

**THE EFFECT OF STIGMA ON HIV AND AIDS TESTING UPTAKE  
AMONG PREGNANT WOMEN IN LIMPOPO PROVINCE**

By

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## **DECLARATION**

I declare that the mini-dissertation hereby submitted to the University of Limpopo, for the degree of Masters of Arts in Clinical Psychology, has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

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## ABSTRACT

In this study, the researcher aimed to establish whether HIV/AIDS-related stigmas (enacted + internal) have an impact on disposition for HIV/AIDS testing uptake among pregnant women in the Limpopo Province.

A total of 457 pregnant women participated for the quantitative aspects, while 40 of the 457 participated in the qualitative aspects of this study. The multiple regression analysis method was used to analyze the relationship between levels of HIV/AIDS related stigmas (enacted + internal) and pregnant women's decision to dispose themselves for HIV/AIDS testing uptake. Further open-ended questions were content analyzed and presented in frequency tables.

The multiple regression analysis indicated that internal stigma was a significant factor negatively affecting pregnant women's disposition for HIV/AIDS testing uptake. External stigma was not a significant factor. Internal stigma accounted for (R-Square= 0.03) 3.0% of the variance. Qualitative, Psychosocial factors (i.e. fear of stigma, fear of being discriminated and lack of confidentiality over test results, as well lack of family and partner support) emerged to be common factors indicated by pregnant women to negatively influence some of the pregnant women's disposition for HIV/AIDS testing uptake.

It is recommended that intensive individual counseling sessions aimed at addressing the effect of internal stigma on HIV-testing, be integrated with existing PMTCT programmes. The involvement of partners, families, and communities in programmes that address HIV/AIDS-related stigma is of paramount importance.

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## **CHAPTER 1**

### **GENERAL ORIENTATION OF THE STUDY**

#### **1. 1 INTRODUCTION**

The continuous rise in the global pandemic, HIV/AIDS infection annually poses an increasing threat to human existence globally. Africa, particularly sub-Saharan Africa is coded to be the pandemic's epicenter (Clark, 2002). Reports from The Joint United Nations Programme (UN/AIDS, 2007) and Population Reference Bureau (PRB, 2007) indicate that of the 788,000,000 population of Sub-Saharan Africa, 22,500,000 people are living with HIV/AIDS, women being the most affected of the two genders. Globally, the percentage of women among people living with HIV has remained stable (at 50%) for several years, although women's share of infections is increasing in several countries. Within the pregnant women population, the prevalence of HIV/AIDS among women attending antenatal clinics in South Africa has been escalating between the year 1990 (0.7%) and 2005 (30.2%), although the rate of the increase in HIV prevalence has been leveling since 2006 (Department of health South Africa, 2007).

It is estimated that more than 90% of children living with HIV/AIDS acquired the virus during pregnancy, birth or breastfeeding, all being forms of HIV transmission that can be prevented (WHO, 2006; UN/AIDS & WHO, 2004). In South Africa, the rate of HIV/AIDS infection continues to rise unabated despite government's several anti-HIV/AIDS campaigns. In 2007, South Africa was documented to be home to 47,900,000 citizens, but in 2005 alone 5,500,000 people were living with HIV/AIDS (PRB, 2007; UN/AIDS, 2007). From these statistics, it is apparent that some of government's anti-

HIV/AIDS campaigns are unsuccessful. One of the stipulated campaigns in the fight against the continuous infection of the disease is Voluntary Counseling and Testing (VCT). The campaign is aimed at encouraging the overall population to participate in VCT. Pregnant women are further encouraged to engage in the Prevention-of-mother-to-child Transmission (PMTCT) programmes at antenatal clinics (UN/AIDS & WHO, 2004). This also aims at promoting the prevention of HIV transmission from mother-to-child, because, it was discovered that most children living with HIV acquired the infection during pregnancy, labour, delivery or during breastfeeding (WHO, 2006).

According to UN/AIDS & WHO (2004), the availability of medications that can block the transmission of HIV during pregnancy, childbirth and the postnatal period has created new opportunities to slow the spread of the virus. The introduction of drugs such as zidovudine and nevirapine to pregnant women and their infants have been clinically proven to be effective in the reduction of transmission rate of HIV (WHO, 2004). While the administration of the Antiretroviral Prophylaxis around the time of delivery, for example, can reduce transmission two-fold in breastfeeding populations (WHO, 2001). Therefore, the practice of prenatal HIV testing offers a very good opportunity for the prevention of HIV transmission in the period around the time of birth. Ramkissoon, Coutsoudis, Coovadia, Mthembu, Hlazo, and Smit (2006) explain that early and routine identification of HIV-infected pregnant women facilitates access to Anti-Retroviral Therapy (ART), contributes to the postponement of orphanhood for children and results in decreased HIV transmission to children.

However, statistics indicate that the consideration of VCT by pregnant women has not been fruitful in South Africa. Carter (2002) discovered that the rate at which pregnant women agree to be tested for HIV at the South African National Prevention of Mother to Child Transmission site is only 51% (about 3, 13 out of 6143 pregnant woman per month). That means, about 49% (about 3, 010 pregnant women) refuse to be tested, while of the total population considering testing, about 30% are HIV positive (Carter, 2002.). These statistics when compared to those of other countries (i.e. the United States) are relatively high. In the United States within the pregnant women population, women who do not consent to prenatal HIV testing range from 15-22% (Carusi, Learman & Posner, 1998; Irwin, Valdiserri & Holmberg, 1996). What accounts for the failure to consent for HIV testing by pregnant women in South Africa, particularly, in the Limpopo Province, is not well known. Studies from other countries have unearthed that consideration of VCT by pregnant women is impeded by several psychosocial factors. Within a pool of factors researched to have a negative effect on pregnant women's disposition for HIV-testing uptake, these two factors, fear of HIV/AIDS-related stigma and discrimination, have been implicated to be the two major factors associated with reluctance to HIV-testing within the pregnant women population (Bond, Chase, & Aggleton, 2002; Shangula, 2006; Toivo, 2005).

The application and generalization of such results within the South African context are to head in the wrong direction, since such studies are documentation of western countries and other African countries. From a racial and social stratification perspective, South Africa offers a very different social, economic and political context when compared to Western countries and the rest of Sub-Saharan Africa, although the situation may have

been changing since 1994 (McLanahan & Sandefur, 1994; Sibanda, 2004). Therefore, the assumption can be made that with knowledge and awareness of HIV/AIDS-related stigma pregnant women in The Greater Capricorn Region in Limpopo Province are likely to refuse going for VCT. In this regard this called for a study of this nature to be conducted aimed at establishing whether, HIV/AIDS-related stigma disposes pregnant women to refuse HIV-testing uptake during pregnancy, which will then account for part of the statistical findings documented by Carter (2002). The results of the study will inform the development of a wider information programme about such stigma and the steps that can be taken to alleviate it.

## **1.2 BACKGROUND OF THE STUDY**

### **1.2.1 Research problem**

Reports from the Department of Health South Africa (2007) indicate that South Africa (SA) is the country with the largest number of HIV infections in the world. PRB (2007) statistical data state that in SA, HIV prevalence among pregnant women attending antenatal clinics has increased from 1.7% in 1991 to 30.2% in 2005. HIV prevalence among antenatal clinic attendees remains among the highest in the country and the infection rate varies from province to province, with the infection rate among antenatal clinic attendees in Limpopo Province being at (19%) (UN/AIDS, 2008). On the one hand, VCT uptake by pregnant woman has been noticed to be limited and the majority of women attending antenatal care do not know their HIV status (Carter, 2002; Ramkisson et al., 2006). Considering research findings that HIV infection is also transmitted during pregnancy, childbirth and the postnatal period through breast-feeding (WHO, 2004),

many countries jointly embarked on programmes and campaigns to encourage HIV-testing among pregnant woman aimed at Prevention-of-Mother-to-Child-Transmission (PMTCT). The PMTCT programmes enable pregnant women to reduce significantly the chances that their infants will be born with HIV (UNAIDS & WHO, 2004).

South Africa, particularly Limpopo Province is no exception in the establishment of the PMTCT programmes. In antenatal clinics in Limpopo Province, HIV counseling and testing are offered free as part of PMTCT programmes, while pregnant women are also educated about the importance of HIV testing and the importance of enrolling for the PMTCT programme during pregnancy. Despite the government's introduction of counseling and voluntary HIV testing for pregnant women in SA in 2002, HIV testing by pregnant women has not been seen either to be desirable nor considered by many pregnant women (Carter, 2002; Ramkissoon, et al., 2006). Thus, this practice continues to put the new generation at the risk of being infected with HIV, which can inevitably be reduced remarkably through prenatal HIV testing.

The documented information of the lack of HIV-testing among the pregnant women population, left the researcher curious to establish what conditions cause a fertile ground for this situation in the Limpopo Province as part of SA, thus presuming that HIV/AIDS-related stigma accounts for the lack of HIV testing among the pregnant women population. This supposition evoked a need to conduct this study to validate the reality of the situation, putting forward the research question “Does **HIV/AIDS-related stigma** negatively affect pregnant women's disposition for **HIV-testing uptake**” in Limpopo Province?

### **1.2.2 Aim of the study**

The aim of this study was to investigate the effect of HIV/AIDS-related stigma on pregnant women's disposition for HIV/AIDS -testing uptake.

### **1.2.3 Objectives of the study**

The objectives of this study were:

- i. To identify if enacted (external) stigma affects HIV/AIDS testing uptake.
- ii. To identify if internal (internalized) stigma affects HIV/AIDS testing uptake.

### **1.2.4 Scope of the study**

The study was conducted in maternity wards of hospitals and antenatal clinics in Limpopo Province, SA. Limpopo Province is home to 5.4 million inhabitants. Among them, 97.1% are blacks, 0.1% are coloured, 0.1% are Indian/Asians, and 2.7% are Whites; of these 45.7% are males and 54.3% are females. Many of the inhabitants live under poor schooling, economic and medical conditions (Health System Trust & Department of Health South Africa, 1997; Statistics South Africa, 2000).

### **1.2.5 Significance of the study**

This study will inform the development of a wider information programme about such stigma and the steps that can be taken to alleviate it. It will help to better understand and control/manage mother-to-child HIV transmission in the Limpopo Province. The result will add knowledge and understanding of the epidemic in the Limpopo Province.

The study was motivated by a need to educate pregnant women about the importance of

considering VCT during pregnancy, to educate woman about alternative feeding mechanisms, as opposed to risky breast feeding and the research was also motivated by a wish to see a large number, if not, all pregnant women considering HIV-testing in the province without fear of stigma.

## **CHAPTER 2**

### **THEORETICAL FORMULATION**

#### **2.1 OPERATIONAL DEFINITION OF CONCEPTS**

This section details definition of major concepts that serve as a framework for the study:

##### **2.1.1 Stigma**

In sociological theory, a stigma is an attribute, behaviour, or reputation which is socially discrediting in a particular way; it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal way (Reitzer, 2006). Stigma has furthermore been defined as “an attribute that is significantly discrediting” (Goffman, 1963), and as “an attribute used to set the affected person or groups apart from the normalized social order, and this separation implies a devaluation” (Gilmore & Somerville, 1994). In this context stigma shares the same meaning as defined by Goffman (1963) and Reitzer (2006).

##### **2.1.2 HIV/AIDS-Related Stigma**

HIV/AIDS related stigma means a real (enacted stigma) or felt/imagined (internalized stigma) negative response to a person or persons by individuals, communities or societies as defined by Seale (2004). In this study, HIV/AIDS-related stigma denotes the shame and guilt associated with being HIV-positive and all discriminatory practices perceived and feared by pregnant women if they are tested HIV-positive.

### **2.1.3 Enacted (external) Stigma**

Enacted (external) stigma refers to the actual experience of discrimination. This may include the experience of dominating, oppressing, the exercise of power or control, harassment, categorizing, accusation, punishment, blame, devaluing, prejudice, silence, denial, ignorance, anger, a sense of inferiority, exclusion, ridicule, resentment, or confusion (Policy Project, Centre for the study of AIDS, USAID, & the Department of Health South Africa, 2003). This study has the same meaning as defined above.

### **2.1.4 Internal (felt/internalized) Stigma**

Internal stigma also described as felt, imagined, or self-stigma is the product of the internalization of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV-positive (Brouard & Wills, 2006). In this paper, internalized stigma (felt or imagined stigma) will denote negative self-perceptions, self-abasement, self-blame, and fear of discrimination associated with being HIV positive by pregnant women.

### **2.1.5 HIV/AIDS**

Human Immunodeficiency Virus (HIV) damages or destroys the cells of the immune system making the body less able to fight infections and more susceptible to often life threatening opportunistic infections (Drugs.com, 2006). The term Acquired Immunodeficiency Syndrome (AIDS) refers to the latter stages of HIV infection. Most individuals infected with HIV will progress to AIDS if not treated; however, there are very small numbers of patients who develop AIDS very slowly or not at all (Drugs.com,

2006). Thus, for the purpose of this study, HIV/AIDS will be used interchangeably to refer to either HIV or AIDS.

### **2.1.6 HIV/AIDS-Testing uptake**

HIV/AIDS-testing uptake as one of the major concepts used in this paper refers to pregnant women's consideration or rejection of Voluntary Counseling and HIV testing in antenatal clinics.

### **2.1.7 Pregnant women**

By pregnant women, the researcher refers to females who are expecting a baby.

## **2.2 Theoretical Perspectives**

This section details with several theories which attempt to explain the social phenomena stigma. These theories have been drawn from sociological and social psychological background. Among others is Goffman's (1963) theory of stigma in explanation of spoiled identity, attribution theory, blaming theory, contact theory, and deviance theory.

### **2.2.1 Sociological theories**

Goffman (1963) in stigma "notes on the management of a spoiled identity" postulates that stigma is an attribute that is significantly discrediting, which in the eyes of the society, serves to reduce the person who possesses it. "Jacoby (2005) explains that Goffman (1963) asserts that an individual who is stigmatized possesses "a trait" that can obtrude itself upon attention and turn those of us whom he meets away from him,

breaking the claim his other attributes have on us". Goffman (1963) argues that the stigmatized individual is hence seen as a person who possesses an undesirable difference. He furthermore states that stigma is conceptualized by society on the basis of what constitutes "difference" or "deviance", and that it is applied by the society through rules and sanctions resulting in what he describes as a kind of "spoiled identity" for the person concerned (Goffman, 1963).

Goffman (1963) specifically mentions two types of stigmatized people, the discredited and discreditable. The discredited are people who visibly vary from ideal humans or an individual whose differentness is self-evident. The discreditable secretly varies from ideal humans and, if their secrets were known, would be rejected by other people. Consequently, for the discredited individual, the key issue is the management of tension in social contact with normals, while for the discreditable individual; the key issue is the management of information regarded as secretive (Camilleri, 2005). It is apparent that the nature and course with which HIV/AIDS follow, inevitably subject HIV/AIDS victims vulnerable to being discredited and discreditable, thus predisposing HIV/AIDS victims to experience stigma and discrimination.

Based on Goffman's (1963) principal conceptualization of stigma, discredited HIV/AIDS patients will inevitably be subjected to isolation, rejection, harassment, abuse, and discrimination amongst other acts that violate human rights, while discreditable victims will continuously self-blame, self-deprecate and not disclose their status, fearing being stigmatized by their friends, families, and at large by their society or communities.

According to Goffman (1963), sociologists define stigma as a special kind of gap

between *virtual social identity* and *actual social identity*. According to the theory, society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories. When a stranger comes into our presence, then, first appearances are likely to enable us to anticipate his/her category and attributes, his/her "social identity". We lean on these anticipations that we have, transforming them into normative expectations, into righteously presented demands. These assumed demands and the character we impute to the individual will be called virtual social identity. The category and attributes he/she could in fact be proved to possess will be called his/her actual social identity (Goffman, 1963).

Furthermore, when a stranger is present before us, evidence can arise of him/her possessing an attribute that makes him/her different from others in the category of persons available for him/her to be, and of a less desirable kind, in the extreme, a person who is quite thoroughly bad, dangerous, or weak. She/he is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive. It constitutes a special discrepancy between virtual and actual social identity.

Sociologist, Falk (2001) describes stigma based on two categories, Existential Stigma and Achieved Stigma. From Falk's view Existential Stigma is a stigma deriving from a condition which the target of the stigma did not cause or over which he/she has little control. On the one hand, Achieved Stigma is viewed as stigma that is earned because of conduct and/or because they contributed heavily to attaining the stigma in question (Falk,

2001). From Jacoby's (2005) point of view stigma may also be described as a label that associates a person to a set of unwanted characteristics that form a stereotype. It is also affixed. When society categorizes individuals into certain groups, the labeled person is subjected to status loss and discrimination (Jacoby, 2005). Society will start to form expectations about those groups once the cultural stereotype is secured.

### **2.2.2 Social psychological theories of stigma**

#### **(a) Attribution model of stigma**

Attribution refers to our efforts to understand the causes behind other's behaviour and on some occasions the causes of our behaviour too (Baron & Byrne, 2003). According to the attribution theory by Weiner (1993), individuals' assignment of the cause of the disease can affect their affective and behavioural responses towards the disease carriers. When the public regards contraction of the disease to be controllable by the individuals, the public is more likely to hold the infected individuals to be responsible for their own illness. Hence, the public is more likely to blame the individuals and reject them from society (Corrigan, River, Lundin, Uphoff-Wasowski, Champion, & Mathisen, 2000). Fundamentally, the attribution model is based on two classic views, the correspondence inference, and correspondence bias.

The correspondence inference asks how we use information about other's behaviour as the basis for inferring that they possess various traits. As Baron and Byrne (2003) notes, the theory is concerned with how we decide, on the basis of observing others behaviour, that they possess specific traits or dispositions that will fairly remain stable over time. In

the process of attribution, we tend to focus most of our attention on certain types of actions, those most likely to prove informative. Unfortunately, people often commit the fundamental attribution error, which is the tendency for observers to underestimate situational influences and overestimate dispositional influences, in their evaluation of others (Myers & Spencer, 2004).

On the one hand, the correspondence bias relates to the tendency to explain others' actions as stemming from disposition even in the presence of clear situational causes. We tend to perceive others as acting as they do because they are "that kind of person", rather than because of many external factors that may influence their behaviour (Baron & Byrne, 2003). As a result, individuals are held more personally responsible for outcomes in situations where they are perceived to have control. If the outcome is negative, the person receives more blame, but less sympathy, pity, and offers of help (Cobb & de Charbert, 2002). With HIV and AIDS, those infected or have the disease attract increased anger and decreased empathy because the public consider their illness a product of personal decisions.

### **(b) Blaming theory**

This model suggests that people often blame groups other than their own for being affected by diseases and conditions such as HIV/ADS, and for putting society at risk of infection (Joffe, 1999). This emotional (rather than cognitive), and often unconscious, response to danger helps people to feel that they are at less risk of contracting serious diseases, but it has many negative effects (Deacon, Stephney & Prosalendis, 2004).

The association between disease, negatively defined behaviours or characteristics, and certain groups of people, results in stigmatization of the disease and most of the people infected by it (Deacon et al., 2004). Some stigmatizing ideas have a very powerful hold on society because of the way in which they fit into existing prejudices and power alliances. The not me-others are to blame phenomenon has become particularly prevalent in relation to disease threats in modern society (Deacon et al., 2004).

Many risks are perceived as predictable and, therefore, controllable because they are considered to be systematically caused and statistically describable (Douglas, 1990). The blaming theory of stigma thus provides an alternative approach to the social control model. The main challenge lies in using this model to help understand the relationship between stigma, discrimination, and power and how to change the way people respond to risk (Deacon et al., 2004).

### **2.2.3 African sociocultural construction of stigma and cultural beliefs of HIV&AIDS**

A report from the Human Science Research Council (HSRC, 2005) indicates that most of the research on HIV/AIDS stigma has been done in the USA. Considerable research attention is now being focused on HIV/AIDS research in Africa because of the severity of the African epidemic, the politicization of the HIV/AIDS issue, and the fact that HIV/AIDS seems to be highly stigmatized in the region. It is, therefore, important to understand HIV/AIDS related stigma in relation to the broader African social, political, economic, and cultural context.

Religion, as defender of the moral and social norms of a culture, often functions in such a way that it reinforces and ritualizes symbolic stigma (Paterson, 2005). For it is symbolic stigma that carries the weight of the religious, moral, cultural, and social baggage associated with particular diseases, imbuing them with negative meanings that go far beyond the instrumental concerns over risk assessment and resource constraint. In the language of religion, the infringement of cultural and social norms may be re-conceptualized as 'sin' (Paterson, 2005). Thus, HIV positive individuals are perceived as sinners and stigmatized.

From an African ideology, to understand the reason why diseases such as HIV/AIDS are highly stigmatized, one needs to look or think of religious settings where punishment theories of illness causation are in force (Rankin, 1994). One such outlook presumes an aroused deity or ancestor bringing illness upon a person in retribution for an offence. For instance, in Ethiopia the belief that HIV is a punishment from God for sins committed is particularly strong (International Center for research on Women [ICRW], 2002). In a South African study Lesko (2005) highlights that the cultural perception that encompasses the explanation of the origins of HIV and AIDS as witchcraft or as punishment from God further reinforces stigmatizing behaviour. Furthermore, the norms and taboos about sex, such as explanations of HIV and AIDS in terms of purity and pollution or associations of HIV and AIDS with deviant behavior, make it difficult to talk about sex, adding further to stigmatizing attitudes and behaviour (Lesko, 2005).

Rankin, Brennan, Schell, Laviwa, and Rankin (2003) indicate that this notion stigmatizes people struggling with their illness. It blames their sickness upon misbehaviours, while at

the same time it rationalizes privileging the well over the ill. These scholars indicate that punishment theories authorize communities to isolate or purge the impure (people whose illness or imagined “sinfulness” would contaminate the whole), while reassuring that virtue and social status will protect the righteous.

Clergy and other religious leaders are as susceptible as others are, to the temptation to exercise power over others. This theological approach warrants valorizing or stigmatizing people as “saved” or “sinner,” “pure” or “impure,” “us” or “them,” and it strengthens the broader social stratifications within which stigma nourishes (Messer, 2004). In most Sub-Saharan Africa, much of the stigmatizing language and description of stigmatizing and discriminatory behaviour centers on the sexual transmission of HIV (ICRW, 2002). Those with HIV get it through their own bad immoral behaviour, namely sexual activity (i.e. pre-marital sex, extramarital sex, and multiple partners) that is not sanctioned socially or goes against religious teachings. Therefore, the infected are “promiscuous,” “careless,” or “unable to control themselves” and have brought HIV upon themselves. Hence, the infected are blamed for bringing HIV into the community, consequently are stigmatized, and discriminated (ICRW, 2002).

### **2.3 Theoretical framework**

These stipulated theories attempt to provide an in-depth analysis of the process of stigma and the overall understanding of it. However, after reviewing all the theoretical perspectives of stigma, the researcher identified this study to be inclined with both the sociological and socio-psychological theories of stigma. Therefore, this study used both socio-psychological and sociological theories of stigma as its pillar of strength.

Africa as a continent is constituted by a variety of societies, sharing and bonded by differing social norms and values, differing cultural belief systems and cultural practices. Thus, this differing cultural beliefs and principles of morality that govern people's behaviour in their social context influences people's responses to diseases like HIV/AIDS. With respect to the African socio-cultural construction of stigma, an attempt was also made in this study to incorporate pregnant women's views on stigmatizing beliefs of HIV/AIDS, in relation to Africans' ideologies of the processes of stigma. Particularly from pregnant woman's point of view in Limpopo Province as to what are some of the beliefs attached to HIV/AIDS that makes it to be so stigmatized, thus influencing their decisions to dispose for HIV-testing uptake.

## CHAPTER 3

### LITERATURE REVIEW

#### **3.1 Enacted stigma (external), and HIV/AIDS testing uptake**

According to Bharat, Aggleton, and Tyrer (2001), three different types of HIV/AIDS related stigma could be identified; Self-stigma which is manifested by self-blame and self-deprecation. Perceived stigma is manifested in the fears that people have around being stigmatized if they are HIV-positive and choose to disclose their HIV status to others. And finally, Enacted stigma is when people are actually discriminated against because they have, or are thought to have, HIV. Enacted stigma “the actual experience of discrimination”, among People Living with HIV/AIDS (PLWHA) is pervasive and ranges from the experience of domination, oppression, the exercise of power or control, harassment, categorizing, accusation, punishment, blame, exclusion, ridicule, or resentment (Policy Project, 2003). The pandemic has led to increased gender-based violence as HIV-positive women are assaulted, prevented from having children, dismissed from employment, disowned, shunned by their families and communities, and sometimes even killed, (ICRW, 2002; UNIFEM, 2001). Stigma and discrimination associated with HIV and AIDS are great barriers to preventing further infections and providing adequate care, support and treatment (Bond et al., 2002; Heijnders & Van Brakel, 2004; Ramkissoon et al., 2006).

Women with HIV and pregnant women assumed to be HIV positive are repeatedly subjected to extensive forms of stigma, particularly once they become sick or if their child dies (Bond et al., 2002). Stigmas associated with HIV/AIDS do not arise out of the

blue, nor are they randomly patterned. They usually build upon and reinforce on pre-existing fears and prejudices; about poverty, about gender, about sex and sexuality, and about race; and they frequently give rise to intolerance and sexist and racist discriminatory actions (Parker & Aggleton, 2002; WHO & UN/AIDS, 2002). These are further reinforced by the fact that HIV/AIDS is associated with risk behaviours such as, sexual promiscuity, homosexuality, sexual exchange, and drug use (Bond et al., 2002; UNIFEM, 2001), which are controllable by victims of HIV/AIDS. It is further stipulated by Berer (2000) that due to fear of violence, stigma, and ostracism, many women avoid taking HIV tests, thereby denying themselves crucial information about their health and excluding themselves from programmes to prevent HIV transmission to their newborns.

A study by McCoy, Besser, Visser, and Dohey (2002) in South Africa explored and unearthed that pregnant women did not take VCT because of long waiting times, and that people would see them. They were not assured of the confidentiality in this situation, which could lead them to being stigmatized. Pool, Nyanzi, and Whitworth (2001) found that pregnant women in rural south west-Uganda were willing to be tested for HIV, but there was a belief that if they were HIV positive, they might be refused assistance by the maternity staff when they should go into labour or that the staff would kill them in order to reduce the infections. This belief contributed to low levels of VCT uptake among pregnant women. Shangula (2006) documented that among pregnant women in Namibia, the fear of being discriminated by the family and the community at large deterred pregnant women from testing for HIV during pregnancy. In support, Goosen and Klugman (1996) found that many people with HIV are being discriminated, once their HIV status is known; they can lose their jobs, friends, homes, and even their families.

Social structures may also have an influence on whether people will get tested for HIV. People infected and affected by HIV/AIDS are often discriminated and stigmatized in areas such as employment, medical treatment, care, and custody of children, as well as in other social relationships (Mabunda, 2006; Seale, 2004). Common forms of external stigma are gossip, verbal abuse and name calling (Bond et al., 2002). HIV/AIDS-related stigma and discrimination pose a serious threat to all people infected, affected, or associated with the disease. The right to health care, the right to freedom of speech and movement, the right to services such as housing and education, the right to confidentiality, dignity, liberty, and security, and ultimately the right to life (Seale, 2004) could be affected. The United Nations Commission on Human Rights Resolutions states that discrimination on the basis of HIV/AIDS status is prohibited by existing human rights standards (Gruskin, 2002). Thus, eliminating such stigma and accepting the disease as it is, will encourage people to use the benefit of VCT services (Ginwalla, Grant, Day, Dlova, MacCintyre & Baggaley, 2002; Van Dyk & Van Dyk, 2003).

### **3.2 Internal (internalized/felt or self) stigma and HIV/AIDS testing uptake**

Brouard and Wills (2006) are of the opinion that internal stigma has received little attention from researchers and programme planners. Leickness, Simbayi, Kalichman, Strebel, Cloete, Henda, and Mqeketo (2007) stipulate that the effects of internalized AIDS stigmas have not been investigated in Africa, thus literature on the effects (i.e. HIV-testing, prevention, and treatment) of this type of stigma on people living with HIV/AIDS and the general population is limited. In the same and first study of internalized HIV-stigma, the scholars identified that experiences of discrimination among

HIV-positive men and women, were accompanied by internalized stigmas in the form of feelings of dirtiness, shamefulness, or guilty as a result of being HIV-positive. Brouard and Wills (2006) furthermore indicate that internal stigma can have a profound effect on HIV prevention, treatment, and care. They further purport that internal stigma can also affect caregivers and family members, who may internalize feelings of shame, guilt, or fear. The fear of stigma, actual experience of stigma, negative self-perceptions, and self-abasement about stigma reduce an individual's willingness to practicing safe sex, prevention, seeking HIV test, disclosing HIV status to others, ask for (or give) care and support, and to begin and adhere to treatment (Bond et al., 2002).

Lee, Kochman, and Sikkema (2002) maintain that studies on the impact of HIV stigma have shown that it harms both HIV-positive persons and HIV-negative persons. Toivo (2005) mentions that being tested HIV-positive during pregnancy increases worries among pregnant women regarding the well-being of their babies, fear and anticipate being stigmatized by the health workers, family members and the entire community if tested positive. Thorne and Newell (2003) also support this by stating that HIV/AIDS related stigma is a barrier for pregnant women from seeking HIV testing, leading to infected mothers to expose their children to HIV infection through delivery, or breast-feeding.

A study by Herek, Capitanio and Widaman (2002) in the USA, revealed that 38% of a sample of adults stated that they would be very disturbed about stigma if they were HIV-positive, and 44% of the persons who expressed this concern, inferred that stigma influences their decisions relating to HIV testing. Stigmas are linked to discrimination and are, therefore, realistic barriers to going for HIV testing (Parker & Aggleton, 2003).

Chesney and Smith (1999) maintain that the stigma associated with HIV/AIDS negatively impacts on people's decisions regarding whether and when to be tested for the virus. Studies and experience in some regions in Namibia have shown that most pregnant women actually desire testing in order to protect their babies, but unfortunately they often fear stigma and rejection if they were to test positive (Ministry Of Health and Social Services, 2004).

Brown, Macintyre, and Trujillo (2003) are of the opinion that internalized/felt stigma can be seen as a survival strategy to limit the occurrence of enacted stigma. Internalized stigma is likely to make an individual more sensitive to both actual and anticipated rejection and discrimination by others, which negatively affects disclosure and testing (Chesney & Smith, 1999). This 'felt stigma' may include actual experiences of stigma and discrimination, as well as assumptions of self-blame and being stigmatized. Felt stigma negatively impacts on psychological wellbeing, treatment and on the processes of coping with HIV/AIDS (Parker, Colvin, & Birdsall, 2006). Hence, for the purpose of this study, the researcher hypothesizes that internalized AIDS stigma serves as another form of HIV-related stigma, that impede pregnant women's disposition for HIV-testing uptake in antenatal clinics.

### **3.3 Hypotheses**

- Enacted (external) stigma negatively affects pregnant women's disposition for HIV/AIDS testing uptake.
- Internal (internalized) stigma negatively affects pregnant women's disposition for HIV/AIDS testing uptake.

## **CHAPTER 4**

### **METHODOLOGY**

This chapter details all the methods that were employed in this study. It provides explanations about samples, the numbers of people contacted for the study, the method of data collection, methods of data analysis, and ethical considerations.

#### **4.1 The Study Design**

The study adopted both qualitative and quantitative research methods. Qualitative research methods were developed in the social sciences to enable researchers to study social and cultural phenomena (Myers, 1997). Creswell (2003) cites that a study based upon a qualitative process of inquiry has the goal of understanding a social or human problem from multiple perspectives. Qualitative research is, therefore, conducted in a natural setting and it involves a process of building a complex and holistic picture of the phenomenon of interest. It furthermore does not usually describe data in the form of numbers, but is an inductive approach, and its goal is to gain a deeper understanding of a person's or a group's experience (Creswell, 2003).

On the other hand, quantitative research is an inquiry into an identified problem, based on testing a theory, measured with numbers, and analyzed using statistical techniques (Creswell, 1994). Therefore, the goal of quantitative methods is to determine whether the predictive generalizations of a theory hold true. This method utilizes strict control of variables and the focus is on static reality.

## **4.2 Participants**

A total of 457 pregnant women participated in the quantitative aspect of this study. Another 40 participated in the qualitative aspect (5 per focus group and per cluster). The participants were drawn from pregnant woman admitted to the hospitals or those who were attending the antenatal clinics in Limpopo Province. All women admitted or attending the antenatal clinics during the period of the study, had the opportunity to participate in the study.

## **4.3 Sampling method**

The stratified random sampling method was used to sample the hospitals and clinics that participated in the study. A combined total of 44 hospitals and clinics in Limpopo Province were sampled for participation. The hospitals and clinics were clustered into 4, depending on their proximity to one another. In each cluster, two hospitals/clinics were selected by ballot for participation in the study.

The availability sampling method was used for inclusion of pregnant women in the study. All consenting pregnant women admitted to and attending the antenatal clinics in sampled hospitals and clinics participated in the study. The researcher continued to sample the participants until the target sample size of 457 women had been obtained.

## **4.4 Instruments**

### **4.4.1 Quantitative instruments**

Quantitative data were collected through the employment of three instruments, the demographic instrument, the AIDS-related stigma scale, and the internal stigma scale. The data were collected by the researcher and field workers; and all questionnaires were available in English, Northern Sotho, Tshivenda, and Tsonga. Services of translators were employed where necessary.

#### **4.4.1.1. Demographic information**

The participants were asked their age, years of education completed, employment status and marital status (See Appendix A).

#### **4.4.1.2 AIDS-related (external) stigma scale**

Kalichman, Simbayi, Jooste, Toefy, Cain, Cherry and Kagee (2005) developed the scale through adapting AIDS stigma items from measures described by Herek et al., (2002); Bauman, Camacho, Silver, Hudis, and Draimin,(2002); and Pequednat, Bauman, Bray, DiClimente, Dilorio, Hoppe, Jemmott, Krauss, Miles, Paikoff, Rapkin, Rotherram-Borus, and Szapocznik (2001). These include three items used in the NIMH International Collaborative HIV/STD Prevention trial conducted in China, India, Peru, Russia, and Zimbabwe. The AIDS stigmatizing beliefs were structured and guided by the theoretical framework offered by Goffman (1963) and previously by Herek, et al., (2002). Three aspects of social stigma identified by Goffman (1963) include blemishes of personal character and stained social identity, and physical deformity or defects.

Blemished personal character and stained social identity as aspects of AIDS formed part of the initial item pool and consisted of 12 items. Of these items, six AIDS stigma items reflect on the repulsion and blame dimension to stigma that include beliefs about negative qualities of people living with AIDS (e.g. dirty, untrustworthy) and shamefulness of the behaviour of people with AIDS (e.g. guilt, shame). The following six items assessed coercion, avoidance, and social sanction dimensions of stigma against people living with HIV/AIDS (e.g. should not work with children, restrictions on freedom, and isolation).

The initial review of Kalichman et al., (2005) showed that three items were redundant, and consequently did not contribute to the overall value of the scale. Finally, the items were revised and written by a team of South African community researchers. Therefore, the final AIDS-Stigma Scale consists of nine items that cover a broad range of stigmatizing beliefs (Kalichman et al., 2005). This nine-items scale is responded to by answering either “Agree” or “Disagree” with responses scored to reflect the endorsement of an AIDS stigma. The reason why a two-option response format was selected was to reduce confusion and minimize the response burden. Previously no multi-item AIDS stigma scales had been shown to be reliable and valid in Africa. The research of Kalichman et al., (2005) reports the development of the nine-item AIDS-related Stigma Scale. Research conducted in five South African communities ( $N = 2306$ ) found the scale internally consistent,  $\alpha = 0.75$  and time stable over 3 months,  $r = 0.67$ . The scale was also reliable in three different languages (English, Xhosa, and Afrikaans). Therefore, in this study this scale was used to identify enacted stigma among pregnant women. (See Appendix C).

#### 4.4.1.3 Internalized stigma scale

In this scale, items were adapted to assess internalized AIDS stigmas among pregnant women. These items were adapted from a scale developed to measure internalized stigma among HIV positive men and women by Leickness et al., (2007). Their scale was adapted from a scale developed to measure AIDS-related stigma beliefs in general South African populations by Kalichman et al., (2005). Originally, seven items from Leickness et al.,'s (2007) scale were selected and the wording reframed to represent possible negative self-perceptions and self-abasement within the pregnant women population, in case they tested HIV-positive. Original items from Leickness et al., (2007), for example, read as follows; "*Being HIV positive makes me feel dirty*", "*I feel guilty that I am HIV positive*", and "*I am ashamed that I am HIV positive*". For this study these items to indicate internal stigma among pregnant women read as follows; "*Being HIV positive will make me feel dirty*", "*I will feel guilty if I am HIV positive*", and "*I will be ashamed if I am HIV positive*".

The participants responded by indicating whether they "AGREE" or "DISAGREE" with the items. If many of the participants agree to an item, it indicated high levels of internal stigma. Items were scored 1=Agree and 0=Disagree, thus the total scale score was obtained by the sum of all endorsed items. In the original scale, each of the seven internalized stigma items' responses were examined as individual indicators of internalized AIDS stigma and the scale was computed by summing up all items endorsed in the direction of greater internalized stigma. Items were responded dichotomously, 1 = agree, 0 = disagree; scale scores represented the sum total of endorsed items and ranged

from 0–7. The internalized AIDS stigma scale score was found to be internally consistent,  $\alpha = .70$  (Leickness et al., 2007) (See Appendix D).

#### **4.4.1.4. Coding**

For the AIDS-related Stigma Scale, all statements made were derogatory in nature. More “I Agree” statements indicated a higher level of stigma. Thus, “I Agree” was scored 1, and “I Disagree” was scored 0. Scores obtained (either high or low scores), which denoted high levels or low levels of enacted stigma among pregnant women were correlated with pregnant women’s decision taken either to agree or refuse to go for HIV testing.

For the Internalized Stigma Scale, similarly to the AIDS-Related Stigma Scale, all statements were derogatory in nature. “I Agree” statements indicated a higher level of internalized stigma. Thus, “I Agree” was scored 1, and “I Disagree” was scored 0. Also on this scale, scores obtained (either high or low scores), denoted high levels or low levels of internalized stigma among pregnant women which was correlated with pregnant women’s decision to agree or refuse to go for HIV testing.

#### **4.4.2 Qualitative instrument**

The qualitative data collection method was a single semi-structured interview conducted with five consenting participants in each participating hospital. The purpose of the interview was to identify significant enacted and internal stigmatizing factors influencing pregnant women’s decisions to agree to or refuse to undergo HIV testing. The questions

are included in the **Topic Guide** (Appendix B). The responses were recorded with tape recorders and the researcher wrote field notes and diaries.

#### **4.4.3 Procedure**

The first step in commencing with this human experimentation research was by obtaining permission from the University of Limpopo (Turffloop Campus) Ethics Committee. Approval of the study led to approach of Limpopo Province's Head of the Department of Health and Social Development with the proposal and all considered ethics. This aimed at enhancing them to award the necessary permission to visit the Province's hospitals and further liaise with municipal and regional hospital managements for their full corporation with the researcher during the data collection period.

After approval was obtained from both parties, the actual data collection process started. The participants were approached in all hospitals that were sampled, until the desired sample for this study was reached. It was compulsory for all these women to go for HIV pre-test counseling before they gave birth. They did, however, have a choice either to accept or to reject the HIV test. The HIV pre-test counseling was done in a private office of the maternity wards of these hospitals. The data were collected after pre-test HIV counseling had been done. Participation in the research was voluntary, confidentiality and anonymity were assured, and all participants completed a consent form.

## **4.5 Statistical Methods**

### **4.5.1 Quantitative data analysis**

This study made use of quantitative data analysis by utilizing the computerized Statistical Package for the Social Science (SPSS) programme. Numbers and tables were used to help the researcher in describing, explaining, and exploring data. Frequency tables were also used to present the number of pregnant women either refusing or agreeing to go for voluntary HIV testing. In addition, Multiple Logistic Regression was used to analyze the relationship between (on the one hand) demographic characteristics, enacted stigma, internalized stigma, and (on the other hand) disposition to go for voluntary HIV-testing.

### **4.5.2 Qualitative data analysis**

The responses were content-analyzed using thematic method of analysis. Field notes and diaries were also analyzed. The themes that emerged during the focus group discussions were used to write up the results from the open-ended questions.

#### **4.5.2.1 Qualitative data management**

The initial aim of the qualitative data analysis was to reduce the large volume of the text data into more manageable units. Coffey and Atkinson (1996) describe the process as data reduction, data preparation, or data management. The qualitative data management went through the following stages:

#### **4.5.2.2 Open coding: getting started**

Open coding is the first stage of analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1998) and involves “breaking down, examining, comparing, conceptualizing, and categorizing data” (Strauss & Corbin, 1998). The primary goal of this phase was to identify different categories or codes (Dey, 1999). Words, lines of text and phrases were compared and consequently grouped together. The initial units of text coded, were single lines; later phrases, followed by whole paragraphs of text. Line-by-line analysis was initially used to interrogate the data as noted by Glaser (1978). Because not all data were meaningful, not everything was coded. Only the most interesting and meaningful phrases were identified, pasted together, and assigned a label or tag as mentioned by Coffey and Atkinson (1996).

#### **4.5.2.3 Axial coding: linking categories**

Axial coding is the second phase of analysis (Strauss & Corbin, 1998). This phase primarily focused on determining relationships between categories. Where the aim with open coding was to fragment the data and identify new categories, axial coding focused on putting the data back again in new ways, thus aiming to make connections between categories and sub-categories (Strauss & Corbin, 1998).

#### **4.5.2.4 Selective coding: building theory**

Selective coding refers to a process where only data that relate to the core category are used to explain the evolving theory (Dey, 1999). Such categories are validated or verified through theoretical sampling, while other categories may need to be further refined and developed (Dey, 1999; Strauss & Corbin, 1998) This third phase of analysis involved

building a provisional theory by interpreting the data. By this time, categories had been developed, labeled, and relate to other categories. Comparisons were made using text from within and across cases. Interpretations were made of the processes, strategies, and social interactions (Coffey & Atkinson, 1996). Text examples and quotes were also used to illustrate the provisional theory.

#### **4.6 Ethical considerations**

Ethics are a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants, and students (De Vos, Strydom, Fouché, Poggenpoel, & Schurink, 1998). Therefore, the researcher needs not to overlook these rules as they are widely accepted in any professional field of research. In this study, the participants completed the questionnaires after they had received pre-test counseling from HIV counselors. They were also informed about the purpose of the research and confidentiality and anonymity were assured. All participants completed a consent form before they took part in the study (Appendix E).

In respect of the emotional arousal the participants might have experienced following completion of the questionnaires, the following precautions were made. Each participant was provided with the contact information of the clinical psychologist and social worker at both hospitals, should they need any help. The researcher arranged with these professionals before the study commenced, in order to assist the participants that might contact them.

## **CHAPTER 5**

### **RESULTS**

#### **5.1. INTRODUCTION**

This chapter presents the findings of the study. The first part focuses on the quantitative results, followed by the qualitative results of this study. The data analysis in this chapter is discussed in accordance with identified themes, categories, and subcategories.

The overall results are presented in this format: frequency tables of demographic variables, hypotheses testing, and results from open-ended questions relating to HIV stigma, and lastly summary results.

#### **5.2. FREQUENCY TABLES OF DEMOGRAPHIC VARIABLES**

The participants in the study were drawn from five districts in Limpopo Province. Table 1 shows the frequency distribution of the study participants according to the districts they came from.

**Table 1: Distribution of participants by districts**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid				
Capricorn	224	49.0	49.0	49.0
Vhembe	78	17.1	17.1	66.1
Sekhukhune	94	20.6	20.6	86.7
Waterberg	25	5.5	5.5	92.1
Mopani	36	7.9	7.9	100.0
Total	457	100.0	100.0	

The greater percentage of the participants came from greater Capricorn district (49.0%), followed by Sekhukhune district (20.6%) and Vhembe (17.1%).

Limpopo Province is characterized by multicultural groups with diverse languages spoken. The table that follows presents the language distribution that the participants were speaking as their home language.

**Table 2: Home language distribution of the participants**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid				
Sepedi	308	67.4	67.4	67.4
Tshivenda	77	16.8	16.8	84.2
Setswana	6	1.3	1.3	85.6
Tsonga	54	11.8	11.8	97.4
Ndebele	7	1.5	1.5	98.9
IsiZulu	1	.2	.2	99.1
Swati	1	.2	.2	99.3
English	3	.7	.7	100.0
Total	457	100.0	100.0	

The distribution reflects that the majority of participants were Sepedi speakers.

Table 3 highlights the religious denominations the majority of the participants were affiliated to.

**Table 3: Religious affiliation distribution of the participants**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid				
Apostolic	35	7.7	7.7	7.7
Christian	192	42.0	42.0	49.7
Turbine Dei	1	.2	.2	49.9
Presbyterian	1	.2	.2	50.1
Zion Christian Church (ZCC)	193	42.2	42.2	92.3
Dutch	1	.2	.2	92.6
African	8	1.8	1.8	94.3
International Pentecostal Holiness Church (IPHC)	11	2.4	2.4	96.7
Muslim	4	.9	.9	97.6
None	11	2.4	2.4	100.0
Total	457	100.0	100.0	

The majority of the study participants were affiliated to Christian denominations, with a large number of participants belonging to the Zion Christian Church (42, 2%).

Table 4 provides information on the age groups of the participants.

**Table 4: Age distribution of the participants**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid				
17 years or younger	19	4.2	4.2	4.2
18-25 years	211	46.2	46.2	50.3
26-35 years	176	38.5	38.5	88.8
36-45 years	46	10.1	10.1	98.9
46+ years	5	1.1	1.1	100.0
Total	457	100.0	100.0	

This table indicates that most of the participants were between 18-35 years of age.

Levels of educational background for the study participants are tabulated in Table 5.

**Table 5: Distribution of years of education of participants**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid No formal schooling	16	3.5	3.5	3.5
1-7 years	35	7.7	7.7	11.2
8-12 years	253	55.4	55.4	66.5
Post-matric diploma	87	19.0	19.0	85.6
University level	66	14.4	14.4	100.0
Total	457	100.0	100.0	

The majority of the participants had at least 8 years of formal education.

The following table provides an indication of the employment status of the participants and the employment sectors mostly attained by the participants.

**Table 6: Employment status of the 457 studied population**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Education	25	5.5	5.5	5.5
Medical/social	14	3.1	3.1	8.5
Admin/comm.	27	5.9	5.9	14.4
Unskilled labour	25	5.5	5.5	19.9
Unemployed	269	58.9	58.9	78.8
Civil servant	14	3.1	3.1	81.8
Student	78	17.1	17.1	98.9
Self-employed	5	1.1	1.1	100.0
Total	457	100.0	100.0	

Most of the participants were unemployed (58, 9%), with relatively few of them being students (17, 1%).

The marital status of the participants is shown in Table 7.

**Table 7: Distribution of participants by marital status**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Single	200	43.8	43.8	43.8
	In-relationship	98	21.4	21.4	65.2
	Married	136	29.8	29.8	95.0
	Cohabitation	16	3.5	3.5	98.5
	Divorced	7	1.5	1.5	100.0
	Total	457	100.0	100.0	

Most of the participants were not married.

The following table shows where the ethnic groups of the participants came from

**Table 8: Ethnic distribution of the population**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Pedi	311	68.1	68.1	68.1
	Tsonga	49	10.7	10.7	78.8
	Venda	71	15.5	15.5	94.3
	Ndebele	14	3.1	3.1	97.4
	White	2	.4	.4	97.8
	Indian	1	.2	.2	98.0
	Afrikaners	9	2.0	2.0	100.0
	Total	457	100.0	100.0	

Table 8 shows that most of the participants were belonging to the Pedi ethnic group.

The findings correlate positively with the language frequently spoken by the participants reflected in Table 2. The frequency distribution of the residential areas is tabulated in Table 9.

**Table 9: Residential areas of the participants**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Urban	28	6.1	6.1	6.1
Semi-urban	64	14.0	14.0	20.1
Semi-rural	14	3.1	3.1	23.2
Rural	351	76.8	76.8	100.0
Total	457	100.0	100.0	

Most of the participants came from rural areas.

The pregnant women's disposition for HIV testing uptake is illustrated in Table 10.

**Table 10: Participants' disposition for HIV-testing uptake**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Definitely agree	286	62.6	62.6	62.6
Agree	119	26.0	26.0	88.6
I don't know	31	6.8	6.8	95.4
Disagree	14	3.1	3.1	98.5
Definitely disagree	7	1.5	1.5	100.0
Total	457	100.0	100.0	

Most of the pregnant women were interested in agreeing to undergo HIV testing.

### **5.3 HYPOTHESES TESTING**

This sub-section focuses on the test of hypotheses, namely:

1. Enacted (external) stigma negatively affects pregnant women's disposition for HIV/AIDS testing uptake.
2. Internal (internalized/felt) stigma negatively affects pregnant women's disposition for HIV/AIDS testing uptake.

Table 11 shows the regression analysis showing the effect of the independent variables (internal and external stigmas) on the dependent (pregnant women's decision to dispose for HIV testing) variable.

**Table 11: Regression analysis showing the effect of the independent variables on the dependant variable**

**Variables Entered/Removed**

Model	Variables Entered	Variables Removed	Method
1	Total Internal Stigma Total External Stigma	.	Enter

a. All requested variables entered.

b. Dependent Variable: Will you be disposed to go for HIV testing?

**Model Summary**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.172 <sup>a</sup>	.030	.025	.85643

a. Predictors: (Constant), Total.Internal.Stigma, Total.External.Stigma

**ANOVA<sup>b</sup>**

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	10.144	2	5.072	6.915	.001 <sup>a</sup>
	Residual	332.998	454	.733		
	Total	343.142	456			

a. Predictors: (Constant), Total.Internal.Stigma, Total.External.Stigma

b. Dependent Variable: Will you be disposed to go for HIV testing?

**Coefficients<sup>a</sup>**

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	
	B	Std. Error	Beta			
1	(Constant)	1.355	.076		17.778	.000
	Total.External.Stigma	-.005	.025	-.010	-.204	.838
	Total.Internal.Stigma	.075	.021	.174	3.640	.000

a. Dependent Variable: Will you be disposed to go for HIV testing?

The result of the regression analyses supports the hypothesis that internal stigma significantly negatively affects pregnant women`s disposition for HIV/AIDS testing uptake (B=0.075, t=3.640, p < 0.05). Thus, as the levels of internal stigma increase, the disposition for HIV-testing declines. External stigma is not a significant factor. Internal stigma accounts for about 3.0% (R-Square 0.30) of the variability of pregnant women`s disposition for HIV testing uptake.

#### **5.4. RESULTS FROM OPEN-ENDED QUESTIONS RELATING TO HIV STIGMA**

This study shows that the majority of the participants (88.6%, N=405) were disposed for HIV-testing uptake, 4.6% (N=21) of them would not agree, and 6.8% (N=31) were undecided (See Table 10). The tables that follow compare the responses of the pregnant women who were not disposed or who were undecided about going for voluntary HIV testing and that of those who were disposed. Only the first three items with the highest frequencies are presented.

Table 12 presents the views of the participants on the reasons for their disposition.

**Table 12: Reasons for disposition/non-disposition**

<b>First three items with highest Frequency</b>	<b>Percentage of those who were not disposed or do not know their disposition ( N= 52)</b>	<b>Percentage of those who are disposed to go for voluntary HIV testing ( N= 405)</b>	<b>Chisquare Value</b>	<b>df</b>	<b>p</b>
1. To know my status	26.9%	54.8%	154.54	17	0.00*
2. Because I have fear of discrimination	23.1%	1.2%			
3. To know my status in order to protect my baby against HIV/AIDS	3.8%	23.5%			
4. To know my status so that I can take care of myself and the baby	3.8%	3.0%			
5. I will be heart broken if I tested positive	3.8%	0.0%			
6. Due to lack of self-confidence	3.8%	0.0%			

\* Significant at  $p < 0.05$

Table 12, shows that those who were not disposed or who were undecided were worried more about discrimination (from the society), and cared less (compared to those who were disposed) about the importance of knowing their HIV status and preventing mother-to-child transmission. Some other barriers mentioned were a lack of confidentiality about the HIV-test results, fear of family rejection, and a lack of self-confidence.

Table 13 shows the response of the participants on what would make them change their disposition.

**Table 13: What would make the participant change her decision regarding the choice to go for HIV-testing?**

<b>First three items with highest Frequency</b>	<b>Percentage of those who were not disposed or did not know their disposition ( N= 52)</b>	<b>Percentage of those who were disposed to go for voluntary HIV testing ( N= 405)</b>	<b>Chisquare Value</b>	<b>df</b>	<b>p</b>
1. If I feel sick in my body	11.5%	1.2%	112.23	23	0.00*
2. Nothing	11.5%	48.4%			
3. If my relationship with my husband is	11.5%	0.2%			

better					
4. If I know my HIV-status	7.7%	6.2%			
5. My husband's disagreement	5.8%	0.5%			
6. If I think negatively	5.8%	3.7%			

\* Significant at  $p < 0.05$

Table 13 shows that among those who were not disposed or who were undecided, the situations that would make them change their minds were:

- a) If they were compelled by illness to go for HIV-testing.
- b) If they anticipated that, the environment would be very receptive of them on knowing their HIV status.

Most of those who were disposed would not change their minds.

Table 14 shows the responses of the participants on what makes pregnant women to go for or not go for Voluntary HIV testing.

**Table 14: Views on what makes pregnant women go for/ not go for voluntary HIV-testing**

First three items with highest Frequency	Percentage of those who were not disposed or do not know their	Percentage of those who were disposed to go for	Chisquare Value	df	p
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	<b>disposition ( N= 52)</b>	<b>voluntary HIV testing ( N= 405)</b>			
1. If they want to protect the baby from HIV	42.3%	62.0%	22.88	17	0.15
2. Fear of being HIV positive	17.3%	11.9%			
3. If they want to know their status	9.6%	3.2%			

Table 14 shows that both groups of women indicated protection of the baby from HIV infection as a strong motivating factor, while fear of being HIV positive was indicated as a strong barrier to voluntary HIV-testing uptake.

Table 15 shows the opinions of the participants on whether other people would find out the results of their test.

**Table 15: If you get tested, do you think people will find out?**

<b>Items</b>	<b>Percentage of those who were not disposed or did not know their disposition ( N= 52)</b>	<b>Percentage of those who were disposed to go for voluntary HIV testing ( N= 405)</b>	<b>Chisquare Value</b>	<b>df</b>	<b>p</b>

1. No	65.4%	72.8%	1.27	1	0.26
2. Yes	34.6%	27.2%			

Many women indicated that other people would not find out, however, many also indicated that others would find out.

Table 16 shows the opinion of the participants on the reasons why other people would find out the results of their tests if they tested HIV positive.

**Table 16: If you think people, will find out your status after you tested HIV positive, why do you think so?**

<b>First three items with highest Frequency</b>	<b>Percentage of those who were not disposed or did not know their disposition ( N= 52)</b>	<b>Percentage of those who were disposed to go for voluntary HIV testing ( N= 405)</b>	<b>Chisquare Value</b>	<b>df</b>	<b>p</b>
1. Yes, because I will explain my status to them	9.6%	8.7%	18.34	15	0.25
2. They will see me going for ARVs and they will notice it when it progresses	3.8%	1.2%			

3. I will loose weight	3.8%	0.7%			
4. Our results are not always kept secret by the testers	3.8%	1.0%			
5. Because I won't breastfeed	1.9%	0.7%			

Many of those who were not disposed or did not know their disposition were concerned about other people seeing them going to collect ARVs, see them loose weight, see them not breastfeeding, or that those who test clients for HIV did not always keep the results secret.

Table 17 shows the opinion of the participants on what their partners or family members would do if they happened to know that they tested HIV positive.

**Table 17: What do you think your partner or family members would do if they happen to know that you tested HIV positive?**

<b>First three items with highest Frequency</b>	<b>Percentage of those who were not disposed or did not know their disposition ( N= 52)</b>	<b>Percentage of those who were disposed to go for voluntary HIV testing ( N= 405)</b>	<b>Chisquare Value</b>	<b>df</b>	<b>p</b>

1. They will take care of me, give love and support	32.7%	37.3%	32.55	24	0.11
2. They will be unhappy and reject me	11.5%	4.0%			
3. They will be disappointed	9.6%	5.7%			
4. Angry, but with time they will support me	7.7%	1.5%			

Many of those who were not disposed or did not know their status indicated that their partner or family members would be unhappy and thus reject them, be disappointed or would initially be angry before supporting them.

Table 18 shows the opinion of the participants on what the community would do if they knew that they tested HIV positive.

**Table 18: What about the community, what do you think they will do if they happen to know that you tested HIV positive?**

First three items with highest Frequency	Percentage of those who were not disposed or did not know their	Percentage of those who were disposed to go for voluntary	Chisquare Value	df	p
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	<b>disposition ( N= 52)</b>	<b>HIV testing ( N= 405)</b>			
1. They will do nothing	17.3%	11.1%	23.52	23	0.43
2. They will give me support	11.5%	15.6%			
3. Isolate themselves from me	9.6%	7.9%			
4. Be disgusted and look at me in a funny way	7.7%	1.7%			
5. Some will discriminate against me and others will support me	7.7%	11.6%			

The two groups of participants indicated that some of the community members would do nothing, support them and some would stigmatize, and discriminate against them.

Table 19 shows the opinion of the participants on people living with HIV/AIDS (PLWHA)

**Table 19: What do you think of people living with HIV/AIDS (PLWHA)?**

<b>First three items with highest Frequency</b>	<b>Percentage of those who were not</b>	<b>Percentage of those who were disposed</b>	<b>Chisquare Value</b>	<b>df</b>	<b>p</b>
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	<b>disposed or did not know their disposition ( N= 52)</b>	<b>to go for voluntary HIV testing ( N= 405)</b>			
1. They are not different from those who are negative	30.8%	26.5%	26.68	23	0.27
2. They don't enjoy life	19.2%	9.4%			
3. They are ordinary people and we have to support them	13.5%	12.4%			

While most of the participants indicated that they would not discriminate against those who were HIV positive, some were of the opinion PLWHA did not enjoy life.

Table 20 shows the opinions of the participants on how the community would look at PLWHA.

**Table 20: How do you think the community looks at people living with HIV/AIDS?**

<b>First three items with highest frequency</b>	<b>Percentage of those who were not disposed or do not know their disposition ( N= 52)</b>	<b>Percentage of those who were disposed to go for voluntary HIV testing ( N= 405)</b>	<b>Chisquare Value</b>	<b>df</b>	<b>p</b>
1. They view them negatively	15.4%	15.4%	18.33	19	0.50
2. They discriminate against them	15.4%	5.2%			
3. They support them	13.5%	10.4%			
4. Some discriminate against them while others support them	13.5%	9.7%			
5. They are not different from the ones who are negative	11.5%	15.4%			

The participants were divided in their opinions. Some stated that the community would discriminate against and stigmatize PLWHA, while others were of the opinion that the community would not discriminate against them and would rather help them.

Table 21 shows the opinion of the participants on whether the community assists/helps people living with HIV/AIDS.

**Table 21: Does your community assist/help people living with HIV?**

Items	Percentage of those who were not disposed or did not know their disposition ( N= 52)	Percentage of those who were disposed to go for voluntary HIV testing ( N= 405)	Chisquare Value	df	p
1. No	51.9%	34.1%	6.36	1	0.01*
2. Yes	48.1%	65.9%			

\* Significant at  $p < 0.05$

Many of the participants who were not disposed to go for voluntary HIV testing or those who did not know their disposition were of the opinion that the community members did not assist/help people living with HIV/AIDS, while many of those who are disposed indicated that the community would assist/help them.

Table 22 shows the opinions of the participants on why the community members might not want to assist people living with HIV/AIDS.

**Table 22: Does your community assist people living with HIV/AIDS, If no, why?**

<b>First three items with highest Frequency</b>	<b>Percentage of those who were not disposed or do not know their disposition ( N= 52)</b>	<b>Percentage of those who were disposed to go for voluntary HIV testing ( N= 405)</b>	<b>Chisquare Value</b>	<b>df</b>	<b>p</b>
1. Nothing/no reason	42.3%	55.3%	32.39	14	0.004*
2. They are afraid of being infected by them	11.5%	9.4%			
3. Because patients hide their sickness	11.5%	2.0%			
4. They are not assisted due to a lack of information about HIV/AIDS	7.7%	11.1%			

\* Significant at  $p < 0.05$

Many participants indicated fear of being infected, lack of adequate knowledge about HIV/AIDS, and the unwillingness of the infected to disclose their status, as the main reasons why many community members would not assist PLWHA.

Table 23 shows the opinion of the participants on the main fears (if any) of the pregnant women concerning going for voluntary HIV testing.

**Table 23: In general, what do you think are the main fears of pregnant women concerning going for voluntary testing?**

<b>First three items with highest Frequency</b>	<b>Percentage of those who were not disposed or do not know their disposition ( N= 52)</b>	<b>Percentage of those who were disposed to go for voluntary HIV testing ( N= 405)</b>	<b>Chisquare Value</b>	<b>df</b>	<b>p</b>
1. All are afraid of knowing that they are HIV positive	28.8%	37.4%	18.30	17	0.37
2. Whether they will be able to protect their babies	13.5%	15.6%			
3. They are afraid of dying, because the disease is not curable	13.5%	8.2%			
4. Knowing	7.7%	4.0%			

their status and that the baby might be positive and how it will affect their families and their partners					
5. The disease is unacceptable and that they will be stressed	7.7%	3.7%			

The participants mentioned fear of knowing that they were HIV positive, not being able to protect their babies, dying, reaction from the family members and stress, as the main fears.

Table 24 shows the opinion of the participants on their knowledge of their HIV status.

**Table 24: Do you know your HIV status?**

<b>Items</b>	<b>Percentage of those who were not disposed or did not know their disposition</b>	<b>Percentage of those who were disposed to go for voluntary HIV testing ( N= 405)</b>	<b>Chisquare Value</b>	<b>df</b>	<b>p</b>

	( N= 52)				
1. No	73.1%	17.3%	79.22	1	0.00*
2. Yes	26.9%	82.7%			

\* Significant at  $p < 0.05$

Most of those who were not disposed or who did not know their status indicated that they did not know their HIV status. Contrary to that, most of those who were disposed indicated that they knew their status.

Table 25 shows the opinion of the participants on whether it is possible to prevent mother-to-child HIV infection or not.

**Table 25: Is it possible to prevent mother-to-child HIV infection?**

Items	Percentage of those who were not disposed or did not know their disposition ( N= 52)	Percentage of those who were disposed to go for voluntary HIV testing ( N= 405)	Chisquare Value	df	p
1. Yes	78.8%	88.4%	3.76	1	0.05*
2. No	21.2%	11.6%			

\* Significant at  $p < 0.05$

The majority of the participants indicated that it is possible to prevent mother-to-child HIV infection. However, a worrisome percentage said that it is not possible.

## **5.5 SUMMARY OF RESULTS**

This chapter focused on the presentation of the study results, which included results from frequency tables of demographic variables, regression analysis hypothesis testing results, and the presentation of results from open-ended questions. The tabulation of demographic variable results provides the basis that the majority of study participants came from the greater Capricorn district. Most participants were between 18-35 years of age and came from rural residential areas. The results are furthermore indicative that most of the pregnant women at the time of conduction of the study were unemployed, not married, while the majority of participants had at least 8 years of formal education.

The regression analysis results support the hypothesis that internal/felt/self stigma significantly negatively affects pregnant women's decision to dispose for HIV/AIDS, while external/enacted stigma was not a significant factor. The results from open-ended questionnaires explored several psychosocial factors (related to being or testing HIV positive) feared by pregnant women and those factors that encouraged them to test for HIV/AIDS. The majority of the participants in this study indicated that they would go for voluntary HIV-testing. However, many of those who would not go for HIV-testing or who were undecided were concerned about the family and community members finding out if they were HIV-positive and the fear of social discrimination and rejection, stigmatization, lack of social support they anticipated would follow, anticipated a lack of confidentiality about HIV-test results, and had a lack of self confidence. Furthermore, most of those who were not disposed or who were undecided did not know their HIV-status. A significant number of all the participants did not believe that it is possible to prevent mother-to-child infection of HIV.

## **CHAPTER 6**

### **DISCUSSION AND CONCLUSION**

#### **6.1. INTRODUCTION**

In this Chapter, findings of this study are presented. These results are discussed in relation to existing literature, integrated, and placed within the theoretical framework of this study. Study limitations, recommendations, and the conclusion are elaborated in this chapter.

#### **6.2. Internal stigma and HIV/AIDS testing uptake**

The Multiple Regression analysis shows an association between internalized stigma and low disposition for HIV testing uptake among pregnant women. Within the context of this study, it was noted that internal stigma denoted negative self-perceptions, self-abasement, self-blame, self-guilt, and fear of discrimination associated with being HIV-positive. The implications of the findings are that as high levels of negative self-attributions and fear of discrimination increase among the pregnant women, there will be a decline in willingness to test for HIV/AIDS by pregnant women. This finding confirms findings of past studies which showed that pregnant women's self-deprecation, self-abasement and fear of being discriminated against had a negative impact on their HIV-testing behaviour; and those are great barriers to preventing further infections and providing adequate care, support and treatment (Bond et al., 2002; Shangula 2006; Toivo, 2005; Ramkissoon et al., 2006).

The impact internal stigma has on pregnant women's disposition for HIV-testing uptake implies that the PMTCT programmes would remain ineffective if this internal stigma remains unaddressed. Therefore, it is important that within PMTCT and VCT programmes, programme planners establish new strategies that would focus intensively on addressing individual pregnant women's negative self-attributions and fear of being discriminated by their families, their partners, or their individual communities should they test HIV positive.

The attributions that the pregnant women assert to themselves, because of externally perceived stigma experienced by the infected are important precursors to their HIV-testing behaviour. Studies and experience have shown that most pregnant women actually desire testing in order to protect their babies, but unfortunately they often fear stigma and rejection if they were to be known as being HIV positive (Ministry of Health and Social Services, 2004; Shangula, 2006; Thorne & Newell, 2003). Brown et al., (2001) notes that felt/internal stigma can be seen as a survival strategy to limit the occurrence of enacted stigma. Therefore, pregnant women's reluctance to test for HIV is directly linked to self-protection against their families, partners, and communities if they were to test HIV-positive.

Their self-protection is of much significance to their well-being, because post research studies found that pregnant women who tested HIV positive experience stigma and discrimination from their families, partners, communities, churches, and from the health workers (Chandra, Deepthivarma & Manjula, 2003; Goosen & Klugman, 1996; Pool et al., 2001; Toivo, 2005). It is further stipulated by Berer (2000) that due to fear of

violence, stigma, and ostracism; many women avoid taking HIV tests. It is indicative that internal stigma should be one of the primary goals that are addressed within PMTCT and VCT programmes. Failure of programme planners to prioritize addressing internal stigma within the PMTCT programmes will warrant the fight against HIV/AIDS ineffective. This will lead to pregnant women continuously denying themselves crucial information about their health and excluding themselves from programmes to prevent HIV transmission to their newborns. If that happens the prevention of mother-to-child-transmission programmes will prove ineffective, and HIV infection prevalence would annually increase.

### **6.3. RESULTS FROM OPEN-ENDED QUESTIONS RELATING TO HIV STIGMA**

#### **6.3.1 Reasons for disposition/non-disposition**

This study found that the majority (88.6%) of the pregnant women were willing to go for HIV-testing. Generally, many participants indicated that they would be disposed because they wanted to know their HIV status and be able to protect their babies from HIV/AIDS. This finding is similar to that reported by Preble, Huber, and Piwoz (2003) who found that the majority (84%) of pregnant women in Lusaka, Zambia, were willing to be tested for HIV/AIDS, in order to protect their unborn babies. The pregnant women who indicated that they would not be disposed for HIV/AIDS or those who were ambivalent about being disposed for HIV-testing uptake in this study cited that they would not be disposed due to fear of discrimination, lack of self-confidence if they thought negatively about their test results, and fear of being heart-broken by testing HIV-positive. Similarly,

Berer (2000) established that those factors were accountable for relatively low HIV-testing up-take by pregnant women.

Pregnant women's lack of self-confidence, their negative cognitions, anxiety, and anticipation of being heart broken should they test HIV-positive are indicative of internalization of stigma. In this regard, their internalization of stigma may serve as a protective factor for them in becoming victims of enacted stigma. Furthermore, the pregnant women who would not be disposed for HIV-testing, stated that if their husbands or partners did not support them or disagreed with their choice for HIV-testing, they rather not test for HIV. Hence, it is crucial for family members, particularly partners, to be involved in the PMTCT programmes. Their inclusion will aid in the establishment of good support systems, which would then lead to reducing pregnant women's anxieties or fears about HIV-testing uptake. This would instill a sense of self-confidence about HIV-testing among them. Toivo (2005) also asserted that education and male involvement are needed as a way of improving the VCT services, which will help pregnant women to gain support and cooperation from their male partners. It was also apparent from the findings that other factors that negatively affected the pregnant women's disposition for HIV-testing were fear of knowing one's status, and fear of dying since the disease is incurable. The findings support Shangula's (2006) finding which mentions that some of the pregnant women in Namibia feared HIV/AIDS. As a result, they would not opt for HIV-testing while others indicated that there was no need for them to opt for VCT, because they were going to die anyway.

### **6.3.2. Opinions on whether other people would find out their HIV-status after HIV testing or not**

Among the pregnant women, the majority (72.8%) of pregnant women indicated that people would not find out about their HIV status after testing for HIV. A limited number (27.2%) stated that people would know about their HIV-status after they would have disposed for HIV-testing. Other pregnant women in South Africa (McCoy et al., 2002) stated that their status would be known, because people will notice them queuing up for Antiretro Viral drugs, because of a lack of confidentiality about their HIV test results among health workers, because they would not breast feed their babies and because they would lose weight. Lack of confidentiality concerning HIV-test results among health workers has been cited by several authors to have a negative impact on pregnant women's disposition for HIV/AIDS-testing (Pool et al., 2001; Toivo, 2005).

The lack of confidentiality has also been noticed to negatively affect the general population's consideration of disposing themselves for HIV-testing. Chandra et al., (2003) have documented that in India, the fear of violation of confidentiality about HIV-test results among health workers, which makes one vulnerable to stigma, serves as a barrier to HIV testing uptake. Similarly, van Dyk and van Dyk (2003) found that among South Africans VCT is largely acceptable by citizens, but people are concerned about the confidentiality of the processes. The lack of confidentiality about HIV-test results among health workers, calls for urgent punitive and disciplinary measures by the health care system against health workers who negligently and intentionally breach their code of conduct by disclosing or gossiping about patients' HIV-test results. Would this concern

be left unaddressed the majority of pregnant women would continuously fear stigma and thus not be disposed for HIV-testing, since confidentiality about their test results is not assured. Therefore, as Zaccagnini (2009) noted, the widespread fear of stigma will often be held accountable for the relatively low uptake of prevention of mother-to-child transmission programmes in countries where HIV/AIDS treatment is even free.

### **6.3.3. Pregnant women's perceptions of families'/partners'/communities' reactions if they tested HIV-positive**

The results revealed that many of the pregnant women mentioned that their families or partners would care, love and support them despite testing HIV positive. The implication of this finding is that fear of stigma, within the family context in the Limpopo Province, is not as common as it is the case in other countries. In comparison, Shangula (2006) found that the majority of the pregnant women in Zambia feared that they would face discrimination and be stigmatized by their families and community should they test HIV positive.

However, some of those who would not be disposed indicated that their partners or families would be disappointed, unhappy and would reject them if they tested HIV-positive. These results, in part support reports which indicate that the HIV/AIDS pandemic has led to increased gender-based violence as pregnant women assumed to be HIV positive are repeatedly subjected to extensive forms of stigma, particularly once they become sick or if their child dies (Bond et al., 2002; ICW, 2004). Some of the pregnant women who would not be disposed (7.7%) stated that their families or partners would be

angry at first after receiving their test results, but with time, they would support them. These results further strengthen the idea that the programmes that seek to address HIV/AIDS related stigma within PMTCT programmes ought to also focus more, on the family setting. If more family oriented HIV/AIDS-related stigma interventions would be put in place, some of the pregnant women who would not be disposed due to fear of being discriminated against and stigmatized by their families or partners may reconsider disposing themselves for HIV-testing. In support of the latter statement, it was gladdening to further discover that the majority of the pregnant women who would not be disposed for HIV-testing felt that if their environment would be receptive of them on knowing their HIV status, they would then be disposed.

From a community point of view, though some of the pregnant women who would test for HIV and those who would not were still concerned about being discriminated against, isolated and looked at in a funny manner if they tested HIV-positive. The majority of those who would be disposed (17.3%) and those who would not be disposed (11.1%) indicated that their communities would “do nothing” even if they tested HIV-positive. In comparison to Berer (2000) who indicates that many pregnant women avoid taking HIV tests because of fear of violence, stigma, and ostracism by their communities, findings of this study portray a different picture. The majority of the pregnant women in this study stated that they would be disposed in order to protect their babies and were less concerned about being discriminated against and stigmatized by their communities.

It is, therefore, imperative that communities’ attitudes and perceptions about HIV/AIDS continuously be challenged and addressed. Pregnant women need not be prevented from

denying themselves crucial information about their health and excluding them from programmes to prevent HIV transmission to their newborns. Community based interventions are proposed, since the pregnant women in this study stated that if they anticipated that their environment would be receptive of them on knowing their HIV status, they would then be disposed for HIV-testing. If they feared that their respective communities would discriminate and isolate them should they test HIV-positive, they would rather not be disposed for HIV-testing.

#### **6.3.4. Pregnant women's perceptions of PLWHA and their perceptions on how the community looks at and treats PLWHA**

The majority (57 %) of the pregnant women of this study indicated that they would neither discriminate against nor mistreat PLWHA, because the PLWHA are not different from HIV-negative persons, and they need to be supported. When compared to other study findings this finding depicts a different picture, particularly in the Limpopo Province. Policy project (2003) and Bond et al., (2002) mention that the majority of the pregnant women view PLWHA as dirty and evil. Noteworthy also is that some of the pregnant women who would not be disposed in this study (19.2%), as compared to those who would be disposed (9.4%), indicated that PLWHA do not enjoy life. This assertion is in line with the idea that there is a need to challenge pregnant women's fears, attitudes, and misconceptions associated with testing HIV-positive.

Many of the pregnant women who would not be disposed indicated that their communities do not assist PLWHA. They further indicated that their communities

discriminate against PLWHA, and view them negatively. Similarly, Mabunda (2006) and Seale (2004) found that people infected and affected by HIV/AIDS are often discriminated against and stigmatized in such areas as employment, medical treatment, care and custody of children, and other social relationships. Pregnant women in this study remarked that their communities would not assist PLWHA because the majority of the people in the community fear that they would be infected by PLWHA. Pregnant women, furthermore, cited that PLWHA are not assisted by their communities, because they are not willing to disclose their HIV-positive status to the community members. Some also indicated that their communities lack HIV/AIDS knowledge, as a result they are not able to assist PLWHA.

The community's unwillingness to assist PLWHA, their fears of being infected by those infected and lack of HIV/AIDS related knowledge as indicated by the pregnant women in this study are of the impression that there is still a greater need for transmission of HIV/AIDS related knowledge to the communities. These, therefore, call for outreach community programmes, and media programmes as part of the community interventions that address the HIV/AIDS related stigma. Such media programmes and community outreach programmes should aim at addressing and educating the community about the pandemic, the negative effect HIV/AIDS-related stigma and discrimination has on the general population, PLWHA and their families.

Interestingly, as noted by Bond et al., (2002), common stigmas PLWHA experience as cited by the pregnant women of this study were that of being gossiped about and being isolated by the community. Moss, Bentley, Maman, Ayuko, Egessah, Sweat, et al.,

(1999) also mentions that HIV/AIDS-related stigmas are closely related to hindrances in seeking HIV-related help and testing. It is, therefore, imperative that community oriented interventions continuously be incorporated within the comprehensive programme that seeks to combat HIV/AIDS stigma.

### **6.3.5 Pregnant women's opinions on whether it is possible or not to prevent-mother-to-child HIV infection**

A large number of both pregnant women who would be disposed (78.8%) and those who would not be disposed (88.4%) stated that it is possible to prevent mother-to-child HIV infection. These findings compliment findings in Namibia which note that the pregnant women in Namibia were aware that an HIV-positive woman can transmit the virus to her baby during breastfeeding (76%) and during delivery (61%), and that a limited number knew that vertical transmission can occur during pregnancy (Shangula, 2006). It is apparent that the pregnant women who would not be disposed in this study were knowledgeable that PMTCT is possible. However, they would not be disposed for HIV-testing despite the knowledge, would their environment not be receptive of them on knowing their positive HIV-status. This finding further strengthens Moss et al.,'s (1999) argument that HIV/AIDS-related stigmas are closely related to hindrances in seeking HIV-related help and testing.

### **6.3.6 Pregnant women's opinions on socio-cultural factors that influence HIV/AIDS-related stigmas**

The results of this study do not support study findings by Rankin (1994) and Lesko (2005), which hold that in Africa the stigmatization of HIV/AIDS is reinforced by beliefs that those infected are being punished by God or the ancestors for evil doing or because they are bewitched. In this study, the pregnant women (11.5%) who would be disposed and 9.4% of those who would not be disposed were of the opinion that those infected experience stigma and discrimination because their communities have a fear of being infected.

Some of the pregnant women (14%) in this study stated that PLWHA are discriminated against and stigmatized by their communities because people perceive them as promiscuous. This finding in part supports study finding by Lesko (2005) that norms and taboos about sex or associations of HIV&AIDS with deviant behaviour reinforce the stigmatization of HIV/AIDS in South Africa.

From a socio-cultural outlook, the finding that PLWHA are stigmatized and discriminated against, because communities blame them for their promiscuity align with blaming theories (Joffe, 1999 & Deacon et al., 2005) about people's illnesses. Addressing HIV/AIDS related stigma with reference to blaming theories denote challenging communities' emotional reasoning about PLWHA. It would suggest challenging the communities' attitudes, prejudices, and anxieties related to the pandemic. The main challenge as indicated by Deacon et al., (2005) would then be how to use the model to clearly establish and understand the relationship between stigma, discrimination, and

power, and how to change the way people respond to risk. Thus, this calls for more research within this field.

#### **6.4. LIMITATIONS OF THE STUDY**

This study focused on the effect of HIV/AIDS-related stigma on pregnant women's disposition for HIV-testing up-take in Limpopo Province. The findings show that internal stigma negatively influences pregnant women's disposition for HIV-testing uptake. Other factors (i.e. self-esteem, motivation, personality types) which could also have the same effect as internal stigma were not explored, thus limiting the study.

This calls for further studies to explore these limitations.

#### **6.5. CONCLUSION**

HIV/AIDS related internal stigma is a problem that makes the fight against HIV infection to unborn babies impossible. Internal stigma, as noted, is one area that seeks urgent and intensive focus in the combat of the HIV/AIDS-related stigma, particularly among pregnant women attending the PMTCT programmes. Families and partners of the pregnant women are also important areas of focus for changing and addressing pregnant women's negative-self attributions and fear of discrimination with respect to HIV-testing.

Other factors such as a lack of confidentiality about test results and the communities' negative attitudes, stigmatization and prejudices of PLHWA and those thought to be infected, will continuously make the fight against HIV/AIDS difficult if left unacknowledged and unaddressed.

## **6.6. RECOMMENDATIONS**

For the purposes of implementing more effective PMTCT and VCT programmes, the following recommendations are made:

1. Integration of intensive individual counseling sessions with PMTCT programmes, which addresses pregnant women's negative self-attributions, self-abasement, and self-deprecation and their anxieties about HIV/AIDS.
2. Encouragement and inclusion of pregnant women's families and partners within PMTCT programmes.
3. Strict implementation of disciplinary measures by the health care system against health workers, who intentionally and negligently disclose patients' status.
4. Intensifying media programmes that address the effect of HIV/AIDS related stigmas on pregnant women's HIV testing decisions and the general population's consideration of VCT.
5. Intensification of community outreach programmes that challenge, educate, and address communities' attitudes and perceptions about VCT and PLWHA

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## APPENDICES

### APPENDIX A

**INSTRUCTIONS:** I would first like to thank you for agreeing to take part in this study. I am now going to ask you a few questions regarding your choice to/not to go for voluntary HIV testing. Please try and answer all questions honestly and remember that all the information obtained during this interview will be considered confidential.

#### 1. Demographic information

Please tick in the most appropriate box.

Age:

17 years or younger	18-25 years	26-35 years	36-45 years	46 years and older
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Years of Education:

No formal schooling	
1-7 years formal schooling	
8-12 years formal schooling	
Post Matric Diploma	
University Level	

Employment Status:

Education	Medical/Social	Admin/Comm	Unskilled Labour	Unemployed	Civil Servant	Student
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Other: specify \_\_\_\_\_

Marital Status:

Single	In-relationship	Married	Co-habitation	Divorced
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Ethnicity:

Pedi	Tsonga	Venda	Ndebele	Other, specify :
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Residential Area:

Rural	Urban	Semi-urban	Semi-rural
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**APPENDIX B**

**2. Topic Guide**

**Will you be disposed to go for HIV-testing?**

- 1. I will definitely agree**
- 2. I will agree**
- 3. I don't know/I am ambivalent about it**
- 4. I will refuse/not agree**
- 5. I definitely refuse/disagree**

**Reasons for disposition (why did you agree or disagree to go for Voluntary HIV-testing?)** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**What will make you change your decision regarding the choice to go for Voluntary HIV-testing?** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**In your view, what makes pregnant women to be tested or not to be tested?**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**If you get tested, do you think that people will find out?**

YES	NO
-----	----

**Why?** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**What do you think your partner or family members will do if they happen to know that you tested HIV positive?** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**What about the community?** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**What do you think of people who have HIV/AIDS?** \_\_\_\_\_

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**What do you think the community thinks of people who have HIV/AIDS?**

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**Does the community assist people who are HIV infected?**

YES	NO
-----	----

**What might be the reason for them not being assisted?**

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**In general, what do you think are the main fears of having an HIV test?**

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**Do you think most of the things you mentioned above cause pregnant women to go for or not go for HIV/AIDS testing?** \_\_\_\_\_

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**Do you know your HIV status? Yes\_\_\_ No\_\_\_**

**Do you think it is possible to prevent mother-to-child HIV infection? Yes\_\_\_No\_\_\_**

## APPENDIX C

### AIDS-related stigma scale (external stigma scale)

Please answer whether you agree or disagree with the following statements

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

## APPENDIX D

### Internalized AIDS-stigma scale

Please answer whether you agree or disagree with the following statements

1. It will be difficult to tell other people about my HIV infection	I AGREE	I DISAGREE
2. Being HIV positive will make me feel dirty	I AGREE	I DISAGREE
3. I will feel guilty if am HIV positive	I AGREE	I DISAGREE
4. I will be ashamed if I am HIV positive	I AGREE	I DISAGREE
5. I will sometimes feel worthless if I am HIV positive	I AGREE	I DISAGREE
6. It will be my own fault if I am HIV positive	I AGREE	I DISAGREE
7. I will hide my HIV status from others	I AGREE	I DISAGREE