancy.

“I found out when I was six months pregnant…” (Participant 9)

“When I got pregnant with my son who is ten years old now I found out during my pregnancy that I’m HIV positive” (Participant 5)

One participant found out after her husband was tested positive and one found out after contracting a sexually transmitted infection.

“I went to the clinic. I had an STI…They asked me if I wanted to go for a test. So I went for the test and I was tested positive” (Participant 10)

“…my husband got it. He had TB and he went for x-rays and tests… I then went and so I found out” (Participant 7)

All the male participants found out after having a tuberculosis test.

“...I was someone who suffered from TB …the doctor told me that I am negative...it turned into TB …to HIV positive…” (Participant 1)

4.4.4 Economic status. Participants indicated that their economic status has been impacted on by their positive HIV status. One participant indicated that she lost her job when it was discovered she was HIV positive. Two participants indicated that they were employed.

“The people at the place where I was working found out because my
Eight participants indicated that they were unemployed at present. Three of the unemployed participants indicated that they received some income by conducting talks on HIV and AIDS.

“...When I hold a session then you will see that they collect for me or they phone me and say that I must come and fetch this or that” (Participant 5)

“But I normally do talks...educational talks at the Day hospitals...”

(Participant 10)

The unemployed participants indicated that they relied to a large extent on the food parcels they receive at the primary health care centres and certain non-governmental organizations (NGO’s).

“They gave us food parcels...” (Participant 9)

4.5 Participants’ perception of HIV and AIDS.

Perceptions relating to HIV and AIDS, as an illness, differed amongst the participants. Three participants indicated that they see HIV and AIDS, at this point, as simply another illness. It appears that they perceive it as not necessarily an end to their lives but rather a challenge for them to overcome.

“it is just another illness...”(Participant 5)

“An illness, yes? Yes, like any other illness” (Participant 8)

“...when I found out that I’m HIV positive I thought that I did not want
to live anymore… many people think it is a curse or something that came over them but for me it is just a…almost like a race that I must run to win…” (Participant 6)

Three participants indicated that they initially thought of HIV and AIDS as a death sentence but then came to see it as just another word.

“...I thought HIV and AIDS was a death sentence” (Participant 3)

“...I thought in the beginning about death...But HIV for me ...it is just a word for me now, it is nothing” (Participant 8)

One participant indicated that at the time of diagnosis the participant knew very little about HIV and AIDS.

“I did not know much about HIV...we are doing a project now and I understand more or less how it comes about...” (Participant 7)

One participant views HIV and AIDS as gift from God which is aimed at providing a second chance in life, as well as that God has a special purpose for him.

“I believe that God has put this thing in me whereby to open my eyes as to live fruitfully...I am a special child to Him and He needs to use me more in the near future...I look at it as a gift whereby He wants me to do a lot of things for Him” (Participant 4)
4.6 Experiences relating to the responses of family and the community to their status

Participants reported both positive and negative responses from family and community members. Negative responses will be presented in terms of indicators of external and internal stigma as identified by the Siyam’kela project (2003) discussed earlier.

4.6.1 Negative responses

a. External (enacted) stigma.

Experiences referred to here are actual experiences of discrimination. Included are avoidance, rejection, moral judgement, stigma by association and abuse. Participants described experiences where the community and family members displayed this type of stigma.

Avoidance includes the following: not sharing objects, socially distancing, physical distancing, gossiping, distancing from family and friends of PLHAs. All participants indicated that they experienced some form of avoidance by family and the community.

Four participants indicated that they experienced family members who no longer wanted to share certain objects once they knew about their positive status.

“...he does not want me to use a cup in their house... to drink water from, and if he comes to the back... then he will just stand by the door when he sees me” (Participant 6)

“My mother actually told me that I must not cook anymore. ...I must not knead bread anymore. If I did cook food then she would ask if I had any
“cuts in my hands…” (Participant 10)

“...the reason I moved from there is that she looks me in the face and say that I mustn’t sit on the toilet pot if the children must go to the toilet”

(Participant 1)

Two participants indicated that they experienced gossiping as a result of their HIV status.

“...they will always gossip (skinner)about someone else, if they know, they will say bad things about that person...” (Participant 2)

Two participants indicated that they experienced social and physical distancing as a result of their HIV status.

“...they just smile at you and say I am just going to the toilet, and you don’t see that person again because they are so scared of sitting next to the person being infected with HIV and AIDS...”(Participant 4)

“...he will just stand by the door when he sees me” (Participant 6)

Rejection includes the following: being abandoned by significant others, having to leave social/organizational settings after disclosure, pressurized to leave place of residence, not welcoming PLHAs into the home. Eight participants experienced rejection by family and the community.

“...the person is HIV positive, now you’ve been rejected...we get rejected from our community, we get rejected from our families, from our friends because it’s like you coming with something and they just scared that they
are also going to get infected” (Participant 3)

Two participants indicated that they were abandoned by significant others as a result of their HIV status. One also indicated that in addition she was forced to move out of her place of residence.

“My mother threw me out because I have HIV. She said to take my things and leave because I am going to infect my children” (Participant 8)

“…where my mother stays, I don’t see them as people who will greet me much. ...the others will perhaps look away…” (Participant 1)

Four participants indicated that they were not welcomed into people’s homes because of their HIV status.

“...they don’t let you come into the house, even if you just go sit with them, they won’t let you come into their house” (Participant 2)

Moral judgement includes the following: blaming where PLHAs are perceived as innocent or guilty based on their behaviour and perceived responsibility, judging PLHAs on bases of religious beliefs or values as immoral. Four participants experienced the community and family as attributing blame to them for their illness.

“They would say that they are a slut or slept around or something like that ...”(Participant 2)

“...the people still think if you are HIV positive that you are bad. ...even though I got it from my husband I was ostracised by my family, my in laws
and my friends” (Participant 5)

“A lot of people have the mentality that you looked for it. Others again think you were bad” (Participant 10)

“But there are some, the majority of them that are very nasty...very nasty with us HIV people. For them it is that they are above us. They sit high and we are low.”(Participant 8)

Stigma by association includes people who are stigmatised based on associations related to HIV and AIDS. Two participants referred to their children as being recipients of this type of stigma.

“What is going to happen to my child if they are like this with me. They might think she also has the virus but she is actually negative...” (Participant 10)

“My children must hear about it at school”(Participant 8)

Abuse includes verbal abuse such as name calling, insults and threats and physical abuse. Five participants indicated that they experienced verbal abuse in different forms.

“...people they will hmm, they scold (skel) them...They would say that they are slut or he slept around”(Participant 2)

“...when the people start swearing at us or point a finger ...almost like you deserve it to have this illness” (Participant 10)

“There are some of them that even throw stones on my roof then they run away”(Participant 8)
“When my boyfriend and I fight then he scolds me about my HIV but
I got it from him” (Participant 9)

b. Internal stigma (felt or imagined).

Experiences referred to here are the shame associated with HIV and AIDS, and the fear of being discriminated against. Indicators of this type of stigma included here are negative perception of self, social withdrawal and fear of disclosure.

Negative perception of self refers to a low self esteem as a result of being HIV positive. Two participants referred to themselves as being sick and having a bad illness.

“...they just see a sick person in front of them and they just cannot take you. ...they are saying that I am an AIDS thing” (Participant 8)

“Sometimes I feel that perhaps this is a bad disease that I have or it is contagious but the clinic and my support group told me that I must not worry myself about them... ” (Participant 9)

Social withdrawal includes fewer interactions with people as result of their status, PLHAs choosing not to have intimate relationships and fewer interactions with HIV negative individuals. Five participants referred to aspects related to social withdrawal.

“...people are going to push you away” (Participant 4)

“...I feel happier, I am out...I am away from those people who treated me so badly” (Participant 9)
“...is causing you to withdraw from the community, to withdraw from your friends, to withdraw from your family...” (Participant 3)

Fear of disclosure includes disclosure to sexual partner, family, children, friends and the public. Four participants referred to a fear of disclosure. This will be discussed later in this chapter as a theme.

“I will never tell the community there on our side...” (Participant 7)

“But I am actually scared to tell people...I am perhaps afraid that they are going to tell my children not to play with their children because their mother is HIV positive...” (Participant 6)

“I was ashamed to tell her that I’m HIV positive...” (Participant 1)

The participants indicated that the abovementioned attitudes and behaviours were evidence for the level of stigma prevalent in their community. They further indicated that they were aware of these attitudes and behaviours prior to being tested positive and expected to be treated in this way once they tested positive. Participants indicated some positive responses from the community and family.

4.6.2 Positive responses

Participants indicated limited positive responses by community and family members to PLHAs. One participant referred to being given food by a neighbour. One participant described the church she belonged to as a source of support. One participant described the assistance given to HIV positive individuals to learn skills as positive. Two
participants referred to individuals who were involved in handing out food to PLHAs as a positive response.

“...she respected me for the tablets that I had to take. She then gave me bread and things to eat...” (Participant 1)

“...there are people who teach you skills...like the beading and sewing...” (Participant 10)

“...I think she is also a volunteer...it is stuff that they drop off at her place then she hands it out ...”(Participant 8)

4.7 Participants’ perceptions of health care workers and health care setting

This theme can be divided into the following sub-themes: changes in attitudes of health care workers, positive experiences in the clinics, negative experiences in the clinics and the issue of gender, race, religion and area.

4.7.1 Changes in attitudes of health care workers.

All participants indicated a change in the attitude of health care workers in the clinics in this area. Three participants mentioned that health care facilities in this area (Mitchell’s Plain) have not always been supportive but have displayed this support for the past four years. They indicated that this change is probably due to improved training received by health care workers, as well as campaigning by NGO’s involved in work with HIV positive individuals. This change has resulted in improved relationships between PLHAs and health care workers. The following quotes reflect the participants’ views on the changes.
“I see the ones who are there now are well trained. I will say the hospitals and clinics have changed a lot, so whenever you need their support they are there…. It wasn't like that before, you know.” (Participant 5)

“...they are very concerned about us positive people”(Participant 7)

“I am very happy at the clinic”(Participant 9)

“...they organised a meeting with us and we said our piece and ever since that time I saw things starting to change”(Participant 5)

“...it showed me that they are well trained...the clinic staff itself...they are training people that hmm, that knows how to deal with this type of issue” (Participant 3)

The participants therefore view health care workers as well trained individuals who are able to respond to their needs. They view the clinics as a positive environment where they can obtain appropriate medical care as well as support.

4.7.2 Positive experiences in the clinics.

Participants described various positive experiences in the clinics. All the participants agreed that they receive a great deal of support from health care workers. The support described by the participants can be summarized in the following manner: health care workers show professionalism; health care workers provide support; and health care workers go beyond what is expected.
a. Health care workers show professionalism. Participants indicated that health care workers show their professionalism by being friendly, by showing respect to health care users, by maintaining confidentiality and by being approachable.

“There is confidentiality…” (Participant 3)

“…the nurses respect me a lot and they sympathise a lot with me. There are always two or three nurses that take my hands and tell me, how are you? Your face is getting a little fuller, are you getting along nicely…” (Participant 1)

“…if they still reject us or discriminate then they must really be hiding it well because they don’t actually show an unfriendly face, they don’t actually show that they are unhelpful. At all times they are there for you and they won’t tell you to come back tomorrow” (Participant 5)

b. Health care workers provide support. Participants indicated that health care workers provide support by being available, showing that they care, offering support in various ways and showing concern.

“They are always concerned about us,… Because if perhaps I don't come for one of my appointments then they will always call me...

So they are very concerned about us. They will do anything just to be there for us... talk a little bit or... and they are very concerned about us positive people” (Participant 7)

“...Yes and the sister at the clinic...she is the only one who pulls
me through. She helps me a lot.” (Participant 9)

“They are very supportive” (Participant 8)

“... there is a concern for treatment because they do advise you and if you don't pitch up for your appointment they are very concerned they want to know where you've been and they concerned about your health, they concerned about the hmm, the nutrition and the losing of weight ...” (Participant 3)

c. Health care workers go beyond what is expected. Participants indicated that health care workers go beyond what is expected by counselling patients when necessary, by knowing patients on a more personal level and always encouraging patients.

“...so happy because I came to the clinic for advice, I got treatment, I got counseling..., smile on your face, the way you people relate to me with a user friendly approach...” (Participant 3)

“...when I go there and I greet them it is Morning, how are you, are you well, what are you doing, are you still coming often to the clinic or the hospital...” (Participant 1)

“...and hmm, but some nurses go out of their way to help you...” (Participant 2)

Although most participants indicated that they experience mostly positive attitudes and behaviour at health care centres, some have had negative experiences as will be discussed below.
4.7.3 Negative experiences in the health care centres.

Participant’s negative experiences in health care centres differ. These were seen by participants as being rare and often perpetrated by staff who were either new, filling in from other institutions or did not appear to be educated around the issue of HIV and AIDS.

“Like we had a doctor who I don't want to mention the name, he came from a certain company, he was appointed by helping a certain doctor that is working with HIV, and you know what he would always do is say to people that, "Are you aware that you are busy dying, so why you coming now at this stage, why didn't you come earlier," you know?” (Participant 4)

“...and when I went in he just looked at me, it was a Nigerian doctor...he did not even touch me he did not even look in my eyes because normally they give you the iron tablets and the Bactrim. He did not even do those things...” (Participant 10)

Two participants also indicated that they have heard of others who have had negative experiences and one participant indicated that four years ago they would only have mentioned negative experiences.

“...but I have heard some patients complaining about the doctors that has not treated them right but I have not experienced that.” (Participant 2)
They also agree that they are aware that health care workers are often overworked and short staffed and this at times leads to negative experiences.

“...at the day hospital the workload is heavy and the staff is too little...they are concerned about this, but because also a lack of staff you know, they don’t have the time or get time...” (Participant 3)

The negative experiences described by participants include the following: being sent from one department to another for the required treatment; health care workers not taking time to sit with the patient; accusing PLHAs of wanting special treatment; judgemental attitudes and ignoring patients. The following quotes reflect what participants said:

“ But sometimes it's like if you go there they kind of ignore you...”

(Participant 2)

“...the first thing the doctors think of is HIV...it is the way they judge people you know...” (Participant 10)

“...they don’t have time to listen to you...” (Participant 3)

“...their attitude stinks...this is not my department, you must go to that room, you must go to that Sister” (Participant 4)

“...he said, yes, you people just think that you must get special treatment every time...” (Participant 5)
4.8 The impact of sex, race, religion and area where they live, on the treatment of PLHAs

Participants differ with regard to their experiences. Five participants indicated that men and women are treated differently. Three participants indicated that they experienced no difference in the way men and women are treated.

"We are all treated the same..." (Participant 8)

"...women and men are both getting treated equally" (Participant 3)

"...woman to woman then yes...they tend to relate more..." (Participant 4)

One participant indicated that if a woman is considered to be the one that initially became infected then she would be treated as the “guilty one” and would be judged by staff, since she is viewed as the care giver. Questions concerning her sexual activities would be posed in a judgemental manner. Men however would not be judged in this manner. Three participants differed with this and indicated that women are perceived by staff as being the innocent party and therefore would attract more sympathy from staff especially if the staff member is a woman as well.

"...sometimes they might think that the women was sleeping around...
they might think differently of women because women are suppose to take care of their children...they will ask them why do they still have sex...it’s almost like women is the bad guy..." (Participant 2)

"...a lot of times when it is a woman the nurses will think, maybe she got it from her husband. And then they try to have more sympathy for the woman” (Participant 10)
One participant indicated that staff appeared to be strict with men because men do not appear to be treating their situation seriously.

“...they treat us very differently than they do the men...they are stricter with the men than with us” (Participant 6)

Four participants indicated that staff considered race when treating patients. One participant felt that the manner in which staff treated you was not determined by your race but rather by how you approach them. One participant felt that the race of the doctor and whether or not one was of the same racial group determined how the doctor would treat you. Two participants felt that racist attitudes were directed at African people.

“I have not experienced that yet, because I am a coloured ... That they treat me a certain way maybe... Or because they are coloureds that work there. I did not get a feeling like that yet...I suppose it is also how you approach them...to determine how they are going to handle you” (Participant 6)

“They are very racist when it comes to Africans...” (Participant 4)

“...but in the meantime the nurses have the mentality that, no, the black people are people who “whatever” around...” (Participant 10)

“...it depends on who the doctor is, if he is coloured or white...I think the coloured doctors treat you better” (Participant 2)
With regard to both religion and area only one participant respectively indicated that these impacted on how patients were treated.

“...I’m Moslem and then some of the staff that are Moslem I can see that they show that rejection...” (Participant 3)

“If you come from say Khayelitsha ...they will treat you differently”

(Participant 2)

4.9 Labeling

The theme of labeling can be divided into the two sub-themes of self labeling and labeling by others.

4.9.1 Self labeling

Self labeling refers to the manner in which participants referred to themselves during the interviews. Participants varied in the way they did this. They appear to see themselves as belonging to a group with whom they can identify based on their positive status. This group they describe as a family, people who understand each other. All the participants referred to “us” and “them”. “Us” refers to people who are HIV positive and “them” refers to people who are not HIV positive. One participant indicated that he valued being part of the group and felt protective towards their group.

“...now that we positive people are coming out and that we are talking about it and that they can see that we live a healthy life and also that we are living a normal life...they can’t blame us for what
was given to us...all we want is that people must respect us like any
other person...” (Participant 5)

“...it was our people, our own people, we positive people...”(Participant 5)

“...I live as a HIV positive... you see people who are HIV positive
as your family...” (Participant 1)

“...we can talk about things that happen in our lives..., we can relate with
one another...” (Participant 6)

4.9.2 Labeling by others

Labeling by others refer to the labels that PLHAs feel are being given to them by those
who are not HIV positive. From participants’ experiences it appears that these labels are
generally negative ones which at times reflect the judgemental attitudes of others.

“She’s an AIDS thing now. They are saying that I am an AIDS
thing...because every time when people look at me then they say,
there is that HIV positive person walking in the road...” (Participant 8)

“...yes, there she’s walking, she is probably going to the clinic again
because she has AIDS...there are people who have their negative things
to say about us” (Participant 6)

“They would say that they are slut or he slept around or something like
that...”(Participant 2)
4.10 Disclosure

Six participants indicated that at this point they have no problem with disclosing their status. Four participants indicated that they had only disclosed to selected people, example, their family. All participants who have disclosed mentioned that initially they struggled with disclosing their status. They mentioned that it is important to disclose since they feel that this is one way to demystify the illness.

“...it is only my husband who knows I have the virus and my mother and a few of my family members...I am actually scared to tell people because...everyone has their own thoughts about it” (Participant 6)

“...there is one lady...who knows I am HIV positive and the woman I’m living with so its two” (Participant 1)

“...I think we Positive people must stand out more and show them that we are here. So it is either you accept us or you kick us out” (Participant 10)

“...I am talking openly to the people...there are a lot of things that have changed because I am living a normal life...” (Participant 5)

The participants who have not disclosed mentioned that they were concerned with how people would react since they have seen the negative effects on an individual who chooses to disclose. Participants have the perception and also the experience that people who are not HIV positive will not respond well to their disclosure. They therefore choose carefully who they will disclose to and often even these individuals have disappointed them.

“...I will never tell the community there on our side...those who know
will maybe tell the whole community.” (Participant 7)

“...but I don’t tell the people...mostly afraid that people will treat them bad
...you get people who have been treated badly...” (Participant 2)

“The people at the place where I was working found out because my sister
told them and I lost my job” (Participant 8)

4.11 Suggestions for the elimination of stigma

All the participants agree that education is possibly the best way of eliminating stigma relating to HIV and AIDS. Those participants who live openly also indicated that they see disclosure and openness by PLHAs as one of the most powerful ways of educating people about HIV and AIDS. The following reflects what participants said:

“ We must go from door to door to explain about ourselves” (Participant 9)

“The more education, the more knowledge we get and the more ways
you can find out how to deal with the actual scenario” (Participant 3)

“...go see for yourself so that you can be educated and say this is
reality and face up to reality and say, now I understand what you going
through...”(Participant 4)

“...I think we Positive people must stand out more and show them that
we are here.”(Participant 10)

4.12 Conclusion

As discussed earlier phenomenology attempts to gain access to the experiences of people as it is experienced by the individual. The results presented indicate that PLHAs
experience stigma in various forms. These experiences are more common in the community and within the families of PLHAs. The participants of this study indicated that the health care setting is one in which they experience the least stigma.
CHAPTER 5
DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

According to Lester (2005), in phenomenological research separating the discussion of the findings from the presentation of the findings allows one to ‘intrude’ into the study through interpretations and linkages, relating the findings to previous research, personal experience or common sense. The following chapter will therefore include a discussion of the results presented in the previous chapter, the implications of these findings, the limitations of the study and recommendations for future research.

5.2 Discussion of results

In the discussion of the results the focus will be on the following: the experience of HIV and AIDS as an illness, experiences of stigma in the community and family, experiences of stigma in the primary health care centre, labeling and disclosure.

5.2.1 The experience of HIV and AIDS as an illness

It is evident from the results that PLHAs do not experience HIV and AIDS in the same manner although some similarities do occur. The additional demographic information that emerged from the interviews provided a deeper understanding of the lives of PLHAs.

Participants indicated that they have reached a point of acceptance of their HIV status. Some indicated feeling that their situations were positive since they now could see a bigger purpose for their lives. The participants however clearly indicated that it has been
a process to get to this stage. They expressed the point that their initial feelings about HIV and AIDS were that it was a “death sentence” and that suicide appeared initially to be an option.

It is evident that ‘God’ and religion are important to some of the participants in terms of being a way of understanding their situation, as well as a means of coping with their illness.

The discussion relating to their marital status is an indication that HIV and AIDS presents challenges in these relationships which might not have been there prior to knowing their status. Finally, the impact of an HIV positive status on economic conditions was highlighted. For some it became difficult to keep jobs or to get jobs. The already desperate economic conditions for some became worse as a result of their illness.

When considering these responses two issues can be highlighted, namely the positive view the participants have of their illness and it appears that belonging to a support group possibly has assisted participants with reframing their illness. The positive view held by participants, reflects an unexpected response. These results differed from that of Lee et al. (2002) who found that the majority of their sample of HIV positive individuals, expressed embarrassment about their illness. Lee et al. (2002) further suggested that PLHAs are likely to hold a negative view of HIV as an illness and of themselves, due to them internalising the stigma associated with the illness. Both Mickelson (2000) and Pinel (1999) concluded from their studies that individuals do not experience stigma
uniformly, although they have the same socially stigmatised stressor. Pinel (1999) further suggested that individuals differ in the extent to which they expect to be stigmatised i.e. the level of stigma consciousness. The results from the present study would appear to support these conclusions derived at by Mickelson’s and Pinel in their studies. It appears from the responses that the participants have not internalised the stigma related to their illness, since all the participants indicated that they experience their illness as a positive, something which they have accepted. Their initial responses to the illness serve as an indicator that participants are aware of the stigma related to HIV and AIDS. This was something which they possibly had to face when they were first diagnosed with HIV. Crocker et al. (1992) in their study concluded that high levels of stigma consciousness might be associated with positive outcomes on an intrapersonal as well as societal level. People high in stigma consciousness would more likely fight against discrimination than those low in stigma consciousness.

Frable et al. (1998) conducted a study which looked at the impact of similarly stigmatised others on the self perception of stigmatised students. Their data suggest that the presence of similar others more often generates positive self perceptions than negative ones. If one considers a support group as providing the opportunity for individuals who are similarly stigmatised to meet, as in the support groups attended by HIV positive individuals, then one can expect individuals belonging to the support group to have more positive self perceptions than those who do not attend support groups. In the present study, the positive manner in which participants see their illness could possibly be understood from this perspective. Alternatively, Lee et al. (2002) in their study raised the question with
regard to the effect of time on the ability of people to cope with the stigma related to being HIV positive. Their study found that individuals with a high level of internalised stigma were more recently diagnosed than those with low levels of internalised stigma. They also found that those who had high levels of internalised stigma were less likely to have attended a support group. The positive manner in which participants view HIV and AIDS could therefore be understood in terms of having a low level of internalised stigma, as well as being part of a support group.

5.2.2 Experiences of stigma in the community and family

The results related to the stigma PLHAs experience in the community and in their families appear to conform to what other studies have found (Kalipeni et al., 2004; Pryor et al., 2004; Weiner, Perry and Magnusson, 1988). The participants indicated high levels of stigma to be present in the community and in their families. Both enacted and internal stigma were identified. In terms of enacted stigma participants provided examples of avoidance, rejection, moral judgement, stigma by association and abuse. In terms of internal stigma participants provided examples of negative perception of self, social withdrawal and fear of disclosure. The positive responses were discussed as being rare experiences and examples included being given food, support and skills.

In their study Pryor et al. (2004) found that immediate reactions to perceived stigma are generally negative in nature and that people have a spontaneous avoidant reaction to stigma. Their study further found that individual differences occur in the initial negative reactions. These results appear to support the results found in the present study. The
study conducted by Pryor et al. further identifies physical contact with the stigmatised as evoking disgust and that contact appears to evoke the fear of the non-stigmatised individual becoming stigmatised. The study by Weiner, Perry and Magnusson (1988) also found that responses of anger, judgements, no pity and little liking accompanied onset-controllable stigmas. Kalipeni et al. (2004) in their study also cited responses which included dismissal from jobs, denial of access to housing, being labelled as promiscuous and mob killings. The findings of this research study, therefore appear to be supported by the studies mentioned here in terms of the types of responses experienced by PLHAs.

When the findings of Heckman et al. (2004) are considered in relation to the stigmatising experiences PLHAs have in the community and with their families, it raises a concern with regard to how these individuals will cope with their illness. The study by Heckman et al. suggests that the greater the HIV related stigma and rejection by family, the higher the level of emotional distress. The study also found that social support and avoidant coping mediated the effects of stigma and rejection. If this perspective is considered one would expect PLHAs who are not being supported by their families to be struggling with coping. The participants in this study, however, are not receiving this type of support, and they have described numerous examples of enacted stigma, as well as internal stigma, yet they do not see themselves as experiencing emotional distress, nor do they see themselves as not coping with their illness.
5.2.3 Experiences of stigma in the primary health care centre

Although positive and negative experiences were described by participants, negative experiences were described as being rare. Participants indicated a significant change in the attitudes of health care workers over the past four or five years. Positive responses included: the professionalism that health care workers show, support provided by health care workers and health care workers go beyond what is expected. Negative responses were limited and included the following: being sent from one department to another for the required treatment, health care workers not taking time to sit with the patient, accusing PLHAs of wanting special treatment, judgemental attitudes and ignoring patients. One can therefore conclude that the participants in this study do not experience the health care setting as stigmatising.

Shabalala et al.(2000) in their study in South African primary health care centres, indicated that some participants experienced both negative behaviours and stigma whereas others experienced positive attitudes. It appears therefore that the experiences of health care users differ at different health care centres in South Africa generally.

Various studies indicate that PLHAs experience stigmatising behaviour and attitudes in the health care facilities they attend (Bond et al., 2002; Brown et al., 2003; Niang et al., 2002). Bond et al. (2002) in their study reported that amongst the forms of stigmatisation reported were the following: denial of drugs and treatment, being dealt with last, breaches of confidentiality. This study also indicated that health care providers found PLHAs to be difficult to work with, they displayed attention seeking behaviour and they were
difficult to work with. Although the results of the present study indicate experiences of stigmatisation to be limited, there does appear to be an overlap with these studies in the types of experiences these participants have had.

Two studies conducted in Scotland could serve as an explanation for the positive experiences the participants in the present study have had in health care centres. In a study conducted by Green and Platt (1997) results indicated that as health care professionals became familiar with treating HIV patients the stigma appeared to decline. The positive experiences that participants have had in the present study could be as a result of the health care professionals in those clinics being experienced in dealing with HIV and therefore not treating it as a stigmatised illness.

Another study conducted by Knussen and Niven (1999) found that negative attitudes to patients who are HIV positive were related to whether or not health care professionals received in service training relating to HIV and AIDS. Their study further identified more social contact with HIV positive individuals as resulting in more positive attitudes towards HIV positive patients. These aspects could be important in understanding the positive attitudes of health care workers in the present study. Participants indicated that health care workers were knowledgeable about HIV and AIDS and that they have received training in HIV and AIDS. They also indicated that health care workers made an effort to get to know them personally. Some participants also knew health care workers on a more social level because they live in the same area. Furthermore, health care workers also conducted home visits and made phone calls which assisted in getting
to know these individuals better. These aspects could account for the positive experiences these health care users have had.

Uys (2003) found in a study conducted in South Africa that respondents credited the standard HIV and AIDS course presented to health care workers as being responsible for the change in their attitudes to PLHAs. This study supports the findings of the present study in terms of PLHAs experiencing more positive than negative attitude in health care settings, after training was introduced with regard to HIV and AIDS.

5.2.4 Labeling

In terms of labeling it was found that PLHAs labeled themselves but they were also labeled by others because of their illness. The self labels can be seen as being more that of establishing themselves as a separated group who have a common identity. The labels by others are seen as more negative, discriminatory type labels.

According to Kalipeni et al. (2004) and Nord (1997), PLHAs have struggled with the “othering” process as long as the illness has been around. Goffman (1963) says that stigmatised individuals are seen as having a ‘spoiled identity’ and as possessing an undesirable difference. Parker and Aggleton (2003) add to this by saying that this stigma reproduces relations of power and control which result in some groups being devalued and others feeling superior. These views appear to provide a means of understanding the negative, discriminatory type labels which participants in this study experience.
According to Joffe (1999) and Nord (1997), the concept of the “other” is widely used and includes those outside of and subordinate to the dominant group. In the example of PLHAs, they are considered to be the “other” in relation to those who are HIV negative (the dominant group). Those considered to be “others” are associated with being contaminating, bad, evil and the dominant group develops an identity opposite to the “others”. Nord (1997) suggests that HIV and AIDS is the only illness where individuals affected by the illness assume the identity of the illness. He ascribes this to the fact that the label provides an identity. In terms of people who are HIV positive, they are therefore seen as responsible for their situation due to their having engaged in some kind of activity which has caused their contamination. From this would develop the negative, discriminatory type labels mentioned above.

To understand the positive way in which these participants describe themselves, the work of Heitzeg (1996) is considered. She proposes that those who are stigmatised address the issue of “spoiled identity” in one of two ways. They can accept the negative label given by others or they can reject this negative societal reaction. Acceptance of the label would imply that they accept the negative connotation of the label. It would also result in the stigmatised displaying certain behaviours such as hiding the stigma symbols, withdrawing, becoming defensive or passive, control information to others and maintaining social distance from those who stigmatise. A rejection of this negative reaction involves a redefining of the stigma as positive. The consequence of this redefinition would be pride rather than shame, there would be no reason to conceal rather, individuals will flaunt the stigma. It will result in a “coming out” for the stigmatised
individual. Heitzer (1996) further says that this coming out could result in a reverse stigmatisation of the labelers.

When one considers the participants in this study one could understand their positive labeling of themselves as a redefining as proposed by Heitzer. By redefining their illness as positive, a gift, something which brings them together as a family, these participants appears to have rejected the negative societal reaction to their illness. The result has been that this group has developed a pride in themselves as a group, who support one another and who assist one another as a family.

5.2.5 Disclosure

Participants differed with regard to the issue of disclosure. Some participants indicated that it was necessary for PLHAs to disclose so that those who are HIV negative would have a better understanding of the illness. Other participants indicated that bad experiences result in fear of disclosure and being exposed to a community who is intolerant.

The results indicate a split between participants in terms of the issue of disclosure. Those who mention that they don’t disclose appear to be supported by the study conducted by Chin and Kroesen (1999) which looked at the disclosure of HIV status amongst Asian/Pacific Islander American women. In this study it was found that fear of stigmatisation influenced the individuals decision to disclose there status. One way of understanding these responses is by considering the issue of internalisation of stigma.
When individuals internalise the stigma associated with being HIV positive, they become more sensitive to both actual and anticipated rejection, and stigmatization, and thus would possibly not want to disclose their status as freely (Deacon et al., 2005; Lee et al., 2002). If individuals have already experienced this rejection and stigmatization it follows that they would not want to continually expose them by disclosing their status.

5.3 Implication of findings
The findings have important implications for primary health care centres and for health care personnel. The results obtained in this study contrast significantly with previous research in this setting. This study indicates an extremely positive view of the health care centres attended by participants in Mitchell’s Plain. Health care personnel must be made aware of this result. The positive change in this setting must be investigated further to determine what has been responsible for this transformation. Health care personnel also have to be made aware of those negative behaviours and attitudes that are still being experienced by PLHAs within the health care setting.

The results of this study provide those who work with PLHAs such as counsellors, nurses, support group leaders and NGO’s with an understanding of how PLHAs construe their illness. It provides an understanding of how PLHAs experience their illness and how this impacts their ability to cope with their illness.

In terms of the phenomenon of stigma the findings provide an understanding of what PLHAs could be experiencing in relation to this phenomenon. By understanding how
PLHAs experience stigma one can direct educational and prevention programs at addressing those issues.

5.4 Limitations of study
The use of the phenomenological approach presents a possible limitation in terms of the raw data being subjective. Error or deceit on the part of the participant is therefore possible (Smith et al., 2003). Although this is only a possible limitation attached to this approach it important to mention it here.

The use of the TAC support groups could also present a limitation to the study. The TAC has a specific agenda relating to how they operate. People who belong to these groups would therefore be expected to align themselves with this agenda. This could be very different to another support group who might have a different agenda. One could therefore speculate with regard to what impact this might have had on the results obtained.

The interviews were conducted at one of the primary health care centres and this might have impacted on how participants understood the role of the researcher. In addition they might have understood the results as possibly having a direct impact on the clinic staff which might have led them to want to present the staff positively.

The study accessed people who are all involved in a support group. It would be important to access people who don’t belong to support groups to determine if there is a
difference in how these two groups experience the primary health care centres, as well as
the differences in their experiences generally, if any.

The manner in which participants were chosen for the study could also be a limitation. The initial recruitment of participants was done by support group leaders and the researcher therefore had no control over how communication was conducted with regard to the aims of the study and what was expected, although the researcher did spend time informing the support group leaders. It would however present a problem in terms of confidentiality if the participants were recruited in any other way. The participants did however conform to what was required in terms of the study.

The fact that participants were compensated for their travelling could place limitations on the study. The participants might have seen this payment as a means of accessing some money and this could possibly have motivated them to volunteer. Although this is a possibility, there was however no clear indication that it happened.

5.5 Recommendations for future research
The results indicate that the participants in this study experience stigma to a large extent in their community and in their families. Future research could therefore focus on stigma experienced in the community and family, and how PLHAs cope with it.

The participants in this study indicated that there has been a change amongst health care personnel at health care facilities in the Mitchell’s Plain area. Since it appears to have
been such a positive change, it would be helpful to understand how this was achieved and what led to this change.

This particular study has accessed people belonging to a support group, it would be helpful to gain an understanding of the experiences of people who don’t belong to support groups but who are HIV positive. This could lead to further understanding with regard to how support groups assist PLHAs to cope with their illness.

The interviews conducted were held at a health care facility and might have impacted on how individuals understood the role of the researcher and the impact the results would have on the clinic staff, even though this was discussed with them. This could impact on the results obtained. It is therefore recommended that interviews be held at a different venue in any future study.

5.6 Conclusion

Findings from the present study show that PLHAs in this study do not feel stigmatised in the primary health care centres they attend. They do however feel that there is stigma related to their HIV status within the community and families that they are a part of. Further research is needed to determine what was responsible for the changes which, according to PLHAs in this study, took place in these centres. Further research is also needed in terms of how the stigma in the community and family can be understood from the perspective of those who are HIV positive. The results of this study have provided valuable information with regard to how PLHAs experience the illness which they have.
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APPENDIX I

LETTER REQUESTING ASSISTANCE

To Whom It May Concern:

Re: Stigma Capacity Building Fellowship Fieldwork: Ms Heidi Wichman

Ms Heidi Wichman has been awarded a fellowship to study stigma related to HIV/AIDS. This project is funded by the National Institutes of Mental Health of NIH and is a five-year partnership between Pennsylvania State University (Department of Biobehavioral Health) and Human Sciences Research Council (Social Aspect of HIV/AIDS and Health) in collaboration with the University of Western Cape (UWC).

As part of this project, Ms Heidi Wichman will be conducting focus groups and interviews with key members of the community and health professionals for the qualitative section of their research into issues and experiences related to HIV/AIDS.

Please could you give the above-mentioned Researcher access and support.

Should you require more information or have any query please feel free to contact the Project Director, Ms. Mpumi Zungu-Dirwayi at the following number 021 467-4440 or you can e-mail her at mzdirwayi@hsrc.ac.za

Yours Sincerely,

Ms. Nompumelelo Zungu-Dirwayi
Project Director: Social Aspects of HIV/AIDS and Health
APPENDIX II

INTERVIEW SCHEDULE

1. What are your views about HIV and AIDS?
   a. What do you think influenced you to hold these views?
   b. Is your views shared by others in the community?
   c. What are some positive things in the community that are supportive of PLHAs?
   d. What are some of the negative things in your community that are against PLHAs?
   e. How about at health care facilities?

2. What are some specific incidents/experiences you have had at health care centres?
   a. Mention some specific behaviours by nurses, physicians, other health care providers.
   b. Are women treated differently? Explain, support.
   c. What about men? Explain, support.

3. To what extent do you think health care personnel consider factors like gender when treating you?
   a. Are there other factors that you think are considered?
   b. Is there a health care facility that you consider to be more friendly and helpful towards PLHAs?

4. How do you think health care providers feel toward PLHAs?
   a. What are some positive or negative feelings?
b. What should be done to remove the negative feelings towards PLHAs?

c. What should the community do to remove discrimination against PLHAs?