

**UNIVERSITY OF KWAZULU-NATAL**

**AN EXPLORATORY DESCRIPTIVE STUDY ON THE PERCEIVED  
LEVELS OF STIGMA AND DISCLOSURE PATTERNS AMONG WOMEN  
LIVING WITH HIV AND AIDS IN A SELECTED HOSPITAL IN  
KWAZULU-NATAL, SOUTH AFRICA**

**BY**

**LUCIA BONISIWE SINEGUGU MDLULI**

**2017**

**AN EXPLORATORY DESCRIPTIVE STUDY ON THE PERCEIVED LEVELS OF  
STIGMA AND DISCLOSURE PATTERNS AMONG WOMEN LIVING WITH HIV AND  
AIDS IN A SELECTED HOSPITAL IN KWAZULU-NATAL, SOUTH AFRICA**

**A DISSERTATION SUBMITTED TO THE:  
SCHOOL OF NURSING AND PUBLIC HEALTH, COLLEGE OF HEALTH SCIENCES,  
UNIVERSITY OF KWAZULU-NATAL, HOWARD COLLEGE CAMPUS, DURBAN, IN  
PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF  
MASTERS IN NUSING (ADVANCED MIDWIFERY AND MATERNAL-CHILD  
HEALTH NURSING)**

**BY**

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**2017**

## **DECLARATION**

I, the undersigned student, do hereby declare that the entirety of this dissertation titled ‘An exploratory descriptive study on the perceived levels of stigma and disclosure patterns among women living with HIV and AIDS in a selected hospital in Kwazulu-Natal, South Africa’ is my own work and all resources and materials used or quoted have been indicated and duly acknowledged by means of complete reference.

.....  
STUDENT: LUCIA BONISIWE SINEGUGU MDLULI

.....  
DATE

## **DEDICATION**

I dedicate this work to the Almighty God, my Lord and Saviour of my soul, who makes all things possible - it wasn't easy.

I also dedicate this study to my dear daughter Nontobeko, she is my pillar and she is the reason for me living.

## ACKNOWLEDGEMENTS

First and foremost, my ultimate thanks goes to my Lord and Saviour, Jesus Christ, who is the only immortal, invisible, all powerful and wise God. He has always made all things possible in His own time in my life. I appreciate and love you so much, Lord.

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I extend my gratitude to my dearest children, Nontobeko and Mzomuhle Mhlongo, for your constant prayers, support and the sacrifices you made to assist me to finish this work. I love both of you.

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Lastly, I gratefully thank the participants who contributed to this project during data collection. Thank you so much to all the women who took part in this project.

## ABSTRACT

**Aim:** The aim of this study is to explore and describe the perceived levels of HIV related stigma and disclosure patterns among women living with HIV and AIDS.

**Objectives:** The objectives of the study are to explore and describe the perceived levels of stigma and disclosure patterns among women, the inter-relationship between demographic variables and perceived levels of stigma, the inter-relationship between demographic and disclosure patterns and the inter-relationship between perceived patterns of disclosure and perceived stigma levels.

**Method:** A quantitative explorative, descriptive study design was used for the study. Purposive sampling was used by the researcher to select a sample of women who were attending a clinic within a selected hospital in KwaZulu-Natal. A self-reported questionnaire was administered to a sample of 90 women, all of which were completed and returned.

The data obtained from the questionnaire was analysed using SPSS version from SPSS Survival Manual Fourth edition, 2011. Descriptive and non-parametric testing was used to show levels of perceived stigma, disclosure patterns and inter-relationships between demographic variables and perceived HIV related stigma and disclosure patterns.

**Results:** The results showed that the majority of the participants had perceived low stigma levels and the majority disclose their status. Item one (1) where 12% have not disclosed their status to family. Item six (6), 43.3% feel that they do not have to keep their status a secret. Item eight (8), 33.3% agreed that they never felt ashamed of HIV and item nine (9), 42.2% disagreed that people with HIV are treated as outcasts.

There was a weak correlation between the age of the participants and stigma, and there was a positive weak relationship ( $r=0.086$ ) between age and disclosure. There was a positive weak correlation between disclosure and stigma ( $r=0.18+p=0.1$ ).

**Key words:** HIV related stigma, HIV related disclosure, women living with HIV

## **ABBREVIATIONS**

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ANOVA	Analysis of variance
ARV	Antiretroviral
DOH	Department of Health
HAART	Highly Active Antiretroviral Therapy
HASI	HIV/AIDS Stigma Instrument
HIV	Human Immune-deficiency Virus
HSRC	Human Science Research Council
IMAGE	Intervention for microfinance and gender equity
MTCT	Mother-To-Child Transmission
NDOH	National Department of Health
NSP	National Strategy Plan
PLWHA	People living with HIV and AIDS
PMTCT	Prevention of Mother-To-Child Transmission
SANAC	South African National AIDS Council
SHAZI	Shaping the health of adolescents in Zimbabwe
UNAIDS	United Nations Program on HIV/AIDS
WHO	World Health Organization

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**Appendix 1: Ethical clearance from UKZN**

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## **CHAPTER ONE**

### **1. INTRODUCTION AND BACKGROUND OF THE STUDY**

#### **1.1 Introduction**

South Africa has the greatest number of people living with HIV of any country in the world (Velloza et al. 2015). High levels of HIV stigma have been documented by many studies in South Africa, which could explain drop-offs in HIV care engagement (Dos Santos et al. 2014). Stigma negatively impacts the uptake of HIV testing, with individuals who perceive HIV related stigma or observe enacted stigma far less likely to get tested for HIV (Nyblade et al. 2013). The evidence based interventions focused on HIV prevention, treatment, care and support have been implemented with some success, although the prevalence of HIV has remained high, while the researcher's review revealed considerable progress in the stigma-reduction field over the last decade (Stangl et al. 2013). South Africa continues to monitor the epidemic and is continually assessing, strengthening and reviewing the response to HIV (Shisana et al. 2014). HIV related stigma prevents the effective use of antiretroviral treatment, especially in women living with HIV, due to fear of partner abandonment or abuse following disclosure of their HIV status (Black et al. 2014).

#### **1.2 Background of the study**

##### **1.2.1 HIV prevalence in South Africa**

South Africa has the biggest and most high-profile HIV epidemic in the world, with an estimated seven million people living with HIV in 2015. In the same year, there were 380,000 new infections while 180,000 South Africans died from AIDS-related illness. South Africa has the largest antiretroviral treatment (ART) programme globally, however HIV prevalence remains high (19.2%) among the general population. HIV prevalence is almost 40% in KwaZulu-Natal compared with 18% in the Northern Cape and the Western Cape representing 17% of the global burden of HIV infection (Zuma, Shisana et al. 2016; UNAIDS, 2013). The results of the analysis of HIV prevalence estimated by key demographic variables which suggests that the overall prevalence differed substantially by provinces, and provincial variation was evident with the top four HIV prevalent provinces being KwaZulu-Natal, Mpumalanga, Free State, and North West, with the lowest being Western Cape (Shisana et al. 2014). It has been indicated that black African females between the ages of 30- 34 have a high HIV prevalence, while female teenagers

aged 15-19 are also high in HIV prevalence in South Africa (Okoror et al. 2014). In KwaZulu-Natal the eThekweni district and Ekurhuleni in Gauteng have the highest HIV prevalence, with women who are of a childbearing age being at a greater risk of exposure to HIV, and therefore the need to access the programme that was introduced to the pregnant women in order to prevent transmission of HIV infection from mother to child during pregnancy, that programme was called the prevention of mother-to-child transmission (PMTCT) is essential (Shisana et al. 2014). In Zimbabwe the prevalence of HIV is high in adolescents from the age of 15-19, therefore their government has introduced shaping the health of adolescents in Zimbabwe (SHAZI), and in doing so they are trying to decrease the high burdens of HIV infection and the HIV stigma which leads to poor economic and lack of educational status in young women, however the poor educational status may also affect the proper understanding of the spread of the HIV infection and PMTCT (Tsai et al. 2013).

Stigmatising attitudes and behaviors are shaped by social and cultural contexts, which reinforces the need to target settings where HIV related stigma is most harmful but also modifiable. Comparative studies conducted throughout Africa have shown that expressions of stigma such as blaming othering differ based on socio-economic resources, norms and the availability of supportive services (Velloza et al. 2015). HIV related stigma continues to affect people living with HIV and affected by HIV disease and their healthcare providers, particularly in regions where HIV and AIDS is widespread, such as in Southern Africa. Pregnant women report difficulties in accessing the PMTCT programmes due to the negative attitudes of healthcare providers, families and spouses (Dos Santos et al. 2014). The National Strategy Plan (NSP) for 2012–2016 states as its primary goal, a reduction of new infections by at least 50%, this will be extremely difficult to attain given the prevailing transmission dynamics in the country (Naidoo, 2014).

HIV related stigma and discrimination remain major barriers to effective HIV prevention as well as to the provision of treatment, care and support in many countries across the globe, including South Africa (Zuma et al. 2016). An important aspect of such stigma is the phenomenon of ‘othering’ whereby some people do not believe they are at risk of HIV infection on account of their sex, race, creed, religion, sexual preferences or national origin (Black et al. 2014). Many countries in the East and the Southern African region, including South Africa were committed in

the National Strategy Plan to the reduction of new infection by 50% (Suofeiya et al. 2017). More than two-thirds (23.5 million) of all HIV infected people worldwide live in Sub-Saharan Africa (Psaros et al. 2015). In South Africa (KwaZulu-Natal), adult HIV prevalence has exceeded 20% for at least a decade (Tsai et al. 2013). Globally, it is estimated that there were 35.3 million people living with HIV and 2.3 million new infections in 2012. Although the burden of the epidemic varies considerably between countries and regions, it is estimated that 0.8% of adults aged 15–49 years worldwide are living with HIV. The HIV and AIDS epidemic remains a serious public health challenge, especially among women of childbearing age, who make up 46% of the global HIV burden (Shisana et al. 2014). Who, 2013 also highlights that women constitute 52% of all HIV infections in low- and middle-income countries (Shisana et al. 2014)

The prevention of mother-to-child transmission (PMTCT) is a complex challenge in heavily affected and resource-limited settings such as South Africa and Sub-Saharan Africa, however management of PMTCT requires a cascade of interventions that need to be addressed to effectively decrease the risk of HIV transmission to infants and the PMTCT cascade includes incremental components that can be shaped and influenced by the patient-provider relationship (Yeji et al. 2014). The impact of stigma manifests itself both at individual and community level and it has been a major obstacle to the effective implementation of and adherence to PMTCT and antiretroviral treatment (Ngarina et al. 2014). Postpartum attrition is of particular concern with up to 50% of women dropping out of care after delivery and among HIV positive adults in Sub-Saharan Africa, the denial of infection, stigma, and lack of family or community support, transport limitations, and long queues at healthcare facilities are cited as barriers to retention (Clouse et al. 2014).

### **1.2.2 Stigma and discrimination as barriers to achievement of global PMTCT and maternal health goals**

In the context of this study HIV stigma refers to any unacceptable label that is given by others to a person who is infected with HIV such as gossip, isolation and labeling. Stigmatising and discrimination against people living with HIV and AIDS has been one of the hallmarks of the global HIV pandemic (Famoroti et al. 2013). HIV related stigma acts as a negative driver in compliance with ART as emphasized in the study conducted in Mpumalanga province in South Africa whereby participants reported their fear to take medication in front of their husbands and

spouses (Dos Santos et al. 2014). Although an ART and PMTCT service has reshaped the AIDS response, the HIV treatment revolution has yet to reach many around the world. Only modest gains in ART and PMTCT coverage have been reported in Eastern Europe and Central Asia as well as the Middle East and North Africa, and ART eligible individuals in West and Central Africa are notably fewer (Black et al. 2014). PMTCT services will not be effective if people are not accessing them, and the lack of uptake and access to HIV testing and subsequently treatment services also diminishes the health benefits of treatment at both the individual and population levels (King et al. 2013).

Stigma continues to prevent quality healthcare for the mother and the unborn baby, therefore it may increase the susceptibility of advancing HIV disease in pregnancy (Turan and Nyblade 2013). Stigma also has other effects on health which include poor mental health, maternal mortality and morbidity, infant mortality and morbidity, adverse health consequences of violence and transmission of infections (Turan and Nyblade 2013). Research has found that the ramifications of HIV related stigma on health seeking behaviours may result in individuals fearing to get tested, and people living with HIV responses include delaying or not adhering to treatment and potentially not adopting preventative behaviours (Churcher, 2013). Women face challenges in disclosing their HIV status which leads to poor health and prevention of disease in Southern Mexico (Ojikutu et al. 2016), as outlined in the following section.

### **1.2.3 Disclosure and perceived HIV stigma**

Perceptions of HIV-related stigma may play a major role in decisions about HIV disclosure (Teklehaimanot et al. 2016). High levels of HIV stigma act as a barrier in prevention of HIV programmes and it also limits the uptake of safer sexual behaviours and HIV testing and treatment (Dos Santos, et al. 2014). However, HIV related stigma is also related to the endorsement of reasons against HIV disclosure to certain relationship partners. It is said that the greater the belief that the public stigmatizes someone with HIV, the greater the endorsement of self-blame, fear of rejection, communication difficulties and protection of others. Hence the reasons for not disclosing HIV status leads to poor support for the person concerned (Akullian et al. 2014).

Further to this, it is also noted that perceived levels of HIV stigma affects HIV disclosure among people living with HIV (Akullian et al. 2014). Hence perceived HIV stigma is associated with

greater sensitivity to the potential negative consequences of disclosing to a friend, parent and intimate partner, however negative consequences affect HIV decision making hence nondisclosure affects or decreases access to support from friends, parents and intimate partners (Velloza et al. 2015). Certain demographic and reproductive factors also affect HIV stigma levels, as outlined in the following section.

#### **1.2.4 Demographic factors and reproductive factors that affects HIV stigma levels**

Socio-demographic factors influence HIV stigmatization and discrimination among women living with HIV (Darlington and Hutson 2016). A study conducted in Nigeria indicates that age and educational attainment have negative influence on HIV stigmatization and discrimination, hence the women reported that once they disclose their HIV status, they are gossiped about, verbally harassed and neglected by Nigerian society (Zuma et al. 2016). A high HIV stigma level was consistently and significantly associated with low social support, poor mental health and age, however the community environment may also influence in shaping HIV related stigma among women such as economic and behavioral aspects of the community environment (Pantelic et al. 2015). Another factor that was mentioned in the literature is the religious factor, which plays a role in people's attitudes about HIV and people living with HIV (Valencia-Garcia et al. 2016). A study that was conducted in Pretoria, South Africa states that a high educational level such as tertiary, and urban or rural residence status was significantly associated with willingness to disclose (Przybyla et al. 2013). However the study in the United States of America indicates that married couples, highly educated, with better housing and those who are less financial dependent disclose more easily and levels of stigma are lower (Ebuy et al. 2015). Education and wealth are positively related to certain risk factors such as premarital sex and associated with high HIV prevalence (Teklehaimanot et al. 2016).

### **1.3 Problem statement**

HIV related stigma remains the major problem worldwide, which affects HIV status disclosure especially in women (Black et al. 2014). HIV programmes and services were implemented long time ago to support people living with HIV, and it shows that people default to take medication due to the fear of being stigmatized. Women are the most vulnerable group especially those of childbearing age from 25-35 years (Darlington and Hutson, 2016). The researchers indicate that

many women get pregnant after initiating antiretroviral drugs (Black et al. 2014, Shisana et al. 2014). Prevention of mother- to-child transmission services were introduced to initiate all HIV pregnant women to lifelong antiretroviral drugs (Clouse et al. 2014). In the context of the recent PMTCT guidelines change where all women commence ART during pregnancy and within Option B+, Option B<sub>+</sub> where women choose exclusive breastfeeding option, lifelong ART for all pregnant women and breastfeeding women with HIV were strategies that has been introduced by World Health Organization guidelines for PMTCT to prevent the majority of women and service providers reinforced a concept raised by researchers of the “triple burden” of accepting that they are pregnant, newly diagnosed as HIV-positive and eligible for lifelong treatment (Govender et al. 2014). Previous researchers have documented high levels of HIV related stigma in South Africa that could explain drop-offs in HIV care engagement (Dos Santos et al. 2014). In KwaZulu-Natal, it is indicated that people who are HIV positive face challenges when they need to take their treatment, due to high levels of stigma among community, family, partners and healthcare workers (Yeji et al. 2014).

Among people living with HIV, HIV stigma is also a significant barrier to linkage to HIV care and adherence to treatment regimens (Velloza et al. 2015). Many women are dropping out of treatment after delivery, as they fear being stigmatized within the community and family when they continue collecting their ARVs in the healthcare centre (Black et al. 2014). The researcher therefore deems it imperative to conduct a study to explore and describe the perceived levels of HIV related stigma and disclosure patterns among women living with HIV in a selected regional hospital in the eThekweni District, KwaZulu-Natal.

#### **1.4 Aim of the study**

The aim of this study is to explore and describe perceived levels of HIV related stigma and disclosure patterns among women living with HIV and AIDS in a selected regional hospital in the eThekweni District.

#### **1.5 Objectives of the study**

##### **1.5.1 Objectives of the study were to explore and describe the**

- (a) Perceived levels of HIV related stigma among women living with HIV and AIDS.
- (b) Patterns of HIV disclosure among women living with HIV and AIDS.

- (c) Inter-relationship between demographic variables and perceived levels of stigma among women living with HIV and AIDS.
- (d) Inter-relationship between demographics and disclosure patterns among women living with HIV and AIDS.
- (e) Inter-relationship between patterns of disclosure and perceived stigma levels among women living with HIV and AIDS.

### **1.5.2 Research questions**

- (a) What are the perceived levels of HIV related stigma among women living with HIV and AIDS?
- (b) What are the patterns of disclosure among women living with HIV and AIDS?
- (c) What is the inter-relationship between demographic variables and perceived levels of stigma among women living with HIV and AIDS?
- (d) What is the inter-relationship between demographic variables and patterns of disclosure among women living with HIV and AIDS?
- (e) What is the inter-relationship between patterns of disclosure and perceived stigma among women living with HIV and AIDS?

### **1.5.3 Significance of the study**

#### **(a) Nursing practice**

The information from this study may assist nursing practice to improve their standards in confidentiality and positive attitudes towards HIV positive women. Findings may also assist the promotion of universal care in the healthcare centres by combining services, such as ARV's treatment, diabetes treatment, hypertensive drugs etc. in one room, as a study in Cape Town where women stated that they are treated in a separate room and even their files are not the same as others due to their HIV status (Turan and Nyblade 2013).

#### **(b) Nursing research**

The research findings will form a baseline for further research to be utilized by the nurse researchers in order to implement this information and also to identify gaps. The implementation of a strategy that might be effective in combating stigma among women is needed, and steps

should be taken to put this in place. The strategy planning to reduce HIV stigma in women was approved at multiple levels and by all relevant parties, including the South African National AIDS Council (SANAC), which is assisting in developing indicators of stigma associated with HIV and AIDS (French et al. 2015).

#### **(c) Nursing policies**

The information from this study may assist policy makers to develop policies related to HIV mitigation strategies tailored for women living with HIV. As the literature states, policy makers need to plan programmes that might combat HIV stigma among women as it is a major barrier for accessing healthcare services (Kamen et al. 2015).

#### **(d) Community**

The information from this study may encourage community members to support people living with HIV. The researchers introduced HIV stigma reduction interventions focusing on the community as a whole, in the form of outreach activities, and their aim is associated with caring for people living with HIV. There are home visit care teams who encourage the community to take care of affected and infected people and reduce the stigmatising of people who are HIV positive (French et al. 2014).

### **1.5.4. Definitions of terms used in this study**

#### **(a) Prevention of Mother-to-Child Transmission (PMTCT)**

PMTCT is the strategic plan that was introduced to reduce HIV transmission from a mother to her child (Simelela et al. 2015). In the context of this study PMTCT refers to the prevention of the unborn babies contracting HIV by the pregnant women taking antiretroviral treatment during pregnancy till delivery if the mother is HIV positive.

#### **(b) HIV positive**

It is the period between a person being infected with HIV and HIV antibodies being detectable by a serological assay human (World Health Organization, 2016). In this study HIV positive means someone who has the HIV confirmed through a positive HIV test.

### **(c) HIV related disclosure**

It is considered as a way to open up the HIV epidemics and hence is a crucial step toward ending stigma and discrimination against people living with HIV and AIDS (Ullah, 2011). In this study HIV related disclosure refers to someone who discloses her HIV status and response from those people she disclosed to.

### **1.6 Theoretical framework underpinning study**

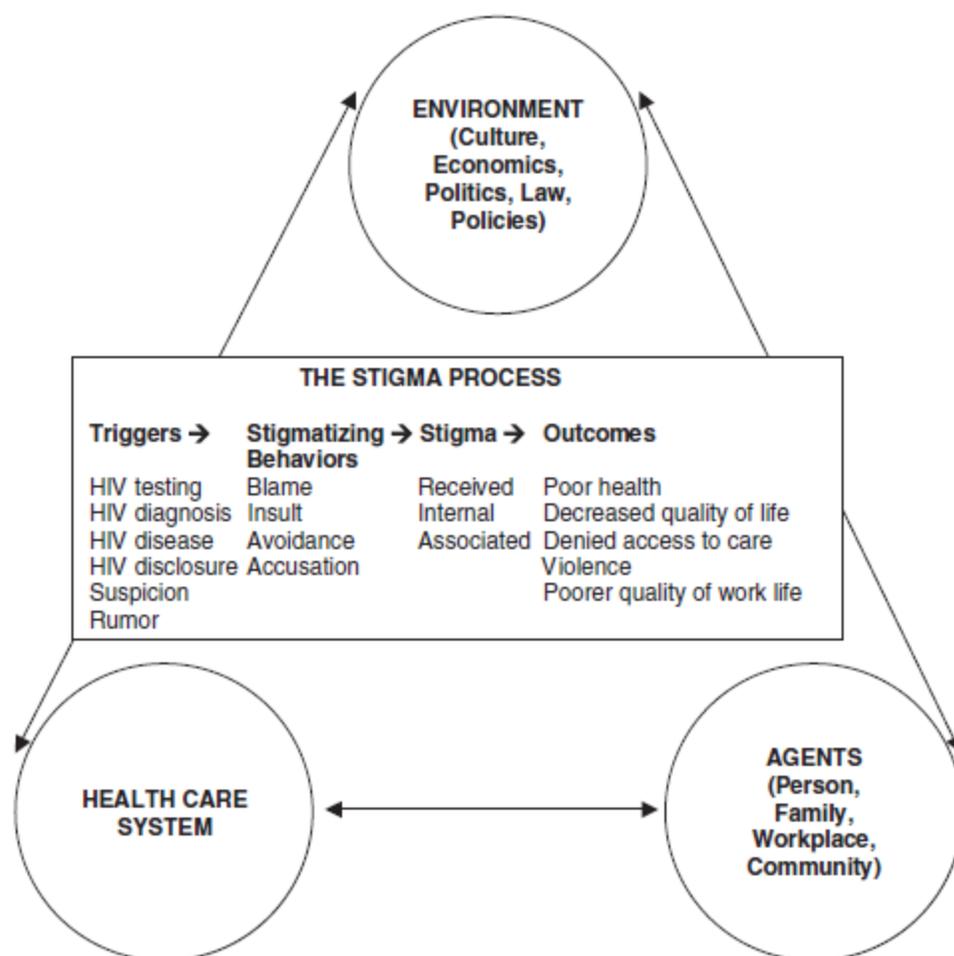
The theoretical framework is the main idea that the researcher holds about the phenomenon of interest which may or may not be written (Frank et al. 1998).

Theoretical framework is the primary conception or model of what is out there that the researcher plans to study and what is going on with such conceptions (Frank et al. 1998). A conceptual framework is a written product that explains, either in narrative or graphical form, the phenomenon to be studied, the key factors, the concepts or variables as well as their relationships (Miles et al. 1994).

The researchers propose a framework of social inequality as a strategy to understanding stigma and also urge the recognition of other contextual factors, such as culture and its impact on power relationships, in order to understand stigmatization as a process of social structures (Holzemer et al. 2007). The contextual framework was proposed in which stigma occurs such as the symbolic context, the economic, political and local community context, and organizational context of institutions working to address HIV and AIDS stigma (Holzemer et al. 2007). Many researchers propose the definitions of stigma, and have investigated its impact and correlate and propose frameworks for thinking about stigma. They use data based approaches to integrate theories on the context and process of stigma which is based on the data and personal experiences that the researchers have working with HIV clients, they conceptualize the stigma process to include triggers of stigma, stigmatizing behaviour, types of stigma and the outcomes of stigma. They combine the stigma process with the context of stigma and create a conceptual model of HIV stigma (Holzemer et al. 2007).

### **1.6.1. HIV Stigma Model**

In this study, the HIV Stigma model developed by Holzemer and colleagues underpinned the study (Holzemer et al. 2007). According to this model, the stigma process is conceived to occur within three contextual factors namely environment, the healthcare system and the agent. Environmental factors include cultural, economic, political, legal and policy environment (Holzemer et al 2007). Politics focuses on the sense of power relationships, whereby people living with HIV and AIDS are stigmatized in the cultural aspects, economic, legal and policy environments. People who stigmatize others may have a secondary gain, which leads them to have the power to stigmatize others. The process of stigmatizing might also increase their perceived power. It also noted that the legal and policy environment are secondary aspects which influence the response to an illness. There is a limited understanding of the elements which increase and decrease stigma to people living with HIV and AIDS. In public health measures, other countries have laws and policies that discriminate against people who are living with HIV and AIDS (Holzemer et al. 2007), as outlined in figure 1.1. The stigma process discussed more details and show in the diagram below:



**Figure: 1.1. Model of the dynamics of HIV and AIDS stigma (Holzemer et al. 2007).**

The stigma process is outlined in more detail in the following sections.

### **1.6.2. The stigma process**

According to the model, the stigma process takes place in context and is proposed to include four elements, such as stigma triggers, stigmatizing behaviour, types of stigma and stigma outcome.

### **1.6.3. Stigma triggers**

The stigma process can be triggered by HIV diagnosis or disclosure of HIV status. Triggers can be defined as any action that allows people to label themselves or others as HIV positive. Received stigma can be triggered by disclosure, and associated stigma can be triggered by continued association with a person who is either suspected of being HIV positive or having AIDS. Many people who are HIV positive indicated that the suspicion of being HIV positive is enough to trigger stigma, such as attending a clinic, or losing weight.

#### **1.6.4. Stigmatizing behaviour**

Triggers lead to stigmatizing behaviour that may harm, isolate, exclude or identify the person in a negative way. However, this kind of stigma is not limited, whereby a person may be forced to move home due to his or her HIV status.

#### **1.6.5. Types of stigma**

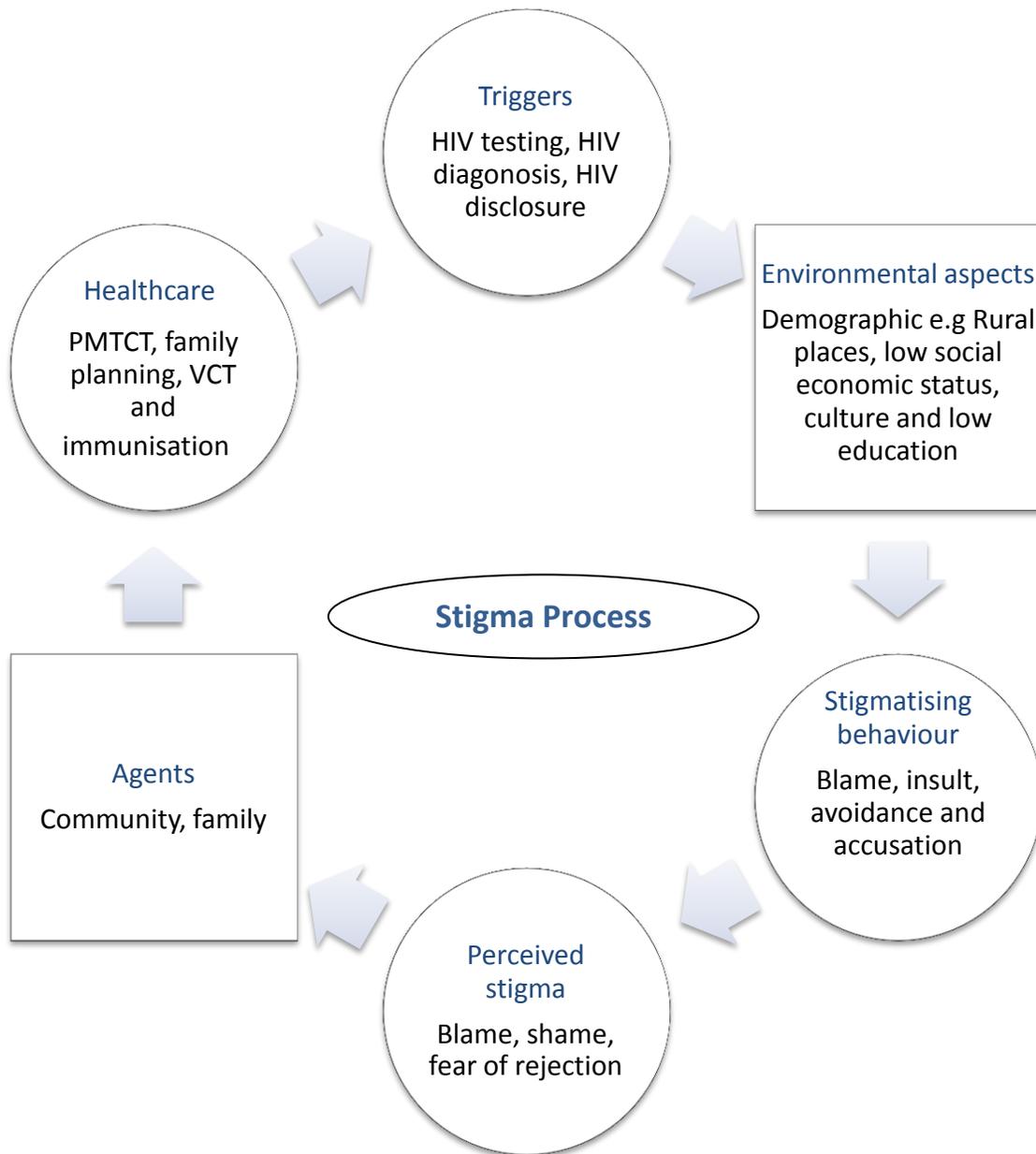
Three types of stigma have been identified from the data such as received, internal and associated. This refers to a state when a person living with HIV is neglected, rejected, avoided by others, and others gossip about her or him due to HIV status, it is referred to as received stigma, whereas internal stigma includes perception of self, social withdrawal, self-exclusion and fear of disclosure. Associated stigma explained by Holzemer and colleagues (2007) involves examples of stigma that result from a person's association with someone living with, working with or otherwise associated with people living with HIV/AIDS. (Holzemer et al. 2007).

Explained by Holzemer and colleagues (2007), the consequences and outcomes of stigma can be categorised within general health, violence, poor quality of life and reduced access to care, and that poor health as an outcome of stigma but not restricted to physical health, but also includes mental health, since social exclusion, rejection, high stress due to stigma and economic pressures may lead to stress-related mental illness. In this study, the researcher did not focus on the outcomes of stigma, but rather on the perceived stigma experienced by the women living with HIV.

#### **1.7. Application of the model of the dynamics of HIV stigma in the study**

Based on the model of the dynamics of HIV stigma, as applied to this study, figure 1.2 shows the stigma process which takes place with contexts and proposes to include three elements such as stigma triggers in relation to this study. These refer to environmental aspects, such as demographics like rural places, low socio-economic status and low education which are factors that influence stigmatizing behaviour. Perceived stigma follows where a person blames herself, is ashamed and fears being rejected by the agents who are the community and family and

highlights the types of stigma. Perceived stigma may affect healthcare and the person may avoid attending services like PMTCT, family planning, and immunization.



**Figure: 1.2. HIV stigma model adapted for study**

### 1.8. Summary of this chapter

HIV stigma on women acts as a major barrier in improving adherence to treatment. Not enough is known about what happens to the care of HIV-infected mother after the completion of the

PMTCT cascade. Keeping women healthy is a worthy and important goal on its own, however, keeping women engaged in HIV care will likely have far reaching benefits globally to reduce HIV transmission (Psaros et al. 2015). Stigma impacts beyond the individual infected with HIV, to affect all those associated with the disease. It can also impact on society more generally, by extending the epidemic and undermining whatever behaviour and treatment interventions are already in place. Thus interventions need to be introduced to reduce stigma and encourage acceptance (Pantelic et al. 2015).

## CHAPTER TWO

### 2. LITERATURE REVIEW

#### 2.1.Introduction

This chapter presents the discussion of the literature that was reviewed in relation to the aims of this study. A review of literature is a process that entails identifying and analysing potentially relevant information resources in relation to one's research study (Terre Blanche et al., 2006). It is necessary to begin this chapter with an overview of the local and global extent of HIV and AIDS, the context of women and HIV, and women receiving treatment such as HIV/AIDS Antiretroviral Treatment (HAART) and PMTCT. This will be followed by success drivers in HIV interventions and the social stigma regarding HIV and AIDS among women. AIDS stigma continues to affect people living with and affected by the HIV disease and their healthcare providers, particularly in regions where HIV and AIDS is widespread, such as southern Africa. Stigma has emerged as a major barrier to HIV and AIDS care, as well as to primary and secondary prevention (Holzemer et al. 2007). As mentioned above, literature was searched via the internet and previous research studies.

#### 2.1.1. Overview of HIV locally

South Africa is at the epicentre of the HIV epidemic and other sexually transmitted infections (STI) continue to be endemic. KwaZulu-Natal, the most densely populated province in South Africa, has been markedly affected by both the HIV and STI epidemic with a disproportionate burden of STI and HIV among women (Naidoo et al. 2014). In South Africa during the past two decades, gender-based violence and gender inequality in relationships have been associated with increased risk of HIV in women, however cessation of violence against women and girls is one of the priority areas in the UNAIDS outcome frame for 2009 to 2011, and national HIV strategic plans, such as acknowledge the need to address gender issues (Putrajaya, 2015). Although preventive measures have been introduced, such as medical male circumcision and condom used and antiretroviral drugs, but women are faced with challenges of new infections. Women are vulnerable due to low socio-economic status (King, 2013). The cross-sectional studies in rural South Africa indicate that women who experience intimate partner violence and have high gender inequality in relationships have increased incidence of HIV infections (Naidoo et al, 2014). In Sub-Saharan Africa, young girls aged 18-24 years are eight times more likely than men

of the same age group to be HIV positive (Yeji et al. 2014). This indicates that HIV affects the majority of women in their reproductive ages and their economically productive years. In sub-Saharan Africa, women remain disproportionately affected by the HIV epidemic, accounting for 58% of all people living with HIV in the region (Colombini et al. 2014).

### **2.1.2. Overview of HIV globally**

In 2015, 36.7 million people were living with HIV worldwide, with new HIV infections in the same year estimated at 2.1 million, and AIDS-related deaths at 1.1 million. Due to women accounting for a huge proportion of people infected and affected by HIV and AIDS globally, the United Nations (UN) agencies and other policy makers have often referred to the phenomenon of feminisation of HIV and AIDS (WHO, 2016). The global HIV epidemic commands our attention study conducted in Asia focuses on women due to the growing feminisation of the HIV epidemic and elevated HIV stigma that women face, particularly in the Muslim world. 87% of Muslim women state that they are reluctant to be tested for fear of gender-based violence or loss of financial support (Turan et al, 2013). The general decline in new HIV infections are noted in sub-Saharan Africa (SSA), however in 2013 the region was responsible for 72% of all HIV infections globally (Mafigiri et al. 2017). Worldwide surveillance data indicate that HIV infections have increased at alarming rates in developing countries (WHO, 2014). African countries such as Malawi and Zambia have had an impact on the morbidity and mortality due to low income, poor nutrition, and insufficient access to medical care (Kamen et al. 2015). The study conducted in South Western Uganda reported higher prevalence of HIV especially among young females and in landing site communities than in the peripheral communities, then the urgent for youth-friendly services is needed in these communities (Mafigiri et al. 2017).

### **2.2. Context of women and HIV in South Africa**

The AIDS epidemic is one of the most destructive epidemics that the world has witnessed (Evangeli et al. 2014). South Africa has the biggest and most high profile HIV epidemic in the world, with an estimated 7.1 million people living with HIV in 2016, however one third of all new infections in the region in 2016 were in one country, South Africa (Zuma et al. 2016). The risk of MTCT ranges from 15% to 40%, however in high income countries the MTCT rate may be as low as 1% to 2%. There are discrepancy in the rate of infection in high income countries compared to limited-resource countries, it is of because the campaign that they introduced such

as a greater awareness among women, accessible information, and higher socio-economic status and educational levels of women and the community (Ebuy et al. 2014). Researchers have widely documented the pervasiveness of HIV stigma and discrimination at a community level, and its impact on accessing HIV prevention and treatment, and care and support services. It can also create barriers to the use of condoms and uptake of HIV testing and the prevention of mother-to-child transmission programmes (PMTCT) as well as other services (such as legal, employment, psychosocial care) (Ngarina et al. 2014). A study in rural Kenya suggests that HIV-related stigma is associated with a low rate of delivery by skilled attendants (Colombini et al. 2014). HIV stigma in Africa has been documented to be an impediment to disclosure of HIV status, with studies indicating that between 3, 5% to 14%, and 6% of women reportedly experiencing a violent reaction from a partner after HIV disclosure (Black et al, 2014). A number of international and local South African studies indicated the complex links between poverty, gender power relations, intimate partner violence, drug use and HIV among women, and findings in a study conducting in Cape Town in a black township, revealed that AIDS was only one of many major social stressor threatening people living in everyday poverty (Dos-Santos et al. 2014).

### **2.3. Women and HIV care and treatment**

A study that was conducted in Cape Town, South Africa states that there were missed opportunities to initiate HAART among pregnant women with advanced HIV disease within the public sector antenatal care services (Okoror et al. 2013). Data from other researchers indicates that only 51% of HAART eligible women initiated treatment before delivery, while another 27% received a short course PMTCT regime, and more than one-fifth of women received no intervention (Dos Santos et al. 2014). The World Health Organization revised its ART treatment guidelines to recommend the initiation of HAART in all adults including pregnant women with CD4 cell counts of 350 cells; however the majority of women prefer Option B+ for PMTCT during breastfeeding period because of the stigma and discrimination associated with HIV and ART in the society (Ngarina et al. 2014). It shows that women are facing challenges in starting HAART due to fear of treatment side effects and disclosure to family members and spouses. Approximately one-third of patients receiving ART in a public sector programme in rural KwaZulu-Natal are depressed, while this depression prevalence is very high, it is comparable to the levels found among ART patients in other settings in Africa (Yeji et al. 2014). Women

reported fears even if they do enrol in PMTCT programs or HIV care, due to of unwanted disclosure and stigma which may make it difficult for them to adhere to ART (Turan et al. 2013). In KwaZulu-Natal, South Africa, women who were pregnant, hide their PMTCT medications from boyfriends, family members, and employers; however in Kenya both rural and urban women reported that they also hide their HIV positive status from their family and neighbours due to stigma and discrimination (Turan et al. 2013).

#### **2.4. Success drivers in HIV interventions**

The South African Prevention of Mother-to-Child-Transmission (PMTCT) guidelines were amended in 2010 aligning them with WHO recommendations and the programme reported to have 98.8% coverage nationally for antenatal HIV testing, 78.3% CD4 cell count testing, 91.8% antiretroviral prophylaxis to mother and or baby, and 89% in feeding advice (Turan et al. 2013). The high coverage and improved efficacy of the interventions have resulted in a substantial reduction in new paediatric HIV infections at six weeks of age from 5.8% in 2009 to 3.5% in 2010 and 2.7% in 2011, however this still translates into thousands of infants being infected annually. South Africa updated the PMTCT guidelines again in March 2013, offering combination ART to all HIV-positive pregnant women irrespective of the CD4 cell count. Data indicates that a personal circumstance affects participation in PMTCT and adherence to therapy (Famoroti et al. 2013). Although great improvements have been made in reducing mother-to-child HIV transmission in South Africa, HIV prevalence remains high (19.2%) among the general population. HIV prevalence is almost 40% in KwaZulu-Natal compared with 18% in the Northern Cape and the Western Cape (Zuma, 2016) hence a combination of individual, biomedical, and health system factors contribute to PMTCT failures (Ngarina et al. 2014). The PMTCT guidelines of 2015 introduced a new policy of doing Polymerase Chain Reaction (PCR) for all babies at birth, and no longer waiting for 6 weeks, and HIV-positive mothers repeated CD4 cell counts after deliver immediately (Psaros et al. 2015).

Repeat testing at these times has since been incorporated into the updated PMTCT guidelines, programme in South Africa, which is a comprehensive community-level intervention that combines gender equity, anti-violence, and an HIV and AIDS education curriculum with a microcredit programme. International Men and Gender Equality Survey (IMAGE) is generally

seen as a successful intervention due to its efficacy in reducing gender based violence and its possible impact on HIV in the future, similarly, in Zimbabwe they introduced Shaping the Health of Adolescents in Zimbabwe (SHAZI) which is based on a microcredit and life-skills training and mentorship programme on gender and power and women's empowerment theories, which attempts to address gender inequality, poverty and HIV risk among orphaned girls (WHO, 2016). They assert that while Treatment as Prevention (TasP) shows great promise as a cost-effective intervention to reduce new HIV infections and reduce the global burden of HIV related disease, the implementation of these programmes face many challenges, because of the large number of people in need of treatment (Govender et al. 2014). The researchers stress that TasP to achieve optimal prevention effects, it will be particularly important to consider the precise context of the epidemic during TasP roll-out, focusing on particular key populations, for example, in more concentrated epidemic settings (Govender et al. 2014). The government also introduced Voluntary Medical Male Circumcision (VMMC) as a strategy plan to reduce spread of HIV to young male. Fear and stigma of HIV testing are regarded as barriers and they also describe perceptions of pain associated with the procedure and adverse events and the need to abstain from sex, the authors note that targeting adolescents for VMMC can be successful together with messages promoting the benefits of VMMC (Govender et al., 2014).

## **2.5. Social trends**

HIV infected pregnant women report that HIV related stigma may be a barrier to the uptake of care, and contributes to the gap between the availability of Prevention of Mother-to-Child Transmission (PMTCT) services and the use of those services (Akullian et al. 2014). A study conducted in Kenya shows lower uptake of ART among women who are pregnant, as they reported that they feel ashamed of their HIV status, and the recent global scale-up of PMTCT services. It is estimated that roughly half of the HIV-infected pregnant women in low and middle-income countries receive ART for PMTCT, with wide country-level disparities in PMTCT coverage ranging from 5% to 10% in Sudan and Chad, to 80% to 90% in South Africa, Botswana, Swaziland, and Namibia (Akullian et al. 2014). In a study conducted in Kenya, fear of stigmatization among pregnant women was thought to account for lower rates of uptake of PMTCT services during childbirth compared to rates of uptake of antenatal care (ANC) services, which are often accessed before a mother's HIV status is known and for which participation does not result in identification as HIV-affected (Akullian et al. 2014).

The study conducted in Malawi indicated that HIV stigma is associated with greater levels of distress in Malawian women, and also highlights the need for more research and programme to reduce HIV stigma (Kamen et al. 2015). Kenya and American surveys indicate that communities' interventions should make a difference in stigma reduction such as influencing leaders, church leaders and healthcare services (Akullian et al. 2014). The stigma of HIV and AIDS is one of a social process that has been broadly assumed to adversely affect multiple facets of engagement in HIV-related care as well as other factors that may undermine antiretroviral drugs(ART) adherence, including HIV serostatus disclosure, social support and mental wellbeing (Katz et al. 2013).

The issue of stigma is very important in the battle against HIV and AIDS in Africa since it may affect patient attendance at healthcare centres for obtaining antiretroviral (ART) medications and getting regular check-ups. Stigmatization creates an unnecessary culture of secrecy and silence based on ignorance and fear of victimization(Famoroti et al. 2013). There has been much progress made in the prevention of mother-to-child transmission (PMTCT) services, hence the serious challenges to these global goals given the low rates of utilization of these services in many settings, literature reviewed from low-income settings indicates that HIV related stigma affects utilization of the series of steps that women must complete for successful PMTCT. Stigma negatively impacts on services uptake and adherence at each step of this PMTCT cascade (Turan and Nyblade, 2013).

Many researchers and activists argue that HIV and AIDS related stigma is a persistent force reducing the effectiveness of preventive measures. Stigma and discrimination are forms of barriers in HIV testing and adherence to treatment (Neuman et al. 2013). HIV related stigma is the most common thing worldwide, although women are the more predominant people who are facing challenges due to rejection by their partners, family members and community. Many researchers indicate that stigma is the major cause of the spread of HIV infection in the world (Marsicano et al. 2014). HIV and AIDS related stigma has been recognized as the third phase of the AIDS pandemic and a facilitator for the transmission of the HIV virus, leading to the lack of testing for HIV and non-adherence to ARV medications (Nyamathi et al. 2013a).

## **2.6. Women and stigma**

A study conducted in Malawi as mentioned in earlier on, indicates that Malawian women faced with greater problem of stigma and discrimination in society, which involves societal rejection and development of a social identity (Kamen et al. 2015). Studies stated that women account for half of the people living with HIV worldwide, and they experience more stigma than men, therefore they are often perceived as vectors for disease transmission who spread HIV to men via sex work and unborn foetuses (Valencia-Garcia et al. 2016). Several studies conducted in African countries, Ethiopia, Mozambique and Uganda also mentioned gender inequality to women and men, hence they view stigma and disclosure patterns as poor health in women due to social rejection (Geary et al. 2014). A study conducted in one of the hospitals in KwaZulu-Natal, South Africa reports that patients are required to undergo HIV tests before surgery, reports that 86% of healthcare workers agree with this action of pre-operative HIV testing (Famoroti et al. 2013). Similarly, another study from Nigeria reports that 56% of healthcare workers indicated that they were not prepared to operate on a person without them being HIV tested. A Polish study amongst doctors and nurses shows that 56% of doctors and 65% of nurses support HIV testing of all inpatient admissions, while pre-operative testing of all surgical cases is supported by over 90% of doctors and nurses. These findings and negative attitudes by doctors and nurses could be traced back to the prejudicial attitudes that some healthcare workers have towards people who are HIV positive, associated with the belief that those infected with HIV and AIDS are promiscuous or prostitutes and deserve whatever they got, however it could also be related to fear of infection (Famoroti et al. 2013).

The stigma motivated some women to avoid taking their medications due to fear of their spouse, as stated by HIV-positive women in western Nepal, and Indian women also mentions high levels of stigma, they are not allowed to share food, utensils and even to care for children (Katz et al. 2013). Stigma relates to the beliefs and attitudes of people and it comes in diverse forms which may include refusal to provide medical care for HIV-positive women (Churcher, 2013). Reviewers of studies report that 15% of women who are HIV-positive experience violence after disclosure in Africa and Asia, and 4% in the United States of America (Neuman et al. 2013). Women who are living with HIV and AIDS face the pervasive all-encompassing stigma which reflects the myriad of challenges such as failure to cope with their illness. A study conducted in Tanzania states that stigma still remains strong, and reveal that stigma is very high in mothers

who are pregnant and the impact of stigma manifests itself and has been a major obstacle to the effective large implementation of and adherence to PMTCT and ART (Ngarina et al. 2014).

## **2.7.Measures of stigma among people living with HIV and AIDS (PLWHA)**

Measuring HIV and AIDS stigma, whenever applicable, encourages the use of valid and reliable stigma measures by research projects and programme implementers. Stigma is considered one of the greatest challenges to addressing the HIV epidemic, data that accurately describes and quantifies stigma is often not available to programme implementers and policy makers. Consistent and widespread surveillance of stigma, utilising valid measures would also enable programme implementers to identify and assist specific at-risk and HIV-positive sub-groups who may be experiencing heightened perceived or enacted stigma when accessing prevention and treatment programmes (Nyamathi et al. 2013). Several instruments designed to measure AIDS related stigma have been published, yet none of them measure the perceived stigma by persons living with HIV and AIDS in an African setting. A quantitative measure of HIV and AIDS stigma was developed in the studies that were conducted in five African countries: Lesotho, Malawi, South Africa, Swaziland and Tanzania from 2003 and 2006. It was developed in three phases: generating items, pilot testing and validating the instrument. Six factors were added: verbal abuse (8 items, alpha\_0.886), negative self-perception (5 items, alpha\_0.906), healthcare neglect (7 items, alpha\_0.832), and social isolation (5 items, alpha\_0.890), fear of contagion (6 items, alpha\_0.795) and workplace stigma (2 items, alpha \_0.758). HIV and AIDS Stigma Instrument which is PLWA (HASI) provide evidence that supports adequate content and constructs validity (Holzemer et al. 2007).

A cross-sectional study done in Kenya, discusses stigma measures, using multivariate logistic regression. They mention the anticipated HIV and AIDS stigma that showed a high 32% who anticipated the break-up of their relationship, and 45% who anticipated losing their friends. Hence women who anticipate male partner stigma are more than twice as likely to refuse HIV testing, after adjusting for individual level predictors (OR=2.10,95% CL:1.15-3.85). This quantitatively shows that anticipations as demonstrated in this study can be barriers to acceptance of HIV testing by pregnant women and developing of interventions to combat fear among women. The multi-item scales that are used to measure HIV and AIDS have been developed and demonstrated to be valid and reliable in Sub-Saharan Africa settings (Colombini et al. 2014).

### **2.7.1. Anticipated HIV and AIDS stigma items**

Anticipated stigma refers to the anticipation that one will personally experience specific types of stigma or discrimination due to HIV and AIDS. In a study conducted in Botswana where a nine-item scale was used to measure construct, the respondent asked, “Do you think any of the followings things might happen to you, if you were to test positive for HIV and others found out about your status?” Items included losing friends, being treated like an outcast by community, treated badly at work or school, physical abuse by spouse, being neglected by family and treated badly by professional healthcare workers (response will be yes or no, then coded 1/0). A total anticipated stigma score was created by taking the mean of the responses for the nine items, for women who had non-missing data for at least six of the items. Reliability of this total score was found to be high in our sample (Cronbach’s  $\alpha = 0.86$ ).

### **2.7.2. Perceived community stigma and scales**

For perceived community stigma, the stigma scale developed by the National Institute of Mental Health Project was used and accepted to measure this construct. There are twenty-two items in this scale which people who have HIV are faced with and people are faced rejection from their homes by their families. Therefore people were asked to rate these statements on a four-point Likert scale from strongly agree to strongly disagree. The scale was previously tested in Tanzania, Zimbabwe, South Africa, and Thailand, and the three sub-scales were found to have acceptable reliability (Turan and Nyblade 2013). In a study conducted in the Netherlands by measuring health related stigma refers perceived stigma to fear of discrimination or, more generally to awareness of negative attitudes and or practices related to a particular condition. Accurate assessment of perceived stigma at both the individual and group level is an essential component of stigma measurement. The most promising instrument is the stigma scale (Famoroti, Fernandes et al. 2013). In a quantitative study (2012) in Ethiopia in the Ukraine; three items were used to measure in depth knowledge of HIV stigma and discrimination (SAD). Perceived institutional support (PIS) was measured by questions about availability of personal protection. Items used to measure stigma and discrimination were scored using a four-point Likert scale with a higher score indicating higher stigma and discrimination. Substantive validity co-efficient calculated each of items (Feyissa and Woldie 2012).

A study conducted in the United States of America developed a questionnaire based on the results of field-testing measuring HIV stigma among health workers; the questionnaire was piloted in six sites namely China, Dominica, Egypt, Kenya, Puerto Rico and St. Kitts Nevis, and developed and tested, focuses four areas, such as fear of infection among healthcare facility staff. The questionnaire was created and researchers field-tested it in China (n=300), Dominica (n=335), Egypt (n=300), Kenya (n=350), Puerto Rico (n=301) and St. Kitts Nevis (n=307) (Nyblade, Jain et al. 2013). In the United States and India, several instruments have previously been tested with women living with HIV. The instruments asked about socio-demographic information, biologic health status, knowledge about HIV and stigma (Nyamathi et al. 2013).

### **2.7.3. Stigma Scales**

South African community researchers write that the final AIDS-related stigma scale consists of nine items that tap a broad range of stigmatising beliefs (Kalichman et al. 2005). However, researchers also mention that there is no perfect tool to measure HIV stigma, thus Ekstrand and his colleagues provide four constructs stigma scales (Feyissa and Woldie 2012).

#### **2.7.3.1. Vicarious stigma**

Ten (10) Items which are similar to those assessed by the Enacted Stigma scale, but measured where participants had heard stories about other people living with HIV and AIDS being mistreated because of their infection. A sample item is, “How often have your heard stories about people being refused medical care or denied hospital services because of their HIV?” Each item has a four-point response set that ranges from never to frequently. Internal consistency reliability as measured by Cronbach’s alpha, was 0.85 for the scale in this sample (Nyamathi et al. 2013).

#### **2.7.3.2. Felt stigma**

This is when researchers discuss how a person would feel when the community give the attitudes to the people who are living with HIV and AIDS, by saying that they deserve their infections and also brought shame on their families. An example is “In your community, how many people think that HIV-infected people have brought shame on their families? “Then ten (10) items were measured on a four-point scale ranging from ‘no one’, or ‘most’(Nyamathi et al. 2013).

### **2.7.3.3. Enacted Stigma**

This scale assesses the participants about their experience if they are HIV infected, such as being asked not to share utensils or plates with others family members, ten items are measured enacted stigma using a yes or no format (Nyamathi et al. 2013).

### **2.7.3.4. Internalised Stigma**

This ten-item scale parallels the felt sigma scale, but it assesses the extent to which respondents believe that, as HIV infected people, they deserved to be stigmatised. Each item has a four-point response format varying from (1) not at all to (4) a great deal. For example, an item is: “How much do you feel that you deserve to have HIV?” Reliability in this sample was 0.89, and internalised stigma scale all items begin with the words “How much do you feel?” Previous studies used scoring for the HIV stigma scale items as follows: strongly disagree =1, disagree =2, agree =3, strongly agree =4 (Barbara Berger, 1996; United States Agency for International Development (USAID) Policy Project’s, 2013 (Turan and Nyblade 2013).

## **2.8. Women living with HIV stigma, and avoidant coping**

Stigma affects negatively on employment, familial reputations and reluctance to be tested for HIV globally (Nyamathi et al. 2013). HIV stigma may be rooted in the belief that the burden of transmission is a bearer for having engaged in risky behaviour (French, et al. 2015). Stigmas have a profound effect on people’s decisions, behaviours, and outcomes and also reduce people’s willingness to engage in HIV testing, treatment, and prevention. Studies have shown that stigma reduces people’s participation in educational meetings and counselling, prevents risk reduction behaviour, and participation in programmes to prevent mother-to-child transmission (Psaros et al. 2015). Stigma has also been linked to a reduction in quality of life among people with HIV. HIV stigma and discrimination adversely affects every aspect of life for people living with HIV and their families. In many settings, HIV diagnosis can still be as devastating as the illness itself, leading to job loss, school expulsion, violence, social ostracism, loss of property, and denial of health services and emotional support (Darlington and Hutson 2016). People living in fear are

less likely to adopt preventive behaviour, come in for testing, disclose their status to others, access care and adhere to treatment, hence reducing stigma and discrimination can dramatically improve the lives of people affected by HIV (Churcher, 2013).

## **2.9. Positive women's perceptions of stigma in a healthcare setting**

The researchers of stigma suggest that poverty is an important driver of HIV stigma (Tsai, Bangsberg et al. 2013). In the Western Cape, South Africa, women revealed that they were being stigmatised in healthcare settings; while PMTCT programmes are effective, pregnant women were reluctant to follow-up due to high levels of stigma (Okoror, BeLue et al. 2014). The HIV and AIDS stigma is more severe for women than men, as they not only bear the burden of providing care for the sick loved ones, but they also bear the responsibility of being labelled as “disease carriers” (Psaros, Remmert et al. 2015). A study conducted in Khayelisha, a township setting in the Western Cape, South Africa, women revealed that in healthcare settings HIV-positive people sit in their own section, which is not acceptable, and that even their files are different from other patients' files. They also mentioned the pharmacy settings in the hospital, which has an isolated section for HIV-positive people, which forces the disclosure of status. There are separate rooms for HIV-positive people within the hospital which is turning into a stigmatised space for them (Okoror et al. 2014).

In the study conducted in two areas, Khayelisha and Gugulethu, in Cape Town the researcher states different views about stigma in healthcare settings. The model shifts the focus from the individual to the cultural context of the behaviour, revealing how culture may influence these perceptions to reduce the stigma from women in healthcare settings, such as identifying behaviour that healthcare professionals need to avoid or embrace and identify healthcare protocols and policies that may enable or hinder care utilisation by HIV-positive women (Naidoo et al. 2014)

A study conducted in India reported high rates of enacted stigma in rural women which derived from community and healthcare professionals (Nyamathi et al. 2013). South African studies indicated that 57% of women experienced stigma and discrimination from community and family, hence 6.4% of women has experienced stigma from healthcare workers (Katz et al. 2013).

## **2.10. Stigmatisation and discrimination in HIV and AIDS**

Stigma could lead to delays and failures seek treatment, however the delay in the seeking of treatment may lead to the continuous spread of the disease within the community (Famoroti et al. 2013). Discrimination may be described as a form of “enacted stigma” or the negative acts that result from stigma which serve to devalue and reduce the life chances of the stigmatised (Famoroti et al. 2013). Most studies indicate that stigma is a barrier in healthcare settings (Tsai, Bangsberg et al. 2013). A study conducted in Russia revealed that the most vulnerable group being women was treated so badly so that they feel uncomfortable accessing health services and they mentioned that people who are HIV positive should be isolated from society and be punished for being positive (Dos Santos et al. 2014).

## **2.11. Interventions to reduce stigma in women**

The National Rural Health Mission launched in India which targets the most under-served populations of rural women and children with the support of Asha or lay village women, who promote the health of pregnant women and infants, and was introduced to minimise stigma in the Indian women society (Nyamathi et al. 2013). However, there remains an ongoing need to develop interventions targeting rural women who are HIV-positive. The study conducted in India indicates that while interventions such as counselling and ongoing health education may reduce stigma, physicians, nurses, spiritual leaders should also be included to give health education including topics such as dealing with illness, the basics of good nutrition and easy ways of cooking tips, and reducing stigma by engagement in a life skills class, such as computer skills, marketing and embroidery (French et al. 2015). The literature indicated that, there are others ways to reduce stigma such as including family members and friends in discussion of treatment. However, at an individual level, interventions might seek to bolster instrumental social support by including family, friends and peers in treatment and services when feasible. At the community level, interventions might seek to enhance services which are available to people who are HIV-positive, ensure that these services are accepting and supportive and are also being advertised in the community (Earnshaw et al. 2014). Studies suggest that until HIV stigma has been eradicated completely, it is critical to identify and bolster resources that enhance resilience to HIV stigma so that people can live full healthy lives, and also mention that community advocates, policy makers, and scientists have made significant strides towards eliminating HIV stigma since the

beginning of the epidemic, effectively reducing stigma in many areas of the world (Dos Santos et al. 2014).

The authors articulated four interventions categories based on psychological conceptualisations of the stigmatisation process; information-based approaches such as written information in a brochure, skills building such as learning sessions to reduce negative attitudes, counselling or support groups for HIV-positive people and contact with affected groups like interactions between public and positive people (Stangl, et al. 2013). Most of the 22 studies reviewed attempted to increase the general tolerance or health providers' willingness to treat HIV-positive people by changing individual level of fear, attitudes or behaviours (Earnshaw et al. 2015). However complex problems require complex solutions (Dos Santos et al. 2014). Poverty and lack of reciprocal exchange are important drivers of stigma, as described in qualitative studies conducted in Sub-Saharan Africa (Tsai et al. 2013).

According to the conceptual model of HIV stigma on five African countries, stigma is a complex process and it occurs within a context (French et al. 2015). A quantitative study conducted in the North-West Province, South Africa, focussing on people in healthcare settings, indicated that increasing the knowledge of HIV and stigma improved coping with stigma and empowerment and also improved voluntary HIV testing by nurses and was effective in reducing perceived stigma by women who are HIV-positive, improving their self-esteem (Yeji et al. 2014). HIV stigma reduction interventions targeting partners like programmes developed to empower women whose partners have died of HIV and AIDS to cope with the accompanying stigma (French et al. 2015). Literature revealed that studies of HIV stigma reduction interventions targeting different groups of people via in-depth interviews conducted with people who are HIV positive, including experiences of people living with HIV, expressed a strong sense of shift in perception regarding HIV stigma experiences, and they reported feeling out of place and unsure initially, especially due to the imminent disclosure that was to take place; "I felt lonely", "I was so afraid", and others reported being too scared to talk about HIV (Govender et al. 2014). The community interventions of stigma reduction were effective in the Setswana culture that is prominent in the North-West Province, where people who are HIV positive expressed a sense of being accepted and respected (French et al. 2014).

## **2.12. PMTCT and levels of stigma among HIV-positive women**

The PMTCT programme was launched to improve maternal and child health, hence the reviewers suggest that PMTCT and maternal health services will not reach their full potential to save lives without addressing the context of women's lives, and in particular the continuing threats of stigma associated with positive HIV status in so many countries (Turan and Nyblade 2013). In KwaZulu-Natal, South Africa, pregnant women reported that they hide their PMTCT medications from their boyfriends, family members, and employers, by doing so adherence is poor as evidenced from one of the regional hospitals (Ngarina et al. 2014). A study conducted in Kenya, stated that fear of stigmatisation among pregnant women was thought to account for lower rates of uptake of PMTCT services during childbirth compared to rates of uptake of antenatal care (ANC) services, which are often accessed before a mother's HIV status is known and for which participation does not result in identification as HIV-affected (Govender et al. 2014).

Stigma is prevalent in diverse contexts from Brazil to Zimbabwe. Stigma is strong in both higher HIV prevalence settings such as Botswana as well as in lower prevalence countries such as India. It also operates within families, communities, institutions such as healthcare facilities and places of employment, the media, and government policies, laws and legislation (Clouse et al. 2014). People living with HIV experience stigma in numerous forms. Social stigma excludes people living with HIV from family and community events, resulting in their loss of power and respect in the community. Physical stigma includes isolation (such as separate sleeping quarters in the home or a separate seating area in places of worship) and violence. Verbal stigma includes insults, taunts, blame, gossip and rumours. Institutional stigma includes job loss due to HIV status, eviction from housing, loss of educational opportunities and sub-standard healthcare (Earnshaw et al. 2014). In South Africa, fear of stigma has led people to grind their drugs into powder, which can result in inconsistent doses, and to avoid taking medicines in front of others (Okoror et al. 2014).

Stigma associated with HIV is frequently layered over other forms of social disadvantage thereby accentuating the exclusion and devaluation of HIV-positive people (Akullian et al. 2014). A study conducted in Cape Town revealed that participants spoke of how their partners rejected them after learning of their status. In a Vietnamese study, 60% of pregnant women who

refused HIV testing cited fear and discrimination as the dominant reasons (Psaros, 2015). In Kenya, pregnant women avoided delivering at a health facility or deliberately destroyed their antenatal cards, which included their HIV status, for fear of discrimination by health providers (Akullian et al. 2014). A survey of more than 1,000 healthcare professionals working directly with HIV patients in four Nigerian states found that 59% believed patients with HIV should be on a separate ward, 12% believed treatment of opportunistic infections wastes resources, and 43% observed others refusing hospital admission to a person with HIV (Ebuy et al. 2015).

### **2.13. Community perceptions of stigma in women who are HIV positive**

A study conducted in the Eastern Cape, Western Cape and KwaZulu-Natal, South Africa states that many women living with HIV are unable to access services, because they fear stigma and discrimination if their HIV status is disclosed, and also mention that violence against women, which has been defined as a form of gender based discrimination, also creates barriers for women living with HIV whom may fear the consequences of accessing HIV testing and medication (Yeji et al. 2014). In women who are living with HIV, the decision to disclose may be influenced by culture and community level stigma, hence the impact of community HIV stigma to women who are positive plays role in prevention to disclose (Ojikutu et al. 2016). A study conducted in Thailand, Brazil and Zambia stated that 45% of women living with HIV agreed perceived community stigma, their community belief that HIV is associated with being a sex worker and having multiple sexual partners (Ojikutu et al. 2016). A study conducted in Uganda stated higher prevalence of HIV among female youth, thus the community in Uganda associated having HIV with risky sexually behaviour to the female youth (Mafigiri et al. 2017).

### **2.14. Stigma on Prevention of Mother- to-Child Transmission**

The literature indicates that there are divided sections in PMTCT such as HIV-related stigma in the context of PMTCT; neonatal survival, and health; healthy early childhood development nutrition; and marginalised groups; and child survival, however it is important to note HIV-related stigma in the context of PMTCT, because it contributes to negative health outcomes for children and their parents, and disproportionately affects poor or marginalised groups (Turan and Nyblade, 2013). HIV-related stigma may be a barrier to uptake of care in pregnant women, hence also contributes to the gap between the availability of PMTCT services (Akullian et al. 2014).

The researchers suggest that PMTCT and maternal health services will not reach their full potential to save lives due to stigma related to women living with HIV in so many countries, however integration of PMTCT and other HIV services into maternal, neonatal, child, and other reproductive health services may be the solution (Turan and Nyblade, 2013). Limited access to and uptake of services for PMTCT as a result of the fear of or the experience of stigma and discriminations is a prominent example of how child survival can be influenced by stigma (Zuma, et al. 2016). There is a need to improve the self-esteem of women as they are being undermined in the societies; hence they are the umbrella of the community. By looking at the literature on PMTCT and HIV stigma among women, it shows that interventions to reduce stigma are needed, to improve child health outcomes in low- and middle-income countries (Psaros, et al. 2015).

### **2.15. Conclusions**

Stigma and discrimination are barriers to access and uptake of health information and services (Naidoo et al. 2014). Finding ways to increase HIV testing in South Africa may help to prevent the spread of HIV by increasing acceptance for HIV prevention behaviours and HIV treatment. However, the high rate of HIV stigma in South Africa is contributing to the low rate of testing. HIV stigma affects testing decisions in the community. A study conducted in the United States of America found that 38% of adults are very concerned about HIV stigma if they tested positive and 44% said that stigma influences their testing decision (Kamen et al. 2015). South Africans who have been not tested for HIV are shown to hold more negative views about HIV as compared to those that have been tested (Turan and Nyblade, 2013).

## CHAPTER THREE

### 3. METHODOLOGY

#### 3.1. Introduction

Research methodology is the details of the procedures of data collection, analysis and writing (Williams, 2011). The section of methods and their application are always dependent on a number of factors, which include the purpose and objectives of the study, the nature of the phenomenon under investigation, underlying theory or expectations of the researcher, the intended audience and the experience of the researcher (Williams, 2011).

Therefore, this study is focusing on perceived HIV related stigma among women, especially those who are living with HIV and AIDS. This chapter discusses the paradigm underpinning the study, population and sampling, the research methods used to collect data, and the rationale explaining why those methods have been chosen, how data was analysed, validity and reliability, and ethical considerations involved in the study.

The purpose of this study is to explore and describe levels of perceived HIV related stigma among women living with HIV and AIDS in a selected regional hospital in the eThekweni District. The research methodology for this study is guided by the objectives of the study which are to explore and describe:

1. Perceived levels of HIV related stigma among women living with HIV and AIDS.
2. Patterns of HIV disclosure among women living with HIV and AIDS.
3. Inter-relationship between demographic variables and perceived levels of stigma among women living with HIV and AIDS.
4. Inter-relationship between demographics and patterns of disclosure among women living with HIV and AIDS.
5. Inter-relationship between patterns of disclosure and perceived stigma levels among women living with HIV and AIDS.

### **3.2. The research paradigm for the study**

Paradigms are described as patterns of beliefs and practices used by researchers to regulate their disciplinary enquiry in order to accomplish their goals (Steward et al. 2008). Paradigm is also referred to as an overall philosophical framework of how scientific knowledge is produced. A paradigm includes the main assumptions, the questions to be answered in the investigation, there are two main competing paradigms in research theory, the positivist, mainly quantitative paradigm and the phenomenological, interpretive, mainly in qualitative paradigm of inquiry. This former was first established at the beginning of the 20<sup>th</sup> century when social sciences were born and adapted to the positivist thinking of the natural sciences (Steele, Lindley et al. 1999). The researcher proposes to study perceived levels of HIV related stigma among women living with HIV within a positivist paradigm, as the positivist paradigm is aligned to quantitative research (Steele, Lindley et al. 1999) and this study uses a quantitative approach of a descriptive design.

### **3.3. The positivist paradigm**

Positivist paradigm is also called the scientific paradigm. The purpose of research in this paradigm is to prove or disprove a hypothesis. It also includes an emphasis on the scientific method, statistical analysis, and generalizable findings. Furthermore, positivist research usually has a control and experimental group and pre-test and post-test method (Steele, Lindley et al. 1999). The positivist researcher views science as value free and the world as objective. French philosophers believed that reality can be observed (Steele, Lindley et al. 1999).

In addressing the ontological question which asks what the nature of reality is; the positivist researcher believes in the existence of an objective reality which can be understood, controlled and predicted by means of cause effects (Mack, 2010). The methodology question regarding the methods and techniques that can be used is addressed by positivists through the use of measuring instruments, such as a questionnaire and observations (Steward et al. 2008). Ontological assumptions and epistemological assumptions tend to overlap. As Mack (2010) points out “to talk of the construction of the meaningful reality assumptions can be divided into two broad categories”.

The positivist paradigm is essential if nursing science is to substantiate claims regarding nursing care and the responses of clients in health and illness situations, provide explanatory models, and

test and generate theory (Mack, 2010). Thus, the researcher conducted this study within a positivist paradigm, which enables the researcher to objectively study perceived HIV related stigma and disclosure patterns among women living with HIV and AIDS in a selected regional hospital in the eThekweni District.

### **3.4. Research Design**

A research design is described as a researcher's overall plan for obtaining answers to research questions or testing the research hypotheses (Polit et al. 2001). The research design serves as a blueprint for the researcher in planning and implementing the study to control factors that can affect its validity and reliability (Polit et al. 2001). The research design for this study was an explorative, quantitative research design used to explore and describe perceived levels of HIV related stigma and disclosure patterns among women living with HIV. The design questionnaire adopted from previous researchers was used to collect data. In this study, a quantitative approach was used; it also employs deductive reasoning to generate hunches that were tested in the real world (Polit, Beck et al. 2001). Quantitative researchers are aligned to the positivist paradigm and therefore gather empirical evidence which is inclined to objective reality that can be obtained through the senses (Polit et al. 2001). The quantitative researcher, as a positivist purist, employs cause and effect thinking, use of hypotheses and questions, measurements, observations, experiments and surveys to collect data and uses methods such as statistics for interpretation (Mack, 2010). By using a quantitative approach, the researcher was able to gain more insight into the perceptions of HIV related stigma among women living with HIV receiving maternal and child health services in a selected regional hospital. The researcher accurately describes and compares the findings between the groups and variables in the findings.

### **3.5. Research setting**

The study was conducted in a selected hospital in KwaZulu-Natal in the eThekweni district of Durban, South Africa. The researcher looked at women, whose age category is between 20 to 35 years, as 31.6% of Black African women living with HIV in South Africa and in KwaZulu-Natal is 16.9 % women of this age are living with HIV as they are sexually active from 18 to 35 years (Human Science Research Council, 2014 and National survey, 2014). The selected hospital is a regional hospital in the eThekweni district, and is one of the largest hospitals in KwaZulu-Natal province, which is the leading province for HIV and AIDS in South Africa according to

statistics. The hospital is government-funded (Ngidi, 2011), and is a 1200 bed facility that serves the surrounding areas, up to and including part of the Eastern Cape. The hospital offers health services to the community at regional and district levels and has 17 clinics attached. The hospital is one of the sites for Prevention of Mother-to-Child Transmission (PMTCT) and has the largest crisis centre - now called the ‘Place of Comfort’. There are two clinics within the hospital which provide HIV services such as voluntary counselling and testing and ARV management.

The hospital has maternity departments, which include the antenatal clinic and Prevention of Mother-to-Child Transmission (PMTCT). According to the monthly statistics register in the antenatal clinic in the selected hospital, the numbers for September 2015–February 2016 were, 1140, 1329, 1300, 1061, 1085 and 1321 respectively. The researcher believes that the large number of pregnant women living with HIV who attended the antenatal clinic in the selected hospital is an appropriate setting for this study. On further count of the women attending the HIV clinic housed within the selected hospital, it shows a range of 265-310 women living with HIV and AIDS between the age of 20-35 years for the months of January to March 2016.

**Table 3.1. Monthly statistics (January – March, 2016) women living with HIV aged 22-35 years**

Monthly	Number of women
January 2016	<b>283</b>
February 2016	<b>265</b>
March 2016	<b>310</b>

### **3.6. Study population**

The study population refers to the aggregate or totality of those conforming to a set of specifications (Polit and Beck, 2012). The members of the population who meet the sampling or criteria are referred to as the target population and those whom the researcher has reasonable access to be referred to as accessible population (Elo and Kyngäs, 2008). The target population for this study was 286 women living with HIV and AIDS, the average number of women attending the HIV clinic in the selected hospital as per the hospital statistics for the three month period of January to March 2016, as reflected in table 3.1.

### **3.7. Inclusion criteria**

1. Women who are living with HIV and AIDS (WLWHA).
2. WLWHA who have been booked in as patients within the selected hospital and clinic where HIV care was received
3. WLWHA who are between the ages of 20-35 years. This age range is based on the national statistics for the highest prevalence of HIV in women in KZN (Shisana, Rehle et al. 2014).

### **3.8. Sampling method**

In this study non-probability purposive sampling was used, this allowed the researcher to purposively select participants from the target population who had the desired inclusion criteria, which is a type of non-probability sampling. Purposive sampling is a form of non-probability sampling which allows the researcher to select study participants consciously based on the inclusion and exclusion criteria (Williams 2011). A sample size of 90 participants was deemed adequate for the study, following consultation with the statistician. The sample size of 90 from the target population produced a two-sided 95% confidence interval with a precision (half-width) of 0, 9 or 9% when the actual proportion is near 0.50-50% (assumes maximum variability given no prior estimates to factor into the calculation).

### **3.9. Data collection**

#### **3.9.1. Instrument for data collection**

Evidence for a study in the positivist paradigm is gathered according to a specified plan, using formal instruments to collect needed information, which is usually quantitative or numeric in nature (Polit, Beck et al. 2001). Data collection occurred over a one month period, to allow enough time to get the desired sample. In this study a structured self-reported questionnaire was developed (see Appendix: 6), the items for the instrument were sought from previous studies which measured HIV related stigma and disclosure patterns.

The stigma scale by Holzemer et al (2007) was used to measure HIV related stigma. This quantitative measure of HIV and AIDS stigma was developed in a multinational study conducted in five African countries: Lesotho, Malawi, South Africa, Swaziland and Tanzania from 2003

and 2006. It was developed in three phases: generating items, pilot testing and validating the instrument. Six factors were added: verbal abuse (8 items, alpha\_0.886), negative self-perception (5 items, alpha\_0.906), healthcare neglect (7 items, alpha\_0.832), and social isolation (5 items, alpha\_0.890), fear of contagion (6 items, alpha\_0.795) and workplace stigma (2 items, alpha\_0.758). The HIV and AIDS Stigma Instrument (HASI), which is used to measure stigma in people living with HIV (PLWA) provides evidence that supports adequate content and construct validity (Holzemer et al. 2007).

The first section includes the client's socio-demographic information such as age, marital status, level of education, and occupation. In addition, this section consists of some questions about the client's reproductive history including parity and the number of live children. This tool is used by other researchers for information on experience, opinion and how people with HIV are treated in the community. The second section includes information about the client's experiences or opinions and how people living with HIV are treated. There are four answers that need to be chosen; strongly disagree (SD), disagree (D), agree (A), and strongly agree (SA). The final score is an aggregate of the responses, with the lowest score indicating low perceived stigma and the higher score indicating higher perceived stigma. The scoring and use of the instrument was aligned to the authors of the scale (Holzemer et al, 2007 and Kalichman et al. 2005). The third section asks about the reaction of people towards others who are living with HIV within the family, community and a spouse or intimate partner. Section C. This section indicates how often people living with HIV are stigmatised. The score will be determined by the number of incidents (Steward et al. 2008). Asks about the HIV status: 0=never, 1=once or twice, 2=several times, 3=most of the time

### **3.9.2. Instrument validity**

According to Pilot and Beck (2001), validity is the degree to which an instrument measures what it is supposed to measure. It determines the extent to which an instrument reflects the abstract construct that the researcher is investigating (Williams, 2011). Therefore, the researcher in this study needs to establish the validity of the instruments adopted. In this study the instrument measured the perceived levels of related stigma among women living with HIV and AIDS.

There are different ways of assessing the validity of an instrument, such as criterion, content and construct validity (William, 2011). This study will be using content validity. Content validity is

the ability of the items on an instrument to represent all the major content of the construct being measured (William, 2011). This method was chosen to assess the validity of the items of the instrument in relation to the study objectives due to the availability of literature regarding the instruments, as reflected in Table 3.2.

### 3.9.3. Instrument reliability and content validity of the instrument

Instrument reliability is the ability of an instrument to consistently provide the same results in repeated measurements or occasions (Polit et al. 2001). Instrument reliability in a study is a major criterion for assessing its quality and adequacy (Burns and Grove, 2009). Reliability exists in degrees and is expressed as a form of correlation co-efficient, with 1.00 indicating perfect reliability and 0.00 indicating lack of reliability (Burns and Grove, 2009). The instrument used in this study has been previously tested showing strong Cronbach Coefficients as reflected in section 3.9. The instrument was translated by a language expert in isiZulu to allow participants who wanted to complete the questionnaire in isiZulu (see appendix 6 and 7). To ensure reliability, the translator used back translation from the isiZulu to English version and compared the items to ensure that the meaning of the words were not altered.

**Table 3.2. Content validity of the instrument**

<b>Constructs</b>	<b>Theoretical constructs</b>	<b>Item</b>	<b>Literature contributing to the questionnaire</b>
Explore and describe levels of HIV related stigma among women	Stigma	Section B	Kalichman et al. 2005; and Holzemer et al. 2007
Explore and describe disclosure among women living with HIV	Disclosure	Section A and C	Do Sontos et al. 2014;and Kartz et al. 2013
Explore and describe demographic variables and perceived levels of stigma.	Demographic	Section A 1 and A 2	Stephenson et al. 2009; and Shisana et al. 2014
Explore and describe inter-relationship between demographics and disclosure	Disclosure and perceived HIV stigma	Section B	French et al. 2015

Explore and describe inter-relationship between disclosure and perceived stigma	Context of women and stigma	Section C	Teklehaimanot et al.2016; and Ebuy et al. 2014
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### 3.10. Data collection procedure

Every researcher collects data using one or more techniques. There are different types of data collection techniques in quantitative study, such as experiments, surveys and content analysis (Williams 2011). In this study, a survey data collection technique was used, as the researcher was obtaining information through the form of a self-reported questionnaire.

Following ethical approval and gate keeper permission, data collection within the selected hospital commenced. Ethical approval was sought from the Biomedical Research Ethics Committee of the University of KwaZulu-Natal (Ethics number BE375/16). Following institutional ethical approval, gatekeeper permission was sought from the selected hospital (see appendix 2 and 3). The data were collected within a period of four weeks from 01 to 30 November 2016. The researcher distributed the information letter and written informed consent was obtained from each participant prior to distribution of the data collection instrument (see appendix 5 and 6). On average it took participants between 20-25 minutes to complete the questionnaire. The participants were sampled and approached during their visit to the sampled hospital during their routine PMTCT visit, participants volunteered to complete the questionnaire (they were no participants who requested IsiZulu version) either before or after their consultation with the nurse or midwife. Participants who volunteered to participate in the study were provided a quiet space, which was an office within the Maternal and Child Health unit of the hospital, this ensured they had privacy while completing the questionnaire. A sealed box was available in the same venue, which allowed the participant to submit their completed questionnaire anonymously. The researcher was within the Maternal and Child Unit, but not in the same room during data collection, this was to ensure availability to the participants, should they need assistance or had queries.

### 3.11. Ethical considerations

Ethical issues in health related research has gathered much attention as an important topic in nursing research and professional practice (Bastida, Tseng, McKeever and Jack, 2010). In

nursing research, researchers are obligated to protect the rights of the study subjects. To ensure this right to protection, formal ethical approval was obtained from the Biomedical Ethics Committee (BE375/16) from the host University of the researcher; following which gatekeeper's approval was sought from the selected hospital management. (See Appendix 1 and 3).

Participants require accurate information about a study to enable them to decide whether or not to participate (Grove et. al., 2013). The researcher ensured that the participants were adequately informed by explaining the purpose and significance of the study both verbally and on the information sheet. To ensure autonomy in the participant's choice to participate in the study, the information sheet and informed consent was provided in both English and isiZulu. The explanations were necessary because the principle of self-determination has it that prospective participants have the right to voluntarily decide on whether or not to participate in a study without any punishment or ill treatment (Polit and Beck, 2004)

As it is unethical to allow unauthorized persons to have access to the raw data of a study (Grove et. al., 2013), the researcher kept the information obtained from the respondents confidential. To protect their rights to privacy, the participants were not required to disclose any personal, identifiable information. Questionnaires were anonymous and information gathered were kept confidential to further protect their rights to privacy. During the data collection process, the researcher informed the participant not to write their names on the questionnaires. Coding was used to eliminate names and other personal identification of respondents throughout the study process to ensure anonymity.

It was clearly stated on the information sheet that participation in the study was voluntary and that they could withdraw from participation at any point of the study. They were also advised that they could seek clarification at any stage if they wished. The contact information of the researcher, the researcher's supervisor and UKZN ethical committee chair were provided for any questions or concerns that the participants may have regarding the study. The study's potential benefits, such as adding to the body of nursing knowledge, were also explained to the participants (See Appendix 4).

### **3.12. Data analysis**

Data was entered and subsequently analysed using SPSS version 21 from SPSS Survival Manual Fourth edition, (2011). Descriptive statistics such as frequencies, percentages, means, medians, standard deviations and interquartile ranges have been used to summarize the data. Descriptive and non-parametric tests were used to assess the levels of perceived stigma, disclosure patterns and inter-relationships between demographic variables and perceived HIV related stigma and disclosure patterns. Data analysis was conducted by the student in support by the statistician provided by the College of Health Sciences.

### **3.13. Data management**

Data were collected by the researcher only, to ensure the confidentiality. After data analysis, all the questionnaires were stored in a secured and locked filing cabinet in the research supervisor's office in the School of Nursing and Public Health at the University of KwaZulu-Natal. The questionnaires will be kept for 5 years after completion of the study, and only the researcher and research supervisor will have access to the data.

### **3.14. Summary of this chapter**

This chapter presented a discussion on the research paradigm which guided the study. It also presented the methodology, research design, the setting for the study, population for the study and the sampling procedure. The instrument for data collection, validity and reliability, and the procedure for data collection were also described. Issues concerning ethics in research, such as consent, voluntary participation confidentiality and data management also included in this chapter.

## CHAPTER FOUR

### 4. DATA PRESENTATION AND INTERPRETATION

#### 4.1. Introduction

This chapter presents the analysis and interpretation of the results of the study. The results of the study are presented under the following sections: A 1, demographic data profile, A 2, reproductive history; B, perceived HIV stigma among women living with HIV; and C, disclosure patterns and levels of stigma. The results are summarized in tables with responses of strongly disagree, disagree, agree and strongly agree.

#### 4.2 Sample realisation

The sample size for the study was 90 women living with HIV. A total of 90 questionnaires were therefore distributed to the participants, all 90 women were able to participate to the study and answered questionnaire. Descriptive and non-parametric tests were used to show the levels of perceived stigma, disclosure patterns and the inter-relationships between the demographic variables and perceived HIV-related stigma and disclosure patterns.

#### 4.3. Demographic characteristics of the sample

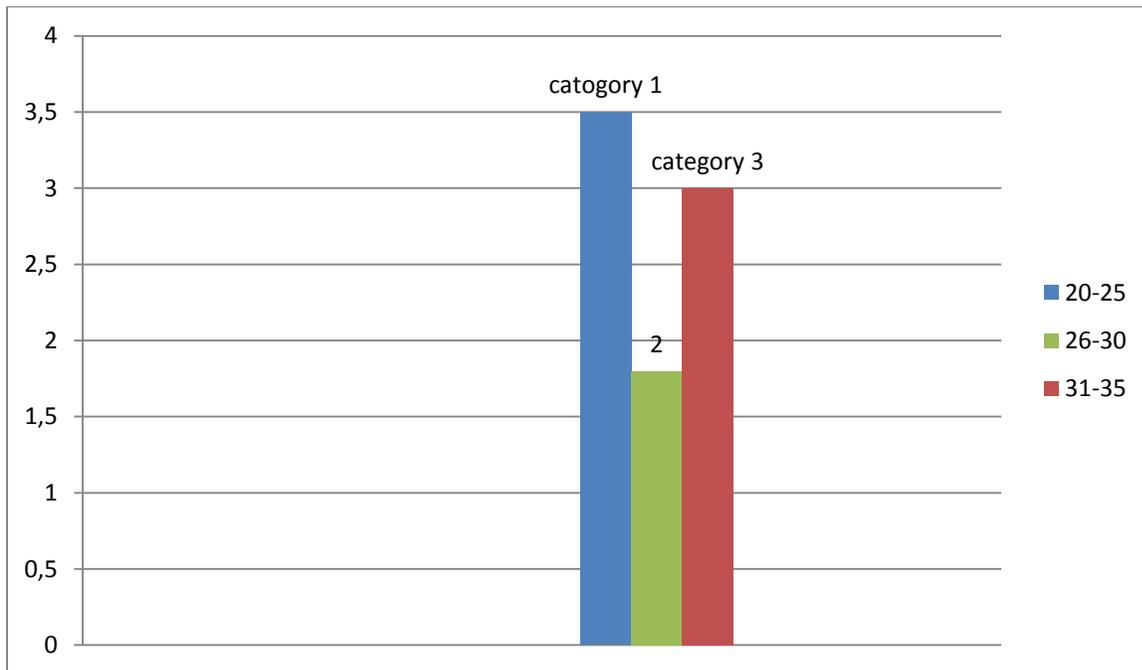
The seven (7) variables under the demographic profile of the participants were age, marital status, ethnicity/race, employment, and level of education, where they lived and who they lived with. The participants were asked to indicate these variables so that the researcher could describe the characteristics of the participants and make correlations to establish the participants' perceived levels of stigma, their patterns of disclosure, the relationship between the demographic and stigma, and the relationship between the demographic and disclosure.

##### 4.3.1 Age of the participants

The ages were categorized to enable the researcher to determine the age distribution of the participants and to determine the influence of age on the perceived levels of stigma and patterns of disclosure. Ages 20-25 years were classified as category 1, ages 26-30 years were classified as category 2 and ages 31-35 years were classified as category 3.

### Distribution of age categories of participants in years (n=90)

There were three age categories in the demographic characteristics section of the questionnaire. The ages of the participants were ranging from 20-35 years. In age category 1, 38.9% (n=35) were aged from 20-25 years. In age category 2, 24.4% (n=22) were aged from 26-30 years, and those from the ages of 31-35 years (36.7%, n=33) fell into category 3. Therefore, the highest number of women were aged from 20-25 years (38.9%), followed by age category 2 of 31-35 year olds (36.7%), and the lowest number of participants (24.4%) were from age category 3, from 26-30 years of age.



**Figure 4.1: Age distribution**

#### 4.3.2 Marital status of the participants

The participants were asked to indicate their marital status as this enabled the researcher to determine whether marital status influenced the participants' disclosure of their HIV positive status or the level of stigma perceived by them. The findings showed that the majority of the participants were single (93.3 %, n=84); (2.2%, n=2) of them were married; and those living with partners but not married accounted for (4.4%, n=4) of the sample. None of the participants were separated or divorced.

Ethnicity/race was not discussed because of the participant's race, all were Black.

### **4.3.3 Employment**

The participants were requested to disclose their employment status, in order for the researcher to determine whether this had an influence or relationship with the disclosure of their HIV or the level of stigma perceived by the participants. The findings showed that the majority of the participants were unemployed (81.1%, n=73), while only 18.9% (n=17) were employed. In instances where the participants indicated that they were unemployed, they were requested to indicate who the breadwinner was at home. The majority of the unemployed participants (44.4%, n=40) indicated that they were themselves the breadwinners in the home, and indicated that their income was derived from government grants and informal trading (selling on the street). Of the remaining unemployed participants, 40.0% (n=36) were supported by their mothers, 11.1% (n=10) were supported by their fathers, and 4.4% (n=4) were supported by an aunt.

### **4.3.4 Level of education**

The participants were asked to indicate their level of education in order to enable the researcher to determine the varying level of education of the participants and whether this has an influence or relationship with disclosure of HIV or level of stigma perceived by the participants. The findings showed that the majority of the participants had completed high school (grade 12) (58.9%, n=53) and 17.8% (n=16) of the participants had completed secondary school (grade 10). A further 20.0% (n=18) of the participants had a tertiary education and 3.3% (n=3) had only completed primary school.

### **4.3.5 Residence**

The participants were asked to indicate their residence in order to enable the researcher to determine the varying residence of the participants and whether this has an influence or relationship with disclosure of HIV or level of stigma perceived by the participants. The findings showed that participants who lived in rural areas accounted for 51.1% (n=46) and 48.9% (n= 44) lived in urban areas. The participants were then asked to disclose whether or not they lived with anyone, as the researcher wanted to determine the influence of these residential factors on the disclosure of their HIV positive status and their perception of the level of stigma associated with their illness. 87.8% (n=79) of the participants lived with their family members; 11.1% (n=10) lived with a friend; while 1.1% (n=1) lived with their partners but not married.

**Table 4.1: Demographics characteristics 1(n= 90)**

	Frequency	Percentage
Age category:		
1: 20-25 years	35	38.9
2: 26-30 years	22	24.4
3: 31-35 years	33	36.7
Marital status:		
Single	84	93.3
Married	2	2.2
Divorced	0	0
Separated	0	0
Living with partner	4	4.4
Employment:		
Yes	17	18.9
No	73	81.1
Breadwinner:		
Mother	36	4.0
Father	10	11.1
Aunt	4	4.4
Self	40	44.4
Level of education:		
Completed primary school	3	3.3
Completed secondary school	16	17.8
High school	53	58.9
Tertiary	18	20.0
Residence:		
Rural area	46	51.1
Urban area	44	48.9
Living with:		
Family	79	87.8
Friend	10	11.1
Partner, but not married	1	1.1

## **4.4 Section A 2: Reproductive history**

The following section discussed about the participant's reproductive history, see below

### **4.4.1 Number of pregnancies**

The participants were asked to indicate the number of pregnancies in order to enable the researcher to determine the varying number of the pregnancy of the participants and whether this has an influence or relationship with disclosure of HIV or level of stigma perceived by the participants. The findings show that participants who were first pregnant accounted for 27.8% (n=25), participants who had their second pregnancy accounted for 40.0% (n=36), participants who were pregnant for a third time accounted for 30.0% (n=27), and participants who had more than four pregnancies accounted for 2.2% (n=2).

### **4.4.2 Number of children**

In response to the question on the number of live children, 15.6% (n=14) indicated that they had no living children and were on their first pregnancy; 32.2% (n=29) indicated that they had one child; 31.1% (n=28) had two children; 20.0% (n=18) had three children; while 1.1% (n=1) had four (or more) children. The researcher aimed to determine if the number of children that the women had impacted on their disclosure of their HIV status or on their perceived level of stigma associated with their disease.

### **4.4.3 Place of delivery**

The participants were asked to indicate the place of delivery in order to enable the researcher to determine the varying of the place of delivery whether this has an influence or relationship with disclosure of HIV or level of stigma perceived by the participants. The findings showed that participants who were delivered at home accounted for 1.1% (n=1), participants who were delivered in the hospital accounted for 82, 2% (n=74), participants who were delivered in health care centre accounted for 3.3% (n=3), participants who were delivered in private clinics accounted for 1.1% (n=1), and participants who were having no previous delivery accounted for 11.1% (n=10).

### **4.4.4 Antenatal visits**

The participants were asked to indicate their number of present antenatal visits as they would have been exposed to information regarding HIV, anti-retroviral treatment and prevention of

mother-to-child transmission of the disease in these clinic settings; and the researcher wanted to determine if varying numbers of antenatal clinic visits influenced their disclosure of their disease or if it impacted on their perception of the stigma attached to the disease in any way. The findings showed that 8.9% (n=8) of the participants had visited an antenatal clinic once prior to the study, and 12.2% (n=11) of the participants had visited an antenatal clinic twice. A further 12.2% (n=11) had visited a clinic three times, 18.9% (n=17) had visited an antenatal clinic four times, and 46.2% (n=42) indicated that they had visited an antenatal clinic more than five times.

**Table 4.2: Reproductive history**

	Frequency(n)	Percentage %
<b>Number of pregnancy:</b>		
First pregnancy	25	27.8
Second pregnancy	36	40.0
Third pregnancy	27	30.0
More than four pregnancies	2	2.2
<b>Number of children:</b>		
None	14	15.6
One child	29	32.2
Two children	28	31.1
Three children	18	20.0
Four children	1	1.1
<b>Place of delivery:</b>		
Home	1	1.1
Hospital	74	82.2
Health Centre	3	3.3
Private Clinic	1	1.1
No previous pregnancy	10	11.1
<b>Antenatal visits:</b>		
One	8	8.9
Two	12	13.3
Three	11	12.2

Four	17	18.9
More than five	42	46.2

#### 4.5. Section B: Perceived levels of stigma (score items)

Section B of the questionnaire consisted of 19 items/statements that were developed to elicit information on the perceived level of stigma among women living with HIV. There were four options from which the participants were required to choose only one. For the first question, the options were strongly disagree (SD), disagree (D), agree (A) and strongly agree (SA).

**Table 4.3: Perceived levels of HIV stigma**

Variables	SD	D	A	SA
1. No one in my family knows that I have HIV	35(38.9%)	35(38.9%)	9(10.0%)	11(12.2%)
2. I feel guilty because I have HIV	27(30.0%)	38(42.2%)	9(10.0%)	15(16.7%)
3. People's attitudes about HIV make me feel worse about myself	34(37.8%)	22(24.4%)	9(10.0%)	25(27.8%)
4. Telling someone I have HIV is risky	33(36.7%)	28(31.1%)	11(12.2%)	18(20.0%)
5. People with HIV lose their jobs when employers find out	30(33.3%)	41(45.8%)	7(7.8%)	12(13.3%)
6. I work hard to	24(26.7%)	39(43.3%)	7(7.8%)	12(13.3%)

keep my HIV status a secret				
7. I feel I am not good as others because I have HIV	39(43.3%)	32(35.6%)	7(7.8%)	12(13.3)
8. I never feel ashamed of HIV	18(20.0%)	29(32.2%)	13(14.1%)	30(33.3%)
9. People with HIV are treated like outcasts	22(24.4%)	38(42.2%)	10(11.1%)	20(22.2%)
10. Having HIV makes me feel dirty	34(37.8%)	38(42.2%)	10(11.1%)	8(8.9%)
11. Most people believe that a person who has HIV is dirty.	23(25.6%)	29(32.2%)	16(17.8%)	22(24.4%)
12. I prefer to avoid having friends because I have HIV	36(40.0%)	45(50.0%)	4(4.4%)	5(5.6%)
13. Since learning I have HIV, I feel set apart	29(32.2%)	47(52.2%)	6(6.7%)	8(8.9%)
14. Most people think that a	33(36.7%)	31(34.4%)	20(22.2%)	6(6.7%)

person with HIV is being punished by God				
15. Having HIV makes me feel that I'm a bad person	35(38.9%)	39(43.3%)	5(5.6%)	11(12.2%)90
16. Most people with HIV are rejected when others find out	14(15.6%)	28(31.1%)	14(15.6%)	34(37.8%)
17. I am very careful who I tell that I have HIV	8(8.9%)	17(18.9%)	30(33.3%)	34(37.8%)
18. Some people who know that I have HIV distance themselves	21(23.3%)	37(41.1%)	6(6.7%)	26(28.9%)
19. Since learning I have HIV, I worry to be discriminated	23(25.6%)	33(36.7%)	5(5.6%)	29(32.2%) 90

Table 4.3 indicates that the majority of the participants strongly disagreed and disagreed with the statement that no one in their family knew that they had HIV (n=35, 38.9% respectively), in comparison to n=9 (10.0%) of the participants who agreed and n=11 (12.2%) who strongly agreed with the statement.

The participants n=27 (30.0%) strongly disagreed, and n=38 (42.2%) disagreed with the statement that they felt guilty because they had HIV; compared to n=9 (10.0%) of the participants who agreed and n=15 (16.7%) of the participants who strongly agreed.

As for the statement that people's attitudes about HIV made them feel worse about themselves, the majority of the participants (n=34, 37.8%) strongly disagreed with it and another n=22 (24.4%) disagreed with it; compared to a few of the participants (n=9, 10.0%) who agreed, and another n=25 (27.8%) who strongly agreed with the statement.

In response to the statement "Telling someone that I have HIV is risky", the majority of the participants (n=33, 36.7%) strongly disagreed and n=28 (31.1%) disagreed; compared to a few of the participants (n=11, 12.2%) who agreed, and n=18 (20.0%) strongly agreed that this was indeed the case.

The majority of the participants (n=30, 33.3%) strongly disagreed with the statement that people with HIV lose their jobs when their employers found out about their HIV status. n=41 (45.8%) disagreed compared to a few participants (n=7, 7.8%) who agreed, and those (n=12, 13.3%) who strongly agreed that this was the case. The majority of the participants (n=39, 43.3%) disagreed and a further n=24 (26.7%) strongly disagreed; while n=20 (22.2%) agreed and another n=7 (7.8%) strongly agreed with the statement that they worked hard to keep their HIV status a secret.

In response to the statement "I feel I am not as good as others because I have HIV", the participants had the following to say: The majority of them (n=39, 43.3%) strongly disagreed that they felt that way, while=32 (35.6%) merely disagreed. n=7 (7.8%) of the participants felt that way and agreed, while a further n=12 (13.3%) strongly agreed that they felt that way.

"I never feel ashamed of HIV, n=18 (20.0%) of the participants strongly disagreed with this statement, and n=29 (32.2%) disagreed with it; whereas the majority (n=30, 33.3%) strongly agreed with the statement and n=13 (14.4%) agreed. The majority of the participants (n=38, 42.2%) disagreed, compared to the few participants (n=10, 11.1%) who agreed with the statement that people with HIV were treated like outcasts.

The majority of the participants (n=34, 37.8%) disagreed that having HIV made them feel dirty, and n=38 (42.2%) strongly disagreed with this statement; however, a few of the participants

(n=10, 11.1%) agreed that they felt dirty because of their disease and a further=8 (8.9%) strongly agreed that they felt that way.

As to the statement that most people believed that a person who had HIV was dirty; the majority of the participants (n=29, 32.2%) disagreed, n=23 (25.6%) strongly disagreed, n=16 (17.8%) agreed and n=22 (24.4%) strongly agreed with it, and n=45 (50.0%) disagreed with the statement, “I prefer to avoid having friends because I have HIV”. Some participants, however, tended to avoid having friends, indicated by the n=4 (4.4%) who agreed with this statement, and n=5 (5.6%) who strongly agreed. In response to this statement “Since learning I have HIV, I feel set apart and isolated from the rest of the world” the majority of the participants (n=29, 32.2%) strongly disagreed, n=47 (52.2%) disagreed, n=6 (6.7%) agreed and n=8 (8.9%) strongly agreed with it.

The majority of the participants (n=33, 36.7%) strongly disagreed, n=31 (34.4%) disagreed, n=20 (22.2%) agreed and n=6 (6.7%) strongly agreed with the statement that most people thought that a person with HIV was being punished by God. The majority of the participants (n=39, 43.3%) disagreed with the statement, “Having HIV makes me feel that I am a bad person”. n=35, 38.9%) strongly disagreed with the statement, n=5 (5.6%) agreed with it and n=11 (12.2%) strongly agreed with the statement

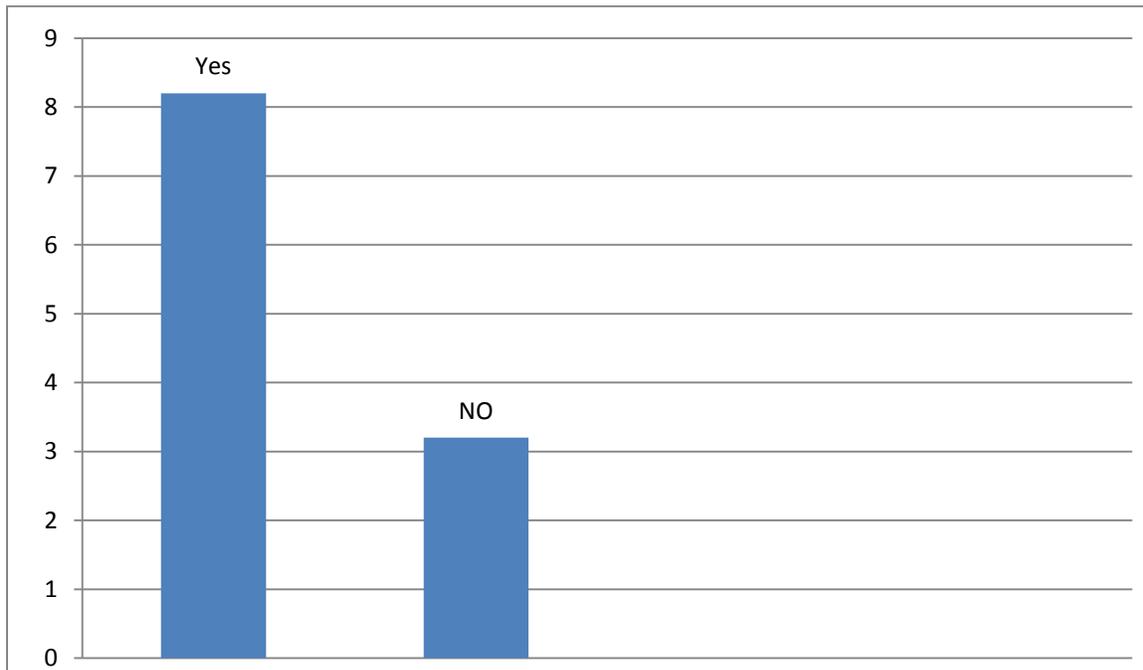
For item 16 (most people with HIV are rejected when others find out), the findings showed that the majority of the participants (n=34, 37.8%) strongly agreed with the statement, and n=28 (31.1%) disagreed with the statement; however, n=14 (15.6%) responded equally with ‘strongly disagreed’ and ‘agreed’. A few of the participants (n=8, 8.9%) strongly disagreed, and=17 (18.9%) disagreed; while several of them (n=30, 33.3 %) agreed and the majority (n=34, 37.8%) strongly agreed with the statement that they were very careful who they told that they had HIV.

For item number 18 (some people who know that I have HIV distance themselves) the participants responded as follows: n=37 (41.1%) disagreed, n=21 (23.3%) strongly disagreed, n=6 (6.7%) agreed and n=26 (28.9%) strongly agreed with the statement.

For item number 19 (Since learning I have HIV, I worry about being discriminated against) the participants responded as follows: n=23 (25.6%) strongly disagreed, n=33 (36.7%) disagreed, n=5 (5.6%) agreed, and n=29 (32.2%) strongly agreed with the statement.

## 4.6 Section C: HIV disclosure

This section discusses the participants' disclosure regarding their HIV positive status. When asked if they had disclosed their HIV status to anyone, n=63 (70.0%) said 'Yes' they had disclosed their HIV status in comparison to the n=27 (30.0%) participants who responded with 'No' (see Figure 4.2).



**Figure 4.2: HIV disclosure**

### 4.6.1 Stigma events related to disclosure

In this section the participants were requested to quantify the number of events related to stigma and HIV. There were four possible scoring rates: 0= never, 1=once or twice, 2=several times and 3=most of the time. Participants were requested to rate these patterns of disclosure so that the researcher could rate the level of stigma perceived by the participants. Table 4.5. Highlights eight items relating to the stigma and disclosure. The table shows that the majority of the respondents did not encounter any stigma following their disclosure (65.6% to 80%), while only a small percentage of them encountered behaviour indicative of stigma most of the time (3.3% to 8.9%).

**Table 4.5: Stigma and disclosure**

<b>Items</b>	<b>Never</b>	<b>Once or twice</b>	<b>Several times</b>	<b>Most of the time</b>
1. Someone scolded me	66(73.3%)	15(16.7%)	4(4.4%)	4(4.4%)
2. Someone insulted me	65(72.2%)	14(15.6%)	7(7.8%)	4(4.4%)
3. I was blamed for my HIV status	60(66.7%)	17(18.9%)	7(7.8%)	6(6.7%)
4. I was told I have no future	63(70.0%)	12(13.3%)	9(10.0%)	6(6.7%)
5. I was told that God is punishing me	72(80.0%)	11(12.2%)	4(4.4%)	3(3.3%)
6. I was called bad names	59(65.6%)	13(14.4%)	10(11.1%)	8(8.9%)
7. Someone mocked me when I passed by	71(78.9%)	8(8.9%)	7(7.8%)	4(4.4%)
8. People sang offensive songs when I passed by	69(76.7%)	12(13.3%)	4(4.4%)	5(5.6%)

#### 4.7. Inter-relationships of Stigma, Disclosure and Demographic variables

The following tests were conducted in order to answer the research questions: Frequencies and descriptive statistics, Cronbach's alpha, Independent Sample t-tests and ANOVA, Pearson product-moment correlations, and standard multiple regressions.

Firstly, the demographic characteristics are presented, and descriptive statistics are presented to determine the normality of the distribution. The results of the Pearson product-moment correlations are presented to determine the relationships of the variables. The results of the Independent Sample t-tests and ANOVA are also discussed to determine the differences in the mean scores between groups of the dependent variables.

##### 4.7.1.

##### **Independent t-test of the demographics on stigma**

Table 4.6 illustrates the results of the descriptive statistics of all the measures used in the study. Descriptive statistics provide the information concerning the normality of the distribution of the scores.

**Table 4.6: Results of the Independent t-test of the demographics on stigma**

Variables	Group	N	Mean +SD	T-value	Sig-value
Employment	Employed	17	40.7 7.8	0.2	0.9
	Unemployed	73	40.3 9.5		
Residence	Rural area	46	41 10.5	0.6	0.52
	Urban area	44	39.7 7.5		
Person lived with	Family	79	40.5 9.5	0.17	0.52
	friend	11	40 4.8		

The Independent t-test was performed to test the two groups for each variable, e.g. employed and unemployed, and their relationship to stigma. Table 4.6 shows that there was no significant impact on stigma by these demographics, however, the results indicated that employed participants experienced slightly more stigma (mean 40.7+SD 7.8) than the unemployed (mean 40.3+SD 9.5), with a sig-value of 0.9. Residents in rural areas experienced slightly higher levels of stigma (mean 41+SD10.5) than those residing in an urban area (mean 39.7+SD7.5) and (sig-

value 0.52). People living with family (mean 40.5+SD 9.5) experienced slightly more stigma than those who lived with a friend (mean 40+SD 4.8) and (sig- value 0.52).

#### 4.7.2 Independent t-test of demographics on disclosure

The Independent t-test was performed to test the two groups of each variable and their relationship to disclosure (see Table 4.7).

**Table 4.7: Results of the Independent t-test of the demographics on disclosure**

Variables	Group	N	Mean+ SD	T-value	Sig-value
Employment	Employed	17	2.7 3.6	-11	0.3
	Unemployed	73	3.8 5.2		
Residence	Rural area	46	2.7 4.2	-1.7	0.1
	Urban areas	44	4.5 5.6		
Person live with	Family	79	3.9 5.1	1.7	0.1
	friend	11	2 3		

The results of the Independent t-test to test the two groups for each variable e.g. employed and unemployed and their relationship with disclosure showed no significant relationship between disclosure and any of these demographics. Participants who were unemployed disclosed their status more (mean 3.8+SD 5.2) than those who were employed (mean 3.8+SD 5.2), with sig-value of 0.3. Those living in an urban area (mean 4.5 +SD 5.6) disclosed their status more than those in the rural areas (mean 2.7+SD 4.2) and (sig-value 0.1). The participants living with family members (mean 3.9 +SD 5.1) disclosed their status to these co-habitants more than those who lived with friends (mean 2+SD 3) and (sig-value 0.1).

### 4.7.3 ANOVA of the demographics on stigma

Analyses of variance (ANOVA) were used to compare the mean scores of more than two groups (see Table 4.8).

**Table 4.8: ANOVA of the demographics on stigma**

Variable	Group	N	Mean +SD	F-value	Sig-value
Age	1(20-25)	35	39.6 7.8	0.3	0.7
	2(26-30)	22	41.5 11		
	3(31-35)	33	40.3 9.2		
Marital status	Single	84	40.2 9.2	0.2	0.8
	Married	2	38.5 13.4		
	Living with partner	4	42.7 7.6		
Breadwinner	Mother	36	40.7 10.6	0.8	0.5
	Father	10	37.1 6.4		
	Aunt	4	45.3 21.1		
	Other(selling in street, Government grant)	40	40.4 6.3		
Level of education	Completed primary	3	39 8.9	0.3	0.6
	Completed secondary(grade 10)	16	42,5 6,9		
	High school (grade 12)	53	40.5 9,6		
	Tertiary level	18	3.11 9.7		

There were no significant differences in the results. Table 4.8 shows that the participants between the ages of 26-30 years experienced more stigma (mean 41.5+ SD= 11). In the analysis

of variance performed on marital status, results showed higher stigma for participants who were unmarried but living with their partners (mean=42.7+SD=7.6), single (mean=40.2+SD=9.2), however married participants experienced less stigma (mean=38.5+SD=13.4). In terms of breadwinners and stigma, the results showed that the participants who were being supported by an aunt experienced a higher level of stigma (mean=45.3+SD=21.1). The participants who completed secondary school experienced more stigma (mean=42.5+SD=6.9) than those with the other education levels.

#### 4.7.4 ANOVA of the demographics on disclosure

The Analysis of Variance (ANOVA) was used to compare the mean scores of the two groups of each demographic variable on disclosure (see Table 4.9).

**Table: 4.9: ANOVA of the demographics on disclosure**

Variables	Group	N	Mean +SD	F-value	Sig-value
Age	1(20-25)	35	2.7 3.6	0.2	0.8
	2(26-30)	22	5.1 6.6		
	3(31-35)	33	3.6 4.8		
Marital status	Single	84	3.7 5.0	0.5	0.10
	Married	2	2.5 2.1		
	Living with partner	4	3.5 5.10		
Bread-winner	Mother	36	4.8 5.6	0.3	0.23
	Father	10	1.9 3.8		
	Aunt	4	2.0 4,0		
	Self	40	3.8 4.6		

Level of education	Completed primary	3	3.0	4.6	0.3	0.9
	Completed secondary(grade 10)	16	4.7	5.1		
	Completed high school (grade 12)	53	3.3	4.9		
	Tertiary	18	3.7	5.3		

In Table 4.9, the ANOVA results showed that there were no significant differences in the results. Participants between the ages 26-30 years disclosed their status (mean=5.1 +SD=6.6) more than the other age groups. Participants who were single disclosed their HIV positive status more than the others (mean 3.7+SD 5.0), while married participants (mean 2.5+SD 2.1) were poor at disclosing their HIV status. The results showed that the participants who were supported by their mothers disclosed their status to them more (mean 4.8+SD 5.6) than those who were supported by their fathers (poor level of disclosure (mean 1.9+SD3.8). With regards to the participants' level of education; those who had completed secondary school disclosed their HIV status more (mean 4.7+SD5.1) than those that had not.

#### 4.7.5 ANOVA of reproductive history on stigma

Analysis of variance (ANOVA) was used to compare the mean scores of more than two groups of reproductive history on stigma (see Table 4.10).

**Table 4.10: ANOVA of reproductive history on stigma**

Variables	Group	N	Mean +SD	F-value	Sig-value
Times Number of pregnancy	First	25	39.9 8.6	0.3	0.39
	Second	36	43.1 9.9		
	Third	27	36.7 7.6		
	Above third	2	40.0 0		

No Number of children	None	14	40.0	9.5	0.3	0.28
	One	29	41.4	11.7		
	Two	28	41.5	7.2		
	Three	18	36.6	7.3		
	Above four	1	50.0	0		
Place of delivery	Home	2	40.0	0	0.7	0.10
	Hospital	74	40.4	9.2		
	Health care centre	3	39.0	10.1		
	Private clinic	1	40.0	0		
	No previous pregnancy	10	40.0	10.5		
Clinic visits	One	8	40.1	12.7	0.4	0.5
	Two	12	38.9	9.1		
	Three	11	38.1	8.4		
	Four	17	43.9	12.3		
	Above four	42	39.9	6.8		

Table 4.10. Shows the correlation of the results of stigma and reproductive history. Participants who had been pregnant more than three times experienced more stigma (mean 45.0+SD7.0) than those with fewer pregnancies. Those participants on their second pregnancy also experienced stigma (mean 43.1+SD7.6). The ANOVA test showed that participants who had more than four children experienced more stigma (mean 50.0 +SD 0) than those with fewer children, and that participants who delivered in a hospital reported more experience of stigma (mean 40.4 +SD 9.2) than those who had delivered elsewhere. Participants who had attended an antenatal clinic more than four times also experienced more stigma (mean 43.9+SD 12.3) than those with fewer visits.

#### 4.7.6 ANOVA of reproductive history on disclosure

Table 4.11 outlines the results of the ANOVA of reproductive history on disclosure.

Table 4.11: ANOVA of reproductive history on disclosure

Variables	Group	N	Mean	SD	F-value	Sig-value
Times Number of pregnancy	First	25	5.8	6.3	0.3	0.06
	Second	36	3.1	4.3		
	Third	27	2.5	3.8		
	Fourth or more	2	0.50	0.70		
No Number of children	None	14	7.0	6.2	0.4	0.73
	One child	29	2.8	4.6		
	Two children	28	3.4	4.7		
	Three children	18	2.7	4.1		
	Above four	1	0.0	0		
Place of delivery	Home	2	0.0	0	0.2	0.7
	Hospital	74	3.2	4.6		
	Health care centre	3	2.0	3.5		
	Private clinic	1	0.0	0		
Number of antenatal clinic visits	One	8	6.9	6.2	0.4	0.27
	Two	12	2.2	4.5		
	Three	11	2.3	3.6		

	Four and Above four	17	3.9	4.9		
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The results in Table 4.11 indicate that there was no significant correlation between disclosure and reproductive history, as those participants on their first pregnancy disclosed their status (mean 5.8+SD 6.3) more than those with a higher number of pregnancies, as indicated by the results for the second pregnancy (mean 3.1+SD 4.3), the third pregnancy (mean 2.5+SD 3.8), and those on their fourth pregnancy or above (mean 0.5+SD 0.7). As for the variable of the number of children, participants who had no children born yet disclosed their status more (mean 7.0+SD 6.2) than the rest of the participants.

#### 4.8 Correlations between demographics and stigma

Table 4.12 shows the results of the relationship between the scales gained from the analyses of the Pearson product-moment correlation coefficient. The Pearson product-moment correlation coefficient was calculated to determine the strength and direction of the relationships between the measures of the study.

**Table: 4.12. Results of correlations between demographics and stigma**

Variable	R	Sig-value
Age and stigma	0.033	0.755
Marital status and stigma	0.051	0.632
Employment and stigma	-0.019	0.857
Breadwinner and stigma	0.007	0.951
Levels of education and stigma	-0.114	0.283
Person lived with and stigma	0.086	0.419
Times Number of pregnancy and stigma	-0.104	0.329
Number of children and stigma	-0.688	0.411
Place of delivery and stigma	-0.029	0.784
Number of antenatal visits and stigma	0.040	0.708

Correlation is significant at the 0.01 level (2 tailed)

Pearson's correlation was performed to establish the relationships between the age of the participants and stigma. Table 4.12 shows that there was positive weak correlation ( $r=0.033$ ) between this variable and stigma. The correlation test between marital status and stigma showed that there was positive weak correlation ( $r=0.051$ ) between the two. The relationship between employment and stigma was negative ( $r=-0.19$ ), while the correlation between breadwinner status and stigma was very weak ( $r=0.007$ ). There was no correlation between the levels of education and stigma (correlation was negative= $-114$ ), whereas there was positive weak correlation between the person that the participant was living with and stigma ( $r=0.086$ ).

The number of pregnancies showed a negative correlation with stigma ( $r=-104$ ); the correlation between the number of children and stigma was also negative ( $r=-688$ ); as was the correlation between the place of delivery and stigma ( $r=-029$ ). The relationship between the number of clinic visits and stigma, however, showed a positive weak correlation ( $r=0.040$ ). The results thus indicated that the relationship between demographics and stigma was very weak and negative, and therefore was not significant.

#### 4.9 Correlations between demographics and disclosure

In order to establish the relationship between demographics and disclosure patterns, Spearman's correlations were conducted (Table 4.13).

**Table: 4.13: Correlations between demographics and disclosure**

Variable	R	Sig-value
Age and disclosure	0.086	0.418
Marital status and disclosure	-011	0.915
Employment and disclosure	0.090	0.400
Breadwinner and disclosure	-136	0.201
Level of education and disclosure	-036	0.733
Person lived with and stigma	-143	0.180
Number of pregnancy and stigma	-263	0.012
Number of children and stigma	-212	0.045
Place of delivery and stigma	0.205	0.053
Number of antenatal visits and stigma	-048	0.651

Correlation is significant at the 0.05 level (2 tailed)

The results in Table 4.13 above show that there was a positive weak relationship ( $r=0.086$ ) between the age of the participant and disclosure. It also shows that there was a negative correlation between marital status and disclosure ( $r= -0.011$ ). There was a positive weak correlation between employment and disclosure ( $0.090$ ), while the correlation between the breadwinner and disclosure was negative ( $r= -0.136$ ), as was the correlation between the level of education and disclosure ( $r= -0.036$ ). The relationship between disclosure and the person/people that the participants lived with was negative ( $r= -0.143$ ), as was the correlation between disclosure and the number of times the participants had been pregnant ( $r= -0.263$ ). The correlation between disclosure and the number of children was also negative ( $r= -0.212$ ); however, the correlation between disclosure and the place of delivery showed that there was a positive weak relationship ( $r=0.205$ ); while the number of antenatal visits also had a negative relationship with disclosure ( $r= -0.048$ ). There was therefore no significant correlation between the participants' demographics and their disclosure.

#### **4.10 Correlation between stigma and disclosure**

Table 4.14 reflects the correlation between stigma and disclosure.

**Table 4.14: Correlation between stigma and disclosure**

Variable	R	Sig-value
Stigma and disclosure	0.18	0.1

In table 4.14, the tabulated results show that there was no significant correlation between stigma and disclosure rate on the part of the participants: There was only a weak positive correlation ( $r=0.18+p= 0.1$ ).

#### **4.11 Summary of the chapter**

This chapter featured a detailed description of the analyses and interpretation of the data collected for the study. The results were presented in tables and interpreted thereafter, and the analyses were based on the data from the 90 participants that participated in the study. The findings

showed that the majority of the participants were aged between 20-25 years (38.9%, n=35). In relation to gender, all participants were females, most of them were single (93.3% n=84).

The results showed that the majority of the participants were unemployed (81.1%, n=73), that the majority of them had completed high school high school (58.9%, n=53), and that the majority of them lived with their families (87.8%, n=79). The majority of the participants had delivered in a hospital accounted for (82, 2%, n=74).

There were five objectives tested:

1. The levels of HIV related stigma among women living with HIV; the information that was given by the participants on their perceived levels of HIV stigma among women indicated that stigma was high. 10 items on the questionnaire indicated this: 2, 4, 6, 7, 10, 12, 13, 15, 17, and 19 had results of 'strongly agreed' and 'agreed', ranging from (n=27 (30.2%) to n=47 (52.2%).
2. Patterns of HIV disclosure among women living with HIV: The results indicated that most of the participants (n=35, 38, 9%) 'Strongly disagreed' and 'disagreed' with the statement, there is no one in the family knew that they had HIV indicating that the women only disclosed their status to their family member.
3. The inter-relationship between the demographic variables and the perceived levels of stigma among women living with HIV: The results indicated that the relationship between the demographics and stigma was very weak and negative, and was therefore not significant.
4. The inter-relationship between the demographic variables and the patterns of disclosure among women living with HIV: No significant relationship was found between them.
5. Inter-relationship between patterns of disclosure and the perceived stigma levels among women living with HIV: The results showed that there was no significant relationship between stigma and disclosure in responses of the participants; there was only a positive weak correlation ( $r=0.18+p= 0.1$ ).

Correlation analysis performed showed a weak positive correlation between demographics and stigma. The correlation between demographics and disclosure patterns was also a weak positive.

The negative weak correlation also identified between the variables was also not significant. The results of the study showed that stigma still existed among women who were living with HIV, hence, most of the women only disclosed their HIV status to their immediate family members.

#### **4.12 Conclusion of the chapter**

In conclusion, the results of the study showed that stigma was still perceived among women living with HIV and that this affected their disclosure patterns, although there was support from family and the community for those who had disclosed their HIV status. Literature has indicated that disclosing of the HIV status to a partner and to family may lower the risk of infection and can be beneficial in gaining social support (Turan and Nyblade, 2013).

## CHAPTER FIVE

### 5. DISCUSSION, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

#### 5.1 Introduction

The aim of this study was to explore and describe perceived levels of HIV related stigma and disclosure patterns among women living with HIV in a selected regional hospital in the eThekweni District of KZN. This chapter presents a discussion of the literature reviewed in relation to the findings of the study described in chapter four. This chapter also presents the summary of the study and the implication of stigma and disclosure patterns among women, recommendations for future research and the conclusion of the study.

In order to address the research questions of the study, the researcher formulated the following objectives: To explore and describe:

- The perceived levels of HIV related stigma among women living with HIV and AIDS.
- The patterns of HIV disclosure among women living with HIV and AIDS.
- The inter-relationship between the demographic variables and the perceived levels of stigma among women living with HIV and AIDS.
- The inter-relationship between the demographic variables and the disclosure patterns among women living with HIV and AIDS.
- The inter-relationship between the patterns of disclosure and the perceived stigma levels among women living with HIV and AID.

A quantitative descriptive, explorative design was used to explore and describe the perceived levels of HIV related stigma among women living with HIV. The design of the questionnaire was adopted from previous researchers and used to collect data. This instrument allowed the researcher to obtain information about the demographic characteristics of the participants and the levels of stigma and disclosure patterns.

#### 5.2 Demographic characteristics of the participants

The demographic variables of the study were age, marital status, employment, ethnicity or race and breadwinner status, the level of education, residence and reproductive history. The researcher did not discuss about ethnicity or race because all the participants in this study were Black African women.

### **5.2.1 Age of the participants**

The findings of this study showed that the majority of the participants were aged between 20-25 years. The mean age of the participants and the standard deviation (mean± SD) were 1.1 ±0.870. The findings of this study were similar to the study of Shisana et al. (2014), who concluded that participants of this age group were likely to experience stigma and were reluctant to disclose their HIV status. This could also have signified that at this younger age (20-25 years), they were not in serious relationships and thus did not have much experience of relationships. The perceived level of community was also seen to influence older women, as they were less likely to disclose their HIV status, according to Ojikutu et al. (2016).

### **5.2.2 Marital status of the participants**

The findings of this study showed that the majority of the participants were single (93.3%, n=84), those who were married accounted for 2.2% (n=2) and those living with their partners but not yet married accounted for 4.4% (n=4) of the sample. None of the participants were separated or divorced. A study that was conducted in Thailand, Brazil and Zambia also indicated that marriage was not a prerequisite for most women aged between 20-25 years who fell pregnant (Costelloe et al. 2015).

### **5.2.3 Employment status of the participants**

The findings of this study showed that the majority of the participants were unemployed, accounting for 81.1% (n=73) of the sample. Those who were employed accounted for the remaining 18.9% (n=17) of the sample. The rate of unemployment in South Africa is very high due to low education levels, poverty and the large number of the population, according to Shisana et al (2014).

### **5.2.4 Levels of education of the participants**

Majority of the participants had completed high school (58.9%, n=53), while 17.8% (n=16) of the participants had completed secondary school, and only 20.0% (n=18) had completed tertiary studies. 3.3% (n=3) of the participants had only completed primary school. These findings were similar to the study done in Cape Town by Shisana et al (2014), which stated that 49, 7% of women left school at the early age of 17 years.

### **5.2.5 Residence**

From the findings, 51.1% (n=46) of the participants were living in a rural area and the remaining 48.9% (n= 44) lived in an urban area. The findings of this study were similar to the study conducted in Thailand, Brazil and Zambia which indicated that a high number of women who are HIV positive lived in rural areas and were less likely to disclose their status than those living in urban areas (Costelloe et al. 2015).

There was a negative correlation between the number of times that the women had been pregnant and stigma ( $r = -0.104$ ). There was also a negative correlation between the number of times that the women had been pregnant and disclosure of their HIV status ( $r = -0.263$ ); this study revealed that participants who were pregnant more than three times experienced more stigma and were more likely to have disclosed their HIV status. In general, the more an antenatal clinic was visited, the more likely the participant was to have disclosed their HIV positive status. Correlation between the number of the pregnancy and stigma was also negative ( $r = -0.688$ ), as was the correlation between the place of delivery and stigma ( $r = -0.029$ ); however, the relationship between the number of clinic visits and stigma experienced showed a positive weak correlation ( $r = 0.040$ ). The results indicated that the relationship between the demographics and stigma was very weak and negative, and that there was therefore no significant correlation. The correlation between disclosure and the place of delivery showed a positive relationship ( $r = 0.205$ ), although it was a weak relationship, and the number of antenatal visits had a negative relationship ( $r = -0.048$ ). Thus there was no significance noted in the correlation of the results.

### **5.3 Levels of HIV related stigma among women living with HIV and AIDS**

The findings of this study showed that the majority of the participants (n=35, 38.9%) strongly disagreed and disagreed with the statement that no one in their family knew that they had HIV. This indicated that the majority of the participants had disclosed their HIV status to their family members. Similarly, a study conducted in the North West Province, South Africa, by Nyblade, Jain et al. 2013) found that increased knowledge about HIV and its related stigma resulted in people feeling less stigma and improved their willingness to disclose their status. Another study by Turan and Nyblade (2013) agreed that disclosure of HIV status could be beneficial in gaining social support and lowering the risk of HIV infection. In contrast, the study in Thailand, Brazil and Zambia reported that the decision to disclose one's status was associated with the perceived

community level influences, which led women to be less likely to disclose their HIV status (Costelloe et al. 2015).

The level of HIV related stigma among the women in this study was low, because of the high percentage of the participants who strongly disagreed with the statements/ items 2, 4, 6, 7, 8, 9, 10, 12, 13, 15 and 17 which were asked about the levels of stigma that the participants felt. This study thus agreed with the results obtained in KZN (Valencia-Garcia, Rao et al. 2016) which stated that although there was stigmatising of women, most people had knowledge of HIV and stigma and were willing to give support to the people living with HIV. HIV stigma continues to impact this pandemic of HIV, the results of a study on Peruvian women by highlighted the experiences of stigma in health care providers and these findings are likely to be the same for women all over the world (Ahmed, 2017).

#### **5.4 Disclosure patterns among women living with HIV and AIDS**

The majority of the participants had disclosed their HIV status to family members, and these results were not in agreement with a study in Thailand (Turan and Nyblade 2013), where 60% of the participants indicated a lack of disclosure, especially to their male partners and to their family members. This lack of disclosure appeared to be a barrier to the use PMTCT. Disclosure improved physical well-being by facilitating people living with HIV's ability to obtain services to manage their illness (Okoror et al. 2014).

In this study the results showed that the majority of the participants had disclosed their HIV status to their family, contradictory to the study conducted in Africa (Zambia) (Ojikutu, et al. 2016) which stated that 67% of women disclosed their HIV status to their sexual partners; and a study conducted in Malawi (Geary et al. 2014), where almost 66% of the survey sample reported that they had disclosed their HIV status to their spouse or to their sexual partners only. Disclosure patterns were also significantly more likely among men compared to women, as they generally had higher levels of education, and were also more likely among those owning a radio as this facilitated greater access to HIV information (Geary, Parker et al. 2014).

HIV status disclosure has proven effective in decreasing transmission to the HIV negative partner by raising risk awareness and heightening the need for HIV prevention, including routine counseling and testing, pre-exposure prophylaxis, and condom use (Kamen, Arganbright et al. 2015). For women living with HIV, the decision to disclose may be influenced by culturally

determined, community-level stigma and norms, and understanding the impact of community HIV stigma and gender norms on disclosure among women living with HIV in different countries may inform intervention development. Further it is noted that single women may be less likely to disclose their HIV status due to fear of loss of relationship and economic security. (Ojikutu et al. 2016).

### **5.5 Correlation between demographics and stigma**

Pearson's correlation was performed to establish the relationships between the age of the participants and stigma. The results show that there was a positive weak correlation ( $r=0.033$ ) between age and stigma. This study indicated that there was no significant correlation; however, the results showed that stigma affects all ages, and all age groups were therefore included in those that had disclosed their HIV status. These findings agreed with those of Velloza et al. (2015) who asserted that most women were willing to disclose their HIV status even though they experienced stigma in their community and family groups. Thus, the study conducted by Shisana et al (2016) revealed that married women experienced more stigma than unmarried women did. In general, if one is married one needs to be honest with one's partner, however men often shift the blame for a positive HIV status to women; therefore disclosing HIV status is not necessarily to the woman's advantage. In support of this, a study in African countries, Thailand, Brazil and Zambia revealed that unmarried women were less likely to disclose their status to their sexual partners (Costelloe, et al. 2015).

This study showed a level of stigma among participants irrespective of employment status, this is aligned to Shisana et al (2016) revealed that unemployed women experienced more stigma than those that were employed. The level of stigma experienced also varied between the participants from urban and rural areas, as those residing in rural areas experienced more stigma than those in the urban areas. In this study the participants in the rural areas disclosed their status more than those in the urban areas, and the researcher thinks that that is why the rural people experienced more stigma and discrimination than those in the urban areas. Research on anticipated stigma has demonstrated that increased fear of discrimination leads to psychological distress, decreased quality of life, and poor retention in care (Ojikutu, Pathak et al. 2016). Although there was no significant correlation between the demographic variables and stigma in this study, research on women revealed that women account for half of the people living with HIV worldwide and may experience more stigma than men, therefore there is a need to develop interventions for HIV-

positive women, especially when many women face various forms of marginalisation including poverty, lack of health insurance, gender inequality and class oppression (Valencia-Garcia, Rao et al. 2016).

### **5.5.1 Correlation between demographics and disclosure**

Pearson's correlation was performed to establish the relationship between the demographics and disclosure. The results of this study showed that there was a positive weak relationship ( $r=0.086$ ) between age and disclosure, however African studies indicated that older women were less likely to disclose their HIV status than those of a younger age; thus age was associated with non-disclosure and the researchers also stated that in pregnant and post-partum women, a younger age was found to be a consistent predictor of disclosure (Ojikutu, Pathak et al. 2016). The findings of this study showing those aged 26-30 years were more likely to disclose their status than those aged 20 -25 and 31-35 years. The results of this study also showed that there was a negative correlation between marital status and disclosure, and the findings from the study in African countries in Thailand, Brazil and Zambia reported that 95% of unmarried women were less likely to disclose their status to their partners, due to fear of rejection by their partners (Ojikutu, Pathak et al. 2016).

### **5.5.2 Correlation between stigma and disclosure**

Pearson's correlation performed to establish the relationships between stigma and disclosure, and the results showed a positive weak correlation ( $r=0.18+p= 0.1$ ). This meant that when the level of stigma rose, so too did the disclosure pattern. Velloza et al (2015) agreed with these results, attesting that when people who were HIV positive disclosed their status, their partners and family stigmatised them.

Disclosure of HIV status is considered essential for prevention, treatment and support of people living with HIV, however disclosing status leads to stigmatising behavior and the argument has been made that disclosure to spouses was positively associated with perceptions of better health for women, but not for men (Geary, Parker et al. 2014).

## **5.6 Recommendations**

In line with the findings of the study, the following recommendations are made for, nursing practice, management education and research.

### **5.6.1 Nursing practice**

The information from this study needs to be presented to the nursing management as the researcher will submit the results of this study to the hospital board, to assist nursing practice to improve the standards of confidentiality and to correct service providers' attitudes towards HIV positive women. The study findings may also promote universal care in the health care centres by combining all services in one room. Understanding the perceived levels of stigma and the disclosure patterns of HIV among women, is an important contribution to nursing practice, as this information can enable nurses working with women living with HIV to better deal with HIV related stigma. Such initiatives can be incorporated within the health education screening performed at antenatal care and maternal and women health services.

### **5.6.2 Nursing management**

The provision of ongoing counselling is required for people living with HIV and AIDS. Proper counselling should be provided with guidelines for PMTCT, and treatment should be in line with the specific needs of the patients.

### **5.6.3 Education**

The educators and nursing staff need to be united and work together to identify problems in health care settings to reduce stigma. They also need to form support group and encourage clients to join them. They also need to do home visits, schools and community to provide health education on HIV and stigma. There is a need for collaboration between educators and nurses so that the appropriate and relevant knowledge on is provided to staff in order for them to provide the proper care and health education for people living with HIV and AIDS. Such knowledge needs to focus on the psychosocial determinates of HIV and especially how it relates to quality of care and the quality of life for the person living with HIV. Nurses and midwives need to adequately prepare in understanding the stigma process and the expressions, actions and nuances that can trigger stigma and lead to received stigma by the person living with HIV. This is important and nurses and midwives are often the first point of care that women or persons living with HIV access and thus, the interaction with the nurse and the person living with HIV can determine how the stigma is managed and the disclosure of the persons HIV status managed,

### **5.6.4 Nursing Research**

More research should be done on this research topic, to include other hospitals as this study focussed on one department in one hospital. A multisite quantitative study to measure HIV

related stigma among women living with HIV may be useful to understand the stigma processes as it is experienced in different contexts within the country. Further to this, a qualitative study will be useful to better understand how women living with HIV manage and experience stigma, this is useful to better understand the coping strategies that are used to manage HIV related stigma.

### **5.7. Limitations of the study**

This study was limited by the method of sampling and the method of data collection. The study used purposive sampling to select the participants for the study and a quantitative method, which meant that the researcher was unable to obtain more in-depth information from the participants as the data collection tools did not allow collection of in-depth information. In future, a qualitative research methodology should be employed to conduct another study to illicit more in-depth information. Finally, as this study was conducted in only one hospital in the eThekweni district of KZN, the findings may not be generalization to every setting.

### **5.8 Summary of the study**

This study focussed on the perceived HIV related stigma and disclosure patterns among women living with HIV and AIDS in a selected hospital in the eThekweni district, KZN. It explored the perceived stigma among women living with HIV, the inter-relationship between demographics and stigma, the inter-relationship between demographics and disclosure, and the inter-relationship between stigma and disclosure. A total of 90 participants were purposively selected for the study and a validated questionnaire was administered to them.

### **5.9 Conclusion**

HIV related stigma among women is a major barrier to disclosing HIV status, and the findings of this study have added to the existing knowledge of the perceived stigma and patterns of disclosure among women living with HIV and AIDS. This study indicated that although there are high levels of perceived stigma, women are willing to disclose their HIV status.

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# Appendix 1



Ms LBS Mdluli (208501659)  
Discipline of Nursing  
School of Nursing and Public Health Medicine  
[Bqshmd68@gmail.com](mailto:Bqshmd68@gmail.com)

Dear Ms Mdluli

**Study Title:** An exploratory descriptive study on the perceived levels of stigma and disclosure patterns among women living with HIV and AIDS in a selected hospital in KwaZulu-Natal.  
**Degree:** M Nursing  
**BREC REF NO:** BE375/16

## EXPEDITED APPLICATION

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application received on 14 June 2016.

The study was provisionally approved pending appropriate responses to queries raised. Your response received on 23 August 2016 to queries raised on 20 July 2016 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval and may begin as from 29 August 2016.

This approval is valid for one year from 29 August 2016. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 676).

The sub-committee's decision will be RATIFIED by a full Committee at its next meeting taking place on 13 September 2016.

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

Professor J Tsoka-Gwegweni  
Chair, Biomedical Research Ethics Committee

cc supervisor: [naidojr@ukzn.ac.za](mailto:naidojr@ukzn.ac.za)

cc postgraduate office: [dhanraj@ukzn.ac.za](mailto:dhanraj@ukzn.ac.za)

Biomedical Research Ethics Committee  
Professor J Tsoka-Gwegweni (Chair)  
Westville Campus, Govan Mbeki Building  
Postal Address: Private Bag 264001, Durban 4300  
Telephone: +27 (0) 31 280 2466 Facsimile: +27 (0) 31 280 4009 Email: [brec@ukzn.ac.za](mailto:brec@ukzn.ac.za)  
Website: <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

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## Appendix 2

MOBENI  
Tel: 031 907 8317/8304 Fax: 031 906 1044 Email:myint.aung@kznhealth.gov.za  
[www.kznhealth.gov.za](http://www.kznhealth.gov.za)

Prince Mshiyeni Memorial  
Hospital

Enquiry: Dr M.Aung  
Ref No: 22 /RESH/2106  
Date: 16/08 /2016

TO: Lucia Bonisiwe Sinegugu Mdluli

**RE: APPROVAL LETTER TO CONDUCT RESEARCH AT PMMH**

Dear researcher;

I have pleasure to inform you that PMMH has considered your application to conduct research on **“An exploratory study on the perceived levels of stigma and disclosure patterns among women living with HIV and AIDS in a selected hospital in KwaZulu-Natal”** in our institution.

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Please ensure this office is informed before you commence your research.
4. The institution will not provide any resources for this research.
5. You will be expected to provide feedback on you finding to the institution.

Thank you.



---

**Dr. M Aung**

Senior Manager: Medical & Consultant in Family Medicine  
MBBS (Rgn), PGDip in HIV (Natal), DO (SA)  
M.Med.Fam.Med (Natal)

## Appendix 3



HRKM Ref: 233/16  
NHRC Ref: KZ\_2016RP48\_558

Date: 1 August 2016  
Dear Ms LBS Mdluli  
UKZN

### Approval of research

1. The research proposal titled '**An exploratory descriptive study on the perceived levels of stigma and disclosure patterns among women living with HIV and AIDS in a selected hospital in KwaZulu-Natal**' was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby approved for research to be undertaken at Prince Mshiyeni Memorial Hospital.

2. You are requested to take note of the following:
  - a. Make the necessary arrangement with the identified facility before commencing with your research project.
  - b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)

For any additional information please contact Mr X. Xaba on 033-395 2305.

Yours Sincerely

**Dr E Lutge**

Chairperson, Health Research Committee

Date: 01/08/16

## **Appendix 4: Consent form and information sheet**

### **Participants' information sheet and informed consent**

**Title of topic: An exploratory descriptive study on the perceived levels of stigma and disclosure patterns among women living with HIV and AIDS in a selected hospital in KwaZulu-Natal**

Dear participant

My name is Lucia Mdluli; I am a student at the University of KwaZulu-Natal, pursuing a Master's degree in Advanced Midwifery, Maternal and Child Health. One of the requirements for the degree is to conduct a research project.

You have been requested to take part in a research study. This form gives information on the study in order to help you to decide if you want to participate. Take as much time as you like to read over this information carefully. Please ask any questions that you may have on the study. It is ok if you decide not to participate, and if you decide to participate, you may stop participating in the study at any time, without suffering any negative consequences. The aim of the study is to explore and describe the perceived levels of HIV related stigma among women living with HIV. This study wants to understand the levels of HIV related stigma among women within the community and family, and the levels of disclosure among the women.

The information provided will be used for research purposes only and will be kept confidential by the researcher and supervisor. The study has no personal gain (financial reimbursement). The researcher will appreciate your participation.

### **Procedures**

If you agree to participate in the study, the following will take place:

You will be issued a questionnaire to answer questions about your demographic data, your reproductive history and your experience or opinion of how people living with HIV are being treated in the community, by the health care services and by the family. The questionnaire will take about 30 minutes to complete.

**Risks and discomforts:** Some of the questions ask about your experience living with HIV, and these questions do not have right or wrong answers, so feel free to answer as you see fit. You are free to stop completing the form at any time, should you wish to do so, and your care at the clinic will NOT be affected. You will be asked sensitive questions about stigma, so feel free to refuse to answer.

### **Confidentiality**

Your name will not be recorded on the questionnaire nor reported in any project document and all of your answers will be kept strictly confidential. It will be only written on the consent form because, when agreeing to participate, it is a requirement that you write your name and sign the form. There will be no link between your consent to participate in the study and your completed questionnaire. This study has been ethically reviewed and approved by the UKZN Biomedical Research Ethics Committee.

In the event of any problems or concerns/questions you may contact the researcher at (provide contact details), the research supervisor, or the UKZN Biomedical Research Ethics Committee, contact details as follows:

**Name of the researcher:** Lucia Mdluli

**Contact details:** School of Nursing and Public Health  
5th Floor Desmond Clarence Building  
Howard College Campus,  
University of KwaZulu-Natal  
Faculty of Health Sciences,  
4041,  
DURBAN,  
RSA  
Cell phone: 0835903095  
Email: [208501659@stu.ukzn.ac.za](mailto:208501659@stu.ukzn.ac.za)

or Bonahmd68@gmail.com

**Supervisor:** Dr. Joanne Naidoo

Email: naidoojr@ukzn.ac.za

Contact details: 0312602213

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building

University of KwaZulu-Natal

Private Bag X 54001, Durban, 4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2602486 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

I have been given a copy of this consent form to keep.

**Consent to participate in research project**

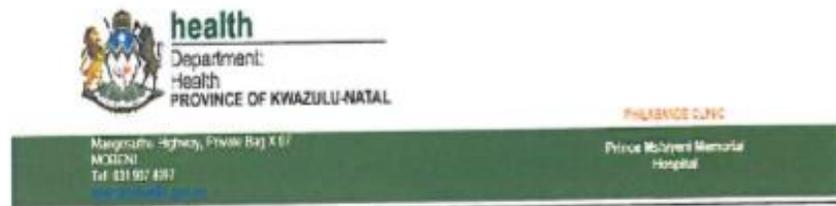
I..... (Your full name) hereby confirm that I understand the contents of this study document and the nature of the research project, and I consent to participating in the research project.

I understand that PARTICIPATION IS VOLUNTARY and I am at liberty to withdraw from the project at any time, should I so desire.

.....

**Signature and Date**

## Appendix 5: Letter from Philasande



To: Lucia Bonisiwe Sinegugu Mduli

### RE: LETTER OF SUPPORT TO CONDUCT ONGOING COUNSELLING

Dear Researcher

I have the pleasure of informing you that Prince Mshiyeni Memorial Hospital (Philasande Clinic) has considered your application to conduct research on "Exploratory study on the perceived levels of stigma and disclosure patterns among women living with HIV and AIDS in a selected hospital in KwaZulu-Natal" in our institution. At Philasande Clinic we specialize in providing counseling to HIV positive post-natal mothers and therefore we are willing to assist you in your study by providing counseling to the participants that are in need of counseling.

Thank you

Sister E.S. Mkhize (Advanced Midwife)

 ADM

## Appendix 6: Questionnaire

### Instructions for the participants

The following questions will be divided into sections A, B and C; please answer all questions.

The following questions relate to your socio-demographic data,

Please place a tick in the appropriate box for the answer(s) below.

### Section A-1 Socio-Demographic Data

1. What is your age in years?

3. What is your marital status?

Single

Married

Divorced

Living with partner but not

Married

4. What is your ethnicity/race?

African

Indian

White

Coloured

Other (specify) .....

5. What is your religion?

Roman Catholic

Christian

Zion

Muslim

Nazareth

other.....

6. Are you currently employed?      Yes            No     

If yes what is your occupation?

Specify.....

5.1. If not employed who is the breadwinner at home?.....

6. What is your highest level of education?

Completed primary school     

Completed secondary school     

High school     

Tertiary education     

7. Where do you live?

Rural area     

Urban area     

8. With whom do you live?

Family     

Friend     

Other specify.....

**Section A-2: Reproductive History**

9. How many times have you been pregnant?

First pregnancy	<input type="text"/>	Second pregnancy	<input type="text"/>
Third pregnancy	<input type="text"/>	More than third pregnancy	<input type="text"/>

10. How many children do you have?

None	<input type="text"/>	One child	<input type="text"/>
Two children	<input type="text"/>	Three children	<input type="text"/>
Four children	<input type="text"/>	More than four children	<input type="text"/>

State the number of children if more than four.....

11. If you were pregnant before, where was your last baby delivered?

Home	<input type="text"/>
Hospital	<input type="text"/>
Health Centre	<input type="text"/>
Private Clinic	<input type="text"/>
No previous pregnancy	<input type="text"/>

12. In the current pregnancy, how many times have you visited the Antenatal clinic?

One	<input type="text"/>
Two	<input type="text"/>
Three	<input type="text"/>
Four	<input type="text"/>

State the number of visits to the antenatal clinic if more than four

**Section B**

The following questions ask about your experience, opinion and how people with HIV are treated.

For each item circle your answer: strongly disagree (SD), disagree (D) strongly agree (SA), agree (A),

<b>Statements</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
1.No one in my family knows that I have HIV	SD	D	A	SA
2.I feel guilty because I have HIV	SD	D	A	SA
3.People’s attitudes about HIV make me feel worse about myself	SD	D	A	SA
4.Telling someone that I have HIV is risky	SD	D	A	SA
5.People with HIV lose their jobs when their employers find out	SD	D	A	SA
6.I work hard to keep my HIV status a secret	SD	D	A	SA
7.I feel I am not as good as others because I have HIV	SD	D	A	SA
8.I never feel ashamed of HIV	SD	D	A	SA
9.People with HIV are treated like outcasts	SD	D	A	SA
10.Having HIV makes me feel dirty	SD	D	A	SA
11.Most people believe that a person who has HIV is dirty	SD	D	A	SA

12.I prefer to avoid having friends because I have HIV	SD	D	A	SA
13.Since learning I have HIV, I feel set apart and isolated from the rest of the world	SD	D	A	SA
14.Most people think that a person with HIV is being punished by God	SD	D	A	SA
15.Having HIV makes me feel that I'm a bad person	SD	D	A	SA
16.Most people with HIV are rejected when others find out	SD	D	A	SA
17.I am very careful who I tell that I have HIV	SD	D	A	SA
18.Some people who know that I have HIV distance themselves from me	SD	D	A	SA
19.Since learning I have HIV, I worry about being discriminated against	SD	D	A	SA

**Section C**

The following questions ask about your HIV status, please tick the correct answer.

1. Did you disclose your HIV status to anyone?

Yes

No

2. If you can share the results with someone, whom would you tell?

Family member

Spouse or partner

Friend

Other (specify).....

3. What was the reaction of that person you told about your HIV status?

Rejected

Gave support

Other (specify).....

4. If not telling anyone about your HIV status, what is your reason for not telling anyone?

Stigma and discrimination

Fear of people not maintaining my confidentiality

Knowing HIV-status has no advantage.

Other reason specify .....

5. In the family or community, how often did the following events happen because of your HIV status? 0=Never,

1=once or twice,

2=several times

3=most of the time

(a) Someone scolded me.....

(b) Someone insulted me.....

(c) I was blamed for my HIV status.....

(d) I was told that I have no future.....

(e) I was told that God is punishing me.....

(f) I was called bad names.....

(g) Someone mocked me when I passed by.....

(h) People sang offensive songs when I passed by.....

Thank you

## **Appendix 6: IsiZulu Version**

### **Ifomu lemininingwane nemvume yobambe iqhaza**

**Isihloko: Ukuhlolwa nokuchazwa kwamazinga ezinkolelongezici kubantu besifazane abaphila nengculazi kwezaba khulelwe nezempilo yabantwana ezibhedlela ezikhethekile zesiFunda saseThekwini.**

Mbambiqhaza

Igama lami ngu-Lucia Mdluli; ngingumfundi eNyuvesiYaKwaZulu-Natali, ofundela iziquze-Master in Advanced Midwifery, Maternal and child health. Enye yezidingo yaleziziqu ukuba kwenziwe ucwaningo.

Uyacelwa ukuba ubambe iqhaza kulolucwaningo. Lelifomu linemininingwane ngocwaningo ukuze ukwazi ukuzinqumela ngokubamba iqhaza. Thatha isikhathi osidingayo ukuthi ufunde lemininingwane ngokucophelela. Ngicela ubuze noma imiphi imibuzo ongaba nayo ngocwaningo. Akunankinga futhi uma ukhetha ukungalibambi iqhaza. Uma ukhetha ukubamba iqhaza, ungahoxa noma inini uma ungasathandi ukuqhubeka. Inhloso yocwaningo ukuhlola nokuchaza kwamazinga ezinkolelongeziciku bantu besifazane abaphila nengculazi. Lolu cwaningo luhlose ukuqonda ngamazinga ezici kwabesifazane abaphila nengculazi emphakathini nasemindenini kanye namazinga okudalula ukubanengculazi phakathi kwabesifazane.

Ulwazi olutholakele luzosetshenziselwa ucwaningo kuphela futhi luzogcinwa luyimfihlo ngumcwaningi nomeluleki wakhe. Ucwaningo alunanzuzo yezimali kumuntu. Umcwaningi uzokuthokozela ukuzibandakanya kwakho.

### **Izinqubo**

Uma uvuma ukubamba iqhaza kulolucwaningo, kuzokwenzeka lokhu okulandelayo:

Uzonikezwa uhlumibuzo lapho uzophendula imibuzo mayelana nawe, umlando wakho kwezocansi noma imibono yakho mayelana nendlela okumele kuphathwe ngayo abantu abaphila nengculazi emphakathini, emitholampilo nase mndenini. Lokhu kuzothatha imizuzu engama-30.

**Ubucayi Nokunga phatheki kahle:** Eminye yemibuzo ozoyibuzwa ngomlando wakho ngokuphila nengculazi. Le mibuzo ayinazimpendula ezilungile noma ezingalungile, ngakho

ungayeka ukugcwalisa ifomu noma yinini. Uzobuzwa imibuzo ebucayi mayelana nezici ngengculazi ngakho khululeka wenqabe ukuphendula.

### **Ubumfihlo**

Igama lakho ngeke libhalwe ohlwini mibuzo noma lisetshenziswe kweminye imibhalo futhi zonke izimpendulo zakho zizohlala ziyimfihlo. Lizo bhalwa kuleli fomu kuphela ngoba kungumgomo ukuba libhalwe futhi usayine. Ngeke kube khona ukuxhumana Phakathi kwemvume yakho yokubamba iqhaza kulolu cwaningo nohlumibuzo.

Lolu cwaningo selubuyekeziwe ngokwe zenkambiso futhi lugunyazwe yikomidi lezenkambiso kwezocwaningo ngezempilo kwelapha lase-UKZN (inombolo yokugunyazwa \_\_\_\_\_).

Uma kuba khona izinkinga noma ukungathokozi/imibuzo ungathintana nomcwaningi (faka imininingwane yomncwaningi), umeluleki wocwaningo noma Ikomidi lase UKZN lezocwaningo ngezempilo kwela lapha kokulandelayo:

**Igama Lomcwaningi:**

Lucia Mdluli

**Imininingwane Yokuxhumana:**

School of Nursing and Public Health

5th Floor Desmond Clarence Building

Howard College Campus,

University of KwaZulu-Natal

Faculty of Health Sciences,

4041,

DURBAN,

RSA

Cell phone: 0835903095

Email: [208501659@stu.ukzn.ac.za](mailto:208501659@stu.ukzn.ac.za)

or

Bonahmd68@gmail.com

**Umeluleki:** Dr. Joanne Naidoo

Email: naidoojr@ukzn.ac.za

Contact details: 0312602213

**Imvume yokubamba iqhaza**

Nginikeziwe ikhophi yalelifomu ukuba ngiyigcine.

**Imvume yokubamba iqhaza kulolucwaningo**

**Mina**..... (Igama lakho eligcwele) ngiya qinisekisa lapha ukuthi ngiyakuqonda okumayelana nalombhalo ngalolucwaningo nohlobo locwaningo futhi ngiyavuma ukubamba iqhaza kulo.

Ngiyaqonda ukuthi UKUBAMBA IQHAZA AKUPHOQELEKILE futhi nginelungelo lokuhoxa nomayinini, umangifisa.....

**Ukusayina**

**Nosuku**

.....

.....

**Uhlumibuzo**

**Imiyalelo yababambe iqhaza**

Le mibuzo izoba nezigaba A, B no C sicela uphendule yonke imibuzo.

Uzobuzwa imibuzo efana nalena mayelana nolwazi ngenhlalobuwena,

Sicela ukhethe ibhokisi elinempendulo efanele lapha ngezansi.

**Isigaba A –1 Ulwazi Ngenhlalobuwena**

1. Uneminyaka emingaki?

2. Ingabe?

Awushadile

Ushadile

Uhlukanisile

3. Ungowaliphi uhlanga/ubuzwe?

UmAfrika

Umndiya

Umlungu

Omunye (cacisa) .....

4. Iyiphi inkolo yakho?

Umkhatholika

Umkhrestu

Umzayoni

Uyisulumane

Umnazaretha

okunye.....

5. Uyasebenza? Yes

No

5.1. Uma uthi yebo, usebenza msebenzi muni?

Chaza.....

6. Izinga lakho lemfundo lingakanani ?

Uphothul eamabanga aphantsi

Amabanga aphakathi

Amabanga aphezulu Imfundo ephakeme

7. Uhlalaphi?

Emaphandleni

Emadolobheni

8. Uhlalanobani?

Umndeni

Umngani

Cacisa.....

**Isigaba A-2:** Umlando Ngezocansi

9. Usukhulelwe kangaki?

Okokuqala  Okwesibili

Okwesithathu  Okungaphezulu kokuthathu

10. Unezingane ezingaki?

Angina zingane

Nginengane eyodwa

Nginezingane ezimbili

nginezintathu

Nginezingane ezine

Ezingaphezulu kwezine

Yisho isibalo sezingane onazo

11. Uma wake wakhulelwa, wazalelwaphi umntwana wakho wokugcina?

Ekhaya	<input type="checkbox"/>
Esibhedlela	<input type="checkbox"/>
Emtholampilo	<input type="checkbox"/>
Angikazengikhulelwe	<input type="checkbox"/>

12. Kulokhu kukhulelwa kwamanje, usuvakashele kangaki eklinikhi yabakhulelwe?

Kanye	<input type="checkbox"/>
Kabili	<input type="checkbox"/>
Kathathu	<input type="checkbox"/>
Kane nangaphe	<input type="checkbox"/>

### IsigabaB

Lemibuzo elandelayo ibuza mayelana nosuke wabhekana nakho, imibono yakho nokuthi kumele baphathwe kanjani abantu abanengculazi.

Esitatimendeni ngasinye kokelezela impendulo yakho:Uphika kakhulu , Uyaphika, Uyavuma kakhulu , Uyavuma,

Izitatimende	Uphika kakhulu	Uyaphika	Uyavuma	Uvuma kakhulu
Akekho owaziyo ukuthi nginengculazi emndenini	SD	D	A	SA
Ngizizwa nginecala ngoba nginengculazi	SD	D	A	SA
Indlela abantu ababuka ngayo ingculazi ingenza ngizisole kakhulu	SD	D	A	SA

Ukutshela umuntu ukuthi nginengculazi kunobungcuphe	SD	D	A	SA
Abantu abanengculazi baphelelwa umsebenzi uma abaqashi bethola ukuthi abasebenzi banengculazi	SD	D	A	SA
Ngisebenza kanzima ukugcina isimo sami sengculazi siyimfihlo	SD	D	A	SA
Ngiyazenyeza ngoba nginengculazi	SD	D	A	SA
Anginamahloni ngengculazi	SD	D	A	SA
Abantu abanengculazi baphathwa njengabantu banga phandle	SD	D	A	SA
Ukuba nengculazi kungenza ngizizwe ngingcolile	SD	D	A	SA
Abantu abaningi bakholelwa ukuthi umuntu onengculazi ungcolile	SD	D	A	SA
Ngincamela ukungabi nabangani ngoba nginengculazi	SD	D	A	SA
Kusukela ngithola ukuthi nginengculazi, ngizizwa ngikhishwa inyumbazane, ngihlukene nomhlaba wonke	SD	D	A	SA
Abantu abaningi bacabanga ukuthi abantu abanengculazi basuke bejeziswa uNkulunkulu	SD	D	A	SA
Ukuba nengculazi kungenza ngizibone njengomuntu ongalungile	SD	D	A	SA
Abantu abaningi abanengculazi bayalahlwa uma abanye bethola	SD	D	A	SA

ukuthi banengculazi				
Ngiyaqaphela ukuthi ngitshela bani ngesimo sami sokuba nengculazi	SD	D	A	SA
Abanye abantu abazi ukuthi ngingengculazi bayaziqhelelanisa nami	SD	D	A	SA
Emuva kokwazi ukuthi ngingengculazi, ngisaba ukuthingizo cwaswa	SD	D	A	SA

### Isigaba C

Imibuzo elandelayo ikubuza ngesimo sakho sengculazi, sicela ukhethe impendulo efanele

(1) Ukhona osumtshelile ngesimo sakho sengculazi?

Yebo

Cha

(2) Uma ungatshela umuntu ngesimo sakho sengculazi, ungatshela bani?

Ilungu lomndeni

Ozwana naye noma obambisene naye

Umngani

Omunye (cacisa).....

(Waku thatha kanjani ukuzwa ngesimo sakho sengculazi lo owamtshela ngaso?)

Wangilahla

Wangiseka

Okunye(cacisa).....

(2) Uma ungatshelanga muntu ngesimo sakho sengculazi, kwakuyisiphi isizathu salokho?

ukuthi bayacwasana

Ukwesaba ukuthi abantu ngeke bagcine lokhu kuyimfihlo

Ukwazi ngesimo sakho sengculazi akusizi ngalutho.



Ezinye izizathu. chaza.....

6. Emndenini noma emphakathini sekwenzeke kangaki lokhu okulandelayo ngenxa yesimo sakho sengculazi?

0-akukaze kwenzeke,

1-kanye nomakabili,

2-kaningana

3-kwenzeka izikhathi eziningi

- (i) Kukhona owangithethisa.....
- (j) Kukhona owangithuka.....
- (k) Kwasolwa mina ngesimo sami sengculazi.....
- (l) Ngatshelwa ukuthi anginakusasa.....
- (m)Ngatshelwa ukuthi uNkulunkulu uyangijezisa.....
- (n) Ngabizwa ngamagama angemahle.....
- (o) Kukhona owangidelela ngidlula eduze kwakhe.....
- (p) Abantu babecula amaculo athukayo umangidlula.....

Ngiyabonga

## **Appendix 7: Letter from Language Practitioner**

Dear Client

This is to confirm that I Njabulo Marvin Manyoni is a full-time Language Practitioner in the employ of the University of KwaZulu-Natal within the Language Planning and Development Office.

I am a qualified Language Practitioner with 16 years of experience as a translator/interpreter/proofreader and editor. Our field does not have a legislated professional body as yet and as such, accreditation is not possible. My current role in the University is to provide the following services:

- Translation
- Interpreting
- Editing
- Proofreading
- Terminology Development
- Transcription

I also provide these services to the general public at a negotiated fee.

I trust the above is in order.

Kind regards

Njabulo M. Manyoni

**Appendix 8: Certificate of completion from ethics**



## Appendix 9: Letter from editor



Pauline Fogg  
54 Grundel Road  
Carrington Heights  
Durban  
4001  
074 782 5234

16 August 2017

### *Letter of Editing*

This report serves to state that the dissertation submitted by Lucia Bonisiwe Sinegugu Mdluli, in fulfillment of the requirements the degree Masters in Nursing (Nursing Research) has been edited.

The dissertation was edited for errors in syntax, grammar, punctuation and the referencing system used.

The edit will be regarded as complete once the necessary changes have been effected and all of the comments addressed.

Thank-you for your business.

*P. Fogg*

Pauline Fogg