

# **AN INVESTIGATION INTO THE NON-DISCLOSURE OF HIV STATUS**

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# AN INVESTIGATION INTO THE NON-DISCLOSURE OF HIV STATUS

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## ABSTRACT

A quantitative, explorative, descriptive research approach was used to investigate why HIV positive people have a problem with disclosing their status. The HIV infection spread is increasing globally, nationally and locally and disclosing would help reduce the spread of infection through preventive measures. Interviews were conducted with 106 respondents at Kagiso primary health care clinics in the West Rand Health Region.

Reasons given by the respondents for non-disclosure of the HIV status were: discrimination, stigma to the HIV positive person and the family by the community, isolation and rejection by the family members, discrimination and possible dismissal at the workplace, fear of losing a partner. The findings illustrate that a large percentage of the population know about HIV and its spread and know that by disclosing, one can get support from health resources and family, but people will not make their status public unless stigmatisation is addressed.

**Key concepts:** investigation, non-disclosure, disclosure, Human-Immune Deficiency Virus (HIV), status.

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## *Dedication*

I would like to dedicate this dissertation to my family members:

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## CHAPTER 1

### INTRODUCTION AND OVERVIEW OF THE RESEARCH

#### 1.1 INTRODUCTION

The Human Immuno-deficiency Virus (HIV) is the cause of Acquired Immune Deficiency Syndrome (AIDS) which attacks and destroys important cells of the body which controls and supports the immune system (Evian 2003:11).

HIV is generally spread in three ways:

- Through sexual intercourse
- When HIV infected blood is passed directly into the body with needle exchange in drug-abusers
- From mother to child, during pregnancy, childbirth and breastfeeding

Men and women are both affected and it embraces all age groups. When the immune system of the body is affected the body responds by different illnesses in a person and the progress rate of the illness differs from person to person.

Once the virus is in the body the person will at different stages suffer from opportunistic infections or may remain asymptomatic for a long period. Some patients progress slowly, some rapidly (Evian 2003:11). It is when the person is ill and noticing some changes in the body that HIV can be suspected and only then they tend to report for testing to detect the virus.

The testing could be done after the person has presented with many chronic illnesses which do not respond to treatment or has had recurrent episodes of the illness. People who are infected by HIV infection or AIDS are known at health centres after they have been tested, but it is very difficult for most of them to disclose their status to families, friends, church members and communities because of the stigma and discrimination attached to the disease. (Van Dyk 2012:100). Gilbert and Walker (2010:141) says that people do not easily if ever disclose their status

because of stigma, discrimination and isolation. Stigmatisation results in silence, secrecy and denial and affects treatment.

Disclosure of HIV status is however the first step towards the management of the disease (Shehan, Uphold, Bradshaw, Bender, Arce & Bender 2005:184); is a tool in fighting stigmatisation and discrimination (Muula & Mfutso-Bengo 2005:288); and could prevent the spread of the disease as people will be less likely to engage in unprotected sex if the sexual partner's HIV status is known (Bird, Fingerhut & McKirnan 2011: 444) and therefore would prevent it from spreading.

## **1.2 BACKGROUND OF THIS RESEARCH**

HIV was first recognised more than 20 years ago (1981) in the United States of America (USA) among young homosexual men who were diagnosed with pneumocystis carinii and Kaposi's sarcoma which were two diseases not previously seen in the population. The next groups to manifest with HIV disease were recipients of blood and blood products, and then followed those by injection drug users (Shaw & Mahoney 2003:1).

In Africa the epidemic was recognised in 1983 and by 1985 at least one case of HIV or of AIDS has been reported in every region of the world. The scale and severity of the condition have exceeded all expectations (Shaw & Mahoney 2003:1).

The global morbidity rates of HIV shows that an estimated 40 million people currently live with HIV worldwide of which 48% are women (Shaw & Mahoney 2003:2). One third of the estimated number consists of young people between 15 and 20 years of age and most of them do not know that they are infected.

The spread of HIV/AIDS is also marked in Asia, the Pacific Islands, United States and other countries in the world. In these areas the spread of HIV is mostly due to injection drug use and homosexual activities where men have sex with men. The figures range from 1 million to 15 million in the islands and in the USA an estimate of 1, 4 million (Shaw & Mahoney 2003:2).

In 2000, 21,704 new patients were diagnosed with HIV in the USA and 70% of these occurred among men (Shaw & Mahoney 2003:2). However, the epidemic is at its most severe in Southern, Eastern and Northern Africa and numbers are continuously increasing with a devastating impact on communities across the continent (Poku 2005:1). Of the 40 million living with HIV in the world, around 2 thirds (25,4 million) are in Sub-Saharan Africa.

The contributing and aggravating factors to the pandemic in Africa are poverty, extensive work migration, gender inequality, low access to reproductive health care and the presence of other sexually transmitted infections which creates an enabling environment for HIV to spread. The poverty has brought about a decline in economic systems and policies (Poku 2005:50). HIV is destroying lives across the African continent due to the cumulative effect of the epidemic. Taking into account spouses, children and elderly dependents, 235 million are affected by the epidemic, 28 million currently living with HIV plus 19 million who have already died, multiplied by a factor of five to represent those directly affected. "This is a staggering proportion of the total population in sub-Sahara Africa – almost one third of Africans are directly affected by the HIV epidemic" (Poku 2005:60-61).

The transmission from mother to child also affected the prevalence rate of the disease which has increased tremendously among pregnant women attending antenatal clinics in South Africa (SA).

The five countries with the highest HIV prevalence rates in the world are situated in Southern Africa and South Africa with an estimated 4.7 million people living with HIV has more cases than any other country.

The high rape rate in South Africa also spreads the disease. SA has the highest statistics of reported rapes of women in the world. A report by the Medical Research Council of SA indicates that the majority of women raped were between age 10-14 years and that the school teachers were often the perpetrators in 33% of these cases. Women from poor communities tend to develop low self image and do not have the necessary skills and knowledge to assert themselves in dangerous

circumstances and they are therefore vulnerable to rape. Poor young women are lured into sexual relations by older rich men (Van Dyk 2012:211).

### **1.2.1 Stigmatisation of HIV/AIDS**

People who are HIV positive go through emotional stress and this might be a life-changing experience for them. Disclosure of HIV positive status affects relationships with other people, affects support by family and friends and there is often rejection and violence, or both from families or partners which lead to anger and stress on the part of the person living with HIV/AIDS. Most of the time rejection, discrimination and isolation prevail. Children who are orphaned because parents died of HIV/AIDS are also stigmatised by relatives and communities (Jenkins & Guarnaccai 2003:409-410).

Clients in principle do not have a problem with voluntary testing, but they often have serious problems and anxiety about breach of confidentiality. They fear the reaction of their sex partners, should the health care professionals disclose their serological tests for HIV without their permission (Van Dyk & Van Dyk 2003:9).

In some communities it is believed that HIV/AIDS is a punishment for the immoral behaviour of people as it is linked to homosexuality and drug abuse resulting in patients and their families feeling stigmatised. The social stigma attached to HIV/AIDS is so strong that few will admit to being HIV positive. Those who do come forward are often shunned. Sometimes the victims are afraid to go to the clinic because they are ashamed to be seen there (Straub 2007:330).

Stigma in HIV/AIDS is viewed by some as ethically unacceptable, is looked at as prejudice, discrediting and discounting, and that persons living with HIV should rather be protected against direct or indirect discrimination. They have the right to the highest attainable standard of physical and mental health. Stigma may also be a barrier to the positive clients to go to clinics for tests and medications (Volberding, Merle, Lange, Warne & Greene 2008:210).

The stigma, discrimination and resulting isolation means that people do not easily, if ever disclose their diagnosis. Stigmatisation resulting in silence, secrecy and denial not only affects care and treatment, it has serious implications for prevention which is critical in the disease (Gilbert & Walker 2010:141).

In many communities the stigma of HIV/AIDS still remains and discrimination against people living with HIV/AIDS still occurs despite legislation that clearly states that discrimination is unlawful (Uys & Cameron 2008:89).

### **1.2.2 Disclosing of HIV status**

Stigma, discrimination and silence about the HIV status have long been seen as factors that fuel the epidemic. Very often people are not really aware that their HIV related stigma arises from associating the infection with behaviour that is regarded as morally improper (Otaala 2003:122). People tend to be afraid of disclosing their status for fear of rejection by friends, neighbours and co-workers. Some may withdraw and become secretive. Keeping this condition a secret may lead to continuous fear that someone might find out about it, which may lead to anxiety and depression, despair, shame and hopelessness which in turn would affect their work and personal relationships (Evian 2003: 115).

Sometimes patients may have a problem of disclosing status due to problems related to having children (pregnancy), fearing that she may be advised not to become pregnant due to the transmission of mother to child during pregnancy. An HIV positive woman has approximately a 30% chance of transmitting the HIV virus to her infant. This may occur during pregnancy, childbirth and during breastfeeding. A high HIV viral load in the mother will increase the risk of mother to child transmission (Evian 2003:115).

According to Van Dyk and Van Dyk (2003:4-9) clients fear the reaction of their sex partners who may be violent or break the relationship or marriage should the health care professional disclose their HIV status without their permission.

AIDS stigma and discrimination continue to impact on those living with and are affected by the HIV disease. Stigma has become a major problem in the provision of care for people living with AIDS in Africa (Greef & Phetlhu 2006:12-23).

Voluntary counselling and testing (VCT) could also play a role if people have known their HIV status and have disclosed it to their sexual partners, as it would have increased condom use. Kalichman, Klein, Kalichman, O'Connell, Freedman, Eaton and Cain (2007: 259) found that people who are HIV positive and unable to disclose their status are unable to receive support from family members and partners. By disclosing their status, other people at risk could be notified and it would protect them from being infected. This is the first step in successful managing and prevention (Kalichman et al 2007: 260).

The rationale of the study is outlined in the next discussion.

### **1.3 RATIONALE OF THE STUDY**

It was on the basis of the following discussion that the research problem was selected:

- People who are HIV positive have a problem of disclosing their status because of social stigma, discrimination and loss of relationships. Other people judge the HIV positive individuals which affects family stability, relationships and quality of life of the infected individual. This is the reason why family members may prefer to hide the diagnosis or cause of death in an effort to avoid disgrace.
- Stigma, silence, discrimination and denial as well as lack of confidentiality undermine HIV prevention, care and treatment.
- The epidemic of HIV is fast spreading and has devastating impacts on communities across the continent and there is a day to day decline in the standard of living. The usual prevention methods such as education and use of condoms have not made the required impact on the morbidity and mortality

rate. Where disclosure of HIV status is promoted, a decrease of these rates are noted.

- Uninfected individuals and health care workers also have a right to protect themselves against infection. If HIV positive individuals would disclose their status, it would safe guard them from becoming infected.
- Disclosure of a patient's status may enable rational discussions to occur about prognosis and treatment options and to assist all to take the correct informed decisions.
- Disclosure of status to, for instance, the sexual partners could save his or her life as they could jointly decide to take proper precaution (Eustice & Ilagan 2010:2097).
- Disclosure of the HIV status can therefore benefit clients, families and communities by protecting themselves and others for safer sex practices.
- To be able to facilitate disclosure it is important to determine why people do not disclose and whether stigmatisation is the only stumbling block and how serious the problem is in communities. As clients/patients attend primary health care (PHC) clinics to receive VCT services and are being monitored and treated for HIV and AIDS, the researcher decided that patients who attend the PHC clinics should be included in the study as they are also representatives of their communities.

#### **1.4 DELIMITATION OF RESEARCH**

The delimitation of the research has to be discussed in this study before the problem statement and objectives of the research, to make it clear where the study was conducted.

The research was conducted in the PHC clinics in the Kagiso Township, West Rand Health District, Mogale City Municipality, SA. This is where the researcher could have access without time frame challenges, because she is employed at a health care institution in this area. See Annexure F for maps of the research area.

## **1.5 STATEMENT OF THE PROBLEM**

The prevalence of HIV/AIDS is still too high in SA, despite educational campaigns to inform the community about the disease, the prevention of the disease and promotion of safer sex. It is believed that disclosure of HIV status would make an impact on the high morbidity and mortality rates. It is however not a notifiable condition in SA but if individuals could disclose their HIV status voluntarily to their sexual partners it would help them to make informed decisions and by doing so prevent the spread of the disease. Unfortunately there seems to be a stigma attached to the condition. Not enough is known about the stigmatisation of the condition or other reasons why people do not establish their HIV status.

From this problem statement the following research questions were derived:

### **1.5.1 The research questions**

The research questions for this study were:

- What do patients who attend clinics in the Kagiso Township, SA, know about HIV/AIDS?
- Why do some patients who attend clinics in the Kagiso Township, SA, have themselves tested to determine their HIV status?
- Why would some patients who attend PHC clinics in the Kagiso Township, SA, prefer not to disclose their HIV status?
- In the opinion of patients who attend PHC services in the Kagiso Township, SA, how does stigmatisation of HIV/AIDS present in their communities?
- What is the opinion of patients who attend PHC clinics in the Kagiso Township, SA, regarding what can be done to promote testing and disclosure of HIV/AIDS status?

## **1.6 THE AIM OF THE RESEARCH**

The aim of the research was to investigate the problem of disclosure of the HIV status.

The objectives of the study were to

- determine what knowledge patients who attended PHC clinics in the Kagiso Township, SA had on HIV/AIDS;
- explore and describe the reasons why some patients who attended PHC clinics in the Kagiso Township, SA, had them tested to determine their HIV status;
- explore and describe the reason why some patients who attended PHC clinics in the Kagiso Township, SA, preferred not to disclose their HIV status;
- explore and describe the opinions of patients who attended PHC services in the Kagiso Township, SA, regarding the way in which stigmatisation of HIV/AIDS presented in their communities; and
- explore and describe the opinions and suggestions of patients who attended PHC services in the Kagiso Township, SA, regarding the promotion of testing and disclosure of the HIV/AIDS status.

## **1.7 SIGNIFICANCE OF THE RESEARCH**

Other measures such as education and promotion of condom use did not make a significant impact on the morbidity and mortality rates in SA. It has been suggested that the disclosure of the HIV status of people might prevent the spread of the pandemic (Golin, Davis, Przybyla, Fowler, Parker, Earp et al 2010: 237). Unfortunately not much is known about the extent of the problem of disclosure of the HIV status. The findings of this research will hopefully contribute to the control of this pandemic.

## **1.8 OPERATIONAL DEFINITIONS**

Concepts relevant to this research include the following:

### **1.8.1 Investigation**

*Investigation* refers to the process of trying to uncover all the details or facts about something in order to discover what caused it or what happened (*Macmillan English Dictionary 2002:757*).

In this research the term *investigation* refers to the research that has been conducted to explore and describe the problem that exists in the disclosure of the HIV/AIDS status of patients. The attitudes and perceptions of patients were explored and their opinions were asked to determine why they would or would not disclose their status should they know that they were HIV positive (Herek, Capitanio & Widaman 2002:36).

### **1.8.2 Non-disclosure**

*Non-disclosure* means failure to give information or discuss information.

In this research *non-disclosure* refers to the decision of people not to reveal their own HIV status to others and not to promote any discussion of the matter.

### **1.8.3 Disclosure**

The term *disclosure* refers to revealing or exposing information about a person with or without permission. It refers to the issue of privacy and confidentiality and to whom information can and under which circumstances be released (Shaw & Mahoney 2003:63).

In this research *disclosure* refers to the act of people making their own HIV status public and placing it in the public domain for discussion.

#### **1.8.4 Human Immuno-deficiency Virus (HIV)**

*Human Immuno-deficiency Virus* (HIV) is the virus that causes Auto Immuno Deficiency Syndrome (AIDS) (Minnaar & Bodkin 2006:7).

#### **1.8.5 Status**

*Status* refers to the level of progress or position in a particular situation (*Macmillan English Dictionary* 2002:1401).

In this research the HIV status of an individual may mean a HIV positive status, which means that the HIV virus is present in the individual's body; or it may mean a HIV negative status, which means that the HIV virus is not present in the individual's system.

### **1.9 RESEARCH METHODOLOGY**

The term *methodology* refers to the methods used to conduct a study and includes all the procedures and processes that have been followed to collect data and ultimately make the findings known (Babbie & Mouton 2004:104). The methodology used in this study was quantitative, explorative and descriptive in nature.

### **1.9.1 Quantitative research**

Quantitative research method is a formal, objective, systematic process of obtaining numerical data. It is suitable for this study as the extent of the problem and how often it occurs in the sample have been measured (Burns & Grove 2009:27).

Quantitative research was chosen for this research because an interview schedule was used during interviews that have been conducted with respondents and their responses were noted, coded and quantified. Quantitative research was therefore the best method for this study. Quantitative research and how it has been applied in this research have been discussed in more depth in Chapter 3.

### **1.9.2 Explorative research design**

According to Polit and Beck (2008:20), explorative research begins with some phenomenon of interest and explores the full nature of the phenomenon. Since no research findings of this nature could be located where this problem has been researched in the Kagiso Township, SA, this research design could also be considered to be explorative by nature.

The characteristics of explorative research and how it has been applied in this research are discussed in more detail in Chapter 3.

### **1.9.3 Descriptive research design**

All research findings are described for the benefit of other scholars and to improve health practices. The purpose of descriptive studies is to observe, describe, and document aspects of a situation in natural circumstances (Polit & Beck 2008: 274). In this study the researcher wished to describe the disclosure of the HIV status of patients who attended PHC clinics in the Kagiso Township, SA.

The descriptive design and how it has been applied in this research are discussed in Chapter 3 and the findings of the research are discussed in Chapter 4.

#### **1.9.4 Conceptual framework of the research**

The aim, research objectives and research questions form the framework for the research.

#### **1.9.5 Research population**

A population is the entire group of persons or objects that is of interest to the researcher (Burns & Grove 2009:42).

The focus of this research is on the disclosure of the HIV status and therefore only researched for the reasons why people would or would not like to make their status known and what could be done to improve the situation. The population identified for the research met the criteria for the study in the specific area and the findings cannot be generalised to other areas (Wood & Haber 2010:22).

In this study the research population comprised of patients who attended the HIV clinics which are part of PHC services in the Kagiso Township, SA. According to the West Rand Primary Health Care 2007-2008 statistics, the recent numbers show that 2823 people attended HIV clinics during this period. The monthly statistics of the patients seen at each clinic is +/- 600 depending on the size of the clinics. The statistics were obtained from the daily clinic occurrence book.

From Satellite clinics

- 1240 patients were seen at Randfontein clinics; and
- 1028 patients were seen at Westonaria clinics.

The above numbers also include patients seen at mobile services, some of the patients already knew their status, some came for voluntary testing and some did not know their status. The above figures are derived from the monthly clinic statistics.

### **1.9.6 Sample**

As it is impossible to study the whole research population, a sample with the same characteristics of the research population is usually chosen. There are various types of samples with their advantages, disadvantages and degree of suitability for a particular study. The researcher decided on a random sample as it would include different respondents of different ages and who were HIV positive or negative. It was believed that these respondents would have all the characteristics that was necessary to attain the research objectives (Burns & Grove 2009:348).

#### **1.9.6.1 Sampling method**

A random sample was selected from all clients, which included the elderly, middle aged, mothers with babies, young adults and the youth, irrespective of their HIV status, who have visited the clinic for various reasons, on different days.

The sampling procedure will be explained in more detail in Chapter 3.

#### **1.9.6.2 Sample size**

As approximately 600 patients were seen at the PHC clinics in the Kagiso Township daily, 60 patients who adhered to the sampling criteria would have been the most appropriate number (10% of the research population). The statistician however advised that more respondents should be interviewed to obtain more reliable statistics. A total of 106 respondents were then interviewed which was 17.6% of the research population.

### **1.9.7 Data collection approach**

Data collection is the precise, systematic gathering of information for a research study to address objectives, questions or the hypothesis of the study (Burns & Grove 2009:43).

The process of data collection should be planned for. The researcher needs to map out procedures to be used when collecting data and also plan how much time will be required to explain the study to the subjects, obtain consent and interviewing or questionnaires for obtaining information (Burns & Grove 2009:429).

To successfully focus on the study the researcher must gather information and must have working knowledge of factors relevant to the study (Streubert & Carpenter 2011:233).

In this study data was collected by means of a prepared interview schedule specifically designed to study the problem of non-disclosure of HIV.

### **1.9.8 The structured interview**

A good deal of information could be gathered by interviewing people (Polit & Beck 2008:369). In order to yield meaningful information relevant to the research questions, and to ensure a high response rate, the researcher decided to conduct interviews to collect data.

#### **1.9.8.1 Structured interview schedule**

The interview schedule consisted of close-ended and open-ended questions. The open-ended questions allowed the respondent to provide answers in their own words and close-ended questions provided them with a number of alternative replies (Polit & Beck 2008:414).

Pre-existing instruments and the literature were studied and then the research instrument was compiled by the researcher. The interview schedule was pre-tested

to identify any questions that might have been difficult to understand, to determine whether the sequencing of the items was sensible, and the time needed to conduct a structured interview was realistic.

The interview schedule consisted of the following sections:

**Section A:**

This section consisted of the biographical data of the respondent.

**Section B:**

Section B consisted of questions that tested the knowledge of respondents about HIV/AIDS.

**Section C:**

This section covered the reasons for having themselves tested (or not tested) for HIV.

**Section D:**

Questions in this section covered disclosure of HIV status and attitudes and feelings after receiving results and making the results public.

**Section E**

This section addressed issues of stigmatisation of the HIV status in families and the community.

**Section F**

This section addressed the opinions and suggestions of the respondents (patients) regarding the promotion of testing for HIV and disclosure of the status.

The interview schedule was submitted to the supervisors at the University of South Africa (UNISA) and a statistician who critically reviewed it. Thereafter it was pre-tested in the study area.

The interview schedule's structure, pre-test and the interview process will be discussed in more detail in Chapter 3. See interview schedule in Annexure E.

### **1.9.9 Analysis of data**

Data analysis was facilitated by the coding of the answers of the respondents during the interview by the researcher and by entering it into a computer by the statistician, using the statistic computer package (SAS/JMP version 9).

## **1.10 RELIABILITY AND VALIDITY OF RESEARCH**

For research findings to be reliable and valid, certain processes had to be applied.

### **1.10.1 Reliability**

Reliability refers to the degree to which the instrument can be depended upon to yield consistent results. This means that if a valid measuring instrument is applied to different groups under different circumstances it should produce the same results (Botma, Greef, Mulaudzi & Wright 2010:177).

The use of a well planned structured interview schedule ensured that the same data could be collected from all the respondents which facilitated the analysis, comparison and discussion of the findings. The interview schedule used for data collection was structured to comply with the research objectives. The researcher obtained knowledge from the literature review to develop the research instrument. Literature and experts in the field were consulted to determine whether the instrument would be suitable and reliable and would yield the appropriate data.

### **1.10.2 Validity**

Validity is a judgement regarding the degree to which the components of research reflect theory, concepts or variables under study.

The validity of the instrument is how well it measures what it is supposed to measure. It refers to the degree to which a measurement represents a true value and it also indicates whether the conclusions of the study are justified based on the design and interpretation (Botma, Greef, Mulaudzi & Wright 2010:174).

The interview schedule was tested for face validity by two supervisors at the University of South Africa (UNISA) and the statistician and during the pre-testing of the instrument.

Reliability and validity have been discussed in more detail in Chapter 3.

## **1.11 AN OVERVIEW OF THE ETHICAL CONSIDERATIONS**

Ethics deal with the moral of good conduct towards the research subjects to avoid any harm. Research should not bring about any psychological harm or impact negatively on any social relations. Researchers and caregivers of research subjects must take every precaution to protect people being studied before, during and after the research (Wood & Haber 2010:247).

The following issues were considered during the study:

Permission was asked to conduct the research and was obtained from

- authorities of clinics in the West Rand Health District, Mogale City Municipality, SA (See Annexure A);
- patients who attended these clinics by asking them if they would like to participate in the research; and
- the Gauteng Provincial research committee (See Annexure B).

During the research, special attention was given to the ethical aspects of the research, such as

- the respondent's rights of self-determination; and
- respect and privacy of respondents and institutions.

Informed consent was obtained from each respondent who was interviewed (Burns & Grove 2003:208). See Annexure D.

Ethical clearance was also obtained from the University of South Africa (UNISA). See Annexure C.

A more detailed discussion on the ethical considerations is provided in Chapter 3.

## **1.12 CHAPTER LAYOUT**

The research report has been divided into the following chapters:

Chapter 1: Introduction and overview of the study.

Chapter 2: Literature review.

Chapter 3: Methodology.

Chapter 4: Data analysis and discussion.

Chapter 5: Summary, limitations, conclusions and recommendations.

## **1.13 CONCLUSION**

Disclosure of the HIV status is still a problem to many people who are infected with the virus. It is believed that unless people start to disclose their HIV status and talk openly about it, the epidemic will not be addressed and innocent people such as partners and medical personnel will die. By disclosing their status, people can make an informed choice and take the necessary actions to prevent being infected. The more people talk openly about the disease the less it would be stigmatised.

This chapter provided an overview of the conducted study, covered stigmatisation as a global and local problem and the issues of non-disclosure. An overview was also given on the design and the method that has been used to collect data and how reliability and validity of the findings were ensured. Definitions of the concepts relevant to the research were also explained as well as some of the ethical considerations attended to. The literature review follows in Chapter 2.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

The previous chapter provided an introduction to the study, highlighted the background, outlined the aims, stipulated objectives of the study and specified the rationale for the study. The research questions that formed the conceptual framework for the study were listed. The methodology and sampling technique were discussed.

This chapter discusses the literature review on the topic. Literature review refers to the locating and critiquing studies and draws conclusions about existing knowledge on a topic. The purpose of a literature review is to point out both consistencies and contradictions in the literature and offer possible explanations for inconsistencies. A literature review puts a research problem in context, identifies gaps of prior studies and gives a picture of what is known about a particular topic (Polit & Beck 2008:105).

The information found in the literature assisted the researcher to formulate the research problem and objectives and to ensure that such study was not previously undertaken in the West Rand district (Burns & Grove 2003:110).

A wide range of literature available to support research could be found in journals, articles, books, reports, conference proceedings, government circulars, grey literature which ranges from pamphlets, health service documents and websites. The researcher conducted a literature review by consulting library books, the Internet and grey literature.

As literature reviews has ethical dimensions, best available methods and high standards of reporting were maintained. Poorly done literature reviews can result in misleading conclusions and recommendations (Griffiths 2009:44).

Unisa's subject librarian consulted the following databases to obtain information on HIV/AIDS and non-disclosure, stigma and discrimination:

- Oasis search of reference to books in the Unisa Library
- Reference to South African material
- Magnet search of reference to material in South African libraries.
- Information from the internet, [http/www](http://www).

Other information to address the problems of non-disclosure in HIV/AIDS status was obtained from the following health sources:

- WHO publications
- Pamphlets from the Department of Health, SA
- Articles from local newspapers such as The Sunday Times, Citizen and Sowetan
- Reports from medical journals and from health websites

Key concepts used for obtaining relevant literature included:

- Problems of non-disclosure of the HIV/AIDS status
- Stigma in HIV/AIDS status
- Rejection and discrimination
- HIV/AIDS stigma and human rights
- Disclosure to children by parents and its impact
- Disclosure/non-disclosure and support
- Non-disclosure, confidentiality and the spread of infection
- Ethical guidelines in HIV disclosure and non-disclosure

## **2.2 EPIDEMIOLOGY OF HIV AND AIDS**

In 1983 it was established that HIV causes AIDS. Since this date millions of people have become infected worldwide and AIDS has become the world's most serious public health problem. No other infection or infectious disease during recent history inflicted as much destruction and pain to individuals, families and communities as

has HIV and AIDS. It has gross negative physical, social and economical and emotional impact and it affects persons of every age, ethnicity, socio-economic status, gender and occupation.

The Human Immuno-deficiency Virus (HIV) is a virus that infects immune cells causing a decline in immune/function. The virus infects by integrating its viral genetic material deoxyribonucleic acid (DNA) into human cells called CD4+ T cells and redirects or takes over their purpose and normal function of fighting infections, by producing more of the same viruses. The CD4+ T cell counts in healthy persons range from 500-1500 cells/mm<sup>3</sup> (WebMD <http://www.webmd.com/hiv-AIDS/cd4-count-what-does-it-mean>). As the virus replicates, more and more of the CD4+ T cells get destroyed and decrease in number and function. The viral load increases in the process (<http://www.webmd.com/hiv-AIDS/cd4-count-what-does-it-mean>). Without treatment, the individual's immune system gets compromised and more prone to other infections known as opportunistic infections (OIs), leading to AIDS which is the final stage of the HIV disease. Individuals contract the HIV infection from sexual intercourse, transmission from mother to child during pregnancy, through direct contact with blood of person living with HIV and through sharing needles or syringes for injecting drugs.

The HI virus infects and is transmitted in humans through

- attacking and destroying cells of the immune system;
- targeting the white blood cells specifically the T4 cells and the virus is acquired by contact with bodily fluids containing white cells;
- oral, vaginal sexual intercourse with HIV infected partners; and
- intravenous drug use with infected needles, infusion of tainted blood, perinatal transmission and needle pricks as in occupational exposure (Minnaar & Bodkin 2006:23).

When the person is infected with the virus, the virus receptor fuse to the CD4 receptors of the T4 cells. The virus may remain latent inside the T4 cells or replicate rapidly. Latent periods can last for as long as 10 years. If the virus replicates, the person may start to develop acute symptomatic HIV infections which includes:

influenza, skin rashes, ulcerations of mucous membrane and lymphadenopathy (Shaw & Mahoney 2003:2).

Up to this third decade of the HIV/AIDS epidemic no cure or vaccine has been developed. The epidemic is continuing. Its impact includes the increased destitution, economic hardship, increased health care demands, social fabric depletion and poor development.

### **2.2.1 The global picture of HIV and AIDS**

HIV/AIDS has brought about a global epidemic far more extensive than what was predicted, even a decade ago. The epidemic is rapidly expanding and is undermining the social and economic security of countries, communities, families and individuals. Men in general are assumed to have a level of infection below that of women and children who remain the worst affected by HIV (Van Dyk 2012:8).

By the end of 1997, the World Health Organization (WHO) established that over 30 million people were infected with HIV worldwide. By the year 2000 there were approximately 40 million people globally living with HIV. According to estimates from the Joint United Nations (UN) Programme on HIV and AIDS and the WHO, 42 million people including 3,2 million children were living with HIV and AIDS worldwide at the end of 2002 (Van Rensburg 2004:276).

Newly infected people with HIV in 2009 have been estimated at 2.6 million people ([http://www.who.int/hiv/pub/global\\_report2010](http://www.who.int/hiv/pub/global_report2010))

The history of AIDS epidemic in the United States of America (USA) dates back to 1982 when in the summer of 1981, the United States' centre for disease control reported unusual outbreaks of pneumocystis carinii pneumonia among small numbers of young gay men in New York City. The reported cases were increasing in numbers among homosexual men and the disease was named "*gay related immune deficiency disease*". As the disease became complex and widely known and recognised through other cases which were reported to the centre for disease control

(CDC) it was obvious that AIDS was not a homosexual disease (Kenneth, Mayer & Pizer 2000:4).

Heterosexual transmission and intravenous drug use are the major methods through which United States women contract the HI virus. The epidemic is far from over in women. There has been an increase of 17% in AIDS cases attributable to heterosexual transmission from 1995 to 1996. Reports indicated that the rate of heterosexual transmitted HIV infection among women, especially black women, is increased in the USA. Black American women living in rural and small town areas such as Alabama were particularly at risk for HIV/AIDS (Lachman 2000:23).

Social and economic inequalities also played a significant role in HIV infection among women in the USA. Women were also at risk and in 1989 a survey was done on six women between ages 15-44 because they had an unexplained underlying cellular immune deficiency, a pneumonia, which was found in young gay men having AIDS, as reported in mortality and morbidity weekly reports in 1981. These women came from poor neighbourhoods, were unemployed and they depended on public assistance and on men for economic survival. This dependency led to an increase in HIV infection among women from poor social backgrounds (Kenneth, Mayer & Pizer 2000:77). Now women worldwide account for 47% of the 36,1 million adult HIV cases and this rate is steadily increasing. The major source for women receiving and transmitting HIV are sexual and through injection use (Shaw & Mahoney 2003:126).

Studies which documented the HIV disease in Central Africa, the Caribbean and other developing regions report that HIV in these regions were mainly transmitted through heterosexual intercourse. Prostitution played a major role in the transmission of the disease, while gay men and injection drug users were a small part of the problem (Kennedy 2004:15).

Significant levels of transmission have been due to unprotected sex and drug injection in Eastern Europe and central Asia (Kelly, Holman, Rothenberg & Holzeimer 1995:19)

The City Press, a South African newspaper, also reported in 2010, that HIV infection statistics are rising among Asian women. It was reported that in 2007 women in Asia accounted for 35% of all people who were living with HIV and it was estimated that 10 million Asian women were commercial sex workers and these circumstances predisposed them to HIV infection. The same report estimated that 50 million Asian women were at risk of acquiring HIV from their partners (City Press 2010:6).

The projected peak of the HIV epidemic in Asia for the year 2000 was 1.3 million infections in that year and the total number of infections is expected to be ultimately greater than that of Sub-Saharan Africa (SSA) (Lachman 2000:55).

In some cities of India, such as New Delhi and Mumbai, the prevalence of HIV is high, between 25-71%, among injectable drug abusing sex workers (Kennedy 2004:17). The fight against HIV/AIDS threat continues to grow. As AIDS advances further into the third decade, the question that faces the global community is whether we shall have the commitment to respond effectively (Walt & Gilson 1994:353-370).

In Thailand an increase in the frequency of HIV infection has been experienced since the late 1980's. Two independent epidemics occurred among injecting drug users. In 1991 it was found that there was also a group who was infected through sexual transmission and this constituted 85% of the HIV infections and then gay's had a different genotype of the virus from those infected through infections of drug users.

The high rate of other sexually transmitted illnesses in Thailand act as co-factors to the prevalence of the HIV disease (Dalgleish & Weiss 1999:31). A study was conducted on perinatal women in Thailand to investigate HIV disclosure and the joint UN programmes on HIV/ AIDS estimated that in 2009 33.3 million people were living with HIV, including 600 000 Thailand adults between the ages of 15-49, 21 000 of whom were pregnant women. More women learn of their HIV infection during the antenatal period when they are tested (Iwelunmor, Zungu & Colins 2010:1393).

In Scotland the epidemic is heavily driven by injecting drug users. Harm reduction initiatives such as needle exchange programmes were implemented to try and reduce the spread of HIV infection through injection drug use (Kennedy 2004:4).

In the world's poorest developing countries, resources are scarce and care for citizens living with HIV/AIDS is unaffordable for governments and families, which aggravates human suffering for individuals, families and countries. The Joint United Nations Programme on HIV/AIDS (UNAIDS) reported that 14 million people died of AIDS by the year 2000 (UNAIDS 2004). The disease in these countries was then mostly spread heterosexually, compared to the situation in developed countries.

It is estimated that in Latin American there were an estimated 1 700 000 people with HIV and AIDS at the end of 2007, of which 43% were from Brazil. Of these 140 000 were newly infected during 2007, and approximately 63 000 people died of AIDS in that same year. There is also a high rate of men having sex with men. Injection drug users in Brazil and the Brazilian government has undertaken HIV protection campaigns that have shown some success although levels of unprotected sex still remain high. Tourists caused HIV infection to spread in Manila due to unsafe sexual practices. Although they were stigmatised by their work and the HIV infection the number of female commercial sex workers were rising and brothels in urban areas also included male gays. HIV infection also spreads in the Philippines among the large gay population (Kennedy 2004:18).

### **2.2.2 HIV/AIDS in Sub-Saharan Africa (SSA)**

To date, nearly 70% of all HIV infection is thought to have occurred in SSA, even though only 10% of the world's population live here. This region can therefore be considered to be the most affected region in the world, followed by Central and East African countries. It can be contributed to the fact that the African populations are characteristically young with approximately 45% of the population younger than 15 years and that most of the world's poorest communities could be found here. Heterosexual sex has always been the primary mode of HIV transmission in this

area and because of large numbers of women of child bearing age there is a large infection through perinatal transmission. This region had the highest overall HIV seroprevalence rate in the general adult (15-49 years) population which was an estimated 9% by the end of 2002. According to Shaw and Mahoney (2003:2) AIDS is the leading cause of death in SSA with 1.3 million deaths of adults and children in 2009.

In SSA, the relationship between sexually transmitted infections, parasitic diseases, tuberculosis and HIV against a background of inadequate care, poverty and poor health has influenced the nature of the epidemic in many African countries. The situation differs from one country to another as Africa is a continent of more than 50 countries. The United Nations AIDS programme estimates that countries such as Botswana, Zimbabwe, Swaziland, Lesotho and SA are leading in the reduction in the prevalence rate. The Ugandan prevalence rate has reportedly also decreased from 28% to 4% among pregnant women between the age 15 to 19 years in Lusaka (Kennedy 2004:16).

Most of the African countries, for example Nigeria, have high HIV/AIDS prevalence rates compared to developed countries. UNAIDS has declared Nigeria the 3<sup>rd</sup> highest HIV/AIDS prevalence nation in the world. About four million of its citizens were said to be infected with the virus. Figures show that 3,5 million Nigerians infected with HIV and AIDS in 2005 account for about 10% of the 40 million people infected worldwide. Of the 20% infected patients who die annually of AIDS related diseases in Africa, about 300 000 are Nigerians. Approximately 1,5 million Nigerian children have been orphaned as a result of these deaths (National Department of Health 2005:2006:23).

In Burundi, the United Nations Children's Fund (UNICEF) has launched a campaign to support and protect tens of thousands of Burundian children living with parents affected by HIV and AIDS. The HIV infection in Uganda is high and this epidemic has had negative results for this country which has a very low health budget. Extensive prevention work has been implemented in Uganda to try and reduce the rate of infection. These strategies are slowly reducing the prevalence although the

epidemic has left the country with a large number (1,900,000 between the ages 0 to 17 years in 2009) of AIDS orphans (UNAIDS 2012).

According to UNAIDS (UNAIDS/WHO 2004) it was revealed that in Egypt both men and women were infected in 2004, but Egypt was then still in the early stages of fighting the disease. There was reportedly public fear and ignorance about the disease and people infected with HIV were rejected. As a result women did not make their status known and were hardly registered in Egypt's official statistics of AIDS. About 80% of HIV positive people registered were men. According to Emlet (2006:350) fear, rejection and ignorance might have had a serious impact on disclosure.

In Sudan the HIV/AIDS prevalence rates were also increasing rapidly. This was revealed by a report by UNICEF, meant as a warning, that the conditions in Southern Sudan were conducive to an explosive spread of HIV/AIDS.

The estimated number of patients who are living with HIV/AIDS has always been the highest in SSA as seen in the figures for 2003.

- SSA 25 million
- 7.4 million for Asia
- 480 000 for North Africa and the Middle East
- 1.3 million for Eastern Europe and Central Asia
- 1.6 million for Latin America
- 950 000 for the United States
- 580 for Western Europe (UNAIDS/WHO 2004)Department of

In 2009 the number of people living with HIV/AIDS in SSA has declined to 22.5 million but is still the highest compared to 770 000 in East Asia, 460 000 for North Africa and the Middle East. The epidemic in SSA is diverse and is severe in Southern Africa where the epidemic is still expanding. Women in SSA are the most affected, they bear the burden of AIDS. Young women between ages 15 and 24 years are four times more likely to be HIV infected than young men (Van Dyk 2012:8).

Since the early 1990s HIV and AIDS have continued to be a challenging public health problem in Southern Africa and in South Africa (SA) in particular. All the countries in Southern Africa were hard hit by the epidemic as they are linked by trade and labour and people move freely between the countries in this region. According to the National AIDS Co-ordinating Agency (NACA) (NACA 2004:12) migratory labour of SA involves the mobilisation of hundreds of thousands of men for work in the mines. Approximately 2,6 million workers from Lesotho, Mozambique, Malawi, Botswana, Swaziland, Zimbabwe and Zambia are officially registered as migrants in SA. In 1986 the South African government began randomly testing miners for HIV and there was a high incidence among the Malawian mine workers. Migratory labour also promoted the spread of HIV infection to the rural women and wives in their countries of origin. Most women died of the infection leaving their children as orphans to be taken care of by relatives. Southern Africa remains the one region with an alarming picture of the HIV epidemic. Almost 1 in 3 people infected with HIV globally lives in Southern Africa (Van Dyk 2012:8).

The South African National HIV survey of 2008, reported that SA had one of the fastest expanding epidemics and the highest number of HIV-infected people in the world and the number accelerated from 1998. Of the 47 countries in SSA, SA had an estimated 5.7 million infected individuals by 2008 and 10,9% of all South Africans were living with HIV (UNAIDS/WHO 2008). Before this period the infection spread was probably limited to isolated communities in Africa who had little contact with the outside world, but various factors such as migration, tourism, prostitution, multiple partners and injection drug abuse ultimately caused the virus to spread all over the world. Valuable information for both incidence and prevalence statistics is also gained from surveys conducted with specific groups such as sex workers and truck drivers or from reports of AIDS related deaths (Van Dyk 2012:9).

The national estimates of HIV prevalence in SA, like in other countries, is based on data from pregnant women tested at antenatal clinics and national household surveys where it involves sampling a proportional cross section of society. The antenatal surveillance programme involves the annual testing of the blood of pregnant women in the public health sector who visit antenatal clinics. This

programme began with the first national antenatal survey amongst women in SA in 1990. This survey indicated that 0.8% of pregnant women tested were found to be HIV positive (Van Dyk 2012:8).

The situation is even more dramatic in some small countries in the region, which have the highest number of HIV-infected people in percentage terms, such as Swaziland 26%, Botswana 24%, Lesotho 23%. Botswana had the highest prevalence with 36% of adults infected with HIV. To be able to manage this epidemic the ex-president of Botswana Mr Festus Mogae declared HIV/AIDS a national emergency in 2002 and national programmes to provide universal access to anti-retro viral treatment was introduced as a health priority (NACA 2004:12).

An annual survey was conducted in SA by the Department of Public Service and Administration (DPSA) to establish the prevalence of HIV infection amongst pregnant women attending antenatal clinics. Extracts from the 2001 survey showed that an estimated 4,74 million adults were infected with HIV of which 2,9 million were women in the same age group. In the past antenatal data at public antenatal clinics has been the source of information for HIV infections, although it has limitations by focusing on a select group which is sexually active women between ages 15 and 49 years who use public health services in designated surveillance areas. These estimates do not include men, younger women and old age groups. They may lead to over estimation and under estimation of the HIV infection (Brookes, Shisana & Richter 2004:1).

It is clear from Table 2.1 that the prevalence of HIV in the South African provinces has increased from 1999 to 2001 (National Department of Health 2004:13), but has since decreased slightly according to the statistics depicted in table 2.2. The province with the highest prevalence remains KwaZulu-Natal.

**TABLE 2.1: The prevalence of HIV in South African provinces during 1999, 2000 and 2001.**

Province	1999 (%)	2000 (%)	2001 (%)
KwaZulu-Natal	32.5	36.2	33.5
Mpumalanga	27.3	29.7	29.2
Gauteng	23.9	29.4	29.5
Free State	27.9	27.9	30.1
North West	23.0	22.9	25.2
Eastern Cape	18.0	20.2	21.7
Limpopo	11.4	13.2	14.5
Northern Cape	10.1	11.2	15.9
Western Cape	7.1	8.7	8.6

(National Department of Health 2004:13).

The provinces with high prevalence rates in the period 1999-2001 were KwaZulu-Natal, Mpumalanga, North West, Gauteng and the Free State, but in 2008 KwaZulu-Natal, Mpumalanga and the Free State were among the provinces with the highest prevalence.

**TABLE 2.2: The prevalence of HIV in South African provinces during 2008**

Province	Rate %
KwaZulu-Natal	25.8
Mpumalanga	23.1
Gauteng	15.5
Free State	18.5
North West	17.7
Eastern Cape	15.2
Limpopo	13.7
Northern Cape	9.2
Western Cape	5.3

(Wikipedia HIV/AIDS in South Africa 2013)

During the period 1999-2001 the Western Cape was the lowest and the Northern Cape and Limpopo slightly higher than the Western Cape and this tendency remained in 2008. The only province with a slight decline in the prevalence rate from 2000 to 2001 was the Western Cape. The National rate also increased during the period 1999 to 2001 from 22.4% to 24.8%.

The Actuarial Research Society of SA estimated that there were 5,4 million people in SA living with HIV/AIDS on 1 July 2006, and of these over 4,9 million (90,8%) were in the age group 20-64 years, and 2,8 million women of child-bearing age (15-49 years). The infection was also being transmitted from mother to child causing infection in infants through breast milk and through the placenta where the virus cross before birth (Kennedy 2004:10).

KwaZulu-Natal accounted for 28,7% of total infections and for a third of infections among youth and children before 2006. Gauteng accounted for 26,2% of infections and 17,3% infections were among youth. Eastern Cape accounted for 12,1% of infections among adults but the third highest proportion (16,4%) of infections among youth. In 2004 the Reproductive Health Research unit in Johannesburg revealed that 15,5% of adolescent girls between 15-21 years were HIV positive. A similar study in the Western Cape showed an HIV prevalence of 5,9% among 15-19 year olds during that same period (Minnaar & Bodkin 2006:209).

Sources often differ when it comes to HIV/AIDS statistics. It is clear from the statistics depicted in Table 2.1 and 2.2 that the HIV/AIDS prevalence rate has decreased between 2001 and 2008.

Estimates of HIV prevalence in SA have relied on the testing of pregnant women attending public ante-natal clinics and this data has also been a source of information on HIV trends, although it has limitations on prevalence of the disease amongst the general public. It only shows information on a select group, pregnant women using public ante-natal services and the tests are not conducted on men (Brookes, Shisana & Richter 2004:1). In order to obtain a better understanding of the dynamics of the epidemic in the country and to determine the national HIV prevalence and monitor the trends of prevalence in the general population the ante-

natal survey is the tool used most to track HIV spread. The 2007 report on the national HIV prevalence survey shows that some factors which may possibly contribute to the rise of the HIV epidemic are AIDS-related sexual behaviours and exposure to high risk groups such as multiple partners with homosexual practices and mining communities. SA, due to its diverse socio-economic and cultural factors and associated risky sexual behaviours, has a high risk for HIV infections (National Department of Health 2007:1).

In Gauteng province the number of women outnumber the number of men, therefore there are more women living with HIV than men. Many young girls date older men in the hope of an economic secure future. Unfortunately older men are much more likely to have HIV than the young boys. The female reproductive structure makes it much easier to contract HIV, particularly in younger women. Cultural, social and economic pressures make women more likely to contract HIV infection than men. Estimates of HIV prevalence in SA show that women are often less able to negotiate safer sex due to factors such as their lower status culturally, economic dependence and fear of violence. Physical violence against women increases the HIV epidemic through rape that results in genital injuries which makes the infection more likely (Riddle 2009:2).

The incidence of infections is one of the most important indicators of the progression of the epidemics and this needs to be monitored. To be able to calculate incidence it is necessary to observe a group of HIV-uninfected people over time to determine how many become infected with HIV during a specific time period (Van Dyk 2012:8).

### **2.3 HEALTH INDICATORS**

National estimates of HIV prevalence in countries with HIV epidemics show from ante-natal statistics, national household surveys and from reports of AIDS related deaths that the spread of the HIV/AIDS disease is high and it impacts negatively on the health of the people.

HIV/AIDS statistics supplied by the medical research council in 2004 reveal a worrying picture. During 2004, approximately five million adults and children became HIV infected across the world. By the end of 2004 approximately 39,4 million people worldwide were living with HIV and AIDS. By 2004 an estimated three million people have died of AIDS (Minnaar & Bodkin 2006:208).

The high incidence rates have affected health indicators as follows:

- An estimated maternal mortality ratio in SA is 400 deaths per 100 000 live births and the peri-natal mortality stands at 31.1 deaths per 1000 births.
- Ante-natal HIV statistics in SA indicate that HIV seroprevalence among pregnant women increased from 7.6 % to 26.5% over the 7 years 1996 to 2003 (Minnaar & Bodkin 2006:210)
- Child mortality has increased to 75 percent per 1000, and 2 million children under the age of 15 years were expected to live with HIV/AIDS in 2004 (Minnaar & Bodkin 2006:210).
- Mortality statistics in SA hospitals show that HIV positive patients accounted for 44.9% of hospital deaths in 2004 (Minnaar & Bodkin 2006:210).
- The probability of a 15 year old dying before the age of 60 years was 27 per 1000 in 1990 and has risen to 40 per 1000 in 2000 (Minnaar & Bodkin 2006:210).

More than 80% of the world's youth live in developing countries, a significant number of them are becoming sexually active at very early ages and due to multiple partners and non-use of condoms they are vulnerable to HIV infection (Van Rensburg 2004:284).

In 2005 estimated figures of HIV prevalence by sex and age showed that the prevalence is higher for women than men for the 15-34 year age group, while it is higher for men in the older ages. Among women the rate is the highest at 32,5% for the age group 25-29 years. Among men, the rate peaks at slightly older ages with 26,5% of those aged 30-34 years being estimated to be infected. Worldwide, the proportion of women who are living with HIV and AIDS has been steadily increasing over the past few years. Women are at the highest risk between age 15 and 20

years especially in poor communities due to limited access to information about HIV/AIDS, sexuality and reproductive health because of social pressures and cultural norms. Women generally lack control over sex and reproduction, whilst cultural beliefs and expectations allow men to make decisions on when, where and how sex will take place. All over the world men are expected to have more sex partners than women including more extramarital partners. This is also reinforced by male migration and mobility. In SSA women constitute 55% of all infected adults, while teenage girls are at a rate 5 to 6 times greater than their male counter parts. HIV and AIDS are also the cause of high mortality rates for infants and young children infected by their mothers (Van Rensburg 2004:283).

In July 2008 the UNAIDS and the WHO published an estimated figure of 18.1% prevalence of HIV in those aged 15 to 49 years old. This implies that around 5,7 million South Africans were living with HIV at the end of 2007. The epidemic is high in SA and affects women more (UNAIDS/WHO 2008).

As mothers play an important role in ensuring the health and well-being of children, the number of maternal orphans under the age 18 years is also increasing. Many children under the age of 18 years have lost a mother or both parents. There was an estimate of 500 000 maternal orphans under the age of 18 years in the country in 1990. By 2006 the number of orphans has increased to over 1,5 million and the number is to increase as a result of the ongoing increase in the number of deaths projected to reach 2,5 million by 2015.

After the death of parents children often lose their rights to family life. As AIDS orphans they may suffer malnutrition, illnesses and also become victims of sexual abuse and be HIV infected. After contracting the HIV infection, accessing health services may also be limited for the HIV/AIDS orphans (Van Dyk 2012:356).

According to Pienaar in a local SA newspaper *Beeld* an article published on the 22 June 2010 showed that there was a decrease in the new infections because people disclose their status and use condoms to protect their partners. When people know their status they practise safe sex (Pienaar 2010:2).

## **2.4 STIGMA AND DISCRIMINATION OF PATIENTS WITH HIV POSITIVE STATUS**

A study conducted on stigma in Botswana by Weiser, Wolfe, Bangsberg, Thior, Gilbert, Makhema, Kebaabetswe, Dickenson, Mompati, Essex and Marklink (2003:385) has found that there are negative outcomes due to the stigma attached to the HIV positive status in individuals. The stigma negatively affected marriages and relationships, patients were rejected by family, ostracised by the community and lost employment. The stigma surrounding HIV and AIDS causes the individual to be treated with a lack of dignity and respect and the fear of rejection could affect the mental state of the individual who is HIV positive (Viljoen 2005:19).

Poku, Linn, Fife, Azar and Kendrick (2005:345) confirmed with their study the findings conducted by Wieser et al (2003:385) that the HIV status affected the individuals negatively, but also found that it had the same affect cross culturally. The study was conducted among the people of Ghana and African Americans. The researchers found that people living with HIV/AIDS, face discrimination and stigma that are associated with the disease and further reduction in their quality of life and physical well-being. They looked at how stigma affected self worth, self depreciation, body image and personal control. It was found that stigma diminished the social standing of the individuals, their identity was tarnished and they felt inferior. The researchers concluded that stigma therefore negatively affects self perception of the patient. Stigmatised individuals experience low self esteem and have limited personal control. The effects of stigma are similar in cross cultural variations as both cultures which were studied had a fear regarding social isolation and ridicule that accompanies disclosure.

Stigmatisation can also be based on gender and the status of women in some cultures. A study of stigma against persons with HIV/AIDS in Uganda demonstrated a strong gender bias where women were more stigmatised than men, rejected by their families, gossiped about and isolated in their communities (Holzemer & Uys 2005:167).

Stigma can be expressed verbally, in the form of gossip, deformation or hate speech which is hurtful and harmful. It is therefore not surprising that SA indicators have shown that 28% of patients do not convey their HIV positive status to anybody outside the doctor's room. Partners or spouses are only informed by 54% of patients, and only 18% have major family support. They may be concerned about losing their jobs because of the status, especially if they are ill and frequently absent from work (Minnaar & Bodkin 2006:83).

Stigma and discrimination of the HIV positive individual are therefore a consequence of disclosure. If the status of an individual is not known they will not be discriminated against. HIV positive people therefore often do not disclose their status for fear of stigma and discrimination. Stigma leads to discrimination and isolation of those who are HIV positive and discredits the individual in the eyes of others. The HIV positive person may internalise the negative responses and reactions of others. When stigma is acted upon, the result is discrimination which can lead to denial or loss of jobs, loss or denial of health benefits, isolation from family, friends and communities as well as lack of access to housing. Families of persons with HIV/AIDS also suffer discrimination and isolation (Shaw & Mahoney 2003:64).

Few empirical studies explore stigma's relationship to quality of life. Persons with HIV/AIDS gave their testimonies that the moment people learned that they are HIV positive, they treated them differently, neighbours isolated them, children avoided touching them and landlords kicked them out of residences (Holzemer & Uys 2005:170).

Stigma is described in three ways which are

- direct discrimination at a person to person level, where activities devalue, reject, exclude or blame the other person;
- structural discrimination in the social environment, such as a sign identifying an HIV/AIDS clinic or VCT room in a PHC clinic and the general public then realise that the individual who attends these services must be HIV positive; and

- separation or isolation of the person from others resulting in self-stigmatisation and going through psychosocial isolation or becoming withdrawn (Viljoen 2005:1).

The HIV infected individuals not only have to live with the stigmatisation of the community they tend to apply labels to themselves, believe in these labels and live accordingly. The individual may have feelings of shame, self blame, worthlessness and this can lead to depression (Viljoen 2005:1).

Stigma has emerged as a major limiting factor in the prevention of the spread of HIV and AIDS. It interferes with VCT and access to care and treatment, as the intake of anti-retroviral drugs assure that their HIV status is no longer kept a secret. Many health care workers in SA have come to the conclusion that unless stigma is conquered the illness will not be defeated (Holzemer & Uys 2005:166).

HIV/AIDS stigma has an impact on the quality of care. The HIV positive clients may experience limitations in accessing health care. Care for patients who are HIV positive might be substandard because caregivers often fail to comply with universal precautions due to stigma (Holzemer & Uys 2005:170).

Stigma is also seen in many institutions such as religious institutions, at schools and at work places. Some religious communities have reinforced stigmatisation and discrimination by giving conflicting messages about condom use and by interpreting HIV/AIDS as God's punishment of sinners. Other religious groups often enhance the stigmatisation associating HIV/AIDS with adultery, which is a sin as people who are married should live in a monogamous relationships and will then not be infected. This again results in self stigmatisation by the members. The lifestyle of homosexuals is condemned by religious groups, which fuels this stigmatisation even more. Most mainline churches however denounce the view that God punishes people with HIV/AIDS and there is a great concern especially with Roman Catholics about the use of condoms (Bouwer 2007:263-264).

Ignorance and lack of education or knowledge about HIV/AIDS have contributed largely to stigmatisation. The lack of knowledge of how the disease is transmitted,

how it progresses to AIDS and how it is spread extended to behaviours such as shaking of hands, sharing food or utensils, coughing and even eating of beetroot to stigmatise others (Viljoen 2005:31). The HIV positive person is often isolated due to ignorance to the extent that members of his or her family do not want to share eating utensils with him or her. Families fear their neighbours when they have an HIV positive person because they will be stigmatised and be discriminated against by the whole community. Many families hide their sick people in their homes for the fear of stigma. Education has an important role to play in reversing the spread of stigma and the disease (Viljoen 2005:31).

The workplace community also has a serious effect on stigmatising HIV positive people. It would be of help to those who have tested positive to get support if disclosure was done to the general public or at workplaces, but fast spreading gossip and distortion discourages a lot of people to disclose. The gossip promotes isolation and rejection. Labelling and separating them as “us from them” gossiping in communities, schools and workplace makes the HIV positive person to withdraw. As rumours about the person spread the person is psychologically traumatised and it becomes difficult for them to disclose their status (van Dyk 2012:142). Morale in the workplace may also be affected where other people fear to be infected by the HIV positive person and start rejecting the person. Knowledge and understanding of HIV and AIDS by others in the workplace may promote an accepting attitude (Van Dyk 2012:272).

Maile (2003:186) says that most of AIDS deaths affect adults, but most of the impact is felt by children when they live with the HIV virus. The impact of HIV status on children directly affects their rights or access to education, to information, the right to participate in learning and sports activities. This is due to the problem of stigma. Ignorance and the belief that AIDS is a punishment for immoral behaviour contribute to discriminatory behaviour towards children. School children who are HIV positive may be at risk of being isolated, shunned by peers, maltreated and discriminated against. Those who disclose their HIV status may experience humiliation and abuse. An example is the report about the case of an HIV positive boy who dropped out of school after been beaten up because his HIV-positive mother disclosed that he had

AIDS as part of educating the community in a campaign. This incidence shows that there is a great need to deal with managing the disclosure of learners' HIV status at school. Issues of confidentiality and who must disclose the learners' HIV status is a problem to educators as the rights of the child are not to be violated (Van Dyk 2012:448).

There was also an indication that the nurse educators need to be educated about HIV and AIDS and the rights and law around HIV/AIDS status. The educators also indicated that parental consent to disclose the child's status is necessary therefore it is not their responsibility to disclose learner's HIV positive status. Maile (2003:185) in his research concluded that learners have the right to privacy to protect their personal information concerning their status. Consent should come from the parent of an HIV positive learner as the guardian of the rights of the child. No learner should be expelled from school due to his or her status as this is discriminatory and a violation of the child's rights to education.

In an article from a local newspaper, *The Sowetan*, a popular gospel singer and member of Swaziland parliament called for all HIV positive people to be branded on their buttocks. This remark promoted further stigmatisation (Maphumulo 2009:10).

From the onset of the HIV and AIDS epidemic, stigma and discrimination have aggravated the transmission of HIV and increased the impact associated with the epidemic.

A stigmatising social environment has a negative impact on support which should be given to the infected individuals. They become afraid to seek information about how to reduce their risk of exposure to HIV. Stigma and discrimination undermine the ability of individuals and communities to protect themselves and also render them less likely to receive care and support. In a study conducted during 2012 at the Child and Adolescent Psychiatric Hospital in Chicago it was found that there is a strong relationship between adherence to anti-retroviral treatment and stigma. The study showed that as much as the treatment changes the lives of HIV infected individuals, those who experience high levels of HIV stigmatisation are three times less likely to

take their medication as prescribed, compared to those who experience less HIV stigmatisation (Martinez, Harper, Carleton, Hosek, Bojan, Glum & Ellen 2012:108).

## **2.5 DISCLOSURE OF HIV POSITIVE STATUS**

HIV/AIDS related stigma and discrimination is one of the problems for people who are HIV positive and this makes it difficult for them to disclose the disease. The negative attitudes, prejudices, gender inequalities and cultural beliefs may promote non-disclosure of the HIV status (Van Dyk 2012:131).

HIV related stigma has been a driving force behind the many failed efforts to respond to HIV. Stigma has been particularly at the centre of the silence and denial surrounding the existence of HIV/AIDS in the African American community (McCree, Jones & O'Leary 2010:60).

Disclosure of the disease or the HIV status should always be in the interest of promoting support, prevention and spread of the disease, lowering morbidity and mortality rates and improvement of the quality of life (Van Dyk 2012:280).

If there was no stigma against HIV positive people they might easily disclose their status. The environment of the family should be nurturing and supportive for the individual to be able to disclose. The individual may feel comfortable by disclosing to a single spouse or sexual partner or to a special friend or close family member. It would be much better and of advantage for partners to have HIV tests together, as it would eliminate the stress of having to disclose later. If they are both tested and know their status it would be easier to make a joint decision about protecting their future health. The impact of non-disclosure of the HIV status is, that keeping the secret, further increases the spread of the disease to partners when there are no safe sex measures practised (Viljoen 2005:67).

Whether or not to disclose their HIV positive status is a difficult decision for most HIV positive individuals, because whatever the decision might be, there are serious

implications that may impact on the life of the infected person. The individual might experience negative reactions such as rejection, dissemination or stigmatisation from the partner, the family, relatives and the communities. Actions resulting from stigma lead to violence against the person as was in the reported case of Gugu Dlamini in KwaZulu-Natal who was attacked for disclosing her status (Maphumulo 2009:10).

On the other hand, there are many advantages of disclosing the HIV positive status to other people. The infected individual might benefit by getting support and this will reduce the stress of coping alone. One might get the correct medical care and medication before it is too late and be in a position to plan for the future. Disclosure may help the positive individual to negotiate for safer sex practices and protect themselves and others (Van Rensburg 2004:283).

Test results of HIV positive individuals should be treated with the highest possible level of confidentiality. The decision whether to reveal the information to other parties involved must be in consultation with the patients.

The challenges affecting HIV positive individuals regarding disclosure affect them psychologically, socially and physical. The physical clinical symptoms may force them to disclose against their will in order to access medical help. Socially at workplaces people are afraid to disclose their HIV status to others fearing that the information will not be kept confidential. People with the HIV status have to endure the social stigma and rejection. Many go into denial when they learn that they are positive. These emotional problems increase stress levels and the incidence of non-disclosure (Minnaar & Bodkin 2006:82).

The other area of disclosure of the HIV status where difficulties are encountered is when mothers have to know the positive status of their children. Mothers of HIV positive children need to know their children's status. Disclosure of the status is in the best interest of the child so that the mother can be able to give support and help the child to participate in the anti-retroviral treatment. The mother might experience problems how to tell the family and relatives about the positive child. As the child grows older, a need arises for the child to be told about his/her positive HIV status

before adolescence. Disclosure at school or day care centre might be a problem due to fear of stigmatisation and discrimination (Evian 2003:198).

### **2.5.1 The impact of disclosure and non-disclosure**

Disclosure may ease the burden of the disease, but keeping the secret may increase the burden.

The number of people living with HIV or AIDS has increased and there is a need to understand how strong the stigma of the infection and disease is in the population. Accepting attitudes may indicate better knowledge and understanding of HIV and AIDS. People should be given education on HIV/AIDS. Those who are infected must also be taught how to reduce risks by changing their behaviour (Van Dyk 2012:136) .

Disclosing the HIV positive status has been a problem for many people because they have to cope with many different problems. They have to deal with medical problems related to their status, psychosocial problems, may lose employment due to ill health subjecting the individual to economic problems. They have to deal with feelings of guilt, shame, helplessness, despair and anger. All these may impact negatively on the immune system because of stress.

Some HIV positive people may wish to disclose so that they can get help while others disclose because of religious reasons. Others disclose their status very late when they experience a feeling of dependence and when there is a need for care and treatment. Others fail to disclose even if they are very ill because of fear of how they will be treated by their families and friends.

Disclosure of the HIV positive status should be done voluntarily by the individual. Each person has the right to privacy and confidentiality. There is also the element of “shared confidentiality” where the individual shares the news with others such as family members, loved ones, care-givers and trusted friends. Sharing confidentiality

must be left to the discretion of the person who has been tested for HIV. Consent should be obtained from the HIV positive person before information is made known to others (Viljoen 2005:65).

In a study on disclosure by peri-natal women in Thailand it was found that HIV disclosure may be influenced by a number of factors such as the psychological state of the person, communication, motivation and anticipated reaction when the infected individual comes to terms with the diagnosis and decisions on whom to tell.

The Bill of Rights for people living in SA promotes the right to equality and these rights are also important for people living with HIV or AIDS. People with a positive HIV status have the right to have their dignity respected and protected. They have the right to privacy, the right to freedom of expression which includes freedom to receive or give out information or ideas. There are circumstances where disclosure of the HIV positive status should be lawfully done in order to protect the rights of this individual such as the right to have an insurance contract for assessment of risks. Non-disclosure can become a problem and questions can be falsely answered, which is viewed as fraud (Barrett-Grant, Fine, Heywood, & Strode 2003:300).

Usually after receiving the news of a positive HIV status there is feeling of disbelief, fear about death, fear about the future or having a job and losing loved ones.

Going through all these negative stressful thoughts a person feels depressed and thinks it is better to keep the status as a secret.

The thought of how others will perceive him or her brings about feelings of guilt because HIV is sexually transmitted, they may be judgemental. The fact that others may think due to the illness he/she may no longer be able to work or the children may think the parent won't be able to financially support them brings about psychological trauma.

The thoughts of discrimination at the workplace may also make one not to disclose his or her HIV positive status.

The feeling of loss is also an experience the HIV positive individual goes through. One thinks he/she has lost physical attractiveness because HIV/AIDS is associated with looking very sick, losing weight and skin problems. One feels he/she loses the respect of the community. There is also a feeling of grief because one has seen others dying of the disease. One may also feel guilty because of lifestyle such as homosexuality or multiple partners. These circumstances make it very difficult for one to disclose. Denial and anger may also be the cause of non-disclosure and some people fear to lose their dignity or their relationships (Van Dyk 2012:300).

Other experiences are denial and anger and these promote non-disclosure and bring about negative outcomes because safe sex practices are not followed and other individuals deliberately infect their partners. One becomes anxious because the HIV status is viewed as a death sentence and one cannot change the status. Anxiety also brings about the fear of being isolated by others, fear of physical pain and whether one will be able to function fully in the future.

Depression and suicidal thoughts are also experienced by HIV positive individuals because they blame themselves for the infection and to avoid shame. They think of poor health; low self-esteem and loss of economic power. They think of losing their jobs and this brings about depression (Van Dyk 2012:295).

A study was conducted on the experiences of disclosure in women infected with HIV during 2009 at Atlanta, United States of America. Some of the findings from the study were factors that influence decision to disclose, which vary from situation to situation. Others prefer to disclose when the disease is severe and they have changes in appearance. Other factors that promoted disclosure were trust, understanding and compassion of the person you disclose to. Other experiences from these women were about concerns to protect their children from stigma of HIV discrimination and confidentiality (Moneyham, Seals, Demi, Sewell, Cohen & Guillory 2009:213).

### **2.5.2 The attitudes of significant others with regard to disclosure of the HIV status of the patient**

Stigma entails labelling, separating “us from them”, gossiping, isolating or rejecting those who are HIV positive. The process of stigmatisation starts with people labelling physical differences, that the HIV positive person should look thin and look ill or be coughing or hair falling out. The person becomes isolated based on these physical symptoms.

A person may be isolated because HIV status is linked with death and there is a stigma attached to you because there is no cure for AIDS. The association of HIV/AIDS with death was one of the reasons why people living with HIV/AIDS were isolated. Communities did not want to associate with them, even if they were healthy because of fear of death (Viljoen 2005:25). Stigma is also linked to how the disease is contracted and a judgemental attitude of looking at the HIV status in relation to promiscuity. People may even distance themselves from HIV positive individuals. This attitude of rejection brings about stigma on the HIV positive individual. The process of stigmatisation creates blaming, shaming and often results in isolation. A person may be denied employment and access to services due to discrimination (UNAIDS 2005:40).

On disclosing the HIV status there could be negative responses experienced although on the other hand there might also be a benefit of support. Those who tested HIV positive experienced discrimination and problems of confidentiality at the workplace and losing jobs once the HIV status is known. After disclosing their HIV status to the health personnel, this information was not kept in confidence, at the resources, health care services and HIV clinics where patients files are kept (Moneyham et al 2009:215-217). The findings of this study suggest that HIV infected individuals are very concerned about disclosure of their status and their use of supportive services and resources is influenced by such concerns. Although they are benefiting from gaining access to needed resources and support there was a potential risk of exposure to discrimination and loss of confidentiality.

The impact of gender in HIV and AIDS disclosure has shown to affect women greatly. Women currently represent the fastest growing subgroup that is infected with HIV, but it has shown that they have shown that until recently they have been largely under represented in HIV research and services. Based on the above concern Moneyham et al conducted a study to examine the disclosure experiences of HIV infected women. Many of the infected women are mothers and factors influencing disclosure may include concerns around protection of their children from the stigma of HIV. From the study conducted, 19 women who were interviewed uniformly experienced a concern about disclosing their status because they anticipated and feared negative responses they would receive. They saw a risk in disclosing but also acknowledged the benefit of support from others when one discloses. A concern about discrimination was one of the greatest problems especially when disclosure was done at the workplace. Some of the participants cited examples of people who were dismissed from positions after disclosing their HIV status (Moneyham et al 2009:213).

Other concerns were confidentiality which limited the participants from using resources and services they needed such as the health clinic where one is seen going there and is stigmatised. It was also difficult to disclose to health care professionals for fear of negative response when they are supposed to undergo procedures such as taking of blood. Disclosing to children was another concern for the HIV positive women. It was more difficult to disclose to children in their early teens because they are very emotional and scared and do not have enough information on HIV. They also had concerns about confidentiality which included fear of their names being put on an HIV computer list that could be used to discriminate against them (Moneyham et al 2009:215-217).

### **2.5.3 The benefits of disclosure and dealing with stigma**

If clients or individuals who have tested HIV positive could be encouraged to disclose, the number of infected persons could be reduced tremendously.

Disclosure is a process and the client should be helped with the plan on how to approach their families, friends and colleagues at the workplace.

The individual must identify whom he/she wants to tell and when information must be given about support groups. Information must be given and the client should be prepared about hostile reaction from other people after disclosure. The client must be given information about a positive life style, improvement on the quality of life and safer sex practices.

Support from counsellors and other health care workers promotes acceptance which decreases stigmatisation. HIV positive individuals should be given an opportunity to express their fears and anxiety and must verbalise how they want their disclosure to be handled (Van Dyk 2012:272). Counsellors must openly discuss any feelings of suicide in depressed HIV positive individuals and encourage the clients to disclose so as to ease the burden by sharing it with somebody for support (Minnaar & Bodkin 2006:83).

Usually after disclosure, because of acceptance and support, the HIV positive persons eventually begin to accept the reality of the HIV infection. The individual starts to take responsibility of dealing with risks. Accessibility to medical care, good nutrition and socio-economic issues are easily dealt with if a person has disclosed.

Emotional support and application of information given to the people closer to the HIV positive individual eases the burden of prejudice from other people around the HIV positive person. Communities eventually accept the person if the closest family members are supportive and accepting after disclosure.

## **2.6 BASIC RIGHTS AND ETHICAL GUIDELINES AROUND HIV STATUS DISCLOSURE**

According to UNAIDS (UNAIDS 2006:31) guidelines, ethical principles and basic rights should be applied to ensure that the clients' confidentiality is protected and

that they are treated with respect and dignity. The treatment given to clients should be non-discriminatory. People with HIV status have the right to disclose or not to disclose.

### **2.6.1 Rights of patients**

Individuals who have tested HIV positive have basic human rights to dignity, equality, non-discrimination, privacy, access to health care, the right to social security and social grants, the right to labour practices and the right to confidentiality.

People with HIV still face many kinds of discrimination and victimisation. These are the main problems of disclosing their status. Continued fear of ignorance and confusion about HIV/AIDS infection make people afraid to talk about the disease and they become violent against people living with HIV or AIDS. Examples of violence are the incidence of a woman in KwaZulu-Natal who was murdered by people in her community for disclosing that she was HIV positive. In SA the rate of female murder by partners is six times the global average. Gender based violence is a huge issue in this country. In 2009 a man stabbed his wife and after stabbing her, he drank poison and forced her to drink the poison and she was in a coma for three months. Gender based violence studies show that rights of many women are violated through rape and their fear to use condoms and this pre-disposes them to HIV infection (Riddle 2009:2).

HIV positive people face a lot of discrimination from employment opportunities, insurance policies, medical aid schemes, victimisation at school and on many occasions their HIV status is disclosed without their consent (Barrett-Grant et al 2003:37).

HIV positive individuals have the right to confidentiality. Many infected employees in the workplace are afraid of disclosing their status to others within the workplace fearing that their information will not be kept confidential.

Every person is entitled to privacy. The HIV positive individuals' information must be kept private and they should give consent to all disclosures regarding their condition. Before they were tested they gave consent and must still give consent if further testing or other procedures in relation to their status are done and in the event of their death, consent for disclosure is obtained from the next of kin, except when required by law (Van Dyk 2012:42).

The HIV positive individuals must be able to access health services for their treatment and should not be addressed as a group unless there is consent for participation in a support group and consent must be obtained to disclose their status to other members of the group.

Governments should enact and strengthen the anti-discrimination and other protective laws that protect people living with HIV. Legislation should ensure their privacy, confidentiality and ethics in research involving human subjects. The HIV positive individuals must also be allowed to work as long as they can carry out functions of the job. When individuals are no longer able to work, they should be given equal access to existing sickness and disability skills (UNAIDS 2006:102).

### **2.6.2 Ethical guidelines on HIV disclosure and non-disclosure amongst health care workers**

Disclosure of HIV status amongst health care practitioners is only necessary for purposes within the scope of rendering the necessary health care. It is recommended that the general rule of obtaining the patient's written consent should prevail in all cases. Before any disclosure is made the person must specify in the consent to which person or a specific team of health practitioners should the status be disclosed.

Although the health team must adhere to keeping information confidential the patient may refuse that his/her status be disclosed to certain members of the health team.

If there is need to access information for the next of kin a consent from the patient is necessary. The family does not have the right to know the patient's HIV status, but the importance of disclosure should be pointed out to the patient during counselling. The patient should be made aware that closest members of family or next of kin may obtain access to their medical records after their death (Barrett-Grant et al 2003:13).

HIV positive persons must also be protected by law against the media. Their information must be kept in privacy and confidentiality.

The HIV positive individuals have a moral obligation to inform their partners about their status and practise safe sex by using condoms. They have the duty to respect the rights and physical integrity of others and have a positive attitude to changing of behaviour (Van Dyk 2012:139).

Ethically, children who are infected with HIV need to be told about their status. This may be difficult but the child's age will be taken into consideration and the child's readiness should be assessed. The principle of confidentiality and privacy must be maintained. Anti-discriminatory and protective laws should be enacted to reduce human violations against children in the context of HIV. Children should be provided access to HIV related information (UNAIDS 2006:36).

## **2.7 CONCLUSION**

Statistics show that HIV infection is still a major public health problem in the world, as the spread of the condition is difficult to control. Unsafe sexual behaviour and non-disclosure of HIV status are of the major problems that contribute to its spread.

Stigma, discrimination, rejection, isolation and prejudice associated with an HIV positive status promote non-disclosure. The negative attitudes of members of the community, employees, employers and even religious groups towards people living with AIDS has influenced HIV positive individuals to keep their status a secret even to their sexual partners. This situation leads to the spread of the disease even in a

marital relationship where the uninfected partner is unaware of the risky situation they are in and cannot make an informed decision to take the necessary precautions. Legislation and ethical guidelines are in place to ensure that patients' information are kept confidentially and HIV positive individuals exercise the rights to disclose only to people they feel comfortable with and can trust. Disclosure would be an advantage for access to medical care, family support and reduction of the morbidity and mortality rates and number of orphans.

## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

#### **3.1 INTRODUCTION**

The previous chapter reviewed literature pertaining to the problem of disclosure of the positive status in HIV of people and the attitude of others towards them.

The current chapter focuses on the research methodology which is discussed in terms of the instrument used to collect data, the method used to collect data, population, sampling, data collection and data analysis procedures to be used.

#### **3.2 THE AIM OF THE RESEARCH**

The aim of the research was to investigate why there is a problem with disclosure of the HIV positive status.

##### **3.2.1 Objectives of the research**

The objectives of the research were to:

- determine what knowledge patients who attended PHC clinics in Kagiso Township, SA had on HIV/AIDS;
- explore and describe the reasons why some patients who attended PHC clinics in Kagiso Township, SA had them tested to determine their HIV status;
- explore and describe the reasons why some patients who attended PHC clinics in Kagiso Township, SA preferred not to disclose their HIV status;
- explore and describe the opinions of patients who attended PHC services in Kagiso Township, SA regarding the way in which stigmatisation of HIV/AIDS presented in their communities; and

- explore and describe the opinions and suggestions of patients who attended PHC services in Kagiso Township, SA regarding the promotion of testing and disclosure of the HIV/AIDS status.

### **3.2.2 Research questions**

The research questions for this study were:

- What do patients who attend clinics in Kagiso Township, SA know about HIV/AIDS?
- Why do some patients who attend clinics in Kagiso Township SA, have themselves tested to determine their HIV status?
- Why would some patients who attend PHC clinics in Kagiso Township SA, prefer not to disclose their HIV status?
- In the opinion of patients who attend PHC services in Kagiso Township SA, how does stigmatisation of HIV/AIDS present in their communities?
- What is the opinion of patients who attend PHC clinics in Kagiso Township SA, regarding what can be done to promote testing and disclosure of HIV/AIDS status?

### **3.3 RESEARCH DESIGN**

A research design is a systematic inquiry that uses orderly or scientific methods to answer questions or solve problems. It is “the overall plan for addressing a research question, including specifications for enhancing the study’s integrity” (Polit & Beck 2008:765). It is the main guide or format. The researcher conducted a quantitative, explorative and descriptive study to investigate problems related to disclosure of the HIV positive status.

A brief clarification of the concepts follow.

#### **3.3.1 Quantitative research design**

A quantitative design is a formal, objective, systematic process in which numerical data is used. This is a useful method when numerical data is collected.

Measurement of qualities or variables present in populations is done by assigning numerical data to them in accordance with the same rule (Burns & Grove 2009:43).

As the aim of the study was to investigate the problems of HIV status disclosure, the quantitative approach was viewed as the suitable approach, because it employed pre-determined questions to interview patients who attended the PHC clinics in Kagiso Township, SA to gather and quantify data that were submitted for statistical analysis.

### **3.3.2 Exploratory research design**

Exploratory research aims at exploring the dimensions of a phenomenon in the way in which it is manifested and other related factors and also increase the knowledge of the field of study (Burns & Grove 2009:359). The purpose of exploratory research is to gain a broad understanding of a situation, phenomenon, community or person, and is usually employed in qualitative research design. However, since structured methods were used for this study and it attempted to explore the attitude and opinions of patients who attended the PHC clinics in Kagiso Township, SA and no published research findings in this region on the topic could be located, this research design could also be considered as explorative in nature.

The exploratory method is selected by the researcher to gain insight and understanding of why there is a problem with disclosure in HIV status. The full nature of this problem will be explored.

### **3.3.3 Descriptive research design**

The main objective of a descriptive study is to describe the phenomena. Descriptive research has its main objective to accurately describe and portray the individual characteristics, situation or groups and frequency with which specific phenomena occur and to generate new knowledge about concepts or topics which were researched with limitations or not researched at all (Burns & Grove 2009: 45).

The study is descriptive in that the researcher collected information available about the problem under investigation and described the phenomenon as it were.

### **3.4 RESEARCH POPULATION**

The research population refers to the entire group to which the results of the research are to apply. Information is collected from this group. Burns and Grove (2009:344) refer to population as all individuals that meet the sample criteria for inclusion in the study.

The researcher needed to have reasonable access to this population and for the purpose of this research the accessible population have been the clients visiting the PHC clinics in the Kagiso Township, West Rand Health District, Mogale City Municipality, SA. (See Maps in Annexure F).

The research population for this study included clients that visited the PHC clinics in Kagiso Township, SA which included the elderly, adults, young adults, and youth. Between 260 to 300 clients per day are seen on average at the clinic for health services ranging from minor ailments, preventive and promotive health care services such as reproductive health care and children immunisation. These clients formed the research population of this study.

As it is impossible to interview the whole research population only a portion of the research population has been selected for inclusion in the study.

### **3.5 SAMPLING PROCESS AND SAMPLE**

The sampling process describes the number of steps that should be followed to select a portion of the research population. It uses a process of selecting a group of people for actual inclusion in the study with as many similar characteristics of the whole research population as possible to ensure reliability, validity and generalisation of research findings (De Vos 2005:199).

A sample is a subset of the population selected to participate in a research study (Bowling 2009:196; Burns & Grove 2009:750). A sample is selected because it is

often impossible or impractical to study the whole research population. A group of people are then selected from the research population who have the same characteristics as the research population. This is termed representativeness (Burns & Grove 2009:243).

### **3.5.1 Sampling criteria and selection process**

Sampling criteria are the characteristics essential for inclusion in the target population. The researcher decides what attributes members of the research population should have to be considered in the sample (Burns & Grove 2009:344).

In this research a random sample was selected from all clients, the elderly, middle aged, young adults and the youth, irrespective of their HIV status, who have visited the clinic on different days until 17.6% of the research population were selected.

After the clients registered at the reception desk and received their patient files and while waiting in the waiting area to be consulted they were informed about the research. The objectives of the research, who was going to conduct the study, and for what purpose were explained to them. Their voluntary participation was requested after their ethical rights have been explained in detail. (See Annexure D).

#### **3.5.1.1 *Criteria for inclusion in the sample***

Sampling criteria are characteristics that are required to make it explicitly clear which respondent should be included in the study to enable the researcher to attain the research objectives. The inclusion criteria for this study were that the respondents

- could be either male or female;
- had to be above 18 years of age;
- could be of any race;
- had to be willing to take part in the research;
- could know their HIV status or not; and
- could be HIV positive or negative.

### **3.5.2 Sampling method**

All respondents who qualified for inclusion were given a number e.g. 001, 002, 003 up to 10 every day and the researcher then pasted the number onto golf balls and placed the balls in a container. Golf balls were used rather than folded papers that tend to stick together. The researcher then shook the container to mix the numbers. Three golf balls were then selected. Respondents were then informed that they were chosen to be interviewed, each number has an equal chance of being selected (Welman, Kruger & Mitchell 2011:60). As the respondents had to wait in a line to be consulted, no more than three respondents were interviewed per day and special attempts were made to help them keep their positions in the line. If necessary the interview was temporarily discontinued and resumed again after the consultation. On another date the same procedure for selecting the sample was followed until the required number of respondents were interviewed.

### **3.5.3 Sample sizes**

The sample size of this study was 106 respondents which is 17.6% of the total number of clients who usually attend the PHC clinics in Kagiso Township, SA per month.

## **3.6 DATA COLLECTION**

Data collection is a way of gathering information relevant to the study conducted (Burns & Grove 2009:429). Information is gathered using the most precise (exact) and systematic methods. In this study the researcher decided to interview the respondents using a prepared and tested interview schedule .

### **3.6.1 The interview**

This method of data collection involves questioning the subjects, talking to them to collect data and record their responses. The interview was chosen to collect data because of the following advantages for the research.

- Interviewing is a flexible technique that allowed the researcher to explain and provide more information and meaning where the respondents did not understand the question asked. This may produce more detailed responses from participants thus giving the researcher more in depth data.
- The interview can be very helpful in cases where the respondents are illiterate. In this research most of the respondents were literate, but this was only established when the data was collected and analysed.
- Interpersonal skills could be used to facilitate cooperation and elicit more information particularly due to the sensitive nature of the topic.
- The response rate of interviews is higher than that of questionnaires, thus a more representative sample can be obtained (Bowling 2009:283).
- The face to face interviews are also helpful in terms on the respondents being available at a certain place and the response rate is high. Thorough data can be collected because it allows probes and follow up questions (Vanderstoep & Johnston 2009:88).

The interview however also had some disadvantages for this research:

- It was time consuming as no more than three respondents could be interviewed per day.
- There is a high possibility of bias from the interviewer and additional bias if interpreters are used for some respondents. For that reason the researcher asked only the questions included in the interview schedule and in the same way they were compiled when interviewing the respondents. Only the researcher interviewed the respondents to prevent additional bias.

In a structured interview the researcher always operates by making use of a written, prepared research instrument which is known as the interview schedule. In this research an interview schedule was used during questioning respondents face-to-face and their answers were written down by the researcher. Although the respondents were asked the same questions, the researcher was able to adapt the formulation of questions including the terminology to fit the background and educational level of the respondents (Burns & Grove 2009:403). The interview was compiled in English for the purpose of the dissertation but the questions have been

translated during the interview by the researcher into Sotho, Zulu and other languages if the respondents could not understand the questions in English.

### **3.6.1.1      *Methodology followed during the interview***

The researcher requested and obtained permission from the authorities and nurses in charge at that particular clinic where the interviews would be conducted. (See Annexure A and Annexure B). Appointments were then made at that particular clinic allocated to the researcher.

On the day of the appointment the researcher ensured that the room for the interviews was prepared and special care was taken to ensure privacy and to limit noises or any form of disturbance.

The interview was conducted in phases which were: the planning phase, doing phase and the analysis phase. In the planning phase the interviewer acquainted herself to the interviewees. The respondents were welcomed and thanked for the willingness to participate in the research. The purpose of the interview was explained to the respondents and their rights were explained to them. Issues such as confidentiality, the right to refuse to participate or to terminate at any stage without incurring any penalty was discussed. The objectives of the research were explained, their role in the research and the role of the researcher were explained. The respondents were asked if they had any questions before the interviews.

The respondents who were willing to take part in the research then signed the informed consent. (See Annexure D). The interviews were then conducted with the selected respondents. The success of the planning stage depended on the plans and preparations that were made before the day on which the data collection took place. In table 3.1 an outline is provided of the dates and times the interviews were conducted at the various clinics. An interview with each client lasted for approximately one hour to one hour thirty minutes.

**TABLE 3.1: Interviews conducted at clinics at Kagiso township**

DATE	CLINIC	TIMES	NO OF CLIENTS INTERVIEWED
11 March 2011	Thusong clinic Kagiso	13:00-16:00	2
14 March 2011	Thusong clinic Kagiso	08:00-10:00	3
15 March 2011	Thusong clinic Kagiso	08:00-10:30	3
16 March 2011	Thusong clinic Kagiso	08:00-10:15	3
17 March 2011	Thusong clinic Kagiso	08:00-10:30	3
18 March 2011	Thusong clinic Kagiso	13:00-16:00	3
19 March 2011	Fanyana Nhlapo Saturday clinic Kagiso	07:30-13:00	4
22 March 2011	Thusong clinic Kagiso	16:00-18:00	2
23 March 2011	Fanyana Nhlapo clinic Kagiso	08:00-16:00	4
24 March 2011	Fanyana Nhlapo clinic Kagiso	08:00-16:00	4
25 March 2011	Fanyana Nhlapo clinic Kagiso	13:00-16:00	2
26 March 2011	Fanyana Nhlapo Saturday clinic Kagiso	08:00-13:00	4
28 March 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	2
29 March 2011	Thusong clinic Kagiso	15:00-18:00	3
30 March 2011	Thusong clinic Kagiso	13:00-18:00	3
31 March 2011	Thusong clinic Kagiso	08:00-16:00	4
1 April 2011	Thusong clinic Kagiso	13:00-16:00	2
2 April 2011	Fanyana Nhlapo Saturday clinic Kagiso	08:00-13:00	4
4 April 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	2
5 April 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	2
6 April 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	2
7 April 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	2
8 April 2011	Fanyana Nhlapo clinic Kagiso	16:00-18:00	2
9 April 2011	Fanyana Nhlapo Saturday clinic, Kagiso	08:00-13:00	3
11 April 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	2
12 April 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	2
13 April 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	2
14 April 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	2
15 April 2011	Fanyana Nhlapo clinic Kagiso	08:00-16:00	4
16 April 2011	Fanyana Nhlapo Saturday clinic, Kagiso	08:00-13:00	3
18 April 2011	Thusong clinic, Kagiso	08:00-16:00	4
19 April 2011	Thusong clinic Kagiso	08:00-16:00	4
20 April 2011	Thusong clinic Kagiso	13:00-16:00	2
21 April 2011	Fanyana Nhlapo clinic Kagiso	08:00-13:00	3
26 April 2011	Fanyana Nhlapo clinic	08:00-16:00	4

	Kagiso		
3 May 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	1
4 May 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	2
5 May 2011	Late clinic, Thusong clinic Kagiso	16:00-18:00	1
6 May 2011	Thusong clinic Kagiso	13:00-16:00	2

- Total number of 106 (hundred and six) patients were interviewed at Thusong and Fanyana Nhlapo Primary Health care clinics in Kagiso Township, SA.
- Saturday clinics operate from 07:30 – 13:00 and is not as busy as week day clinics. It was easier to interview more patients on Saturdays because some of them came only to collect their chronic medication as they are working during the week.

The number of interviews per day depended on the number of respondents who agreed to be interviewed. No more than 2-3 respondents were interviewed per day.

During the actual conducting of the interviews a pleasant atmosphere was maintained through the interviews and the cultural background and the language that would be best understood were taken into consideration. Confidentiality in the interview room was maintained. Disturbance during the interview was eliminated as much as possible.

The success of the doing phase largely depended on the interview skills of the researcher, such as listening, probing more on questions and explaining of the questions so that the subject could be better understood. As the researcher is employed in a PHC and is trained in counselling of patients it was not a problem.

The respondents' responses to the open-ended questions were noted verbatim and analysed by the researcher (Polit & Beck 2008:349). Fortunately the interview schedule contained mostly closed-ended questions and the respondents' choices to the questions were indicated.

In a qualitative study the closing phase of an interview involves verification, clarification, reflection and expression of appreciation from the interviewer (Polit & Beck 2008:349). In this research, which is quantitative, the researcher thanked the respondents for their participation and gave them an opportunity to ask questions should they had any. This was done because the closing of the interview should

bring the respondent back to the normal environment and to also give an opportunity to affirm the respondent's contribution to the research (Vanderstoep & Johnston 2009:227).

### **3.6.2 The research instrument**

Pre-existing instruments and the literature have been studied where after the research instrument, an interview schedule was compiled by the researcher. The interview schedule is a list of prepared questions used by the researcher during interviews (Polit & Beck 2008:234).

The interview schedule consisted mostly of closed-ended questions and very few open-ended questions. The open-ended questions allowed the respondents to respond in their own words and to give their own opinion. Enough space was provided in the schedule for the researcher to write the exact words of the participants for open-ended questions.

The interview schedule was constructed in such a way that the answers to the closed-ended questions could easily be analysed by computer, as the respondents were asked to choose from the alternative answers provided.

#### **3.6.2.1 *Format of the interview schedule***

The interview schedule consisted of the following main sections and covered the research questions and the objectives:

##### **Section A:**

This section consisted of the biographical data of the respondent.

##### **Section B:**

This section consisted of questions that covered the

- knowledge of respondents on HIV;
- knowledge of their status;
- knowledge of testing for HIV; and
- disclosure of the HIV status with someone.

**Section C:**

This section covered the respondents' knowledge of the disease and reasons for having themselves tested (or not tested) for HIV.

**Section D:**

Questions on the following were included in this section:

- Disclosure if respondent knows his or her HIV status
- Feelings/attitude after receiving the results
- Attitude of other people after disclosing their status
- Who were told of the results
- Knowledge about obtaining help after disclosure of the positive status

**Section E**

This section addressed issues of stigmatisation of the HIV status in families and the community.

**Section F**

This section addressed the opinions and suggestions of the respondents (patients) regarding the promotion of testing for HIV and disclosure of the status.

**3.6.2.2      *Pre-testing of the interview schedule***

Pre-testing of the research instrument is necessary to determine whether the questions were clearly stated and understood by the respondents; to identify problems in the design and sequencing of the questions; and the recording of responses (Welman, Kruger & Mitchell 2011:165). The interview schedule was also tested to determine whether the objectives of the research will be attained and to ensure reliability and validity. The drafted interview questions should be compared with the research problem several times to test consistency and to determine if these questions are correct enough to elicit information (Welman, Kruger & Mitchell 2011:165).

For this research, pre-testing of the interview schedule was done by conducting six interviews with clients who were not part of the main study.

The following corrections were made to the interview schedule after the pre-test:

- All the coding had to be corrected from section B to the end of the interview schedule
- The words “are” and “to” were added to the instructions on page 8
- The instruction on page 10 was also corrected
- Grammar mistakes in Section C and F were corrected
- Question numbers were corrected

The interview schedule has been evaluated by the supervisor, the joint supervisor, editor and by the Research and Ethics Committee of the Department of Health Studies, University of South Africa (Unisa). (See Annexure C).

### **3.7 ANALYSIS OF DATA**

Data analysis is a mechanism for reducing and organising data to produce findings that require interpretation by the researcher (Burns & Grove 2009:461). Data collected have been systematically re-organised into a format that is easy to analyse using a computer. This is termed coding. The coding procedure is a set of rules stating that certain numbers are assigned to variables or attributes.

In the interview schedule each variable was allocated with a number (presented as the “key”). The number of the key was then written in the allocated space (Neuman 2006:344). (See the Interview Schedule in Annexure E).

After all the interviews were conducted the schedules were sent to a statistician who entered the data into the computer using the statistic computer package program *SAS/JMP version 9* to analyse the data. The data was then presented in frequencies and bar graphs and discussed by the researcher.

### **3.8 RELIABILITY AND VALIDITY OF THE RESEARCH**

The quality of a research instrument is determined by means of evaluating its accuracy and its consistency. Validity is the extent to which the instrument can accurately measure the attributes of the concept (Wood & Haber 2010:286).

### 3.8.1 Reliability

Reliability refers to whether a particular technique applied repeatedly to the same object will produce the same results each time. This refers to consistency when using the instrument (Babbie 2007:143).

In this study, the researcher ensured reliability by:

- discussing the interview schedule with the supervisors (who have wider experience in the use of reliable instruments) and a statistician prior to the testing of the interview schedule and the actual data collection,
- discussing the interview schedule and questions with colleagues in the field to ensure that the questions were relevant to the topic,
- pre-testing the interview schedule, to avoid words that were vague or would yield data that was not in line with the research objectives,
- checking the questions and correcting it where necessary after the pre-test, before the main study commenced, and
- analysing the data by computer and discussing the findings with the statistician and supervisor.

### 3.8.2 Validity

Validity refers to the degree to which an instrument actually measures what it is supposed to measure (Polit & Beck 2008:457). Like reliability, validity has a number of aspects and assessment approaches, such as face validity, content validity, criterion-related validity and construct validity.

The researcher as well as the supervisor and the co-supervisor were of the opinion that the research instruments used in this research had *face value*, as the instrument looked as though it would measure the appropriate construct. This judgment was also based on their expert knowledge of the subject and supervising postgraduate students with their dissertations.

The instrument was also judged for *content validity* by studying relevant literature and assessment by experts in the field. Content validity should represent the universe of the content which is the framework and basis for developing the items

that will adequately represent the content. The same instrument was used for collecting data from all the participants (Wood & Haber 2010:288).

No other test for validity of the research instrument was conducted.

### **3.9 ETHICAL CONSIDERATIONS**

For any research involving people, well established ethical principles must be considered to prevent the risk of harm and to protect subjects' confidentiality (Griffiths 2009:42).

Ethical principles, when undertaking a research study should be adhered to and the principles involving human subjects must be taken into consideration. The principles adhered to during this study were:

#### **3.9.1 Permission to collect data**

For this study, permission to collect data was requested and obtained from the West Rand Health District Office and Research Committee to allow the researcher to interview clients in their clinics (See Annexure A). Permission was obtained to use Kagiso clinics (See Annexure B). Permission was also requested and obtained from the Research and Ethics committee of the Department of Health Studies, Unisa to conduct the research (See Annexure C).

#### **3.9.2 Informed consent**

The researcher should disclose specific information to each prospective subject and there should be an agreement to participate in the study by the subject. Informing comprises the transmission of essential ideas and content from the researcher to the prospective participants. This information includes telling the subjects about the benefits and foreseeable risk or discomfort, assurance about anonymity and confidentiality (Burns & Grove 2009:201).

In this research each prospective respondent was given the opportunity to choose whether to participate in the research or not. Information was given on the following:

- Participation of the respondents were voluntary and they were free to withdraw at any time;
- Duration of the interview which should not be longer than  $\frac{3}{4}$  hour, and that they would not lose their place in the waiting room;
- The way the results or information will be handled;
- The way privacy, confidentiality and anonymity of all information will be maintained (See Annexure D). This is to ensure the protection of human rights (Babbie 2007:64).

### **3.9.3 The right to self determination**

The right to self determination refers to the principle of respect for persons. People must be given the freedom to choose what they want and be given an opportunity to control their own destiny.

The respondents should be allowed to voluntarily choose to participate or not. There should be no violation of rights by coercing or threatening subjects to participate (Burns & Grove 2009:190).

In this research respondents were treated as autonomous beings that have all the freedom to choose voluntarily to participate or not. The following were done to ensure their right to self-determination:

- Participants were informed about the study;
- They were allowed to choose to participate or not to participate in the study;
- They were allowed to withdraw from the study at any stage without fear of any penalty;
- Nobody was forced into participation, all subjects were fully informed;
- Information was given to participants in the preferred African languages commonly used in townships i.e. Sotho, Zulu, and Tswana including English to those who preferred to be interviewed in English.

### **3.9.4 Right to Privacy**

In this research the participants' privacy was maintained and protected by interviewing them in a closed room and they were assured that their information will not be discussed with anybody except people involved in the research.

### **3.9.5 The right to confidentiality and anonymity**

Confidentiality means no unauthorised person should gain access to information shared by the subject. Private information of the subject must not be shared with others without permission of the subject.

Anonymity refers to keeping the identity of an individual secret. The subject's identity should be kept anonymous from others and should also not be linked even by the researcher with his or her individual responses (Burns & Grove 2009:196). This was ensured by the fact that names of the participants did not appear on the interview schedule.

All data collected was kept confidential and completed interview schedules were destroyed by the researcher. In the research report no individual names have been mentioned.

Every individual must determine circumstances under which his or her personal information can be shared with others or can be withheld from others (Burns & Grove 2009:195).

In this research the respondent had the freedom to determine when, what information and under which circumstances private information could be shared or withheld. It was decided that all information collected from the respondent was only discussed with the respondent and private information was not shared with anyone.

### **3.9.6 The right to fair treatment**

This principle is based on the right to protect respondents from discomfort and harm. The respondent should be treated fairly and the ethical principle of justice should apply (Burns & Grove 2009:198). Subjects should not be harmed regardless of

whether they volunteered for the study. No information that can embarrass or endanger their lives, relationships or jobs should be revealed (Babbie 2007:63). Precautions were taken by the researcher to ensure that the respondents were not exposed to any harm which could affect them physically, emotionally, socially and economically. The researcher ensured that the respondents who took part in the study were consulted without delay, the interviews were held in a private room and the completed interview schedules were kept safe until it could be analysed.

### **3.9.7 Benefits for taking part in research**

Subjects must benefit from the study by having an understanding of the research process and must have an opportunity to know about the findings of the study. They must also be told who will benefit. Risks that subjects may undergo should be assessed. The researcher should check if there are no physical, emotional, social and economic risks. These should be closely spelled out in the consent whereby an explanation is given about benefits and foreseeable risks or discomfort (Burns & Grove 2009:200).

The respondents in this research were informed that they would not receive monetary benefits from the study. Society as a whole and not the individual respondents would benefit in future, should the findings of the research be implemented.

### **3.9.8 Scientific honesty**

Each researcher has an ethical obligation to colleagues in the scientific community about the analysis of data and the way the results are reported. Science progresses through honesty. Researchers must discuss all findings truthfully and correctly (Babbie 2007: 69).

In this research all original interview schedules and documents were monitored all the time. The findings of the research was discussed with the statistician and he was also asked to check the discussion of the findings for correctness. The researcher agreed not to deviate from the original findings when writing an article on the research for publication.

### **3.10 CONCLUSION**

In this chapter the methodology that was used to conduct this research was discussed in detail. A quantitative, exploratory, descriptive research design was chosen as the most appropriate paradigm for the research problem. An interview schedule was used for the data collection process. Measures that were taken to ensure reliability and validity of the research were discussed. The steps that were taken to ensure that the research was conducted in an ethical manner was also discussed in this chapter.

In the next chapter the findings of the analysed data will be discussed.

## **CHAPTER 4**

### **ANALYSIS AND INTERPRETATION OF DATA**

#### **4.1 INTRODUCTION**

The previous chapter outlined the methodology applied in this research. A quantitative, exploratory, descriptive research design was discussed. Interviews using a pre-tested interview schedule were used to collect data.

This chapter focuses on the analysis, interpretation and discussion of the findings of the research.

#### **4.2 AIM OF THE RESEARCH AND THE RESEARCH QUESTIONS**

The aim of the research was to investigate the non-disclosure of the HIV status.

##### **4.2.1 The objectives of the research were to**

- determine what knowledge patients who attended PHC clinics in the Kagiso Township, SA had on HIV/AIDS;
- explore and describe the reasons why some patients who attended PHC clinics in the Kagiso Township, SA had them tested to determine their HIV status;
- explore and describe the reason why some patients who attended PHC clinics in the Kagiso Township, SA preferred not to disclose their HIV status:
- explore and describe the opinions of patients who attended PHC services in the Kagiso Township, SA regarding the way in which stigmatisation of HIV/AIDS presented in their communities; and
- explore and describe the opinions and suggestions of patients who attended PHC services in the Kagiso Township, SA regarding the promotion of testing and disclosure of the HIV/AIDS status.

### **4.3 DISCUSSION OF THE RESEARCH FINDINGS**

Data was collected from hundred and six (n=106) respondents from PHC services in the Kagiso Township, West Rand Health Region, SA by means of an interview schedule consisting of six sections. The six sections of the interview schedule, which represented the objectives of the research, were used as the framework for this study. Respondents were not forced to answer all the questions. They were continuously reminded that they could omit questions should they feel that it was too sensitive.

#### **Section A**

This section portrayed respondents' demographic information.

#### **Section B**

This section addressed the knowledge respondents had about HIV/AIDS.

#### **Section C**

This section addressed issues of voluntary testing and why people had them tested.

#### **Section D**

This section addressed issues of disclosure of the HIV status.

#### **Section E**

This section addressed issues of stigmatisation of the HIV status in families and the community.

#### **Section F**

This section addressed the opinions and suggestions of the respondents (patients) regarding the promotion of testing for HIV and disclosure of the status.

The data was analysed by a statistician using the statistic computer package program *SAS/JMP version 9* to allocate variable and value labels. The findings have been discussed and presented in graphs and tables.

### 4.3.1 Biographical data of respondents

Section A dealt with the respondents' biographical data including age, gender, home language, marital status and religious affiliation.

#### 4.3.1.1 *Age of respondents (n=106)*

Of the respondents 43.3% (n=46) were in the age group younger than 29 years. The ages ranged from younger than 29 years of age to older than 59 years (5.6%; n=6]).

**Table 4.1: Age of respondents (n=106)**

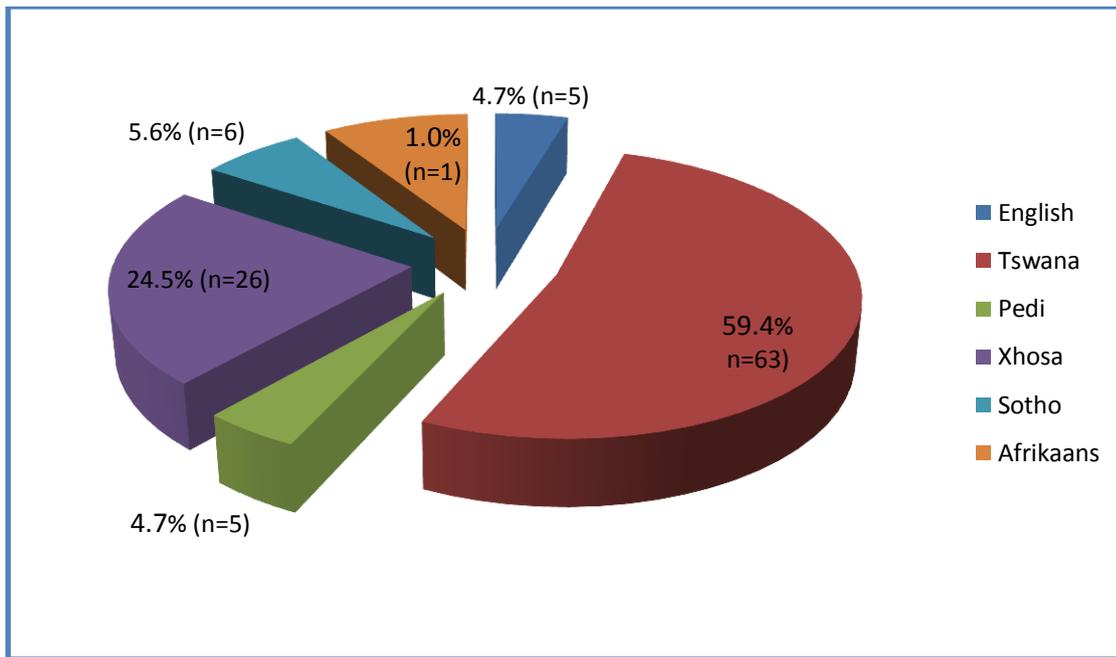
Age group	Frequency	Percentage
Younger than 29 years	46	43.3
30-34 years	9	8.5
35-39 years	9	8.5
40-44 years	8	7.5
45-49 years	11	10.4
50-54 years	9	8.5
55-59 years	8	7.5
Older than 59	6	5.7

#### 4.3.1.2 *Gender of respondents (n=106)*

More females 82.1% (n=87) than males 17.9% (n=19) were interviewed. Females generally attend PHC clinics more often than men, as they accompany their children to the immunisation sessions, attend well baby and sick baby clinics, attend ante-natal en post-natal and contraceptive clinics.

#### 4.3.1.3 *Home language of respondents (n=106)*

The home language most spoken by the 106 respondents was Tswana 59.4% (n=63).



**Figure 4.1: Home languages of respondents (n=106)**

None of the respondents indicated that they used any other home language than those listed in the interview schedule.

#### **4.3.1.4 Marital status of respondents (n=106)**

Of the respondents, 67.0% (n=71) never married, whereas 20.8% (n=22) were married, 6.6% (n=7) were widowed, 4.7% (n=5) divorced and 0.9% (n=1) were living together.

#### **4.3.1.5 Religious affiliation of respondents (n=106)**

The majority of the respondents, namely 94.3% (n=100) indicated that they belonged to the Christian faith, 2.8% (n=3) were Muslims and 1.9% (n=2) indicated that they belonged to another faith. One respondent (0.9%; n=1) did not answer the question.

#### **4.3.1.6 Level of education of respondents (n=106)**

The respondents all completed primary education and could therefore be considered literate and the largest group namely 45.2% (n=48) of the respondents had tertiary education. Of the respondents 4.7% (n=5) indicated that they had “other” education but did not reveal what it was.

**Table 4.2: Qualifications of respondents (n=106)**

Qualification	Percentage	Number of respondents
Completed primary education	3.7	4
Lower high school education	16.0	17
Completed high school education	30.2	32
Tertiary education	45.2	48
Other	4.7	5

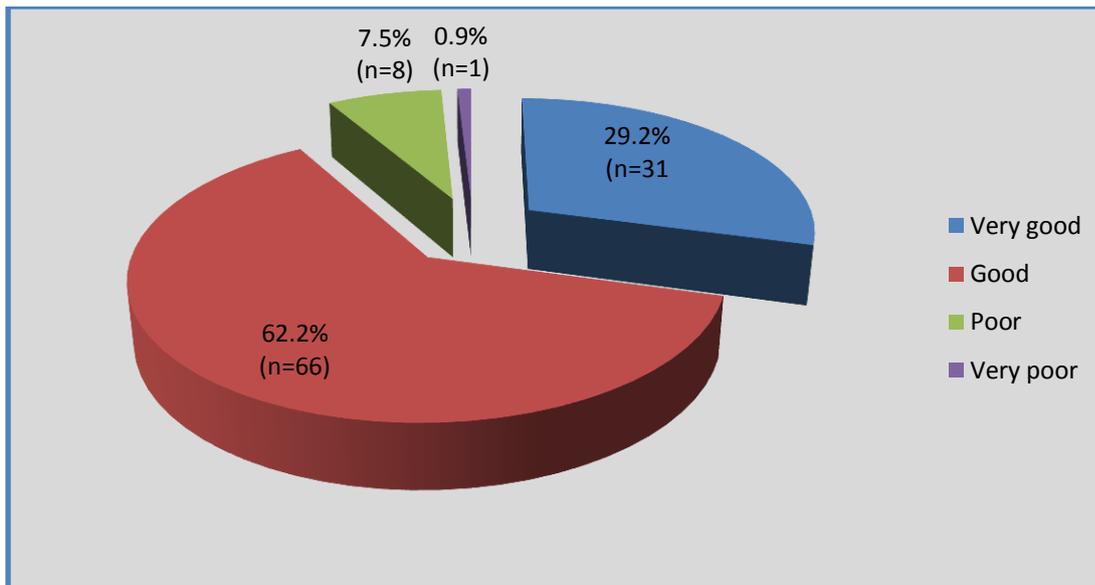
Research conducted in Nigeria amongst 341 youths of two churches revealed that by the age of 19 years 42% of females and 44% of males had become sexually active and that 28% had more than one sexual partner (Nweneka 2007:966). Although it was not established in this research it could be deduced that all the respondents had sexual relationships some time in their lives and were therefore at risk of contracting HIV/AIDS.

#### **4.3.2 Respondents' knowledge of HIV/AIDS**

In this section the general knowledge of the respondents about HIV/AIDS were tested.

##### **4.3.2.1 Respondents' rating of their own knowledge of HIV/AIDS (n=106)**

The majority of respondents, namely 91.5% (n=92) rated their knowledge of HIV/AIDS as very good and good.



**Figure 4.2: Respondents' rating of their knowledge of HIV/AIDS (n=106)**

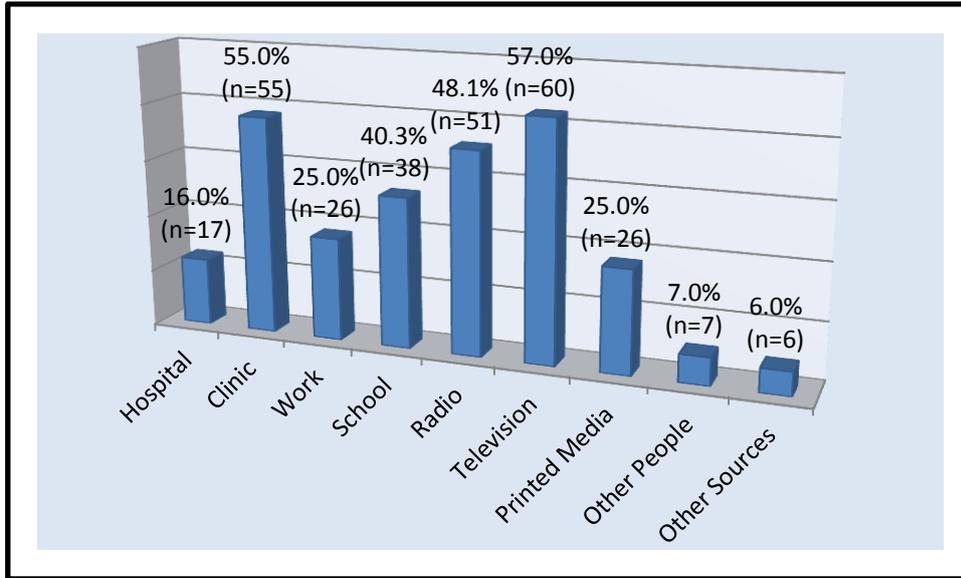
#### **4.3.2.2 Respondents receiving health education on HIV/AIDS (n=106)**

On the question whether they received any health education on HIV/AIDS, 93.3% (n=99) of the respondents indicated that they did, 5.7% (n=6) said that they did not and 1.0% (n=1) respondent indicated that she was not sure.

#### **4.3.2.3 Institution where respondents obtained health education about HIV/AIDS (n=106)**

It is clear from the findings depicted in figure 4.3 that television 57.0% (n=60) was the most popular medium of receiving health education on HIV/AIDS followed by the clinic 52.0% (n=55). The least place where the respondents received health education from was from "other people" (7.0%; n=7). It could be due to the fact that HIV/AIDS is a sensitive topic to discuss whereas malaria, for instance, is discussed openly by members of the community. This was found in a study by Dinho (2009: 87) conducted in Bukumbi village Tanzania, where the majority, namely 96.7% (n=29) of respondents obtained some malaria information from other villagers.

The respondents could choose more than one answer in this item from the interview schedule and therefore the findings (% and n) would not compute to 100% or n=106.



**Figure 4.3: Where respondents obtained health education on the prevention of HIV/AIDS (n=106)**

Of the respondents 5.7% (n=6) indicated that they received health education from other sources than those listed in the interview schedule. Unfortunately this aspect was not investigated further by the researcher.

#### **4.3.2.4 *The specific information obtained about HIV/AIDS through health education (n=106)***

The respondents were asked what specific information about HIV/AIDS they obtained and the findings revealed that there should have been a high level of awareness of HIV/AIDS amongst the respondents as they were educated on most topics related to HIV/AIDS.

The findings of this item has been portrayed in table 4.3.

**Table 4.3: Health education topics about HIV/AIDS the respondents received (n=106).**

Topic	Percentage of respondents	Number of respondents
(B10) HIV/AIDS is caused by a virus	91.5%	97
(B11) HIV/AIDS is a dangerous condition	100.0%	106
(B12) The condition can be prevented	93.3%	99
(B13) HIV/AIDS cannot be cured	79.2%	84
(B14) People become very ill from the infection	85.4%	88
(B15) HIV/AIDS can be treated	63.1%	65
(B16) People should disclose their HIV status	85.6%	89
(B17) People should know the status of their sexual partner	95.2%	99
(B18) People should use condoms with multiple sexual partners	95.1%	99

It is important to note that 85.6% (n=89) of the respondents indicated that they learned through health education that people should make their HIV status known.

#### **4.3.2.5 Transmission of HIV/AIDS (n=106)**

A number of statements were listed in the interview schedule and the respondents had to indicate whether they were correct or not. In this way it could be determined what the level of knowledge of the respondents were, regarding the transmission of HIV.

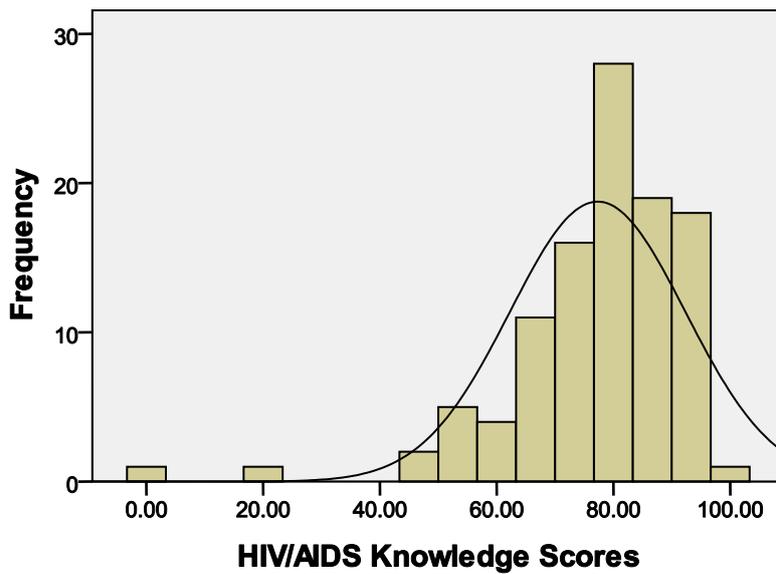
**Table 4.4: Respondents' knowledge about the transmission of HIV/AIDS  
(n=106)**

Method of transmission of HIV/AIDS	Yes	No	Uncertain
<b>(B19) You can become infected with the virus from the bite of a mosquito</b>	4.7% (n=5)	91.5% (n=97)	3.8% (n=4)
<b>(B20) It is transmitted directly, through casual contact between two people</b>	18.8% (n=20)	77.4% (n=82)	3.8% (n=4)
<b>(B21) It is transmitted through the handling of contaminated food.</b>	4.7% (n=5)	90.6% (n=96)	4.7% (n=5)
<b>(B22) You can contract HIV/AIDS by drinking contaminated water</b>	3.8% (n=4)	91.5% (n=97)	4.7% (n=5)
<b>(B23) You can contract HIV/AIDS through sexual intercourse.</b>	95.3% (n=101)	1.9% (n=2)	2.8% (n=3)
<b>(B24) You cannot contract HIV/AIDS when using a condom during sexual intercourse</b>	75.5% (n=80)	20.7% (n=22)	3.8% (n=4)

It was clear from the findings that the majority of respondents knew how HIV/AIDS was transmitted or not transmitted. It was however disturbing to note that

- 18.8% (n=20) of the respondents indicated that HIV/AIDS could be transmitted through casual contact between two people and that 27.3% (n=6) of these respondents had tertiary education;
- any one respondent who believed that it could be transmitted through the bite of a mosquito and by handling contaminated food was one too many as it is an indication that they did not receive proper health education; and
- there were some respondents who were still uncertain and did not know what the correct answers to some of the questions were.

A knowledge score was calculated for each respondent for the knowledge question on HIV/AIDS and the transmission thereof. The following histogram provides a distribution of these scores.



**Figure 4.4: Knowledge of respondents about HIV/AIDS and transmission of infection**

The influence of the biographic profile of the respondents upon the Knowledge Score were investigated by the use of Analysis of the Variance technique (ANOVA) and the following were found:

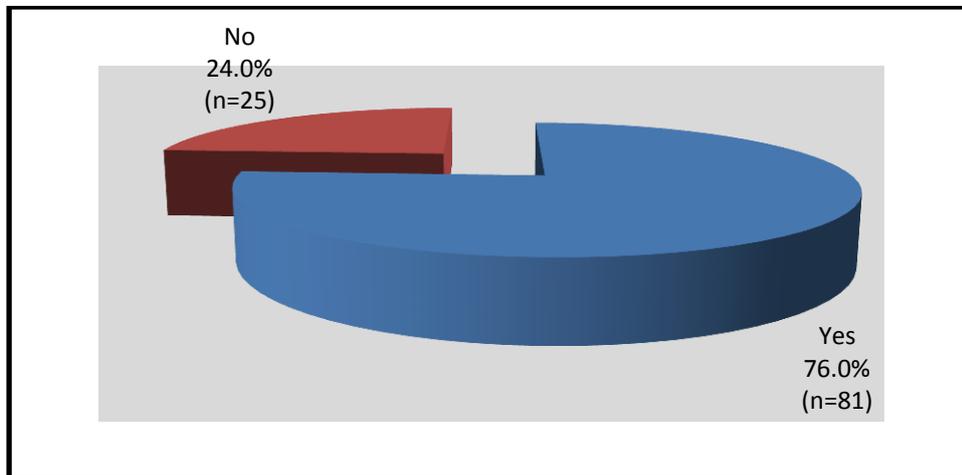
- The knowledge score is not influenced by biographic features of the respondents.
- There is no significant relationship between respondent rating of knowledge and the actual calculated knowledge score.
- The lack of education on the prevention of HIV/AIDS does not influence the knowledge score.

### 4.3.3 Voluntary testing for HIV/AIDS

In this section (Section C of the interview schedule) the respondents were asked to indicate whether they had themselves tested for HIV and to indicate by choosing the possible answers listed, why they did or did not do it.

#### 4.3.3.1 *HIV testing of respondents (n=106)*

The majority of the respondents, namely 76.0% (n=81) indicated that they had themselves tested for HIV.



**Figure 4.5: Respondents who had themselves tested for HIV (n=81)**

#### 4.3.3.2 *Reasons why respondents had themselves tested (n=81)*

All the respondents who had themselves tested 100.0% (n=81) wanted to know their HIV status and therefore had the test done and 64.2% (n=52) had themselves tested because health professionals motivated them to have it done. The following reasons were not so important: “After having a blood transfusion”; “due to persistent health problems”; “because of own risky sexual behaviour”; “because they took out a policy” and “because of their partner’s infidelity”. These were not important reasons for having the HIV test done. See summary of findings in table 4.5.

The respondents could have more than one reason for having themselves tested. Of the respondents 55.6% (n=45) indicated that they had themselves tested for other reasons. Unfortunately these reasons were not established.

**Table 4.5: Reasons why respondents had themselves tested for HIV (n=81)**

REASONS FOR TESTING FOR HIV	YES	NO
(C26) Wanted to know HIV status	100.0% (n=81)	-
(C27) Were worried because of your own risky sexual behaviour	37.0% (n=30)	63.0% (n=51)
(C28) Because of your partner's infidelity	34.6% (n=28)	65.4% (n=53)
(C29) Because health professionals motivated you to have it done	64.2% (n=52)	35.8% (n=29)
(C30) Because of persistent health problems	23.5% (n=19)	76.5% (n=62)
(C31) Because you had a blood transfusion	3.7% (n=3)	96.3% (n=78)
(C32) Because you took out a policy and the company requested it	22.2% (n=18)	77.8% (n=63)
(C33) Other reasons	55.6% (n=45)	44.4% (n=36)

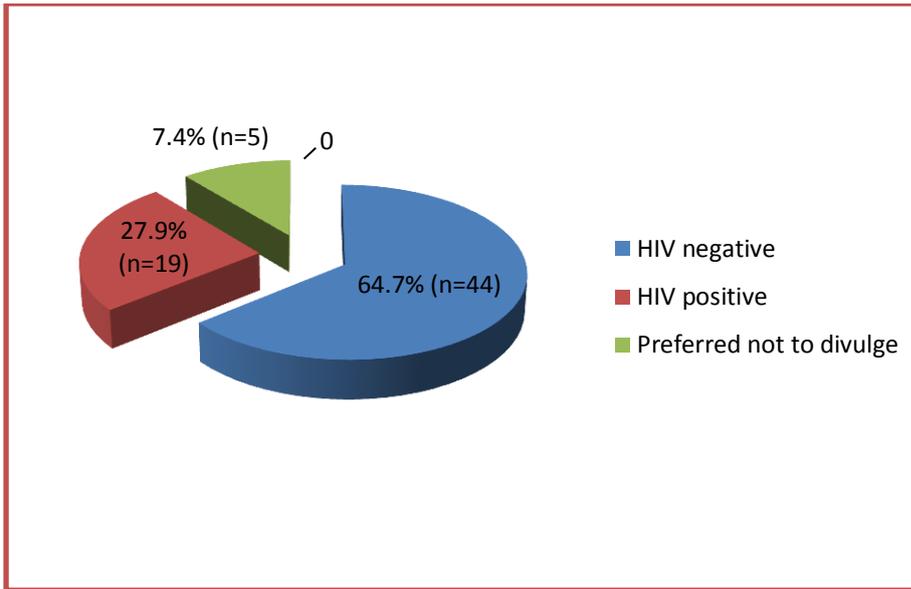
In a qualitative study conducted in Uganda among 6 men and 6 women the participants revealed in a focus group that having the test done was like getting a death sentence. They affirmed that the incentive for testing was the possibility of accessing free Anti-RetroViral (ARV) (Nyanzi-Wakholi, Lara, Watera, Munderi, Gilks & Grosskurth 2009:903).

#### **4.3.3.3 Respondents who had an unprotected (risky) sexual relationship since the last HIV test was done (n=81)**

Of the 106 respondents, 81 responded to the question and 79.0% (n=64) indicated that they did not have an unprotected sexual relationship since the last test, 21.0% (n=17) respondents said they did so.

#### **4.3.3.4 The HIV status of the respondents (n=68)**

In this question respondents were asked to reveal their HIV status to the researcher. They were not forced to answer the questions as explained in chapter 3.



**Figure 4.6: Respondents' HIV status (n=68)**

Of the 68 respondents who responded to the question 64.7% (n=44) indicated that they were HIV negative, 27.9% (n=19) indicated that they were HIV positive, and 7.4% (n=5) preferred not to reveal their status. In total therefore only 63 (77.7%) of the 81 respondents who had themselves tested, made their HIV status known to the researcher.

#### 4.3.3.5 *People informed of respondents' HIV status (n=27)*

Of the 27 respondents who answered this question preferred to inform their partners 52.0% (n=14) and family members 52.0% (n=14) about their HIV status rather than friends 30.0% (n=8) and employers 15.0% (n=4). It is possible that the remaining tested respondents who preferred not to answer the question made their status known to someone other than those listed in the interview schedule, such as a pastor.

**Table 4.6: People told about HIV status (n=27)**

PEOPLE TOLD	YES	NO
(C37) Partner	52.0% (n=14)	48.0% (n=13)
(C38) Family member(s)	52.0% (n=14)	48.0% (n=13)
(C39) Friend(s)	30.0% (n=8)	70.3% (n=19)
(C40) Employer	15.0% (n=4)	85.2% (n=23)

Note that of the abovementioned 27 respondents 70.4% (n=19) indicated in item 4.3.3.4 that they were HIV positive, 11.1% (n=3) were HIV negative and 18.5% (n=5) did not want to disclose their status. It can therefore be deduced that it is not the fact that they tested positive that prevented them from disclosing their HIV status but that they probably just felt that it was confidential information. This possibility was however not verified with the respondents.

In a study conducted in Johannesburg among women who attended prevention of mother-to-child HIV transmission services 93.5% voluntarily disclosed their HIV+ status within a week of receiving the test results – usually to the partner. A confidentially breach by the partner contributed to the observed high rates of involuntary secondary disclosure and negative disclosure experiences. Where primary disclosure was ultimately constructive, the secondary disclosure led to stigmatisation, rejection and withholding of financial support (Varga, Sherman & Jones 2006:952).

#### **4.3.3.6      *Respondents' willingness to advise people to disclose their HIV status (n=81)***

On the question whether respondents would advise other people to disclose their HIV status, 76.4% (n=81) of the total sample of respondents indicated that they would do so.

#### **4.3.3.7      *Respondents's feelings regarding their HIV positive status (n=19)***

All the respondents (n=19) who answered this question indicated in item 4.3.3.4 that they were HIV+. Of the respondents 94.7% (n=18) indicated that they initially felt depressed after they heard that they were HIV+ and had feelings of guilt (78.9%; n=15), but did not contemplate to commit suicide (100.0%; n=19). Despite their status they still made plans for the future (100.0%; n=19), have since accepted their status 94.7% (n=18), do not have negative feelings anymore (84.2%; n=16), believe that they can still live a healthy life (100.0%; n=19) and feel positive about the future (94.7%; n=18). They indicated that they did not live in fear that someone would know their secret (58.0%; n=11) and felt relieved that their HIV status was known. The respondents could choose more than one answer in this item in the interview schedule and therefore the findings (% and n) would not compute to 100% or n=19.

**Table 4.7: Respondents' feelings regarding their HIV+ status (n=19)**

<b>Emotion experienced</b>	<b>Agree</b>	<b>Disagree</b>
<b>(C41) Respondents initially felt depressed after they heard that they were HIV+</b>	94.7% n=18	5.3% (n=1)
<b>(C42) Respondents had feelings of guilt because of the HIV+ status</b>	78.9% (n=15)	21.0% (n=4)
<b>(C43) Respondents still made plans for the future</b>	100.0% (n=19)	--
<b>(C44) Respondents contemplated to commit suicide after hearing about the HIV+ status</b>	--	100.0% (n=19)
<b>(C45) Respondents have since accepted their status</b>	94.7% (n=18)	5.3% (n=1)
<b>(C46) Respondents did not have negative feelings due to the HIV+ status anymore</b>	84.2% (n=16)	15.8% (n=3)
<b>(C47) Respondents believe that they can live a healthy life irrespective of their HIV status</b>	94.7% (n=18)	5.3% (n=1)
<b>(C48) Respondents felt positive about the future</b>	42.1% 8	57.9% 11
<b>(C49) Respondents used to live in fear that someone would know their secret</b>	68.4% 13	31.6% 6

The negative responses reported are depicted by item C41 and C42 and the positive responses by item C43, C44, C45, C46, C47, C48 and C49. The findings therefore revealed that the respondents who answered these questions were positive about their lives despite their HIV+ status.

In the study conducted in Uganda among 6 men and 6 women, the participants revealed that they experienced stigmatisation and depression on confirming their HIV status and commended the role of counselling in supporting them to adopt positive living (Nyanzi-Wakholi et al 2009:903).

#### 4.3.3.8 **Main reasons why respondents did not have themselves tested for HIV (n=24)**

The following are the findings of the list of questions read to the respondents who revealed that they did not have themselves tested for HIV. See also item 4.3.3.1. Three main reasons, as depicted in table 4.8, were found.

- *Fear about the disease.*  
That they might be HIV positive prevented them of having the test done, as depicted by items C50, C60, C61, C62.
- *Anxiety and fear of rejection (stigmatisation).*  
These feelings could be summarised by items C51, C52, C53.
- *Felt they lived a healthy life and therefore could not have been HIV positive*  
This is depicted by items C54, C55, C58, and C59.

**Table 4.8: Reasons why respondents did not have themselves tested for HIV (n=24)**

Reasons for not being tested	Disagreed	Agreed
(C50) Afraid of what the result of the test would be	4.2% (n=1)	95.8% (n=23)
(C51) Afraid that someone would know that they had the test done	21.0% (n=5)	79.0% (n=19)
(C52) Worried what the family would say	21.0% (n=5)	79.0% (n=19)
(C53) Worried what their friends would say	8.3% (n=2)	91.7% (n=22)
(C54) Believed that test would be negative in any case	8.3% (n=2)	91.7% (n=22)
(C55) Have always been healthy	4.2% (n=1)	95.8% (n=23)
(C56) Still planning to have it done, but have not had the time to do it	4.2% (n=1)	95.8% (n=23)
(C57) Only had one faithful partner	12.5% (n=3)	87.5% (n=21)
(C58) Currently not in a sexual relationship	79.0% (n=19)	21.0% (n=5)
(C59) Always use a condom when having sex	91.7% (n=22)	8.3% (n=2)
(C60) Worried about partners' HIV status	45.8% (n=11)	54.2% (n=13)
(C61) Never want to know HIV status	79.0% (n=19)	21.0% (n=5)
(C62) Worried because of own risky sexual behaviour	91.7% (n=22)	8.3% (n=2)

<b>(C63) Was not informed about the importance of the test</b>	41.7% (n=10)	58.3% (n=14)
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AIDS is usually associated with homosexuality, multiple sexual relationships, drug use and other immoral behaviour, as well as a high mortality rate (Shehan et al 2005:185; Nyanzi-Wakholi et al 2009:903). In the study done amongst six women and six men in Uganda Nyanzi-Wakholi et al (2009:904) found that the men's group deliberately postponed VCT until evidently sick. Both men and women reported that they would take the test if they could be certain to receive free HIV/AIDS care. HIV positive confirmed results were necessary for this in Uganda. People realise that they need to weigh the fear of stigma against the need for support.

In a study conducted in Thailand among 103 main care givers of HIV infected children it was found that one-third (30.1%) of the children knew their HIV status at an average age of 9.2 years. Most common reason for not disclosing their status was the fear that disclosure might have negative psychological consequences to the child. Of the respondents 88.7% agreed that children should be told in future but that they needed health care providers to help them with it (Oberdorfen, Puthanakit, Louthrenoo, Charnsil, Sirisanthana & Sirisanthana 2006: 283).

The tool for the fight against HIV and AIDS is public disclosure of HIV status which will result in behaviour changes in people living with HIV and AIDS in relationships (Muula & Mfutso-Bengo 2005:288).

#### **4.3.4 Disclosure of HIV status**

Section D of the interview schedule contained questions directly related to disclosure of HIV status and all the respondents were asked these questions, although they could also decide not to answer any of the questions.

##### **4.3.4.1 *Opinion of respondents regarding disclosure of HIV status (n=106)***

On the question whether people should make their HIV *negative* status known 77.3% (n=82) answered that people should do so, 8.5% (n=9) said that they should not and 14.2% (n=15) said they did not know. Respondents who answered that people

should make their HIV *positive* status known were 81.1% (n=86), 7.5% (n=8) said that they should not and 11.4% (n=12) said that they were uncertain. It is therefore clear from the answers of the respondents that the majority felt that whatever the serological result for the HIV test is, the result should be made public.

In the next subsection the respondents were requested to answer whether they agreed or disagreed to the list of questions put to them.

#### 4.3.4.2 ***Advantages of disclosing HIV status to others (n=106)***

Table 4.9 summarises the responses of all the respondents (100.0%; n=106) who answered the question on the advantages of disclosing people's HIV status.

**Table 4.9: Responses of respondents regarding the advantages of disclosure of HIV status (n=106)**

<b>Advantage</b>	<b>Agree</b>	<b>Disagree</b>
<b>It would help prevent spread of HIV</b>	92.5% (n=98)	7.5% (n=8)
<b>It would decrease HIV/AIDS mortality rate</b>	91.5% (n=97)	8.5% (n=9)
<b>It would lesson stress by not keeping a secret</b>	93.4% (n=99)	6.6% (n=7)
<b>It would safe guard healthworkers' health</b>	81.1% (n=86)	18.9% (n=20)
<b>Patients would get correct treatment</b>	95.3% (n=101)	4.7% (n=5)
<b>Partner would be able to make informed decision</b>	93.4% (n=99)	6.6% (n=7)
<b>It would prevent transmission from mother to child</b>	88.7% (n=94)	11.3% (n=12)
<b>Patients would obtain support from health workers</b>	92.5% (n=98)	7.5% (n=8)

#### 4.3.4.3 ***Serological findings of partners and children (n=106)***

Most of the 106 respondents namely 96.2% (n=102) were of the opinion that partners should go together to the clinic and be tested for HIV. This will also make it easier for partners to reveal their status to each other. The majority of the respondents, namely 94.3% (n=100) were of the opinion that people should know the status of their sexual partners and 91.5% (n=97) felt that mothers should also know the HIV status of their children.

#### **4.3.4.4 *It is possible to detect whether people are HIV positive (n=106)***

Of the respondents 60,3% (n=64) felt that members of the community cannot identify people who are HIV positive, however 39.6% (n=42) respondents said that they could do so as infected people always looked sick. Of the respondents 82.1% (n=87) were also of the opinion that members of the community tend to think that people who are slim, are infected or that people who have TB (62.3%; n=66) were also infected with HIV.

#### **4.3.4.5 *Expected reaction of family (n=106)***

Of the 106 respondents who answered this question 50.9% (n=54) indicated that families would not desert a family member when their HIV positive status is disclosed, and on another question 78.3% (n=83) respondents indicated that families would support HIV+ individuals. Even in cases where an HIV+ individual is not supported by the family or they did not initially accept the situation, 78.3% (n=83) of the respondents were of the opinion that families would ultimately accept their HIV status.

#### **4.3.4.6 *Expected reaction of partner (n=106)***

Of the respondents 46.2% (n=49) were of the opinion that HIV+ individuals could not rely on the support of their partners and 65.1% (n=69) believed that people who disclose their HIV positive status are actually abused by them.

#### **4.3.4.7 *Expected reaction of friends and employers (n=106)***

Respondents were of the opinion that HIV+ individuals could rely on the support of their friends, as revealed by 39.6% (n=64) respondents.

Of the respondents 58.5% (n=62) indicated that people tend to lose their work as soon as their HIV+ status is made known, but in a similar question asked in section E the respondents were rather divided in their answers, as only 51.0% (n=54) felt that HIV+ individuals tend to lose their jobs.

Support from family, friends and community would motivate HIV+ individuals to disclose their status. In a quantitative study conducted in 2004 amongst two groups

of people living with HIV and AIDS in Durban, South Africa, it was found that the one group that received integrated community/home-based care (IHC) accepted their status more and disclosed their status easier than the second group who was not part of the IHC-programme. Therefore an IHC programme can serve as catalyst for acceptance and disclosure of a positive HIV status (Ncama 2007:391).

#### **4.3.4.8 Confidentiality with regards to HIV status (n=106)**

The majority of respondents 89.6% (n=95) were of the opinion that individuals who are HIV+ prefer not to have their HIV status made known and 55.6% (n=59) feared that health personnel would not keep their status confidential.

Case managers (223 respondents) who took part in a study in New York State, indicated that they realised that people living with HIV and AIDS need to disclose their HIV status but revealed that they did not have the necessary training or resources to assist with disclosure to sex and drug sharing partners. They indicated that this was only one of the many pressing issues they had to deal with which included housing, food, medical care, mental health treatment and preventing HIV transmission (Tompkins 2007:259).

#### **4.3.5 Stigmatisation of HIV status**

In this section (Section E of the interview schedule) all the respondents were supposed to answer the listed questions.

##### **4.3.5.1 Respondents' opinion regarding stigmatisation of HIV/AIDS in community and own feelings regarding people with HIV/AIDS (n=106)**

Respondents were asked a number of questions directly related to stigmatisation of HIV.

**Table 4.10: Stigmatisation of HIV+ status (n=106)**

Statements regarding stigmatisation of HIV+ status	Agree	Disagree
A serious problem in community	88.7% (n=94)	11.3% (n=12)
Serious problem for people with TB	88.0% (n=93)	12.0% (n=13)
HIV+ people always think about death	70.8% (n=75)	29.2% (n=31)
HIV+ people are promiscuous	28.3% (n=30)	71.7% (n=76)
HIV+ people are homosexuals	15.1% (n=16)	84.9% (n=90)
HIV+ people are dirty	(n=19) 17.9%	(n=87) 82.1%
AIDS is God's way of punishing people's undesirable sexual behaviour	47.2% (n=50)	52.8% (n=56)
HIV+ people are discriminated against	72.6% (n=77)	27.4% (n=29)
People always gossip about HIV+ people	88.7% (n=94)	11.3% (n=12)

The majority of the 106 respondents who answered the question, namely 88.7% (n=94) indicated that stigmatisation of HIV/AIDS in their communities was a serious problem, particularly for people with TB (88.0%; n=93).

HIV and AIDS stigmatisation create significant barriers to HIV prevention, testing and care and can adversely affect health and mental health (Kalichman, Simbayi, Cloete, Mthembu, Mkonta & Ginindza 2009:87).

#### **4.3.5.2 Presentation of stigmatisation of HIV/AIDS in communities**

An open question was asked to allow respondents to explain how stigmatisation of HIV/AIDS presents in their communities. The answers to the open question confirms the findings depicted in table 4.10 that respondents experienced stigmatisation, discrimination and negative attitudes in their communities.

Here are some of the typical *verbatim* answers received:

- *Very, very bad. HIV+ people are just not accepted.*
- *In the Indian community there is a very high degree of stigmatisation.*
- *HIV+ people are mostly considered as dirty and are isolated and at times burned or abandoned by their family and friends.*
- *Gossiping, termination of friendships.*
- *People ostracizing people who are HIV+.*

- *The community will not want to share anything with people who tested positive and don't want to befriend them, always isolating them.*
- *HIV is still treated as a secret and others think they won't have it and they still have negative attitude to those who are positive and die of HIV.*
- *You are isolated and discriminated. Once you look sick and lose weight people gossip and start suspecting that you are HIV+.*
- *People hide themselves. Do not take their treatments. They isolate or are withdrawn.*
- *They make you feel guilty, they spread news that can cause divorce.*
- *If you hear how your husband date other women once you lose weight they say all your husband partners are going to die and you as well.*
- *They think that when you are slim you are HIV.*
- *They point fingers at you when you pass, you become afraid to go to your local clinic, you hide yourself and go to a clinic far away.*
- *People are getting used to the disease but a lot of education is still needed.*

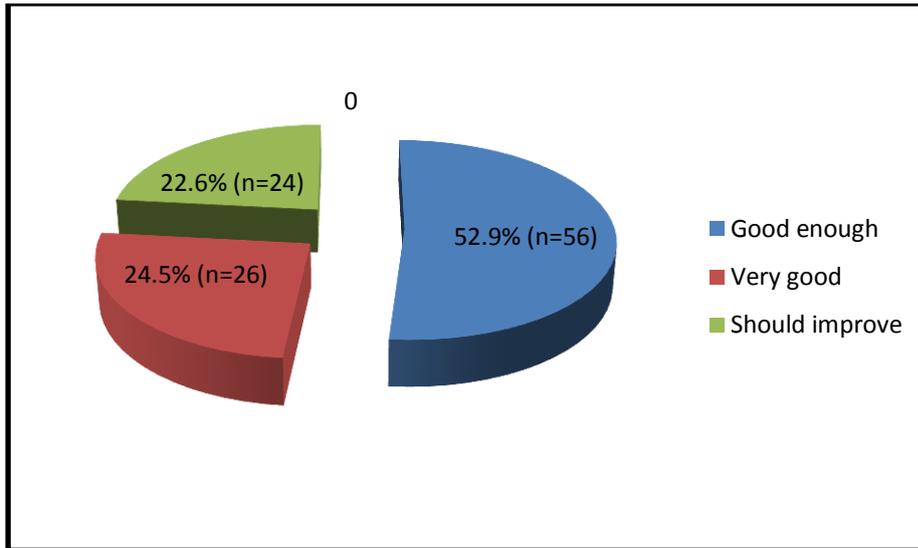
The majority of respondents namely 93.4% (n=99) revealed that they knew people who were HIV positive.

#### **4.3.6 Promotion of testing and disclosure**

In this section (Section F) respondents were asked a number of questions related to the promotion of testing for HIV and AIDS and what they believed could be done to promote the disclosure of people's status.

##### **4.3.6.1 Rating by respondents of the motivation provided by health personnel to patients to have themselves tested for HIV (n=106)**

The respondents were generally satisfied with the motivation provided by health personnel to have themselves tested for HIV as depicted in figure 4.7 as only 22.6% (n=24) were of the opinion that it could improve.



**Figure 4.7: Motivation provided by health professionals to have test done**

#### **4.3.6.2 Labeling of rooms for testing and its effect on patients (n=106)**

According to 52.0% (n=55) of the respondents, the room where the testing is done is clearly marked and 75.0% (n=79) were of the opinion that this fact could be the reason why patients do not want to be tested. Of the respondents 68.0% (n=72) indicated that health personnel never called out in the waiting room to indicate where the HIV testing room was; 23.5% (n=25) indicated that they often did it and 8.5% (n=9) indicated that they always did so.

#### **4.3.6.3 Leaders of the community should have themselves publicly tested for HIV (n=106)**

The majority of respondents namely 86.0% (n=91), indicated that should leaders of the community publicly have themselves tested for HIV, it would motivate other people to do the same.

#### **4.3.6.4 Community leaders should also disclose their HIV+ status (n=106)**

Of the respondents 83.0% (n=88) were of the opinion that should the community leaders also reveal the results of their HIV test when they test positive, it would motivate other people to do the same.

#### **4.3.6.5 Respondents' rating of the knowledge members of their communities have about the benefits of disclosing HIV status (n=106)**

Most of the respondents (73.6%; n=78) indicated that members of the community have knowledge (although not enough) of the advantages of making their HIV status public.

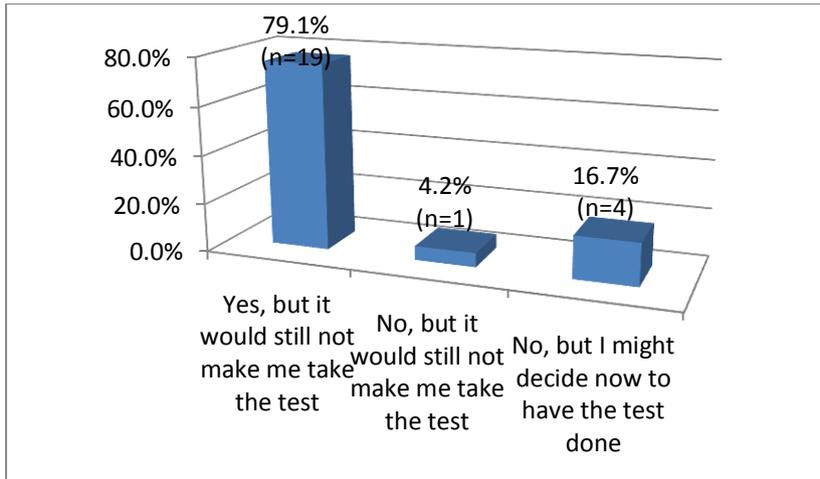
The following questions were answered only by those respondents who indicated that they did not have themselves tested for HIV in Item 4.3.3.1.

#### **4.3.6.6 Counselling of patients before HIV testing, might help respondents to decide to have themselves tested (n=24)**

In item 4.3.3.1 twenty-four respondents indicated that they did not have themselves tested. Of these respondents (79.1%; n=19) indicated that although they knew that people were counselled before testing, they would not have the test done, and 4.2% (n=1) one respondent who did not know it, would not have the test done. Of the respondents 16.7% (n=4) who initially did not, is now considering to have it done, now that they know that they will receive counselling from health professionals before the test is carried out.

#### **4.3.6.7 Counselling of patients before HIV test results are given to patients might help respondents to decide to have themselves tested (n=24)**

Respondents were asked whether the fact that patients are counselled before they receive the results of the HIV tests might motivate them to have the HIV test done. The results indicated that 79.1% (n=19) respondents would not be motivated to be tested, despite the fact that they knew that counselling would be available should they want to make use of these services. One respondent (4.2%), while only hearing during the interview that counselling could be done before the test results are made known to the patient, still insisted that even this knowledge would not persuade her to have the test done, even though the remaining 16.7% (n=4) are now considering to have it done.



**Figure 4.8: Pre-test counselling and its effect on respondents' decision to have themselves tested**

#### **4.3.6.8 Improvements that should be made before respondents would have themselves tested (n=24)**

In this section the respondents were given a list of possible changes or improvements that could be made and whether the implementation of these changes would motivate them to have themselves tested for HIV.

The findings revealed that the respondents might have themselves tested if family members 79.1% (n=19); health workers 58.3% (n=14); the community 95.8% (n=23), friends 83.3% (n=20) and partner 95.8% (n=23) could change their attitude toward HIV+ people, accept and support them. Of the respondents 79.1% (n=19) also indicated that they would have the test done if their safety could be guaranteed (that people stop acting against them) if they tested HIV+. It would also motivate them to have the test done if they knew that there is a cure for HIV/AIDS as indicated by 75.0% (n=18) of the respondents and immediately receive treatment when found to be HIV+ (83.3%; n=20). Of the respondents 79.1% (n=19) indicated that they would have the test done if their status could stay confidential and the same respondents said that they would have it done if more people would make their status known. It could be deduced that they would prefer that their HIV results to be guaranteed to stay confidential, but that they would also make their own status known if other people did it.

#### 4.3.7 CONCLUSION

In this chapter the findings were discussed and depicted in figures and tables.

The sample consisted of 106 respondents. The largest group fell in the age group “younger than 29 years”, were mostly females and were Tswana speaking. It is important to note that all the respondents had at least completed primary school education and could therefore be considered to be literate.

The majority of respondents received health education on HIV/AIDS through television programmes and health education provided by health personnel at the clinic. It is clear from the findings that they had or received the necessary knowledge that should help them to make an informed decision and to have safer sexual relationships.

Many of the respondents had themselves tested for HIV because they wanted to know their status or because the health professionals motivated them to have the test done. Many of the respondents made their HIV status known to the researcher.

Respondents were more inclined to inform their partners and family members than friends or employers about the results of the test. Please refer to Table 4.6. Most of the respondents indicated that people should have themselves tested and reveal their status whether the results are negative or positive and that they would advise people to do so. They however believed that fear of rejection and discrimination would be reasons for people not having themselves tested.

Respondents believed that there are some advantages in disclosing one’s HIV status, such as that it would prevent the spread of HIV and decrease the HIV/AIDS mortality rate. Respondents were of the opinion that sexual partners should have the test done together and that they should know the HIV status of their partners. They then could make informed decisions regarding their sexual relationships.

Respondents indicated that they could rely on the support of their families, but that HIV+ people could generally not rely on the support of their partners, friends, employers or larger community.

HIV/AIDS is highly stigmatised in their communities as the respondents indicated that people believe that you have AIDS if you are slim or have TB. They also

indicated that HIV+ people live in fear for their safety as their partners might abuse them, they might lose their jobs and are the topic of gossiping in the community and are ostracised by other people.

Community leaders could help to remove the stigmatisation of HIV if they themselves had the test done and made their results public.

The results revealed that some respondents were afraid that health professionals would make their status public, but that they did well to motivate people to have themselves tested and that they were generally discreet in the clinic in managing patients who report for VCT.

The negative attitude of family members, friends, and the community in general toward HIV/AIDS should have to change greatly before the respondents who did not have themselves tested, would do so.

## CHAPTER 5

### SUMMARY, CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

#### 5.1 INTRODUCTION

In the previous chapter, data obtained from the structured interviews were analysed, discussed and presented graphically.

In this chapter, the research findings are summarised, research limitations and conclusions of the research are discussed, and recommendations are made, as deduced from the research findings.

#### 5.2 SUMMARY

The first cases of HIV were identified in 1981 in the USA among young homosexual men. It was then discovered that the disease was also transmitted through blood, blood products and amongst drug users who shared contaminated injection needles.

Since then it has developed into an epidemic throughout the world and also amongst heterosexuals. Transmission from mother to child has also become a serious public health problem.

Factors such as poverty, extensive work migration, gender inequality, low access to reproductive health care and the presence of other sexually transmitted infections fuel the spread of the disease. Poor countries in Africa are the worst hit. HIV has destroyed lives and 28 million people are currently living with HIV and 19 million have died in Africa alone. Almost one third of Africans are directly affected by the epidemic (Poku 2005:60-61).

South Africa has the highest number of reported rape cases of women in the world. HIV is then spread to innocent young women whose future is wasted as their lives spiral downwards to poverty, poor education and they are then often driven to prostitution which aggravates the outcome of their personal health and spread of the disease (Van Dyk 2012:211). Although much has been done in SA regarding the prevention of HIV/AIDS the usual prevention methods such as education and use of condoms have not made the

required impact on the morbidity and mortality rate. Stigmatisation of HIV/AIDS and the resultant non-disclosure of HIV status jeopardises the campaign to eradicate the condition completely. Disclosure of a patient's status has many advantages for the patient, health workers, community and country at large. It will assist all involved to make the correct informed decisions to protect themselves from contracting and spreading the condition.

The aim of the research was to investigate the problem of disclosure of the HIV status.

The objectives of the study were the following:

- Determine what knowledge patients who attended PHC clinics in the Kagiso Township, SA had on HIV/AIDS.
- Explore and describe the reasons why some patients who attended PHC clinics in the Kagiso Township, SA had them tested to determine their HIV status.
- Explore and describe the reason why some patients who attended PHC clinics in the Kagiso Township, SA preferred not to disclose their HIV status.
- Explore and describe the opinions of patients who attended PHC services in the Kagiso Township, SA regarding the way in which stigmatisation of HIV/AIDS presented in their communities.
- Explore and describe the opinions and suggestions of patients who attended PHC services in the Kagiso Township, SA regarding the promotion of testing and disclosure of the HIV/AIDS status.

The quantitative research method was used as it is a formal, objective, systematic process for obtaining numerical data, and most suited to study the extent of the problem and how often it occurs in the sample (Burns & Grove 2009:27). Since no research findings of this nature could be located where this problem has been researched in the health clinics of West Rand Health Region, SA this research design was also explorative in nature (Burns & Grove 2009:359). The findings were presented in graphs and tables, discussed and contrasted with other research findings for the benefit of improved health practice – it therefore could also be seen as a descriptive research design.

The research population for this study included clients that visited the PHC clinics in Kagiso Township, West Rand Health Region, SA which included the elderly, adults, young adults, and youths. Between 260 to 300 clients are seen on average at the clinic for health services ranging from minor ailments, preventive and promotive health care services such

as reproductive health care, and children immunisation. A random sample was selected of the abovementioned research population, irrespective of their HIV status. A total of 106 respondents were interviewed. An interview schedule was compiled in English for the purpose of the dissertation but the questions have been translated during the interview by the researcher into Sotho, Zulu and other languages if the respondents could not understand the questions in English.

The number of interviews per day depended on the number of respondents who agreed to be interviewed. At least 2-3 respondents were interviewed per day.

The interview schedule consisted mostly of closed-ended questions and very few open-ended questions. The following issues were addressed in the different sections:

**Section A**

Respondents' demographic information.

**Section B**

Knowledge respondents had about HIV/AIDS.

**Section C**

Voluntary testing and why people had them tested.

**Section D**

Disclosure of the HIV status.

**Section E**

Stigmatisation of the HIV status in families and the community.

**Section F**

Opinions and suggestions of the respondents (patients) regarding the promotion of testing for HIV and disclosure of the status.

## **5.2.1 Research findings**

### **5.2.1.1 *Demographic information***

The sample consisted of 106 respondents of which 43.3% (n=46) fell in the age group "younger than 29 years"; most were females (82.1%; n=87) and most were Tswana speaking (59.4%; n=63). The largest group 67.0% (n=71) of the respondents indicated that they were never married; almost everyone belonged to the Christian faith (94.3%;

n=100) and 45.2% (n=48) had tertiary education. All of the respondents have at least completed primary school education and can therefore be considered literate.

#### **5.2.1.2 Respondents' knowledge of HIV/AIDS**

The most popular medium of receiving health education on HIV/AIDS was the television 57.0% (n=60) followed by the clinic 52.0% (n=55). Specific information they received were that HIV/AIDS is dangerous, that the condition can be prevented, that people should know the HIV status of their sexual partner and that people should use condoms particularly if they had multiple sexual partners. The respondents clearly did know how HIV/AIDS was transmitted or not transmitted, although some of the respondents had incorrect information on this or were uncertain. Although only 21.0% (n=17) had unprotected sexual relationships after they had themselves tested it is dangerous when involved in risky relations. Please refer to 4.3.3.3. Therefore most of the respondents knew that they should take precautionary measures.

#### **5.2.1.3 Reasons why some patients had them tested to determine their HIV status.**

Of the respondents 76.0% (n=81) of the total (n=106) respondents who had themselves tested indicated that they did so because they (100.0%; n=81) merely wanted to know what their HIV status were, or health personnel motivated them (64.2%; n=52) to have the test done. See table 4.8.

Of the respondents 77.7% (n=63) who were tested, made their status known to the researcher of whom 64.7% (n=44) tested negative. See Figure 4.6. Respondents were more inclined to inform their partners (52.0%; n=14) and family members (52.0%; n=14) than friends (29.6%; n=8) or employers (14.8% n=4) about the results of the test.

All the respondents who had themselves tested (76.4%; n=81) would advise others to do the same and reveal their HIV status.

Although some respondents indicated that they experienced negative feelings, such as depression (94.7%; n=18) after they received their HIV positive test results they have since accepted their status (94.7%; n=18) and feel positive about the future (42.1%; n=8). Please refer to 4.3.3.7

Fear (95.8%; n=23) for what the test results would reveal and what other people would say n=19 (79.0%) to n=22 (92.0%) were two of the main reasons why respondents were of the opinion that people would not have the test done. Please see table 4.8.

#### **5.2.1.4      *Disclosure of HIV status***

Respondents were of the opinion that HIV status should be made public whether it was negative (77.3%; n=82) or positive (81.1%; n=86).

Respondents believed that there are some advantages in disclosing one's HIV status, such as that it would prevent the spread of HIV (92.5%; n=98); decrease the HIV/Aids mortality rate (91.5%; n=97) and safeguard health workers' health (81.1%; n=86) to name but a few.

Respondents were of the opinion that sexual partners should have the test done together (96.2%; n=102) and that they should be informed of the findings of both their tests 94.3%; n=100).

A large group of respondents (60.3%; n=64) believed that members of the community would not be able to identify people who are HIV positive. However some members of the community (39.6%; n=42) tend to think that people who are slim or has TB are HIV+.

Respondents were of the opinion that families tend to support (78.3%; n=83) their HIV+ family members and would not desert them (50.9%; n=54); whereas partners would not support them (46.2%; n=49) and might even abuse them (65.1%; n=69); friends cannot be relied on as indicated by 39.6% (n=42) respondents; and people might lose their work as soon as their HIV+ status is made known as indicated by 58.5% (n=62) of the respondents.

The majority of respondents (89.6%;n=95) believed that people who tested positive prefer not to have their status made public and that they feared that health professionals would not keep their status confidential as revealed by 55.6% (n=59) of the respondents.

### **5.2.1.5 Stigmatisation of HIV status**

People living with HIV/AIDS have an extra burden to carry, namely to deal with stigmatisation, as respondents felt that HIV/AIDS is highly stigmatised in their communities as mentioned in item 4.3.5.1 and confirmed by their own statements listed in this item.

The questions listed in the closed-ended questions in the interview schedule were not constructed in a way to elicit answers that would reflect their own personal experiences. The respondents however clearly referred to themselves and their own personal experiences of the stigmatisation in their answers to the open-ended questions, eg.

- *They point fingers at you when you pass.*
- *You become afraid to go to your local clinic.*
- *You hide yourself and go to a clinic far away.*

### **5.2.1.6 Promotion of testing and disclosure**

The motivation by health personnel was rated as “Good Enough” to “Very Good” by 77.4% (n=82) of the respondents.

The findings revealed that community leaders should set an example by having themselves tested according to the opinion of 86.0% (n=91) of the respondents, and that other people will then follow their example.

Of the respondents 83.0% (n=88) indicated that community leaders should set an example by disclosing their HIV+ status, and that others will then do the same.

Only 8.5% (n=9) of the respondents felt that HIV testing is done discreetly and indicated that health personnel call patients from the general waiting area to a special room for HIV testing.

Respondents (73.6%; n=78) feel that members of the community don't know enough about the benefits of disclosure of their HIV status.

The fact that respondents are counselled before they take the HIV test does not motivate them to take the test, as indicated by 79.1% (n=19) of the 24 respondents that did not have themselves tested.

### 5.3 CONCLUSIONS

The conclusions have been sorted according to the objectives of the study:

- Determine what knowledge patients who attended PHC clinics in the Kagiso Township, SA had on HIV/AIDS.

The age group younger than 29 years were the most represented in this sample and also consisted mostly of Tswana speaking females. The majority of respondents were literate and were enlightened about all aspects regarding HIV and AIDS. They therefore could make informed decisions about sexual relationships and how to prevent contracting the condition.

- Explore and describe the reasons why some patients who attended PHC clinics in the Kagiso Township, SA had them tested to determine their HIV status.

Most of the respondents knew their HIV status because they merely wanted to know it, as it is the responsible thing to do, or were motivated by staff of the clinic to have the test done.

Fear for what the test results would reveal and what other people would say, were two of the main reasons why people would not have the test done.

- Explore and describe the reasons why some patients who attended PHC clinics in the Kagiso Township, SA preferred not to disclose their HIV status.

Of the respondents 94.3% (n=100) were of the opinion that people should know the status of their sexual partners, while 81.1% (n=86) answered that people should make their HIV *positive* status known to other people, which were generally their partners and members of their direct families.

Respondents were of the opinion that individuals' HIV status should be made public whether it was negative (77.3%; n=82) or positive (81.1%; n=86), as it would be to the benefit of the patient who could start treatment when tested positive, control the spread of the condition, decrease the mortality rate and safeguard health workers' health. They also believed (94.3%; n=100) that sexual partners should be informed of the test results to allow them to make informed choices as to the use of condoms and they should have the test done together.

The respondents indicated that should a person who tested HIV positive reveal the test results to members of the family they would be able to rely on their support. The respondents however indicated that partners might not support them and might even abuse them. Respondents indicated (60.4%; n=64) that one can rely on the support of friends, while others (58.5%; n=62) were of the opinion that people might lose their work as soon as their HIV+ status is made known.

The majority of respondents believed that people who tested positive prefer not to have their status made public and that they also feared that health professionals would not keep their status confidential.

- Explore and describe the opinions of patients who attended PHC services in the Kagiso Township, SA regarding the way in which stigmatisation of HIV/AIDS presented in their communities.

Respondents believed (60.3%; n=64) that although members of the community would not be able to identify people who are HIV positive, they do tend to think that people who are slim or have TB are HIV+. This is discriminatory as it involves all people who are healthy but slim.

Stigmatisation, discrimination, isolation and name calling are still outstanding attitudes of families, partners and the community towards HIV positive people. These are serious problems that make it difficult for HIV positive people to disclose their status.

- Explore and describe the opinions and suggestions of patients who attended PHC services in the Kagiso Township, SA regarding the promotion of testing and disclosure of the HIV/AIDS status.

The findings revealed that the respondents were of the opinion that more people will have themselves tested and reveal their status if family members, health workers, the community, friends and partners could change their attitude toward HIV+ people, accept and support the patients who tested HIV+. It is also important that their safety could be guaranteed if they tested HIV+. It would also motivate them to have the test done if they knew that there is a cure for HIV/AIDS and immediately receive treatment when found to be HIV+.

On the other hand 76.0% (n=19) of the 24 respondents who did not have themselves tested, indicated that they would have the test done if their status could

stay confidential. It could be deduced that they would prefer that their HIV results be guaranteed to stay confidential, but that they would make their own status known if other people did the same.

The clinic environmental setting must also limit stigmatisation by not marking testing rooms on the doors, but have all patients using common facilities. Rooms for testing and the dispensary for anti-retroviral drugs should be away from the general waiting room of the clinic to avoid gossip and stigma. The health personnel must also ensure that there is confidentiality maintained for those who come for HIV testing.

From verbatim responses there were suggestions of forming support groups where people could disclose their status.

The findings revealed that the respondents were of the opinion that all patients visiting the clinic should be tested and that they should be motivated to disclose their status. HIV should not be treated as a secret.

The respondents suggested that house to house campaigns should be done to give information on HIV and motivate people for testing.

The attitude of people toward HIV positive people must change so that they are motivated to disclose.

#### **5.4 LIMITATIONS**

The limitations associated to the findings of this research were the following:

- The research area for his study covered only the Kagiso Township, SA and therefore the findings cannot be generalised to other parts of SA.
- The presence of the researcher during the face to face interview might have influenced the responses from the respondents. Other research methods might have revealed other findings.
- The majority of the respondents were people up to the age of 59 years. It is not certain whether by including more elderly people in the sample the research could have had a different outcome.

## 5.5 RECOMMENDATIONS

The following recommendations have been derived from the findings

:

### 5.5.1 Recommendation for services

- Health personnel should make use of every opportunity to educate people who attend the PHC clinics about HIV as a disease, the spread of the infection lifestyle and safe sex practices.
- Health personnel should motivate their clients to have themselves tested and reveal their status to at least their sexual partners. There is less success in controlling the HIV pandemic if people keep their status a secret and infect others.
- Awareness and information about anti-retroviral drugs should be made available to all those who test positive.
- Availability of support systems should be explained during the pre- and post-test counselling. Clients should clearly know what to do after knowing their status.
- Emphasis on destigmatisation should be done through health education. Education sessions in health services and in work places should be offered.
- Workshops should be conducted to enlighten employers and employees on recent developments about HIV/AIDS and anti-retroviral treatments.
- HIV positive individuals should be taught about the benefits of disclosure, their rights as individuals against discrimination in the workplace and in communities.
- Families should be encouraged to give support to HIV+ people.

### 5.5.2 Recommendations for further research

The researcher recommends that further research be conducted on the following:

- The benefits of disclosure should be researched to determine whether disclosure leads to increased support and early initiation of anti-retroviral treatments.
- Research should be conducted to find ways of dealing with negative attitudes of individuals, families, partners and the communities against HIV infected persons.

- New and innovative methods should be sought to remove discrimination and stigmatisation against HIV infected people.
- Research could be conducted to determine whether special rooms for HIV testing in the clinics play a role in promoting stigmatisation.
- This study could be repeated using the qualitative research paradigm and focus groups to collect data.

## **5.6 CONCLUSION**

The aim of the research was to investigate whether there is a problem with disclosure of the HIV positive status. To do this a quantitative, explorative, descriptive research design was used. Data was collected by compiling and using a previously tested interview schedule during the interview of a carefully selected sample of people who visited the PHC clinics in the Kagiso Township in SA.

The findings revealed that although people are more educated and enlightened about HIV and AIDS they are afraid of having themselves tested and reveal the HIV status to others. This is because there is still a great deal of stigmatisation, discrimination and judgmental attitudes toward HIV positive individuals and their families.

This problem will not be solved overnight as there is a deep rooted fear to be harmed by others. Health personnel could do more to keep information confidential when requested, but to motivate people to rather reveal their status to others. They should also involve community leaders to take the lead by having themselves tested and to make their status public.

Proper health care should be ensured for those who need it, if that is not forthcoming people will never have the test done or make their status known, and by doing so infect innocent people.

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**ANNEXURE A**  
**Permission requested to conduct research**

Department of Health Studies

012-429-6636

Fax: 012-429-6688

2010-08-27

**To whom it may concern**

Ms TM Selebogo is currently a registered student for her Masters' degree with the title: *An investigation into the non-disclosure of HIV status* at the University of South Africa.

She applied for ethical clearance to the Research and Ethical Committee of the abovementioned department. As we have to wait for the official clearance certificate to be issued by the Ethical Clearance Committee of UNISA and this takes time, I as her supervisor, would like to assure you that ethical clearance have been provided at the abovementioned Departmental meeting and that she should be allowed to test her research instrument and collect data in the health services.

The Committee looked at her proposed methodology and ethical considerations and was satisfied that no patient/client will be harmed in any way and that the findings of the research will be valuable for the fight against HIV infection.

Should you have any queries on this matter you may contact me or prof MC Bezuidenhout the chairperson of the department.

Yours faithfully,



Mrs M M van der Merwe

[martie.vdm@telkomsa.net](mailto:martie.vdm@telkomsa.net)

083-653-2075

10331 Thutlwa Street  
Extension 4  
Kagiso  
1754

21 June 2010  
Tel: 082 630 3343

To:  
The Research Committee  
West Rand Region Gauteng  
Provincial Health  
Krugersdorp  
Attention of: The Chairperson:

I hereby request permission to conduct a research study in at least two of your clinics in Kagiso.

Presently I am working at Ann Latsky Nursing College in the 'Primary Health care and Community Nursing' Department.

I am registered with the University of South Africa for a master's degree and my topic is "An investigation into the problem of disclosure in HIV positive patient".

Permission is therefore requested to interview patients who are positive and those who are not positive in order to establish the problem they have with disclosure of the status.

Ethical principles through *obtaining* their consents, maintaining confidentiality and privacy will be ensured. Only those who are willing to participate will be included in the study.

If allowed to interview the clients this will take place two days per week until approximately 60 patients are interviewed.

Hoping that my request will reach your favourable consideration and promise to give feedback about the outcome of the research.

Thank you  
Yours sincerely  
M.T Selebogo

-fV  
U

**ANNEXURE B**

**Permission obtained to conduct research**

**RESEARCH PROPOSAL EVALUATION FORM**

**FOR APPROVAL BY DIRECTOR: POLICY, PLANNING AND RESEARCH**

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**health and  
social development**

**Department: Health and Social Development  
GAUTENG PROVINCE**

Vision of the Department

**"To be the best provider of quality health and social services to the people in Gauteng"**

**POLICY, PLANNING AND RESEARCH (PPR) DIRECTORATE**

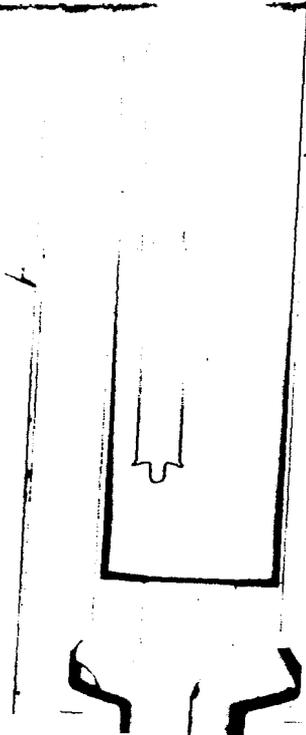
Enquiries: Sue le Roux or Siviwe Mkoka

Tel: +2711 355 3212/3249

Fax: +2711 355 3675

Email: [Sue.LeRoux@gauteng.gov.za](mailto:Sue.LeRoux@gauteng.gov.za) / [Siviwe.mkoka@gauteng.gov.za](mailto:Siviwe.mkoka@gauteng.gov.za)

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**SECTION B: PROPOSAL REVIEW**

	YES	NO	Comments
1. Is this research project within the scope of the Department of Health key policy priorities/directives?	✓		
2. Content of Research:			
• Original work	✓		
• Patients New facts, ideas	✓		
• Confirmation of uncertain data		✓	
• Repetition of known data and consequently of limited importance		✓	
• Insufficient research information	✓		
• Confusion of topics/questions		✓	
3. Is the title of the research project suitable?	✓		
4. Are the objectives of the research project adequate?	✓		<b>Yes</b>
5. Could the objectives be limited to better focus on the project's main objective?		✓	

This approval is granted only for a research proposal entitled  
**"An Investigation into non disclosure of HIV Status"**

	YES	NO	Comments
<b>6. Writing style</b>			
• The text of the proposal is clear	✓		The protocol is written in an academically acceptable manner.
• The nomenclature used is correct	✓		
• The references used are relevant, comprehensive and accurate (corrected)		✓	
• The spelling and grammar are correct	✓		
• The language needs improvement		✓	
• The research proposal needs restyling and rewriting		✓	
<b>7. Are the research methods appropriate to the study</b>	✓		Yes
<b>8. Does the study have ethical approval? If yes, name the ethics committee</b>	✓		Yes University of South Africa  Ethics Reference Number: 5709474
<b>9. Is data collection method in line with study design?</b>	✓		Yes
<b>10. Is time frame of the proposal adequate to meet the objectives?</b>	✓		Yes
<b>11. Is it stated in the proposal the method of dissemination of the results of the research project?</b>	✓		A report of findings will be made available to GDHSD and West Rand Region.
<b>12. Is the possible conflict of interests clarified?</b>	✓		
<b>13. Are financial implications and financial support transparent?</b>	✓		There is no financial implication for GDHSD

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This approval is granted only for a research proposal entitled  
**"An Investigation into non disclosure of HIV Status"**

**SECTION A**

<b>Researcher/Principal Investigators Name</b>	T Selebogo
<b>Physical Address</b>	University of South Africa
<b>Postal Address</b>	10331, Thutlwa Street, Ext 4, Kagiso, 1754
<b>Contacts</b>	+2782 630 3343
<b>Email Address</b>	<a href="mailto:vdmermm@unisa.ac.za">vdmermm@unisa.ac.za</a>
<b>Institution</b>	University of South Africa
<b>Research Topic</b>	An investigation into non disclosure of HIV Status
<b>Date Received by the PPR Directorate</b>	05 November 2010
<b>Date Received Reviewer</b>	23 November 2010
<b>Final Review Date</b>	26 November 2010
<b>Date Submitted to PPR Director</b>	26 November 2010
<b>Research Site(s)</b>	60 Patients will be recruited from PHC Clinics in the West Rand Region
<b>Type of research</b>	Mixed Methods, a questionnaire will be used to collect data
<b>Supervisor</b>	MM van der Merwe

This approval is granted only for a research proposal entitled  
**"An Investigation into non disclosure of HIV Status"**

## **SECTION C - SUMMARY OF THE RESEARCH PROPOSAL**

The study proposal submitted for approval by GDHSD is for a Master of Arts in Health Studies Degree qualification. Entitled "An Investigation into non disclosure of HIV Status" the study will explore reasons for non disclosure. Patients will be recruited from various PHC clinics in West Rand Region and data will be collected by an open ended questionnaire.

Ethics Approval for the study was granted by University of South Africa

Ethics Reference Number: **5709474**

The study has no financial implication for the department or the region involved. There is no potential to disrupt service delivery and the study presents no danger or violation of human rights of participants. The researcher will however observe all the Helsinki Declaration principles in conducting this study and will adhere to all terms stated in the accompanying letter of agreement between researcher and GDHSD. Prior arrangement with management (facility manager/CEO) must be made and this letter together with the proposal and ethics certificate made available before collection of data.

This study is therefore recommended for approval.

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This approval is granted only for a research proposal entitled  
**"An Investigation into non disclosure of HIV Status"**

**SECTION D - RECOMMENDATION AND APPROVAL**

Reviewed and recommended or not recommended for approval by:

  
\_\_\_\_\_

Siviwe Mkoka

Deputy Director: Policy, Planning and Research

Date: 26/11/2010  
\_\_\_\_\_

Approved by:

  
\_\_\_\_\_

Sue le Roux

Director, Policy, Planning and Research

Date: 29/11/2010  
\_\_\_\_\_

*Research*

  
\_\_\_\_\_

This approval is granted only for a research proposal entitled  
**"An Investigation into non disclosure of HIV Status"**

**ANNEXURE C**

**Ethical clearance requested and obtained from UNISA**

**DEPARTMENT OF HEALTH STUDIES****UNIVERSITY OF SOUTH AFRICA****TEL:012-429-6758 FAX: 012-429-6758****[vdmermm@unisa.ac.za](mailto:vdmermm@unisa.ac.za)****2010-06-30****To whom it may concern**

Ms TM Selebogo is currently busy with her Master's degree and currently registered for the dissertation titled: *An investigation into the non-disclosure of HIV status*.

Many studies have been conducted on HIV/Aids, but it is never enough when the prevalence of HIV infections is still too high and the suffering associated with it is so devastating. It has been found in countries where HIV and Aids are notifiable by law that the prevalence of new cases declines. As it is not a notifiable condition in South Africa, the voluntary disclosure of HIV status by clients/patients could help in the fight against the spread of the disease. It is however necessary to determine why some people have them tested and others not, why some people disclosed their status and other not and what reactions they encountered from people after they disclosed their status. Only then can this matter be addressed.

The research findings of this study, when implemented, are envisaged to benefit the health system of South Africa with regards to service delivery, health education and training of personnel, to name but a few areas, in that it could decrease the prevalence of new cases. If the health professionals could prove to clients that the disclosure of their HIV positive status to their partners could save their lives, as they then could make a combined decision to, for example, always use protection, it would decrease the rate of new cases.

This research will also be to the benefit of Ms Selebogo as she would attain her master's degree and it would also benefit the University financially, (subsidy for research) as well as its record of research.

We therefore would like to make a friendly request that she be allowed to test her instrument and then collect the final data in the field. We at UNISA will make sure that she considers all ethical issues.

Yours faithfully,



Mrs MM van der Merwe (Supervisor)

UNIVERSITY OF SOUTH AFRICA  
Health Studies & Ethics Committee  
(HSREC)  
College of Human Sciences

**CLEARANCE CERTIFICATE**

Date of meeting: ...6 October 2010                      Project number...5709474.....

Project title: **An investigation into the non-disclosure of HIV status**

Researcher: **MT Selebogo**

Supervisor/Promoters:            **Mrs MM van der Merwe**

Joint Supervisor/Joint Promotor:    **Mrs JE Smith**

Department: **Health Studies**

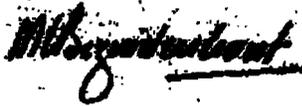
Degree:            **MA**

**DECISION OF COMMITTEE**

**Approved:**

Date: ...6 October 2010

  
**Prof A D H Botha**  
**p/p: RESEARCH & ETHICS COMMITTEE: DEPARTMENT OF HEALTH STUDIES**

  
**Prof MC Bezuidenhout**  
**ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

**PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES**

**ANNEXURE D**

**Informed consent from patients**

I am Ms TM Selebogo a student at the University of South Africa.

- ◆ I need to collect data for my research, and have chosen you to take part.
- ◆ The purpose of the research is to determine why some people choose to make their HIV status known and why others choose not to do it.
- ◆ The data collection process should not take more than 2 hours.
- ◆ You are requested to answer the questions as honestly and truthfully as possible.
- ◆ The results of the research will be printed in the master's dissertation of the researcher and will be examined by examiners to establish whether the researcher is able to do research on her own. This research is therefore only for the researcher's own development and studies.
- ◆ The findings of this research will be confidential as no name will be mentioned and in no way will it be possible to identify the participants.
- ◆ Your participation is voluntary and you may withdraw at any stage of the study if you feel threatened.
- ◆ No harm will be done to you and no information you share with the researcher will be used to harm you.
- ◆ The information collected might however benefit the fight against HIV infection should the research findings be implemented.
- ◆ Your privacy will be ensured during the interview.
- ◆ Should you feel uncomfortable during the interview in any way, please discuss it with the researcher.
- ◆ Should you have any questions at any time, please direct it to the researcher.



I believe that the person signing this form understands what is involved in the study and voluntary agrees to participate.

.....

.....

.....

Signature of researcher

Date

Printed name

**ANNEXURE E**

**Interview schedule**

# INTERVIEW SCHEDULE

## AN INVESTIGATION INTO THE NON-DISCLOSURE OF HIV STATUS

1-2

Answer the questions by entering the number allocated to the choices provided in the key, into the blocks in the right hand margin. Please ignore the coding of the blocks.

### SECTION A – BIOGRAPHICAL DATA

THIS SECTION SHOULD BE ANSWERED BY ALL THE RESPONDENTS

#### 1 How old are you?

Key:	Younger than 29 years	=	1
	Between 30 - 34 years	=	2
	Between 35 - 39 years	=	3
	Between 40 - 44 years	=	4
	Between 45 - 49 years	=	5
	Between 50 - 54 years	=	6
	Between 55 - 59 years	=	7
	Older than 59 years	=	8

A1

#### 2 What is your gender?

Key:	Male	=	1
	Female	=	2

A2

#### 3 What is your home language?

Key:	English	=	1
	Tswana	=	2
	Pedi	=	3
	Zulu	=	4

Xhosa	=	5
Sotho	=	6
Afrikaans	=	7
Other	=	8

A3

**3.1 Please specify other home language**

A3.2

**4 What is your marital status?**

Key: Never married/single	=	1
Married	=	2
Divorced	=	3
Widower	=	4
Living together	=	5

A4

**5 To what religion do you belong?**

Christian	=	1
Muslim	=	2
Hindu	=	3
Other	=	4
Don't have any	=	5

A5

**6 What is your level of education?**

Key: No formal education	=	1
Lower primary education	=	2
Completed primary education	=	3
Lower high school education	=	4
Completed high school education	=	5
Tertiary education	=	6
Other	=	7

A6

Xhosa	=	5
Sotho	=	6
Afrikaans	=	7
Other	=	8

A3

**3.1 Please specify other home language**

A3.2

**4 What is your marital status?**

Key: Never married/single	=	1
Married	=	2
Divorced	=	3
Widower	=	4
Living together	=	5

A4

**5 To what religion do you belong?**

Christian	=	1
Muslim	=	2
Hindu	=	3
Other	=	4
Don't have any	=	5

A5

**6 What is your level of education?**

Key: No formal education	=	1
Lower primary education	=	2
Completed primary education	=	3
Lower high school education	=	4
Completed high school education	=	5
Tertiary education	=	6
Other	=	7

A6

Xhosa	=	5
Sotho	=	6
Afrikaans	=	7
Other	=	8

A3

**3.1 Please specify other home language**

A3.2

**4 What is your marital status?**

Key: Never married/single	=	1
Married	=	2
Divorced	=	3
Widower	=	4
Living together	=	5

A4

**5 To what religion do you belong?**

Christian	=	1
Muslim	=	2
Hindu	=	3
Other	=	4
Don't have any	=	5

A5

**6 What is your level of education?**

Key: No formal education	=	1
Lower primary education	=	2
Completed primary education	=	3
Lower high school education	=	4
Completed high school education	=	5
Tertiary education	=	6
Other	=	7

A6

6.1 Please specify other education \_\_\_\_\_

A6.2

## SECTION B – KNOWLEDGE OF HIV/AIDS

THIS SECTION SHOULD BE ANSWERED BY ALL THE RESPONDENTS

1 How would you rate your knowledge of HIV/AIDS?

Key: Very good	=	1
Good	=	2
Poor	=	3
Very poor	=	4

B7

2 Have you ever received any health education on the prevention of HIV/AIDS?

Key: Yes	=	1
No	=	2
Uncertain	=	3

B8

3 Where did you get this health education?

Key: From the hospital	=	1
From the clinic	=	2
From work	=	3
From school	=	4
From the radio	=	5
From the television	=	6
From the printed media	=	7
Other people informed me	=	8
Did not receive any health education	=	9
Other sources	=	10

6.1 Please specify other education \_\_\_\_\_

\_\_\_\_\_ A6.2

## SECTION B – KNOWLEDGE OF HIV/AIDS

THIS SECTION SHOULD BE ANSWERED BY ALL THE RESPONDENTS

### 1 How would you rate your knowledge of HIV/AIDS?

Key: Very good	=	1
Good	=	2
Poor	=	3
Very poor	=	4

B7

### 2 Have you ever received any health education on the prevention of HIV/AIDS?

Key: Yes	=	1
No	=	2
Uncertain	=	3

B8

### 3 Where did you get this health education?

Key: From the hospital	=	1
From the clinic	=	2
From work	=	3
From school	=	4
From the radio	=	5
From the television	=	6
From the printed media	=	7
Other people informed me	=	8
Did not receive any health education	=	9
Other sources	=	10

B9

**3.1 Please specify the other sources**

B9.1

**4 What did you learn about HIV/AIDS?**

Key: Yes = 1

No = 2

Uncertain = 3

4.1 That the condition is caused by a virus.

B10

4.2 That HIV/AIDS is a dangerous condition.

B11

4.3 That the infection can be prevented.

B12

4.4 That a patient infected with HIV cannot be cured.

B13

4.5 That people become very ill of the infection.

B14

4.6 That the condition can be treated.

B15

4.7 That patients should disclose their HIV status.

B16

4.8 That you should know the HIV status of your sexual partner.

B17

4.9 That you should use a condom when having sex with multiple partners

B18

**5 How does the transmission of HIV/AIDS take place?**

Key: Yes = 1

No = 2

Uncertain = 3

- 5.1 You become infected with the virus from the bite of a mosquito. **B19**
- 5.2 It is transmitted directly, through casual contact between two people. **B20**
- 5.3 It is transmitted through the handling of contaminated food. **B21**
- 5.4 You can contract HIV/AIDS by drinking contaminated water. **B22**
- 5.5 You can contract HIV/AIDS through sexual intercourse. **B23**
- 5.6 You cannot contract HIV/AIDS when using a condom during sexual intercourse. **B24**

### SECTION C –VOLUNTARY TESTING

**ONLY SOME QUESTIONS IN THIS SECTION SHOULD BE ANSWERED BY ALL THE RESPONDENTS. THOSE QUESTIONS ARE INDICATED WITH (\*)**

**1 Did you have yourself tested for HIV? (\*)**

Key: Yes = 1 (Answer next questions)

No = 2 (Move to question 11)

**C25**

**THE FOLLOWING QUESTIONS SHOULD BE ANSWERED BY PEOPLE WHO HAD THEM TESTED FOR HIV.**

**2 Why did you have the test for HIV done?**

Key: Yes = 1

No = 2

2.1 You wanted to know your status.

**C26**

2.2 You were worried because of your own risky sexual behaviour.

**C27**

2.3 Because of your partner's infidelity.

C28

2.4 Because health professionals motivated you to have it done.

C29

2.5 Because of persistent health problems.

C30

2.6 Because you had a blood transfusion.

C31

2.7 Because you took out an assurance and the company requested it.

C32

2.8 Other reasons

C33

2.8.1 Please specify "other reasons"

C33.2

---

**3 Were you involved in unprotected risky sexual relationship since you had the test done?**

Key: Yes = 1

No = 2

C34

**4 Would you please tell me what your HIV status is?**

Key: Yes, I am HIV negative = 1 (Please move to Section D)

Yes, I am HIV positive = 2 (Please answer questions 5-10 and then move to Section D)

No, I would like to keep it secret = 3 (Please move to Section D)

C35

**5 Did you tell your partner that you tested positive?**

Key: Yes = 1

No = 2

C36

**6 Did you tell (a) family member(s) that you tested positive?**

Key: Yes = 1

No = 2

C37

**7 Did you tell (a) friend(s) that you tested positive?**

Key: Yes = 1

No = 2

C38

**8 Did you tell your employer that you tested positive?**

Key: Yes = 1

No = 2

C39

**9 Would you advise people who are HIV + to disclose their status?**

Key: Yes = 1

No = 2

C40

**THE FOLLOWING QUESTIONS SHOULD ONLY BE ANSWERED BY RESPONDENTS WHO ARE HIV+ AND ARE WILLING TO CONTINUE WITH THE INTERVIEW.**

**10 Indicate to what extent you agree with the following statements.**

Key: Agree = 1

Disagree = 2

10.1 You initially felt depressed after you heard that you are HIV +.

C41

10.2 You had feelings of guilt because of your HIV + status.

C42

10.3 You still make plans for your future.

C43

10.4 You contemplated to commit suicide after you heard of your + status.

C44

10.5 You have since accepted your status.

C45

10.6 You do not have negative feelings due to your HIV + status anymore.

C46

10.7 You believe that you can live a healthy life irrespective of your HIV status.

C47

10.8 You feel positive about your future.

C48

10.9 You used to live in fear that someone would know your secret.

C49

**THE FOLLOWING QUESTIONS SHOULD BE ANSWERED BY PEOPLE WHO *DID NOT* HAVE THEM TESTED.**

**11 Indicate to what extent you agree that the following statements are applicable to you as reasons why you *did not* have yourself tested for HIV.**

Key: Agree = 1

Disagree = 2

11.1 You were afraid of what the result of the test would be.

C50

11.2 You were afraid that someone would know that you had the test done.

C51

11.3 You were worried what your family would say.

C52

11.4 You were worried what your friends would say.

C53

11.5 You believed that you would test negative in any case.

C54

11.6 You have always been healthy.

C55

11.7. You still plan to have it done, but have not had the time to do it.

C56

11.8 You only have one faithful partner.

C57

11.9. You are not in a sexual relationship.

C58

11.10 You always use a condom when you have sex.

C59

11.11 You are worried about your partner's HIV status.

C60

11.12 You never want to know your status.

C61

11.13 You were worried because of your own risky sexual behaviour.

C62

11.14 Nobody told you how important it was to have the test.

C63

## SECTION D – DISCLOSURE OF HIV STATUS

**THIS SECTION SHOULD BE ANSWERED BY ALL THE RESPONDENTS.**

**1 Should people make their negative HIV status known?**

Key: Yes = 1

No = 2

Uncertain = 3

D64

**2 Should people make their positive HIV status known?**

11.6 You have always been healthy.

C55

11.7. You still plan to have it done, but have not had the time to do it.

C56

11.8 You only have one faithful partner.

C57

11.9. You are not in a sexual relationship.

C58

11.10 You always use a condom when you have sex.

C59

11.11 You are worried about your partner's HIV status.

C60

11.12 You never want to know your status.

C61

11.13 You were worried because of your own risky sexual behaviour.

C62

11.14 Nobody told you how important it was to have the test.

C63

## SECTION D – DISCLOSURE OF HIV STATUS

**THIS SECTION SHOULD BE ANSWERED BY ALL THE RESPONDENTS.**

**1 Should people make their negative HIV status known?**

Key: Yes = 1

No = 2

Uncertain = 3

D64

**2 Should people make their positive HIV status known?**

**2 Should people make their positive HIV status known?**

Key: Yes = 1

No = 2

Uncertain = 3

D65

**3 Indicate whether you agree or disagree to the following statements**

Key: Agree = 1

Disagree = 2

3.1 Disclosure of status would help prevent the spread of HIV/AIDS.

D66

3.2 Disclosure of status would decrease mortality due to HIV/AIDS.

D67

3.3 Disclosure would cause less stress by not keeping status secret.

D68

3.4 Disclosure would safe guard health workers from becoming infected.

D69

3.5 Disclosure would help patients to get the right treatment.

D70

3.6 Disclose of spouse's status would help partner to decide on taking the necessary precautions.

D71

3.7 HIV+ mothers should disclose their status to prevent transmission to child.

D72

3.8 Disclosure of status would help patients to obtain support from health workers.

D73

**4 Indicate whether you agree or disagree to the following statements regarding testing and serological findings of partners and children**

Key: Agree = 1

Disagree = 2

4.1 Spouses/partners should be tested together.

D74

4.2 People should know the status of their sexual partners.

D75

4.3 Mothers with children should know the status of their children.

D76

**5 Indicate whether you agree or disagree to the statements related to appearance of people who are HIV+**

Key: Agree = 1

Disagree = 2

5.1 Members of the community can identify people who are HIV+

D77

5.2 People who are infected always look sick.

D78

5.3 People think that when you are slim you are HIV+.

D79

5.4 People think that when you have TB you are also HIV+.

D80

**6 Indicate whether you agree or disagree with the statements related to the reaction of your family to HIV status**

Key: Agree = 1

Disagree = 2

6.1 When people disclose their + status they are deserted by family.

D81

6.2 People who disclose their + status can rely on the support of their families.

D82

6.3 People ultimately accept a member of the family's HIV + status.

D83



**7 Indicate whether you agree to the following statements related to the reaction of partners to HIV status**

Key: Agree = 1

Disagree = 2

7.1 You can rely on the support of your partner when you are HIV +.

D84

7.2 People who disclose their + status are abused by their partners.

D85

**8 Indicate whether you agree to the following statements related to the reaction of friends and employers to HIV status**

Key: Agree = 1

Disagree = 2

8.1 People who disclose their + status can rely on the support of their friends.

D86

8.2 People who disclose their + status lose their work.

D87

**9 Indicate whether you agree or disagree with the statement below.**

Key: Agree = 1

Disagree = 2

9.1 Patients fear that health personnel will not keep their status confidential.

D88

9.2 People who are HIV+ prefer not have their status known.

D89

**SECTION E – STIGMATISATION OF HIV + STATUS**

**THIS SECTION SHOULD BE ANSWERED BY ALL THE RESPONDENTS**

**1 Indicate whether you agree or disagree to the following statements.**

Key: Agree = 1

Disagree = 2

1.1 Stigmatisation of HIV positive people is a serious problem in your community.

E90

1.2 Stigmatisation is a serious problem for people with TB.

E91

1.3 People who are HIV + always think about death.

E92

1.4 People who are HIV + are promiscuous.

E93

1.5 People who are HIV + are homosexuals.

E94

1.6 People who are HIV + are dirty.

E95

1.7 AIDS is the way in which God punished people for their sexual behaviour.

E96

1.8 People who are HIV positive are discriminated against.

E97

1.9 People always gossip about HIV + people in the community.

E98

2 How does stigmatisation of HIV/AIDS present in your community?

3 Do you know people who are HIV positive?

Key: Yes = 1

No = 2

E99

## SECTION F – PROMOTION OF TESTING AND DISCLOSURE

**THIS SECTION SHOULD BE ANSWERED BY ALL THE RESPONDENTS EXCEPT QUESTIONS MARKED WITH \*\* WHICH SHOULD BE ANSWERED BY RESPONDENTS WHO DID NOT HAVE THEMSELVES TESTED.**

**1 How would you rate the motivation health personnel provide for patients to have them tested?**

Key: They motivate patients very well = 1  
 Their motivation is good enough = 2  
 Their motivation should improve = 3

F100

**2 Are the rooms where HIV testing is done in the clinic clearly marked?**

Key: Yes = 1  
 No = 2

F101

**3 Do you feel that the fact that the rooms are marked as HIV testing rooms is the reason why patients do not want to be tested?**

Key: Yes = 1  
 No = 2

F102

**4 How often do personnel call out the name of a patient for all to hear in the general waiting room and then direct them to the room marked for HIV testing (VCT)?**

Key: Always = 1  
 Often = 2  
 Never = 3

F103

**5 Would it motivate people to go for testing if they see that their community leaders have them tested?**

Key: Yes = 1  
 No = 2

F104

**6 Would it motivate people to disclose their HIV status if the leaders also do it when they actually test positive?**

Key: Yes = 1

No = 2

F105

**7 How would you rate the knowledge members of your community have about the benefits of disclosing HIV status?**

Key: They know all the benefits of disclosure = 1

They have some knowledge, but not enough = 2

They have no knowledge of the benefits of disclosure = 3

F106

**\*\*9 Do you know that patients are counselled before being tested?**

Key: Yes, but it would still not make me take the test = 1

No, but it would still not make me take the test = 2

No, but I might decide now to have the test done = 3

F107

**\*\*10 Do you know that patients are counselled when they get their HIV test results?**

Key: Yes, but it would still not make me take the test = 1

No, but it would still not make me take the test = 2

No, but I might decide now to have the test done = 3

F108

**\*\*11 What should improve before you would decide to have the HIV test done?**

Key: Agree = 1

Disagree = 2

**\*\*11.1 The attitude of members of your family towards HIV + people.**

F109

**\*\*11.2 When you can be sure of the support of your partner.**

F110

**\*\*11.3 The way in which people that are HIV + are treated by health workers.**

F111

**\*\*11.4 The general attitude in the community towards HIV/AIDS.**

F112 **\*\*11.5** As soon as you know that your friends will accept your HIV + status.F113 **\*\*11.6** When there is a cure for HIV/AIDS.F114 **\*\*11.7** When your safety from prosecution by community can be guaranteed.F115 **\*\*11.8** As soon as you are sure that you will be treated when you test positive.F116 **\*\*11.9** When confidentiality of your status could be guaranteed.F117 **\*\*11.10** As soon as more people make their HIV + positive status known in public.F118 **THANK YOU**

**ANNEXURE F**

**Maps of research area**

