# THE EXPERIENCES OF HIV SERO-DISCORDANT COUPLES AT THE PERINATAL HIV RESEARCH UNIT IN SOWETO, GAUTENG PROVINCE

Ву

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I declare that THE EXPERIENCES OF HIV SERO-DISCORDANT COUPLES AT THE PERINATAL HIV RESEARCH UNIT IN SOWETO, GAUTENG PROVINCE is my work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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#### **ABSTRACT**

This qualitative exploratory and descriptive study explored and described the experiences of HIV sero-discordant couples post diagnosis at the Perinatal HIV Research Unit in Soweto, Gauteng Province. Data was collected using in-depth interviews with each individual from seven HIV sero-discordant couples. Following thematic analysis, four themes emerged: immediate response to HIV sero-discordant results; challenges in relation to disclosure of HIV sero-status; limited information on HIV sero-discordant; and the impact of HIV sero-discordant on the couples. All these were mainly linked to poor counselling and inadequate support to HIV sero-discordant couples. The findings of this study have both clinical and policy development implications. Recommendations have been put forward for development of contextual relevant HIV Sero-discordant Couple Counselling and support guidelines focusing of enhancing knowledge and skills of health care professionals responsible for counselling and supporting HIV sero-discordant couples.

**KEY CONCEPTS:** Couple; experiences; heterosexual; HIV; sero-discordance

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# LIST OF ABBREVIATION AND ACRONYMS

AIDS Acquired Immune Deficiency Syndrome

CHCT Couples HIV Counselling and Testing

HIV Human Immunodeficiency Virus

NFHS National Family Health Survey

NIH National Institute of Health

PAPM Precaution Adoption Process Model

PHRU Perinatal HIV Research Unit

UNAIDS The Joint United Nations Programme on HIV/AIDS

UNISA University of South Africa

VCT Voluntary HIV Counselling and Testing

WHO World Health Organisation

#### **CHAPTER 1**

#### **ORIENTATION TO THE STUDY**

#### 1.1 INTRODUCTION

The term HIV sero-discordant is generally used to describe people of different HIV antibody statuses in intimate relationships in which one partner is known to be HIV positive and the other is HIV negative. In countries with generalized HIV epidemic, HIV sero-discordant relationships are common. Improvements in the effectiveness and availability of HIV treatment in recent years that enables HIV positive individuals to live longer and healthier, have also led to an increase in the number of HIV serodiscordant couples (Rispel, Cloete, Metcalf, & Moody, 2009:9). An estimated twothirds of infected heterosexual couples have been classified as HIV serodiscordance. De Walque in the AIDSTAR-One report (2010:1) indicates that among the sero-discordant heterosexual couples, infected female partners constitute 30 to 40% of sero-discordant couples. According to the World Health Organisation (2012:2), only 40% of people living with HIV and AIDS (PLWHA) globally, know their status. The report further notes that up to 50% of PLWHA in on-going relationships have HIV negative partners. Of those PLWHA who know their status, many have not disclosed their HIV status to their partners, and neither knows their partners' status. Consequently, a significant number of HIV sero-discordant couples get infected.

Couples HIV Testing and Counseling (CHCT) offers couples the best opportunity to test, receive their results, and mutually disclose their status in an environment where support is provided by a counselor or a health worker. A range of prevention, treatment and support options can then be discussed and decided upon together, depending on each person's HIV status.

HIV sero-discordant among couples is an increasingly important issue in HIV counseling and prevention activities. HIV counseling is defined as confidential dialogue between an individual and a health care provider aimed at enabling the person to cope with stress and make personal decisions related to HIV and AIDS (Asefa, 2006:1). For the person being tested, HIV testing and depending on post-testing information has consequences far beyond the diagnosis.

This chapter provides a general overview to the research study outlining the study background, rationale of the study, statement of the problem, purpose and objectives of the study and the significance of the study. The research design and methodology are also outlined in brief.

#### 1.2 BACKGROUND INFORMATION ABOUT THE RESEARCH PROBLEM

In this section, the source of the research problem and background to the research problem are discussed.

#### 1.2.1 The Source of the Research Problem

It is important to note that prior to undertaking this research, the researcher of this study has worked in the Perinatal HIV Research Unit (research site) in Soweto as a social worker. One of her responsibilities included the counselling of clients who were referred to her by other health care professionals. In most cases, these clients were HIV sero-discordant couples. She realised that couples in these situations, find it hard to understand and accept HIV sero-discordant. During the course of her work, the researcher had witnessed several couples terminating their relationships even those not infected with the HIV virus as a result of fear of the possibility of being or getting infected. The researcher also had relatives and friends who were in HIV sero-discordant relationships and unfortunately for some of them, even though they had

separated in their relationships, it was sad to know that they had been infected with HIV. The dynamics of these relationships motivated the researcher to develop further interest to know more about HIV sero-discordant and better understand the experiences of couples who were in such relationships and even those who are still in one.

# 1.2.2 Background to the Research Problem

This section gives a general overview of HIV and AIDS. Information related to HIV in hetero-sexual relationships and issues relating to sero-discordant couples are highlighted. According to Hailemariam, Kassie and Sisay (2012:1), the emergence of HIV epidemic is one of the biggest public health challenges the world has ever experienced in recent history. In the last three decades HIV has spread rapidly and affected all sectors of society including the young and old, children (unborn and living) and adults, men and women, the rich and poor etc. Sub-Saharan Africa is at the epicentre of the epidemic and continues to carry the full brunt of this health malaise. Among the estimated 40 million people worldwide currently living with HIV-1 infection, 65% reside in sub-Saharan Africa, and of those 23.5% are infected with HIV, with heterosexual exposure as the primary mode of HIV transmission. Prior studies have found high rates of HIV transmission occurring between HIV discordant partners (one partner is HIV infected and the other uninfected) who are often in stable partnerships but unaware of both partner's HIV sero-status, (Lingappa, Lambdin, Bukusi, Ngure, Kavuma, Inambao, et al.,, 2008:1).

In Africa, 85% of adult HIV infections are due to heterosexual transmission. Although HIV sero-negative partners amongst HIV discordant couples are at a 10% annual risk of acquiring HIV infection, a large proportion of new HIV infections in Africa occur in stable relationships. Most HIV prevention programs in Africa focus on reducing the number of casual sexual partners, the use of condoms during casual sex, and increasing fidelity among married partners (Lingappa, et al., 2008:2). A

study conducted in Uganda indicates that 83% of HIV infected men and 77% of HIV infected women are or have been married. Lingappa et al. (2008:1) also indicate that amongst HIV infected married persons, 75% of men, and 96% of women report having sex only with their spouses. They further noted that heterosexual couples in Africa currently represent the world's largest HIV risk group. As such, it seems much difficult to adopt a set of preventive behavior with a regular partner than with an occasional partner. In a conjugal relationship, women face many difficulties in using or asking for protection during sexual intercourse. Overall the majority of men and women who live as a couple where one partner is HIV infected, do not know their own HIV status. Hence, developing effective HIV prevention interventions that target HIV sero-discordance couples could potentially contribute to reducing HIV transmission in many countries. Moreover, the provision of target specific services to sero-discordance couples could help them manage their status in a more comprehensive HIV response manner (United States Agency for International Development (USAID), 2010:1).

In most sub-Saharan African countries with generalized HIV epidemic status, three-quarters of adults aged 20–49 years reported being in cohabiting relationships (Lingappa, et al., 2008:1). Among people with HIV who are in stable relationships, up to half have HIV-negative partners, implying that they are in a sero-discordant relationship (Chemaitelly, Cremin, Shelton, Hallett and Abu-Raddad 2012:88). Such proportions have been reported in both the general population and specifically among women and their partners attending antenatal clinics (De Walque, 2007:3).

With regards to South Africa, the size and nature of the country's HIV epidemic is of dire concern. According to a report by the South African government (2011:2), the HIV 'epidemic' of the 1990s with the disease outbreak of unexpectedly high occurrence, has become 'endemic'. Thus, the unexpected increase in new HIV infection incidence in the country has settled at a high level to an extent that there are now significant numbers of persons living with HIV (18% of adults aged 15-49) (ibid). South Africa is one of several countries most impacted by HIV. A recent statistical report indicated that there are approximately 5.5 million people living with

HIV in South Africa (UNAIDS, 2012:1). The prevalence of HIV in South Africa is 18% among 15-49 year old adults and 30% among female antenatal attendees, implying the continuing need for effective HIV prevention.

Because of the high level of HIV infections in the country, South Africa's HIV epidemic has escalated to a hyper-endemic epidemic. The South African government report (2011:2) further asserts that such 'mature' level of epidemic characterised by large numbers of persons infected and continuing new infections, require long term sustainable response of large scale to bring about change, as opposed to a short-term, emergency response because in reality HIV prevalence in this context is not going to reduce dramatically in the near future, even if new infections were almost entirely halted.

Epidemiological projections and initiatives reinforce the view of an endemic HIV infection in South Africa, which makes a complete reversal in the foreseeable future extremely difficult, if not impossible. The long term monitoring system of HIV surveillance confirms that South Africa's HIV hyper-endemic is growing. The prevalence of HIV sero-status discordance amongst couples is high and varies in sub-Saharan Africa with figures ranging from as low as three percent in the general population to over 60% among married or cohabitating couples (Bunnell, Nassozi, Marum, Mubangizi and Malamba (2005:17). Authors such as Mujugira, Baeten, Donnell, Ndase, Mugo, et al. (2011:6) maintain that HIV negative persons of discordant couples remain at critical high risk of contracting the infection in settings where antiretroviral therapy is not universally available. Evidence also shows that HIV sero-discordant couples contribute to new HIV transmission events in mature epidemics (Rispel, Cloete, Metcalf, Moody, & Caswell, 2012:14).

WHO (2012:5) asserts that in most studies of HIV sero-discordant relationships, half of the infected partners are males and half are females. Data from 27 cohort study totalling 13,061 HIV sero-discordant couples in sub-Saharan Africa and Demographic and Health Survey (DHS) data on 1145 HIV sero-discordant couples in 14 countries suggests that the proportion of HIV-positive women in stable heterosexual HIV sero-discordant relationships is 47%. This may partly be due to

women contracting HIV infection during premarital sex. Furthermore, it seems that a high proportion of young women in Africa are infected by HIV during their teen-age years, before marriage, because they engage in transactional relations with older men. De Walque's (2007:3) analysis also suggests that extramarital sexual activity among women in union, as described for men, is also a critical source of vulnerability to HIV infection. A study in rural South Africa had also shown that the direction of the spread of epidemic was not only from returning migrant men to their female partners, but also women to their migrant partners (Lurie, Williams, Zuma, Mkaya-Mwamburi, Garnett, Sweat, Gittelsohn, Karim ,Lurie, et al., 2003:2245).

Rispel and colleagues (2009:15), reported a high prevalence of HIV discordance among couples that participated in a multi-site clinical trial in 12 communities in Eastern and Southern Africa with some regional differences. Guthrie, de Bruyn, & Farguhar (2007:418) in a review of studies of HIV discordant couple's summarised HIV incidence rates, biological and behavioural risk factors for HIV transmission. The rate of HIV sero-discordant in heterosexual couples underscores the fact that the risk behaviours of men put their monogamous partners at risk. This is exemplified by data from the National Family Health Survey (NFHS) in India, which revealed that at least one partner in every 200 married couples in the country, is infected with HIV. Women are HIV negative in about 0.76 million couples and men are HIV negative in about 0.16 million couples. These data indicates that there is a large cohort of HIV sero-discordant married couples with either the man or the woman is HIV positive. Representative surveys on sexual behaviours in the region have found that very few women report having had more than one lifetime sexual partner. These findings also highlight that there is a need to carry out better research in order to understand the underlying mechanisms of HIV transmission.

Rispel et al (2009:15) have reported that HIV negative partners in discordant relationships may have HIV incidence rates of 10-20% per year which is approximately 10 to 100fold higher than relationships where both partners are HIV-negative. A one-year long study of HIV transmission amongst HIV discordant couples in Pane, India (Hugonnet, Mosha, Todd, Mugeye, Klokke & Ndeki 2002:75)

found the HIV incidence rate among HIV-negative partners to be 1.2% per year, which is much lower than the HIV incidence rates reported among discordant couples in Africa. The authors concluded that higher rates of condom use, lower rates of STI's and higher CD4 counts among the Indian HIV sero-discordant couples might account for the lower rates.

Based on the above reports, it is evident that HIV sero-discordant is prevalent globally, but more common in Sub-Saharan Africa. This continues to be dire concern that calls for serious and immediate intervention services to address it since heterosexual couples are now classified as the high risk group due to low protective measures or the lack thereof in their relationships.

#### 1.3 RESEARCH PROBLEM

Existing literature has shown that HIV sero-discordant couples are experiencing several challenges which in some cases results in separation or infection of the previously uninfected partners(Hugonnet, et al., 2002:75; Rispel, et al., 2009:15). This was also observed by the researcher during her work at the Perinatal HIV Research Unit in Soweto, South Africa prior to conducting this study. Such separations may contribute to further spread of HIV as separated individuals in stressful, unstable emotional-psychological state tend to enter into new relationships thus risk being infected or infecting new partners with HIV. Stress stemming from separation may also cause an infected person to quickly progress to full blown AIDS. The researcher also experienced HIV negative female patients being supportive to their infected male partners which escalated their risk of been infected with the HIV virus. This was alluded to by Mujugira and colleagues (2011:6)in their report stating that HIV negative members of discordant couples are at high risk of HIV infection. Similar findings also have shown that HIV sero-discordant couples strongly contribute to new HIV transmission (Rispel, et al., 2012:14). According to a Perinatal

HIV Research Unit report (Essien, 2012), from a total of 27,027 individuals, 2,312 (8.5%) were couples. Of the total number of couples tested, 37% had discordant HIV results. Nothing is documented regarding what these discordant couples go through in their lives. The 2,312 (8.5%) discordant couples cited in the Perinatal HIV Research Unit report above represents all of the couples tested and is a large number of people. If nothing is done to explore their experiences as HIV sero-discordant couples to find suitable solutions to assist them, the number will increase gradually or exponentially over time and defeat the South African government's (2011:6) goal of Zero new HIV infection by 2015. This background provides a rationale for exploring what the HIV sero-discordant couples experience in their relationships.

# 1.4 PURPOSE AND OBJECTIVES OF THE STUDY

In this section, the research purpose and objectives are presented.

#### 1.4.1 Research Purpose

The purpose of this research was to explore the experiences of HIV sero-discordant diagnosis amongst heterosexual couples at Perinatal HIV Research Unit in Soweto, Gauteng Province, South Africa.

#### 1.4.2 Research Objectives

The objectives of the study were to:

 Explore and describe the experiences of HIV sero-discordant diagnosis amongst heterosexual couples at Perinatal HIV Research Unit in Soweto, Gauteng Province.

#### 1.5 RESEARCH QUESTION

What are the experiences of heterosexual HIV sero-discordant couples at Perinatal HIV Research Unit clinic in Soweto, Gauteng Province?

#### 1.6 SIGNIFICANCE OF THE STUDY

Significance refers to the relevance of the research to some aspects of a profession, its contribution towards improving the knowledge-base of a profession and its contribution towards evidence-based practice (Burns & Grove, 2005:2; Polit & Beck, 2008:86). Information on strategies used by HIV sero-discordant couples to sustain their relationships, make appropriate sexual and reproductive choices, sustain their health, and avoid HIV transmission is scanty or quite limited. Hence, it is important to address knowledge gaps in order to develop programmes to help discordant couples make informed sexual and reproductive choices, and sustain healthy mutually-supportive relationships.

A research of this nature was relevant because some couples assume that if one partner is sero-positive, then the other partner or all partners in contact are positive. This unfounded assumption results in non-infected partners not taking precaution to protect themselves. This study was further relevant because a study of this nature

has not been conducted previously at Perinatal HIV Research Unit clinic with regards to the experiences of HIV sero-discordant heterosexual couples.

It was anticipated that the results of this study will contribute to the solutions of the aforementioned research question with timely interventions for heterosexual couples with HIV discordant so that issues relating to emotional, psychological, and sexual challenges, disclosure, support system, risk behavior, among other things can be profoundly addressed. Heterosexual couples are a critical target for counseling, testing and evaluation of new preventive interventions. Thus, building capacity for couples with development of messages centered around testing as couples and the importance of HIV discordance in HIV transmission is an important sustainable public health initiative in Africa(Lingappa, et al., 2008).

Furthermore, a study of this nature was clinically relevant because it can contribute towards improving evidence based practice in addressing the research problem. The results indeed shed light on the direct impact or consequences of HIV sero-discordant amongst heterosexual couples. This has helped the researcher to better understand the experiences of sero-discordant heterosexual couples.

#### 1.7 DEFINITIONS OF KEY CONCEPTS

**Couple**: Two persons in an on-going sexual relationship, each of these person is referred to as a "partner" in the relationship(World Health Organisation, 2012:7).

**Experience(s)**: Is skillful, accumulative knowledge and direct personal participation that a person has undergone (Mini Dictionary & Thesaurus, 2002:214).

**Heterosexual**: A person sexually attracted to people of the opposite sex (Oxford Mini Dictionary & Thesaurus, 2002:165).

**HIV**: The human immune-deficiency virus – the virus which causes AIDS, (Van Dyk, 2008:4).

**Sero-discordance**: It refers to the situation where one partner is HIV positive and the other partner is HIV negative, (World Health Organisation, 2012:8).

#### 1.8 THEORETICAL FOUNDATION OF THE STUDY

#### 1.8.1 Theoretical Framework

The theory of the Precaution Adoption Process Model (PAPM) has been identified in explaining the behaviour and experiences of HIV sero-discordant couples. According to (Glanz & Rimer, 2005:18), this theory specifies seven distinct stages in the journey from the lack of awareness to adoption and/or maintenance of behaviour. It is a relatively new model that has been applied to an increasing number of health behaviours. Glanz & Rimer (2005:18) also asserts that, in the first stage of the PAPM, an individual may be completely unaware of a hazard e.g. unprotected sex and HIV. The person may subsequently become aware of the issue but remain unengaged bringing him/her to stage 2. Next, the person faces a decision about acting - stage 3; then may decide not to act - stage 4, or may decide to act - stage 5. The stages of action - stage 6 and maintenance - stage 7 follows (See figure 1 below).

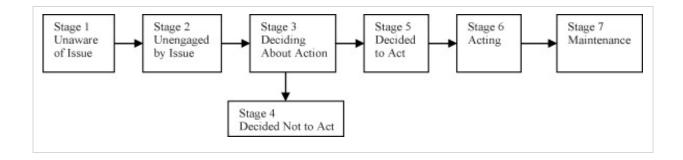


Figure 1: Theory of Precaution Adoption Process Model (PAPM)

According to the PAPM, people pass through each stage of precaution adoption without skipping any of them. It is possible for people to move backwards from some later stage to earlier ones, but once they have completed the first two stages of the model they do not return to them. For example, a person does not move from unaware to awareness and then back to unawareness, (Glanz & Rimer, 2005:19). The PAMP recognises that people who are unaware of an issue, or are unengaged by it, face different barriers from those who have decided not to act. The PAMP prompts practitioners to develop intervention strategies that take into account the stages that precede active decision making.

By and large, the HIV sero-discordant couples in relation to the above theory often seem to be in stage 1 because they are unaware of their HIV statuses until their first diagnosis when tested together. After receiving their results, which is basically at stage 2 they tend to still be in denial of their results even though they were in contact during pre-test and post-test counselling. While some couples may make the right decision pertaining to improving their health, others will fail to do so particularly at stages 3 and 4. Those who decided to act (stage 5) after been informed of their HIV status and respecting their health, will often manage to access the anti-retroviral treatment (ART) so that they can improve their health. At the same time, some couples though aware of their HIV status and knowledge of HIV transmission, they just decide not to act (stage 4), but rather continue practicing high risk sexual

behaviour. Those who decided to act positively (stage 6) and take ART tended to maintain their stance by adhering to treatment, and in turn improved their health.

#### 1.9 RESEARCH DESIGN AND METHOD

## 1.9.1 Research design

Polit and Beck (Polit & Beck, 2008:66) defines research design as an overall plan that helps a researcher obtain answers to the research questions and helps the researcher address challenges that may arise while conducting the research. The researcher used exploratory and descriptive qualitative research design to explore and describe the experiences of HIV sero-discordant diagnosis of heterosexual couples.

# 1.9.2 Study Site

According to Polit and Beck (2012:66), study site refers to the overall location where a study is undertaken. The study site was the Perinatal HIV Research Unit in Soweto, Gauteng Province, South Africa.

# 1.9.3 Study Population

Population refers to the entire aggregation of cases, individuals, or units of study which contains representatives of all measurements of interest of a researcher (Burns & Grove, 2005:343). The population for this study was the HIV sero-discordant heterosexual couples from the catchment area of the study site.

# 1.9.4 Sample and Sampling Technique

Burns & Grove (2005: 343) asserts that sample is the number of elements that are included in the study. Sampling is the process of taking part of the study population. Researchers study the specific or target sample to make inference to the target population from which the sample was drawn (De Vos 2005:198). A purposive sampling technique was adopted and sampling size consisted of 14 individuals who made up the seven couples.

#### 1.9.5 Data Collection

Data collection refers to gathering of information to address a research problem (Polit & Beck, 2008:725). It also entails precise, systematic gathering of information relevant to the research purpose or the specific objectives, questions or hypothesis of a study(Burns & Grove, 2005:733). In-depth individual face to face interviews were conducted with each HIV sero-discordant individual member of the heterosexual couples and data recorded by the principal researcher. The data was quantified and analysed.

# 1.9.6 Data Analysis

Data analysis refers to breaking up the data into manageable themes, patterns, trends and relationships. The aim of analysis is to understand the various constituent elements of one's data and to identify or isolate any patterns or trends, or establish themes in interpretation (Mouton, 2008:108). The researcher used qualitative content analysis to analyse the data. Polit and Beck (2012:564) further states that, qualitative

content analysis involves breaking down data into small units, coding and naming the units based on the shared concepts.

#### 1.10 ETHICAL CONSIDERATIONS

Ethical clearance was provided by the University of South Africa prior to the study commencement. Furthermore, approval from the study site was provided to conduct the study. All other relevant aspects were ethically maintained and respected throughout the study.

## 1.11 STRUCTURE OF THE DISSERTATION

This dissertation is structured as follows:

**Chapter 1**: Introduces and gives an overview of the study.

**Chapter 2:** Provides a discussion of research design and methodology adopted in this study. Ethical and relevant measures undertaken to ensure trustworthiness of the research process are thoroughly described.

**Chapter 3:** Focuses on presentation of the results based on participant interviews and supported by direct quotations from the participants.

**Chapter 4:** Provides a discussion of results in relation to previous studies around the experiences of HIV sero-discordant couples.

**Chapter 5:** Presents conclusions, recommendations and limitations of the study.

#### 1.12 SUMMARY

This chapter has covered the introduction of the study, background to the research problem, research problem, research aim, research question, significance of the study, definitions of terms, theoretical foundation of the study, research design, and method, scope of the study and the structure of the dissertation. In-depth discussion regarding the study methodology is provided in chapter 2 below.

#### **CHAPTER 2**

#### **RESEARCH DESIGN AND METHOD**

## 2.1 INTRODUCTION

The previous chapter had focused on introducing the study problem and highlighted relevant literature. This chapter focuses on the research design and methods covering the following: research paradigm, research design, research sample and population, data collection, data analysis and ethical considerations.

## 2.2 PURPOSE AND OBJECTIVES OF THE STUDY

As already noted, the purpose of this research was to explore the experiences of HIV sero-discordant diagnosis amongst heterosexual couples at Perinatal HIV Research Unit in Soweto, Gauteng Province, South Africa.

#### 2.3 RESEARCH CONTEXT

This section highlights the setting and site for this research.

#### 2.3.1 The Context

Soweto is a well-known tourist black urban township with a population of over one million people. It is situated in Southern Johannesburg, Gauteng Province, South Africa. As an urban-rural township and though surrounded by good businesses areas and improved infrastructures for both small and medium enterprises which benefits the general Soweto community, Soweto has challenges of high unemployment, overcrowding, informal settlement, crime and poor housing. The increase in informal settlements with people moving from rural to urban areas in search of improved schools and employment further stifles the urbanization, increases overcrowding, crime and poor housing.

Soweto residents have different services available to them including schooling, recreational facilities, service facilities such as health clinics and hospitals and police stations among others. There are numerous Non-Governmental Organizations that work very closely with the government with the aim of improving the health and living conditions of the community. The present improved transportation system makes it easy for individuals to access surrounding areas and community members stay close to each other.

The prevalence of HIV in South Africa is 18% among 15-49 year old adults and 30% among female antenatal attendees, implying the continuing need for effective HIV prevention. In Gauteng province in which Soweto is located, the household probability prevalence rate of HIV is 17.3% (UNAIDS, 2012:1). About 60% of Soweto's population is unemployed and learners who drop out of school are often forced to get some income work to take care of their families. As such, some females get engaged in transactional sex or sexual relationships with older and financially better-off men with the hope of benefiting financially from them to improve their livelihoods. This has resulted in the spread of HIV/AIDS in the community. Little is known about the HIV sero-discordant couples who seek for services at Perinatal HIV

Research Unit clinics, and this presents challenges and effects that cause them to be in denial of their HIV status after testing.

## 2.3.2 The Setting of the Study

The research study focused on HIV sero-discordant couples who had received HIV Counselling and Testing (HCT) services from Perinatal HIV Research Unit in Soweto where the researcher had previously worked at this unit with sero-discordant couples. While working there, it was evident that sero-discordant couples were presented with numerous challenges which impacted negatively on their relationships. The PHRU was selected because it provided a variety of HIV/AIDS services to the community of Soweto in particular, and it's surrounding areas.

The Perinatal HIV Research Unit is one of the leading research centres in Gauteng Province in South Africa and is affiliated to Witwatersrand University. The unit is typically involved in research, training, policy formation and advocacy in issues concerning adults, HIV positive women and children. Currently it provides adult, paediatric and adolescent HIV treatment, and HIV prevention services. In addition, it also covers research relating to tuberculosis (TB) and other HIV co-infections. It also conducts behavioural and social science research, advocates for research access and provides needed care to the people of Soweto. It further provides general and other specialized care and treatment to many Soweto residents and these services complement government's social and healthcare programmes.

The HCT Centre, which is part of the Perinatal HIV Research Unit, where study participants were purposively selected, serves individuals from the age of 12 and provides a variety of services such as individual and couples' counselling, CD4, Hypertension, diabetic and sexually transmitted infection services etc. It caters to approximately a total number of 40 and 65 people daily for HCT services and refers

other patients to government or private facilities for further intervention and management services. However, if patients are willing and do meet the requirements of their research studies they are invited and informed of the studies so that they can make informed decisions should they wish to participate.

#### 2.4 RESEARCH PARADIGM

According to Polit and Beck (2012:736), a research paradigm is a way of looking at natural phenomena, a world view that encompasses a set of philosophical assumptions that guide one's approach to inquiry. The researcher adopted constructivist paradigm. Constructivism is an approach that focuses on the role of human beings as social actors in the generation of scientific knowledge (Golinski, 2005:1). Qualitative research is also referred to as constructivist research based on the assumption that individuals construct reality in the form of meaning and interpretation of phenomenon or experiences by studying research participants in their natural settings (Houser 2012:420). Further, qualitative research generally aims at exploring and understanding the experiences and attitudes of participants (Combs & Onwuegbuzie, 2010:3,Brikci & Green, 2007:3).

Qualitative research focuses on obtaining deep and meaningful information from small groups which fulfil certain criteria set out by the researcher (Polit & Beck, 2009:752). Generally speaking qualitative methods are typically more flexible-implying that the researcher has greater spontaneity and adaptation of the interaction with the study participants (Hancock, Windridge, & Ockleford, 2007:6). For example, qualitative methods mostly ask open-ended questions that are not necessarily asked in exactly the same way with each participant. With open-ended questions, participants are free to respond in their own words rather than simply "yes" or "no". Qualitative methodology was employed in this study to investigate the experiences of HIV sero-discordant diagnosis of heterosexual couples. Since qualitative methods provide in-depth information about people's experiences and

why problems occur, adopting this research method is justified. In-depth individual interview was used stemming from a grand tour question. This approach was followed as it allowed Participant's to narrate their experiences freely and in turn allowed the researcher to construct the meaning of participants' experiences relating to living with HIV sero-discordant partners.

#### 2.5 RESEARCH DESIGN

According to Kerlinger (cited in Mouton, 2005:55) a research design is a plan or blueprint of how one intends to conduct research. Welman and colleagues (2006:46)states that study design is a plan of action to which researchers obtain research participants (subjects) and collect information from them.

# 2.5.1 Qualitative Design

According to Burns and Grove (2005:747), qualitative research refers to a systematic, interactive subjective approach that is used to describe and give meaning to life experiences. According to Polit and Beck (2010:752), qualitative research method displays how events and things are put together, more or less coherently and consciously into frameworks that makes sense of their experiences. In addition, participants have the opportunity to respond more elaborately and in greater detail than is typically the case with quantitative methods (ibid).

# 2.5.2 Exploratory Design

According to Polit and Beck (2012:18), exploratory research begins with a phenomenon of interest than simply observing and describing it. Exploratory research investigates the full nature of the phenomenon, the manner in which it is manifested, and the other factors to which it is related. The use of an exploratory approach or method allowed and provided an opportunity to understand the participants' experiences relating to living with HIV sero-discordance partners. This design further permitted participants to express their experiences freely since the nature of the study was sensitive.

# 2.5.3 Descriptive Design

Babbie (2007:89) stipulates that descriptive designs are those used to describe situations and events. A researcher observes and then describes what was observed. Application of this design in this study was found to be very useful as it enabled the researcher to better understand and describe the experiences of sero-discordance diagnosis among heterosexual couples. Participants, during the interviews were better able to describe their experiences of HIV sero-discordant diagnosis.

# 2.6RESEARCH METHOD

Research methods according to Polit and Beck (2008:66), refers to the steps, procedures and strategies for collecting and analysing data in the research process. The following research methods are discussed further in this section: population, sample and sampling procedure, data collection and data analysis.

# 2.6.1 The Study Site

Polit and Beck (2012:743) defines a 'study site' as the overall location where a study is undertaken. The study site for this research was Soweto, situated in the Gauteng Province of South Africa.

# 2.6.2 Population

Brink (2009:123) refers to a 'population'as the entire group of persons or objects of interest to the research that meet a set criteria of interest. For this study, the target population was HIV sero-discordant heterosexual couples in Soweto, Gauteng. All participants were expected to meet the inclusion criteria of the study.

# 2.6.3 Sample and Sampling

Sampling is the process of selecting specific cases of interest to represent an entire population so that inferences about the population can be made (Polit & Beck, 2012:275). According to Burns and Grove (2005:343), sample size is the number of elements that are included in the sample. The envisaged sample size for the study was 20 participants who made up of ten couples; however data was only collected from 14 individuals who made up of seven couples as data-saturation was reached.

Non-probability sampling involves selection of participants available at the time of data collection or participants that can significantly contribute meaningfully to the study (Moule & Goodman, 2009:272). Non-probability sampling method commonly

uses convenience and purposive sampling (Polit & Beck, 2012:375). And for this study, a non-probability sampling approach was used.

As indicated above, a convenient and purposive sampling technique was used as participants were selected based on availability. According to Polit and Beck (2012:285), purposive sampling is when the researcher selects information-rich cases or group that will best contribute to the research study. This type of sampling was used because the researcher knew the couples who met the sample eligibility criteria for the study. The following eligibility criteria were considered for participants for the study:

- Heterosexual couples with confirmed HIV sero-discordant results
- Should be in a relationship for 6 months and more
- Should be between 18 50 years
- Should be willing to participate in the study voluntarily
- Willing to sign a consent form and be audio-recorded with their approval

# 2.7. DATA COLLECTION

Polit and Beck (2010:725) defines 'data collection' as the gathering of information to address a research problem. It also entails precise, systematic gathering of information relevant to the research purpose or the specific objectives, questions or hypothesis of a study (Burns & Grove, 2005:733). Data was collected using a grand tour question approach in which research participants freely express their feelings and experiences since they were diagnosed as HIV sero-discordant couples.

# 2.7.1 Development and Testing of the Data Collection Instrument

The 'grand tour' tour question was developed stemming from the purpose of the study and the research question. A sero-discordant couple who was not part of the sample was interviewed as a pilot to check the feasibility of the approach before conducting interviews with all the participants. The transcripts from these interviews were submitted to my study supervisor to check the approach used and also the follow-up questions and the probes which I used. Guidance were offered were it was seen that the probes where irrelevant and also where closed and leading questions were use. The two transcripts from study were excluded during data analysis.

## 2.7.2 Data Collection Process

A healthy positive rapport and an atmosphere of trust were built prior to interviewing with each participant. The importance of the research purpose and the importance of ethics were discussed with the participants. Consent forms were signed before conducting interviews and permission for recording was also sought from the participants.

## 2.7.3 Data Collection

In-depth individual interviews were conducted with all the participants who volunteered to participate. Interviews were initiated from a central question: "please share your personal experience since your diagnosis as HIV sero-discordant couple"

Using Kvale's (1996: 124-135) guidelines, interviews were conducted as follows:

• The interview primarily centred on HIV sero-discordance.

- Each session started with questions on a variety of informal, conversational aspects about life in general, and moved unto the broad question of the experience of living as sero-discordant couple.
- Using open-ended probing type question, more information regarding serodiscordancy were asked. This was done to encourage participants to elaborate on their statements, clarify any information or identify emotions around the topic.
- Participants were interviewed individually in their residential area.
- Though some participants showed discomfort, shame, or anger in talking about HIV status, the researcher strived to make them feel comfortable.
- Interviews were conducted in English though somewhere clarification was sought, the participant's' mother tongue was used e.g. Southern Sotho and Zulu and then interpreted in English. All interviews were recorded with the participants' consent. During the interview, the researcher used field notes to capture observations that could not be captured on audio-tape, including non-verbal gestures, the interview setting and the researchers' own impressions.
- Validation was done through asking related questions to verify observations
  of non-verbal cues, and to avoid wrong assumptions that might have
  invalidated the results.
- The researcher was sensitive to the knowledge and background of the participantsand reassured them from time to time about confidentiality and respect for human dignity.
- Throughout the interview process and with each question, the interviewer
   (i.e. the researcher) carefully and attentively listened without interruption,
   thus allowing each participant time to express herself freely. Interpersonal
   interaction during interviews was promoted with minimal encouragement.

# 2.7.3 Data Analysis

According to Mouton (2005:108), data analysis refers to breaking up the data into manageable themes, patterns, trends and relationships. Mouton further maintains

that, the aim of analysis is to understand the various constitution elements of one's data to see whether there are any patterns or trends that can be isolated or identified and discussed. For this study, content analysis was used to analyse data obtained from participants. Content analysis as Polit and Beck (2012:564) puts it, refers to the content of a narrative data in identifying prominent themes and patterns. This involves breaking down data into small units, coding and naming the units based on shared concepts (ibid).

## 2.8. ETHICAL CONSIDERATIONS

Babbie (2007:62) refers to ethics as typically associated with morality, and both words concern matters of right and wrong, conforming to the standards of conduct of a given profession or group. Throughout the research process, steps were implemented to ensure that the study complied with ethical principles of research.

# 2.8.1 Ethical Approval

Both UNISA and the research site reviewed the researcher's proposal and granted permission to conduct the research. This allowed the researcher access to the study site to collect data from participants.

# 2.8.2 Protecting the Rights of the Institution

A pseudonym has been used to identify the research institution for confidential purposes.

#### 2.8.3 Informed Consent Form

Consent forms were provided to study participants to ensure that they understood the nature of the study and were free and willing to participate in the study. The purpose of the study was discussed and participants were informed that participation was voluntary. Participants were informed and requested to be audio-recorded during the interviews as this ensured that data was captured for proper analysis and that such data could be shared with the supervisor if needed. Participants were also told that they could withdraw from the study at any time if they wished to do so without consequences. They were also assured that their rights would be respected before and throughout the study process.

## 2.8.4 Reimbursement

Participants were informed that there was no compensation for participation and that data collected would be used for research purposes only.

# 2.8.5 Anonymity

Participants were informed that their identities would not be revealed in the research report and none of their details would be divulged. During the interviews pseudonyms were given to each participant and similarly their names were changed for confidential purposes in data reporting.

# 2.8.6 Privacy and Confidentiality

Participants' privacy was respected and was interviewed in the place of their choice e.g. at home and in their preferred home languages – English, Southern Sotho or Zulu etc.

# 2.8.7 Protecting Participants from Harm or Injury

Given the nature and sensitivity of the research, participants were treated with respect and dignity. Sufficient time was given to participants to respond to each question and they were encouraged to ask questions as well to enhance understanding and clarity. Some participants presented with emotional questions during the interviews cried and were referred for counselling services for further intervention and management.

# 2.8.8 Publication of Results

Participants were informed that their data will be kept safe and only to be used for thesis purpose. The actual names of the participants would not appear in any report, or publications.

## 2.9 MEASURES TO ENSURE TRUSTWORTHINESS

Polit and Beck (2012:745) states that trustworthiness is the degree of confidence qualitative researchers maintain in their reporting. Trustworthiness is assessed using the criteria of credibility, transferability, dependability, conformability (objectivity) and authenticity.

# 2.9.1 Credibility

Data presented in qualitative research should be a true representation of the participants' view, experience or belief (Sullivan & Sargeant, 2012:452). It refers to confidence in the truth of the data and its interpretations(Polit & Beck, 2012:724). Data collected was transcribed verbatim and the audio tapes were made available to the supervisor in case verification of data was needed. The researcher described participant's experiences accurately as emphasised by Holloway and Wheeler (2005:8).

# 2.9.2 Transferability

Polit and Beck (2012:745); Streubert and Carpenter (2003:39) are of the opinion that 'transferability' refers to the ability to generalize or extrapolate data to the extent to which the findings from data can be transferred to other settings or groups. This entailed a full description of the participants' responses in the data report.

# 2.9.3 Dependability

Dependability, according to Polit and Beck (2012:725) refers to a criterion for evaluating integrity overtime and over conditions analogous to reliability in research. Data presented in qualitative research should be a true representation of the participants' view, experience or belief (Sullivan & Sargeant, 2012). The research findings were reported with transparently.Precise methods of data gathering, analysis and interpretation were described and audio-tapes were made available for reference purposes.

# 2.9.4 Conformability

Conformability refers to objectivity which is the potential for congruence between two or more independent people about the data's accuracy, relevance, or meaning. This criterion is concerned with establishing that the data represents the information collected, and that the interpretations of those data are not invented by the inquirer (Polit & Beck, 2012:723). All interviews with participants were audio-recorded, transcribed and thematically coded for analysis and reporting of the findings.

#### 2.10 SUMMARY

This chapter discussed the research design and methods. It has further covered the research paradigm, research design, sample and population, data collection, data analysis as well as ethical consideration. The following chapter will present data analysis, presentation and description of the research findings.

#### CHAPTER 3

# **RESULTS AND DISCUSSIONS OF FINDINGS**

## 3.1. INTRODUCTION

The previous chapter provided a discussion around the research design and methodology, ethical issues and measures to ensure trustworthiness. This chapter presents the results from this study. Results are discussed under themes, categories and sub-categories based on the verbatim transcription of in-depth individual interviews.

#### 3.2 DATA ANALYSIS

According to Mouton (2008:108), data analysis refers to breaking up the data into manageable themes, patterns, trends and relationships. As indicated before, the overall aim of data analysis is to understand the various constituent elements of the data to see whether are any isolated or identifiable patterns or trends that can be established in the interpretation of the results. De Vos (2005:336) asserts that, this process is important because it begins at the early stages of the data collection process through the emergence of ideas in making sense of the data.

Polit and Beck (2012:562) alludes that analysis of qualitative materials typically begins with broad categories or themes. A theme is an abstract entity that brings meaning and identity to current experiences and their variant manifestations. Themes emerge from the data. Data in this study was analysed manually using thematic analysis. Polit and Beck (2012:562) agrees that thematic analysis involves

not only discovering commonalities across participants, but also seeking natural variation since themes are never universal.

# 3.2.1 Audio Taping Data

All participants were informed of the study and its purpose. Consent for participation and permission to be audio-recorded was sought. Upon completion of each interview, information collected was transcribed and translated within 48 hours. Hard copies of each interview were individually completed and recorded transcripts reviewed to ensure proper recording was done so as to minimize or eliminate possible errors. The researcher repeated this process several times to familiarise herself with data collected and ensure the correct data was recorded.

# 3.2.2 Participant/ Couple Checking

Each interview had unique number to avoid confusion and repetition of transcription. Transcribed data was double-checked against the audio-taped interviews to eliminate possible errors and to ensure that proper data had been recorded. Polit and Beck (2012:298) states that this approach allows the researcher to develop and code open ended responses into categories, transform responses to fixed categories in a post hoc fashion for tabulation purpose.

# 3.2.3 Coding

Data collected was coded according to themes, categories and sub-categories. The Carbin and Strauss method was adopted and it involved two types of coding; namely open and axial coding (Polit & Beck, 2012:573). In open coding, data is broken down

into parts and concepts identified and their properties and dimensions are delineated. In axial coding, the analyst relates concepts to each other. This process

enabled the researcher to identify themes that emerged from the data collected. The

first step in integrating the findings was to decide on the 'central category' also

known as the 'core category' which is the main theme of the research. With this

research four main themes were identified as follows:

**Theme 1:** Immediate response to HIV positive results;

Theme 2: Disclosure of HIV sero-status;

Theme 3: Limited information regarding HIV sero-discordant, and

**Theme 4**: Living with HIV sero-discordant diagnosis.

Each theme has categories and subcategories relating to the same. All themes with broader categories and subcategories have been discussed in the preceding chapter.

## 3.3 BIOGRAPHICAL DATA

Participants were discordant couples with varying demographics on age, gender, marital status, HIV status and duration of being in the relationship as shown in table 3.1.

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Table 3.1: A summary of sample characteristics

Characteristics	Value	Frequency	Percentage
Age	20-29	2	14. 1
	30-39	6	42.8
	40-49	6	42.8
Age differences	1-5	6	85.7
among couples	6-10	1	14.3
Sex	Female	7	50
	Male	7	50
Marital status	Married	1	14.2
	Cohabiting	4	42.8
	Unmarried (Living separately)	2	28.6
Number of children	0	2	28.5
	1	2	28.5
	2	3	43
Educational level	Below grade 12	1	7.1
	Matric (Grade 12)	8	57.1
	College certificate	2	14.3
	Degree	3	21.4
HIV status	HIV positive males	2	28.6
	HIV positive	5	71.4
	females		
Duration in the	6 months - 2 years	1	14.3
relationship	2 years – 6 years	3	42.9
	6 years and above	3	42.9
Length of	6 months - 2 years	6	85.7
diagnosis			
	2 years -6 years	1	14.3
	6 years and above	0	0
Employment status	Employed	12	85.7
	Unemployed	2	14.3

A total of 14 individuals who made up seven couples participated in the study. About two individuals of the couples were aged between 20-29 years, six individuals were aged between 30-39 years and another six individuals were aged between 40-49 years. They all met the research age inclusion criteria. Gender strata of the couples indicated 50% - 50% males and females, respectively. Marital status indicated that of seven couples, one couple was married, four were in a cohabitation relationship while two couples were single/living separately/unmarried. Regarding the number of children, of seven couples two couples had no children, two couples had only one child and three couples had two children each. Regarding the couples educational level, of 14 individuals only one did not had grade 12 certificate,, eight had completed grade 12, two had college certificates while three had degrees qualifications. The HIV status of seven couples revealed that two males were HIV positive, while five females were HIV positive. The duration of the couples in their relationship indicated that of seven couples, one couple had been in their relation between 6 months and 2 years, while three couples had been together between 2 and 6 years, and another three couples had been together for over 6 years. The length of sero-discordant diagnosis in couples indicated that, of seven couples 6 couples were diagnosed as sero-discordant between 6 months and 2 years, while only one couple was diagnosed within 3-6 years. Employment status of 14 individuals indicated that 12 individual were employed and while only two were unemployed.

## 3.4 OVERVIEW OF THEMES AND CATEGORIES

Analysis of the interview transcripts showed four main themes, several categories and sub categories as summarised in Table 3.2 below.

Table 3.2: Summary of Results

Theme	Category	Sub-category
		Embarrassment
	Psycho-social impact	Fear
Immediate		Blame
response to HIV		Guilt
sero-discordance	Physical impact	Pain and hurt
results	T Tryologi Impact	T and and trait
	People disclosed to	Partner
		Family members
		Colleagues
Disclosure of HIV	Reactions of significant others	Support
sero-status	on hearing the results	Disbelief
		Shock
Limited information	Lack of understanding of sero-	Lack of understanding how
regarding HIV	discordant by clients	results can be different
sero-discordant	Lack of understanding of sero-	Denial of negative result
	discordant by family members	
	Insufficient explanation of HIV	Denial of negative result
	sero-discordant by health care	
	professionals	
		Lack of intimacy
		Failure to practice risk
	Impact on the relationship	reduction behaviour
		Communication breakdown
Living with HIV	Sustainability structures	Counselling
sero-discordant		
diagnosis		Antiretroviral treatments

# 3.4.1 Theme 1: Immediate Response to HIV Positive Results

Immediate response to HIV positive results is discussed under two sub-categories namely psycho-social response and physical response.

# 3.4.1.1 Psychosocial Response

Participants reacted differently to discordant results. The reactions included embarrassment, pain and hurt, blame and guilt.

## **Embarrassment**

Embarrassment is one of the reactions felt by the participants after receiving results different from their partner's especially those who tested HIV positive while their partners tested HIV negative. The main source of embarrassment was related to the thought that the HIV negative partner would suspect that the positive partner might have been in extra-relationship or had extra-marital affair, hence the difference in results and the excerpt below:

"Aishh...I was not scared but embarrassed because I thought my partner would think I cheated while I was with her. And the thought that I was the one who accused her of cheating and that she will infect me with her AIDS only to found that she and the baby have tested negative and I am the one who is positive makes me feel so embarrassed."

#### Fear

Some verbalized fear as mainly relating to suffering from HIV and AIDS related conditions and eventually death. This fear seems to have escalated with emotional feeling of facing death and in lieu of some knowledge of the effects of HIV sick patients no steps were taken to mitigate the situation. Fear also seemed to have resulted in escalated panic clouded by the feeling of early death.

"And I tell myself that I'm going to die when I think of that. Have you seen HIV sick patients when they are sick how they look like? I panic and think that I will die, (silence and crying)"

In this mixture of emotions, hatred resurfaces for the source of her infected state mangled with so much fear. The source of hatred was mainly based on fear of death as indicated by the following except:

'What hurts me the most is why such a thing happened to me?'

The above statement relates to a participant's hatred concerning why she became infected.

## **Blame**

Blame has been noted as an emotional reaction that let participants take comfort in blaming another, in shifting responsibility of accepting their HIV diagnosis to their partners that somehow relieves anger and pain. Blame also allows the guilty party to

take some responsibility of their actions and the consequences inflicted in light of acknowledged their unacceptable high risk behaviour. One person evidently stated:

"I too wanted to blame someone"

"Sometimes I blame myself that I was not responsible behaviorally (Silent)

Self-blaming further drew some concerns as to why only that person was found in such a situation.

## Guilt

Participants reported feelings of guilt after being diagnosed with HIV. These feelings were reportedly self-directed at them (participants) and their partners as well as all that affected the relationship. It is evident that the impact of discordant results can have negative consequences to couples. Some feeling of guilt was also evident in the expressions of suspicion about the other partner with regards to bringing the infection in the relationship.

One participant told her partner personally saying that she wished her partner's HIV status was the same as hers. Another participant suggested they break-up with her partner due to their difference in HIV status. These feelings threatened the relationship of the couples.

"I just wished at first I had a partner which was positive, he thought I was joking and lying, I told him personally"

'I just wanted and wished her HIV status was the same as mine hence I felt guilty, maybe I am to be blame because I did not behave accordingly'

# Wanting to End the Relationship

HIV sero-discordant in other instances resulted to ending their relationship. This was mainly initiated by a HIV positive partner, as stated by one of the participants:

"I told him we better breakup because I'm positive and I suggested he get a negative partner. The reason was I wanted to protect him from being infected and he refused but I thought it's better that way so that I get a partner that is positive and I will understand him better, so I told him that he will not understand me due to our different HIV status."

# 3.4.1.2 Physical Response

The immediate response to HIV was not only psycho-social but also of physical turmoil in the form of pain and hurt.

# **Pain and Hurt**

Often pain and hurt are some of HIV's emotional reactions that was expressed after diagnosis and reported as a concern by participants. This is what participants had to say:

"I was hurting and concerned or her as if I brought some illness or I cheated on her, and yet she did not do that."

"OOhh... my heart was painful, at first it was hurting and I consoled myself to accept. I told myself that I will end up getting sick if I don't accept myself. I

spoke to my heart and told my heart that I'm in a situation and told my heart to accept so that I can be fine. I work at the department of health and they counseled me until I became much better. I forgot but I told my mother and my brother, you see..."

## 3.4.2 Theme 2: Disclosure of HIV Sero-Status

Disclosure is one of the important aspects of this infection and plays a key role in the lives of those infected and affected and has serious advantages and disadvantages for both the infected and the affected individuals.

# 3.4.2.1 People disclosed To

Results indicate that participants disclosed their HIV status to different people including the partner, family members and/or colleagues.

#### **Partner**

Disclosure of HIV status to a partner emerged as one of the subcategories. The duration of silence before disclosure differed among individuals as some participants mentioned immediately disclosing the information to the partner after testing whilst others took sometime before disclosure as stated below:

"I told her that I came from testing and I tested positive"

By and large, disclosure of HIV status has great benefits especially for partners since they share their lives together. Disclosure by PLHIV and those with AIDS is critical for HIV prevention and care.

# **Family Members**

Disclosure with some couples played an important role to the extent that a couple will discuss and agree to share their diagnosis with their family members. The support of families enabled participants to cope better and accept their status. No challenges were reported by participants pertaining to any negative treatment from families. This was supported by the following verbatim:

'My partner and I discussed about it and I told her that I want to disclose to my family about what is happening, and she agreed.'

'Better I told my mother and my younger brother.'

"After that, they were supportive 100% from day one onwards; this includes my mother and my siblings.

"This is because of the support I got from my family at home. My mother was very supportive because and she organized the whole family so I tell all of them about what is happening about my status and they also supported me."

# Colleagues

Disclosure was further extended to colleagues of participants in the workplace as shown by the following statement:

"At work they know, my friends know as well."

"Yes, I even told them at work and they asked me whether I'm HIV positive and I told them so and they did CD4 as well and they found that it was still high.

"When I tested at work I met one sister who told me that she has been infected as well for years and had told me not to worry. I was encouraged because she told me that she has lived for so many years and it's possible for me too to live long as well."

# 3.4.2.2 Reactions of Significant Others on Hearing the Results

The findings further revealed that not only partners of the discordant couples reacted differently after finding out about test results, but rather some family members of the discordant couples equally had challenges in understanding and accepting the HIV test results. Some were even in denial of believing and accepting the results. This is supported by the following excerpt:

"His family could not believe and wanted us to retest again"

"They were shocked and wanted clarity when I could not understand it myself how possible, but regardless of that they supported us".

# 3.4.3 Theme 3: Limited Information Regarding HIV Sero-Discordant

Research participants cited lack of understanding by HIV sero-discordant in the majority of the interviews. The theme was further subdivided into lack of understanding by clients, Lack of understanding by family members and insufficient explanation of HIV sero-discordance by health care professionals.

# 3.4.3.1 Lack of Understanding of HIV Sero-Discordant by Clients

It was evident that the HIV sero-discordant diagnosis and dynamics are not well understood and not easily accepted by many participants. This was strongly shown by Lack of understanding how results could be different with one person testing HIV negative and the positive.

# Lack of Understanding How Results Can be Different

Reactions to test results showed that participants did not understand the meaning of discordance and were unable to perceive and digest the after effects, and questions why a situation as that occurs. One participant stated:

"I can't say I do understand, because I did not know the terminology, I know that she is negative and I tested positive."

# HIV Negative Partner Assuming That They Are Also Infected

Some participants who were HIV negative believed tests results were faulty / untrue and they still had HIV hidden in their blood system regardless of numerous tests done which confirmed their HIV negative status. Unfortunately, this really shows that they didn't understand and they didn't believe they were HIV negative. To some, it seemed to be taking too long to detect the HIV virus lodged in their blood. This confirmed lack of knowledge of their sero-discordant status and were in complete denial of the dissimilar test results. Some participants stated:

"I tell myself that I'm HIV positive but just that it's still hidden you see".

'I mean I tell myself that we live with HIV maybe my blood system has hidden HIV and it has not exposed it yet you see, so I think about it all the time I don't know maybe next time when I go for testing they might tell me that I'm HIV positive and that's when they can see it'.

# 3.4.3.2 Lack of Understanding by Family Members

Not only was diagnosis of HIV sero-discordant not understood by couples but as well by the family members who always questioned the couple to explain the discrepancy. They did not believe that they were discordant as stated below.

"My partner told people about our status and they did not understand it. Especially my sister she did not understand it when I told her" "Honestly I'm not even sure they understand, at my partner's family they did not understand it why he was infected and I am not infected. The first time when we told his family, they wanted to see my results if I tested as well and I told them" "They were also surprised on how can it happen that he is negative while I am positive especially his mom".

The meaning of HIV sero-discordant diagnosis was surely not making sense to other people and participants had to struggle to explain what it meant to family members.

# 3.4.3.3 Insufficient Explanation of HIV Sero-Discordant by Healthcare Professionals

Participants reported that they did not receive sufficient explanation from healthcare professionals about HIV sero-discordant results. The inadequate information or explanation about HIV sero-discordant from healthcare professionals contributed to clients getting confused by the situation. Most of the interviewed HIV sero-discordant couples failed to show understanding of the explanation given them when they received post-test counseling. The statement below attests to that:

"I understand just a little bit of it but I want to know what causes one to be positive and the other to be negative if you can explain that to me because when they explain it, they say our cells are not the same, his cells are closed I don't know, some say HIV has not yet appeared, some say his blood type is zero but I say even my blood type is also zero is not as is, they tell us such different things. So, tell me I am right or wrong?"

# 3.4.4 Theme 4: Living with HIV Sero-Discordant Diagnosis

This theme elucidates information on how HIV sero-discordant diagnosis impacted the lives of these couples. Effect on couples' relationships and sustainability structures emerged with strong need for counseling and antiretroviral treatments.

# 3.4.4.1 Impact of sero-discordant on the Relationship

The impact effect of HIV sero-discordant diagnosis on couples' relationship was expressed with regards to lack of intimacy, failure to practice risk reduction behavior and communication breakdown.

# Lack of Intimacy

The research results further indicated that some of the couples were not even sexually active together and this seems to have had a ripple effect on the relationships. The HIV positive partner felt that the other partner was not interested in having sex when he or she turned down the request to make love. This was reflected in the following verbatim:

'I told him to be ok first, and he would think I don't want to make love to him because of his status.'

One participant mentioned that the frequency of intimacy and level of libido had somehow reduced as stated below:

'Yes, my sexuality has been affected with my partner; we used to sleep for 4 rounds and now only one or not at all. So all that has challenged our sexuality I don't know why is that...'

'The sex part of it is tough as he could not get an erection and I understood all that, and I told him that perhaps it is related to medication and it's fine'.

#### Failure to Practice Risk Reduction Behaviors

Unprotected sexual intercourse was the obvious major mode of HIV transmission. To aid the reduction of sexual transmission of HIV, the Republic of South Africa made condoms freely available and accessible as they are the most efficient technologies available stop or minimize sexual transmission of HIV and other sexually transmitted diseases.

Despite knowing their sero-discordance status, participants confirmed and acknowledged not using condoms consistently and in some cases not using condoms at all. One of the sero-positive discordant partners indicated that his partner was impregnated even after confirmation of the partner's status, suggesting that the couple was having unprotected sex. The excerpt below from participants alludes to the lack of protection during intercourse.

"He refused to use the condom until I became pregnant. And even during my pregnancy and also now after the birth of my child we have not used any condoms and he knows well that I'm positive and has no problem with that".

'I don't know but she's my partner and its long this thing happen since she was positive. We never used a condom. I'm negative and it's just happen and it was not planned. So if I become positive also, it will be fine'.

#### Communication Breakdown

Communication is one of the important values in any relationship. However, among the HIV discordant couples it appeared to be nonexistent. Each person seemed to be highly sensitive to how another person communicated and minor disagreement are often taken too seriously or out of context as indicated in the following verbatim:

'But there is no communication in terms of the relationship. We had communication before but since he mentioned things like I'm waiting for him to die I got angry. And I told him that if you feel that way...then ...agg...he told me that he has his family, and they will take care of him. You don't even know where all that comes from...he says if you feel this is too much for you.....such things. So, I got angry'.

'Sometimes I would tell him that I don't like the way you're talking to me especially when he talks to me roughly, I would tell him when you speak to me like that it doesn't sit well with me'.

'I used to tell her that I'm sick that I know you are dating someone infected and you are not infected, I know you could leave me. I was not feeling for her in terms of how she could feel for me; I would say anything I like.'

Seemingly, results further indicate that there was unhealthy communication, combined with hurtful exchange of words between the couples. Sometimes couples acknowledged hurting their partners to relieve their anger and feel better. Some reported displacing the feelings of guilt and shame to their HIV negative partners on the pretext of being ill. This was proven by the way they had been communicating during their difficult times together and some research participants had this to say:

'A lot, a lot of difference because all that happened I caused them, I used my illness as a weapon to hurt my partner and when I was talking to her, I would quote my illness negatively and tell her that you can't date someone infected for such a long time.'

# 3.4.4.2 Sustainability Structures

In addition to all the aforementioned effects in relationships of sero-discordant couples, certain services which the couples felt that they needed for them to cope well in their relationship as discordant couples such as counselling and proper treatment were absent.

# Counseling

It was quite obvious that from the interview indicate that research participants' valued counseling and understood the importance of counseling with their situation. However, they did not benefit much from short term counseling post HIV diagnosis status. All participants believed that should they have received proper and prolonged counseling which could have individually and collectively improved things and helped them coped much better. Participants reported to have received brief pre-test counseling and a short term post-test counseling during their testing visit. Some research participants stated the following:

"No, we only got counseling once, when we found out about our HIV status. From there nothing more, as we did not receive any further counseling." "The last time when we received counseling we were at KK clinic that was the first and the last. We were hoping we will get individual counseling and that has also not happened'.

'I think if we had received counseling, things could have been much better. The way I was so angry, it contributed negatively to our relationship hence we don't have a good relationship today.'

"But I still think that for us not getting counseling and further information about our situation contributed negatively to the present situation, and I also blame the government for dumping up us and doing nothing. No follow-ups were made, no counseling, the information I had was only on the diagnosis."

#### Antiretroviral Treatment

HIV medication is very important and improves the quality of life. It is very important for one to take medication and adhere to prescription in order to prevent drug resistance effects. The following reports from research participants indicate that they appreciated treatment received and adhered to the instructions relating to routine medication very well. Most of the participants reported improved health condition from the time they started taking medication. There were signs of deep appreciation of the medication as their quality of life seemed impressive and improved. The impressive part from the participants was that their HIV negative partners always encouraged the HIV positive partners to comply with the treatment schedule by constantly reminding them. The HIV negative partners acted as treatment support buddies who played an important role in ensuring compliance.

'I take my medication in the correct manner and everyday'.

'She sometimes calls and checks if I have taken my medication. I can only be late with minutes but I take it responsibly.'

'If I go somewhere, like when I go to watch soccer she make sure that I take my medication and water in a bottle and she also phone to remind me.'

## 3.5 SUMMARY

Results and discussions of findings have been presented in this chapter. In summary, about 14 individuals who made up seven couples took part in the study and the results were presented using themes, categories and sub-categories. Four main themes were identified as immediate response to HIV positive results, limited information regarding HIV sero-discordant and living with HIV sero-discordant diagnosis.

**Theme 1:** immediate response to HIV positive results identified 3 categories as psycho-social impact, disclosing HIV status and reaction of significant others after hearing the results. The theme focused on a different psycho-social emotional challenges participants experienced.

**Theme 2:** focused on disclosure of participants' HIV status to their partners, families and colleagues at work as well as the reactions of their significant others.

**Theme 3:** pointed to limited information regarding HIV sero-discordant and identified 3 categories which included lack of understanding of sero-discordant by clients, lack of understanding of sero-discordance by family members, and insufficient explanation of sero-discordance by health care professionals. The focus was on lack of understanding of the HIV results including denial of such results.

**Theme 4:** dealt with living with HIV sero-discordant diagnosis and identified 2 categories namely - impact on the relationships, and sustainability structures. This theme focused on a variety of challenges experienced by HIV sero-discordant couples including supportive structures that were available or absent at their times of need.

#### **CHAPTER 4**

## DISCUSSION OF FINDINGS AND LITERATURE CONTROL

## 4.1 INTRODUCTION

The previous chapter presented the study findings with reference to the existing body of knowledge in relation to HIV sero-discordant couples.

#### 4.2 DISCUSSION OF THEMES AND LITERATURE CONTROL

This section presents the discussions of findings and literature control. The findings of the study will be supported by data from literature consulted for the study. The findings from the research study on the experiences of HIV sero-discordant diagnosis of heterosexual couples are discussed under 3 different themes. The findings indicate that there were challenges related to immediate response to HIV positive results, limited information regarding HIV sero-discordance and living with HIV sero-discordant diagnosis.

# 4.2.1 Immediate Response to HIV Sero-Discordant HIV Results

Participants indicated several responses following the diagnosis of HIV, and responses ranged from psychosocial response effect to disclosure of status and reaction of significant others on hearing about the results.

# 4.2.1.1 Psychosocial Impact

The study findings clearly indicated that HIV diagnosis was not a simple test result to digest for HIV sero-discordant couples who experienced a variety of emotional responses to the diagnosis. These emotional responses included embarrassment, hurt, shock, sadness, pain, fear, guilt and blame. Anyone diagnosed with HIV has obviously undergone HIV testing (Rizza et al. 2012:919). This is one test that needs to be willingly and voluntarily undertaken because receiving an HIV-positive diagnostic report has deep emotional impact. Moreover, people often react differently to the HIV diagnosis result. Regardless of the provision of pre-test and post-test counselling, people just often react differently to their HIV diagnosis and this was deeply expressed by the heterosexual sero-discordant couples. Some of their experiences closely brought about crisis in the respective relationships, and acceptance for some took longer than envisaged. Varied emotions and reactions such as shock, denial, depression, loneliness and feelings of loss, uncertainty, grief and sadness were readily. It is vital to know and understand that these complex feelings are normal and should be expected.

The results concurred with findings by other researchers (Rizza, et al., 2012:919) who had reported that different emotions and reactions such as shock, denial, depression, loneliness and feelings of loss, uncertainty, grief and sadness can manifest themselves. The reactions are regarded as normal and usually experienced by people when they receive HIV positive results (Van Dyk, 2008:256).

The feeling of embarrassment mentioned by some participants agrees with reports by Van Dyk (2002:256) which states that these feelings manifests in such a way that causes a person to withdraw from disclosing HIV diagnosis information to his/her family because of the embarrassment they feel inside. However, this was not the case with this study's participants who seemed to have freely and openly disclosed their status to their partners and some to their family about their diagnosis.

Embarrassment may be related to the fact that the diagnosis of HIV sero-discordant is further complicated by feelings of infidelity as couples blame each other for bringing the illness into the relationship through cheating. The aspect of blaming the other or self-blaming and other unfounded assumptions such as a partner got infected through infidelity contradictsprior studies which suggest that high rates of HIV transmission occurs between HIV discordant partners who are often in stable partnerships but unaware of their HIV or their partners HIV sero-status (Lingappa, et al., 2008:1). Furthermore, this is also evident in a report by (Lingappa, et al., 2008;1) who reported that 83% of HIV infected men and 77% of HIV infected women are or have been married. And among HIV infected married persons, 75% of men, and 96% of women reported having had sex only with their spouse.

Disclosure of being HIV positive to a partner seems to have behaviour and emotional implications. This was alluded to by Rizza and colleagues (2012:219) who mentioned that in relationships, the diagnosis of HIV may reveal aspects of a person's behaviour that he/she may have wanted to keep private/hidden/unknown. In Africa, it is predicted that 85% of adult HIV infections are transmitted through heterosexual relations. A large proportion of new HIV infections in Africa occur in stable relationships and most of the HIV prevention programs in Africa focuses on promoting safer sex methods like using condoms during casual sex, and increasing fidelity among married partners (Lingappa, 2008:2).

Another key finding of this study revealed that the reaction of fear was mainly related to pain and suffering associated with HIV opportunistic infection and also the dying process from HIV and AIDS related conditions. This reaction of fear concurs with what Bokhour, Solomon, Knapp, Asch, & Gifford (2011) also reported on the impacts of HIV diagnosis that generates fear, panic, anxiety and negative attitude among couples. The effect has such intense, weighty, reflective, and deep impact on the couple's psychological aspects of life, particularly interactions with others. Most of those infected by the virus seem lonely and struggle to cope with strong stigmatization, suffers disruption of family and peer relationships. Participants in this

Study are confronted with prolonged uncertainty about their lives, experiences intense and constant fear of disclosure of their illness with concern of being rejected by society, yet are not always able to discuss these fears and anxieties openly with partners, friends and families. Van Dyk (2002:256) reportedly observed that HIV infected people are afraid of being isolated, stigmatised and rejected. They are uncertain of the future, afraid of dying alone and in pain. Fear could also be caused by not knowing enough about what is involved in HIV infections and how the problems can be handled.

Blame is one of the emotional reactions identified by participants. The blame was targeted to self or to the partner. The issue of self-blame was also discussed by Rizza et al (2012:219)mentioning that the diagnosis of HIV may reveal aspects of person's behaviour that may have wanted to keep private. This may include infidelity of sexuality which mainly results in feelings of guilt and blame.

Besides blame, another reaction expressed by participants is guilty feeling. The HIV infected individual feels guilty about having contracted the HIV infection. Also, some participants based on their HIV status in relation to their partners along with feelings of guilt felt like ending their relationship. This is perhaps based on fear of infection or infecting another partner coupled with feelings of guilty, shame and embarrassment. This finding alludes to reports of other studies that had indicated that separation is more likely to occur among couples affected by HIV and that women living with HIV may experience a particularly high risk of abandonment (Floyd & Crampin, 2008:13). All the psychosocial experiences highlighted by participants concurred with the findings by Bokhour et al (2009:1111), who described related emotions or stages that individuals or couples go through when confronted by or experiencing HIV positive diagnosis, personal problems, overwhelming situations, and trauma or even when they are sick or facing death. The emotional stages include denial and isolation, rage, bargaining, depression and acceptance.

# 4.2.1.2 Physical Response

Feeling of pain and hurt were also mentioned by the participants following the news of discordant results. Experiencing pain and hurt attested to Van Dyk (2008:269) stating that people with HIV often experience some pain and hurt because they feel they have lost so much in life and they themselves are to blame for it. He further maintains that, the following factors all serve to increase hurt and pain among HIV people: the absence of a cure and resulting feeling of powerlessness; knowing others who have died of AIDS and the loss of personal control over their lives.

### 4.2.2 Disclosure of HIV Sero-Status

Another theme that emerged was aspects of disclosing the HIV status. Participants mentioned disclosing status to different people including sexual partners, selected family members and colleagues. According to Kebede, Woldemichael, Wondafrash, Haile, & Amberbir (2008:81), HIV positive persons face significant challenges to disclose their HIV status and failure to disclose can place their sexual partners at risk. The WHO (2004:4) on a study on gender dimensions reported that disclosure can lead to increased HIV prevention behaviours. Disclosure of HIV test results to sexual partners is associated with less anxiety and increased social support among women (Kebede, et al., 2008:81).

The findings that HIV positive individuals received support from their partners, family members and colleagues contrast WHO's (2004:12) findings on gender dimension which indicated that the most common barriers to disclosure was fear of abandonment, fear of rejection/discrimination, fear of violence, and fear of upsetting partner, family members and colleagues.

Additional study findings indicated that HIV sero-discordant diagnosis had threatened the relationship of discordant couples. Some partners wanted to end their relationships claiming they might cope better without their partners. Floyd and Crampin (2008:13) mentions that discordance can threaten the relationship of couples by weakening, strengthening or even causing separation. Other studies suggest that separation is more likely among couples affected by HIV and that women living with HIV may experience a particularly high risk of abandonment (Floyd & Crampin, 2008:13).

Couples also reported disclosing their results to their partners, family members and colleagues. It seemed that disclosure was not a challenge for all couples interviewed. They all reported a healthy relationship and a good support system received from their families. Though similar studies have indicated that the fear or concern of stigma and discrimination may result in hiding diagnosis, yet such a decision can prevent wider support from extended family or the community (Rizza, et al., 2012:919). Monjo and Gir (2009:3) states that some people tend to avoid disclosing their status to their partners in order to maintain their relationships. But HIV positive participant in this study were more open in disclosing their HIV status to their partner. Upon disclosure of their status to their partners, family members and colleagues, participants reported that they received strong support and advice on how to live with HIV. Such support system decreases negative reactions like embarrassment, pain and hurt, fear, blame, and guilt (Kebede et al 2008:81). According to the WHO (2014:12) Report on gender dimensions, the most common barriers to disclosure included fear of abandonment, fear of rejection/discrimination, fear of violence, and fear of upsetting family members. This in contrast to observation and research findings of this study as none of the participants in this study reported the above mentioned challenges.

It was also evident that participants were free at work, accepted their HIV status, and had a good support system from colleagues and from the workplace. Providing services to HIV employees is vital for all so that they can be able to cope better.

Provision of services at workplace plays a key role in improving the lives of participants. According to Van Dyk (2008:462) the workplace provides an ideal gateway to HIV/AIDS prevention and care. Though findings showed that some participants found it easy to disclose their results, this is not so in some cases (see World Health Organization, 2004:12).

Issues of discrimination and stigma have been cited in the literature as possible factors that may hinder disclosure to sexual partners (Thupayagale-Tshweneyagae, 2010:260). Thus far from the study finding and wealth of literature on this subject, there seem to be more benefits in disclosing than not disclosing (Thupayagale-Tshweneyagae & Benedict, 2011:6), because individuals or partners will ultimately receive a good support system and proper care that will better enabled them to accept their status.

Based on the findings, not only partners of the discordant couples reacted differently after finding out of about their results. Even family members of the discordant couples as well had challenges in understanding and accepting the results of couples. As reported by participants, they were in denial of believing and accepting the results. This could also be due to their lack of knowledge and understanding of HIV sero-discordant.

# 4.2.3 Limited information regarding HIV sero-discordance

Observations and the study findings revealed that, not everybody was aware of the terminology nor understood what was meant by sero-discordant. There was limited information regarding HIV sero-discordancy and this puzzled participants, and family members. A WHO's (2012:5) report mentioned that despite growing evidence of its

importance, the concept of 'sero-discordance' and the frequency of its occurrence are poorly understood in most communities.

# 4.2.3.1 Lack of Understanding by Couples

Couples in this study did not understand HIV sero-discordant and they were given insufficient explanation by health care professionals. Couples did not understand either the difference of their HIV results between them. During the interviews some couples even requested for explanations on how results could be different, how different their blood groups were from other people because some of them were type O category. Bunnell and colleagues (2005:8) reported that there are misconceptions about HIV sero-discordance that very often lead to demand of re-testing by couples. The lack of understanding of HIV sero-discordancy had contributed to denial of negative results among couples in this study. A study in Abidjan among HIV women showed that their partners did not seek testing, although it was offered free of charge, because they thought their sero-status was seemingly the same as their wives (Brou, Agbo, & DesgrÃ, 2005:2).

# 4.2.3.2 Lack of Understanding by Family Members

Lack of understanding of the sero-discordancy concept and results challenged participants as they were unable to explain it to their family members. Family members needed some clarity to understand how results could possibly be true if one person is HIV positive and the other HIV negative. This lack of understanding brought some concerns and frustrations for couples. Similar reaction has been reported by the WHO (2012:2) that sero-discordant is poorly understood by the general population especially the family members of the HIV sero-discordant couples.

# 4.2.3.3 Insufficient explanation by health care professionals

The insufficient explanation of HIV sero-discordance by health professionals has compounded the problem of non-infected individuals or persons denying their HIV negative results. Non-infected partners of HIV positive participants reported that they had to seek re-testing. The findings concur with Bunnell, Nassozi, Marum, Mubangizi, Malamba, Dillon (2005:8) who reported that HIV negative partners visited counselling and testing centres repeatedly for testing with the belief that they were HIV positive.

# 4.2.4 Living with HIV sero-discordance diagnosis

The results further revealed that HIV sero-discordant living with HIV diagnosis negatively impacted their relationships. The impact was more felt around lack of intimacy, failure to practice risk reduction behaviour and communication breakdown.

# 4.2.4.1 Impact on the Relationship

Couples revealed that since their diagnosis as HIV sero-discordant, sexual intimacy declined to the extent of failing to be sexually active. A case study conducted in the US, found that fear of HIV transmission, coping with the uncertainty of potential illness, shifts in emotional intimacy, and reproductive dilemmas were the most commonly experienced emotional issues for HIV sero-discordant couples. A qualitative study conducted in Uganda explored HIV discordant couples' challenges and strategies for living in an HIV sero-discordant relationship and reported challenges such as constrained relationships following disclosure of HIV-positive status to their partners. Moreover, the risk of HIV infection has such adverse effects on people's sex lives leading to feelings of discomfort about sex partners.

But couples in denial consequently engaged in unprotected sex (World Health Organization, 2005:10). And even sexually active partners failed to practice risk reduction behaviour and acknowledged not using condoms. Close observations and personal experiences of the researcher reveals how female partners risked their lives to be infected so as to maintain or sustain their relationships with their male partners. On the other hand some couples wanted to protect their partners from the infection by encouraging protective sex. A similar study in Uganda disclosed that because of fear of losing partners, spouses were engaged in certain actions like unprotected sex, sometimes resulting in conception, to secure their relationships (Beyeza-Kashesya, Kaharuza, Mirembe, Neema, & Ekstrom, 2009:1).

The study in Uganda also revealed that many HIV sero-discordant couples desire to have children as pressure from relatives is a major cause of their desire, and relatives are part of the decision-making process (Kanniappan, Jeyapaul, & Kalyanwala, 2008:6). As such HIV discordant couples who desire children require strategies or appropriate treatment to protect HIV negative partners and their unborn children from HIV infection. But discordant couples who have unprotected sexual intercourse are at the risk of HIV transmission and acquisition by the non-infected partner. Unprotected sex has contributed to more new infections especially with HIV sero-discordant couples. Lingappa and colleagues (2008:1) in Uganda reported that with the high rates of HIV transmission occurring between HIV discordant partners in stable partnerships they seem not to be aware of their HIV status.

Estimates of HIV incidence rates among HIV-negative partners in discordant relationships have ranged between 1.2% and 19.0% per year, with the risk of HIV transmission per coital act being nearly 12-fold higher during the first two and a half months of infection than during the subsequent period of established infection. Early studies on HIV incidence rates among discordant couples were generally small, with limitations, but reported overall HIV incidence rates of 8.3% per year (Lingappa, et al., 2008:1).

Communication breakdown was shown by hurtful words being exchanged between couples. WHO (2005:10) study conducted in the United States of America about HIV discordant showed that heterosexual couples had difficulties in communicating about HIV.

# 4.2.4.2 Sustainability Structures

Living in an HIV sero-discordant relationship has highlighted the importance of sustainability structures. The sustainability of HIV/AIDS supportive programs like counselling and treatment have impacted on couples living with HIV sero-discordant diagnosis.

# Counselling

According to Van Dyk (2002:200), counselling is a structured conversation aimed at facilitating a client's quality of life in the face of adversity. The intention of counselling is to help or assist client's to cope with reality and the options or choices they have for dealing with these problems. The aim of counselling the HIV infected individual or significant other is to focus on life beyond infection and not to dwell on the constraints of the disease. The findings provided evidence that counselling services were not received by couples. Couples believed that if some kind of counselling service was received, it could have improved their relationship to minimal challenges and they could have coped much better.

### Anti-retroviral Treatments

At least and in light of all the challenges that the study participants were facing, participants were on medication and adhering to medication regime through the support of their HIV negative partners who acted as treatment buddies. This confirms that some services are available and accessible.

There were signs of appreciation of the medication been received that was improving health and quality of life. The HIV negative partners were very encouraging of their HIV positive partners to comply with the treatment schedule with constantly reminding them. According to UNAIDS (2012:33), HIV treatment is for life and people living with HIV need to take pills every day without fail. Discordant couples do benefit from access to antiretroviral therapy to protect their partners from HIV. As a new prevention strategy, the South African government now seeks to find HIV positive persons to put them on ARV's irrespective of CD4 count. This strategy was recently recommended by the WHO and its partners, given the positive results of the HPTN052 (96% reduction in risk of HIV transmission from index partner to HIV negative partner in the relationship).

## 4.3 SUMMARY

This chapter has presented the discussions of the findings above. In summary, about fourteen individual or seven couples took part in the study and the results were presented by themes, categories and sub-categories.

There were four themes identified namely as: immediate response to HIV positive results, disclosure of HIV sero-status, limited information regarding HIV sero-discordancy and living with HIV sero-discordant diagnosis.

**Theme 1:** immediate response to HIV positive results identified 2 categories as psycho-social impact and physical impact.

**Theme 2**: disclosure of HIV sero-status relates to people whom participant disclosed their status to and this includes their partner's, families and colleagues at work as well as the reactions of significant others upon disclosure of results.

Theme 3: discussed limited information regarding HIV sero-discordant and identified three categories as, lack of understanding of sero-discordant by clients, lack of knowledge relating to HIV sero-discordant by family members and insufficient explanation of HIV sero-discordant by health care professionals. The focus was on lack of understanding of how HIV results can be different resulting in denial of results. This theme identified two sub-categories as impact on HIV sero-discordant relationships and sustainability structures. A variety of relationship challenges experienced by HIV sero-discordant couples as well support received from sustainability structures e.g. ARV's were also discussed.

### CHAPTER 5

# CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

### 5.1 INTRODUCTION

The previous chapter addressed the discussions of the findings and literature control. This chapter is based on the main themes of the research study. As noted earlier, the objectives of the study were to:

- Explore the experiences of HIV sero-discordant diagnosis of heterosexual couples at Perinatal HIV Research Unit in Soweto, Gauteng Province.
- Provide recommendations based on the outcome activities which could assist in improving the quality of life of HIV sero-discordant heterosexual couples.

### **5.2 MAIN FINDINGS**

# 5.2.1 Immediate Response to HIV Positive Results

The research findings showed that HIV sero-discordancy had serious impact on the individual partners and the couples in serodiscordant relationship regardless of individual status. The impact of HIV sero-discordant is seen from the immediate response of the results and a ripple effect occurs on a variety of psycho-social emotions presented as embarrassment, hurt and pain, fear, blame and guilt. This

also negatively impacts couples because they experienced a lot of pain and hurt as reported. Since couples were in their relationship for more than 6 months, they were not aware of their status until they were tested HIV sero-discordant.

This is seen in the PAMP model which shows that the individual may be completely unaware of a hazard in which and in this case was HIV infection. Couples were not aware of their HIV sero-discordant status until they got tested. This confirmed that their sero-status results were brought to their attention during post-test counselling. Thus, they were engaged after being informed of their HIV sero-status. All this has awakened attention in couples and after becoming fully aware, the diagnosis negatively impacted on them and their relationship.

# 5.2.2 Disclosing of HIV Sero-Discordant Status

Upon been told about their HIV status, individual couples who were infected discussed and disclosed their status to their partners, families and colleagues at work and they received a good support system from all of them. However, the challenges reported were their inability to explain the HIV sero-discordant concept or dynamics which brought some concerns. There were some reactions by significant others after hearing the results which brought disbelief and couples were expected to explain how possible it is for HIV sero-discordant situation to occur. This was difficult for them to understand.

Regardless of knowing and being made aware or engaged with their HIV serodiscordant status, the PAMP model maintains that the second stage known as 'unengaged by the issue' applies. This is in line with couples who failed to understand their statuses even when made aware of it because they were in the denial stage of accepting the results.

# 5.2.3 Limited Information Regarding HIV Sero-Discordant

There was limited information regarding HIV sero-discordant by both participants and their family members which left them all in denial of the negative results. This caused some negative partners to repeatedly retest regardless of their HIV negative status. Health care professionals as well provided limited explanation on sero-discordant which further left participants with numerous unanswered questions.

Further findings showed that the HIV sero-discordant status impacted other areas of couple's lives including their lack of intimacy, failure to practice risk reduction behaviour and communication breakdown. With lack of intimacy, some couples were not sexually active due to medication effects and fear of being infected. While failure to practice risk reduction behaviour was acknowledged by some couples who reported not to have used any protection. The HIV negative partners claimed that they believed to be already infected regardless of their failure or practice of risk reduction behaviour. Believing that one is already infected regardless of whether any test proves otherwise, calls for concern regarding knowledge and skills pertaining to HIV education. Failure to practice risk reduction behaviour was reported as a regular practice which can increase the spread of HIV in the relationships of couples. Indeed this could possibly contribute to the spread of HIV/AIDS in the Soweto community.

HIV sero-discordant status was also reported to impact on communication of couples since they took pleasure in exchanging hurtful words hence tension in relating to each other escalated. The PAMP model suggests that at stage 3, a person faces the decision about acting, but may decide not to act (stage 4), or may decide to act stage 5). Participants upon knowing their status, decided to act. Since the HIV status of infected persons is truly a confirmation of their pseudo practise of safe behaviour, it is imperative that infected persons take responsibility and consider their risky behaviour which exposes or puts others (HIV negative persons) at risk. Some participants decided to act responsibly by taking medication upon becoming aware

that their health needs a boost of ARV's to improve the quality of their lives. The taking of ARV's was reported to have definitely improved the lives of participants. Furthermore, due to a good support system they had, this has maximised their adherence to treatment intake.

# 5.2.4 Living with HIV Sero-Discordant Diagnosis

Living with HIV sero-discordant diagnosis highlighted the importance of sustainable structures reported as counselling and antiretroviral treatment. The couples received pre-test counselling and post-test counselling only during their diagnosis and no further on-going counselling was recommended or proposed for further intervention and management of supportive counselling. This has negatively impacted couples since they were unable to deal with their HIV sero-discordant diagnosis which caused tension and threatened their relationships. This lack of counselling services as reported that if it was provided, it could have made changes and increased understanding of HIV sero-discordant status with better coping skills.

The importance of antiretroviral treatment was reckoned to have played a key role in the lives of couples. Participants had respect and had acknowledged the importance of treatment and adherence to treatment regime. Participants had a good support system and had buddies that had reminded them to take medication. Some participants were independent and were accountable in taking medication by themselves without being reminded. This showed that they had increased knowledge about the importance of medication and its benefits of improving the quality of life.

This is in line with the PAMP model which confirms that the stage of action (stage 5) and maintenance (stage 6) was maintained by participants. Participants were able to act by consulting their respective clinics and taking their medication accordingly.

Their health had improved to such an extent that encouraged them to continue doing the right thing of taking medication throughout life.

### **5.3 LIMITATIONS OF THE STUDY**

The study was conducted in only one Soweto clinic. Some participants were older than the researcher and it made them to feel uneasy. The study participants were purposively selected and do not reflect the experiences of other sero-discordant couples. The study was conducted in the urban Soweto area; it has excluding rural areas because the study site is situated in Soweto area as well as the study participants. Some participants needed their partner's approval to participate before responding to the research request to interview them. Participants changed agreed scheduled appointments to their preferred date and time and has impacted on the time frame of data collection since appointments had to be rescheduled. Interviews were conducted at participant's homes and some minor destruction was experienced, e.g. the participants had to attend to visitors, respond to the knocks at the door. The findings of the study cannot be generalised to other areas. Most infected participants were emotional and resulted in increased time for the interviews. Brief immediate supportive, emotional and educational counselling was provided during the interviews.

### **5.4 RECOMMENDATIONS**

Recommendations are discussed under services for HIV sero-discordant couples, training of health care practitioners, media intervention, risk reduction strategies, department of health intervention and further research.

### 5.4.1 Recommandations On HIV Sero-Discordant Services

The PAMP model prompts practitioners to develop intervention strategies that take into account the stages that precede active decision making. This can be implemented as follows:

- To develop programme services targeting couples directly. On-going counselling to all HIV sero-discordant couples identified should be provided so that they can be able to understand the full impact of HIV diagnosis.
- Support groups system should be implemented at clinics to empower HIV sero-discordant couples with education, knowledge, life and coping skills.
- Services for the families of the HIV sero-discordant couples should be implemented to ensure a good support system and address challenges facing such families, e.g. family therapy that may possibly include extended family members if necessary.

# **5.4.2 In-service Training for Healthcare Professionals**

- Extensive on-going trainings for the health care professionals should be provided. The acquired positive knowledge and skills will enable professionals to identify couples with challenges on time and they can be able to provide timely intervention and management.
- Health care professionals should also be trained on counselling to ensure they understand the relationship dynamics facing couples and intervene for further management.

# 5.4.3 Media Intervention and Improvement

- The media should not focus on individuals, rather extend their services to include couples and their messaging as well, thus media messaging should be directed at and be inclusive of HIV sero-discordant couples.
- Dramas and reality shows should focus on HIV sero-discordant couples when they promote HIV/AIDS awareness.

# 5.4.4 Risk Reduction Promotional Services Should Be Adopted At Personal, Local / Community And National Level

- National policies should be reviewed and implemented to focus on couples.
- The importance of risk reduction behaviour should be emphasised in couples because failure to do that could contribute to the spread of HIV among discordant couples.

# 5.4.5 Involvement of the Department of Education

 The importance of HIV sero-discordant education should be adopted and implemented in schools and be added in the subject known as life orientation programmes.

### 5.4.6 Recommendation For Further Research On HIV Sero-Discordant

Since the prevalence of HIV sero-discordant is growing, it is recommended
that some further research be done in some other areas. Although this study
was birth out of a concern in the community of Soweto, but similar situation
might be happening in some areas hence the need for intervention should be
implemented.

## **5.5 SUMMARY**

The study was aimed at exploring the experiences of HIV sero-discordant diagnosis in heterosexual couples in PHRU, Soweto of Gauteng Province in order to put forward appropriate recommendations for the development of possible programs for supporting sero-discordant couples. An exploratory qualitative study was conducted with a theoretical framework of the PAMP model to explain the behaviour and experiences of HIV sero-discordant couples.

A non-probability sampling was adopted and purposive sampling used. A grand tour guide question with such questions as: 'tell me about your experience as a HIV discordant couple' was administered to all individual couples who participated in the

study. This approach allowed the researcher to conduct face-to-face structured interviews. This method also enabled participant's to communicate their priorities and provide detailed responses on the issues raised. A total of fourteen 14 participants who made up seven couples participated in the study and met the eligibility criteria.

The study discussed four themes which emerged as immediate responses to HIV positive status results and these included:-disclosure of HIV sero-status, limited information regarding HIV sero-discordant and living with HIV sero-discordant diagnosis. First hand and an in-depth insight pertaining to the experiences of HIV sero-discordant diagnosis amongst heterosexual couples was observed and experienced. The study findings enabled the researcher to provide recommendations that would be of significant benefit to HIV sero-discordant couples.

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# ANNEXURE A: UNISA CLEARANCE CERTIFICATE



# UNIVERSITY OF SOUTH AFRICA Health Studies Higher Degrees Committee College of Human Sciences ETHICAL CLEARANCE CERTIFICATE

HSHDC/237/2013

Date: 23 October 2013 Student No: 3400-083-6

Project Title: The experiences of HIV sero-discordant couples at the perinatal HIV

research unit in Soweto, Gauteng Province.

Researcher: Miss Constance Matshidiso Lelaka

Degree: Masters In Public Health Code: DLMPH95

Supervisor: Dr AH Mavhandu-Mudzusl

Qualification: PhD

Joint Supervisor:

**DECISION OF COMMITTEE** 

Approved 

√ Conditionally Approved

Prof L Roets

CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE

Prof MM Moleki
ACADEMIC CHAIRPERSON: DEPARTMENT O

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

TEIT VAN SUI

PRETORIA

# ANNEXURE B: PHRU APPLICATION LETTER TO CONDUCT STUDY

Clinical HIV Research Unit University of Witwatersrand Perth Road, Westdene 2092 Johannesburg, South Africa 16 September 2013

The Chief Executive Officer

Perinatal HIV Research Unit

Chris Hani Baragwanath Hospital

**New Nurses Home** 

Diepkloof,

Dear Sir/Madam

Re: Request for approval/permission to undertake a research study on the "The experiences of HIV sero-discordant couples at the Perinatal HIV Research Unit in Soweto, Gauteng Province."

I Constance Matshidiso Lelaka student number 34000-836 hereby request permission to undertake a research study at Perinatal HIV Research Unit. I am currently pursuing Master of Public Health at the University of South Africa (UNISA), I am in my final year and as such I am in the process of writing my Master's Thesis. I am hoping to conduct this study at Perinatal HIV Research Unit and I am writing to seek permission in order to gain access to the organisation.

The purpose of this research was to explore and describe the experiences of HIV

sero-discordant diagnosis of heterosexual couples in order to develop appropriate

recommendations for development of possible programmes for supporting HIV sere-

discordant couples.

The choice of this study was primarily guided by the fact that previous studies have

found high rates of HIV transmission occurring between HIV discordant partners who

are often in stable relationships but unaware of both partners HIV-1 sero-status.

Under such conditions, marital sex becomes one of the higher risk factors of HIV

transmission or acquisition. Besides this far, there's limited understanding of HIV

prevention challenges and issues surrounding HIV sero-discordant heterosexual

couples.

The study will involve 10 participants (20 individual couples) of HIV sero-discordant

heterosexual couples who meet the eligibility inclusion criteria. A consent form has

been developed which outline key issues pertaining to the study for the participants

who are willing and interested to participate in the study. All research ethics

pertaining to the study have been outlined.

If approval or permission is granted, data will be gathered by means of a grant tour

guide question. One-on-one unstructured interviews with each individual couple will

be held to ensure each individual feel free to express them. Interviews will be done

at a place of their choice e.g. home or PHRU. The process will take less than 45

minutes. The results will be pooled out to benefit my thesis project. Participant's

results will be kept safe, anonymous and confidential. I have attached the consent

form, proposal and ethical clearance from UNISA for your perusal.

Your favourable response will be highly appreciated.

Yours Sincerely,

Constance Matshidiso Lelaka (Ms)

Tel: +27 11 276-8800 / Direct: +27 11 276-8899 / Mobile: +27 83 359 7673

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Fax: 011 482-2130

E-mail: tlelaka@witshealth.co.za

# **ANNEXURE C: PHRU APPROVAL LETTER**



UNIVERSITY OF THE WITWATERSRAND

CHRIS HANI BARAGWANATH HOSPITAL

PO BOX 114 DIEPKLOOF SOUTH AFRICA

1264

Phone: (011) 989-9700 Fax: (011) 989-9762

15 Oct. 13

To Whom It May Concern:

Re: Data Collection for MPH - Constance Tshidi Lelaka

It is with great pleasure that we grant you permission to interview discordant couples in our programme for the purposes of completing your MPH. We understand that that you will be the person interviewing all the couples and that you will follow the research ethical conduct.

We wish you all the best in your studies.

Kind Regards

Thandekile Essien

Project Manager

Perinatal HIV Research Unit

Tel: 011 989 9916/9840 Email: essient@phro.e<u>o.za</u>

### ANNEXURE D: CONSENT FORM

Title of the research study: The experiences of HIV sero-discordant diagnosis of heterosexual couples at Perinatal HIV Research Unit, (Soweto, Gauteng Province).

Principal Investigator: Constance Matshidiso Lelaka

**Institute**: University of South Africa (UNISA)

### Introduction

My name is Constance Matshidiso Lelaka, student at the University of South Africa doing research on the "The experiences of HIV sero-discordant couples at the Perinatal HIV Research Unit in Soweto, Gauteng Province". I want to investigate the experiences of HIV sero-discordant diagnosis of heterosexual couples so that I can draft and propose guidelines on how to manage challenges faced by HIV sero-discordant heterosexual couples. The purpose of the study is to explore and describe the experiences of HIV sero-discordant diagnosis of heterosexual couples at PHRU in Soweto, Gauteng Province and to provide recommendations which could assist in improving the quality of the life of HIV sero-discordant heterosexual couples.

The duration of the study will less than 45 minutes and all participants are required to sign a consent form for their approval including to be recorded for analysis of data purposes. The interviews will be conducted individually so that privacy and confidentially be fostered. The risk to this study is to lose your time and one can be emotional as they share their experiences. However, emotional and supportive counselling will be arranged for such participants should they agree to consult for further intervention and management or could also be referred should they wish so. Your details will be kept private and confidential and will not be used against you

anyhow. Kindly feel free to ask any questions if do not understand. If you wish to
withdraw from the study at any moment you are welcome to do so. Therefore, if you
wish to volunteer and willing to take part please sign this consent form:
Ion this day of2013 hereby give
consent to participate in the study known as "the experiences of HIV sero-discordant
diagnosis in heterosexual couples PHRU, in Soweto, Gauteng Province".
Participant's signature
Researcher's signatureDateDate

**ANNEXURE E: INTERVIEW TRANSCRIPT** 

SS Female (Recording)

Date: 23 Oct 2013

**Demographics:** 

**Age**: 31 yrs.

**HIV status**: Positive

Gender: Female

Date of diagnosis: Sep 2012

**Duration in relationship**: 3 years and more

**Tshidi**: Hi and thank you for making yourself available for this interview. As indicated following our telephone conversation. I'm here to conduct the interview on your experience; your name will be SS for confidentiality reasons, are you fine with that?

**SS:** Hi too, yes I remember the discussion over the phone, I'm fine with that name no problem we can talk.

**Tshidi**: Ok thanks for that. Please tell me about your experience as a discordant couple

**SS**: I just wished at first I had a partner which was positive, he thought I was joking and Iying, I told him personally. It all firstly started when I tested alone and was tested positive, I then informed my partner who did not believe me at the time. Then I suggested we test together which he agreed and went for testing then found out we were discordant towards December. I told him we better breakup because I'm positive and I suggested he get a negative partner. The reason was I wanted to protect him from being infected and he refused but I thought its better that way so that I get a partner that is positive because I will understand him better, so I told him that he will not understand me due to our different HIV status.

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**Tshidi**: hmm... (nodding and nodding)

**SS**: such things, I had to change things and my life and I told him that I will be alone doing that since this will be facing me alone you wont be there, so if I'm with someone who is HIV positive I will be able to tell him what to do, to encourage him, telling him when to take treatment when the time comes, we will encourage each other and aaaaiii...he (partner) refused up until I became pregnant so... so....since then we have not used any condoms and he knows well that I'm positive and has no problem with that. So, I told myself that it means he has accepted that I'm positive...positive...there are no changes.

**Tshidi**: Are you saying that you have not used condoms since he (partner) found out that you are HIV positive?

**Ss**; Yes....yes...

**Tshidi**: I understand how you have felt about him. So, when they gave you the results, how did you feel?

**SS**: OOhh my heart was painful, at first it was hurting and I counseled myself to accept, I told myself that I will end up getting sick if I don't accept myself. I spoke to my heart and told my heart that I'm in a situation and told my heart to accept so that I can be fine. I work at the department of health and they counseled me until I became much better. I forgot but I told my mother and my brother, you see.

**Tshidi**: So, you disclosed to your family?

**SS**: Yes, Better I told my mother and my younger brother

Tshidi: How was it to disclose?

**SS**: Yes, it was easy because I'm talkative person and I was not scared of my mother, I told her that I came from testing and I tested positive.

**Tshidi**: and...How did they react?

**SS**: My mother is supportive; yes...up until now. When I tested at work I met one sister who told me that she has been infected as well for years and had told me not to worry. I was encouraged because she told me that she has lived for so many

years and it's possible for me too to live the same. Form there I started eating healthy, I accepted, I did CD4 tests at PHRU (nurses home) and it was high at 800, I also checked at work up until I became pregnant and I took treatment while was pregnant. Aren't you supposed to take treatment while you're pregnant?

**Tshid**i: What where you told about treatment and pregnancy in a person living with HIV?

**SS**: That I should take treatment to prevent infecting the baby. I even told them at work and they asked me whether I'm HIV positive and I told them so and they did CD4 as well and they found that it was high. I wanted to know why they would give me medication, so they told me that they want my CD4 to be high because when one is pregnant it drops.

**Tshidi**: So...are you on treatment?

**SS**: yes, since I became pregnant.

**Tshidi**: Since you became pregnant to date?

**SS**: Yes, I'm taking it since they told me they are doing it so that my CD4 count should not drop down.

**Tshidi**: Hmmm (nodding)

**SS**: And they told me after having a child if I want I can stop taking it and stop breastfeeding the child as well, but if I still want to breastfeed I should continue with treatment.

**Tshidi**: Since you are currently pregnant, did you plan for this pregnancy?

**SS**: No...o.k. I wanted a child, we planned. We talked about it, my partner thought I will end the relationship but I told him that since I have one child, I want another one.

**Tshidi**: Hmmm...Do you mind sharing the reasons why you fell pregnant?

**SS**: I proved him in all ways that I love him as much as he loved me, and I did not expect that I will find someone like him to love me when I'm infected you see....I thought along the way he will reject me after some time and with time he showed me he's not there. And I asked him that what if I get sick, will you be able to stand and

handle that since you are not infected and I'm infected, and he confirmed that he will

cope and deal with that. He often retests to check his status though.

**Tshidi**: Ok, what are your challenges in this relationship regarding this experience?

SS: At the moment there's not much compared to after we were diagnosed, most of

the time my partner is supportive, he does not give me any stress and I tell him that I

don't want any stress in my life since I'm infected. I told him in my life I don't want

anyone to give me stress, I want someone who will understand me and I also don't

want to think a lot about HIV, so since he has not given me any stress related

problems. He's good, he understands, he sometimes reminds me of taking treatment

such things. But he also gets worried that I take treatment and we don't use

condoms. I tell him yes it can happen but I'm taking treatment so that my CD4 count

should not decrease and to prevent transmission to the baby but since we are in a

relationship you can go to the clinic they will explain to you, but he's scared to talk.

But I do ask questions at work and I ask them that my partner is not positive and we

don't use condoms. They told me that there's nothing that will happen but eventually

he might be infected with HIV because I do take treatment, I don't know if it's true or

not? It's true

Tshidi: let me ask you this question now that you're a in a discordant

relationship...kindly explain your understanding about sero-discordant results.

SS: I understand just a little bit of it but I want to know what causes one to be

positive and the other to be negative....if you can explain that to me because when

they explain it, they say our cells are not the same, his cells are closed I don't know,

some say HIV has not yet appeared, some say his blood type is zero but I say even

my blood type is also zero is not as is, they tell us such different things. So, tell me I

am right or wrong?

**Tshidi**: What was your HIV status before you enter into this relationship?

SS: Before I was right (negative), then I thought of so many things when I tested

positive?

Tshidi: like?

93

**SS**: I thought of my previous relationships and his previous relationships such things...

**Tshidi**: HHHmmmmm (nodding)

**SS**: I think of such things that I got it from whom and who, same as him but then warn myself that it won't help since I'm already infected

**Tshidi**: I heard you at the beginning you mentioned that one lady from work encouraged you and gave you support. Apart from her, who else is giving you support?

**SS**: No one. I did not get any counseling, only when I got tested and it was hard to accept this condition but now I'm better.

**Tshidi**: How could have counseling helped you?

**SS**: I could not understand my results and even my partner, my family was worse and could not believe us. I think counselling would have helped me to understand what really happened.

**Tshidi**: How would you recommend counseling to any individual couples who are discordant?

**SS**: I would tell them they need to understand their HIV status first and accept it because this can make you fight with your partner, again when I'm alone I feel so painful but I think counseling could had helped me. I find it difficult to explain to people and they ask me so many. But my partner is there for me always.

(Silence, crying)...

**Tshidi**: I see you are emotional do you want to talk about it?

**SS**: Aishhh....sometimes I forget about my status just like a normal person but when someone asks me about my status I get hurt.

Tshidi: What makes you feel that way?

**SS**: AAiii... (She continued sobbing for 2 minutes)

**Tshidi**: I understand your situation.

**SS**: You know, when I think about it, (continue crying). What hurts me the most is that why such a thing happen to me? And I tell myself that I'm going to die when I think of that...have you seen HIV sick patients when they are sick how they look like? I panic and thinking that I will die... (Silence, then resumed...crying): (Crying) Sometimes I blame myself that I was not responsible behaviorally... (Silent)

**Tshidi**: Why do you think that way?

**SS:** If I have not had several relationships before this, I would have not been in this situation. I think I should have tested with the last partner I have and If we were both positive, I would have enjoyed life, But this? I'm concerned how long I will live...

**Tshidi**: So, you think you won't live long? I'm sorry about that. Ok, anything you want to share that you think you left it out

**SS**: Yes, I feel that anytime I can just die. And... but maybe I will live long. I'm doing all that is right, I follow a healthy diet, I take my treatment and I told myself I will do all that. I'm careful when eating, I eat veggies and fruits. I tell myself that I am a strong women who will do the best for the sake of my kids and I believe with time HIV will be cured because I belief

**Tshidi**: Anything you want to share that you think you left it out

SS: No

**Tshidi**: thank you for your time, we are done. But I see this is hurting you and I don't mind to offer you counseling if you wish. We can arrange I came to you, you come to me, or we can meet somewhere. I'm flexible; I'm prepared to support you especially since you're the infected partner. I'm happy that you have a supportive partner who accepts you. This is not an easy journey...please if you have issues please discuss together, should you wish a joint couple counseling please speak to me as well. Do you have anything which you want to talk about?

**SS**: What causes discordance really?

**Tshidi**: Causes of discordance cannot be explained... like I said there is still some research going on. What I can tell you now is that, no one is immune to the virus...so it's important to use protection at all time with your partner to reduce the risks of

transmission. There are different types of HIV and that does not mean one cannot get infected from other viruses, that's why it's important for such couples to use protections always. If you do not mind, I will give you the contact number of my study supervisor. She has worked in the HIV field for a long time. Maybe she will give you more information or refer you to people who can assist you in understanding or coping with sero-discordance.

**SS:** ok I do understand but my partner does not want to use condoms

**Tshidi:** Any reason for not using the condom?

**SS:** He said that he is also infected; nurses are just using weak machines which cannot detect HIV very fast. I think I will need to ask your supervisor maybe she will also help. If she assists, that will help us a lot; I know he will agree we need that please

**Tshidi:** So please speak to him and discuss it together, then let me know.

**SS:** I will do so, and since he's unemployed lately he's very down, he was retrenched two months ago.

**Tshidi:** I'm sorry about that, let's talk about that at out session so that I can refer you to relevant people who can assist. How do you feel after the discussion about your personal experience?

SS: I think I am not so fine. I don't know.

Tshidi: Thank you so much for your time). If you are comfortable, kindly call this number (handing the psychologist card), send her a please call message, she will call you and offer you counselling. I have already discussed with her., take care... (Giving hugs).