

**EXPLORING THE NARRATIVES OF WOMEN WITH HIV/AIDS IN A  
DESIGNATED HEALTH SETTING**

**By**

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## ABSTRACT

This research study explored the experiences of HIV positive women with particular reference to their challenges, coping and survival strategies after an HIV positive diagnosis. A review of literature revealed that research on the lived experiences of South African women with HIV/AIDS is limited.

The aim of this study was to explore the narratives of women with HIV/AIDS in a designated health-care setting in KZN. Social constructionism and ecosystems approaches were adopted as guiding frameworks for the study. Fifteen HIV positive women were sampled using, purposive and availability sampling. Qualitative data was collected using semi-structured interviews. The pertinent themes were identified and analyzed accordingly.

Some HIV positive women experienced challenges in dealing with their HIV diagnosis which ranged from being stigmatized, rejected, or socially isolated, while some received support and acceptance from their environment. The life-prolonging effect of ART has allowed HIV infected women to implement coping and survival strategies in order to reduce HIV/AIDS fatigue. Immersion in spirituality and 'reaching out' were some of the survival strategies adopted by HIV infected women in this study.

Micro, Mezzo, and Macro recommendations were made with regard to provision of appropriate services for HIV positive women. The study may be of value to service providers as it may enlighten them on the various experiences (whether challenging, positive, or adaptive) of women with HIV/AIDS. Furthermore, HIV positive women may benefit from knowing that they are not alone in this fight against the dreaded disease.

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This dissertation is also dedicated to all the HIV positive women who participated in this study.

## DECLARATION OF ORIGINALITY

I declare that this short dissertation is my original work. All references to the work of others has been appropriately acknowledged and referenced in accordance with university requirements.

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This dissertation has been submitted with my approval.

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## ABBREVIATIONS

|        |  |
|--------|--|
| AIDS   | Acquired Immune Deficiency Syndrome        |
| ARV    | Antiretroviral                             |
| ART    | Antiretroviral Therapy                     |
| CBO    | Community Based Organisation               |
| HAART  | Highly Active Antiretroviral Treatment     |
| HCT    | HIV Counseling and Testing                 |
| HIV    | Human Immunodeficiency Virus               |
| KZN    | Kwa-Zulu Natal Province                    |
| NGO    | Non Governmental Organisation              |
| PLWHA  | People Living With HIV/AIDS                |
| PMTCT  | Prevention of Mother-To-Child Transmission |
| STI    | Sexually Transmitted Infection             |
| TB     | Tuberculosis                               |
| UNAIDS | United Nations - AIDS                      |
| VCT    | Voluntary Counselling and Testing          |
| WHO    | World Health Organization                  |
| WLWHA  | Women Living With HIV/AIDS                 |

## CHAPTER ONE

### INTRODUCING THE STUDY

#### 1.1 INTRODUCTION

On World Aids Day, in the year 1998, Gugu Dlamini (who was a resident of the township of Kwa-Mashu, KwaZulu-Natal) openly disclosed her HIV (Human Immunodeficiency Virus) status on radio. Her aim was to break the silence on the disease that was and is still claiming the lives of South African citizens. Sadly, a few weeks later, she was beaten to death by her neighbours for bringing shame to their community. The incident highlighted the stigma of HIV, and how HIV positive women continue to suffer different forms of discrimination. It also exposed the patriarchal nature of South African societies which force women to suffer in silence. Just over a decade later, with the latest medical advances, the researcher sought to explore the narratives of HIV positive women with special reference to their challenges, positive experiences, coping and survival mechanisms adopted after receipt of an HIV positive diagnosis.

In this chapter the researcher presents the background to the study, and the statement of the problem in relation to the epidemiology of HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome). Thereafter, the rationale for the study will be given, followed by the value of the study, the research aims with the objectives, the research questions, and the theoretical framework that guided the study. Lastly a preview of the research report layout is outlined at the end of the chapter.

#### 1.2 BACKGROUND TO THE STUDY

According to the 2009 report on the global summary of the AIDS epidemic, 33.4 million people were living with the AIDS virus globally at the end of 2008. The report further highlighted that at least 5.6 million of those infected were from South Africa (UNAIDS, 2010). Additionally, UNAIDS (2010) announced that about three quarters of women living with HIV/AIDS were from Sub-Saharan Africa. The UNAIDS (2010)

global report is significant in that it shows a decline in new HIV infections. However, women are still found to be most at risk.

AIDS (Acquired Immune Deficiency Syndrome) has had a dramatic effect on the global health care systems since its identification in 1981 (Avert, 2010). HIV's progressive degeneration of the immune system exposes infected persons to various opportunistic infections which have debilitating effects on the HIV positive individual's life and his/her immediate environment (Avert, 2010; Van Dyk, 2001). To address this challenge, the South African DOH (Department of Health) set out Clinical Guidelines for the prevention of Mother-to-Child Transmission in order to reduce mortality by "keeping women and children healthy and improving (their) quality of life" (Department of Health, 2010:14). The availability and accessibility of ARV's (Antiretroviral Treatment) has prolonged the life expectancy of HIV positive adults in South Africa, thus making survival years post HIV diagnoses unknown even by medical experts (USAID, 2010; Kohan et al., 2008).

### **1.3 STATEMENT THE PROBLEM**

In a study by Dorrington et al. (2006) at least 2.8 million women between the ages 15-49 years were HIV positive. This study suggests that women in their early 20's are more vulnerable to HIV infection, and that women in their late 40's continue to be at risk. In all age groups, more women than men were living with HIV/AIDS in South Africa. Dorrington et al. (2006) noted that Kwa-Zulu Natal (KZN) had the highest prevalence with 28.7% HIV infected people, while the Western Cape had the lowest prevalence, with 5.4% people living with HIV/AIDS. These alarming statistics have prompted the urgency for South African (SA) government to increase their rollout of ARV's.

Developing countries, including South Africa find it hard to respond adequately to the needs of women living with HIV/AIDS (Avert, 2010; Nyirenda et al., 2006). The patriarchal structures in South African societies that view women as economically and socially dependent on their male counterparts are amongst the reasons why women remain vulnerable to HIV infection and re-infection (USAID, 2010). Urdang (2006) contends that the current AIDS awareness campaigns do not take into

account the socio-cultural and economic factors that compromise women's ability to negotiate safer sex.

Higgins et al. (2010) argue that women's physical make up, together with society's acceptance of men having more than one sexual partner further increases women's risk of being HIV infected. Furthermore, programmes like the PMTCT (Prevention of Mother to Child Transmission) often depict women as posing a risk of transmitting the deadly disease to their unborn children (Nyirenda et al., 2006), thus implying that they need to be 'managed' accordingly. HIV positive women therefore require a platform to safely 'tell' their stories of trials and tribulations, a need that this study sought to fulfill.

#### **1.4 RATIONALE FOR THE STUDY**

Having worked at a health institution for eight years, the researcher noted an ever-increasing emphasis placed on early HIV testing, and improved access to antiretroviral treatment. The urgency of HCT (HIV counselling and testing) is undeniable, as lamented by the KZN Minister of Health (Dr Sibusiso Dhlomo) in his announcement that KZN had reached 79% of their HCT target set for end of June 2011 (BuaNews, 01 December 2010). Importantly, he added that health care service providers needed to move beyond seeing HIV infected patients as just statistics and view them as people that need to be listened to and supported, a notion supported by the current study. This study sought to provide a safe environment for women to openly discuss their experiences in relation to their HIV positive diagnoses.

Positive living is not always possible against the backdrop of multiple stresses. Murphy and Greenwell (2006) argue that when HIV enters lives of women, it joins the other pre-existing stressors such as unemployment, domestic violence, single parenting and lack of food and shelter for themselves and their children. These researchers found a correlation between the HIV positive mother's stress/anxiety and parenting manner, pointing to the negative effects of stress on children of HIV positive women. Research relating to HIV/AIDS has largely been quantitative in nature and does not account for the complex interaction of socio-cultural factors. Murphy and Greenwell (2006) contend that South African HIV positive women have

unique challenges, and therefore require specific interventions. The present study uncovers both the challenges and survival strategies adopted by HIV infected women, pointing to tested interventions that could be further tested and elaborated.

In Kenya, HIV positive women contracted opportunistic infections, and displayed little hope for survival, due to unhealthy living conditions and poverty (Amuyunzu-Nyamongo et al., 2007). In contrast, Anderson and Doyal (2004) found that the HIV positive African women living in London (which is comparably well resourced) expressed the need to continue living positively in order to see their children through their adult years. Both these studies revealed how HIV not only affects the individual, but also his/her environment; and how one's environment can promote or inhibit adjustment to HIV. In the current study, context-rich data sought to reveal the full extent of an HIV positive diagnosis from all levels of the ecosystem (micro, mezzo and macro levels).

The current research study sought to explore narratives of women with HIV/AIDS in relation to their challenges and coping mechanisms adopted after receipt of seropositive status.

## **1.5 VALUE OF THE STUDY**

The advent of ART (Antiretroviral Therapy) has significantly transitioned the HIV/AIDS epidemic from a deadly disease to a chronically managed illness similar to diabetes, epilepsy, and other life-long illnesses (UNAIDS, 2010).

Nyirenda et al. (2006) argue that health programmes and interventions have ignored the psychosocial impact of HIV/AIDS on women. The introduction of ART (Antiretroviral therapy) was a milestone for the African Continent. However, one cannot ignore the challenges such as stigma, self-blame, and social isolation experienced by HIV positive women. According to Uchino (2009), these challenges contribute to non-adherence and non-compliance to ART. Based on the literature reviewed, the researcher is of the assumption that the voices of the HIV positive women have not been heard properly. This study provides insight into the challenges confronted by Women Living with HIV/AIDS (WLWHA) in relation to fears

of disclosure; experienced challenges after disclosure; positive experiences after disclosure; and the needs expressed by these women. The coping and survival strategies of HIV positive women are also explored in this study.

Women are historically viewed as nurturers, good listeners, and providers of strength to the ill. Makoae and Jubber (2008) argue that when women themselves become ill, very little social support is at their disposal. Therefore, exploring the narratives of women living with HIV/AIDS might provide an understanding of not only their psychosocial needs, but also their survival strategies after receipt of an HIV positive diagnosis. This study will benefit the multidisciplinary team (MDT) that provides comprehensive care to HIV positive women, with information on the needs of HIV positive women. The recognition of women's distinct needs may offer an opportunity for service providers to explore alternative management interventions for HIV positive women. Moreover, the study may benefit the participants themselves, as they narrate their experiences of living with HIV/AIDS, in a safe environment. The study may also inform policy on HIV/AIDS that could be applicable to the needs of HIV infected women.

## **1.6 RESEARCH AIMS, OBJECTIVES AND QUESTIONS**

The main aim of this study is to explore the narratives of women with HIV/ADS in a designated health-care setting in KZN.

### **1.6.1 Research Objectives**

- To explore the life stories of HIV positive women in KZN.
- To explore how HIV positive women have dealt with challenges that arose from their HIV diagnoses.
- To ascertain the contributory factors to HIV positive women's adjustment/maladjustment to their HIV diagnoses after disclosure.
- To ascertain the service requirements of HIV positive women.

### **1.6.2 Research Questions**

Terre Blanche et al. (2006) argue that research questions are more appropriate in qualitative studies as contrasted to the use of hypothesis in quantitative research. The questions below follow a non-positivist paradigm (also refer to Methodology, Chapter 3). The questions sought to explore in-depth narratives of women with HIV/AIDS, as follows:

- How do HIV positive women internalize their stories of HIV in relation to their past, present, and future narratives?
- What are the challenges that arose from being diagnosed HIV positive?
- What are the coping strategies of HIV positive women?
- What supportive structures and services do HIV positive women have and/or need?

### **1.7 RESEARCH APPROACH IN BRIEF**

Due to the sensitivity of HIV issues, this study utilized a qualitative method in order to explore the experiences of HIV positive women in a designated health setting. Within a qualitative paradigm, the research employed a non-positivism exploratory research design. In addition, purposive sampling was utilized. Fifteen women (over 18 years old) who had been living with HIV/AIDS for 3 years and above were selected. Permission was sought from the institution's CEO (Chief Executive Officer) in order to conduct the research and University ethical clearance secured.

Qualitative data was collected using semi-structured individual interviews, where narrative interviewing techniques were employed in order to explore the 'life stories' of women with HIV/AIDS. Interviews were conducted at the place most convenient to each research participant (office, or home). In order to obtain a clear account of the narratives, sessions were audio-taped, translated and transcribed accordingly. Sessions were conducted in IsiZulu, as the sample comprised of only Zulu speaking women. Open ended questions were drawn up, with themes which assisted in guiding the interview. (Also refer to Methodology Chapter 3)

## 1.8 THEORETICAL FRAMEWORK

The social constructionism perspective and an ecosystems approach were utilized to gain insight into the experiences and challenges of HIV positive women in this study. While social constructionism claims that meanings and personal views are socially determined (Mwaria, 2006), the ecosystems theory emphasizes the mutual interdependence of subsystems. The latter theory explains how change in one system (micro, mezzo, or macro) influences change in another (Potgieter, cited in Dano, 2007). These approaches were most appropriate for this study since they both view the person in the context of his/her environment.

### 1.8.1 Social Constructionism

Social Constructionism is the use of background assumptions and life experiences to define what is real.

([http://wiki.answers.com/Q/What is Social Constructionism#ixzz1HE8d0v4g](http://wiki.answers.com/Q/What_is_Social_Constructionism#ixzz1HE8d0v4g))

This post modern perspective is concerned with the description, explanation and interpretation of knowledge as perceived by specific individuals or groups (Gergen, 1985). Social constructionism has its roots in Social Psychology, focusing on studies of Berger and Luckmann. In their book '*The Social Construction of Reality*', Berger and Luckmann (1966) argue that people are born into a socio-cultural context with pre-existing norms, and thus assume that the way they perceive their world is the same natural way for everybody. Berger and Luckmann align themselves with Durkheim's definition of the structure of society as being '*reality sui generis*', claiming that all meaning that is expressed by society is subjective in nature. It is through the processes of social interaction, institutionalization, and legitimization that such meanings get transmitted from one generation to the next (Bury, 1986; Berger & Luckmann, 1966).

While social constructionism theorists maintain that the foundation of meanings occur "outside the head", and are socially determined, social constructivists argue that meaning formations are psychologically determined, thus occurring "in the head", (Hruby, 2001:11). It is clear that the two theories assume distinctive aspects

of their respective disciplines of sociology (constructionism) and psychology (constructivism), a distinction which Hruby (2001) also claims to be a social construct. Language appears to be the most common medium of transferring social constructs. It is through the use of language by means of social interaction, negotiations, and meaning regeneration that PLWHA (People Living With HIV/AIDS) learn to accept and manage their illness. In social constructionism research, Terre Blanche et al. (2006:278) posit that people's lives are "fundamentally constituted in language and that language itself should therefore be the object of study."

Eisenber, in Conrad and Barker (2010) posits that illness as a socially constructed concept has its basis on the widely known distinction between illness as a 'social' state and disease as a 'biological' state. Social constructionism as an approach to illness, according to Conrad and Barker (2010), emphasizes how culture and society shape individuals' illness experiences, as opposed to models that view diseases as universal, not taking into account contextual or spatial differences. Similarly, discourses of gender and chronic illnesses tend to derive meaning from individuals' social contexts.

In South Africa, women are known to be more susceptible to HIV infections, mainly due to their physiological and social predisposition (Van Dyk, 2001). Most recently, there has been a growing consensus on the contributory impact of patriarchy, stigmatization, and poverty to the perpetuation of the AIDS epidemic (Nyirenda et. al., 2006; Urdang, 2006). Urdang (2006) reiterates that pre-existing socio-cultural norms reinforce the role of women as reproductive agents with no input in sex negotiation. A social constructionist assumption of HIV positive women recognizes that meanings of HIV as an illness are socially constructed. Therefore the study sought to look at the individual experiences/narratives of HIV positive women in a contextual manner.

### **1.8.2 Ecosystems Theory**

The research study was also guided by ecosystems theory. This approach supports circularity in the interaction of individuals, as opposed to linearity. The ecosystems theory "...views the person as developing within a complex system of relationships

affected by multiple levels of the surrounding environment” (Berk, 2001:25). The circular nature of this approach acknowledges the wholeness and mutual dependence of living organisms. The main premise of the ecosystems model is that the structures of society play a role in the regulation and governing of social relations. An ideal example of this is South Africa’s historical apartheid system, with its insistence on white domination. The researcher incorporated the micro, mezzo, and macro systems into the current study in order to fully understand the experiences of women with HIV/AIDS in KZN.

The microsystem in this study comprises of HIV positive women, their spouses, children, siblings etc. Mturi et al. (2006) view family as the basic or primary institution of a society. In addition, Dano (2007) emphasizes the interactive nature of family subsystems and how society and culture play a role in determining such interactions. A microsystemic change takes place as soon as the woman receives her HIV positive diagnosis. Issues of disclosure of an HIV positive status, and the overall change in the person’s lifestyle are likely to have an impact on all other subsystems. At the individual and familial level, the presence of HIV often implies loss of income which has devastating effects on the financial position of the family. In the Free State province, Bachmann and Booyesen (2003) found that the average income and expenditure of AIDS affected households was 9% lower than those not affected by the pandemic.

The mezzosystems level refers to the surrounding community which contributes enormously in the acting out of dominant HIV/AIDS discourses (Urdang, 2006). The open narration of experiences of being HIV positive is still a taboo issue in many communities of South Africa. At this level, the HIV positive women could be experiencing stigma and discrimination within their immediate environment. Some HIV positive women might receive support and acceptance from their neighbours and communities at large. It is therefore important to comprehend how HIV positive women’s involvement at a mezzo level contributes towards their adjustment or maladjustment to their diagnoses.

The macrosystem refers to the higher systems that influence ideology and policy formulation, which potentially have direct impact on the microsystems and

mezzosystems respectively. An example of how the pandemic affects the macrosystem is mentioned in the KZN Local Economic Department HIV/AIDS Final Report conducted by Colvin et al. (20005:35) as follows:

*“The vulnerability of women and the youth to poverty and their reliance on state provided welfare will increase, whether through infection of themselves or that of family members. The Department of Social Development predicts that the increasing number of people affected by HIV/AIDS will lead to continued growth in demand for state support”*

The inclusion of ecosystems theory ensured that systemic influences were taken into consideration during the research process.

## **1.9 PREVIEW OF THE RESEARCH STUDY**

The rest of the research report is structured in the following manner:

**Chapter Two:** This chapter provides an in-depth review of studies on HIV positive women on a global and local perspective. Special attention is afforded to the challenges that women experience and their coping and survival mechanisms that facilitate adjustment after an HIV positive diagnosis.

**Chapter Three:** This chapter discusses the research design and the research methodology utilized in relation to the research problems and objectives of the study. The research methodology focuses on the sampling procedure, research instruments utilized, and methods of data collection and analysis. This chapter also encompasses the ethical issues considered before and during the study, and lastly the limitations of the study are discussed.

**Chapter Four:** This chapter presents the findings of the study. The themes and sub-themes that emerged from the data analysis are presented and discussed in relation to the literature review.

**Chapter Five:** This chapter provides a summary of the entire study, together with the overall conclusion and recommendations for future research.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1 INTRODUCTION

A review of literature is a process that entails identifying and analyzing 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 global and local extent of HIV/AIDS. This will be followed by a contextual discussion on women and HIV, particularly why they carry an inordinate proportion of the infection burden when compared to their male counterparts.

Women's vulnerability in relation to the ecosystems and social constructionist framework adopted in the study is also discussed. Thereafter the psychological challenges faced by HIV positive women upon disclosure namely stigma, discrimination, and social isolation are examined separately as they straddle several theories. In view of the life prolonging impact of antiretroviral therapy, South African women's coping strategies and survival stories are also discussed.

#### 2.2 A BRIEF OVERVIEW OF HIV/AIDS IN THE WORLD

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 'feminization of HIV/AIDS' (UNICEF, 2011; WHO, 2004). HIV transmission patterns have changed. Over two decades ago, HIV infections seemed more prevalent among men (gay men in particular). In 1998, women accounted for 41% of people living with HIV/AIDS (Boesten & Poku, 2009). However, by December 2009, it was estimated that 33.3 million people were living with HIV/AIDS globally, of which 15.9 million were women. A slight decline was evident in the number of HIV infected women as compared to 17.5 million in 2005 (Avert, 2010).

The main mode of HIV transmission is now mainly through heterosexual sexual contact. Other modes of transmission include blood transfusion, needle sharing, vertical infection during labour from mother to child (MTCT), or during breastfeeding. According to the United Nations Millennium Development Goals (MDG) Report (2010), 2.1 million children were living with HIV/AIDS in 2009. Ninety percent of these children were infected while in the womb, during birth, or through breastfeeding. The PMTCT (Prevention of Mother to Child Transmission) programme has managed to reduce the number of children born with HIV from 190 000 in 1994 to 130 000 in 2009 (USAID, 2010). In support, the United Nations commended global AIDS organizations for their consistent commitment to scale up maternal and child services, thus reducing the HIV/AIDS burden among women and children (United Nations MDG Report, 2010).

### **2.3 HIV/AIDS IN SUB-SAHARAN AFRICA**

Although the rate of new infections has decreased slightly, Sub-Saharan Africa still carries a disproportionate share of the global HIV burden. In 2009, 72% of the global total of HIV-related deaths were from Sub-Saharan Africa, while 22.5 million people were living with the disease, with women outnumbering their male counterparts (UNAIDS, 2010). Despite such alarming statistics, Irwin et al. (2003:1) argue that AIDS is not an “African problem”, but rather a “transnational problem”, attributing HIV proliferation to Africa’s history of colonialism and neoliberal policies. These authors clearly pronounce AIDS as “a global medical and moral crisis that demands a global response” (2003:1). This urgency has led to the unprecedented distribution of ARV’s (antiretroviral treatment) across Africa, in the hope of reducing the number of AIDS related deaths.

In Sub-Saharan Africa, young girls (18–24 years) are eight times more likely than men (of the same age group) to be HIV positive (UNAIDS, 2010). This indicates that HIV affects the majority of women in their reproductive ages, and also during their economically productive years. The recent antenatal surveys indicate that one in four women in most African countries is living with HIV/AIDS (Niens & Lowery, 2009). To curb these alarming statistics, UNAIDS (2010) proposed for the protection

of women against gender based violence and encouragement of young girls' economic independence from older men.

Although there has been a slight decline in the rate of new HIV infections, the total number of people living with the virus in Sub-Saharan Africa continues to be disproportionately higher when compared to other regions (AVERT, WHO, & UNAIDS, 2010). Ethiopia, Nigeria, South Africa, Zambia, and Zimbabwe, with considerable epidemiological variations, account for 72% of the global AIDS related deaths totaling 1.8 million (UNAIDS, 2010).

A number of factors contribute to women's vulnerability to HIV infection in Africa. Sub-Saharan research on HIV/AIDS reveals that it is the women's cultural and economic inequalities that make HIV more prevalent among females than among males (Niens & Lowery, 2009). These socio-cultural conditions force some women to prostitution or survival sex (Brijnath, 2007). In addition, Orubuloye et al., as cited in Clark (2005) reveal that traditional African practices such as female circumcision, and the use of vagina tightening substances put women at an increased risk of HIV infection. The non-lubrication of the vagina's epithelial lining, according to Inungu and Karl (2006) provides pleasure for the male partner at the cost of compromising the woman's health.

In order to curb the scourge of HIV/AIDS in Sub-Saharan Africa, Inungu and Karl (2006) proposed 6 important activities that needed to occur:

1. Education on HIV transmission modes and condom use, while encouraging abstinence for school children. Remaining faithful should be a norm in married adults.
2. Knowledge of one's HIV status
3. Training and developing health personnel to provide optimal HIV/AIDS management.
4. Caring for the vulnerable groups, including both the HIV infected and affected population.
5. Encouraging self efficacy by empowering women, and young girls.

6. Discouraging primitive and harmful rituals, rather opting for universal love and justice.

Although virginity testing is viewed by some as a 'harmful ritual' that violates and perpetuates discrimination against women (Commission on Gender Equality, 2007), Leclerc-Madlala (2001) maintains that some South Africans still see it as the only option in curbing the spread of HIV infections. The researcher notes that this suggestion speaks to the gendered nature of HIV, which supports the notion that women are responsible for the spread of HIV and therefore need to be 'controlled'.

## **2.4 HIV/AIDS IN SOUTH AFRICA**

Most of the statistics on the prevalence and incidence of HIV in South Africa are obtained from surveys conducted at the Department of Health's antenatal clinics. Having begun in 1990, these surveys have shown a gradual increase in the national HIV prevalence among pregnant women from 25.8% in 2001 to 29.4% in 2009, with provincial prevalence in 2008 ranging from 3.8% in Western Cape to 15.8% in Kwa-Zulu Natal (AVERT, 2010), where the current study is located. These surveys indicate that HIV challenges the government's public health system, particularly its resources. A limitation of these surveys is that women attending the antenatal clinics are not representative of women in the general population (Department of Health, 2010). However, pregnant women's prevalence rates provide a useful indicator of changes in prevalence over time.

The Minister of Health, Dr. Aaron Motsoaledi, in his response to the 2008 provincial prevalence survey, lamented that "the burden of HIV and AIDS is now weighing heavily on the shoulders of our country", quoting Kwa-Zulu Natal as the worst affected province (Gezubuso Projects, October 6, 2009). The call was for all stakeholders to come together to fight HIV and AIDS jointly. As earlier stated, women of child bearing age appear to be worst affected, with 32.7% prevalence, 17% higher than that of males in the same age group (see table 1 of the estimated HIV prevalence (%) among South Africans, by age and sex, 2008). More recent statistics were not available, despite the researcher searching for same.

The government of South Africa, in collaboration with various NGOs (Non-Governmental Organizations), and broadcast media has implemented various HIV awareness campaigns like the ABC (abstain, be faithful, condomise), Khomanani, Love-Life, etc. The researcher agrees with Avert (2011) that these programmes have had minimal impact in curtailing the epidemic as they do not represent multi-stakeholder engagement and are not well coordinated. The UNAIDS Executive Director, Michel Sidibe recommended that a strategic approach on HIV and AIDS education should be designed to suit the “local epidemiological reality” in order to reduce individual and social HIV vulnerability, and also to mitigate the impact of AIDS (UNAIDS, 2009:07).

Table 1

**Estimated HIV prevalence (%) among South Africans, by age and sex, 2008 (Avert, 2010)**

| Age   | Male prevalence % | Female Prevalence % |
|-------|-------------------|---------------------|
| 2-14  | 3.0               | 2.0                 |
| 15-19 | 2.5               | 6.7                 |
| 20-24 | 5.1               | 21.1                |
| 25-29 | 15.7              | 32.7                |
| 30-34 | 25.8              | 29.1                |
| 35-39 | 18.5              | 24.8                |
| 40-44 | 19.2              | 16.3                |
| 45-49 | 6.4               | 14.1                |
| 50-54 | 10.4              | 10.2                |
| 55-59 | 6.2               | 7.7                 |
| 60+   | 3.5               | 1.8                 |
| TOTAL | 7.9               | 13.6                |

Among females, HIV prevalence is highest in those between 25 and 29 years of age; among males, the peak is in the group aged 30-34 years. Both these age groups in men and women represent prime economic and reproductive years. These statistics warrant attention, as they imply socio-economic challenges that require multi-

stakeholder engagement. Such engagements embrace both the systems perspective and the social constructionism theory which underpin this study.

Goliber (2002) argues that South African political leaders have not been exemplary in the management of HIV/AIDS. In support, an article in the Times Live by Ray Hartley dated 16 December 2009, blames both Thabo Mbeki and Manto Tshabalala-Msimang for the 330 000 deaths that could have been prevented. At this time, the then President Thabo Mbeki was entertaining questions about whether HIV causes AIDS, the then Minister of Health, Manto Tshabalala-Msimang was encouraging HIV infected patients to eat beetroot and garlic in order to suppress the progression of the disease. Sadly, seropositive patients continued to die at an alarming rate and children were born infected with the virus (Van Rijn, 2006; Goliber, 2002; Cauvin, 2001). This led to 5000 scientists signing the so called 'Durban Declaration' in the year 2000, which declared that HIV did indeed cause AIDS. Protest actions from organizations like the TAC (Treatment Action Campaign) had major influence in the Pretoria High Court's ruling which compelled the state to provide ART to all HIV infected pregnant women (Van Rijn, 2006). Mark Heywood, TAC's then general secretary stated: "This judgment is significant, but it doesn't solve the problem of AIDS in South Africa by any means, all it does, I think, is, it gives hope and confidence to address other aspects of the problem of AIDS in South Africa" (cited in Cauvin, 2001: <http://www.nytimes.com/keyword/manto-tshabalala-msimang> ).

## **2.5 WOMEN AND HIV/AIDS**

For a variety of social and biological reasons, women seem to be more vulnerable to HIV infections than their male counterparts. It is therefore crucial to obtain a clearer understanding of biological and social factors contributing to women's vulnerability to the HIV infection.

### **2.5.1 Biological Vulnerability of Women**

The biological make up of women places them at an increased risk of HIV infection (Van Dyk, 2001). Women, as recipients of semen are easily infected during unsafe

sexual intercourse as their period of exposure to semen is longer than men's contact with vaginal fluids (Higgins et al., 2010).

STI's (Sexually Transmitted Infections) pose a major threat to the global public health system, especially in developing countries. The presence of untreated STI's, genital tract lesions, exacerbated by the women's larger mucosal surfaces allow for easy access of HIV into the blood stream (Higgins et al., 2010; Van Dyk, 2001). Contrary to men, women's sores may be undetectable or hard to see, making women feel less at risk of infection. This is corroborated by a Tanzanian study which aimed to compare the occurrence of STI's among HIV infected and uninfected pregnant mothers (Msuya et al., 2009). The study revealed that genital tract infections were more prevalent in HIV infected than in uninfected women, suggesting a strong correlation between STI's and HIV vulnerability. Chersich and Rees (2008) in their study of African women's knowledge of STI's, recognize the challenge in increasing the number of people, especially women to detect sexually transmitted infections and seek immediate health treatment. These researchers found that only less than 50% of heterosexual women in their sample knew at least one STI symptom. In addition HIV transmission is more likely to occur just before, during and after menstruation (Higgins et al., 2010; Van Dyk, 2001)

Younger women are particularly vulnerable because of their less developed genital tracts (Van Dyk, 2001). A national study by Pettifor et al. (2008) identified a higher HIV infection risk among South African young women aged between 15-24 years, who had only had one lifetime partner. This study suggests that despite reporting only having had one lifetime partner, these young women continued to be at a high HIV infection risk. The researcher believes this to be possible as they may not have been practicing safer sex and because it is possible that their partners may have been engaging in unprotected sex with other women. Although almost all new infections occur in women of childbearing age, young girls and post menopausal women are still affected (de Bruyn, 2006). Women over 50 are at an increased risk of infection as they often regard condoms as "contraception rather than a barrier against infections" (<http://www.thefreelibrary.com/How+could>). The need for educating women on negotiating safer sex practices is abundantly clear.

### **2.5.2 Socio-economic Position of Women**

The experiences of people living with HIV are to a certain extent universal, for both women and men (Higgins et al., 2010). However, evidence suggests that women's socio-economic dependency on their male counterparts places them at a distinct disadvantage (Dageid & Duckert, 2008; Picasso, 2008; Murphy & Greenwell, 2006; Drimie, 2002).

Socio-economic position (SEP) according to Arnold et al. (2011) refers to the hierarchical stratification in respect of the individual's level of education, income and employment status as defined by society. Like all other communicable diseases, HIV/AIDS is bi-directionally linked to poverty (Colvin et al., 2005; Drimie, 2002). This bi-directional link implies that although poverty exacerbates the spread of HIV/AIDS, the disease itself also impoverishes affected households. Research suggests that women's increased infection risk is due to poverty, unemployment, and financial reliance on their male sexual partners (Drimie, 2002).

For South African women, Booysen and Summerton (2002) identified poverty as one of the factors contributing towards lack of access to HIV/AIDS education. Similarly, failure to negotiate safer sex with partners is attributed to gendered power relations. In Atlanta, USA, impoverished women resorted to drug abuse, transactional sex, and selling of property as they could not cope with being poverty stricken (Stratford et al., 2008). These authors unanimously agree that poverty propels women to engage in risky behaviour, thus increasing their vulnerability to HIV infection.

As regards education, Pettifor et al. (2008) also found in their study that women who had not matriculated were at an even higher risk of HIV infection when compared to those that had matriculated. To reduce the risk of HIV infection, these researchers identified education (MDG 2) as a priority for young women. Furthermore, Michele Sidibe of UNAIDS contends that although HIV/AIDS education is school-based, it should also recognize that those at risk have often never attended school or have dropped out of school (UNAIDS, 2009).

In another study by Burgoyne and Drummond (2008), African men were found to be more knowledgeable about HIV/AIDS issues than their female counterparts. Women with little or no formal education and those residing in the rural areas were worst affected. Burgoyne and Drummond (2008) proposed the tailoring of appropriate HIV awareness programmes for disadvantaged women.

Although Arnold et al. (2011), in their study, could not identify a consistent correlation between SEP and HIV risk increasing behavior, they did not dispute that economic interventions may be pivotal in the reduction HIV infection risk among impoverished women.

Critiques have also argued that South Africa, Botswana, and Zimbabwe, although worst affected by HIV/AIDS, are considered to be economically better off than other countries in the African region (Canning, 2006; Poku, 2002; Smith, 2002; Whiteside, 2002). These authors contend that poverty does not predict the risk of HIV infection. This suggests that there is no consensus on the relationship between poverty and HIV infection. The researcher believes that a relationship between poverty and HIV does exist. However, it is the exact correlative statistics that still need to be determined.

Eligibility for a disability grant in South Africa requires one to be mentally and/or physically disabled, and be declared unfit to commence or resume employment (Department of Social Development, 2011). Moreover, laboratory CD4 cell count results must be below 50, and/or a major opportunistic infection must be diagnosed. Hardy and Richter (2006) and Leclerc-Madlala (2006) argue that a disability grant is often the only household income for poor families, which are mostly headed by women. These authors refer to the dilemma some HIV infected patients confront when their disability grants lapse. Some opt to commence ART (reducing the viral load, and increasing the CD4 cell count) and lose the grant, while others might delay ART initiation in order to have the grant renewed. This provides insight into the extreme, often life threatening poverty-avoidance approaches that poor HIV infected patients adopt. Leclerc-Madlala (2006:252) suggests that policy makers should comprehend the bi-representation of AIDS against the backdrop of poverty, as “a threat and a means for financial survival”.

The Minister for the Department of Social Development Ms Bathabile Dlamini in her address at the National Women's Conference held in Boksburg, Gauteng, on the 2<sup>nd</sup> of August 2011, mentioned that her department provided assistance to over 15 million vulnerable individuals. However, she conceded that the feminization of poverty apparent in the over-influx of women in the informal sector and underpaying jobs remained a challenge for gender mainstreaming, and proposed community based approaches to reduce poverty.

'Wola Nani', based in Cape Town is both a skills development and income generating project which helps unemployed HIV infected women from South Africa. A brief narration of the two group members proves the impact that such projects have on disenfranchised HIV infected women whose lives are beset by poverty:

*"I like to learn because I want to know everything and I can work*

*I can send my children to school and when I'm very sick, I can use the money to go to a private doctor"*

*"Wola Nani helped a lot as I had no money to buy food. Making beaded ribbons and bangles means I can now buy food, vitamins and send my 2 children to school"* (voices of the women from the Wola Nani Support Group, (<http://www.wolanani.co.za/skills.htm>).

The above narratives indicate some of the survival strategies adopted by HIV infected women. Such strategies are further discussed in this chapter under coping and survival strategies of HIV infected women.

A more macro systemic strategy is evident in Rwanda's project, aiming at improving the well being of all Rwandans as stipulated in their Vision 2020 plan. In collaboration with UNAIDS and UNDP, the Rwandan government pledged to integrate HIV into the economic development and poverty reduction strategy (EDPRS) for the period 2008-2012 (UNDP, 2008). The reduction of poverty-induced

HIV infection and creation of income generating projects for disenfranchised women form part of the EDPRS, a project which could be adopted by South Africa.

On 8 March 2010, a panel of experts on 'Women's economic empowerment in the context of the global economic and financial crisis', proposed for inclusion of women in decisions made about allocation of economic resources to various populations (Commission on the Status of Women Conference, 2010). Moreover, various measures to ensure that women are not inordinately affected by the financial crisis had to be put in place. The above recommendations are in line with Vogli and Bibeck's (2005) view that adjusting economic policies at a macro level is paramount for the modification of mezzo-economic conditions, which in turn get filtered down to the micro level in order to alleviate poverty in households.

Balyamujura et al. as cited by Drimie (2002:07) argue that poverty is embedded in societal structures and gives rise to gender stereotypes, which in turn groom gender-based violence. Various scholars define gender-based violence in many different ways, but the definition proposed by the 1995 Beijing Platform for Action (as cited in Hale and Vazquez, 2011) is by far the most comprehensive:

*Violence against women includes: violation of the rights of women in situations of armed conflict, including systematic rape, sexual slavery and forced pregnancy; forced sterilization, forced abortion, coerced or forced use of contraceptives; prenatal sex selection and female infanticide. (p.6)*

Like poverty, a correlation has been established between forced sex and the risk of HIV infection and re-infection respectively (WHO, 2005). Receipt of a seropositive HIV status for women does not put a stop to domestic violence, resulting in HIV infection and re-infection as noted in the study by Kasiram et al. (2011). However, HIV infected women remain silent about this and all other forms of injustices perpetrated against them such as shunning, maltreatment by service providers, food deprivation, blame for infecting their partners etc. The story of Promise Mthembu (1998) depicts the challenges of HIV infected women in South Africa. Mthembu narrates how her husband who had infected her with the virus continued to physically abuse her on a daily basis. This story highlights the painful experiences

of HIV infected women, and the need for incorporation of domestic violence awareness into HIV programmes for women.

In a study of unemployed rural women in India, women saw the financial implications of leaving an abusive relationship as outweighing the risk of HIV infection (Nyamathi et al., 2010). Women in these situations find it difficult to negotiate safer sexual practices as they are mostly subjected to 'survival sex'. Such findings clearly show that poverty compels women to stay in relationships even if the situation is life threatening.

According to Jewkes and Morrell (2010), a distinction exists between sex (as being biologically rooted) and gender (as being socially rooted). In their paper, they draw on Raewyn Connell's masculinity that is hegemonic in notion, and argue that male violent, coercive sexual practices are socio-culturally constructed. In addition, the two authors argue that it is the controlling nature of men that inhibits women from initiating condom use, thus increasing their vulnerability to HIV infection and re-infection. Conversely, Peacock et al. (2009) of Sonke Gender Justice warn that focusing so much on low income men's perpetuation of violence and inability to display emotions may contribute to the normalization of such attributes by society. The Sonke Gender Justice lobbies for the avoidance of general gender stereotypes by:

- Recognizing that men's human rights have to be taken into consideration and also how inaccessible health care is for them.
- Utilizing policy approaches to scale up on gender transformation with boys and men (p.8)

The researcher believes that these suggestions have to occur simultaneously with women's empowerment in order to have the desired effect. In order to curb the spread of HIV infection, transformation of gender idealization, as opposed to focusing on sexual behaviour of individuals has to take place (Jewkes & Morrell, 2010; Peacock et al., 2009).

Hunter (2005) presents a well documented historical perspective of masculinity in Kwa-Zulu Natal which traces back to how men got to assume the title of *'isoka'* (a man with several girlfriends) and women, *'isifebe'* (promiscuous, loose woman). It is significant to note that the man who is a *'soka'* is celebrated and envied by society (even by women) while *'isifebe'* is, if 'caught' grossly shunned, and often sent back to her maiden home in order to return with *'inhlawulo'* (a fine, in the form of a cow) as a sign of repentance. Mulligan (2006:233) also argues that "it is not uncommon for a 'double-standard morality' to exist, whereby certain sexual activities are acceptable for men but denied for women". The researcher believes that such blatant gender based sexual biases might only drive women to keep their sexual behaviours secret and increase their risk of contracting HIV.

In a study conducted in Kenya and Zambia, young girls, who were married were found to be at increased risks of HIV infection when compared to single girls, who also engaged in frequent sexual activities (Clark, 2005). The findings of this study suggest that early marriage exposes women to HIV infection due to their decrease in condom usage, coupled with their inability to say no to sex within a marriage institution. This finding finds support in Kasiram et al.'s (2011) study where women were found to be re-infected because their partners had multiple partners, and continued to re-infect them. Interestingly, a study by Bongaarts (2007) also revealed that late marriage positioned women at an above average risk of HIV infection. This vulnerability was attributed to women's prolonged engagement in pre-marital sex. In reconciling the findings of the above studies, it is clear that early sexual debut, and not being able to negotiate safer sex, place women at an increased risk of HIV infection, even within a marriage institution. Thus contextually relevant approaches are needed in order to address the gendered nature of HIV infection.

The Recognition of Customary Act of 1998 extends the government's recognition and regulation of marriage to both monogamous and polygamous customary unions (RSA Government Gazette, 1998). While its supporters view this act as restoring their cultural heritage, which had been distorted by the apartheid regime, those against it, Christians, human rights' and feminist activists see it as disempowering to African women (Thabane, 2010). It is possible that without changing gender based

sexual biases, such regulations may pose greater risks for increased HIV infections among women in particular.

The South African National Strategic Plan for 2007 – 2011 maintains that in order to reduce women's vulnerability to HIV infection, the following has to occur:

- Acceleration of strategies that aim to reduce poverty, and strengthening of poverty mitigating interventions (safety nets).
- Acceleration of women empowerment programmes, and offering human rights education to both men and women.
- Creation of an enabling and confidential HCT (HIV Counselling and Testing) environment.
- Creation of supportive efforts to retain the family structure, and also promote community social cohesion (HIV/AIDS and STI Strategic Plan for South Africa, 2007:13)

Although the above plan provides hope for HIV management, it is not uncommon for South Africa to formulate policies which look attractive on paper but rarely reach the implementation phase.

### **2.5.3 Women's Psychosocial Experiences**

According to Sachdeva and Wanchu (2006), HIV infection is higher among women with low self-esteem. Unlike men, women suffer more with post-traumatic stress disorder (Tolin & Foa, 2006; Seedat et al., 2005; Yehuda, 2002). The above authors argue that psychological factors for women, affect their decision making abilities. The disruption in will-power of women is therefore most likely to increase their HIV infection risk because of inability to negotiate safer sexual practices.

A qualitative study in Limpopo found involvement of the Makotse women's club in vegetable gardens as providing not only nutritional and financial gains, but also a 'sense of meaning' (Lekganyane, 2008). The findings of Lekganyane's study are consistent with those of a study by Kasiram et al. (2011) on survival strategies of

HIV positive women. In Kasiram et al.'s study, an HIV positive woman who had witnessed the murder of her only son and subsequent rape of her daughter, reported finding solace and nutrition from her vegetable garden.

A variety of social issues have an effect on women's general well being after receipt of an HIV positive diagnosis. These include disclosure of one's status, stigma, discrimination, social isolation, and loss of identity.

Disclosure is an important, yet complicated process which involves deciding how to disclose, to whom, and under what circumstances to disclose (Makin et al., 2008; Medley et al., 2004). HIV infected individuals often have difficulty disclosing their status to others, or may even end up not informing anyone of their diagnoses (Makin et al., 2008) as the disclosure outcome can be either negative or positive. In their study of HIV infected women attending a Pretoria antenatal clinic, Makin et al. (2008) found that the decision by HIV diagnosed women to disclose their status to spouses depended on the couple's current and past relationship status. Women who had experienced domestic violence were less likely to disclose to their spouses, with Kasiram et al. (2011), finding that some women neither notified their spouses that they had tested, nor that they were on treatment. Women in depressive and abusive environments find it difficult to adhere to prescribed medication (Whetten et al., 2008). The researcher notes that women abuse and the continuous fears of being abused impact enormously on the experiences of HIV infected women.

Women who are economically dependent on their male counterparts are less likely to disclose their HIV positive status for fear of enduring financial sanctions and destabilizing their relationships (Makin et al., 2008; Ironson & Hayward, 2008; Lurie et al., 2003; Serovich et al., 1998). The above findings (as reviewed earlier under socio-economic vulnerabilities) are disheartening as they point to the vice-like grip that AIDS holds on HIV infected women, in being unable to change their situation or their lives.

HIV positive women disclose their diagnoses to their respective families for various reasons. For every infected person, there is a family that is affected. Family, as perceived by Bor and Elford (1998) is the primary provider of physical and socio-

economic support for its HIV infected members. Earlier HIV studies (Serovich et al., 1998) found that some families reacted with shock while some showed relief after disclosure of HIV status. In one instance, after disclosure, the mother of an HIV infected woman remarked: "Is this why you lost weight, you should have told me sooner" (Serovich et al., 1998:4). This is indicative of the family's supportive role in the experiences of HIV infected individuals. In the same study, perceived social support was found to encourage HIV infected individuals to disclose their HIV status. This study highlights the mezzo level's possible impact on the HIV infected women's adjustment to the disease.

In the Ostrom et al. (2006) study, mothers disclosed their status to their children in order to make them aware of what might occur in the future, to ensure that they did not hear about it from anyone else, and to gain social and emotional support. In fact in Kasiram et al.'s (2011) study, it was noted that children helped the women-mothers to follow the strict ARV treatment regime. Armistead et al. (1999) argue that disclosing to children is rather difficult especially when the mother is unsure of the most suitable age for disclosure. In two studies, Murphy et al. (2006) and Murphy et al. (2001) found that the mother's non-disclosure of her HIV status was attributed to the immaturity of children, fear of burdening them emotionally, and also fear of seeing them worried about their mother's death. The researcher notes that these studies suggest that HIV positive women may remain silent for fear of their children's reactions and also for protecting them from learning of their illness until as late as possible.

Disclosure of an HIV diagnosis is also largely influenced by the individual's contextual socio-cultural belief (Mkhize, 2009). Spiritual beliefs are linked to the individual's adherence to treatment. Serovich et al. (1998), in their study saw women being prayed for by those to whom they had disclosed their status. Interestingly, spirituality also played a role in further stigmatizing the infected individual. One reaction was "Get right with God", meaning that God had turned against the infected person. Another reaction was: "Why did God do this to us?" meaning that HIV may be viewed as punishment from God (Serovich et al., 1998:18).

Findings by Serovich et al. (1998) concur with those of Lekganyane et al. (2011:6), where one HIV infected woman opted to disclose only her breast cancer to her church group (“...they do not know anything about my HIV positive status but they are very supportive to me”). The above suggests that cancer is perceived as less stigmatizing when compared to HIV/AIDS. In the researcher’s professional experience, clients have no problem disclosing their TB status, inferring no further underlying illnesses, perhaps because this is more acceptable than having AIDS.

In keeping with the above findings, Ashforth (2002), in his study conducted in Soweto, argues that for Black families, traditional beliefs have an influence on the HIV infected individual’s reasons for disclosure or non-disclosure. The presence of HIV related symptoms such as weight loss, skin rashes and respiratory tract infections may be associated with “*idliso*” (witchcraft in the form of black poison) symptoms. This form of witchcraft is assumed to be inflicted by the husband’s mistress, a jealous neighbour, or even the evil mother in law. As part of the healing process, women are forced by traditional healers to remain silent, as talking openly may show the ‘*enemy*’ that the ‘*muthi*’ (potion) is working. Without undermining the effectiveness of traditional healers, the researcher believes that such acts as those asserted by Ashforth could delay the HIV infected woman’s access to appropriate medical interventions, and cause further HIV transmission as the status remains unknown.

In the article: “Traditional healers on board to fight HIV/AIDS”, the Human Sciences Research Council explains the importance of collaboration of traditional healers and medical personnel in the fight against HIV/AIDS in Kwa-Zulu Natal. The council commends the development of a proper ‘referral system’, and views this as essential in monitoring and evaluating the “effectiveness of interventions by traditional healers” (HSRC, 2006: [http://www.hsrc.ac.za/HSRC\\_Review\\_Article-26.phtml](http://www.hsrc.ac.za/HSRC_Review_Article-26.phtml).)

Given the cultural diversity of South African communities, the researcher aligns herself with Mkhize’s (2009:26) remarks that HIV infected individuals would benefit “if the traditional belief system of an individual (is) better assessed and incorporated in the mode of treatment and or intervention”.

Much has been documented on the importance of disclosure and also the influences of disclosure and non-disclosure respectively (Mkhize, 2009; Ostrom et al., 2006, & Serovich, 1998). For many WLWHA (Women Living With HIV/AIDS), there seem to be less motivation for disclosure of status, and more fear around possible negative feedback. Women with lower self-efficacy encounter challenges in disclosing their HIV positive status (Simbayi et al., 2007). The secrecy about one's status to sexual partners may place further risk to women for HIV infection, re-infections and other STI's. By not disclosing their status, women may be trying to avoid stigma, discrimination, social isolation, and losing their sense of identity, but at what cost?

HIV as a stigma continues to prevent most HIV positive women from disclosing their status. In their study, Anderson and Doyal (2004) found that HIV positive women did not disclose to their partners because of fear of rejection, or they had witnessed others being physically and verbally abused by their spouses after disclosure. Similarly Long (2009) found in a study conducted in a Johannesburg clinic that 57% of his sample of HIV positive mothers reported rejection after disclosure HIV positive status, with 26% not informing anyone of their status. Long (2009:331) concluded that responses like: "I can't tell," and "I don't know what to say", suggested that HIV infected women saw their partners as violent and dangerous, and therefore had to take the responsibility to manage their virus (as well as the men's violence) on their own. This is a further stress in HIV positive women's lives.

Goffman in Lekganyane and du Plessis (2011:1) defines stigma as a "powerful and discrediting social label that radically changes the way individuals view themselves and are viewed by others". These authors maintain that HIV related stigma disrupts the care and management of the infection, thus facilitating its faster progression to AIDS. Stigma is also found in health care institutions and practiced by health professionals who label HIV infected patients as infectious beings (Andrewin & Chien, 2008). These authors recommend an investigation of the effectiveness of HIV/AIDS policies at a macro level to curb this tendency.

One of the unfortunate consequences of HIV/AIDS is the vertical infection of babies also known as MTCT (Mother-To-Child-Transmission). Stevens (2008) argues that while more resources are allocated to 'saving unborn babies' HIV positive mothers

continue to be stigmatized. In the study of HIV infected pregnant women, Stevens (2008) found that health care professionals referred to pregnant women in the PMTCT (Prevention of Mother to Child Transmission) as 'suicide bombers waiting to explode'. Such stigma could deter pregnant HIV positive women from seeking medical assistance, thus increasing chances of MTCT of HIV. The development of appropriate treatment and counselling guidelines for women is therefore necessary.

The Department of Health's (2010) Guidelines state that PMTCT entails three phases which have clear goals. Firstly, the antenatal care involves the identification of HIV infected women and ensuring that they are enrolled early in the programme. Their enrolment ensures provision of AZT from week fourteen of pregnancy or commencement of ART as soon as possible at the discretion of the medical practitioner. The second phase is the labour and delivery phase which entails reducing maternal nevirapine resistance, and initiating newborn babies with prophylactic treatment at birth. The final phase is the mother and infant post-natal follow-up. This phase is as important as the earlier phases as it incorporates identification of HIV exposed infants, reduction of HIV related deaths in victims of MTCT (Mother to Child Transmission) by initiating ART early, and providing a choice between breastfeeding and formula feeding.

Although PMTCT in South Africa has resulted in more babies being born HIV negative (UNAIDS, 2010), Andrewin and Chien (2008) argue that HIV infected women's concerns have been poorly addressed. A study was conducted by Doherty et al. (2006) in three sites (Paarl in the Western Cape, Rietvlei in the rural Eastern Cape, and Umlazi in Kwa-Zulu Natal). The aim of the study was to explore the experiences of infant feeding against the backdrop of the AIDS pandemic. HIV positive women who opted to exclusively formula feed their babies often encountered problems in accessing the formula because of inconsistent policies or it being out of stock. Some women felt compelled to introduce solids early and also breastfed for fear of disclosing their status and experiencing stigma. Participants in Doherty's (2006:92) study reported as follows:

*“Here at home they were complaining but I told them I’m stopping. They asked why I am stopping to give the baby the breast so early and I told them that it was not enough to make my baby full.”*

*“...my mother asked me why I did not breastfeed. I told her that they said I mustn’t breastfeed because they said I have problems in my breast.”*

*“...neighbours asked why I am not breastfeeding the baby and I then told them that the baby did not want to breastfeed.”*

The afore-mentioned experiences illustrate the various lies that women often have to tell in order to escape being stigmatized. Interestingly, Doherty et al.’s study found that stigma was experienced in all three diverse settings irrespective of their socio-cultural contexts.

At Chris Hani Baragwanath Hospital, in Johannesburg, HIV positive women chose to isolate themselves from others because of fear of rejection (Lekganyane & du Plessis, 2011). Involvement in support groups for HIV infected women provides a sense of identity and acceptance (Lekganyane & du Plessis, 2011; Visser et al., 2005). Moreover, being with other women may be empowering as each woman learns about coping strategies used by other HIV infected women in the group.

From these findings, it is clearly necessary that open communication occurs about mother to child transmission and that de-stigmatization happens urgently. This will mean micro, mezzo and macro-systemic interventions coming together jointly to address the range of problems discussed herein.

## **2.6 HIV Positive Women’s Coping and Survival Strategies**

Literature on coping with HIV/AIDS is limited to studies on children’s coping after parent’s HIV/AIDS disclosure or demise (Ebersohn & Eloff, 2003; Drimie, 2002) while other studies, although limited, explore how couples cope with HIV sero-discordance (Dano, 2007; Beckerman, 2002). Findings by Dano (2007) suggested that HIV negative women were more likely to accept and support their spouses after

disclosure of the discordant status, while the negative males used avoidance as a coping strategy, illustrating women's resilience and innate nurturing qualities. This section of the literature review is dedicated to exploring the coping and survival strategies of HIV infected women.

Coping strategies, according to WHO (1998:3) are "remedial actions undertaken by people whose survival and livelihood are compromised or threatened". HIV infection follows the same trajectories as other chronic illnesses. HIV infected individuals experience confusion, fear, avoidance, grief, and difficulty in handling reactions from significant others. In order to cope with such adverse reactions, those who are ill should assume control through problem solving, planning and utilizing support networks ([http://www.cc.nih.gov/cc/patient\\_education/pepubs/copechron.pdf](http://www.cc.nih.gov/cc/patient_education/pepubs/copechron.pdf)). In addition, empowerment of self through initiatives to learn as much as possible about the disease is critical in order that correct action follows (Kasiram et al., 2011).

Levy and Storeng (2007) conducted a qualitative study with 12 newly infected HIV positive women from Khayelitsha in Cape Town. The study focused on individual meanings of 'living positively' and concluded that the dictum of 'positive living' provides women with alternative narratives in spite of an HIV positive status. However, Levy and Storeng's study did not take into account the socio-economic factors which could have impacted positively or negatively on such a dictum. The current study is unique in that it not only looked at the coping strategies of HIV positive women, but also their challenging and positive experiences in relation to living with a lifelong illness in a KZN setting.

In exploring the transitioning of recently released prisoners from prison to the community, Copenhaver et al. (2009) saw social support networks like PLUS (Positive Living Using Safety) as crucial in the prisoner's adaptation to ARV adherence outside of prison. Also in a South African study by Visser et al. (2005), involvement in a structured support group proved beneficial for HIV positive women's coping with their status. Both studies found that group members regained their sense of identity, felt less stigmatized and more 'normal' when included in group work. Although participation in a support group is beneficial, various sources of literature still view family involvement as pivotal in facilitating coping with an HIV

infection. Kasiram et al. (2011) also found that individual time afforded women the opportunity to feel important and provided time and space to interrogate personal issues and plan for the future.

The use of art as a survival strategy is promoted by Kirkwood (2008). She uses art to represent female and male condoms and to create awareness on the 'survival' impact of using condoms. This helps making use of these condoms easier because of their artistic appeal. Furthermore, she draws the attention of the public to the female condom, which is not as popular as the male one. Kirkwood encourages HIV positive women to become involved in such activities as well.



Kirkwood installing Survival at the Workshop Shopping Centre, in Durban, South Africa, 2004 (Kirkwood, 2008:59).

Fiona Kirkwood, and HIV positive women's 'Survival Installation' epitomizes the role of citizen therapists as discussed by Rojano (2005). Kasiram et al. (2011:13) also found that HIV positive women assisting in community programmes like soup kitchens, and motivation of others, helped them adjust to their HIV positive

diagnoses. In fact one woman in the study reported that “you grow when you give” depicting the important role of looking outside of yourself rather than being obsessed about the disease.

Stories of coping for South African HIV positive women were very limited. This further reinforced the need to conduct studies on women’s survival strategies.

## **2.7 Conclusion**

In conclusion, the literature reviewed on women living with HIV/AIDS has unveiled the following:

- Women, both locally and globally are mostly at risk of HIV infection as compared to their male counterparts. In Sub-Saharan Africa, young girls (18–24 years) are eight times more likely than men (of the same age group) to be HIV positive (UNAIDS, 2010).
- The biological make up of women places them at an increased risk of HIV infection (Van Dyk, 2001). Women’s prolonged exposure to semen makes them even more vulnerable to HIV and other STI infections.
- A bi-directional link was found between HIV/AIDS and poverty (Drimie, 2002), making poverty both a cause and product of HIV/AIDS.
- Education was found by Pettifor et al. (2008) to have an impact on women’s risk of HIV infection.
- Women’s powerlessness in safer sex negotiation makes them even more vulnerable to being infected with the virus (Kasiram et al., 2011; Bongaart, 2007; Clark, 2005).

- Culture, spirituality, and traditional practices construct meaning of an HIV diagnosis (Ashforth, 2002; Serovich et al., 1998). A historical perspective on the gendered perspective of women was found in Hunter (2005).
- Psychosocial reactions to HIV disclosure were reviewed together with the reasons for disclosure and non-disclosure. The findings were mostly focused on how HIV positive women experience stigma, social isolation and discrimination.
- Lastly, HIV infected women's coping and survival strategies were explored. The researcher also noted the limited number of studies available on HIV positive women's survival strategies.

The literature reviewed offered recommendations for reducing women's vulnerability to HIV/AIDS (Peacock et al., 2009; SA National Strategic Plan, 2007). It also highlighted a need for interventions that are directed to HIV infected women's needs. The researcher's current study explores the narratives of HIV positive women, their coping and survival strategies, and might further influence policy formulation for women specific programmes. The following chapter discusses the research methodology.

## CHAPTER THREE

### RESEARCH METHODOLOGY

#### 3.1 INTRODUCTION

The researcher dedicates this chapter to a discussion on the research method utilized in this study. This chapter provides an outline of the research method, research design, sampling and sampling procedure, data collection, and data analysis techniques implemented during the study. Trustworthiness, validity and reliability of the study are also discussed briefly. The researcher concludes this chapter with a discussion of ethical issues and limitations of the study.

#### 3.2 RESEARCH METHOD

In order to adequately uncover the experiences and challenges of HIV positive women, the researcher employed a qualitative approach. Contrary to quantitative methods which rely on numerical measurements, qualitative methods are used by researchers to identify whether something is present or absent and to further express it in words (Babbie & Mouton, 2001). Adoption of a qualitative approach permitted individuals to share their experiences in an unrestricted manner. The flexibility of this method assisted the researcher to probe participants further in order to obtain rich, in-depth data. Social constructionists argue that interpretation of events by individuals contributes enormously to the construction of reality (Sparks & Smith, 2008; Rohleder & Gibson, 2006), which further highlights the importance of having used qualitative research as endorsed by constructionist theory, one of the theory frames used in this study.

A qualitative approach, according to Greef (2002) allows participants to 'tell' stories about their past and present experiences, not forgetting their future aspirations in a dignified manner. This research approach enabled the researcher, who is a social worker to elicit the lived experiences of HIV positive women, while at the same time restoring their dignity by providing debriefing and referral for follow-up services.

### **3.3 RESEARCH DESIGN**

The task of design selection is a pertinent aspect of the research process as it entails strategic planning based on what the research wishes to find (Babbie & Mouton, 2001). Within a qualitative paradigm, the research employed a non-positivistic exploratory research design. This research design was appropriate for this study as it employs an approach that is open-ended, flexible and inductive (Terre Blanche et al., 2006). In support, Rohleder and Gibson (2006) maintain that such an approach places value in detailed and contextual data, which was the focus of this study.

The researcher felt comfortable with this design as it integrated with the qualitative approach. Terre Blanche et al. (2006:44) argue that an exploratory study is utilized “to make preliminary investigations into relatively unknown areas of research”. The researcher, in the latter chapter discovered that HIV/AIDS has been widely explored in the South African context (Higgins, 2010; Chersich & Rees, 2008; & Ashforth, 2002), with limited studies focusing on the lived experiences of HIV positive women. This study not only aimed to uncover the unique experiences of these women, but also explored their coping strategies after an HIV diagnosis, as an early preliminary study using the exploratory design. It is hoped that later studies could use different designs to examine the topic more in-depth.

Terre Blanche et al. (2006) also claim that there is no clear distinction between research studies that explore, describe, or explain phenomena as all qualitative studies allow for some flexibility, as experienced by the researcher during this study. Borrowing some descriptive and explanatory design traits, the researcher was able to describe and explain the challenges of HIV positive women in this study.

### **3.4 SAMPLING**

Sampling can be best understood as a detailed plan on how the researcher selects elements to be studied (Terre Blanche et al., 2006). For the purposes of this study, purposive and availability sampling were utilized. Contrary to random sampling, Terre Blanche et al. (2006) contend that availability sampling is non-random and

utilizes a small sample to elicit thick and rich data. This implies that although the sample of HIV positive women in this study was not representative of the general population of women with HIV/AIDS, the findings may be used to understand the extent of the problem/topic in an in-depth manner.

The criteria for selecting the sample were as follows:

- From the researcher's work context, the researcher selected 15 women (over 18 years of age) living with HIV/AIDS. The reasons for choosing participants 18 years and above were firstly that women in these age groups are regarded as adults and securing their consent was less difficult.
- Secondly, the participants were expected to have known about their HIV positive diagnoses for at least 3 years and above, in order to explore the medium to long-term implications of living with an HIV diagnosis together with the coping mechanisms they had adopted.

### **Sampling Process**

The study was conducted at Inanda Community Health Centre where the researcher was working as a social worker. This Health Institution has an HIV/AIDS unit. The researcher informed patients (in the waiting area) of her research aims and objectives. Due to the sensitivity of this pandemic, the researcher relied on the willingness of participants to consent to sharing their narratives. In addition, a session with the multidisciplinary team was held in order to provide them (team) with information on the research plan and to explain their role in the referral of HIV positive women. This task was not difficult as the researcher had pre-existing relationships with the multidisciplinary team (MDT) members. Out of the sample of 15 women, 7 were referred by the MDT and the rest were sampled by the researcher.

The sample was thus derived from referrals by MDT and patients (who satisfied the sampling criteria) that were available and willing to participate in the study. Thus

sampling procedures were purposive (to satisfy specific sampling criteria outlined earlier) and available.

Upon referral, preliminary interviews were conducted with potential participants in order to thoroughly explain the research process prior to obtaining their consent and to offer them the option to opt out.

The final sample included in this study had the following characteristics:

- The women were between the ages 19 – 55.
- All women were Black, Zulu speaking and attended the same health care centre.
- 14 women had children.
- 4 women were married.
- 6 women were employed.
- 3 women had completed Grade 12.

At the time of the research, the researcher was in the employ of the designated health care setting, and permission to conduct the study was sought (Appendix E). Terre Blanche et al. (2006:73) view permission seeking from “gatekeepers of particular communities”, in this case the community health centre, as essential but not substitutive of individual’s informed consent. In fulfilling the ethical obligation, the researcher obtained permission from both the gatekeepers and the individuals concerned.

Permission to conduct the study was also granted by the University under whose auspices the study was conducted. (Appendix D)

### **3.5 DATA COLLECTION**

#### **3.5.1 Method of Data Collection**

In-depth qualitative data was collected from HIV positive women using semi-structured individual interviews. The use of this interview style, according to Babbie and Mouton (2001) and Terre Blanche et al. (2006) allows the researcher to obtain raw data in an unrestricted manner. Moreover, these authors agree that for access to such privileged information, a trusting relationship must be built between the researcher and the participants. The researcher utilized her social work skills to initiate a trusting relationship with the HIV positive women, which enabled them (HIV positive women) to openly discuss their experiences. Greeff (2002) argues that although semi-structured interviews allow for flexibility between the researcher and the participant, the questions utilized should still follow a logical sequence. In order to adequately explore the lived experiences of HIV positive women, the researcher drew up a set of themes with key issues that had to be explored. These issues or themes assisted in guiding the interview.

Because of the multiple problems associated with being HIV positive, it was important not to get completely side-tracked but stick to the research agenda. The use of a research guide therefore proved useful.

The following outlines the steps followed during the research inquiry.

#### **3.5.2 Actual Data collection**

Interviews were conducted at the place most convenient to each research participant. Six interviews were held at the participants' homes, 7 were held at the community health centre, while two were held at the researcher's home. Each participant was interviewed individually so as to ensure confidentiality. Moreover, a consent form had to be signed prior to involvement in the study (see Appendix B).

In order to obtain a clear account of the HIV positive women's narratives, the sessions were audio-recorded with the permission of each participant. However,

two participants refused to be recorded, and this was respected. Babbie and Mouton (2001) claim that the use of a tape-recorder allows the researcher to 'tune in', and be less distracted during the interviewing process. The researcher agrees with these authors as she was able to relax and focus on in-depth questioning when she used the tape recorder. In the case of the two interviewees that could not be recorded, the researcher had to write and transcribe as much of the participant's responses as quickly as possible to ensure reliability, as memory loss could have potentially compromised research data.

Sessions were conducted in IsiZulu, as Inanda residents are Zulu speaking. The interviews lasted for one to one and a half hours. Participants were assured of anonymity and confidentiality. Debriefing was offered to all participants who required it, and some participants were referred for ongoing Social Work services.

### **3.6 DATA ANALYSIS**

Corbin and Strauss (2008) and Mouton (1996) maintain that the process of data analysis entails reducing collected or available data into manageable sizes while identifying pertinent themes and patterns. Throughout the data collection process, the researcher identified consistent themes for women with HIV/AIDS. In addition, Terre Blanche et al. (2006) ascertain that qualitative data analysis incorporates 5 steps namely: Familiarization and immersion, inducing themes, coding, elaboration, and interpretation, and checking. The researcher transcribed verbatim all audio-recorded interviews before employing the data analysis procedures suggested by Terre Blanche et al. (2006).

#### **3.6.1 Familiarization and Immersion**

Terre Blanche et al. (2006) recognize that after completion of data collection, the research analysis should not be delayed. Immediately after collecting the data on the experiences of HIV positive women, the researcher transcribed and translated data with the help of a good Zulu speaker. This process took more time than anticipated as the researcher had to listen to each interview several times to transcribe it properly.

### **3.6.2 Inducing themes**

Termed a “bottom-up approach”, inducing themes involves moving from general to specific themes. The researcher used the narrative data of women’s HIV/AIDS experiences in order to formulate main themes and sub-themes. Moreover, the researcher conceptualized data with special reference to the literature reviewed in chapter two, identifying concurrency, contradictory findings etc. The researcher was fascinated by this process as it allowed for delving into language, as used by the HIV positive women in order to code or categorize themes as supported by the social constructionist perspective. The larger themes also cohered with the interview schedule and objectives of the study.

### **3.6.3 Elaboration**

This process enabled the researcher to bring the stories of HIV positive women that were far away from each other closer. This process was done repeatedly with the intention of capturing finer details that were missed during the coding process.

### **3.6.4 Interpretation and Checking**

During this final process of data analysis, the researcher identified the points in the interpretation that required fixing. This step allowed the researcher to personally reflect on her role as both the collector and interpreter of data on the experiences of HIV positive women (Terre Blanche et al., 2006: 324-326).

This process was important to complete as it was necessary to ensure that the researcher-social worker role did not compromise results.

## **3.7 VALIDITY, RELIABILITY AND TRUSTWORTHINESS**

Patton (2001) outlines some key questions for evaluating the validity and reliability of qualitative studies such as the one on the narrative experiences of HIV positive women. According to Patton (2001), researchers should interrogate the measures

taken to ensure trustworthiness, accurateness, and validity of the research findings. Moreover, the researcher's experience and level of education should be questioned together with its relevance to the study. These questions are essential in the assessment of reliability of qualitative research studies, and the researcher focused on them during the study.

The researcher ensured that all data collection methods were documented in a reliable manner. Essentially, the researcher presented as much of the authentic research data as possible, and constantly checked that the narrative experiences of HIV positive women were not distorted during data transcription and interpretation. Although the researcher has considerable experience in the field of HIV/AIDS counselling, she consulted her University Research Supervisor for guidance to ensure she did what was required in conducting reliable, valid and trustworthy research. This process not only clarified research concerns and allowed for scrutiny by supervisor, but it also motivated the researcher to remain confident and persevere throughout the research process.

Reliability, for quantitative studies refers to the extent to which the same research tool can be used repeatedly in similar contexts and still produce relatively similar results (Rolfe, 2006). However, replication for qualitative studies refers to the degree to which the research findings can be reinterpreted from another angle, and similar issues explored in different settings. Sandelowski in Rolfe (2006) therefore argues that validity in qualitative studies should be linked not to 'truth' or 'value' as these are for the positivists, but rather to 'trustworthiness'.

Trustworthiness refers to the extent to which the research process can be tracked and verified by its readers (Babbie & Mouton, 2001). In the present study, trustworthiness will be discussed under credibility, dependability, transferability and confirmability.

### **Credibility**

Throughout the research study, the researcher utilized paraphrasing, probing, and member checking in order to elicit honest responses from the HIV positive women.

In addition, transcriptions of recorded data and field notes were done in order to ensure accurate accounts of the responses.

### **Dependability**

A clear account of the data collection methods and analysis was maintained in the study process. Dependability was further achieved by keeping all field notes and transcripts as emphasized by Lincoln and Guba in Rolfe (2006).

### **Confirmability**

Confirmability refers to the extent to which the findings of the research study reflect the participants' responses. The researcher employed neutrality as recommended by Babbie and Mouton (2001) in order to divert from biasing the findings to suit her study objective. A research journal was also used by the researcher to reflect on critical incidences that occurred during the study.

### **Transferability**

The researcher included a clear, biographical description of the participants and their social context in the data analysis. This process might allow other researchers to assess the applicability of the current study's findings in other contexts.

## **3.8 ETHICAL CONSIDERATIONS**

Babbie and Mouton (2001) argue that the researcher's right to search for information, should not compromise the rights to privacy. The rights of the HIV positive women were taken into consideration throughout the research study. The researcher also recognized and appreciated the socio-cultural context of these women, as guided by the social constructionist perspective.

The researcher obtained ethical clearance from the University Ethics committee (see appendix D). Permission was also sought from the health care centre's manager. Social Workers are governed by ethics, as stipulated by the South African Council

for Social Services profession (SACSSP) [www.sacssp.co.za](http://www.sacssp.co.za), thus Social Work ethics also guided the research study.

In consideration of the sensitivity of HIV/AIDS, and women's vulnerability, the researcher performed the following ethical obligations:

**1. Ensured anonymity and confidentiality of participants by the use of pseudo-names.**

To ensure anonymity, pseudo-names were allocated for each participant. The participants were further assured that identifying research information would be kept confidential. This facilitated openness of participants during the interviews.

**2. Obtained informed consent from the participants. This form was translated to the local language (see annexure )**

In this study, all participants signed an informed consent form after the research and its procedures had been explained to them. The consent form highlighted the aims of the research study and the voluntary nature of participation.

**3. Informed all participants on their voluntary involvement in the study and not promising monetary gains**

Openness, honesty, and transparency were exercised by the researcher in the explanation of the participants' voluntary involvement in the study. The participants were neither promised any reward for their participation, nor were they penalized for their refusal thereof. In addition, all respondents were alerted to their right to withdraw from participation at any phase of the interview, when they felt uneasy. Due to the honest approach adopted by the researcher, coupled with her social work skills, none of the participants expressed discomfort during the interview.

#### **4. Sought permission to use the tape-recorder**

Participants were provided with the option to allow or disallow the use of a tape recorder. As earlier explained, two participants refused to be recorded, and notes were taken by the researcher.

#### **5. Discussed the safekeeping of transcripts**

Participants were informed on the safekeeping of research material for a period of five years.

#### **6. Offered debriefing when the need arose**

The researcher acknowledged the traumatic effect of exploring HIV/AIDS issues and offered debriefing, counselling and referral for ongoing services to some participants.

### **3.9 LIMITATIONS OF THE STUDY**

- Although there is ample literature on HIV/AIDS, there appears to be limited studies conducted on women's experiences on HIV in the South African context. Similarly, studies on coping strategies for HIV positive women were few and far between. The researcher then consulted literature on coping with other chronic illnesses.
- The researcher-social worker role was at times conflated, but did not pose a limitation. Instead it allowed for better entry into the lives of HIV positive women. Further, the researcher was not the designated social worker of the women who were interviewed, allowing some 'research distance' to prevail.
- As participant involvement did not encompass any monetary gain, some participants claimed to be too busy to make time for the scheduled interviews. In perseverance, the researcher conducted the interviews at their place of convenience.

- Some participants may have been dishonest or responded in a socially desirable manner, given that they needed the services of the health centre. In response, the researcher consistently reaffirmed data and utilized her social work skills to elicit honest, reliable information from the respondents.
- Research at the study site (the health centre) was a foreign concept. The researcher had to dedicate much time to informing the multidisciplinary team on the purpose of research and its implication and benefit for future practice. Research participants too needed to be convinced before they consented to participate in the research study.
- The findings of this study of HIV positive women cannot be generalized to other population.
- Some participants were intimidated by the use of an audio-tape. To address this concern, the researcher accepted that two participants did not give permission to be tape recorded, although transcribing of the written data and filling in gaps had to occur as soon as possible for authenticity reasons.

The topic was painful and taxing. The researcher had to utilize her Social Work therapeutic skills in order to attend to the emotions that arose during the interviewing process. Some participants agreed to be referred for follow-up sessions. This was time consuming and draining.

In this chapter, the research methodology was described. The sampling, data collection and data analysis processes were discussed. The trustworthiness, validity and reliability of the study were explored, and lastly the ethical considerations and the limitations of the study were highlighted. The presentation and the discussion of the research findings will be discussed in Chapter 4.

## CHAPTER FOUR

### RESULTS AND DATA ANALYSIS

#### 4.1 INTRODUCTION

This chapter outlines the results of the study. It provides an in-depth analysis and discussion of the results from interviews with HIV positive women within a designated health setting.

The researcher employed a qualitative approach in exploring the experiences and challenges of these women. To gain more insight into the lived stories of the women with HIV, this chapter will be divided into two sections. The first part of the chapter will provide demographic details of the participants, while the second part will focus on unpacking and analyzing the themes that emerged from the process discussed in the Methodology chapter. Analysis of emerging themes will be linked to the study objectives as explained in the first chapter. Furthermore, the literature reviewed in chapter two will be used to support or contradict the results of this study.

As outlined in the latter chapter, the sample in this study comprised of fifteen HIV positive women who had all known their status for more than three years and were over eighteen years of age. Pseudo names have been used so as to preserve the confidentiality and anonymity of the participants. Seven participants were referred to the study by the MDT (Multidisciplinary Team), while eight were sampled by the researcher (through availability and purposive sampling). All participants provided verbal and written consent, and were constantly reminded of their right to opt out of the study. The same interview guide was utilized for all participants in order to explore their challenges and experiences of living with HIV/AIDS, and the various coping/survival mechanisms that they adopt.

Guided by Social Constructionism and ecosystems theoretical framework, the focus of this analysis is on how the identified women constructed meaning of their

HIV/AIDS experiences, and also how the disease affected their interaction with their external world. The narratives of the women were translated from Zulu, their mother tongue, to English so that their stories could be understood and appreciated by all readers.

The demographic information of the participants is tabulated as follows:

### DEMOGRAPHIC DETAILS

| *Participant | Age | Marital Status | Employment Status | Level of Education | Number of Dependants | Year of HIV Diagnosis |
|--------------|-----|----------------|-------------------|--------------------|----------------------|-----------------------|
| Nothemba     | 55  | Widowed        | Unemployed        | Grade 6            | 5                    | 2002                  |
| Zandi        | 44  | Married        | Employed          | Grade 10           | 3                    | 2006                  |
| Gugu         | 41  | Single         | Employed          | Grade 8            | 4                    | 1999                  |
| Lihle        | 36  | Single         | Unemployed        | Grade 7            | 4                    | 2002                  |
| Smangele     | 36  | Married        | Employed          | Grade 12           | 4                    | 2005                  |
| Noma         | 31  | Single         | Unemployed        | Grade 9            | 1                    | 2002                  |
| Senzi        | 30  | Married        | Employed          | Grade 10           | 2                    | 2002                  |
| Zanele       | 29  | Single         | Unemployed        | Grade 11           | 3                    | 2004                  |
| Phindile     | 27  | Single         | Unemployed        | Grade 9            | 1                    | 2007                  |
| Carol        | 27  | Single         | Unemployed        | Grade 12           | 4                    | 2006                  |
| Duduzile     | 24  | Married        | Employed          | Grade 10           | 2                    | 2007                  |
| Busi         | 23  | Single         | Employed          | Grade 9            | 1                    | 2008                  |
| Slindile     | 21  | Single         | Unemployed        | Grade 7            | 2                    | 2006                  |
| Fikile       | 21  | Single         | Unemployed        | Grade 12           | 2                    | 2008                  |
| Hlengiwe     | 19  | Single         | Unemployed        | Grade 11           | 0                    | 2008                  |

All participants were Zulu speaking

\*Not the real names of participants

Table 4.1 indicates that most of the participants were in their 20's and 30's. The oldest, Nothemba, was 55 and the youngest Hlengiwe, was 19. As earlier stated in Chapter two, HIV affects the majority of women in their reproductive ages and also during their economically productive years (UNAIDS, 2010; Niens & Lowery, 2009).

Fikile, Carol, and Smangele were the only participants who had completed Grade 12. These findings concur with Pettifor et al.'s (2008) study findings that found women without Grade 12 qualification being at an even increased risk of HIV infection.

Zandi, Smangele, and Duduzile were the three married participants. Even though the other participants were not married, the majority of them were cohabiting with their partners and often referred to them as "*umkhwenyana wami*" (*my husband*), except for Nothemba, who is widowed, and the four younger participants (Busi, Silindile, Fikile, and Hlengiwe) who had boyfriends, and were still staying with their biological families. They explained their living circumstances as follows:

*"I can say I am single, but in the true sense, I am married to this man. I have been staying with him for 5 years now, and he is the father of my youngest baby...You see, he came to pay lobola for me . . . we have been living together since 2004"* (Lihle)

*"I stay with my mother, but I see him often"* (Hlengiwe)

All participants reported to having a companion. Nothemba (widow) reported to having her boyfriend come over sometimes as follows:

*"In this area, you must have a man otherwise they will take you for granted. He doesn't stay with me but they see him come every now and then"*

This statement emphasizes the pressure placed by society for women to be in relationships. It is interesting that Nothemba makes no mention on what she gains from the relationship but rather how others perceive her. This highlights the role of society in constructing meaning and dictating behaviour as per the theory of Social Constructionism.

The following section will present and discuss themes and subthemes of the experiences of HIV infected women that emerged from the data collected. The main themes include: initial psychological reaction to an HIV positive diagnosis, their

adjustment to HIV/AIDS, disclosure fears and challenges, significant other's reaction to HIV positive status disclosure, expressed needs after being diagnosed, and coping/survival strategies they adopted. The researcher's incorporation of the Social Constructionism and Ecosystems theory framework was to understand how this specific group of women constructed meaning of an HIV diagnosis, and how their environment contributed towards their adjustment or maladjustment to the illness. It was befitting to regularly use the women's exact words this being a qualitative study, so as to bring the women's lived stories to the reader's attention.

## **4.2 INITIAL REACTION TO AN HIV POSITIVE DIAGNOSIS**

The participants in this study had all known their HIV status for over a period of three years. All participants received pre-post test counselling by lay counsellors. While a few participants reported to remaining calm when told of their HIV positive status, some described the incident as painful and unforgettable. It was apparent that some participants had not fully recovered from that traumatic discovery. Almost all respondents reported the challenge of when to disclose of their HIV positive status, to whom, and how.

### **4.2.1 Shock, confusion and disbelief**

For some women, receipt of an HIV diagnosis was a shocking experience that was saturated with much confusion and disbelief. These women gave the following narrations in relation to the above experience:

*"I got tested in 2002 when my biological father died of AIDS. Out of curiosity I went and got tested. I was so shocked because I was still fat and I had not had any signs of illness that people with HIV usually have" (Lihle)*

*"My then boyfriend and I decided to go and test before we started having sex. You see, I was 16 then. He went in first and came out negative, but when the counsellor told me I was positive, I could not believe it, I was so confused, even now I can't get over it." (Hlengiwe)*

*"In 2006, I had shingles and didn't know what caused them... the doctor said I must test. When they said I'm HIV positive, I cried because I could not believe it, I went to (another clinic) and they told me the same thing." (Slindile)*

Lihle's 'curiosity' and most participants' willingness to test concur with the study by Kasiram et al. (2011), which found that women were more willing to get tested and sought help quicker than their male partners. An exception was noted in Hlengiwe's narrative as her (then) boyfriend was as willing to get tested as she was. Most women's confusion was based on the socially constructed myths about HIV. Lihle didn't expect to be HIV positive because she was not losing weight. Hlengiwe also felt less vulnerable because of her young age.

As stated earlier, Van Dyk (2001) argues that younger women are particularly vulnerable because of their less developed genital tracts, even though they do not expect to be vulnerable to HIV infection. The above narratives of the participants in the study show that most women reacted with shock, confusion and disbelief when told of their HIV positive status. These reactions appeared to be rooted in the socially constructed assumption of HIV as being a lifelong illness that cannot be managed.

#### **4.2.2 Blame, anger, fear and guilt**

Participants expressed blame and anger towards those whom they claimed responsible for infecting them with HIV.

*"My late boyfriend loved girls, and when his other girlfriend died I asked him and he said he had not had sex with her... I knew he was lying then he started having diarrhea...so when I tested positive, I knew it was him because he was my only sexual partner...he is dead now and I am married to someone else but I am still angry." (Smangele)*

*"Yazi (you know), this man knew his status long before going out with me. When I saw the cartons of ARV's hidden in his bottom drawer, I asked him*

*and he said that they were for his friend in prison. Now I am positive and I blame him. What can I do now? I have to stay with him.” (Busi)*

*“Receiving those results really traumatized me ... I lost so much weight and even had to be hospitalized. I have never had sex with anyone . . . he knows I was a virgin when we met . . . so I had a right to be angry. I received good counselling and I forgave him.” (Senzi)*

Smangele's narrative highlights women's acceptance of men having more than one partner. Such gender biases have been found to increase women's vulnerability to HIV infection (Mulligan, 2006; Hunter, 2005). Having remained a virgin and marrying early did not reduce Senzi's risk of HIV infection. Similar findings were found by Clark (2005) where young girls who married early had difficulty negotiating safer sex practices, thus increasing their risk of HIV infection. The current study findings, together with previous studies (Bongaarts, 2007; Clark, 2005) indicate the need to address the gendered nature of HIV.

Some participants were not certain as to whom to direct the blame (themselves or their partners).

*“I tested positive in 2004. I don't know exactly when I got this thing, but I was a prostitute (I only stopped in 2007, when my boyfriend found a job). I had to take care of my children. He can't blame me because his ex-girlfriend died of meningitis – is that not AIDS?” (Carol)*

The above narration concurs with the literature reviewed whereby poverty was found to propel women to engage in risky behavior, thus increasing their vulnerability to HIV infection (Stratford et al., 2008; Booyesen & Summerton, 2002). Contrary to reviewed studies, Carol provided financial support to her boyfriend when he was unemployed. This narrative indicates that socio-economic circumstances may force women to prostitution, thus increasing their HIV infection risk. Although Carol has a Grade 12, she still succumbed to prostitution for her survival. Carol's narrative contradicts Pettifor et al.'s (2008) finding on education and reduced HIV risk; and

concur with that of Booysen and Summerton (2002) where poverty was found to increase lack of HIV/AIDS education.

One participant felt guilty for infecting her child and feared for the future.

*"I took my son to the clinic when he was sick, then the nurse said I should test him for HIV. I was scared and went to test myself instead, the results were positive, I felt so guilty for making my boy sick, who will look after him when I die. Although he is currently on ARV's, he is just helpless and his father does not care for us...we have destroyed his future." (Noma)*

*"I really felt bad and said to myself 'nakumina sekufikile' (even to me this thing has come). I received counselling but I was not focused, I can't even remember what the counsellor said...I kept thinking oh God, why me?"*  
(Hlengiwe)

One participant's biggest fear was narrated as follows:

*"I got so upset, but my biggest fear was who will marry me, and how would I tell him about my status." (Busi)*

This indicates that HIV positive women view their status as negatively affecting their prospects of marriage. As a result of this fear, most women often choose to not disclose their HIV positive status to their partners (Kasiram et al., 2011 & Makin et al., 2008). However, Simbayi et al. (2007) warn that such secrecy about one's status to sexual partners places women to further risk of re-infections and treatment failure.

#### **4.2.3 Relief and Acceptance**

Receipt of an HIV diagnosis can be traumatic. However it can also bring about a sense of relief. Nothemba narrated her sense of relief as follows:

*"My husband died in 1998, and my daughter's death followed in 2000. 'ngangihlaselwe ifu elimnyama' (a dark cloud had descended upon me) I started to lose weight – I went from a size 44 to a size 32. Everyone was worried that I was stressed and that I was also dying (just like them). I went everywhere for help, but when I tested positive in 2002, I felt relieved because at least I know what is wrong with me"*

It is clear that Nothemba associated her husband's and daughter's deaths with bad luck or demonic spirits. When the researcher probed about her going 'everywhere', she elaborated that she went to 'abathandazi nezinyanga' (spiritual and traditional healers). Nothemba reported that she accepted her status immediately as she was desperate to find the cause of her illness.

Most participants' narration of bad luck highlights the role of socio-cultural beliefs in constructing meaning of an HIV positive status. In agreement with the above findings, Ashforth (2002), in his study conducted in Soweto, found that for Black families, traditional beliefs have an influence on the HIV infected individual's reasons for disclosure and non-disclosure, which will be discussed further in 4.3 and 4.4.

Like Nothemba, some participants reported to have instantly accepted their status upon receipt of diagnosis. A few narrated as follows:

*"For me, I only tested to confirm my suspicions and when they told me, I accepted it. You see, I had been having these sharp body pains, I had TB twice and lost my job because I was always sick, now I'm fine and taking ARV's." (Zandi)*

*"Most of my friends are positive, so when I tested I accepted because I had seen them fighting this thing". (Carol)*

*"You see, being HIV positive is not scary anymore because there is medication. I accepted it because I have seen people dying not because they were positive but because they did not accept their fate." (Busi)*

Receipt of an HIV diagnosis had a debilitating effect on some participants which resulted in disruption of future goals for some:

*“Even though I acted as if I accepted my diagnosis, after that day I got really sick and started looking like an HIV positive person. I wanted to study, but I don’t see that happening any time soon”. (Duduzile)*

The above narration highlights the trauma and hopelessness that HIV infected women experience. The literature reviewed also found that women suffer more with post-traumatic stress disorder as compared to men (Tolin & Foa, 2006; Seedat et al., 2005; Yehuda, 2002).

#### **4.2.4 Concerns about the future**

Almost all participants expressed concerns about their future and the future of their children:

*“When they told me my status I just thought of my children and cried because I’m their only parent”. (Zanele)*

*“Even though I accepted my results, I thought to myself that my life will never be the same again... also when I get sick, who will look after me?” (Nothemba, 55)*

Receipt of an HIV positive diagnosis for the women in the study was saturated with emotions of shock, confusion, disbelief, blame, anger, fear and guilt. All participants reported to have received pre- and post test counselling. One respondent narrated that she was not focused during the pre-test counselling session due to confusion and shock. Some reactions were more extreme as one participant had to be hospitalized. The majority of the participants confessed to crying upon receipt of their ‘fate’, while some expressed a sense of relief as they were desperate to find the cause of their illness. Almost all participants expressed concerns for their future and the future of their children. These concerns were based on the social construction of HIV/AIDS as a deadly disease.

The researcher wondered how these women would have narrated the initial receipt of their HIV diagnoses, as it cannot be determined how their later HIV experiences reconstructed receipt of their diagnoses experience.

Almost all the participants reported that the support they received from the health centre and significant others assisted them to accept their status. Choosing who to disclose their status to was of great concern. The participants expressed various reasons and consequences for disclosure, selective disclosure or non disclosure of their HIV positive diagnosis, which will be discussed in detail in the next section.

### **4.3 DISCLOSURE AS A FEAR**

The majority of women's non-disclosure of HIV positive status was due to fear of being rejected, stigmatized, and isolated. Almost all participants feared losing their relationship with significant others.

#### **4.3.1 Fear of being rejected**

Most participants expressed fear of rejection as follows:

*"I have been with my partner since 1993. We use condoms, but sometimes we don't. He always sees me going to the clinic.... One day I asked him what would happen if I told him I was positive, he said that he would leave me". ()*

*"My ex-boyfriend knows about my status, but this one, I can't tell him, he will just shout and tell his family that I brought this deadly disease and he has paid lobola for 'this'..My fiancé has a good job and supports me."(Lihle)*

*"I can't tell my children, I don't think they are ready yet. They would just leave and go to stay with their father. That would be his chance to take them away from me...as for my mother, she will throw me out of the house because she always talks about these other people who are positive". (Gugu)*

Most of the participants expressed fear of being rejected by their intimate partners. They all identified disclosure as the most difficult process to manage as it had devastating implications for their families, intimate partners and in some cases employment. One participant expressed fear around being rejected by her employer (*"I look after their kids and they will never allow me to continue working, so whenever I go to the clinic I tell them that I'm taking my mother for her BP"*). Most participants narrated that they felt they would be stigmatized by their families before being rejected, while some narrated that they had anticipated stigma first before being (or choosing to be) socially isolated.

Makin et al. (2008) and Lurie et al. (2003) also found that women who were financially dependent on their partners feared enduring monetary sanctions and destabilizing the relationship. The researcher found that those participants who did not disclose to their mothers had pre-existing strained relationships with them (even without HIV disclosure). Murphy et al. (2006; 2001) also found that mothers chose to hide their status from their children due to the immaturity of children. The majority of participants in the present study feared that their children would tell others (neighbours, extended family, etc), and they (participants) would suffer further stigma as a result. The current study findings concur with the findings of the reviewed study by Murphy et al. (2006; 2001)

#### **4.3.2 Fear of being stigmatized**

Two participants in the present study expressed their fear of stigma as follows:

*"I did not tell my sister because she trusted me, how do I tell her that I have a Z3?" (Hlengiwe, 19)*

*"Because I know I will be going to the clinic often, I told him that the doctors said I have cancer of the cervix...and he said, at least it's not AIDS...I'm going to start ARV's soon, I don't know how I will hide them". (Duduzile)*

The social construction of HIV prevented most participants from disclosing. The participant's referral to HIV as the 'Z3' (a speedy BMW car) is a common term in the

local black townships. This slang denotes the fast, deadly speed of HIV and its progression to death. One participant found that her partner would support her if she told him she had cancer. The above finding correlates well with a study done by Lekganyane et al. (2011), who also found that HIV infected women saw cancer as less stigmatizing when compared to HIV/AIDS. Interestingly, the researcher found that the participant's (in the current study) 'disclosure' of cervical cancer assisted her in initiating condom usage, and prevent HIV re-infection. Most participants' fear of stigma was due to fear of social isolation.

#### **4.3.3 Fear of social isolation**

The fear of social isolation was communicated by most participants:

*"I think I will only tell my family when I get really sick because if I tell them now, they will take me to hospice and I need to be with my children and live like other people" (Gugu)*

*"My friend disclosed her status at church, and she had to join another church because she just didn't fit in anymore, I will never tell them because 'bayasizakala' (they will start gossiping)". (Zandi)*

An overlap was found in the participants' narrations of fear of rejection, stigma and social isolation. Although all participants were aware of the importance of disclosure of their HIV diagnoses, as communicated by their health care team, some saw it as challenging and also potentially risky. Disclosure is also found by Makin et al. (2008) and Medley et al. (2004), to be an important, yet complicated process and that HIV infected individuals should decide how, to whom and under what circumstances to disclose.

The concern regarding disclosure for most participants occurred immediately after receipt of an HIV positive diagnosis. The majority of the participants expressed their lack of trust towards their significant others, fearing that they would 'tell others'. The

above narrations highlight the fear that HIV positive women experience when contemplating disclosure.

#### **4.4 CHALLENGING EXPERIENCES OF DISCLOSURE**

Although some women expressed fear around disclosure of their HIV positive status, most women pursued this task by notifying significant others and narrated their experiences of being shunned, labeled, and discriminated against. These excerpts confirmed that the women's fears were not unfounded. Under this theme, the researcher will discuss the participants' lived experiences of disclosure in relation to rejection, stigma, and social isolation.

##### **4.4.1 Actual rejection**

Most of the participants narrated rejection by their partners as follows:

*“When I told the father of my baby that I was HIV positive, he started blaming me for infecting him and then he took my baby because... he didn't want to see my face”. (Gugu)*

*“The counsellor told me to tell my partner but when I told him, he insisted that he was negative and that I should go and get another HIV positive man...I continued staying with me but it was hard because he would swear at me when he was drunk and even hit me at times”. (Fikile)*

*“When I told Bongani (not real name) about my status, he didn't say anything. He just never came back. I don't regret telling him because at least he knows now even though I heard he has a new girlfriend”. (Zanele)*

From the above narrations, it is clear that disclosure of an HIV positive status risks the possibility of rejection. Some women were denied their parental rights, while some were verbally and physically abused. In concurrence, a study of rural Indian women found that poverty compelled these women to remain in abusive relationships even if the situation was life threatening (Nyamathi et al., 2010). Most participants

indicated that rejection was generally not verbally expressed but acted. One participant's response was *"I didn't tell him anything, when he saw that I was losing weight and I had 'ibhande' (shingles), he just said I should go back to my mother since he couldn't take care of me, I never saw him again."* Even without verbal disclosure, the above participant experienced rejection by partner.

It was interesting that even though most women experienced rejection, they did not regret informing their partners about their HIV positive status. However, regrets were expressed by two participants in relation to disclosure of HIV status to their families. The following are excerpts from the women who experienced rejection by family members.

*"I told my mother and she called my sisters and told them that I was not going to stay with them anymore since I was sick...and that she had been warning me about this...they (my sisters) should also learn a lesson from it...it was really painful and I regret ever telling her". (Slindile)*

*"I told my sister and she told her husband, he became different towards me". (Carol)*

The two participants in the current study experienced rejection by family members. Bor and Elford (1998) perceive family as the primary provider of physical and socio-economic support for its HIV infected members, which was not evident in these two participants' experiences.

One participant experienced rejection from her church as follows:

*"My Pastor came to tell me that one guy was interested in me and that God had approved of this...that's how couples are joined in our church. I was honest and told him that I am HIV positive, his exact words were "hayi chanyeke kulunge" (that is unfortunate). I knew that he rejected me because of my status, that guy is married now." (Zanele)*

This narration suggests that the participant experienced rejection at the place where she least expected it. Being rejected at church was painfully expressed by the above participant. This is not particularly new, as a study by Serovich et al. (1998) also found that HIV positive women were shunned and stigmatized by their church members who saw HIV as a punishment from God.

The participants' narrative of rejection overlapped with their experiences of stigma. The majority of participants experienced stigma before rejection. The narrations of stigma will be discussed and analyzed next.

#### **4.4.2 Actual stigma**

Slindile felt stigmatized after she had disclosed to a church friend that had provided her with a place to stay:

*"She didn't say anything when I told her but the following week she bought me a mug, spoon, and plate as a gift, and it was not my birthday...she said I should use just them...that was my sign to leave...we are no longer friends and I also left the church."*

The above narration highlights the extent of stigma and how myths around HIV/AIDS continue to exist in spite of awareness campaigns. Avert (2011) and UNAIDS (2009) unanimously criticized the effectiveness of these programmes and emphasized the need to develop context specific interventions in order to dispel the local myths around HIV/AIDS. The above narration suggests the need for education around HIV transmission. The above participant was able to leave her friend without hesitation, while other participants found it hard to leave their families even though stigma was experienced on a daily basis.

Some participants' experiences of HIV stigma by their siblings were narrated as follows:

*"My sister tried to act like she doesn't mind but then she told me not to wear her clothes because I had a rash all over my body." (Busi)*

*"They (my siblings) used to do it to me 'bengicwasa' (discriminating me) and I don't care anymore, but now they are doing it to my son daily...it makes me sad because he can see it...and we have nowhere to go, I only get his child support grant, my CD4 doesn't allow me to get the other grant." (Noma)*

All the above participants indicated during the interview that they informed their families' with the aim to solicit support, sympathy and compassion. It is clear from the above narratives that myths around the spread of HIV need to be addressed. Although Noma expressed her sadness towards the stigma directed to her son by her sisters, she expressed guilt for infecting him, which made her experience internalized stigma. She felt helpless that she could not 'get the other grant', which in this case is the disability grant. Such a grant is usually the only hope for HIV infected individuals (Hardy & Richter, 2006; Leclerc-Madlala, 2006). The absence of financial security propelled most women to remain with their families in spite of the experienced stigma.

One participant expressed her experience of stigma from her husband as follows:

*"My husband and I know our status but now that I am on ARV's, he is different towards me. He is forever commenting about my weight... saying that being thin does not suit me...does he think I like to look like this? One day he will also be like me." (Senzi)*

It was interesting to find the above scenario as both Senzi and her husband knew their status. In spite of their commonness, a stigmatizing attitude ensued. Whetten et al. (2008) also found that women in depressive and abusive environments find it difficult to adhere to medication, which may well be the case in the latter narrative. The participants who reported rejection and stigma due to disclosure of their HIV diagnoses also experienced social and emotional isolation.

#### 4.4.3 Actual social and emotional isolation

Owing to the stigma and rejection experienced, a few women in the present sample socially isolated themselves and withdrew from interacting with significant others. For one participant, even when she attended family functions, she felt stigmatized and different from other people. Her experience was narrated as follows:

*"I don't even like going to family functions because I know they will say 'arg shame', and I don't like that. I prefer to just stay indoors". (Phindile)*

One extreme act of social and emotional isolation was narrated as follows:

*"...even when I die I don't want them to know, if they hate me now, how will they love me when I am gone...you must help me because my children can't stay with them when I die". (Slindile)*

For these participants, social and emotional isolation was a strategy for coping with the illness. The above findings correlate well with a study conducted at Chris Hani Baragwanath Hospital, in Johannesburg, where HIV infected women chose to isolate themselves from others because of fear of rejection (Lekganyane & du Plessis, 2011). Other coping and survival strategies adopted by HIV positive women in this study are discussed in greater detail under theme number six.

This theme discussed how disclosure was a negative experience for the participants in the present study. These findings show that HIV positive women may prefer to remain silent about their illness for fear of experiencing the challenges unveiled in this section. In the present study various experiences in relation to rejection by partners, family and even by the church were discussed. Abuse by partners was also reported, and how it consequently could have an effect on treatment adherence for some women. Even after rejection by intimate partners, most women did not regret informing them about their status. Some participants remained with their families even though they were continuously stigmatized for revealing their HIV diagnoses. Stigma associated to a debilitating physique was experienced by one HIV infected woman even though both she and her husband were aware of their HIV

status. The stigma was even experienced by a participant's son, who was an unfortunate victim of MTCT (Mother to Child Transmission). They experienced stigma which lead to social and emotional isolation; resulting in some participants withdrawing from interacting with family and friends. The researcher saw stigma and rejection as both a cause and result of social and emotional isolation for HIV infected women.

The researcher found that all women's experiences of HIV/AIDS were not negative. Some of the participants reported the support they received from significant others after disclosure of HIV status. The next section will focus on the positive narratives of disclosure, as experienced by the participants in this study.

#### **4.5 DISCLOSURE AS A POSITIVE EXPERIENCE**

The following section will present the positive experiences of disclosure for HIV infected women. An ecosystems perspective was utilized to analyze the reaction of different sub-systems after an HIV disclosure.

##### **4.5.1 Reaction from partner**

The following narratives highlight the positive experiences of HIV positive women after disclosure of their status to partners:

*"Although my husband has not tested for HIV, he was supportive when I told him about my status, he has no problem with using the condom and he assured me that nothing will change and he still loved me." (Zandi)*

*"You see, he knew his status before mine and I helped him to get better and start treatment, so when I tested positive 'akusithusanga' (it was never a shock for us) He even takes time to remind me about my ARV's, he has told me that he plans to marry me." (Busi)*

Reaction from the partners seemed to play a pivotal role in the women's outlook on life. The women, whose partners were supportive towards them, reported how HIV further strengthened their relationships, and also how easy it was for them to communicate safer sex practices. A study by Kasiram et al. (2011) found that payment of 'lobola' (bride worth) made HIV positive women feel needed and validated. Women in Kasiram's study easily forgave their partners for infecting them, which was also the case with the women in the current study. In Busi's case, her partner knew her status first and she nursed him. The researcher wondered how the situation would have been different, had she tested before her partner, whether or not he would have accepted her.

#### **4.5.2 Reaction from family**

Disclosure to family members was narrated as a positive experience by some participants in the study. The following are excerpt from the women's lived experiences of disclosure of HIV diagnosis to family members:

*"I told my mother (who is on hypertension treatment and her response was that "these things happen", she was supportive. I thought she would go mad because my brother died of AIDS two and a half years ago." (Busi)*

*"I told my sister, who is also HIV positive. She has bought this 'mbiza' (African herbal tonic) for me, and I am using it because it helped her...I will not use it when I start ARV's though." (Fikile)*

*"I was scared to tell my children but the counsellor advised me to tell my 14 year old child...she cried at first but now we are the best of friends, she is my pillar of strength...with her by my side, I know I am going to fight this thing all the way." (Zandi)*

It is clear from the above narratives that some women attained support and acceptance from their family members, even though some (Busi) anticipated otherwise. These narratives concur with a study by Serovich et al. (1998) where family members reacted with relief when their members had disclosed their HIV

status to them. In the same study, perceived social support was found to encourage HIV infected individuals to disclose their HIV status, even though the reaction may be negative (as discussed earlier under disclosure challenges):

Busi's mother normalized the situation for her by stressing that 'these things happen', implying that anyone can be HIV positive. For Fikile (21), her sister stepped in immediately after she had disclosed her status to her, especially since she (sister) was also infected. The use of traditional medicine is not uncommon for Africans, as indicated in various studies (Mkhize, 2009; Ashforth, 2002; Serovich et al., 1998). Contrary to the study by Ashforth (2002), the participants in this study did not describe their HIV infection as witchcraft or in relation to demonic spirits.

Zandi's disclosure of her HIV status to her daughter appears to have given her strength to continue living. Her narrative concurs well with a study by Ostrom et al. (2006) where mothers disclosed so that they could gain social and emotional support from their children. In addition, disclosure was found to assist women to adhere to their treatment regime (Kasiram et al. 2011).

Family support and acceptance was found by all participants in the present study as important in helping them cope with their diagnoses. The HIV positive women expressed that even if they were shunned by other people in their lives, acceptance at the family subsystem level was considered the most significant.

#### **4.5.3 Reaction from the community**

The following narratives highlight the positive experiences of some participants after disclosure of HIV status to their community:

*"I told my municipality councillor that I am positive and when he was allocating plots for houses to be built, I got one because he knew my condition." (Nothemba)*

*"I told my neighbour and guess what? She is also HIV positive and we are now part of the support group." (Zandi)*

*“Although I have never addressed the community in a gathering, the majority of them know my status because I speak openly about it, and people come to me for advice... really it's not a problem for me.” (Noma)*

It was interesting that Nothemba used her HIV status to request for government housing from her local councilor, as opposed to using her widowhood status. By this she implied that being HIV positive is more of a disadvantage than being a widow. Zandi's disclosure to her neighbour assisted her in gaining support and joining a support group, which is found to assist in providing support and acceptance of status for the HIV infected individuals (Lekganyane et al., 2011). Noma's openness about her status not only helps her accept her status, but also encourages other people to come out and seek help. These are characteristics of a citizen therapist (Rojano, 2005) which will be discussed further under coping and survival strategies.

#### **4.5.4 Reaction from service providers**

Almost all participants were satisfied with the level of service by their local clinic. However, a few expressed their concern of HIV/AIDS services being provided separately from other health services. One participant narrated as follows:

*“The nurses and doctors really take good care of us, but every time when I go there, I wonder who will see me because our files are different, our department is different. No matter how I try to hide, other people will see that I am positive”. (Smangele, 36)*

The current study findings contradicted those found by Andrewin and Chien (2008) of health care professionals labeling HIV infected patients as infectious beings. The current study findings suggest that health care professionals play a distinctive role in dispelling HIV related stigma.

Although the above participant expressed satisfaction on the services rendered by the health practitioners, she also narrated the stigma implications for having a separate department for HIV/AIDS services. One participant had a different view on the latter:

*"I really don't mind because this is my health and if other people see me... so what? I am on ARV's now, but when I started at the clinic I was wasted and dying..."* (Busi)

None of the participants expressed any dissatisfaction with the services provided by the clinic staff member. The researcher wondered how participants' narratives in relation to the services provided by the clinic would have differed had the researcher been a non-clinic staff. The HIV positive women, however, expressed certain needs, which will be discussed in the next section.

## **5. EXPRESSED NEEDS OF HIV POSITIVE WOMEN**

One of the objectives of the current study was to ascertain the needs of HIV infected individuals. The HIV positive women in the current study expressed various needs in relation to their daily management of their illness. The narrated needs will be discussed at various levels of the HIV infected women's lives, as per ecosystems theory framework.

The majority of the HIV infected women narrated their individual needs as follows:

*"I just want to get a job and be able to provide for my children".* (Zanele)

*"I want to accept this sickness and take it like other normal illnesses".*

*(Carol)*

*"I need more information on how to disclose to my children, I am so scared"*

*(Gugu)*

The majority of the women in the study expressed their need for financial security. The highest household income was found in Busi's household (R2500 per month), whereas the lowest was R260 per month which was from a child support grant (Phindile). These figures indicate the burden of poverty against the backdrop of HIV/AIDS. Like all other communicable diseases, Drimie (2002) found a bi-

directional link between poverty and HIV/AIDS. Contrary to that, Poku (2002) disputes the correlation between poverty and HIV. To address this South African crisis, the HIV/AIDS National Strategic Plan (2007) was envisaged for acceleration of strategies that aim to reduce poverty, and strengthen poverty mitigating interventions. This strategy has not been implemented in the lives of the majority of women in this sample, as most of them remain unemployed.

Mental health needs were also expressed by some participants. These participants have not fully accepted an HIV positive status, even if they were diagnosed more than three years ago. Some of them still cried as they narrated their diagnoses. HIV positive mothers expressed the need to disclose to their children, without emotionally burdening them. The same needs were expressed by mothers in a study by Ostrom et al. (2006), where mothers indicated the need for their children to know about their mothers' HIV status, and also what the future implication of living with HIV/AIDS entailed.

Mezzo needs were expressed as follows:

*"I need to bring my husband so that he could hear from the counsellor about the importance of using a condom...he just doesn't take me seriously".*

*(Senzi)*

*"I want to join a support group, as long as I know they will not judge me".*

*(Hlengiwe, 19)*

*"Even though I am HIV positive, I am still a woman and there are many problems for us in our families and community, women need to be empowered". (Noma)*

For Booyesen and Summerton (2002), the poverty experienced at the micro level infiltrates into the mezzo level resulting in gendered power relations like the inability to negotiate safer sex. The above narrations indicate that women need to be empowered to take control of their lives. In order to curtail feminization of HIV, transformation of gender idealization, as opposed to focusing on sexual behavior of

individuals has to take place (Jewkes & Morrel, 2010; Peacock et al., 2009). The advantages of joining a support group have been previously discussed, with women in this study seeing group sessions as a platform to raise 'women' issues such as intimate partner violence and income generation projects.

The majority of the women in the present study narrated a sense of wanting to be heard, and recognized. This willingness to be heard penetrated into macro needs, which are discussed lastly under the needs of HIV positive women.

Lastly, macro needs were narrated as follows:

*"I wish the president can come and see where I stay, and then he could tell me that I don't need social assistance." (Phindile)*

*"If only we could get funding for our support group, we already registered a community based organization but it hasn't done anything for the past 2 years as there are no finances." (Nothemba)*

Some of the women in the study narrated the need for their involvement in decisions that affected their lives. These concerns were around policies (from national to local level) on the management of HIV/AIDS for women. The women in this study expressed the need for development of gender specific programmes to address poverty issues for HIV positive women, especially at grassroots level. The above expressed needs are in line with Vogli and Bibeck's (2005) view that adjusting economic policies at a macro level is paramount for the modification of mezzoeconomic conditions, which in turn get filtered down to the micro level to alleviate poverty in households.

This section discussed the needs of HIV positive women utilizing an ecosystems perspective. At all levels, the need for economic empowerment in the form of employment, access to social assistance, and funding for community based initiatives was expressed. The need for mental health initiatives in order to fully come to terms with one's HIV diagnosis was also communicated, together with the need to join support groups in order to be heard and gain recognition.

In light of the needs expressed above, the HIV infected women in the current study narrated some of the coping and survival strategies that they have adopted. The following section provides an analysis of the manner in which HIV infected women cope with their diagnoses.

## 6. COPING AND SURVIVAL STRATEGIES

The women in the present study mentioned several approaches that they utilize in coping with the illness. Contrary to the latter, in this section, the researcher sought to explore how the HIV infected women utilized what they had in order to cope with their illness. Some of these approaches helped the women forget about being HIV positive while some helped them confront the reality of HIV. The survival strategies narrated by some HIV infected women have far-reaching effects on other people in similar conditions.

The majority of HIV infected women narrated their use of spirituality as a coping mechanism in the following manner:

*"I go to church often and love singing in the choir". (Duduzile)*

*"I just read the bible." (Zanele)*

The above findings correlate with a study by Peterson et al. (2010). In their study, these authors found that HIV positive women drew their strength, hope, peace and well being from their spirituality. This sense of hope was expressed by Zanele in the current study (*when God brings the HIV cure...and I know he will... I want it to find me alive*). The researcher found this narration of hope by Zanele, phenomenal, and contributing towards her coping with the HIV illness. Almost all the women in the study expressed their church attendance as helping them cope with the illness. The support they received from church was vaguely narrated since the majority of them confessed that they were not ready to disclose their status to their church members. It was not clear as to whether the support they received was due to their obvious symptoms of HIV or to their general religious involvement in a church. Lekganyane

et al. (2011) also found that HIV positive women found support in their churches even without disclosure of their status.

Other ways of coping with the disease were narrated as follows:

*"I just keep busy doing my garden, even though it is small, because when I work, I forget." (Lihle, 36)*

Preoccupation with other things was a strategy used by the majority of participants in the study. The women narrated that these avoidance acts assisted them in escaping HIV/AIDS fatigue. These findings concur well with studies by Kasiram et al. (2011) and Lekganyane (2008), where a vegetable garden served as a nutritional supplement and provided of a 'sense of meaning'. This sense of identity was also expressed in the following manner:

*"I am part of (name of the group) support group, and we meet once a month, there I find peace."*

As discussed previously, involvement in support groups assisted the HIV infected women to share their stories of trials and tribulations in relation to surviving with the disease. Visser et al. (2005), involvement in a structured support group proved beneficial for HIV positive women's coping with their status. In their study, Visser et al. found that group members regained their sense of identity, felt less stigmatized and more 'normal' when included in group work. One participant narrated how she is able to joke openly about her illness in the support group. The participants who had participated in support groups for WLWHA (women living with HIV/AIDS) appreciated the openness on HIV related issues like condom use, STI's and intimate partner violence.

Some HIV infected women narrated their preference to just be alone as follows:

*"I like shopping, even when I buy a small thing. What makes me happy is that these clothes are for everyone, whether negative or positive". (Carol, 27)*

*"I read books and magazines". (Hlengiwe, 19)*

*"I sleep". (Phindile, 27)*

Women who spent time alone expressed their need to focus on their individualistic needs. As discussed by Kasiram et al. (2011) women viewed individual and therapeutic time as affording them opportunity to feel important and provided time and space to interrogate personal issues and plan for the future. Retail therapy was narrated by one HIV infected woman as providing a sense of normality as she expressed her excitement on clothes that fit well, irrespective of HIV status. One woman in the present study appreciated time alone for a different reason, and narrated the value of time spent alone as follows:

*"Sometimes I wait for my family to leave and my children to go to school, and I just cry and cry, knowing that no one will stop me...maybe after a couple of hours I feel better (sobs). Maybe I am weak, but crying really helps me to cope with this disease." (Gugu)*

Crying was expressed by Gugu as way of coping with the illness. One woman saw helping other people who are HIV infected as a way of coping with her illness, and expressed the following:

*"Whenever I see someone who is sick or showing signs of HIV and not going to the clinic for help, I always tell them about me and how I nearly died with a CD4 of 6...they should not be ashamed. I am a perfect example because they know what I looked like before getting help from the clinic...I have helped many of them in this way." (Zanele)*

*"People thought I had died, but I told myself that now that I am well, I must help others. I am a home based care worker and I only get a stipend, but I am happy when I have helped at least one person a day". (Busi)*

The above narrative highlights the far reaching impact of one person reaching out to help others. This selfless acts narrated by Zanele and Busi are in line with Rojano's

(2005) definition of citizen therapist, and concur with a study by Kasiram et al. (2011) where one woman acknowledged that 'you grow when you give'. In the current study, this woman expressed her need to be open about her status, thus allowing other women to feel less stigmatized and seek medical assistance early. There were other women who said that they '*talk about it.*' Contrary to Zanele's way of coping, the other participants who claimed to talk about it only spoke to those whom they trusted. According to these women, being listened to by significant others assisted them in coping with their illness. Another citizen therapy act was well demonstrated by the latter participant, who not only woke up from her death bed, but also saw the need to help others. Her narrative suggests that she derives pleasure from assisting other individuals who are ill.

Based on the all the above narratives, it is clear that women have adopted different strategies in coping with HIV/AIDS. Almost all participants sought spirituality as a coping mechanism. Going to church, reading the bible, praying consistently and singing gospel songs were some of the exercises of spirituality adopted by the HIV infected women. One woman narrated how her involvement in her 'small' garden helped her to avoid thinking about her terminal illness, while other women saw joining a support group as allowing for openness about one's status. In addition, openness of one HIV infected woman's status assisted her and others to cope with an HIV diagnosis. The use of retail therapy as a survival strategy was also narrated by one woman, and also how time spent alone was utilized by some for reading magazines, sleeping, and for crying.

As previously discussed in Chapter Two, coping strategies come into effect when other innate strategies have failed (WHO, 1998). It is clear from the narratives presented that HIV infected women continue to explore innovative ways to cope with the disease.

Chapter Five will provide in-depth conclusions and recommendations in relation to the study findings.

## CHAPTER FIVE

### CONCLUSIONS AND RECOMMENDATIONS

#### 5.1 INTRODUCTION

This chapter provides a summary of the overall findings of the study together with a discussion of the recommendations and the conclusions that emanated from the findings. The themes that are discussed in the preceding chapter will be revisited with the aim of integrating their relevance to the research aims, objectives, and theoretical framework underpinning the study.

The study aimed to explore the narratives of women with HIV/AIDS in a designated health-care setting in KZN. The study objectives included exploring life stories of HIV positive women and ascertaining the factors that contributed to their adjustment or maladjustment after receipt of an HIV positive diagnosis. The requirements/needs of these HIV infected women were also explored.

The research employed a non-positivistic approach that was qualitative and utilized an exploratory design. The theoretical frameworks used were social constructionism and ecosystems theories. Qualitative data was collected using semi-structured individual interviews, where in-depth interviewing techniques were employed in order to explore the 'life stories' of women with HIV/AIDS. Interviews were conducted at the place most convenient to each research participant (office or home). Fifteen HIV positive women were sampled using purposive sampling as outlined in Chapter three. The women in the study were between the ages of 19 and 55 years old and had received their HIV positive status between the years 1999 and 2008. Four of the women were married, one was widowed, and the rest were either single or cohabiting. The rest of the chapter is dedicated to providing a summary of the findings and discussing conclusions and recommendations related to the study.

## **5.2 SUMMARY OF THE FINDINGS**

The summary of the findings will be discussed under the following categories:

- Reaction to an HIV diagnosis
- Fear of HIV status disclosure
- Challenges after HIV status disclosure
- Positive experience of HIV status disclosure
- Needs of HIV positive women
- Coping and survival strategies of HIV positive women

### **5.2.1 Reaction to an HIV diagnosis**

The findings of the study have shown that HIV infected women react in various ways after receipt of an HIV positive diagnosis. The majority of the participants had made the decision themselves to go for an HIV test (just as in Kasiram et al.'s 2011 study), while some were referred by medical practitioners. All participants received pre and post test counselling.

Some women reported to not have expected an HIV positive diagnosis because of their trust in their partners and because they displayed no outward signs and symptoms of having HIV. These participants were shocked upon hearing that they were HIV infected. Their feelings included confusion and disbelief. These feelings were mostly related to the socially constructed meaning of HIV as a deadly disease as per social constructionism theory. This finding highlights the need to strengthen educational programmes on HIV transmission, as well as the signs and symptoms thereof.

The discovery of an HIV positive status propelled some women to react with blame, anger, fear and guilt. Those who were sure of who had infected them directed their anger towards them (the infectors), while some blamed themselves for their carelessness, and a few were not sure of their source of

HIV infection. Most women in the study feared how their significant others would react upon disclosure of a seropositive status, while some of them feared for the future, most importantly, the future of their children. None of the women expressed any guilt for infecting their partners, while guilt was expressed towards infection of child. Almost all women reported how they were 'victims' in their contraction of HIV. As a result of fear, most women chose not to disclose their status to anyone. These findings point to the need to enroll HIV infected pregnant mothers into the PMTCT programme early (National Department of Health, 2010) in order to prevent MTCT. In addition, counselling strategies should aim to destigmatise HIV and promote acceptance of status.

Some women expressed a sense of relief upon receipt of an HIV positive diagnosis. Such immediate reactions were because these women had long been searching for the cause of their illness. Other participants had long been presenting with some of the socially constructed and clinical HIV/AIDS symptoms. A few women had approached other socio-cultural avenues for answers to their undiagnosed illnesses. It was clear from the results that some women pretended to have fully accepted their status, yet their responses reflected that they were still experiencing difficulties with being HIV positive. This finding supports the need for the inclusion of socio-culturally relevant approaches in the management of HIV.

There were expressed concerns regarding the participants' future in light of an HIV positive diagnosis. An HIV diagnosis meant disruption of earlier identified goals, or plans for themselves and their families. These concerns were based on the social construction of HIV/AIDS as a deadly disease that steals one's future. These women appeared to have lost their direction in life which deterred them from identifying their new goals. This suggested that some of the HIV positive women were waiting to die and did not attempt to start anything that they would not finish. This finding points to the need to develop programmes that increase the self-esteem and self efficacy of HIV infected women.

The care and support that the HIV infected women received from their health care providers was reported to be significant and assisted them in accepting and coping with their diagnoses. The ability of the counsellors to handle emotional and psychological reactions of patients after receipt of an HIV positive diagnosis was vaguely narrated. All participants reported to have received pre and post test counselling with little mention of the quality of the counselling services received.

A conclusion can be drawn from the results, that HIV infected women require assistance in handling the emotional and psychological reaction to an HIV positive diagnosis. Counselling should be consistent and ongoing so as to identify any adverse effects after receipt of a seropositive status and should incorporate the strengthening of future goals.

Another finding was that most participants' immediate concern upon receipt of an HIV positive diagnosis was to whom they were going to disclose their status. The fear to disclose one's HIV positive status was an experience that most HIV infected women narrated during the interview.

### **5.2.2 Fear of HIV/AIDS disclosure**

The majority of the women who chose not to disclose their status expressed that they feared rejection, stigmatization and social isolation in relation to an HIV positive diagnosis.

The findings of the study indicated that HIV infected women found it difficult to disclose to their intimate partners. One of the reasons was that they feared rejection by their partners, which had the potential of destabilizing their financial circumstances. This finding was expected as the majority of women were unemployed, with little prospects of adequate employment as only a few of them had completed grade twelve. A need to empower women to be financially independent arose from this finding.

Another finding was that HIV infected women who had pre-existing unhealthy relationships with their mothers feared disclosing as they feared that they would suffer further rejection. This reciprocal influence was best understood in terms of ecosystems theory. Some women in the sample also feared disclosing to their children for fear that their children were not mature enough to handle the news, while some feared that their children would tell others, who would then stigmatize them.

Stigma in relation to being HIV infected was frequently cited by almost all participants as one of the reasons for non disclosure of an HIV positive status. Participants in the study who feared stigma chose to conceal their status for as long as possible for fear of being labeled negatively, while some chose to lie and provide false diagnosis (i.e. cancer) in order to be accepted as 'normal'. This finding confirmed that there is still HIV related stigma and that some women still prefer to conceal their status for as long as possible. This finding points to the need to address the stigma that prevails in communities. In the community where the study was conducted, terms like 'Z3' appeared to be common when referring to AIDS meaning that the illness was like the Z3 car, it is fast and has deadly characteristics. The fear of stigma was largely driven by the fear of social isolation.

The narrations of fear of social isolation indicated that HIV infected women saw the importance of mutual interdependence as per ecosystems theory, and did not want any disruption in their interacting systems. The participants were all aware of the universally communicated importance of disclosure of one's HIV status, but some still considered the potential risks of disclosure outweighing potential benefits.

These findings conclude that disclosure of an HIV positive diagnosis is an important, yet complicated process, as argued by Makin et al. (2008) and Medley et al. (2004). The HIV infected women who feared consequences of disclosure opted to remain silent because of fear of rejection, stigma and social isolation. This also prevented them from negotiating safer sex practices, thus increasing their re-infection risks. These findings suggest that

HIV infected women require assistance with disclosure of their status to significant others, without the risk of interrupting the mutual interdependence, as supported by the ecosystems theory.

### **5.2.3 Challenges after HIV positive disclosure**

For those women who managed to disclose their HIV positive status, the findings revealed that some of these women were shunned, labeled, and discriminated against. The fears expressed in the latter findings were reported as actual and painful by some women who had disclosed their status to significant others.

The findings of the study revealed that rejection by a partner was an experience for some HIV infected women subsequent to an HIV positive disclosure. Some women had their children taken away from them, while some were verbally and physically abused. These findings highlight the gendered nature of the HIV epidemic, and how women continue to carry the burden of the HIV infection. A conclusion drawn from this finding is that gender based violence infiltrates many systemic levels and in the case of women with HIV, is more acutely experienced. Such findings point to the need to address intimate partner violence first before tapping into other HIV/AIDS issues for women. Even with the suffering experienced, the women who had disclosed to their partners did not regret having done so.

A few women regretted having informed their families of their HIV diagnoses. This finding was contrary to Mturi et al.'s (2006) definition of family as the primary source of physical, social and economic support. This finding indicated that perceived physical and socio-economic support by families of these HIV infected women did not correlate with the actual support provided after an HIV positive disclosure. A more comprehensive family oriented HIV management programme appears to be needed in order to address such family issues emanating from an HIV/AIDS disclosure. Such an approach is supported by the ecosystems perspective where mutual dependence and wholeness of living organisms is acknowledged (Berk, 2001).

The findings of this study also saw the church as perpetuating rejection. This led to some women having to leave their respective congregations because of experienced rejection and stigma. Spirituality for HIV infected women was found by Peterson et al. (2010) and Kasiram (2006) to facilitate coping with a lifelong illness by providing strength, hope, and peace, all which were not present in these findings from these women. This finding points to the need to extend HIV awareness programmes into the spiritual arenas in order to dispel stigma and rejection so that there is support, rather than rejection and judgment of infected persons.

One finding that the researcher noted was how stigma perpetuated against the infected offspring of an HIV positive woman can have a major impact on the HIV/AIDS experience as a whole (ecosystems theory). The HIV infected woman in the current study internalized the stigma by her siblings as directed at her and not her child, thus pointing to the various ways in which stigma can be interpreted (both directly and indirectly) and internalized. This finding indicated the need to address the psychosocial challenges post MTCT (Mother to Child Transmission) and the need to provide ongoing counselling services to the mothers of the infected children.

The current study results showed an overlap in the experiences of rejection, stigma and social isolation for some HIV infected women. Hence, reciprocal influences of various factors as per ecosystems theory are herein evident. Social isolation was found to emanate from the experienced rejection and stigma. A few women in the study chose to withdraw from their normal interaction with their environment as a way of coping with their diagnoses. This finding highlights the social disequilibrium that is perpetuated by the stigma and rejection, and how the environment can contribute to HIV positive women's maladjustment to their diagnoses.

#### **5.2.4 Positive experience of HIV status disclosure**

Findings under this sub-theme indicate that disclosure of an HIV positive diagnosis is not necessarily negative for all HIV infected women. Some of the HIV infected women reported to have received support from all systemic levels after disclosure of their HIV positive diagnosis.

Disclosure of an HIV positive status, for some women, allowed for their relationships with their partners to be strengthened and also allowed for communication of safer sexual practices. The findings revealed that some women in the current study forgave their partners for infecting them, and also used their HIV positive diagnosis to insist on marriage with their partners. Women, whose partners had tested first, had no problems disclosing their status to them. This further highlights the gendered nature of HIV.

Participants' reasons to disclose to family members were mostly prompted by the social support that they expected. Family members intervened immediately after disclosure of HIV positive status. Assistance came in the form of physical, social and emotional support. All participants in the study valued the support they received from their family members and reported how family support assisted them in coping with their diagnoses and living positively.

Openness about one's HIV positive status at a community level was reported to encourage other people to come out and seek help. This is one of the characteristics of a citizen therapist, as communicated by Rojano (2005). Involvement in a support group was also found to aid acceptance of one's status, while HIV positive status disclosure to prominent community members had impact on resource allocation. This finding highlights the need to encourage formation of groups that address the needs of HIV infected women. Almost all participants in the current study were satisfied with the level of service by their local clinic. A few women were concerned about the geographical location of the HIV/AIDS unit in relation to other health units, as this meant that they were easily identified as patients with HIV/AIDS. Stigma

was also an expressed concern at some of the clinics with staff themselves displaying prejudicial attitudes to them. A few women simply stated that having a clinic available to them was good enough. Note must be taken of the fact that respondents may not have offered honest, detailed responses here as the researcher was a staff member of the same clinic (see limitations, chapter 3).

#### **5.2.5 Needs of HIV positive women**

Participants in the current study expressed various needs during the interview. They were also requested to mention their needs based on the challenges they faced as HIV infected women. The needs expressed were influenced mostly by their socio-economic background. The women in the study expressed their need for adequate housing, and shelter. Most women narrated how the plight of HIV infection corroborated with other pre-existing socio-economic adversities, as asserted by Murphy and Greenwell (2006). This finding supports the need to incorporate poverty reduction strategies into interventions for HIV positive women.

Another major finding was that some HIV positive women in the study still required mental health services as they had not yet recovered from discovering their HIV positive status. In this regard, some women indicated the need to join support groups and be with other people who will not judge them.

Further requirements were around the need to be involved in decisions that affected them especially with policy formulation at national and local levels, and become involved in developing gender specific programmes that not only focused on HIV but also the socio-economic and cultural aspects of HIV and women.

### **5.2.6 Coping and survival strategies of HIV positive women**

The HIV infected women's construction of HIV/AIDS as a life long, incurable illness propelled them to adopt various coping and survival strategies. Some strategies helped these women to confront their illness while other approaches helped them to forget about the disease. The findings revealed that despite the challenges faced by these women, they still remained resilient, hopeful and found other ways for to continue living with a dreaded illness. There is therefore a need to enhance the inherent coping abilities of HIV positive women so that they could adjust to HIV related stressors.

Spirituality (through prayer and church attendance) was the widely communicated strategy utilized by HIV positive women in coping with their HIV positive diagnosis. Spirituality provided hope, strength, and well being for the participants in the current study. This finding highlights the need to incorporate HIV/AIDS issues into the church and other faith-based organizations, and the need for religious and spiritual systems to dispel myths and reduce stigma on the epidemic.

Involvement in a support group enabled some women to cope better with their illness. The women expressed the ability of the support group to destigmatise the disease and provide joy and laughter for them in light of their HIV/AIDS burden. This highlights the need for HIV infected women to belong and be provided with a sense of temporary normality. Interestingly, some women saw crying as a way of coping with HIV. Shopping was also a way of coping with the illness. Spending time alone was also a strategy that allowed some women to interrogate personal issues and plan for the future. Both these findings indicate the value of the micro and mezzo systems in assisting women to cope with their HIV positive diagnosis. This finding therefore points to the need to strengthen these ecosystemic levels so as to optimize the level of coping for HIV infected women.

Most of the survival strategies of the HIV infected women were inferred and not clearly expressed. Reaching out to the community, and serving as an

example for others was one of the survival strategies adopted by the women in the current study. HIV infection led to assuming of the role of citizen therapist (as explained earlier). The 'giving back' was also communicated as a responsibility to the community. This finding indicates the **generous duties** some HIV positive women perform without expecting to be remunerated. This finding suggests the need to empower more women (especially the HIV infected) with relevant skills in order for them to become good citizen therapists.

### **5.3 RECOMMENDATIONS**

The following provides recommendations from different levels as per ecosystems perspective:

#### **5.3.1 Micro level recommendations**

##### **Individual counselling**

This study highlighted the need to strengthen the skills of counsellors to enable them to identify psychological distress in clients during pre- and post-test counselling.

Counsellors should be trained to provide therapeutic and educational programmes for HIV infected women with a focus on improving their self esteem. Such programmes could include life skills, negotiation and assertiveness training skills in order to empower women to become more self efficacious, as proposed by Inungu and Karl (2006).

Moreover, counsellors should acknowledge the HIV myths that exist in the communities and also develop strategies to minimize their impact on the HIV infected women's lives. Hence, socio-cultural relevancy is important when counselling is offered.

Ongoing counselling should be considered in order to address challenges that may arise during living with an HIV diagnosis. A resource manual that is electronically available and constantly updated of HIV counselling services should be made available to individuals, groups and communities at large in order to mitigate the challenges that arise from an HIV positive diagnosis. HIV counsellors should be encouraged to refer cases that go beyond their scope of practice. Social workers need to apply their learned skills to assist HIV infected women to cope better with their HIV diagnoses challenges. .

### **Couple counselling**

Couple HIV Counselling and Testing (CHCT) should be encouraged in order to reduce gender-based violence. Such a strategy could assist in communicating consensus around condom usage in a non-threatening environment. The simultaneous counselling of couples could reduce feelings of fear, blame and anger and also reduce the occurrence of intimate partner violence. Simultaneously, men should be regarded as 'strong' when they display sensitivity to their partners' needs. This learning may be imparted early in life whilst youngsters are at schools.

At a CDC (Centres for Disease Control) seminar on Couple HCT held Pretoria on the 21<sup>st</sup> of September 2011, introducing couple HCT was viewed as a strategy to enter into the lives of South African couples. The aim was to not only offer HIV testing and counselling but to also attend to other social issues that couples often experience.

### **Family Counselling**

Family therapy techniques could be employed in dealing with disclosure to significant others, and to assist children in coping with the disclosure of their parent's HIV status. It is recommended that such therapy should take into consideration the unique challenges of HIV infected women in the South African context, as discussed by Murphy and Greenwell (2006).

Families could be encouraged to provide practical, social and emotional support to their HIV infected family members. Education is also necessary in order to dispel myths around risks of transmitting HIV to other family members. Families should also be made aware of services available for HIV infected women in the community so as to occasionally relieve them of burnout associated with caring for the ill.

### **5.3.2 Mezzo level recommendations**

#### **Groups**

HIV infected women are often stigmatized and rejected by society and this leads to social isolation. Involvement in a support group can promote a sense of belonging and provide a safe platform for ventilation of emotions. It is therefore recommended that HIV infected women are encouraged to join support groups. The use of media to show women living positively with the disease (like the Siyanqoba programme) could also facilitate acceptance and destigmatisation of HIV infected women in society and to encourage the formation of, and attendance in support groups.

#### **Community**

Communities need to be educated on HIV transmission and on HIV transmission risk reduction strategies. In order to de-stigmatize HIV, and encourage acceptance of HIV infected women in communities, the challenges of these women should be well understood. Socio-cultural messaging by and for the community is important in order to implement culturally appropriate interventions for HIV infected women. Programmes that target men also need to be implemented in order to address gender imbalances in the management of HIV/AIDS.

## **The Church**

The involvement of churches in HIV/AIDS awareness programmes should be encouraged as the church plays a role in the HIV infected women's adjustment and maladjustment to their diagnoses. Church ministers should be encouraged to bring discussions of HIV/AIDS, sexuality and gender into the church. Spirituality should be used positively to comfort and offer hope to those infected and affected by HIV/AIDS.

## **Traditional Healers**

The inclusion of traditional healers in HIV/AIDS interventions could ensure immediate referral of individuals with HIV symptoms. Traditional healers should also be trained on HIV/AIDS so that they could be able to identify symptoms of HIV infection and be able to intervene culturally and refer for other medical interventions. They could also be helped to work in concert with other helping professionals so as to reduce team competition one finds in practice.

### **5.3.3 Macro level recommendations**

It is recommended that structures be created in communities that will filter the needs of HIV infected women to the sectors that influence policy formation and vice versa. Further, women should be encouraged to become involved in policy change or formulation themselves, so that 'nothing is about them without them'. Funders need to be encouraged to fund programmes for women living with HIV/AIDS.

The Department of Social Development needs to ensure that women who are in receipt of temporary disability grants are referred to income generating projects. This strategy could reduce HIV infected women's dependency on social assistance. They could also be less economically dependant on their male counterparts.

A multisectoral approach in the development of programmes for HIV positive women could foster intersectoral collaboration and reduce duplication of HIV/AIDS services. An example of such a strategy is evident in 'One Stop Centres' which are convenient and integrated. Stakeholders' meetings should also be a platform for all service providers to showcase their services and report on progress or non-progress of community HIV interventions.

The Department of Health and Department of Social Development should offer financial and material support to the Non-Governmental Organizations that have Home Based Care workers so as to boost their morale and encourage them to continue caring for HIV infected individuals in the community.

HIV/AIDS and gender issues need to be incorporated in the university curriculum in order to empower social work students with relevant skills. Social workers also need to work closely with the home based care workers in order to be aware of the needs of community members in relation to HIV/AIDS services.

Guidelines should be clear in relation to implementation of HIV/AIDS programmes for women at all levels of service delivery. 'Strategic plans' should be put into action and not only look good on paper. Practitioners in the field of HIV should have their skills updated regularly and this should receive financial and other support, since HIV/AIDS information is constantly advancing.

It is recommended that findings of this study be disseminated in conferences and seminars that target practitioners and policy makers in the field of HIV/AIDS.

#### **5.4 FURTHER RESEARCH**

The research study explored the experiences of women with HIV/AIDS in a designated health care setting in KZN. There is a need for further research

on a larger scale, in a different context as findings from this study cannot be generalized to the entire population of women with HIV/AIDS. Other studies could be conducted in order to uncover the experiences of service providers and family members of HIV infected women, in order to obtain a clearer view of their challenges and concerns regarding their HIV diagnoses.

This research has highlighted the experiences of HIV positive women, which were either: challenging, positive, or adaptive. Further research is required on the survival strategies that assist HIV positive women in coping with their HIV diagnoses.

## **5.5 CONCLUSION**

The aims and objectives of the study were met as the study has highlighted the challenging and positive experiences of HIV positive women. The study revealed the everyday struggles that women endure from receipt of an HIV diagnosis to disclosure to significant others and eventually adjusting to living with a dreaded disease.

This study has argued that stigma and discrimination discourages HIV infected women from disclosing their status and often forces some of them to conceal their diagnoses for as long as possible. Most women's experiences were challenging not because of the disease but due to the meaning that they (HIV infected women and society) attached to the disease. Moreover, HIV infected women were concerned about the reactions of significant others to their HIV positive status and focused less on themselves. This research process allowed women to focus on themselves and realize the importance of owning their HIV positive experience by 'living positively'.

Some participants were referred for ongoing counselling to the relevant institutions (as discussed in chapter 3). A few participants' coping and survival strategies proved that HIV does not mean an end to life but a beginning of a selfless venture. These selfless acts assisted HIV infected

women to feel comfortable about their HIV status. These survival strategies are worthy of further testing and research.

I conclude with the words of my HIV positive colleague and friend...*"You grow when you give!"*

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## APPENDICES

### APPENDIX A

#### INFORMED CONSENT FORM FOR PARTICIPANTS

**Title of the Study:** Exploring the narratives of women with HIV/AIDS in KZN.

##### *To Whom It May Concern*

My name is Nolwazi Pearl Ngcobo, employed by the KZN Department of Health as a senior social worker at Inanda Community Health Centre. I am currently registered as a Masters student in the School of Social Work and Community Development at the University of KwaZulu- Natal (Howard College). I am conducting a research study aimed at exploring the experiences of HIV positive women in KZN. I believe that my study will impact service delivery positively to HIV infected women

You are kindly requested to participate in one in-depth interview, which will be utilized only for the purposes of this study. Participation in this interview is voluntary, and anonymity will be ensured in the research report. Permission is also requested for audio taping, which will be used by the researcher for record purposes only.

I \_\_\_\_\_ hereby confirm that I understand the content of this document and the nature of the research project. I consent to participate in this study and did so under my own free will.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

## APPENDIX B

26 June 2011

The CEO  
Inanda Community Health Centre  
INANDA  
4310

**RE: PERMISSION TO CONDUCT RESEARCH STUDY AT THE HCT/ARV  
UNIT AT INANDA COMMUNITYHEALTH CENTRE**

I am a Masters student registered in the School of Social Work and Community Development at the University of KwaZulu-Natal. I seek permission to conduct a research study with the patients under the ARV/HCT unit, focusing on HIV positive women. The main aim of the study is to explore the narratives of women with HIV/AIDS with special reference to their experiences, challenges and to identify their coping strategies.

The research findings will provide key recommendations for the services rendered by the Social workers, and the HCT/ARV staff, to the HIV infected women. This study aims to contribute to the existing (although limited) body of knowledge regarding the experiences of HIV positive women.

---

N. P. Ngcobo  
Senior Social Worker

## APPENDIX C

### Semi-Structured interview schedule (Draft)

#### DEMOGRAPHIC INFORMATION

##### Participant

Race:

Age:

Marital Status:

Occupation:

Home Language:

Highest Grade Passed:

Residential Address:

Number of Dependants:

Total number in a household:

Total Household income per month:

Using narrative therapy, the following themes will be explored in **the interview:**

**1. Diagnosis of your status- the development your narrative**

- First discovery of your HIV positive status.

**2. Receipt of this information**

- Your feelings upon receipts of HIV positive status
- Pre- and post-test counselling, explain.

**3. Plotting your adjustment to AIDS (explore biological, psychological, social, ecological challenges and successes)**

- Challenges encountered after receipt of HIV diagnosis

- How challenges have affected your life in general
- Disclosure as a challenge
- Sources of support (emotional, financial, etc)
- Support required.

**4. Your experience of "mastery" over AIDS- what, when, how?**

- Coping with an HIV positive status, explain
- When did that happen?
- How did you feel when it happened?

**5. Your message to others for positive living?**

**NB. The above questions were used as an interview guide. No particular order was followed.**