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## List of abbreviations

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AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARVs	Antiretroviral Drugs
BAIS	Botswana HIV and AIDS Impact Survey
BOTUSA	Botswana-USA partnership.
CHCT	Couple HIV and AIDS Counselling and Testing
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
IEC	Information, Education and Communication
IPPF	The International Planned Parenthood Federation
MDGs	Millennium Development Goals
NACA	National AIDS Coordinating Agency
NGOs	Non-Governmental Organisations
PMTCT	Prevention of Mother-To-Child Transmission
STIs	Sexually Transmitted Infections
SRH	Sexual and reproductive Health
USAIDS	United States agency for AIDS
PLWHA	People Living with HIV and AIDS
TB	Tuberculosis
UNICEF	The United Nations International Children's Fund
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNPFA	The United Nations Population Fund
USAID	United States Agency for International Development
UNODC	United Nation Office of Drug and Crime
WHO	World Health Organization

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Annexure A

Unisa Clearance Certificate

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Annexure F

Consent form

Annexure G

Interview guide and observational tool

# CHAPTER 1

## BACKGROUND AND ORIENTATION TO THE STUDY

### 1.1 INTRODUCTION

This phenomenological study aims to gain a deeper understanding on the lived experiences of sero-discordant families in Botswana. A cursory glance at the literature revealed a high rate of Human Immunodeficiency Virus (HIV) positive individuals in some families as well as between couples with stable relationships. Some of the infected may not even be aware of the sero-status of their partners (Lingappa, Lambdin, Bukusi, Ngure, Kavuma, Inambao, Kanweka, Allen, Kiarie, Makhema, Were, Manongi, Coetzee, De Bruyn, Moretlwe, Magaret, Mugo, Mujuria, Ndase&Celum2008:01). This is certainly worrying as such lack of knowledge could contribute to the growth in the number of people living with HIV. The Botswana AIDS Impact Survey (BAISIII 2009:04) also reveals that most of the affected are widows and the married couples, while Odendal (2009:01) also asserts that a large number of new infections occur in stable heterosexual relationships. This implies that couples are most affected as compared to those who never got married, or those not in stable relationships. This condition does not only threaten to destabilise the peace that prevails in the couples' relationships but also the economies of the countries.

The Botswana National AIDS Coordinating Agency (NACA) (2008:14-15) reports that the effects of HIV and AIDS will negatively impact the economy of Botswana resulting in a fall of the projected Gross Domestic Product (GDP) from 4.5% without HIV and AIDS to approximately 2.8% under the current scenario, and after 20 years the economy will drop by 30% from the number projected without HIV and AIDS. This economic downturn will ultimately affect the country's aspiration to attract investors, thus leading to a series of problems such as: wage stagnation, underdevelopment, and reduced capital stock. The National AIDS Coordinating Agency (2008:15) report further contends that as the country has introduced the provision of antiretroviral therapy (ART), the population will continue to grow but at a slower rate than in the past. However, as a result of the introduction of antiretroviral (ARV) and the increasing population, the prevalence rate of HIV is likely to increase tremendously. This poses a challenge on the

non-infected population who live with those who are infected as they have to apply measures to prevent getting infected.

A phenomenon that relates to HIV and AIDS, which has received very little attention is the one called “discordance”. Discordance is referred to as HIV tests outcome of body fluids from the same couple, but the results show that one is positive, while the other is negative (Stout 1998:02). Another researcher, Walque (2006:3) asserts that a discordant HIV couple is a situation where only one of the partners in a monogamous relationship is infected with HIV. Taking into account the discussion thus far, the general definition of HIV discordant couples is a situation in which a couple, that is, a man and a woman living together in a heterosexual relation, or either man or woman living in a homosexual relationship, who exchange and share intimate sexual feelings, without any use of birth control methods or preventative barriers for sexually transmitted diseases, one partner gets infected with HIV but the other remains uninfected (Ligangapa et al 2008:2).

Discordant HIV situations are perceived by many researchers, including those in discordant relationships, as a misery. This is because one partner in the sexual relationship is HIV positive, whilst the other is HIV negative. This condition has perplexed scholars of this subject in many parts of the world. Nasser (2008:01) described it as quite confusing, and unbelievable, it is socially and logically not expected, unrealistic, not easy to explain both theoretically and scientifically but it does exist. It is, therefore, worth investigating with the view of developing a better understanding of the HIV status of those couples.

## **1.2 BACKGROUND TO THE STUDY**

The HIV and AIDS and its effect poses a very serious threat and continues to be a worry to human kind since its discovery in early 1980s. In Botswana, for example, life expectancy before 1985 when the first diagnosis of AIDS was made was at sixty-five (65) years. By the years 1990–1995, the life expectancy had fallen to below forty (40) years (Fredrickson-Bass & Kanabus 2006:1).

The efforts by different countries such as the United States of America, Uganda, Botswana, and institutions like BOTUSA, USAIDS and UNAIDS, have been to combat

the growing rate of HIV and AIDS. The focus was mainly directed towards prevention programmes for individuals who are HIV negative. However, the discovery of antiretroviral therapy resulted in a significant change in treatment strategy that focused both on individual or partners living with HIV, and those who are HIV negative.

Many of the early prevention programmes were directed towards identifying HIV positive individuals through testing and promoting safer sex between partners. It is believed that this approach would prevent infection and re-infection with a different strain of the virus to partners who are HIV negative and those who are HIV positive respectively. There was a growing assumption among researchers and members of the general public that once an individual in a sexual relationship is identified as HIV positive, the partner of such individual is undoubtedly generally expected to be infected with the virus as well, Lingappa et al (2008:12). However, the growth of this assumption has been halted by the discovery of the phenomenon of sero-discordance. Even though this is the case, researchers are so mystified by this situation and this prompted this investigation which focuses on its epidemiology and factors related to its occurrence. It is critical to state that the occurrence of new cases in partners living with HIV indicates a possible new case of discordance, (Quinn, Wawer, Sewankambo, Serwadda, Chuanjun, Wabwire-Mangen, Meehan, Lutalo & Gray 2000:921-929). If this is the case, it could be assumed that the high prevalence of HIV in any population is associated with an increase in the incidence of discordance. For instance, Sub-Saharan Africa where the HIV rates are estimated at 80% (Allen, Meinzen-Derr, Kautzman, Zulu, Trask, Fideli, Musonda, Kasolo, Gao and Haworth, (2003:733) and are higher than anywhere in the world has a significant number of discordance cases.

Studies carried out in some African countries identified a sizable number of discordant couples (Walque 2007:7-9). In investigations that were carried out in Ghana, Burkino Faso, Tanzania, Cameroon, and Kenya, it was discovered that at least two-thirds of the HIV infected couples have differing HIV status. Interestingly, though not convincingly, the percentages of the discordant females in Ghana and Tanzania have decreased from around 30% to 19% and 21.9% respectively, while that of the other countries (that is, Burkino Faso, Cameroon and Kenya, are still around 30%) (Walque 2007:9).

Three quarters of the people in the world fall within the reproductive age of 15–49 years (WHO 2009:11). It is noted in the literature that HIV transmission is mainly through

sexual intercourse. This means that the majority of the world's population at risk of contracting HIV is this sexually active age group. Taking Uganda as an example, Beyeza-Kashesya (2010:2) reports in 2008 a 43% incidence of HIV in the age group of 15–49 years. It is critical that this incidence was only noted among individuals in discordant monogamous relationships. Similar outcomes were observed in Zambia by Allen, Meinzen-Derr, Kautzman, Zulu, Trask, Fideli, Musonda, Kasolo, Gao and Haworth (2003:733), who asserted that in Zambia one fifth of the HIV positive individuals are discordant.

Most of these live in the capital where cohabitating is common (Lingappa et al 2007:07). Studies in East Africa (Kisumu – Kenya) and Southern Africa (Ndola – Zambia) revealed HIV average incidence of 13% and 18% discordant couples respectively. Taking into account the discussion thus far, Beyeza-Kashesya (2010:2) concludes that in Africa about 5% to 31% people live in discordant relationships and most of them are either married or cohabitating. In the same study, it is revealed that discordance is not discriminative of gender, age or race. This has also been discussed affirmatively by Lingappa et al (2008:1371-1411), Odendal (2009:01) and (BAIS II 2008:4) who contended that discordance is predominant in stable relationships or among widowers.

Quinn et al (2000:929) studied the HIV transmission in Rakai, Uganda and support the view that discordance is not discriminative of gender or race. In that study, they noted that 228 (53.6%) out of 425 couples studied, the male partners were HIV positive and the female partners of the rest of 187 couples were observed to be HIV positive as well. To date, no empirical studies have been carried out in Botswana. However, unpublished statistics from Tebelo-pele, a national voluntary and testing and counseling centre in Botswana, indicates cases of discordance. The statistics also suggest a gradual reduction in the discordance rates by 20.2%, 17.4%, 14.4% and 8.9% noted in 2004, 2005, 2006, and 2009 respectively. Although no empirical study was conducted, such a reduction in the rate can be attributed to behavioral change in response to education and counseling on safer sexual acts (BAIS III 2009:21).

In a country with a high HIV prevalence rate like Botswana, the possibility of having one partner being HIV positive while the other is HIV negative increases. This possibility may also be increased by the introduction and effectiveness of antiretroviral therapy (ART) programme. This is in concurrence with Quinn et al (2008: 921-929) and Sheth

and Thorndyraft (2009:97), who asserted that effective HAART is associated with a marked reduction in HIV load in semen. This means that the risk of sexual transmission of HIV is lower in individuals on HAART with undetectable blood viral loads.

As mentioned before, although different countries and institutions have invested in raising awareness within individuals, many people, despite such knowledge still engage in risky behaviors. Beyeza-Kashesya (2010:48) and Allen et al (2008:738) report that some discordant couples continue not to be committed to condom use, which does not help them to prevent the virus. Beyeza-Kashesya (2010:48) further reports that in some African countries where patriarchal culture is very strong, the male counterparts normally enjoy superiority over the females and deprive the female from deciding what they feel or know is good for them. Even if the woman wants to use a condom, she cannot if the male partner is not willing. The societal expectation to have children as a form of procreation also puts pressure on the young couples to practice unsafe sex. However, apart from the societal commitment and desire to gain satisfaction during sexual intimacy, some couples remain ignorant regarding how discordance comes about, while others are clouded with myths (Botswana Ministry of Health 2008:13).

For infection to occur there has to be one partner who is HIV positive and the infected partner must carry enough viruses in his/her body fluids, which maybe in the blood, semen, vaginal secretions or breast milk to be able to thrive amidst the environmental factors that would prevail during risky periods. During such periods, Sheth and Thorndyraft (2009:02) assert that a certain number of viruses from an HIV infected individual must be able to enter the uninfected partner, whereupon they will start to multiply and invade the surrounding and distant tissues whereupon they ultimately overpower the body's defence system. For Human Immune Virus, the virus gets inside the cells called CD4+cells. The CD4+ is the immune cells that the HIV target. An individual will then have a weakened or destroyed immune system as a result (Sheth & Thorndyraft 2009:02). In HIV discordance, this whole cycle is not complete, or is broken at some point leading to failure of the virus to find homage into another partner.

Some experts have tried to identify and explain the factors that could facilitate the acquisition of HIV or contribute to the occurrence of discordance. However, there is no conclusive explanation that answers the question of how discordance takes place. Different authors such as Quinn et al (2000:921-929), Sheth and Thorndyraft (2009:2),

and the Draft participant's Manual for HIV counseling and testing by Botswana Ministry of Health (2008:97) unanimously agree that discordance is influenced by the following factors:

- i. frequency of sexual exposures
- ii. the body's defence system
- iii. quantity of microbes (HIV) in blood/semen on transmission
- iv. coexisting other infections (e.g., sexually transmitted infections (STIs))
- v. stages of HIV and infectiousness
- vi. probability ratio of infection per coitus

### **1.2.1 Frequency of sexual exposure**

HIV is mostly transmitted through sexual intercourse (Quinn et al 2000:921). This puts everyone who engages in it at risk of contracting HIV. Every time an individual who is HIV negative has sex with someone who is HIV positive, he or she predisposes himself or herself to getting HIV. The more exposure to HIV one has, the more likely she or he will become infected. Gray, Wawer, Brookmeyer, Sewankambo, Serwadda, Wawire-Mangen, Li, Van Cott and Quinn (2001:1149-1153) carried out studies on the transmission of HIV in Uganda and discovered that there is a probability of 0.0011 per coitus. He, however, noted that the probability of transmission differs in both male and female. The probability of transmission per coital from an HIV positive female partner to an HIV negative male was 0.0013 while it is 0.0009 per coital from an HIV positive man to an HIV negative woman. The probability is further enhanced by other factors such as genital ulcer which could increase the probability to 0.0041 per coital and the low state of immune system, These findings are congruent with that of Kaul, Pettengell, Sheth, Sunderii, Bernger, MacDonald, Walmsley and Rebbapragada (2008:32-40) who reported on intactness of mucosal epithelial and mucosal immune factors that play a vital role in protection against HIV.

This is also consistent with the findings by Wilde (2008:677-684), who contend that higher rates of transmission probability per coital act are associated with increased HIV viral loads. In other words, increased viral load increases the probability of HIV transmission, and this is the reason why after some clients have been started on ARV, they become HIV negative after a certain period of time, signaling a successful



suppression, though not necessarily meaning eradication of the virus. This is the time when the virus is very low to an undetectable level in the blood.

### **1.2.2 Quantity of microbes (HIV) in blood or semen**

The quantity of the Human Immunodeficiency Virus (HIV) per milliliter of every medium that transports them is highly correlated with transmission. Quinn et al (2000:921-929) in their study of the role of viral load in heterosexual transmission of human immunodeficiency virus discovered that during pregnancy, the transmission rate increases from 2.2 to 23.0 per 100 person in a year. The study also revealed that a person whose viral load is undetectable is very unlikely to transmit the virus to the negative partner. This provides hope that reduction in viral loads which is common in people who are on antiretroviral drugs could potentially reduce the rate of transmission in many communities. The number of viruses in the body fluids or transport media like semen or vaginal secretions is the main predictor of the risk in heterosexual relationship. This therefore greatly reduces the chances of infection if such media contain the viruses' equivalent to less than 1500 per milliliter (Quinn et al 2000:921-929).

Walde (2008:679) also studied the factors that affect the transmission of HIV. His findings revealed unequivocally that the HIV RNA level in the donor partner was highly correlated with the risk of heterosexual transmission. His results further affirmed the findings by Quinn et al (2000:921-929) that infected individuals with low viral loads were very unlikely to transmit to their partners. No transmission was documented from individuals with HIV RNA levels less than 1,500 copies/ml. However a 10-fold increase in viral load is believed to lead to more than two fold risk of transmission.

When the HIVs increase in numbers and overpower the body's defence system, the person gets to a stage called AIDS. This is because the great number of HIV prevails over the defence of the body, that is, the higher numbers of the virus is consistent with its virulence (Draft Participant's Manual for HIV counseling and testing)(Botswana Ministry of Health 2008:323).

Another theory associated with the viral load and its relation to HIV infection is the use of antiretroviral therapy or the “Highly Active Antiretroviral Therapy” (HAART). HAART consists of a number of drugs combined in the management of HIV and AIDS. The main goal of this treatment is to limit replication of HIV, suppress its normal growth, delay their maturity and slow down progress of the disease, as well as reduce the level of HIV in the immune system. ARVs also help in reducing HIV and hence rendering them less effective in their virulence (Sheth & Thorndycraft 2009:53). A person taking HAART correctly is, therefore, likely to have reduced blood viral load. For those individuals the risk of HIV transmission would be low. Apparently, this is the case in a study conducted among 205 discordant heterosexual couples in Uganda. The research discovered no single case of transmission of HIV from HIV positive partners on potent anti-HIV medications to their respective HIV negative partners. However, the experts caution that drug therapy should not be considered a panacea for couples who are HIV discordant, (Sheth & Thorndycraft 2009:53).

### **1.2.3 Stage of HIV and infectiousness**

Whenever a person who is at risk is infected with a disease causing organism like HIV, the virus gets into the body system and grows in size and in number. During this time, the virus activities stimulate the body to produce some antibodies to defend its self against the organism. The action and counteraction of the organism (virus) and the human body results in effects in the body that is often called signs or symptoms.

The stage of HIV infection, like in any condition, plays an important role in how someone is likely to transmit an infection. The first stage of an HIV infection called the acute stage, normally lasts around six months. During this time the virus replicates and increases in number. The number of the viruses increases dramatically leading to increased possibility of transmission. Sheth and Thorndycraft (2009:53) argue that the normal average or overall transmission rate of HIV is 0.0012 per vaginal sex. He, however, reports that during the first stage of HIV infection the transmission rate increases to 0.0082. The possibility of transmission then decreases over time in the next ten months. This period is referred to as the latent stage, and may not necessarily last ten months but would depend on the individual immunity, lifestyle and other health-related conditions. During the latent stage, the transmission rate may fall as low as 0.0015, and may even fall to 0.0007 per act of vaginal sex in chronic HIV infection.

Estimates of HIV transmission per instance of vaginal sex in heterosexual partners follows a “U” shaped model. This suggests that infectiousness is at peak during the initial stage, which is soon after sero-conversion. It then drops to lower levels during chronic period which takes years before it picks up again during the late stage of infection when AIDS develops. This model is supported by Sheth and Thorndycraft (2009:53), who affirms that analysis of plasma viral load for HIV is highest (more than 100 000) during early stage and late stage of HIV disease while during the chronic stage is at minimal. When an infected person is exposed to factors that may precipitate the AIDS, or when the person does not get any treatment, he or she goes into the late stage where the transmission rate increases again to 0.0036 per vaginal sex (Sheth & Thorndycraft 2009:54).

Sheth and Thorndycraft (2009:55) further report that since the Human Immuno Viruses in the blood are almost ten times higher during the acute stage of infection, there could be up to 50% of new infection occurring through heterosexual act or sharing sharp instrument with a recently infected partner. This however occurs in an innocent situation because many would not be aware that they are HIV infected as so many do not take necessary precaution to avoid infecting their sexual partners.

#### **1.2.4 Presence of other coexisting infections**

Presence of other infections of the genitals may inflame the mucosal membrane of the genito-urinal track and destroy its natural structure and function (Kaul et al 2008:36). If the genital track is destroyed, during sexual intercourse when there is rubbing and mingling of the genitalia, there is an increased risk of infection, including HIV, if present in semen or vaginal fluids. Wilde (2008:677-84) reports that damage can occur as a result of trauma during intercourse or from pre-existing infection of the genital tract by bacteria, trichomonas, or viruses such as herpes simplex. The presence of a genital tract infection in the male partner is associated with an increase in the HIV load in semen, presumably due to passage of the virus from the blood into the genital tract at sites where the lining has been damaged by the infection. Whenever there is an increased semen viral load, there will be an increased risk of transmission (Sheth&Thorndycraft2009:05). Mayaud and McCormick (2001:129-153) also acknowledge that STIs can facilitate transmission while Fleming and Wasserheit

(1999:3-17) studied how Sexually Transmitted Diseases (STDs) facilitate the transmission of HIV. They discovered that there is strong evidence that both ulcerative and non-ulcerative Sexually Transmitted Diseases promote HIV transmission by augmenting HIV infectiousness and HIV susceptibility through a variety of biological mechanisms.

A similar argument has been advanced by Plummer, Simonsen, Cameron, Ndinya-Achola, Kreiss, Gakinya, Waiyaki, Cheang, Piot and Ronald (1991:233-239) who contend that HIV transmission may be facilitated by the presence of other sexually transmitted diseases as HIV has been isolated directly from genital ulcers. STDs or STIs that present with ulcers in the genitalia may bleed during sexual intercourse and thus leading to increased risk of HIV transmission through blood. Patients who are HIV infected and at the same time have Genital Ulcer Diseases (GUD) tend to have increased HIV within the exudates in their ulcer. The US Community Health Status Report (2010:09) states that persons with STIs, such as chancroid, are four-time more likely to be HIV sero-convert as compared to their counterparts who do not have ulcer. This, according to Liebman, Cooley and Levine (2012:02) and Plummer, et al (1991:233-239) increases the infectiousness of HIV. Another study by Pearce (1998:650-651) revealed that GUD disrupts mucosal integrity and increase HIV susceptibility by the recruitment and activation of HIV target cells, such as lymphocytes and possibly by HIV taking advantage of chemokine receptors.

The non-ulcerative STIs are also reported to increase transmission as they have shown increase in the frequency of HIV – DNA shedding in cervico-vaginal secretions among HIV positive female, (Duerr, Curtis, Shelton and Meirik, 1998:294-295). Affirmatively, Butt, Johnman and Nandwani (2001:796) reported that there is an 8-fold increase in the secretion of HIV RNA in semen of HIV positive men who had non ulcerative conditions such as gonorrhoea and chlamydia compared to their HIV negative counterparts. Management of STI has therefore been found to be somehow effective in reducing the incidence of HIV infection among people at risk by approximately 40% (Grosskurth, Mosha, Todd, Mwijarubi, Klokke, Senkoro, Mayana, Changalucha, Nicoll & Kacina 1995:530-56). Noar (2008:340) also reported that changes in the vaginal flora which is common in conditions like bacterial vaginosis increase the risk of HIV transmission as well. This is because such conditions destroy the natural biological protection of the mucosal membrane.

In view of afore cited discussion by several authors, it is apparent that STIs and HIV have a very close relationship. Firstly, their primary mode of transmission is through sexual intercourse. Secondly, despite having ulcerative and non-ulcerative forms of manifestation, STIs increase the risk of HIV transmission by triggering the body to produce cells that are vulnerable to HIV in the genital tract and hence increasing the susceptibility in uninfected individuals. On the other hand, HIV infected persons with STIs have increased genital tract HIV viral loads which increase infectiousness.

### **1.2.5 Probability**

Probability is the likelihood that a given event will occur. It is a determination of a possibility and measures of the likeliness of the occurrence of a phenomenon. HIV transmission is still not easy to understand. Whether or not the virus is passed during specific exposure relies partly on chance. Furthermore, transmission of the virus can be enhanced by certain factors (such as coexisting sexually transmitted infections, frequency of exposure, or stage of infection within an individual) that one has been exposed to. These factors also influence the likelihood of the transmission and acquisition of HIV. In a study by Mastro, Satten, Nopkesorn, Sengkharmya and Longini (1994:204-207) which gave an estimate of the probability of female to male transmission of HIV in Thailand, they discovered that the probability of HIV transmission per sexual contact with a high risk person, like prostitutes, is 0.0031.

### **1.2.6 The defence system**

#### **a. Skin and mucosal membranes**

The body's first line of defence is the anatomic barrier, or the skin. According to Sherwood (2010:453), the body's defence against foreign microbes is not limited to the intricate, interrelated immune mechanism that destroys microorganisms that have actually invaded the body. The body however is equipped with yet another external immune defence mechanism, which is designed to prevent microorganism from penetrate the body wherever its tissues are exposed to the external environment. These are called the skin and the defences of the lining of the digestive, urogenital and reproductive, and respiratory airways tract. Kaul et al (2008:32-40) also contend that

protection is afforded by an intactness of the mucosal epithelium as well as innate and adaptive mucosal immune factors present in the genital tract.

The skin is the largest organ in the body. Its primary function is to protect the body from the environment (McCain & Huether 1998:256). Mucous membranes are tissues that line the surfaces of body cavities, such as the nostrils, mouth, throat, vagina, urethra, anus and rectum. Mucous membranes are moist and in some places secrete mucus that helps to keep out foreign invaders (such as viruses and bacteria). According to Brock (1991:40), a pathogen must first gain access into the host tissue and multiply before tissue or organ damage can occur. In most cases this requires that the organism penetrates the skin, mucous membranes, or intestinal epithelium surfaces which normally act as microbial barriers. Passage through the skin into the subcutaneous layers almost always occurs through wounds; only in rare instances do pathogens penetrate through the unbroken skin. Most microbial infections begin on the mucous membranes of the respiratory, alimentary, or genitourinary tracts (Sheth & Thorndycraft 2009:07). Brock Madigan (1991:40) further attest that the epithelial cells of these surfaces secrete defensins on attack by microbial pathogens, thereby killing the would be invaders by disrupting their membranes. In addition, the Sebaceous glands in the skin secrete antibacterial and antifungal fatty acids and lactic acid. Perspiration, tears and saliva also contain an enzyme called lysozyme that attacks the cell walls of some microorganism. As a result of these glandular secretions, the surface of the skin is acidic (ph 3-5), making it inhospitable to most microorganism. However, Varghese, Maher, Peterman, Branson and Steketee (2002:37-42) argue that there is considerable evidence that bacteria or viruses that have the potential of initiating infection generally adhere specifically to epithelial cells. The evidence for specificity is wide-ranging. First, there is tissue specificity. An infecting microbe does not adhere to all epithelial cells of the body where it normally gains entrance. For instance, *Neisseria gonorrhoea* adheres much more strongly to urogenital epithelia than to other tissues. Secondly, the host specificity, the bacterial strain that normally infects humans will adhere more strongly to the appropriate human epithelial cells than to similar cells in another animal.

## **b. The immune system**

The human immune system is amazingly a complex constellation of responses to external attacks by microorganisms (McCain & Huether 1998:248). It has many facets,

a number of which can change to optimise the response to unwanted foreign bodies such as viruses. It defends the body against infectious organisms through a series of steps called the immune response, the immune system attacks organisms and substances that invade body system and cause diseases. The immune system is made up of a network of cells, tissues, and organs that work together to protect the body. The cells involved are the white cell called the leukocytes, which destroy disease causing organisms substances.

The presence of invasive normal flora such as *Lactobacillus* helps to minimise the possibility of infection. *Lactobacillus* is the name given to a group of Gram-negative bacteria that do not form spores but derive energy from the conversion of the sugar glucose into another sugar known as lactose. *Lactobacillus* is part of the normal microbial population of the human adult vagina, which exerts a protective effect within the vagina. Varghese et al (2002:40) affirm that *Lactobacilli* play an important role in maintaining vaginal health. These bacteria can inhibit other potentially harmful microorganisms by producing lactic acid, hydrogen peroxide, and antimicrobial substances. In most healthy women, *lactobacilli* are the dominant microorganism in the vagina. McCain and Huether (1998:248) further argue that, theoretically, the anaerobic bacteria are suppressed by *lactobacilli* and cannot replace *lactobacilli* unless the latter is first diminished. In other words, *lactobacilli* are capable of lowering the pH of the environment that the bacteria dwell in. In the case of the vagina, this acidic change can inhibit the growth of other, harmful invading organism.

In conclusion, HIV is mostly transmitted through heterosexual mode which is very common in Sub-Saharan Africa and also increasing in Asian and some of the industrialised countries (Kaul, Ahaawat & Gupta2009:145). According to Kaul et al (2009:146), a number of risk factors, including behavioural and biologic risk factors are associated with the risk of transmission, including the frequency and type of sexual contact, the body's defence system, the quantity of microbes (HIV) in blood/semen, coexistence of other infections (e.g., sexually transmitted infection (STI), stage of HIV and infectiousness and probability. These factors do not stand on their own in determining whether one acquires infection or not. An interrelated network of these is always at play for infection of HIV to occur. During discordance, some of these factors would remain dormant until such a time when all or some factors become risky and result in sero-conversion.

### **1.2.7 Background information about the research problem**

Botswana is one of the countries in the Sub-Saharan Africa which is experiencing one of the most severe and devastating HIV and AIDS epidemic in the world. According to the Botswana AIDS Impact Survey (BAIS II 2004:2), the estimated prevalence among the general public was at 17% and four years later in 2008, the estimated National HIV prevalence had slightly increased to 17.6% (BAIS III 2009:1). On the other hand the Incidence rate was at 2.89 by 2009. (BAIS III 2009:16, 20). This has been a great concern because the condition mainly affects the age group, which is still active in reproduction and workforce. According to Fredrickson-Bass and Kanabus (2006:1), life expectancy at birth fell from sixty-five years in 1990-1995 to less than forty years in 2000-2005.

The Botswana government therefore employed different approaches to curb the effects of the condition within the society. Programmes such as Public Education, Education of young people, Condom distribution, Targeting highly mobile population, PMTCT of HIV, and Introduction of antiretroviral therapy were initiated. These, according to Fredrickson-Bass and Kanabus (2006:9), are bearing fruits. However, as argued by Sheth and Thorndycraft (2009:53), Quinn et al (2000:922) and Wilde (2008:679), some of these efforts may lead to a situation where an HIV infected partner may not infect the HIV negative partner, resulting in HIV discordant. Although this is one situation, which may be desirable, it is not always guaranteed and it is worrisome especially that HIV discordant couples have received little attention from both the researchers and care implementers in Botswana. The fact that few studies have been carried out on lived experiences of HIV discordant couples makes it possible for their needs not to be attended to and counseling guidelines to be inadequate. Interventions aimed at preventing HIV transmission in sero-discordant couples are urgent. The National Collaborating Centre for Infectious Diseases (2010:1) acknowledged that there is a need for interventions to prevent spread of HIV among the sero-discordant couples. Masupe, Van Rensburg and Human (2012:19) reported that lack of disclosure of HIV status to a partner makes educational counseling a challenge to the Tebelo-pele centre counselors where statistics have been noted at 20.2% in 2004, but somehow decreased down to 8.9% in 2009, (Tebelo-Pele: 2011, unpublished data). It is therefore imperative



to establish their educational needs and the risk factors posed by this increase of HIV discordance in Botswana. Challenges faced by counselors for discordant couples need to be addressed through relevant counseling guidelines for HIV discordant couples.

Literature on sexual experiences of discordant couples is very scarce. However, dealing with feelings of intimacy and sexual closeness among the HIV discordant couples can be challenging because of anxieties over HIV transmission, initiating safer sex and the health status of the affected partner. These issues may downbeat sexual longing and may result in psychosexual problems. The present study intends to contribute relevant literature on the sexual needs and experiences of HIV discordant couples.

The limited studies on HIV discordance and knowledge show that discordant couples reported the use of condoms as the major role for reducing the risk of infections (Tenthani, Cataldo, Chan, Bedal, Martiniuk & Van Lettow 2012:08). The knowledge regarding other issues, such as childbirth, and formula feeding, was not mentioned by participants in the Tenthani study. This scarcity of information also motivated the researcher to look into the experiences of HIV discordant couples thereby narrowing the existing gap on the knowledge of HIV discordance.

Research carried out in developed countries has indicated that stress increases in couples after one partner tests positive (Bunnell & Cherutich 2008:2149; Dunkle et al 2008:1415; Walque 2007:3). The stress may emanate from different sources, such as the HIV negative partner blaming the HIV positive partner, the HIV negative worrying about the health of the HIV positive partner, feeling of anger by the HIV negative partner, feeling of betrayal and sadness to the reality of one partner's possible infidelity. Those sources or causes of stress need to be validated in Botswana and strategies for counseling developed.

Experiences of HIV discordant couples can be very challenging to both partners. A study conducted in Mexico among the gay community found that the negative couples are always in constant battle to put the needs of the positive partner first (Nieto-Andrade 2008:1). The negative partners always have to try and keep their self-esteem up and this was found to be a serious challenge. Issues of stigma and discrimination are also a challenge that they have to face. The study done in Botswana, an African

country with many cultural innuendoes, might reveal different findings. The findings from the study will inform the development of counseling guidelines for HIV discordant communities.

Discordance may occur in any population where there are many cases of people living with HIV. This is because people who are HIV positive will, at one point, live with those who are not HIV infected. As much as there are risks and factors that contribute to acquiring HIV, there would, in one way or another, be discordance. A study by Beyeza-Kashesye (2010:12, 13) reveals that there are couples in HIV discordant relationship in a high number in African countries. The researchers assert that “given the importance of procreation and the lack of assisted reproduction to avoid partner transmission, members of these couples are faced with a serious dilemma even after the challenge of disclosing their HIV status to their spouses”.

According to Robinson, Reinecke, Abdel-Malek, Jiaand Chow (1996:540-549), a significant number of HIV infections in Sub-Saharan Africa is noted among married HIV discordant couples. Yet few interventions currently target these couples. Prevalence of HIV discordance among married and cohabitating couples in Africa is high, ranging from 3% to 20% in the general population and 20% to 35% within couples in which one partner seeks HIV care services (Kabatesi, Ransom, Lule, Coutinho, Baryarama & Bunnell 2003:6).

### **1.2.8 Background to the research problem**

The research investigated the lived experiences of the HIV discordant couples in Botswana, which also included their perception and focus on their needs as service recipients in the health sector. From time immemorial, the focus of care has been on the HIV infected, prevention and treatment of the condition, but very little, if none, to the HIV discordant. This is one area, which is important because someone who is HIV positive belongs to a social environment in which he/she lives and interacts with others. It is very important to understand how the spouse, the family and the society perceive this client and his/her condition. They also have needs as sexual beings hence there is the need to investigate their understanding and needs in this area as well as the prospects of functioning as a procreative family.

The HIV negative partner also needs to be investigated. This individual can be very helpful in the provision of care to the HIV positive partner, and in preventing further spread of the infection but yet, according to Naran (2009:6), these people have remained forgotten though they may also be scared and confused as the positive partner and that their psychosocial issues are also given less attention. As we move from individualised approach to systems approach, we cannot afford to leave the HIV negative partner outside the care. She/he becomes important and the pillar in our care.

### **1.3 RESEARCH PROBLEM**

The HIV/AIDS scourge is continuing to threaten the lives of many around the world. Like any other condition or disease that affects mankind, efforts are directed towards curbing the effects of such disease. The transmission of HIV from one person to another has been identified, but nevertheless, more people are continuing to be infected despite knowing how this can be avoided. Couples in married and stable relationship are equally at risk. In Botswana, some programmes have been initiated for curbing the spread of HIV. Stable partnerships are usually not targeted by these programmes because they focus primarily on reducing unprotected casual sexual contact. Although the reduction of such contacts is important, additional interventions targeted at stable partnerships may need to be considered for two reasons, first, the sero-negative individuals in discordant relationship may be at high risk of HIV infection as a result of continual sexual exposure, and secondly, as asserted by Hugonnet, Stephane, Mosh, Frank, Todd, James, Mugeye, Kokugonza, Klokke, and Ross (2002:16) that the proportion of new HIV infection occurring within regular partnerships is likely to increase as the epidemic matures and spreads beyond highly sexual active core groups.

### **1.4 JUSTIFICATION/RATIONALE FOR THE STUDY**

The HIV discordant couples have not been studied before in Botswana. Very little is known, yet the country is one of the hardest hit by the HIV and AIDS scourge (BAIS III 2009:2). The unpublished data from Tebelo-pele Counseling Centre (2011) also reveals the HIV discordant to be at 17%. This information clearly indicates a need for an empirical study to verify the findings.

Discordant couples sometimes face more problems than the sero-concordant positive or negative. These may range from violence, physical and verbal abuse, possible HIV infection or sero-conversion, and loss of employment (Naran 2009:8; Cichocki 2007:2). It is, therefore, important to investigate whether such problems are experienced by the couples in Botswana. Inversely, some couples continue to be together even after the HIV discordant results are known. These people may either be held by bondage of marriage, or are coping well, or maybe ignorant of the situation.

## **1.5 PURPOSE OF THE STUDY**

### **1.5.1 Research purpose**

The purpose of this study is to explore the lived experience of HIV sero-discordant couples in Botswana. At the end of the study, the results would be used to design a guideline for counselors and to help them offer effective counseling services to HIV discordant couples

### **1.5.2 Research questions**

In order to meet the purposes of this research, five questions were addressed as follows:

- What knowledge do couples have about HIV discordance?
- What has been this experience of HIV discordance couples as far as psychological, social and sexual wellbeing are concerned?
- What meanings and challenges do they experience?
- How do/did they coping with the situation?
- What coping strategies are used by HIV sero-discordant couples?

### **1.5.3 Research objectives**

The objectives of this study were to:

- identify HIV discordant couples living in Botswana and explore their knowledge and understanding of the condition
- explore the psychological, social and sexual experiences of the HIV discordant couples and determine the impact on their lives
- examine the meaning they attach to such experiences and the challenges they face as well as their coping strategies
- Identify the possible coping mechanisms being used by some couples to lead a normal life

## 1.6 SIGNIFICANCE OF THE STUDY

The government of Botswana, in response to escalating cases of HIV and AIDS and the general concerns to its effect has initiated and implemented different programmes in an effort to reduce the effect of the condition. This has been hailed by other countries and organisations as a good example in the fight against the HIV scourge (Noble 2006:03). These efforts, however, have not taken into consideration that an HIV positive client is a psychosocial and sexual being who has an impact and is also influenced by other people in his/her environment, importantly, the partner and or other family members. The couples' corporation and support for each other may have far reaching benefits for the couple, and support to the health care providers. This study aims to bridge this gap. While it is important to consider the partner in the care or his/her beloved one, it is also important to understand that they probably also go through a tough time in accepting and understanding the situation (Machado, Fontenelle, Santos Lima, Loja, Meireles & Pacheco 2004:11-16).

This research will provide guidance to counselors, inform and influence policy formulation and enhance the practice of clinicians and the other health care providers. The findings will expand the knowledge based and strengthen the capacity of policy makers, donors and implementers to design evidence-based, family-centered, integrated and sustainable programmes that will respond to the health needs of the HIV discordant couples in Botswana and across the borders.

## **1.7 DEFINITION OF KEY TERMS**

### **1.7.1 Human Immunodeficiency Virus (HIV)**

HIV is a type of retrovirus that causes weakened human immune system and ultimately leading to human immunodeficiency (UNAIDS 2012:12). The virus lives inside human and is transmitted from one person to another primarily through sexual intercourse. It is the one responsible for causing the Acquired Immune Deficiency Syndrome (AIDS).

### **1.7.2 Discordance**

The word discordant suggests disharmony and tension (Persson 2007:01). In this study the term discordant is going to be used to refer to a state where there is mismatch of HIV results between couples.

### **1.7.3 Couple**

A couple is a pair or group of two individuals or entities. The Macmillian English Dictionary (2007:338) describes it as two people who are married or involved in a romantic relationship with each other. A couple will be used in this study to refer to people who live together as partners in a heterosexual relationship. Some studies have considered couples in a homosexual relationship, but because in Botswana such relationships are not legal, they would not be considered.

### **1.7.4 Discordant couples**

Discordant couples is a pair or group of two people, that is a man and a woman who live together, either under the same household or visiting each other but bound together in a heterosexual relationship. These people, for them to be said they are discordant need to have been HIV tested and their test result be different, that is, one being HIV positive and another negative (Ligangappa et al 2008:14). The term will not be confined to married people only as it is commonly semantically used.

In Botswana, there are two main types of marriages, the traditional marriage and the common law marriage. The traditional marriage involves agreement between the

marrying couple, their parents and the authentication by the traditional leader. The common law involves a signed agreement between the couples by the District Commissioner or Ordained Religious Leader. However, it has become common to many to live together without being bound by any of these types of marriages. Such couples end up living together like husband and wife, bear children and share property. Couples in this study will include every union that is being recognised by both partners.

### **1.7.5 Experience**

Experience is the knowledge that one gets from life and from being in a lot of different situations (Schelbred & Nord 2007:317-324). This refers to an episode that affects one's health and health care, and brings about a need that needs to be satisfied. The context used in this study relates to Macmillan's definition in that it is the knowledge and skills that have been acquired during exposure to a discordant situation that is studied.

### **1.7.6 Risk**

Risk is an aspect of personal 'behaviour' or lifestyle or an exposure which on the basis of epidemiological evidence is known to predispose one to acquire HIV. The UNAIDS (2011:11) assert that risks are exposures to HIV or likelihood that a person may become infected with HIV, that certain behaviors create or increase the possibility to acquire HIV.

### **1.7.7 Highly Active Antiretroviral Therapy (HAART)**

Highly active antiretroviral therapies (HAART) are drugs specifically used for the management of AIDS patients. They help in suppressing viral replication, reducing the amount of virus in the blood to a level that is undetectable and slowing the progress of HIV disease (USAID 2011:11).

### **1.7.8 Voluntary counseling and testing (VCT)**

USAID (2011:23) describes it as 'client-centered testing and counseling', in contrast to 'provider-initiated testing'. Every country has centres where all individuals willing to undergo an HIV test would go to instead going to the clinicians who already have

overburdening number of clients. The centre is staffed with counselors to take the client through a test with minimal psychological stress. For this study, voluntary testing and counselling (VTC) would be particularly useful in helping the research identify the clients and as a source where clients are counseled and a possible referral center referred by the researcher.

#### **1.7.9 Words used interchangeably in the study**

**Couple (s)** – partner(s)

**HIV positive/negative** – HIV infected/uninfected

**Clinicians** – Health care providers

**Study** – research

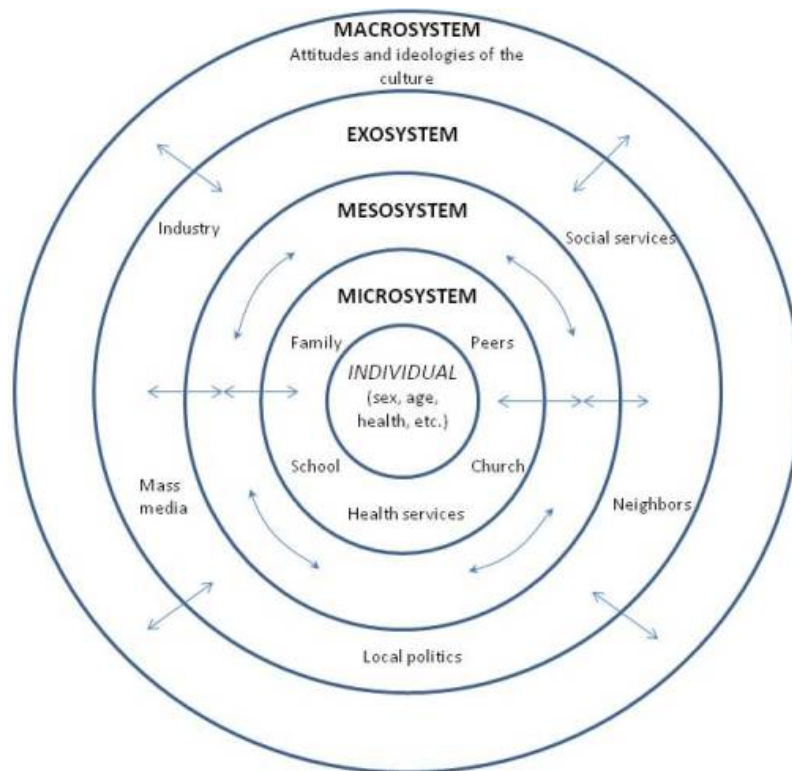
### **1.8 FOUNDATION OF THE STUDY**

Man is a psychosocial and sexual being. This means that he is influenced and also influences the environment he leaves in. The environment is an aggregate of both living and nonliving things, there is therefore an exchange of perception and experiences between every living person and his environment. Anything within man's environment would have a direct influence in the way he reacts with it. To understand this concept further, a Social Ecological Model has been selected as a basis to guide this study.

The Social Ecological Model was primarily developed to further the understanding of dynamic interrelations among various personal and environmental factors. The model largely pays explicit attention to the social, institutional, and cultural contexts of people and environment relations. It bridges the gap between behavioral theories that focus on small settings and anthropological theories that analyse larger settings. This perspective emphasises the multiple dimensions (example, physical environment, social and cultural environment, personal attributes and others) at multiple levels for instance, Individual, groups, and organisations. The model also incorporates concepts such as interdependence and homeostasis from systems theory to characterise reciprocal and dynamic person-environment transactions.

The research will be based on the principle demonstrated in the framework below.





**Figure 1.1 Illustration of Bronfenbrenner’s Ecological Framework for Human Development**

(Bronfenbrenner 1998: 993-1023)

This model was originally developed by Bronfenbrenner (1989:187-249) who believed that to understand human development, the entire ecological system in which growth occurs needs to be taken into account. The system has five sub-systems that support and guide human development. Because we potentially have access to these subsystems we are able to have more social knowledge, an increased set of possibilities for learning problems solving and access to new dimensions of self-exploration. For the purposes of this study the subsystems are explained below in the context that they will be considered in this study.

### 1.8.1 Micro system

Micro system is the layer closest to the HIV discordant couple and contains structures which a couple has a direct contact with, for example their family. It may also be an individual who is in the HIV discordant relationship who in this case will have partner as hi/her micro system. The micro system provides a nurturing centerpiece for an individual.

### **1.8.2 Mesosystem**

The mesosystem moves beyond the dyad relation for the individual or couple. The subsystem connects two or more systems in which a couple lives.eg, the work place or health facility where they most often interact with.

### **1.8.3 Exosystem**

According to Bronfenbrenner (1999), the exosystem defines the larger social system in which an individual does not directly function. Although Bronfenbrenner's framework deals with child development, this could be applicable to HIV ser-discordant individual who may also be directly be influenced by the same factors as the child who needs to develop. The individual may not be directly involved at this level, but he experiences the positive and negative impacts involved with the interaction with his own system. Such factors may include peers, family social networks, neighborhood community, local politics, industry etc. Exosystem can be empowering or degrading, for example, high quality of social support care would be positive while excessive stress at work may impact on the whole family. The absence from the system however, makes it no less powerful in life. For example, an individual may experience the stress of his/her partner without actually getting involved in such stressors.

### **1.8.4 Macrosystem**

This subsystem includes cultural values, customs and laws in which a couple lives. This is important because HIV test unlike other health test is regulated by the public health act. HIV is also stigmatised and therefore HIV discordant couples need to be treated with care, not to disclose their results.

Application of this framework will be used where relevant throughout the study and documentation of findings.

## **1.9 RESEARCH DESIGN AND METHODS**

This is a descriptive study, analyzing the lived experience of HIV discordant couples in Botswana using a qualitative method. A qualitative design is a type of design that uses a systematic, interactive, subjective approach which aims at organising, providing structure to and eliciting meanings from data, (Burns & Grove 1997:27; Polit & Beck 2010:463). The research intends to describe human feelings, perspectives, experiences and understanding. The use of this method is known to provide in-depth information as described by the informant. It is regarded as quality because it provides information from a controlled environment and as mentioned by Polit and Beck (2004:245), uses an emergent design, which emerges as the researcher makes an ongoing decision reflecting what has already been learned. They are holistic because they strive to understand the concept of the study as a whole and hence require the researcher to become intensely revolved and allow for collection of firsthand information.

### **1.10 SCOPE OF THE STUDY**

#### **1.10.1 Setting**

The study sites will be purposefully sampled because of their HIV historical background, commercial and economic background, geographical setting and already well-established VTCs. These would be Gaborone as the capital city in the southern part, Selibe-Phikwe as an industrial and mining town in the east and Francistown as the second largest city famous for commercial activities in the north east part of the country. These cities/towns will allow for collection of relevant data because they have a population characteristic that cuts across the socio cultural and economic representation of the country.

#### **1.10.2 Population and sample selection**

##### ***1.10.2.1 Study population***

The study population consists of the following:

- couples who are both aged 21 years and above. Although people may start sexual partnership at an age younger than twenty-one years, many of these would not be established. The Setswana culture and marital laws also do not allow for formalization of relationship before a certain age.
- Couples who are both mentally fit. Many people who are not mentally fit do not have the ability to intelligently choose or decide what is good for them. Some of them are being taken advantage of.
- Couples who have or live in a discordant relationship. Those who have experienced life in a differing HIV status.
- Couples who live in Botswana in Gaborone, Selibe-Phikwe, and Francistown or their periphery/catchment.

### **1.10.3 Sampling**

Because of the sensitivity of the status of the participants, purposive sampling was used. Purposive sampling is recommended for qualitative studies as it allows for flexibility in determining the appropriate participants for the phenomenon under investigation (David & Sutton 2007:152). Selection of the respondents was facilitated by the help of the VCT personnel.

According to David and Sutton (2007:153), sampling and sample size estimation for a qualitative research is based on the researcher's knowledge and experience of the most appropriate respondents to pick from the population. Usherwood (1996:29) suggest that a sample size could be based on an estimate of the number of participants that will provide saturation of information required to make a valid conclusion. The sample size for this study was therefore ten couples per location.

## **1.11 STRUCTURE OF THE THESIS**

The following structure will be adopted in the write up of this thesis:

## **Chapter 1: Orientation of the study**

This chapter presents an overview of the entire study and highlights the background to the study through description of the statement of the problem, research purpose, and questions. It also covers the presentation of the research design and methods, scope of the study and conclusion.

## **Chapter 2: Literature review**

The chapter presents relevant publications that the researcher reviewed. It also evaluates the views of other researchers on the topic under study. The purpose of this review was to obtain deeper meaning of the topic under investigation, along with the method that could be applied for study validity and reliability.

## **Chapter 3: Research design and method**

The researcher presented the research design and the methods employed during the study. These included the setting, population, and sampling methods. It further covered data collection and the plan for analysis of the study.

## **Chapter 4: Analysis and presentation of the research findings**

The chapter presented detailed information on analysis of the findings.

## **Chapter 5: Discussion**

In this chapter, further analysis and discussion of the findings presented in chapter 4 were done. The discussion linked literature review with the study findings.

## **Chapter 6: Evidence informed operational guidelines for possible research consumers**

This chapter provided evidence-based information to guide the would be consumers of the research findings

## **Chapter 7: Conclusion and recommendations**

The chapter presented the conclusions based on the study, as well as the framework limitations and implications of the findings for nursing practice.

### **1.12 CONCLUSION**

This chapter has down the framework for the descriptive qualitative study of Lived Experiences of HIV Discordant Couple in Botswana. The purpose of the study was to explore the psychological, social and sexual experiences of the HIV discordant couples and determine its impact in their lives. This was achieved through in-depth interview of the selected informant who were selected using convenient sampling technique. Data was analysed and recommendation were presented to the prospective consumers.

## CHAPTER 2

### REVIEW OF THE LITERATURE

#### 2.1 INTRODUCTION

The purpose of this chapter is to present the literature relevant to the topic of study. The literature reviewed also served to explicate the findings of the study and to inform the researcher on what questions to ask during data collection. The literature review mainly focused on HIV and AIDS and on the sero-discordant couples and their experiences.

##### 2.1.1 Methods of literature search

An electronic literature search was used to find information on experiences of HIV sero-discordant couples on databases such as 'PubMed' CINAHL, EBSCO, Proquest Central (Proquest), psychoINFO (OVID). The search was limited to publications in English. Key words included: HIV and AIDS, experiences of sero-discordant couples, Ser-discordance and discordant couples.

**Inclusion criteria:** The review considered any research that used the following methods: observational studies with or without interviews; systematic reviews, grounded theories; and phenomenological research to examine the experiences of sero-discordant couples. The majority of the articles that related to the following topics were included: emotional experiences of HIV sero-discordant couples, sexual experiences of HIV sero-discordant couples, psychosocial experiences of sero-discordant couples and concept papers written on sero-discordance.

#### 2.2 OVERVIEW OF HIV AND SERO-DISCORDANCE

The HIV and AIDS scourge and the HIV discordance remain a serious medical and public health challenge. Despite the efforts made to mitigate their effects, there still remain many challenges that impact both the individual infected, persons affected, and

the health needs of those affected and infected. Sero-discordance is a serious challenge in the lives of the couples especially the youth who still aspire to have children and expect to have longer and enjoyable sexual relation (Hailemarriam, Kassie & Sisay 2012:900).

Reports of sero-discordance have been reported in literature. For instance, in Uganda, Beyeza-Kasheya (2010:4) reported that up to 75% of new HIV infections take place within the HIV sero-discordant couples and about 30% of marriages are discordant. Within this group of married couples, majority of them fall within the child-bearing age and, therefore, their desire to have children is high in order to keep and own a family as well as to maintain the relationship with the spouse. HIV discordance in this situation creates a serious dilemma for fertility decision-making partners. To the infected and affected, the major challenge is with stigma, discrimination and disclosure, which by extension pose another greater challenge on HIV transmission among their partners, Naran, ( 2007:18,23 ).

The possibility that in the near future AIDS may become a chronic condition due to utilisation of antiretroviral drug and the society which is becoming aware of some coping strategies may result in some discordant couples considering a positive follow up to their desire to bear children. This decision on itself is a challenge since it calls for bravery in accepting the non HIV preventative stand in a sexual life. For both partners, the symbolic value of leading a “healthy partnership life” may be high, which might be accompanied by family pressure and societal expectation to have children. Such decision may be taken without thorough consideration of other risks, and would need concerted efforts of health care providers and a robust programme to guide the couples.

In any relationship, whether it is homosexual or heterosexual, the general expectation is that couples should live in an environment where there is serene care, understanding, support, love and sharing. Unfortunately, however, this is not always the case. Couples often times, or at least at one point in time, go through moments of stress. Cichocki (2007:2) explored the challenges faced by HIV sero-discordant couples and discovered that up to 90% of the stress causing factors among couples are the same for every relationship and the remaining 10% are the ones which are peculiar to the HIV sero-discordant couple. Cichocki (2007:3), therefore, implies that there is added stress, strain and problems within the discordant couples than in a normal relationship.



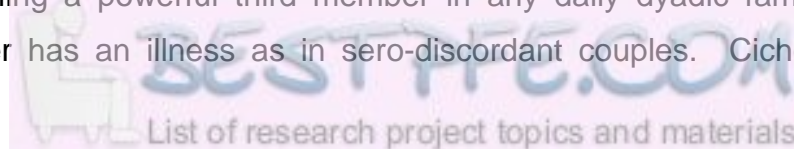
This review of literature attempts to critically explore the lived experiences of sero-discordant couples. Cichocki (2007:2) reported that 10% of all infected individuals are sero-discordant. Reviewing literature on sero-discordant assisted in the understanding of their lived experiences, their needs, and their coping strategies. It covered some of the experiences by the HIV discordant couples regionally and internationally.

Bunnell, Nassozi, Marum, Mubangizi, Malamba, Dallan, Kalule, Bahizi, Musoke and Mermin (2005:999-1012) studied the knowledge, challenges and prevention strategies of HIV discordant couples in Uganda. The study revealed that most clients lack accurate knowledge about HIV discordance. This was revealed by their expression of doubts about their diagnosis and questioning why they should engage in risk reduction measures to protect the HIV uninfected partner. There was generally a notable evidence to lack of clarity on HIV discordance which rendered them highly susceptible to popular myths and misconception such as the belief that other people are immune to HIV, and that if people engage in gentle sex they cannot contract HIV. Bunnell, Nassozi, Marum, Mubangizi, Malamba, Dallan, Kalule, Bahizi, Musoke and Mermin (2005:1002) further revealed that discordance may be marred by misconception, traditional and religious beliefs.

The bulk of the literature on sero-discordance is from East and Central Africa, and a few sources from Southern Africa and Western Countries. Literature on HIV sero-discordance is limited in Botswana and therefore very little will be discussed about Botswana. The review mainly focuses on the psychological, sexual and social experiences as well as the coping strategies for both partners involved in the HIV sero-discordant relationship.

### **2.3 PSYCHOLOGICAL EXPERIENCE**

Bunnell et al (2005:1000) pointed out that being diagnosed with HIV causes a struggle within oneself. The diagnosis alone brings about a feeling of shock and shame. Rolland (1994:327), on the other hand describes the diagnosis of a chronic disorder as being capable of becoming a powerful third member in any daily dyadic family especially where one partner has an illness as in sero-discordant couples. Cichocki (2007:1)



shares the same sentiments that there are many challenges experienced by HIV sero-discordant couples but the predominant one is stress.

### **2.3.1 Stress**

Stress is described by McCain and Huether (1998:286), as being transactional or interactional and that it stimulates our thinking processes. According to them, stress is transactionally viewed as the state of the affair arising when a person relates to situations in certain ways. McCain and Huether (1998:287) purport that people are normally not disturbed by changing or adverse situations per se, but by the way they perceive and react to them. All people have demands and when a person's demands exceed his coping ability, there could be disturbance in cognition, emotion and behavior that may adversely affect a person's well-being. A person with stress shows physical and psychological symptoms, such as headaches, high blood pressure, heart diseases, anxiety, depression and decreased satisfaction and interest in the environment. They also exhibit behavioral symptoms, like reduced productivity (Kay & Tasman 2006:628).

Stress in HIV discordant couples may be compounded by needs, such as money, where there is a need to consult health care practitioners. The stress was more compounded at the time when antiretroviral (ARV) medications were paid for. In some cases, the infected person may be unable to work because of ill health. If it gets to this stage, the family, mostly the infected, may experience significant stress, anxiety and resentment, especially if he/she had significant contribution to the family finances (Cichocki 2007:1). The person may also feel guilty because he/she has become the major consumer of the family resources (Cichocki 2007:1).

Stress itself can be a barrier to a successful relationship. A person who is stressed may tend to withdraw from other people who would otherwise help him/her make appropriate decisions to face the condition. At times the couple may make erroneous decision because they act impulsively out of stress and frustration.

A study conducted by the University of Medicine and Destiny of New University of New Jersey discovered that psychological distress, along with drugs and alcohol abuse are common in people who are sero-discordant (Cichocki 2007:3).

The stress in couples arises immediately after the discovery of discordance within the relationship. The uninfected partner would normally question how the other partner contracted the infection. The stress is underpinned by wondering whether the infection is the result of unprotected sex outside the relationship or a consequence of sharing needles while injecting drugs in case that the uninfected partner had no idea that they were using drugs. The stress in sero-discordant couples consists of anger, betrayal, and sadness, as the reality of their partner's infidelity and or use of drugs set in (Cichocki 2007:3).

The same sentiments were expressed by Mabudza (2010:99) who noted that attitudes and behaviors in the sero-discordant couples are influenced by stressors and factors such as cultural beliefs, blame, guilt, anger, fear, and trust in the relationship. Fear is always a result of stigmatisation and discrimination, which ultimately causes problems of disclosure. It is also linked with constraining oneself from infecting another partner as well as how the HIV infected partner will develop AIDS.

Some studies reported that partners who are HIV discordant often times prefer to engage in sustained condom use. They therefore become overly cautious that they should not infect the negative partner (Allen et al 2003:733-740; Beyeza-Kasheya et al 2009:6). This oversensitivity may affect the couple's liberty to participate freely in sexual activity, and as eluded to by Beyeza-Kasheya et al (2009:6) there would be decreased sexual interest. Individuals may even stop any sexual intimacy because they fear that they would infect the HIV negative partner. In many instances this kind of action may lead to feeling of frustration, loneliness, and ultimately deteriorating relationship (Robbins 2009:2). The feeling of being a burden is also one of the major psychological issues within the sero-discordant couples.

### **2.3.2 Being a burden to the care-givers**

In some other cases the HIV infected partner feels guilty that they maybe burdening care takers especially the negative partner. When they become ill, they normally feel that they have brought curse, stress and uncertainty in the home. The negative partner on the other hand may also feel deprived of the conjugal rights. All these factors are likely to bring frustration, stress and feeling of neglect, (Thupayagale-Tshweneagae & Benedict 2011:7). Where the couple is used to expressing love intimately, the sero-

negative partner may feel lonely and isolated. The HIV uninfected partner would want to be continuously caressed and sexually satisfied and if this is not achieved infidelity may result.

In some African cultures, or at least in Botswana, when someone is sick, the care is not necessarily provided by the spouse or the caretaker alone. It becomes a conjoined effort of the relatives from both sides of the man and the woman. The family members would convene at the home of the sick, or may take turns and rotate to come and check the sick. As they come and go, they increase the financial expenditure in the form of groceries, and other social amenities expenses for the family. Some other people come with extreme sympathy, which at times burden the emotional wellbeing of the sick.

A study by Nieto-Andrade (2008:2), in which she investigated the challenges faced by gay men in Mexico revealed that HIV discordant gays go through stressful situations, such as:

- The HIV uninfected partners having to put their needs in the second place. As it has been alluded by Cichocki (2007) that the HIV uninfected partners would extend their care to the infected such that they sacrifice their uninfected status and wellbeing. This is not just in Mexico alone, the caregivers in Botswana, especially the elderly always feel unlimitedly responsible in caring for their sick ones so much that they would feel like they discriminate them when it comes to issues of self-protection.
- The HIV uninfected partner has to deal with the other partner's mood changes due to antiretroviral therapy. The art of caring at times is not an easy one. It calls for absolute alteration of plans. Within the Botswana practices, the care is basically upon the wife and or mother if the patient is the husband, or mother and sisters if the patient is the wife. If one or both caretakers are working, their employment is somehow compromised or in serious cases one may quit job, impounding more stress on the family finances. While one has his/her own integrity and feelings, they are expected to adjust and accommodate changing moods and attitudes of the other partner.

- The HIV infected fears that he/she might lose the uninfected partner who may not withstand the stress of caring and the risk of acquiring infection through the infected partner. Losing a partner while already infected may be very stressing especially while one has to think of who else will he/she find as lover. The fear would be who can stand the situation.
- Having a partner who has a contagious condition by itself lowers one's esteem. An HIV infected person would always battle with keeping the self-esteem up amidst the stigma and social discrimination that may be attached, as well as sexual dissatisfaction due to having to continuously embark on safe sex practices.

### **2.3.3 Need for children**

Rispel, Cloete, Metcalf, Moody and Casswell (2013:257) in their exploratory study of discordant couples in South Africa, Tanzania and Ukraine discovered closely related information about the most common concerns of the discordant couples. Four major areas of concern were, firstly, consideration on having own biological children. Having a knowledge that the most common mode of transmission of HIV is through sexual intercourse, which is also the only simple and natural way of procreation is by itself stressful to the couples. They have to think of risking HIV infection transmission or fulfill their desire of having their own children.

### **2.3.4 Preventing infection to the non-infected partner**

Preventing HIV transmission to the HIV non-infected partner is another psychological issue for sero-discordant couples (Rispel et al 2012:260). It is well understood that the most common and simple method of prevention is condom use. If the couple has to adopt condom use for the rest of their lives then it requires full dedication and commitment from both partners. Some couples express a differing view in the consistent use of condoms alluding that there is lack of pleasure and sexual dysfunction (Beyeza-Kashesya 2010:6). The main concern is the need to safeguard the HIV infected partner. Attention is always focused on the health of the infected partner. There are always some disturbing thoughts related to the prospects of deteriorating health of

the HIV infected and the impending death. Such feelings expressed and not expressed may lead to the feeling of aloneness.

### **2.3.5 Feeling of loneness**

Studies reported that a partner living with HIV usually struggles alone before telling the other partner (Ross et al 2011:735). Ross et al (2011:736) further assert that the normal process after an HIV diagnosis is the synthesis and discovery of the meaning of the diagnosis alone before disclosing to anybody. Many people tend to keep the news about the diagnosis to themselves because they get shocked, and embarrassed by the condition. Initially they might think or believe that their current partner is the one responsible for the condition. In some patriarchal societies, there is a common fear that if a woman is first diagnosed with HIV and they disclose to their spouses, the partner may think otherwise and reject or divorce her (Ross et al 2011:740). This therefore makes them feel like they are living alone in a land where there is no help. In some cultures like the Thai, particularly the Buddhist belief, it is a sin to hurt your parents or significant others. Divulging hurting information like being HIV positive to your family members therefore is a challenge because you will be subjecting them to anguish, frustration and pitiful sympathy. Although some clients may end up telling their partners about their condition, they normally keep it a secret to their neighbor and friends fearing stigmatisation. This situation becomes so stressful that other people who are HIV infected would initially tend to have suicidal ideas because they feel there is no future for themselves. They are mainly stressed by fear, stigmatisation, and the possibility of spreading the virus to others, suspicion of receiving inadequate support from their significant others, and weakening health. Supportive structures like counseling, which have been adopted by many countries, do play a pivotal role in helping. Couples discover themselves amidst the stressful situation. However, when they are alone they keep thinking about these situations and this brings them more stress.

### **2.3.6 Suicidal ideation**

Suicidal ideation is a common occurrence among sero-discordant couples. The infected partner may feel that the stress of living with an HIV negative partner is too much to bear, this is mostly common if the negative partner is a male. However, Ross et al (2011:735-742) observed that following the initial feeling of suicide, the clients tend to

have another contrary idea of wishing to share the experience with others who are also HIV positive. The period normally takes some weeks to months after the individual has struggled with the situation alone and come to an alternative in coping with the situation. Meeting others who are also in sero-discordant relationship during group counseling or in whatever forum helps them to voice their concerns and share the problems surrounding them. It is emotionally and socially supportive. Most people, contrary to what they thought disclosing their condition would lead to rejection and isolation, discover that it is even more beneficial as they get full support from the sympathisers. In many chronic illnesses, there is always anxiety and fear of the outcome of the condition. There is some fear related to the prospect of deteriorating future health. The negative partner may be too much concerned about questions like, will there be a time when the positive partner will get sick, how long will he live? Fortunately advances in HIV, care and treatment have resulted in promising future for those infected. As lifespan continues to improve, couples should become more optimistic about what their future holds.

### **2.3.7 Denial**

Another psychological phenomenon prevailing among some discordant couples is devastation and denial. Okwemba (2007:02) noted that in their devastation and denial, HIV discordant couples would want to visit other facilities to confirm the results beyond any doubt. Couples would always differ in feelings and thinking when they are first told of their results. The infected partner may show an outburst of anger, grief and shock. This may result in extreme confusion, which has also been cited by Chama and Kayawe (2004:02) who assert that many people are overwhelmed by positive HIV test results and they may hasten to act before they really absorb the news. Some, in fear of being rejected or accused of being HIV infected, would wish to have someone to break the news to their partners and convince them to continue living with and loving them.

Naran (2007:75-76) studied the sero-negative partner's experience and emotions in HIV discordant couples. He asserts that amongst the HIV discordant couples, there are emotional problems that always emerge. Some of the emotional problems include fear and anxiety. Thinking of going for an HIV test with the knowledge that your partner has tested positive for HIV is a challenge and inflicts fear and anxiety while at the same time they know that they have the responsibility to themselves and their partners to share the sero status. Many partners experience a range of emotions including fear, disbelief,

amusement, unhappiness, loss of hope, shock, feeling stunned, and a suspicion that it must be a mistake. The same feelings are experienced even by the negative partner who learns of the positive results of their partners. Naran (2007:75-76), further revealed that fear is not only about the partner's condition, which at times has stigma attached to it but also for an uncertain future they will face and the fact that they were unsure whether they had given correct results. Some partners who test negative may also feel that their results might have been mistakenly labeled negative or that they are still on a window period.

The infected gets worried out of guilt whether their uninfected partner would stand the situation. The uninfected worries whether the infected would understand and accept to be helped. At times some partners complain that their partners were using their HIV positive situation to manipulate them and make them feel guilty when they had a disagreement since their infected partners often brought up the issue of their positive status in any argument, Naran (2007:75-76).

Frustration, a phenomenon closely related to fear and stress, is also common amongst the discordant couples (Naran2008:31; Okwemba 2007:2). This is mostly experienced when the HIV infected refuses to maintain communication, or when they are overwhelmed by guilt and shame such that communicating with the uninfected burdens them. To some, there could be blame and loss of hope. One would even regret having made a choice of accepting or proposing love to their partner in the first instance. Being told that you are HIV infected makes you immediately think of your future plans. One may tend to think of the other HIV infected persons that they know who developed AIDS and died, then they think that maybe they will also follow suit. This thought makes them lose hope on their future plans and some become bitter with their partners. Despite all these feelings, what is interesting is that male partners remain resilient in keeping the relationship while the female counterparts get divided on the issue.

The uninfected partners normally have no problem with the issue of disclosure. To them, disclosing the condition to their family members will help them get assistance and ease stress. The infected partners normally are opposed to this, or if they do, it is done secretly. Suicidal thoughts are a common and serious but not totally an unexpected experience. Thoughts to commit suicide follow loss of hope by the partners. It is also a



result of compounded pressure on the infected partner due to conflicting and confronting ideas on how to deal with the situation.

Bunnell et al (2005:999-1012) described how challenges associated with discordant status would lead to considerable emotional stress. Disclosure was particularly evident. However, some couples who had disclosed their status reported experiencing support rather than stigma from friends and family. Many couples feared disclosing their discordance to their significant others. This happens because they fear that others could not understand. Those who had not disclosed and have no or few children commonly experienced pressure from relatives to have more children. The individual or couple would then withdraw and go into isolation. The problem of withdrawal and isolation is that in many cases an individual does not get motivated to receive advice from other people or share the experience such that the whole situation may be understood. Bunnell et al (2005:1000) noted that many of sero-discordant couples have limited knowledge on the prevalence of HIV discordance. If they do not have adequate information, they would have no idea of the prevalence and the incidence rates of HIV and discordance. As a result if they are diagnosed of discordant HIV, they feel isolated by their test result, thinking that they are alone in the situation. In Bunnell et al's (2005:1011) study, couples were shocked after joining the study participants to learn that they were not alone but many other couples faced the same challenge.

## **2.4 SEXUAL EXPERIENCES**

One of the basic reasons couples come together is to share sexual intimacy and for procreation. While it is not the most important part of a relationship, sexual intimacy is the key component of any love relationship. Couples, whether married or simply living together as boyfriend and girlfriend, do provide sexual access to one another. Haralambos and Holborn (1995:321) assert that with regard to affording sexual access to each other, partners are regulated by rules that forbid and or limit sexual activity outside marriage or confinements agreed by the two parties. This, according to Haralambos and Holborn (1995:322) provide sexual gratification for the spouses and strengthens their relationships since the powerful and often binding emotions which accompany sexual activity unite the man to his spouse. In this regard, the sexual role helps stabilise the couples leading to a more stable society. It is therefore against this

background that the normalcy of sexual relationship and sexual activities are likely to get disturbed during HIV sero-discordance, and this may disrupt the stability in couples.

One most important issue is to understand and acknowledge that as human beings, we are sexual and therefore failure to attain a sexual role may increase chances of unsafe sexual acts. People need to be able to speak freely about sex, safe sex practices, and how it can be enjoyed. When a person is HIV infected, any discussion about sex becomes thorny to him except to those activists who have openly come to the open. If one is in a sero-discordant relationship, fear of transmission always emerges which disrupts the flow of relationship.

As mentioned by Cichocki (2007:3) sero-discordant couples face a number of issues that are unique to their situation. This would include making a decision as to what level of sexual activity is comfortable for them. While safer sex, which ideally involves the use of a condom, reduces the chance of transmitting the virus, it does not absolutely eliminate the risk of transmission to the HIV negative partner. Discordant couples are, therefore, burdened with the use of condoms which they are aware that is not an absolute and sure protection.

There is also new research which shows that the risk of transmission is greatly reduced when the positive partner is on anti-retroviral therapy and their viral load is undetectable (Quinn et al 2002:921-929; Gray, Wawer, Brookmeyer, Sewankamo, Serwadda & Wabwire-Mangen 2001:1149-1153). Couples who live in HIV discordant relationship are enrolled in PMTCT of HIV and AIDS programme need to critically consider how much risk they are willing to take if they think of having a child. Some couples lack understanding on when and how to conceive while at the same time employing risk reduction measures against HIV transmission.

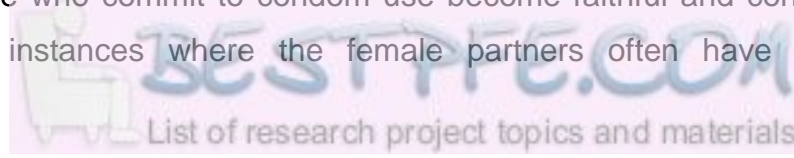
Rispel, Metcalf and Moody (2009:27) conducted a study on exploring coping strategies and life choices made by HIV discordant couples in long term relationships in South Africa, Tanzania and Ukraine. The purpose of the study was to gather preliminary information about the coping strategies and choices made in the context of long-term HIV discordant relationships. The results were not different from that of Cichocki (2007), which revealed that most of them expressed that discordance has affected their sexual relations. Major concerns in their sexual life include lack of or lost spontaneity

where couples become overly cautious during sexual intercourse. Rispel et al (2009:27) also concur with Cichocki (2007) that discordant couples experience decrease in frequency of sexual intercourse, libido and strain related to avoiding certain sexual acts like oral sex. This is mainly because they get emotionally stressed up when in the event of enjoying sex, they also have to consciously consider risk reduction measures, hence lose desire for sexual activity. Truly, sex is both physical and emotional and if anything disturbs, the psychological wellbeing would hamper even the physical activity (Cichocki 2007:4).

#### **2.4.1 Sexual violence**

Hailemariam, Kassie and Sisay (2012:3) studied the “Experience of Sexual Violence Among Women in HIV Discordant Unions After Voluntary HIV Counseling and Testing”. They noticed that women’s experiences evoked different reactions and feeling, including concern over the need to have children, fear of infection, having thoughts to separate from their spouse/partners, helplessness, anger and suicidal tendencies. Hailemariam, Kassie and Sisay (2012:3) also noted that couples in this situation normally experience challenges of life that require their resilience, or else they become devastated and may despair resulting in an unsettled and uncertain relationship.

While women in Eastern Africa, like Kenya, Rwanda and Uganda, face sexual violence, in Zambia, Allen et al (2003:739) discovered that, following HIV testing and counseling, most of the discordant couples start to engage in safe sex by using condoms. However, a couple in which a male partner is not infected had more frequent sex both and without condom compared to couples whose male partner is infected. This phenomenon is related to the one observed by Okwemba (2007:2) that men become more compassionate about their female couples to an extent of engaging in risky behavior that may also infect them. Compared to couples who are sero-concordant-negative, sero-discordant couples experience reduced sexual contact, an experience reported by Cichocki (2007:1) and Gray et al (2001:1151). The rationale for that centres around the psychological stress which ultimately reduces libido in infected males. Interestingly, even though couples with an infected male partner have less frequent sex, those who commit to condom use become faithful and consistent. This confirms that in instances where the female partners often have difficulties in



negotiating safe sex, some men who know they are infected willingly use condoms to protect their spouses from getting infected (Allen et al 2003:738).

Ndandali, Allen, Karagirwa and Sahunkwe (2004:3) studied 100 discordant couples. Of these, 74% had ignored the possibility of HIV discordance and engaged in risky sexual behavior before consulting the health care providers. Only 26% of the couples surveyed had temporarily stopped all sexual activity and 3% had stopped permanently. A total of 29% of the discordant couples, some being coerced and some having consented continued to have unprotected sex at times, an indication of risk behavior amongst couples. The results reveal the existence of the problems that need to be arrested in order to avoid sero-conversion. These could be due to ignorance of the condition and its impact on the couple, and or the existing cultural factors that directly have an influence in the HIV spread.

Sexual relations posed the most formidable challenge for couples particularly women. Bunnell et al (2005:1000) reported that after receiving discordant results, men and women experienced disagreements over sex and blaming one another for bringing HIV into the home. Many HIV infected clients stated that they lost interest in sex completely due to their discordant status. In some cases, HIV infected women reported violence from their partners. These women would report that their partners are reluctant to use a condom. Some husbands would threaten to stop condoms completely questioning how long they would use a condom on their spouses. Such acts by the husbands are a risk to the vulnerable wives, because at times they may force them to have sex even without protection.

#### **2.4.2 Sexual abstinence**

Bunnell et al (2005:1011) further reported that although few couples had chosen abstinence as their strategy, many of the HIV uninfected females who preferred abstinence had their HIV infected partners refusing to comply with abstinence. As one HIV negative woman said of her husband, "I insisted that we abstain and suggested that we separate our beds, but he refused saying that as long as I am still in his house, abstinence is completely impossible and would never work". However, not all men shared this view, and abstinence appeared to be easier if an HIV infected man endorsed it. Those males express love for their partners and feel having sex with their

wives is like killing someone you love who would even look after your children. This type of couples is one which had good communication and would go to the extent of writing a contract in which the man agreed that the woman could look for an HIV negative partner outside their relationship, provided she continues to live with him and take care of him when sick.

A study by Stevens and Galvao (2007:1020) in which they investigated the HIV infected women's struggle in primary relationships with sero-discordant partners discovered some familiar reports complementary to those of Bunnell et al (2005:999) that majority (58%) was not sexually active, at least during the time of their prospective data collection. Sadly (18%) of the total sample engaged in unprotected sexual intercourse which occurs in the context of primary partnerships almost all which are sero-discordant. Notably, the proportion of women who practice safe sex do so not because their symptoms are any more or less under control than those who practiced unsafe sex. It is because the interpersonal dynamics of their relationships are different. Their primary male partner welcomes and accept condom use, or because they don't live with them or are not present in their daily lives. However, women who engage in unprotected sex while knowing that they are in a sero-discondant relationship do so reluctantly fearing that they will pass the virus to their male partners (Galvao 2005:1113).

This report suggests that HIV infected women do not carelessly engage in sexual behavior, rather they are well informed and are deeply concerned about sexual risk. They do not want to harm or infect their partners. Unfortunately, under consistent circumstances of interpersonal duress, they give in to their male partners who always show dominance.

## **2.5 SOCIAL EXPERIENCE**

Worldwide, societies have cultures, norms and values, which regulate their behavior. These cultures, norms and values are learned over generations and passed on to new members of the society during both primary and secondary socialisation. Every society is identified through its culture which is absorbed and internalised during socialisation. Culture, therefore directs actions and defines the outlook on life of the people and defines acceptable ways of behaving. Within the culture are a number of guidelines

that direct conduct in particular situations called norms (Haralambos&Holborn1995:3-5). It is therefore important to note that since a relationship is life shared by two or more people, the same culture, norms and societal practices would affect all those who are involved during HIV discordant relationship. An infected person is ordinarily accountable to his/her spouse and by extension to the significant others. The most common question that normally comes to mind is: "How did it happen"? Many speculations may be framed, ranging from infidelity to misfortune and acceptance of an infected partner. This is usually influenced by cultural norms.

Culturally, in Botswana and in most of African communities one of the major functions of the family is procreation. Even when the couple is not married, the more they become settled in the relationship, the more the society starts to expect children from them. In African societies reproduction is a prestigious role, and a family's worth is measured by its ability to reproduce. In sero-discordant relationship, the decision to reproduce can be a distressful one. There is atypical stress when a couple has to decide on precautionary measures but at the same time know what they are likely to be labeled "infertile

Hailemariam, Kassie and Sisay (2012:4-8) reported that discordant couples are faced with varied issues regardless of sexual orientation, age race and societal status. These couples normally strive to sustain the relationship and explore strategies to maintain it. After realising that they are discordant, they start to have conflicting and unstable ideas. There is therefore a need to maintain a state of equilibrium within the relationship. This is reported to be afforded through efforts such as, (i) entertaining partners' interests. The HIV negative partner may continue to sacrifice own interest despite feeling that he/she is losing freedom for the sake of retaining value of the relationship. (ii) Entering into a transition whereby the couple shifts from their previous life experience to the new one due to their HIV status. (iii) Accepting the facts so as to normalise the relationship.(iv) Sharing life with the community, which includes disclosure and active participation on action groups.

Discordant heterosexual couples may also struggle with HIV stigma especially in communities where HIV and AIDS is labeled as a disease for homosexuals. For gay couples who live in societies that still shun homosexuality, overall lack of support for such union is noxious enough already, so the reality of discordant couples rarely draws

sympathy and understanding. The situation is worse when trying to obtain social services that address the needs of both partners. This can be a shameful and frustrating process. In some or even some of the developing countries such services simply don't exist (Salyer 1999:2).

The major hindrance in good behavior seeking effort is the associated stigma in HIV and AIDS. Stigma is described by Dinos, Stevens, Serfaty, Weich and King (2004:176-181) as a social construction that defines people in terms of a distinguishing characteristic or mark. Boss, Reeder and Stutterheim (2012:3) assert that the concept of stigma dates as far back as the history of the Greeks, but recently it is known not merely as a physical mark but rather an attribute that results in widespread social disapproval and discrediting social difference that yields a spoiled social identity. Boss et al (2012:4) further contend that stigma may be overt if it manifests as aversion to interaction, avoidance, social rejection, discounting, discrediting, dehumanisation and depersonalisation of others. This may happen if the people within the environment of the discordant couples openly show a disapproval of them verbally or otherwise. Boss et al (2014:4) continued to content stigma may be non-verbally expressed and hence become subtle. According to them, it involves perception of deviance and extends to more general attribution and character and identity. Stigma is more inclusive than prejudice because it involves individual based responses to deviances as well as group-based reaction as a function of category membership. Stigma is socially defined, hence varies across cultures.

A stigmatised person tends to internalise negative values placed on him/her by those stigmatising them. Such people end up showing behavioral characteristics such as shame, isolation and self-hatred. From the beginning of the HIV scourge, the condition was associated with socially undesirable behavior such as multiple sex partners, homosexuality and drug use. Stigmatisation in HIV would therefore worsen when it is viewed as the responsibility of the infected individual (Rongkavilit, Wright, Chen, King, Chuenyam & Phanuphak 2010:126).

People who are aware of stigmatised character or behavior in others may seek to isolate or avoid the deviant individual. The nature and intensity of emotional and behavioral responses are normally driven by the degree of fear and ignorance related to the situation. If an individual is defined or labeled as a member of the stigmatised

group, she may have difficulty in re-establishing himself in the minds of others as a welcomed member of the mainstream of the society. In our African societies, like Botswana, when HIV and AIDS started in the 1980s it was severely stigmatised as a sexually transmitted disease and associated with people who are careless in their sexual lives.

A study by Lieber et al (2006:465) on HIV/STD stigmatisation fears as health seeking barriers in China provided a number of insights into the impact of HIV and AIDS stigmatisation fears on seeking behaviours. Certain factors such as suspicion about the quality and reliability of diagnosis and treatment concerns about the monetary and time costs, and concern about exposing oneself to social sanction do influence the health seeking decision. In China the strength of socio-moral values and beliefs are particularly salient and powerful determinants of behavior. One outstanding implication of this social force is stigmatisation and in order to avoid social reprimand, individuals take extraordinary measures to prevent exposure after having engaged in risky behaviours. Consequently, stigma fear presents a powerful obstacle to the individual's willingness to discuss risky behavior with others (Lieber et al 2006:470).

Studies done in Africa on HIV discordant couples have close correlation with the findings by Lieber et al (2006:463). Mabuza (2010:90) investigated the impact of HIV sero-discordance on married couples attending the infectious disease clinic at One Military hospital in South Africa and observed that most couples feared being discriminated against at work, which has led them not to come into the open and tell their supervisors. The participants expressed indeed having experienced discrimination because when people saw them at the infectious disease clinic, they assumed that both are HIV infected and this hurt the HIV uninfected. Salyer (1999:2) also reported that discordant couples sometimes struggle with HIV stigma because it is perceived as a disease of the homosexual in America. Sadly, if one is HIV infected and dates an HIV non-infected person, a lot of people usually assume that both are already or will soon be infected. Some HIV uninfected people will not date a person they know is infected out of fear of infection, but also because they do not want be associated with the infected.

Okwemba (2007:2) reported that for couples who are not yet married, it has become evident that when a man tests negative while the woman is positive, most men continue



in the relationship and give the woman an emotional support. Ironically, and contrary to that, if a woman tests negative, they normally leave the relationship and forsake the man. The report reveals that the woman usually does not leave the relationship immediately, they normally put up for some while before deserting the man. Although Okwemba does not explain why this happens, the most probable reason could be that the women do this out of fear that they will not be able to fulfill the men's desire of procreation. This may also be out of fear that in communities where women's rights are least regarded, the women do not have the right to negotiate for safer sex practices.

Consistent with Okwemba's (2007:2) report is Bunnell et al's (2005:1011) study which reveals that separation or divorce at times becomes inevitable and that separation is expected if the woman is HIV infected, but contrary to that it is the infected partner who normally initiates the separation. However, men have shown to be more empathetic to their HIV infected partners and in most cases would keep their partners as compared to the women counterparts.

Associated with discrimination and stigmatisation is the issue of disclosure. Disclosure is defined by McMillian English Dictionary (2007:418) as a process of giving information to a person, especially information that is secret. Mabuza (2010:78) discovered that some people take time to disclose their HIV sero-discordance fearing rejection. The people that they normally prefer to disclose to are family members, including parents, siblings, and nieces. Interestingly, in Mabuza's report, most people that they disclose to, show acceptance and sympathy. However, and disturbingly so, acceptance by the partner is always accompanied by responses of mixed feelings.

Norman, Chopra and Kadiyala (2007:1776) contend that disclosure of HIV is important because it leads to modification of behavior, access to and adherence to treatment by people who are HIV infected. The researchers investigated the factors related to HIV disclosure in two South African communities. From their investigations, they discovered that disclosure is a catalyst for access to a variety of important and often essential resources, including institutional support and opportunities to take positive leadership roles in the community. In Botswana, a neighboring country to South Africa, people who have publicly disclosed their HIV status are used as activists and seized the opportunity for employment in HIV and AIDS programmes. It also opens the door to a dynamic response encompassing community involvement and support of the HIV

infected individuals and their families and enabling a platform for public disclosure and eradication of stigma (Norman, Chopra & Kadiyala 2007:1779).

Norman et al (2007:1780) further assert that the process of HIV disclosure by the infected to their family, loved ones and professionals is very important in helping the individual to cope with the stressful situation. Successful disclosure of the HIV infection is often seen as a way for HIV infected person to regain freedom that their HIV status had taken from them. People with better family support are able to maintain their situation, both financially and emotionally much better following the disclosure. Disclosure also has community benefits such as the reduced incidence of HIV infection and reduction in stigma and discrimination. Norman et al (2007:1780) further argue that disclosure is fundamental to the management of HIV infection and has become an entry criterion for many treatment programmes in resource constrained setting. It also plays an important role in the adherence to complex treatment regimens.

Although disclosure seems to have some good benefits, the HIV infected often times struggle to initiate it. People normally want to wait for a ripe time to disclose and this time differs with whom to disclose to and how one is close or related to such a person. Van Dyk (2007:271) observed that HIV infected partners react differently when faced with the issue of disclosure. Some partners open up on disclosure within a day after testing positive, while others take some time from months to years before they could disclose. The United Nation Office on Drug and Crime (UNODC) (1995) reported that studies done in the Asian continent reveal that HIV positive males are less likely to disclose their status to their partners than the HIV infected female. However, marriage seems to have an impact on whether or not to disclose as a study done in Kolkota revealed that 65% of men had disclosed their HIV status to their partners as compared to 100% of women who disclosed to their partners. In Africa, Uganda being an example, the rate of disclosure is somehow higher but requires a stepwise process of sensitisation and agreement by the infected partner and encouragement from the counsellors. In a report by Kairania, Gray, Kiwanuka, Makumbi, Sewankambo, Seradda, Nalugoda, Kigozi, Semanda and Wawer (2010:1041-1051), they noticed that 81% of HIV infected partners disclosed to their uninfected partners in the presence of the counselors. The rates of disclosure were 81.3% for men and 80.2% for females, and that the disclosure did not vary by age, education or occupation.

Disclosure, however, has its own benefits and challenges. If a partner discloses his/her status to a partner, this will help in earlier prevention of infection of the uninfected partner. On the other hand, disclosure can fuel tension in the marital relationship and uncertainty with regard to further disclosure to the external family. The infected thus have to decide if they want full disclosure that is, publicly revealing their HIV status or partial disclosure, which is telling only certain people, such as relatives and friends. Cichocki (2007) concurs and contends that there could be barriers to a successful sero-discordant relationship. It has become evident that disclosure becomes a problem when one partner wants to disclose to more people than the other partner for purpose of care and support, as may happen when one is sick. In such instances, the two must agree and the voice of the infected has to take precedence except in situations of medical emergency where the caretaker or the guardian must decide on behalf of the infected or the sick. If the infected partner says “no” to disclosure, then the HIV uninfected partner must abide by his/her wishes without question.

Certain factors may influence disclosure, such as religion, culture, education background, state of the condition of the client and personal character. Weiner et al (1998:116) pointed out that people would do so for the reasons listed below in order of their importance:

- A desire for emotional closeness with support from others
- A forewarning for significant others
- Health transmission concern
- A desire to be honest with others
- A need for tangible assistance like information material about HIV and AIDS

On the other hand, the same factors may influence non-disclosure. Some of the reason for non-disclosure may include the following as stated by Weiner et al (1995:116).

- A fear of rejection or ostracism
- A desire to protect the feelings of significant others
- A fear that others will gossip
- An act of ignorance
- Uncertainty about how to disclose

- A desire to keep others from making sacrifices or fear of disrupting relationships
- Geographical separation, such as when an infected person does not want to disclose over the telephone

In most cases, the relationships are strained because one partner blames the other for the existence of the discordance without considering that the infected partner might have been infected way before the existence of their relationship. The negative partner normally would blame the positive one for bringing the HIV in the home. The initial reaction for most people in a discordant relationship is to associate discordance with infidelity on the part of the HIV infected partner. Some HIV uninfected clients, who are confident that their partner had been faithful, searches for other explanations for their partner's HIV infection, citing injections, sharing of sharp instruments, caring for relatives who had died of AIDS, or other non-sexual modes of transmission as explanations for their partner's infection (Bunnell et al 2005:1004). A similar report by Mabudza (2010:82) asserts that just a few partners either doubted their spouses or did not trust them at all. Most couples indicated that they trust each other. Those who do not trust each other cited reasons surrounding sexual behaviours, which include multiple sexual partners.

In other African countries like Kenya, the situation is further aggravated by diverse cultural practices, beliefs and tradition. Discordance has led to breakage of families and family interactions within the communities. The uninfected partners have difficulty in accepting to live with the infected partners and instead of supporting the infected partner, they continue to question the faithfulness of their partners. This pessimism by the uninfected partners perpetuates stigmatisation of the disease and the discrimination of the infected resulting in hesitance by other people to come up for the test or even to disclose.

Another important issue of concern is sharing medical information. While attending to the doctor's visits, some infected couples want to be accompanied by their partners to give them moral support and help them understand the doctor's instructions. On the other hand infected people prefer not to share medical information or discuss their medical condition. Some uninfected partners sometimes have a hard time understanding this feeling. The partner may need to know whether the infected partner is medically okay and follows the doctor's instructions. Fear of the unknown can be

powerful. Being left out of the medical aspect of their partner's life spawns fear and doubt, and one may even think one will be deemed not to be doing enough to support the infected partner.

Beyeza-Kasheya (2010:10) conducted a study on "My partner wants a child: A cross sectional study of the determinants of the desire for children among mutually disclosed sero-discordant couples receiving care in Uganda". They found that 59% of the participants in their study desired to have children. The belief that their partner wanted children was a major determinant of the desire to have children, irrespective of the HIV status. Even though 55% of participants reported that their relatives wanted them to have children, 82% thought that this would not be the case if the relatives knew that one member of the couple was HIV positive. However, 69% of participants believed that their relatives would still care for them during childbirth even if knew they were HIV positive. In addition, 90% of the participants believed they would obtain support from health workers/counselors if they become pregnant. This is an indication that societal pressures, especially on married couples have a major influence in their live. Societal pressure becomes pronounced among couples in which the woman is HIV positive. The young age and parent's expectations for children significantly increase fertility desire.

## **2.6 COPING STRATEGIES**

Bunnell et al (2005:1009) assert that although the usual trend for the sero-discordant is to be entangled with seemingly unanswered questions, most couples end up accepting their situation and adopt prevention strategies. Quite a number of people take the challenge and lead a positive live. The negative partners would conditionally or unconditionally take the responsibility of supporting their infected partners through severe depression and attempted suicide. The couples go through stages of mixed feelings. The first stage where a person thinks he/she cannot stand the thought of an HIV positive diagnosis. This is a stage characterised by fury, denial and anger. Later the individual 'polarises' and gets used to the situation where things just become normal. Some participants exhibit a high degree of resilience in coping with a very challenging life situation. Bunnell et al (2005:1011) report that the resilient ones adopt common strategies including condom use, separation and abstinence. Many couples use a combination of strategies that evolve over time. Condom use is the commonest and most preferred strategy used by discordant couples. A number of couples transit to

condom use after failing to abstain or sufficiently reduce their frequency of sex. However, Bunnell et al (2005:1011) discovered that there were some inconsistencies within couples, men are more likely to report that there have been no problems, while women emphasise that condom use is inconsistent.

Apart from condom use, separation is being found to be preferred too, particularly by couples whose relationship is not that old and who do not have children. This separation varies with gender, depending on how much counseling they have received. In most cases, it is the positive partner who prefers separation before being convinced to stay in the relationship by their HIV negative partner. Bunnell et al (2005:1012) noted that sometimes separation was not complete, but influenced by factors such as age of the relationship, level of understanding by one or both couples, the health condition of the affected, and the perception about the condition. Couples who have strong communication and ties such as children appeared more able to work out successful coping strategies regardless of which partner was infected.

Chama and Kayawe (2004:3) concur and further point out that “though there are certain immediate reactions to positive results like anger, shock, denial or doubts about the results, clients usually overcome these through subsequent follow-up and counseling which focuses on their feelings and anticipated negative consequences of the test results’. Counseling plays a major role in helping these couple find their workable and lasting solutions to the situation. Follow ups include repeat HIV testing for those who are negative after three months, followed by regular appointments on 4-6 monthly basis. About 99% of HIV negative clients continue to be negative on subsequent repeat tests.

Allen et al (2003:733-740) identified ten strategies that give HIV discordant couples a hope even in such trying moments to stand the distresses of life through:

### **2.6.1 Good communication**

HIV sero-discordant find refuge of their stress in meeting someone they regard as a confidante and engage in good communication with. They also find comfort in discussing their condition with their fellow infected colleagues, partners, nurses, doctors and counselors. Sharing of feelings and thoughts is considered beneficial for both negative and positive partner. Allen et al(2003:736) discovered that when there is lack

of communication, the negative partner feels frustrated because the positive partner may be going through a phase of depression resulting in them being moody at times. This frustrates the non-infected partner because they want to help their partner deal with these feelings but they do not know how their infected partners feel, think and what they want being done for them and how. The bottom line is that communication is very important as it conveys feelings and thoughts.

### **2.6.2 Support**

The general perception in the care for the loved ones by most African cultures is to do it and do it whole-heartedly. Caretakers, particularly the parents of the sick feel that by supporting the positive partner, they derive from a benefit from this as it eased tension and understanding in the relationship. Acceptance by the negative partner helps the positive partner to be able to cope better with the situation knowing that they have someone to confide in who is both understanding and nonjudgmental. HIV uninfected partners also feel a sense of relief at being able to assist their positive partners in their treatment especially with regard to their adherence to medication. By involving the negative partner in their treatment participants had better adherence and prognosis.

### **2.6.3 Education**

Education is identified by Allen et al (2003:735) as a coping strategy in that people feel that they needed to be educated and informed about HIV and AIDS. This helps them in being proactive during the care of their partners rather than wait for problems like opportunistic infections to attack before learning about them. They recognise that knowledge empowers them and enables them to participate and deal with problems timeously and effectively.

### **2.6.4 Religion**

Religion is a strong belief in the supernatural powers, an institution that helps to express our beliefs to a heavenly power. It helps in the spiritual growth of a person, as well as spiritual worth. People who believe in God normally find solace in communicating with Him through any means. This communication gives them spiritual healing and sometimes even divine miracle beyond scientific explanation. Some people would

express strongly how God and their church had helped them through the crisis. Faith gives both partners hope for the future. They have a positive outlook on life even though they are dealing with this problem. While religion can play a very important role in assisting infected patients and their partners and families to cope, some researchers as reported by Quinn et al (2000:924), Okwemba (2007:3) and Allen et al (2003:734) show that some of the negative partners were prepared to put themselves at risk of contracting HIV by not using condoms, because they believed they have an unconditional responsibility for care and that their faith in God would protect them from contracting HIV as it has been.

### **2.6.5 Disclosure**

Disclosure to other family members is found to be an important and emotionally soothing experience simply because it opens up the discussion and allows a platform for the infected to know what the other people think about the situation. While some positive partners were opposed, some of the negative partners were favoured it and feel it may help them to cope by decreasing the stress on them and giving them someone to talk to. The negative partners feel that disclosing reduced the burden of keeping secrets.

### **2.6.6 Attention from doctors**

A word of courage, assurance and inspiration by health personnel is better able to give comfort from stress. By asking questions such as how they are feeling, how the family is doing helps to take their minds off situation. It also assures them that the doctor cares and understands their situation. To many, this treatment or attention by the doctor is regarded as holistic rather than just a medical care.

### **2.6.7 Safe sex**

While several authors such as Rispel et al (2009:6) and Cichocki (2007:2) consider safe sex mainly as the use of condom, many people do not faithfully and consistently use it. As mentioned earlier, there is some diversity on the use of condoms. Women tend to have a drive to consistently continue using them while most men use them sometimes. In Allen et al (2003:736) study, there was a misconception amongst some men that if



they remained negative so far, they would always remain negative. If the negative partner was a female they were adamant that they had to use condom while others refused to have sex with their partners. These diversities come about because of lack of knowledge on preventive methods. For couples who understand and are willing to resiliently maintain the discordance such that they prevent sero-conversion, the best strategy is condom use throughout.

### **2.6.8 Acceptance**

Acceptance is a state when a person's assent to the reality of a situation recognises a process or condition without an attempt to change it, protest or exit. Although it has been mentioned that in most cases the negative partner often times is overwhelmed by questions such as "how did their partners acquire the virus", ultimately they have to give up in seeking answers to their questions and learn to live with the situation. Acceptance of the situation and positive attitude help the couple cope and move forward. By accepting that they cannot change the past and that what has happened has happened, no one is to blame for the situation, the couple is able to move forward and support each other through the ups and downs of the situation.

### **2.6.9 Good news about improving CD4 count**

Counseling is fundamental to coping by the infected partner. In counseling, topics such as how to improve own health is discussed. These would include monitoring CD4 count and keeping check of the viral load as well as treating opportunistic infection. This knowledge can help empower the infected on how to delay effects of the condition and prolong life. This gives the positive partner hope that their life is not about to come to an end due to this disease. They have a positive outlook on life and this also beneficial to the negative partner as they share this joy with their partner.

### **2.6.10 Social support**

Social support is one of the most important factors in determining the coping ability of an individual. The absence of social support shows some disadvantages among the infected individual and can be a determinant to predicting the physical and mental health of a person, as well as the individual's ability to cope with stress. Knowing that

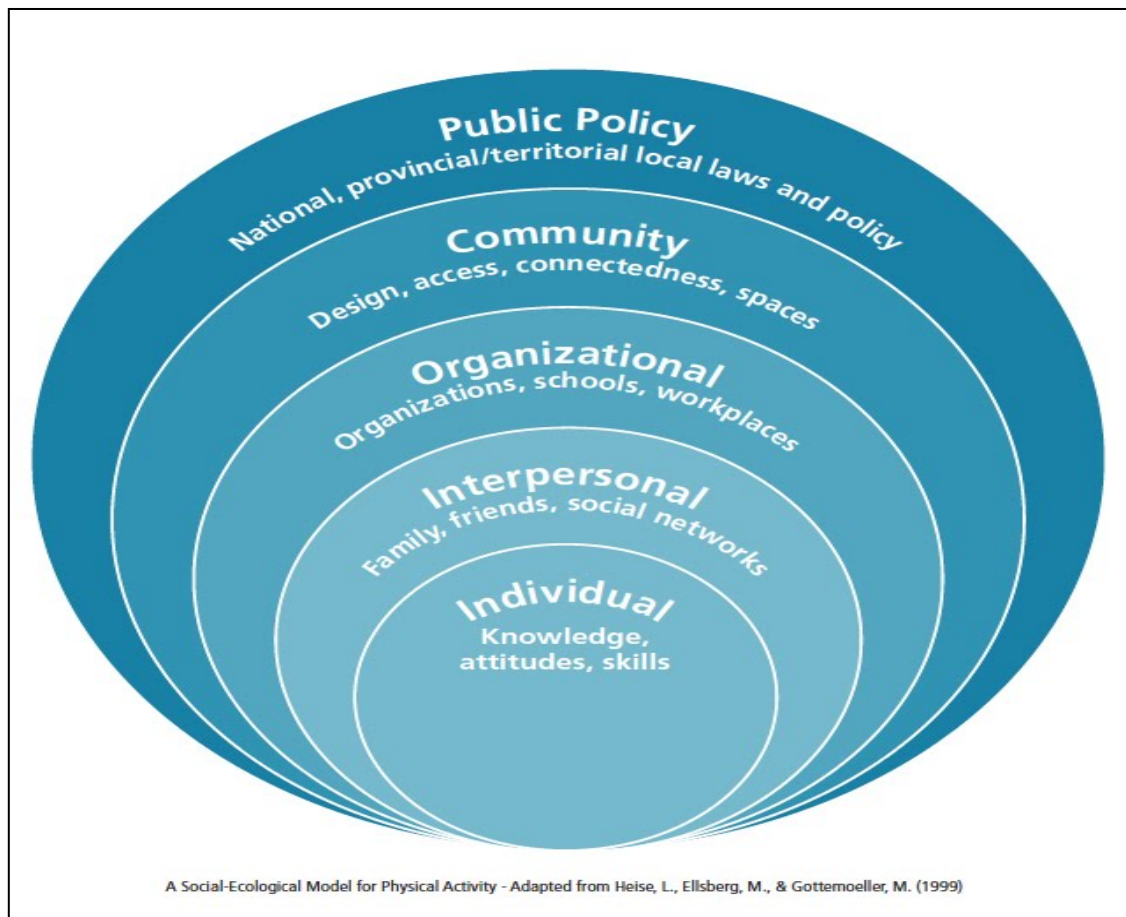
people value you is an important psychological factor in helping a person to forget the negative aspects of life but think positively about their environment. Structure like family session, church going, getting involved in community activities and social entertainment are ideal to divert the mind from thinking about negative things.

## **2.7 THE THEORETICAL/CONCEPTUAL FRAMEWORK UNDERPINNING THE STUDY**

One of the characteristics of a qualitative research is the aspect of validity (Onwuegbuzie & Leech 2006:233-249). The validity therefore must be ensured by the comprehensiveness of the design and analysis of the data. To achieve this, a qualitative researcher must decide on which is the best design, guided by profound and renowned theory that would suit his study. Different conceptual frameworks, which are a set of concepts, with proposition that describe them and express the relationship between them (Miller-Keane Dictionary of Medicine 2003) have been designed. Conceptual frameworks help in guiding research studies, nursing practices and educational programmes (Bronfenbrenner & Morris 1999:995) asserts that choosing a conceptual framework in a qualitative study therefore entails critically deciding on the following six criteria: (1) comprehensiveness of the content, (2) logical congruence, (3) clarity, (4) level of abstraction, (5) clinical utility and (6) cultural perspective.

The conceptual model to be used in guiding this study is therefore the “Socio-Ecological Model” by Bronfenbrenner and Morris (1999:993-1023). The model was initially developed after the First World War by different psychologists, and continually revised by Bronfenbrenner until his death in 2005. It is regarded as the most appropriate because it considers man in his totality in relation to his internal and external environment. It also takes into account his interaction with his/her family, existing organisations and the community at large. Importantly, it acknowledges some statutes within the political systems that may affect HIV discordant couples.

Figure 2.1 shows different levels of the conceptual framework and their relation to the individual or couple



**Figure 2.1 A Social-Ecological Model**  
 (Adapted from Heise, Elsberg & Gottemoellor1999:8)

### 2.7.1 Explanation of the social-ecological model

The ultimate goal is to understand what the HIV discordant couples experience with an aim of preventing the effects associated with self-worthless, stigma, discrimination and stress. These will in turn help raise the individual's self-esteem and encourage disclosure. Individuals will ultimately build self-confidence and be encouraged open up and discuss about their own condition. Prevention therefore requires understanding the factors that are fundamental in the lives of the couples psychologically, socially and sexually. Though one partner is HIV infected, this infection should not be allowed to spread to the uninfected partner.

The Socio-Ecological Model uses a four-level approach that guides how an individual interacts within his own environment, his relationship with other people, community and the society at large (McLaren &Hawe 2005:6-14). It is important to recognise that apart from the social environment, there are also physical and policy environments that directly impact on our lives (Heise 1998:262-290). The model considers the complex interplay between individual, relationship, community and societal factors.

### **2.7.2 Individual**

The model identifies factors within an individual such as biological and personal makeup that increase or decrease the likelihood of becoming a victim to effects of HIV sero-discordance. Some of these factors are age, education, income, substance use, or experience with a similar situation before. Intervention strategies at this level are often designed to promote attitudes, beliefs and behaviors that ultimately prevent stress; isolation shame, anger and frustration, while at the same time encourage acceptance and disclosure.

### **2.7.3 Relationship**

According to the Socio-Ecological Model, close relationships also play a very vital role in the individual's understanding and handling of the experiences of a situation. A person's closest social circle like partner(s), family members, peers, and family and confidants influences their behavior and contributes to their range of experience and influence the coping strategies for HIV discordance.

### **2.7.4 Organisational**

Organisational environment refers to commercial organisations, social institutions, associations and clubs which have structure, rule and regulations, that HIV discordant would or may directly be connected to and have impact in the way they perceive the condition. These rules and regulations may also enable them to pursue specific objectives and have direct influence over the physical and social environments maintained within the organisation.

### **2.7.5 Community**

The community is identified as an aggregate of characteristics of the people, such as neighbourhood, schools, workplaces and churches in which social relationships occur (McLeroy, Bibeau, Steckler & Glanz 1988:351-377). Community environments can either promote health or be a source of stigma to HIV discordant. Examples of such would sharing injection devices, indiscriminate sexual contacts etc, are necessary in mediating HIV acquisition and transmission with and amongst people (Baral, Logie, Grosso, Wirtz & Beyrer 2012:482).

### **2.7.6 Societal**

The Social-Ecological Models are used to explain interaction that occurs between an individual and the social environment. These according to Poundstone, Strathdee and Celentano (2004:22-35), are social networks and structural factors (such as, access to health facilities), individual practices and the health care system. The social environment is sometimes called public policy. It involves local, state and national laws that govern the interaction within which the HIV experiences happen.

## **2.8 CONCLUSION**

This chapter provided a review of literature. It explored the works of various scholars and researchers locally, regionally and afar. It focused on issues about HIV infected and HIV discordant couples around the globe. The major emphasis was on the psychological, social and sexual experiences as components of a human being that are normally affected during discordance.

Literature reviewed revealed that HIV discordance exists everywhere in the world, and it is common in married couples or those staying together. It is also common in widowers and widows. HIV discordance also negatively affects the relationships especially couples' psychologically, socially and sexually. Certain strategies are implored by couples in their strive to maintain harmony in the relationship and these have proven to be working for many. These may be helpful in formulating guidelines for educators and clinicians.

The chapter concluded by illustrating the Socio-Ecological Conceptual Framework that will be used to form the foundation of this study.

## CHAPTER 3

### RESEARCH METHODOLOGY

#### 3.1 INTRODUCTION

This chapter outlines and elaborates on the methodological aspects and processes which were used to explore the lived experiences of HIV discordant couples in Botswana. Aspects of the methodological issues, such as research design, sampling, data collection methods and data analysis that are used, and ethical considerations undertaken during the research were discussed.

#### 3.2 CONTEXT

The study was done in Botswana. An African country situated at the centre of Southern Africa. Botswana shares borders with Namibia in the west, South Africa in the South West, stretching northwards where it joins Zimbabwe in the North-east. Zambia occupies just a small stretch in the North. The actual position of Botswana is at the geographical coordinates 2.200S, 2.400E with an area size of 581.730sq kilometres as shown in figure 3.1.

The study was conducted in three cities in Botswana. The cities are Gaborone, the capital city of the Republic of Botswana, Francistown, the second largest city located in the Northern part of Botswana, and Selibe-Phikwe, which is situated in the Eastern part of the country. The specific location of the study was the Tebelo-pele counseling and Testing Centres. In the three cities, the centres provide testing and counseling on HIV.



**Figure 3.1 Map of Botswana, showing her position and neighbours**  
 (Source: [www.worldatlas.com/webimage/country/bw](http://www.worldatlas.com/webimage/country/bw))

Botswana has been chosen for two reasons, firstly the researcher himself is a resident in the country, and secondly, as mentioned in chapter 2, no research on experiences of HIV discordant couples has been done or officially reported in the country. For the past two decades, Botswana has been reporting high cases and prevalence of HIV and AIDS more than any other country in the Southern African region. The epidemic has been reported to be at 13% of the general population and the most productive group of 15 years to 49 years was estimated to have infection rate of 23%, by the year 1996 (Ministry of Health (MoH), AIDS Update 1996:8). The MoH (1998:2) further revealed that sero-prevalence amongst women in 1997 stood at 42.9% in Francistown and 34% in Gaborone. According to Preliminary Botswana HIV and AIDS Impact Survey III (BAIS III) (2009:1) by 2008, the national HIV prevalence rate was 17.7% and the national incidence rate was 2.9%. The prevalence and incidence rates continued to vary according to gender and geographical location, as shown in the table below.

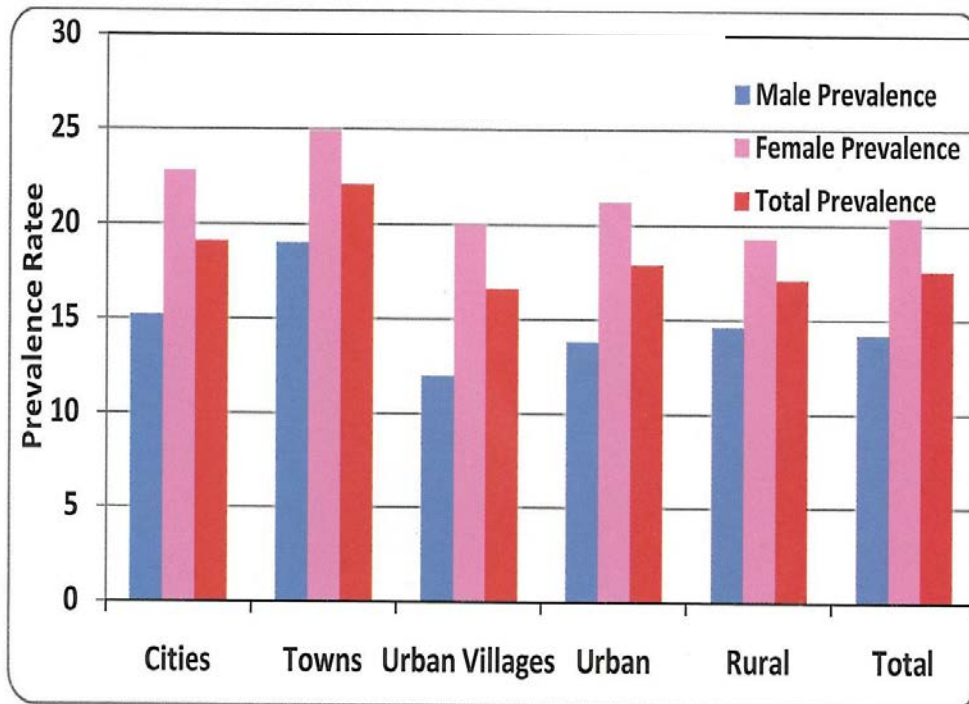


**Table 3.1 Prevalence rate of HIV in Botswana by district and gender**

District	HIV Prevalence Rate by Gender		
	Male	Female	All
Gaborone	13.6	20.5	17.1
Francistown	18.3	27.2	23.1
Lobatse	14.4	17.9	16.3
Selebi-Phikwe	21.4	31.2	26.5
Orapa	19.9	11.5	16.7
Jwaneng	16.4	15.2	15.7
Sowa	16.6	34.6	25.4
Southern	9.3	16.6	13.3
Barolong	12.4	15.4	13.9
Ngwaketse West	10.9	20.9	16.1
Southeast	9.3	15.6	12.6
Kweneng East	15.3	17.8	16.7
Kweneng West	5.7	13.6	10.3
Kgatleng	14.5	16.8	15.8
Central-Serowe	15.8	23.2	20.0
Central-Mahalapye	15.3	18.7	17.1
Central-Bobonong	15.6	21.4	18.9
Central-Boteti	12.6	16.2	14.6
Central-Tutume	15.4	23.5	20.0
Northeast	14.8	27.4	21.8
Ngamiland East	16.4	22.6	19.8
Ngamiland West	10.9	21.0	16.5
Chobe	13.1	30.0	23.0
Ghanzi	10.6	16.0	13.5
Kgalagadi South	17.0	20.7	19.1
Kgalagadi North	9.3	14.7	11.8
Total	14.2	20.4	17.6

(Extracted from BAIS III 2009:15)

Although cases of incidents and prevalence rates may not necessarily denote or imply the same cases of HIV discordance, one may safely assume that there is correlation between increased incidence rate of HIV and HIV discordant. However, as mentioned earlier in chapter 1, unpublished figures by the Tebelo-pele Counseling and Testing Centre stand at around 18%, which is the same as other countries in the region. These figures obviously reveal Botswana as having a high prevalence of HIV discordance.



**Figure 3.2 HIV and AIDS prevalence rates according to residence**  
(Extracted from BAIS III 2009:16)

Following high rates of infection in Botswana, the country has embarked on efforts to reduce both the prevalence and infection rates. Among the strategies employed are services such as PMTCT of HIV and AIDS, provision of anti-retroviral therapy Heavy Active Antiretroviral Therapy (HAART) and circumcision. All these efforts according to literature in chapter 1 play a major role in mitigating transmission of HIV and consequently influence possibility of discordance. It may not be a surprise therefore to find sero-discordance among couples who have one partner having or using the same services.

According to Botswana Ministry of Health (1998:2), approximately 40% or two out of five pregnant women in most urban areas are HIV positive. It is for these three reasons that the research is being conducted in three major urban areas namely: Gaborone, Selibe-Phikwe and Francistown. Gaborone is in the South-east of the country and is the commercial and capital city attracting people from different backgrounds, culture and countries. Selibe-Phikwe is in the eastern part of the country. It is a mining and

industrial town attracting basically miners and business entrepreneurs. Francistown is at the North-east and is the second city in the country. It is also a commercial industrial city.

### **3.3 RESEARCH DESIGN**

Conducting a research of this nature requires deciding on an appropriate design, which acts as a blueprint that will maximise control over factors that could interfere with the validity of the findings (Burns & Grove 2011:49). The design selected should be able to guide the researcher in planning and implementing the study in a way that is most likely to meet the intended aim. Burns and Grove (1997:225) describe the design as an end-result of a series of decisions decided by the researcher on how the study will be implemented and will also help in increasing the probability that the study results are accurate/reflections of reality. Furthermore, the methodology can be structured out such that it provides detailed research plan for data collection and analysis, which will finally direct the implementation of the study.

The study on lived experiences as posed by the research question explored both the depth and breadth of the phenomenon of HIV discordant couples in order to understand the human behaviour and reasons that govern such behaviour. The researcher therefore, conducted the study to gain insight and understanding about an event, which in this case is the “experience of HIV sero-discordant couples”. It is not easy to measure human behaviour or attributes like experience, so unlike in a quantitative study where researchers can measure or weigh, or quantify, human attributes like experiences cannot be given values of measures amenable to data analysis. The qualitative approach was used because of its appropriateness for the understanding of human experience such as pain, grief, or unfair phenomenon (Brink, Van der Walt & Van Rensburg 2006:113).

Qualitative approach is considered a systematic and subjective approach used to describe the life experiences and giving them meaning (Burns & Grove 2005:52). These scholars further assert that qualitative approach helps in gaining insights through discovering meanings. These insights are obtained not through establishing causality but through improving our comprehension of the whole. The insight gained can guide nursing practice and aid important processes of theory development for building nursing

knowledge. Holloway (2008:5) complements Burns and Grove (2005:52) and purports that qualitative researchers believe that individuals do not live in a vacuum, but rather are affected by their social environment which consists of the significant others and the culture into which they are socialised. The qualitative researchers recognise that people have their own preferences, expectations and beliefs and such must be taken into account during a qualitative study. The explorative and descriptive method was used to answer the research question.

### **3.3.1 Qualitative research**

The research questions lend themselves to a qualitative design. A qualitative design is a type of design that uses a systematic, interactive, subjective approach which aims at organising, providing structure to and eliciting meanings from data (Burns & Grove 1997:27; Polit & Beck 2010:463). A qualitative research is particularly suited to study the human experiences of health. LoBiondo-Wood and Haber (2006:131) point out that qualitative methods focus on the whole of human experiences and meanings ascribed by individuals living the experience. These methods permit broader understanding and deeper insight into complex behaviours than what might be obtained from surveys. A qualitative research is based on the concepts of manipulation and control of phenomena and verification of results, using empirical data gathered through the senses (Nieswiadomy 2008:59).

The research intends to describe human feelings, perspectives, experiences and understanding. This type of study is not overly concerned about numbers but detailed data as gathered through open ended questions that provide direct quotations on a quality of a process of an entity and meanings that are not experimentally examined or measured in terms of quality, amount, frequency or intensity (Lobiono-Wood & Haber 2006:131).

A fundamental assumption in qualitative research is that the informants' perspective on the phenomenon of interest unfolds during the interview process and the analysis of the research as the informant views it, and as the research views it (Polit & Beck 2010:464). This helps the researcher to be in control and manipulate the direction of the research process. The researcher formulates questions such that at the end they elicit the informants' true experiences on their HIV discordant life. For this research, experiences

begin during the time of breaking news about their discordance, disclosing the status of the partners, early life and long time life endeavours after disclosure, experiences on feeling about telling significant others such as friends, parents, siblings etc and experiences with community and health care interaction. This qualitative design is also envisaged to elicit experiences on beliefs, attitudes, values and demands by the discordant couples.

Holloway (2008:07) argues that qualitative research, as compared to the quantitative research has recently gained popularity in the medical fields. More researchers have started to recognise its applicability and usefulness in health research. Some of the advantages that qualitative research has according to Holloway (2008:07) include:

- It can generate insight into patients' and professional' thoughts, belief and feelings as well as into their individual meanings and explanation of an experience.
- It can provide an understanding of what is like to live with an illness, disablement and pain.
- It studies the interaction of the person and the disease.
- It demonstrates how patients make sense of their condition.
- It explores patients' perspectives on treatment and care.
- It assists in understanding of how people manage their condition.
- It can examine cultural practices and patterns of behaviour of both patients and professionals.

In addition to the above advantages, Burns and Grove (2005:231) contend that qualitative research are useful when a subject is too complex to be answered in simple "yes" or "no" terms. It can also generate more information as it can cover broader scope. The method is not dependent upon sample size like in quantitative methods. In this study, where the researcher is interested in the experiences of HIV discordant couples, information or data cannot be obtained through numerical values, it cannot be obtained through observation nor through measurements. Data can mainly be obtained through description as narrated by the subjects/interviewees. They will give a full account of their history or experience and what they deduce as a meaning to it. According to Lobiondo-Wood and Haber (2006:132), qualitative research includes case

study, ethnography, phenomenology and many others. For the purpose of this research study, the phenomenological theory has been preferred.

### **3.3.2 Phenomenology**

Phenomenology is a theoretical enterprise that takes ordinary experience as its point of departure, which, through an attentive or sensitive examination of that experience, aims to reveal the transcendental conditions that shape or structure it. Burns and Grove (2005:55) describe phenomenological approach as both philosophy and a research method. Brockopp and Hastings-Tolsma (2003:332) also assert that it is a branch of philosophy that emphasis the meaning that social behaviour has for the individual, while LoBiondo-Wood and Haber (2006:140) argue that it is based on phenomenological philosophy. From these arguments, it is convincing therefore that phenomenological approach is based on philosophy. Its whole intention is to answer questions of meaning and is therefore descriptive in nature. It describes the subject reality of an event as perceived by the study population. Phenomenology therefore is appropriate for an inquiry seeking to discover the experiences such as of lived couples in HIV sero-discordance because according to Polit and Beck (2010:267), the phenomenology is concerned with extracting essence of phenomenon as experienced by informants.

According to Brink et al (2006:113), phenomenological studies examine human experiences through the descriptions that are provided by the people involved. According to Brink et al (2006:113), these experiences are called “lived experiences”. The purpose of the phenomenological research is then, to describe what people experience in regard to certain phenomena. It is also to describe how they interpret the experiences or what meaning they deduce from such experiences. The practice is drawn from the recognition that for any action performed by an individual, meaning is developed that helps create a unique reality for that person. It is considered to be an approach that concentrates on a subject’s experiences rather than on the person as a subject. It is for this reason that the researcher has decided to employ this method with a hope that using it will yield appropriate experiences relevant for this study.

The aim of phenomelological research is to examine the meaning of life through the interpretation of peoples lived experiences (Streubert-Speziale & Carpenter 2003:467).It is, in other words, a process of learning and constructing the meaning of human

experience through intensive dialogue with persons who are living the experience. The researchers' goal is to understand the meaning of the experience as it is lived by the participants (Lobiondo-Wood & Haber 2006:154). Meaning is pursued through dialoguing between the researcher and the participant/informant. The dialogue extends beyond a simple interview to a thoughtful inquiry into a participant's experience. It is therefore fitting that peoples' lived experiences from people who have the first hand information be studied to find out their true life experience.

Streubert-Speziale and Carpenter (2003:54) contend that phenomenology utilises special descriptive strategies such as intuiting, bracketing, analysis and description.

Intuiting, according to Polit and Beck (2010:268), is when a researcher remains open to the meaning attributed to the phenomenon by those who have experienced it. It is a process of thinking through the data in order to achieve an accurate interpretation of what is being described. It would be a good attribute of a researcher to be absorbed by the phenomenon under study, but remain non-influential on the participant responses. This will help the researcher to have a deeper understanding of the phenomenon being studied. The researcher in this study achieved this by allowing all the informants to freely express themselves without interference whilst at the same time keeping notes of what they say and how they react to the phenomenon that they talk about.

Bracketing is another form of descriptive phenomenon that refers to the process of identifying and holding in abeyance preconceived beliefs and opinions about the phenomenon under study (Polit & Beck 2010:268). It is essential, although not an easy thing for researchers to be able to identify their own assumptions and presumptions so that they do not interfere with the information being given by the participant.

In the present study, the researcher, kept knowledge of this concept and held himself so that he did not interfere with his own assumption, nor project onto the informants' conversation.

Analysis involves the identification of the essence of the phenomenon under investigation based on the data obtained and how it was presented (Woods & Catanzaro 1998:140). During analysis the researcher listens to the participants' descriptions and compares and contrasts the description of the phenomenon to identify

recurring themes. Description is the last step in the phenomenological approach. It aims to communicate and describe in detail the critical elements of the phenomenon (Woods & Catanzaro 1998:140).

### **3.4 RESEARCH METHODOLOGY**

Research methodology is a detailed discussion of the actual application of the design. It describes the methods, techniques and procedure that are employed in the process of implementing the research design (Streubert-Speziale & Carpenter 2011:366). Methodology relates to the rules and procedures that specify how the researcher must study or investigate what they believe must be known (Botma, Greef, Mulaudzi & Wright 2010:41). For the purpose of this study the research methodology would describe the specific methods followed to collect and analyse data and focus on the population, sampling, data collection and data analysis.

#### **3.4.1 Study population**

Commonly understood, a population is a component of demography. However in research, it refers to entire aggregation of cases in which a researcher would be interested (Polit & Beck 2012:59). Population in research can be multi-dimensional. The individual units of a population, according to Burns and Grove (2011:290), are called elements and elements may be a person, event, behaviour or any other single unit of study. When doing a research on people and using them as elements they are normally referred to as subject or informants. The study population is sometimes called target population, which is the entire set of individuals or elements who meet the sampling criteria. It is consistent with accessible population, which is a portion of target population to which the researcher has reasonable access. The population or subject of this study are HIV sero-discordant couples living in Botswana, and have lived together for six months or more.

##### **3.4.1.1 Sampling**

Sampling refers to a process of choosing a certain portion of the population. A sample in research is a subset element or subject, sampling is therefore a process of selecting a certain portion of the population to represent the total aggregates of population (from



which information regarding a phenomenon is obtained) (Polit & Beck 2004:291). There are two main approaches to sampling, which are probability and non-probability sampling. The non-probability sampling is used in qualitative studies and does not produce a statistically representative sample. For the purpose of this study purposive sampling was used to select both the participants and the sites because they can purposefully inform an understanding of the research problem (Creswell 2007:125).

#### **3.4.1.2 Purposive sampling technique**

Purposive sampling as a technique relies on the judgement of the researcher when it comes to selecting participants to be studied (Polit & Beck 2012:59). For the present study the researcher chose purposive sampling because the researcher had a good working knowledge of the population under study and anticipated that the participants would provide information relevant to meet the study objectives (Burns & Grove 2009:355).

Experiences of being in an HIV sero-discordance relationship is complex and would be better understood or explained by those who have lived it. In this study, discordant couples were chosen to share their lived experiences. The researcher therefore decided to set the criteria as listed below. The criteria were meant to guide in choosing research participants and ultimately shape the analysis.

##### *3.4.1.2.1 Inclusion and exclusion criteria*

Inclusion criteria or eligibility criteria are specific characteristics that the participants must possess to be part of the target population (Burns & Grove 2009:345). To be included in this study the participants had to meet the following criteria:

- i. Aged 21 years and above. Although people may engage in sexual partnership at an age younger than twenty-one years, many of these would not be established. The Setswana culture and marital laws also do not allow for formalisation relationship before age 21 (Botswana Laws 1995:5).
- ii. Participants should not have a known diagnosis of mental illness or any mental health incapacitation. Many people who are not mentally fit do not have the capability to voluntarily make sound decision.

- iii. Couples who have been in a discordant relationship for more than six months at the time of data collection who have or lived in a discordant relationship.
- iv. Living in Botswana in the Gaborone, Selibe-Phikwe and Francistown.
- v. Attending the Tebelo-pele centres.
- vi. Willing to participate in the study.

Conversely, exclusion criteria are used to filter out participants with specific characteristics that are not relevant to the study to be undertaken (Burns & Grove 2009:345). For this study, participants were excluded if they had experienced discordance for less than six months and were known to have had a diagnosis of mental illness such as depression.

#### *3.4.1.2.2 Sample size*

In qualitative research there are no written rules for sample size (De Vos, Strydom, Fouche & Delport 2009:328). The number of participants in qualitative research is deemed adequate when no more information can be obtained (Burns & Grove 2009:361). The sample size in this study was determined by data saturation.

A total of forty-six (46) interviews were conducted with participants who met the inclusion criteria.

### **3.5 DATA COLLECTION**

The main purpose of research is to collect information that the researcher can use to synthesise and analyse in order to find meaning from large raw information which can be generalised into smaller headings and subheadings that are a summary of a phenomenon. Burns and Grove (2011:52) explain that data gathering is the precise, systematic collection of information relevant to research problems. In nursing research, there are different methods of collecting data which include interviews, reflective journals, focus group discussion, narratives, case history and photo elicitation. The data collection method utilised in this study used a single qualitative approach face-to-interview schedule and field notes which the researcher developed throughout the face interview. The researcher collected data by means of an unstructured in-depth process of data collection.

For the purpose of uniformity and in-depth understanding of the phenomena, the researcher did the data collection himself. Some semi-structured questions were formulated and used during the data collection process. Key interviewees were purposefully sampled individuals who met the inclusion criteria. Although the intended informants were couples living in a discordant relationship, some of the informants in the study were not couples per se, but members of the couples family whose partners were not reached due to varied reason ranging from:

- Staying far away from the other partner due to work commitment
- Unwilling to consent
- Already having separated with the partner

The study questions required experiences of both the HIV infected and uninfected so as to draw information on what the infected experience and how they affect the uninfected and vice versa. Three clinics with VCT centres were chosen due to their ease access to the research. All the clinics are government funded hence run under the policy of the government. Contact persons in each VCTcentres were identified and helped in selecting the informants. After the informants were selected, the contact person phoned them and asked if they could participate in the ongoing research. Those who showed interest were given an appointment to meet the researcher at a place convenient to them.

In Selibe-Phikwe and Gaborone, four and five clinics were chosen respectively. The criterion used was the known high number of HIV discordant couples in such clinics. The same process was followed as the one used in Francistown.

### **3.5.1 Development and testing of data collection instrument**

Two main tools were developed and used to collect data from the HIV sero-discordant couples who consented. These were the interview guide and observational tool. The tools were developed by the researcher himself. The interview guide was used by the researcher during the face to face in-depth collection of data. The researcher used open-ended question to collect information related to experiences of HIV discordant

couples. The other tool was the observational tool, which was used to gather non-verbal information and clues during the interview. It was important for the researcher to determine how the respondent or informants behaved under certain circumstances. LoBiondo-Wood and Haber (1994:349) contend that some informants or respondents may not be able to answer questions appropriately. In other cases they may not be able to quantify their experiences, or may distort their responses to please the researcher. In such cases, it would help the researcher to continuously observe the behaviour so as to deduce the non-expressed clues.

### **3.5.1.1 *Unstructured in-depth interviews***

Unstructured approach to data collection begins with a broad question referred to as the grand tour question (Polit & Beck 2008:392). The grand tour question is related to the research topic. This question is followed by probes that are guided by the responses from the grand tour question. For the purpose of this study, the grand tour question was: “Tell me about your experiences of being in a discordant relationship” This question was followed by many probes as shown in Annexure G.

In-depth interviewing is a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, programme or situation (Boyce & Neal 2006:3). In-depth interviews are useful for eliciting detailed information about a person’s experience, thoughts and behaviours. The interviews offer a more detailed and complete picture about the phenomenon under study (Boyce & Neal 2006:3). The interviews were tape-recorded with the permission of the participants.

### **3.5.1.2 *Field notes***

Data collection from interviews was augmented by filed notes. Field notes are notes taken by the researcher as instructed observations in the field (Polit & Beck 2008:304). Field notes are notations made to document observations that become part of the data analysis (Streubert & Carpenter 2011:42). According to Polit and Beck (2010:354), field notes are some of the common forms of record keeping for particular observation. The notes are interpretive and represent the observer’s captured and recorded information

within the environment which is not expressed verbally. Field notes can also be reflective of the researcher's feelings and thoughts during data collection.

Reflective notes reflect the researcher's personal experience, reflections and progress in the field. Whereas personal notes, are comments about the researcher's own feelings during the research process. During the time of data collection, the researcher kept a self-reflective diary of emotions, feelings and thoughts that were experienced by the interviewee during the process of data collection. The researcher also kept a record of any observed phenomenon in the field notes.

The field notes were written immediately after each interview as the record of the researchers' impressions (Burns & Grove 2009:408). The researcher had a written account of the occurrences that were heard, seen, felt, experienced and thought about during the interviews. No writing was done during the recording on interviews as the researcher wanted to have eye contact and observe non-verbal cues as much as possible. Instead, writing was done immediately after the interviews when the researcher could still remember (Polit & Beck 2008:405).

### **3.5.2 Process of data collection**

Data collection process was in three phrases. The preparatory phase, the pilot phase and the interview phase.

#### **3.5.2.1 Preparatory phase**

Polit and Beck (2008:399) assert that the researcher has to prepare beforehand the equipment that will be needed for data collection. In the study, the researcher needed a battery-operated tape recorder, audio-cassettes, notes pads, pens and extra batteries. The researcher also needed to have a person with experience in transcription and translator for use as research assistant.

Permission was obtained from the Ministry of Health in the National Health Research Unit (see Annexure C) to conduct the study in Botswana. Furthermore, permission was granted by the management of the District Health Management Teams (DHMTs) in

Gaborone, Selibe-Phikwe and Francistown to do interviews in respective sites (see Annexure C (i), (ii) and (iii) and Annexure D). The following arrangements were made:

- Venues where data collection took place were secured
- Consent forms were signed
- Dates and time for the interviews were agreed
- Counselors were also made aware of the dates in writing and verbally

#### *3.5.2.1.1 Recruitment of participants*

Recruitment of participants was achieved through consultation with the officers at clinics for VCT centres who knew the potential participants. The centres are designed to provide counseling and testing to any person willing to take the HIV test. However, majority of the people coming to these centres are:

- The pregnant mothers who are being tested for HIV in order to enroll for the PMTCT of HIV.
- Referred partners whose spouses or partners have been tested before.
- Volunteers who just want to know their status.

Following the acceptance by the Health facility manager for the researcher to do the study in a respective clinic, the researcher was introduced to the VCT staff, to whom the researcher explained the purpose of the research and how it was going to be done. The critical issue during the discussion was the confidentiality of the patient's condition, which was not to be violated by the researcher. The clinics keep the register for all who were counseled and tested. It has contacts and biographical data of the clients, which helped the researcher to identify all the discordant couples. Identified couples then formed the study sample chosen purposively because they were regarded so due to their availability.

#### *3.5.2.1.2 Validity and reliability*

Validity is concerned with accuracy and truthfulness of scientific findings. According to Brinket al (2006:118), establishing validity requires determining the extent to which

conclusions effectively represent empirical reality. It also requires assessing whether the construct selected by the researcher represents or measures the categories of human experience that occur. On the other hand, reliability is concerned with consistency, stability and repeatability of the informants' accounts as well as the researcher's to collect and record information accurately (Brink et al 2006:118).

The data collection tool was pre-tested on six participants for two days in Mogoditshane, a sub-urban area within the periphery of Gaborone in the North West. The aim was to check its consistency, validity and reliability. This was important because appropriate adjustments were done within the tool in light of the experiences from the pre-testing and finalised for use in the field. The tool was later employed after amendments on similar conditions in collecting data from the participants for the study.

#### *3.5.2.1.3 Characteristics of the data collection instrument*

An interview guide was developed by the researcher comprising of two parts. The first part aimed at eliciting the biographic data of the informants. Because it focused on specific information, it was structured such that it was the same for both the infected and the uninfected. The second part consisted of open-ended questions that aimed at exploring experiences. The questions allowed the respondents to provide their own responses in their own context.

#### **3.5.2.2 The interview phase**

As mentioned earlier, interviews were organised and arranged according to the interviewee's preference. The informants were given an opportunity to decide when and where to be interviewed. This was made so as to afford them the autonomy and comfort during the interview process. The interview was conducted in a quiet area, with minimal interference so that informants may open up and talk freely. The researcher re-introduced himself to the respondent, explained in detail the purpose of the interview and reiterated the importance of consent, confidentiality and usefulness of the data to be collected. The researcher asked permission from the informant to audio record the interview and explained the importance of the procedure. After obtaining the consent and permission, the researcher asked the respondents about their demographic information and wrote it in the interview guide. At the end of the demographic

information, the researcher then reminded the informant that now the recording starts. During the recording the informants were encouraged not to mention their names, nor the real names that can reveal their identities. Non-verbal clues noted during the interview were recorded in the observational tool as vital information to complement the interview information.

Most of the informants preferred to be interviewed at their home or at the health facilities. For the purpose of confidentiality a one to one session of interview was done. This was consistent with Brink et al (2006:151), view which asserts that interview is the best method for data collection in which an interviewer obtains responses from subjects in face to face encounter. Brink et al (2006:151) further contend that interviews are ideal for collecting information during explorative and descriptive researches.

During interview, the researcher used unstructured questions. This is because the unstructured interview is free flowing and occurs like a normal conversation, hence minimising the strictness like in formal interview. Unstructured interviews also produce more in-depth information on the subject's beliefs and attitudes. Probe follow-ups were frequently used to increase detailed exploration. Most of the probing was done to encourage the informants to elaborate on the issues, to clarify and expand responses explicate meaning (Brink et al 2006:151).

### **3.5.2.3 *Post interview phase***

At the end of every interview, the informants were informed that the interview was coming to an end. They were asked if there was any other information they would like to provide in addition to the one already asked. Informants were further asked if they had any questions, and their questions were answered appropriately. Needs that emerged during the interview, such as the need for further counseling, need for referral, need for education/reassurance etc, were attended to post interview. Lastly, the researcher thanked the respondent and expressed well wishes.



## **3.6 STUDY ETHICAL CONSIDERATIONS**

### **3.6.1 Permission to conduct research**

When doing a research with human beings, it is crucial to consider that respondents have rights and these rights have to be protected (Burns & Grove 2005:83). Brink et al (2006:64-65) assert that if the purpose infringes on the rights of the respondents, it is necessary for it to be re-examined or it may have to be abandoned if it cannot be changed. The principles “always doing good “that is, beneficence and “doing no harm” That is, non-maleficence is necessary to be observed when doing research in human lives. Other fundamental principles, such as, confidentiality, that is, protection of respondents’ autonomy, which is freedom of choice and justice, that is, fair treatment and equality are important to preserve (LoBiondo-Wood & Haber 1994:322-331).

The Ministry of Health in Botswana subscribes to the idea of maintaining ethical standards during research studies. A unit has been established called Human Research Unit with the responsibility of ensuring respect, beneficence, and justice to human subjects (see Annexure B). After approval of the topic by the Department of Health Studies at UNISA (see annexure A), the researcher sent the research proposal to the unit for review and clearance and approval.

Before embarking on the actual research, the researcher further obtained permission from the clinical service department in the Ministry of Health to use the clinics in sampled site (see Annexure E).

### **3.6.2 Voluntary participation (autonomy)**

Some human beings are socially disadvantaged because of their social status, physical ability, or medical wellbeing. Researchers should protect these people so that they may afford them justification (Burns & Grove 2005:183-184). Every human being is unique, has rights and needs to be respected. They have the right therefore to decide to participate in a study and have to be duly informed of the benefit of doing such. Permission to conduct a study on them has to be sought from an able bodied, or next of

kin or if not, abandoned. Any form of coercion should be avoided. Where payment or other incentives are offered, there should be a strict procedure ensuring that participation is by individuals who qualify according to the study protocol. In all cases participation should be voluntary.

Voluntary participation is linked to disclosure of adequate factual information to potential participants on details of the study, including the risks and benefits. It is expected that people are able to make informed decision regarding their participation when sufficient information has been provided to them. To ensure autonomy in this study, a written statement explaining the purpose of the study and procedure for data collection was developed and attached to the interview guide (see Annexure G – first part). This was done to ensure consistency in information provided to all participants. They were informed of the purpose of the study and its implication to their continued care during every visit to VCT centers. Participants were given a choice to either participate or decline participation in the study.

### **3.6.3 Informed consent**

Informed consent aims at providing essential information to the prospective participant so as to gain his agreement to participate in the study (Burns & Grove 2005:193). The prospective participant should be informed of the purpose, procedure, risks, benefits and limits of confidentiality. When equipped with sufficient information, participants would be empowered to voluntarily take decision on whether or not to consent for the research. If the participant consents, they should be given a consent form to sign.

A consent form for this research contained aspects of the purpose, procedure, risks, benefits and limits of confidentiality as presented by (Burns & Grove 2005:193)(see Annexure F). Participants who consented to participate in the study were given a consent form, which they read and signed and returned to the researcher. The consent form was written in both Setswana and English for all people to read and understand.

### **3.6.4 Confidentiality**

This requirement of respecting peoples' privacy applies to all health care practice, and is critical in conducting ethical research. It is the basis of appropriate interaction with

human beings. According to Burns and Grove (1997:204-205), confidentiality is not revealing the identity of the participant to anyone other than the researcher and or his/her staff. Data collected should be shared only with other researchers and should be kept anonymous where identification is not required for further follow up research. Separating documents such as consent forms with applicants' names from the completed questionnaire is one way of ensuring confidentiality as was practiced in this study.

Confidentiality and the protection from invasion of privacy were prioritised throughout this study. The interview sessions were carried out in secluded setting to ensure privacy and confidentiality. Emphasis was placed on information being shared between interviewee and interviewer in privacy and in confidence. Participant's names were not used on the data collection forms, rather numbers were assigned to data collection forms for identification. However, names and organisations of key informants were recorded for the purposes of follow up, if necessary. All forms with information about the participants are stored in secure storage.

### **3.7 DATA PROCESSING AND ANALYSIS**

During the process of data collection, the researcher recorded some of the observed information on small note cards. This information was later carefully coded, organised and filed into categories at the end of the interviews. This information was later combined with the transcription notes from the respondents. According to LoBiondo-Wood and Haber (2006:256), though there are several techniques for data analysis when using phenomenological approach, the guiding principle towards moving from the participants' description to the researcher's synthesis of all participants' description are the same. These were adopted during the data analysis in this study. The following are the principles to follow:

- Thorough reading and sensitive presence with the entire transcription of the participant's description.
- Identification of shifts in participant thought resulting in division of the transcription into thought segments.
- Specification of the significant phrases in each thought segment, using the words of the participant.

- Distillation of each significant phrase to express the central meaning of the segment in the words of the researcher.
- Grouping together of segments that contain similar central meaning of the segments in the researcher's words.
- Preliminary synthesis of the central meaning of thoughts segments for each participant with a focus on the essences of the phenomenon being studied.
- Final analysis of the essences that have surfaced in all participants' description resulting in exhausting the lived experiences.

### **3.8 MEASURES TO ENSURE TRUSTWORTHINESS**

In qualitative research, trustworthiness is described as the degree of confidence that researchers have in their data related to the concepts of credibility, validity, dependability, and reliability (Polit & Beck 2010:490). Trustworthiness is established when findings closely reflect the meanings of the phenomenon under study. The nature of this phenomenological study requires the researcher to represent as closely as possible, the experiences of HIV sero-discordant couples. The integrity of the researcher to maintain the ethical standards is therefore required in such a research. In this regard attentiveness to the issues of trustworthiness, which requires adherence to the concepts of credibility, dependability, transferability and conformability, was considered throughout the research process.

Thus far, threats to trustworthiness in this study have been managed through:

- a. Sampling decision: although it could have been ideal to gather information from couples who live together, some couples did not share the same place of residence due to work commitments, nature of job, or status of the relationship. The researcher therefore selected as sample, members of the study population who have experienced the HIV discordance both infected and uninfected and not necessarily partners.
- b. The sample size: the sample size seems to be big, however, this was made to accommodate all sampled sites and to ensure saturation.
- c. Data collection: two tools were used, namely interview guide and observational tool. The interview was audio recorded and latter transcribed for ease of analysis.

### **3.8.1 Credibility**

LoBiondo-Wood and Haber (2006:192) contend that credibility is the truth of findings as judged by participants and other researchers within the discipline. In other words, it involves establishing that the results are credible or believable from the participants' perspective. The understanding is that the participants are the only ones who can legitimately confirm or ascertain the credibility of the research. The researcher in this respect would continuously consult some of the participants who reported experiences that reveal new information from the one that has been noted in the literature review during analysis. Most of the participants' phone numbers have been kept and were used to contact them. Specific attention in ensuring credibility was ensured through prolonged and varied engagement in the field, reflexivity, peer debriefing and member checking.

#### **3.8.1.1 *Prolonged and varied engagement in the field***

Prolonged engagement refers to the investment of time in the study site in order for the researcher to become familiar with the participants' culture and to build trust (Lincoln & Guba 1985:302). Spending time in the research site enables the researcher to detect any distortions from self or others in the participants' sphere.

Prolonged engagement was one of the strategies used by the researcher to increase the study's credibility. The researcher only started to collect data after knowing the participants for six weeks. This allowed the participants and the researcher to establish trust and to agree upon their mutual goals without coercion.

#### **3.8.1.2 *Reflexivity***

One of the methodological concerns that frequently emerge when conducting research is the degree to which the researcher can be personally involved in the research process and still retain some measure of objectivity (Burns & Grove 2003:380). Reflexivity is a process in which an investigator seeks to understand how her/his personal feelings and experiences may influence the study, and then strives to integrate this understanding into the study (Burns & Grove 2005:380). Reflexivity requires the investigator's self-awareness and considers the possible influences of the researcher's

personal characteristics on the study. According to Lincoln and Guba (1985:130), reflexivity is incorporated into the research method in order to offset researcher bias.

In this study, the researcher frequently reflected on what he had recorded in his field notes during the interviews with participants to ensure that the analysed data adequately represented the contributions of participants (Lincoln & Guba 1985:304). Furthermore, the researcher shared and discussed with his supervisor and other colleagues the personal feelings he had experienced during the data gathering when the participants related some of their painful experiences. During those occasions, he was especially cautious not to impose his own ideas on the research participants.

### **3.8.1.3 *Member checking***

Member checking is a technique used by researchers to help improve the accuracy, credibility and validity of the study (Polit, Beck & Hungler 2001:433). Member checking provides the researcher with an opportunity to correct errors and challenge wrong interpretations. It also gives the research participants an opportunity to volunteer new information. In this study the researcher would regularly read out to the participants what he had written to validate the recorded information.

### **3.8.2 *Dependability***

Dependability is a criterion used to establish the trustworthiness of the study. Like in quantitative research, where validity is measured through reliability, qualitative research uses dependability to gauge trustworthiness (Brink et al 2006:119). Dependability is the description of changes that may occur during the course of the research process, and understanding how these changes may affect all the research results. The idea of dependability in qualitative research emphasises the need for the researcher to be accountable forever changing context of the research. Because sometimes is difficult for one to recognise or realise one's own mistake, the researcher asked the assistance of other researchers and expect to review his work at the end of every chapter to check whether the procedure used are acceptable (see annexure H).

### **3.8.3 Conformability**

According to Brink et al (2006:119), conformability guarantees that the findings, conclusions and recommendations are supported by the data, and that there is internal agreement between the investigator's interpretation and the actual evidence. It is the degree to which the results can be confirmed or verified by other researchers. To achieve conformability, the researcher accomplished conformability by incorporating an audit procedure, which looked into the processes of data collection, and analysis procedures to make judgment about the potential for bias and distortions before handing in the research for final approval.

## **3.9 CONCLUSION**

The chapter provided a description of the study design, methods used to achieve the study purpose and the response to the research question put forward. Qualitative research approach has been proposed for data collection, and analysis of the results. Purposive sampling has been applied in order to target a sample.

This chapter further discussed the data collection process, ethical issues to be observed in data collection and analysis. The discussion also focused on how the study will guarantee trustworthiness, validity and reliability.

## CHAPTER 4

### RESULTS

#### 4.1 INTRODUCTION

The aim of this chapter is to draw deductive meaning from the many raw data collected for the study. In this chapter, data was be presented, analysed and the results described. The first part of the chapter was the presentation of the biographic data of the participants. The next part focused on the participants' experience of discordance followed by their lived experiences which was discussed under psychological, social and sexual considerations.

#### 4.2 BIOGRAPHICAL DATA

The study focused on couples who have experienced discordance. The study had intended to interview couples who live together. However, this was not been possible due to:

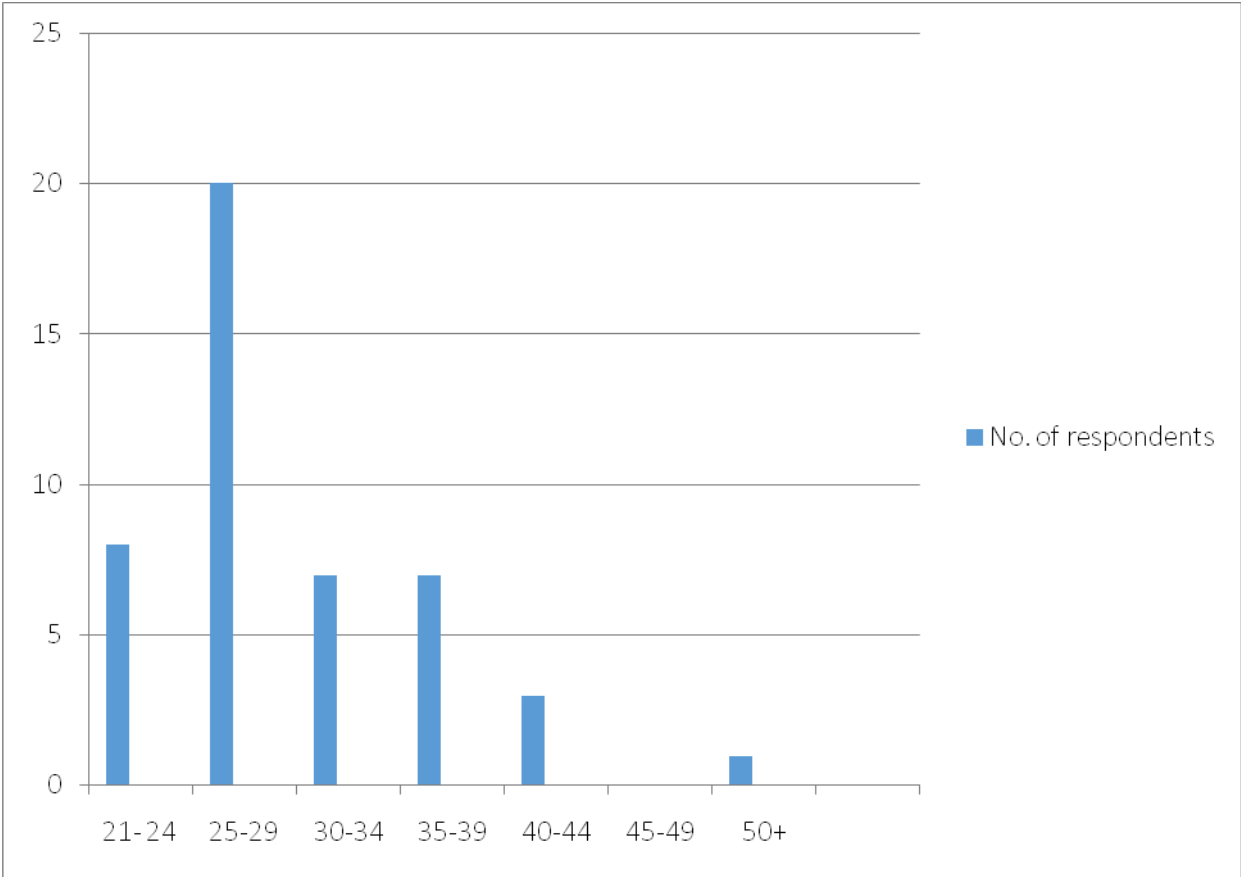
- work commitments in which one partner would be living in one town away from the other or in a place which is not the study site
- Partners having separated but having lived together as discordant couples before separation
- one partner not willing to consent
- for personal and private reason the primary partner not willing to divulge the identity of their partners

A total of forty six (n=46) participants were interviewed from the three mentioned sites. The majority of those interviewed were females. This has been so because primary participants were contacted through Voluntary Counselling and Testing (VCT) clinics, which are mainly attended by women. Female partners came to VCT for HIV screening during pregnancy for legibility of PMTCT and their data is captured for record. This was



where the researcher was able to identify the discordant couples. Data was further separated according to whether the participants were infected or non-infected. Twenty-nine female (n=29) were interviewed, thirteen (13) were HIV infected and sixteen (16) were non-infected. Seventeen (n=17) male participants were interviewed and among them twelve (n=12) were HIV non-infected, while five (n=05) were infected.

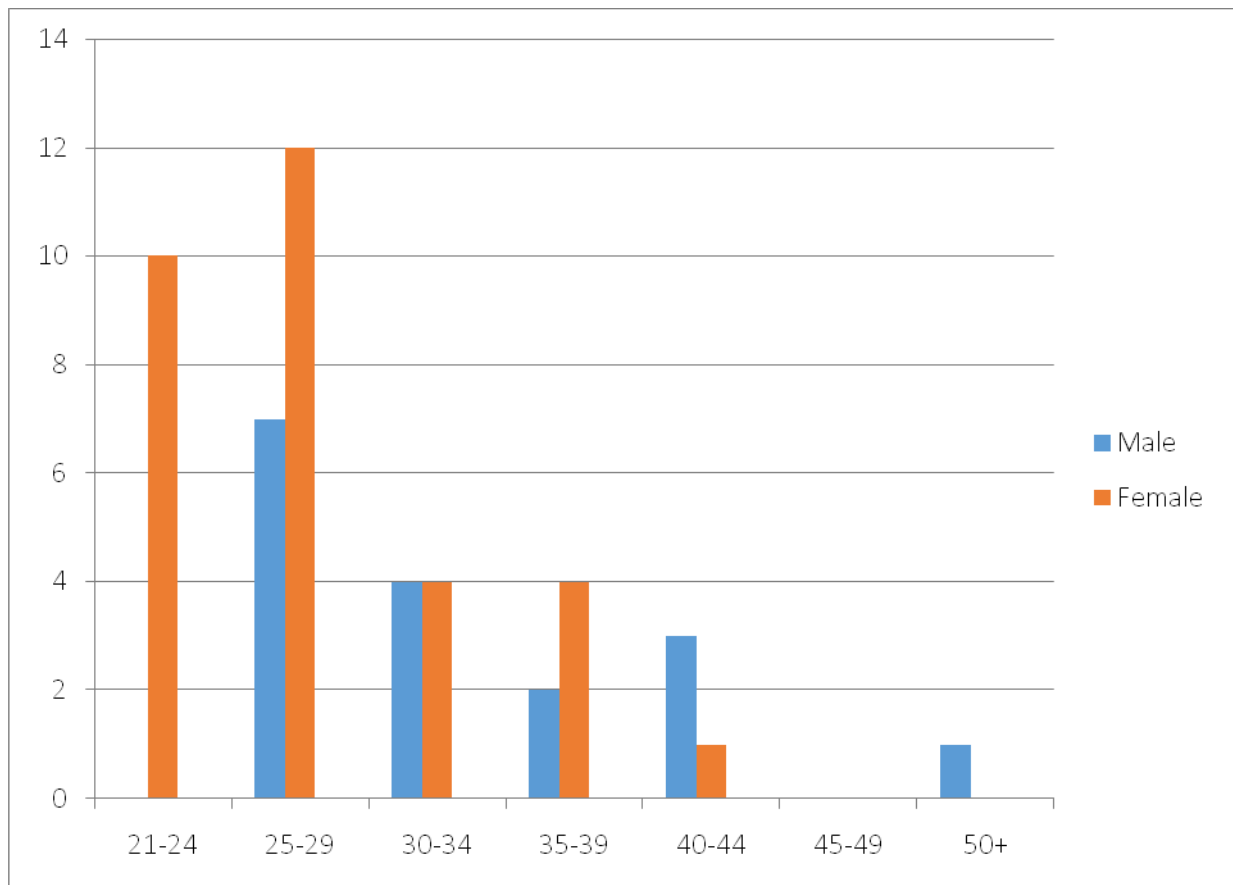
The age range of the participants was from 21 to 53 years. The figure below depicts the age group of all the participants.



**Figure 4.1 Age of participants**

The majority of affected people are those in the age range of 25-29 years. This is probably because this age group is the most sexually active.

The figure below depicts the distribution of the respondents by age group and gender.



**Figure 4.2 Age and gender distribution of participants**

All the participants except one (n=01) have some formal education. More than 63% of the participants (63.3%; n=29) had secondary education, which means twelve years of formal education. Ten of the participants had formal primary education, which translates into seven years of schooling and seven had tertiary education which means more than twelve years of schooling.

The majority of the participants were not married. Seventy-two percent (72%) were not married, but had been in stable relationships with one partner for more than six months continuously. Most of the unmarried couples (29/33 or 88%) cohabit, the remaining four (04) live in what the researcher called “visiting relationship”. This is the type of relationship, which is not bound by any agreement. Couples act as friends and only meet when time is convenient. About twenty-eight percent (n=13) are married. The types of relationships that existed among participants are summed in table 4.1.

**Table 4.1 Types of relationships among participants**

Type of relationship	Number of years in relationship	Number of years in discordance relationship
<b>Married</b>		
Less than 6 months	0	2
6 months to 1 year	1	3
1 year to 4 years	5	6
5 years to 9 years	3	0
10 years and above	4	2
<b>Cohabiting</b>		
Less than 6 months	2	3
6 months to 1 year	7	11
1 year to 4 years	14	12
5 years to 10 years	6	3
10 years and above	0	0
<b>Visiting partner</b>		
Less than 6 months	0	0
6 months to 1 year	0	1
1 year to 4 years	2	3
5 years to 10 years	2	0

According to table 4.1, the duration of one to four years is common to both the number of years the participants have been in the partnership relationship and the period they have been in discordant relationship. These tallies with the duration group of the respondents who would ordinarily be in the same relationship for the same period of four years. However, the same period is being noted for the period in the discordant relationship. This may necessarily not be true for all the cases, the fact is that the discordance was only realised within the said period, but may have been in existence for more years.

#### **4.3 GETTING TO LEARN ABOUT DISCORDANCE**

Forty out of the forty-six participants interviewed have had a sexual relationship before the current relationship. How one happened to have acquired HIV, therefore, would be easily understood or traceable from the previous relationship. Many participants

(eleven out of eighteen infected i.e., 61%) could reflect back and identify the possible sexual partner from whom they acquired the HIV from. Three participants narrated this about their HIV positive partner.

RESP 026

*“... that woman (former girlfriend) did not tell me that she was HIV infected. She just allowed us to have sexual relationship even though she knew she was positive. I felt helpless because it meant that I had already contracted the virus...”*

GAB 015

*“... actually I had a relationship with someone who was supposed to marry me. I am sure that I contracted the virus from him ...”*

RESP 006

*“aah, I think when I came to “village 200” that is where I messed up. When I think about the lady I dated in “village 200” and the other women that I slept with in “village 200” I realised that the time I spent in “village 200” got me into the trouble I am in now (meaning my HIV positive status)”*

Although some participants responded by “I don’t know” to the question of where they could have acquired the HIV from, this may be due to having had more than one partner in a short space of time without having taken the HIV test together, or having concurrent partners.

Despite the different biological characteristic and factors that enhance the transmission of HIV, forms of transmission are not considered, and only sexual act is thought to be the transmission mode. The negative partners also attributed the infection to their HIV positive partners and gave the following reasons for why the partners had contracted HIV infection:

*“...many girlfriends he has”*

*“...mischievousness”*

*“...former boyfriend”*

*“...previous unprotected sex”*

### **4.3.1 Forms of discordance**

Though discordance is a situation where two people's test does not match, it has been found to have three forms. It has come out in the analysis of data that discordant partners experience discordance differently, hence it cannot be generalised but identified as being experienced by the couples. The following are forms of discordance identified in the current study.

#### **4.3.1.1 Discordant unaware**

Some couples were not aware of their HIV status. Couples had entered into a relationship and engaged in sexual relationship without discussing HIV related issues. A need to go for HIV test arises after some time when the other partner who is more knowledgeable on HIV issues or had an experience of caring for AIDS clients in their home insists on going for a test, or sometimes when the other partner is suspicious about the behavior of his/her partner. In this study, twenty-three partners reported having been aware of their HIV status but not that of their partners'. They either have not talked about HIV or have casually discussed about it without taking initiative of testing. However, most of the tests leading to discovering of discordance are normally done through:

- i) One partner, normally the female partner being pregnant and offered HIV test in order to find eligibility for the PMTCT of HIV.
- ii) One partner falling sick and getting tested for HIV because of probable signs of AIDS condition.
- iii) Volunteering to take an HIV test.
- iv) One partner doing a medical examination prior to being sent to school.

Some informants affirmed to this as noted:

GAB 015

*"I just went to the clinic to take up an HIV test. The test came out positive. I wondered if I could tell him. Well finally I decided that it is no use to keep it to myself, then I told him..."*

GAB 014

*"ummm ... 2006, I started to discover some signs of illness in him, that he must be having some kind of diseases though he claims to be fit. I felt he should be tested for HIV, but he refused. Later on he felt sick and was diagnosed with tuberculosis. HIV test was also done and he was positive..."*

GAB 005

*"Aah ... we used to talk about HIV test, just a simple talk that how would we do if one could be HIV positive. Both of us used to say "I will be sharp" (meaning okay or will accept). So when we went for a test and he became positive and I negative ... Aaa ... My head stopped (I got confused ...)"*

GAB 002

*"... because when you are pregnant you are advised to test. So I went to register ... When I took the HIV test I thought I was negative, only to discover that I am positive"*

#### **4.3.1.2 Discordant aware**

Out of forty-six participants for this study, fourteen entered into the relationship knowing their HIV status or being aware that they are discordant with their partners. Eight of these were female partners and six males. Participants reported having been told by their partners that they were HIV infected right from the very first time when they met. Those who did not disclose at the first contact did so some few days or weeks into the relationship. Partners who went into the relationship before disclosure reported strict condom use until they disclose to their partners. Partners on the other hand also

reported being overly cautious about protection, something, which made the other partner suspicious of HIV infection. Interestingly, self-disclosure has made it easier for most partners to accept one another unconditionally.

Most of these couples would discuss the issue of HIV before any agreement is made or if it happened after the agreement, the HIV infected would declare the status before any sexual contact is done. The HIV infected are normally cautious not to compromise the relationship by hiding the HIV status and seem like endangering the health of the HIV negative. Some respondents declared:

RESP 022

*"... I told him ... I told him and he said to me 'it is not an issue ... I was just open knowing very well that this is my life. I just told him that, sir I am infected and he said it is not a big deal we will live together'".*

RESP 003

*"I was positive when I met him. I told him my status and he said he was thankful for my honesty because it was the first time in his life that he has ever met a woman who is honest".*

RESP 008

*"after meeting this lady, she never hid anything from me about herself. She told me that sir, this is my status. At first we were hesitant but then later we started using condoms. After some time she started to get comfortable around me and she told me her status, but it was not a long time after we met. Then I said "really" and she said "yes" I am telling you the truth. I realised that she was stressing what she was saying so it must be true. I then just accepted her".*

Participants who were aware of their discordant status reported that their relationship was stable and was based on trust. This was confirmed by statement from one partner who said:

RESP 008

*"I was shocked just as anybody else can be shocked but not to a great extent ... because she is not careless about her life... she got infected a long time back..."*

#### **4.3.1.3 Discordantly discordant**

From the forty-six participants interviewed, nine (19.5%) reported having had a problem of living with a partner who knew his/her status but decided to keep quiet about it. The report about such behaviours was only given by the interviewed negative partners as the positive never wanted to give an account of such behaviour about themselves. Partners in this type of relationship normally experience problems as shown in the study findings. As the name implies, disagreement or differing opinion characterise the relationship. Dishonesty and non-self-disclosure prevail. The HIV positive partner would be fully aware of his/her HIV status but conceals it or pretends to be negative. Although the couple may discuss issues of HIV and AIDS and sexuality prior to agreement of love, the HIV positive partner would remain silent about his/her HIV status while the negative partner would resiliently press on for them for the HIV test. One partner lamented how she got to know her boyfriend's status.

GAB 009

*"I was at his house and he left me going to work in the morning. I was actually on leave. As I was cleaning the house, I became inquisitive to search for possible evidence of his mischief. As I continued arranging and folding his clothes, I came across many tablets of different types. Some of them I knew them because I once met people who use them. I was also shocked to find his medical cards next to the tablets. I asked myself how come! I discovered that the names on the cards and tablets labelling are his and even when he started the treatment. I then remembered that there were times when he used to set an alarm clock and when it rang, he would go to his car, take tablets and got into the kitchen to take them. I had observed this kind of behavior and is the one which made me suspicious... Sometimes he would kind of smell tablets in his body... I did*



*not ask him immediately because I know it's a sensitive issue. I also did not know how to approach him. I came back from where he lived. When I was back I called him and said, I want to ask you something but I don't know where to start or say it. Then he said "feel free" I then said okay I will send you a phone message. In the message I said, is there anything that you do that I don't know. He replied to say what do you mean? I then said "no, just tell me yes or no ... He told me yes there is something ... but I cannot tell you now ... After two days he called me and asked about this suspected issue. I told him I saw some tablets and cards bearing his name. Now I am wondering why we have stayed together this long and you did not tell me".*

Another similar narrations is depicted below:

RESP 004

*"There is a long story about that. I had tested in 2003 and I was negative. We met in 2010 and she did not tell me that she is positive and on ARV therapy. After a while in our relationship, while taking a bath, I found that she is on ARVs which she had hid behind the toilet. I was very stressed out and angry. I scolded her for doing this to me, why did she not tell me that she is on ARV therapy. She told me that she thought that I might leave her but I told her that we could have talked about it and reached a solution before we did anything together. ... Her intention was that we should build a life together and even get married. After I found out, she asked for forgiveness from me and I forgave her".*

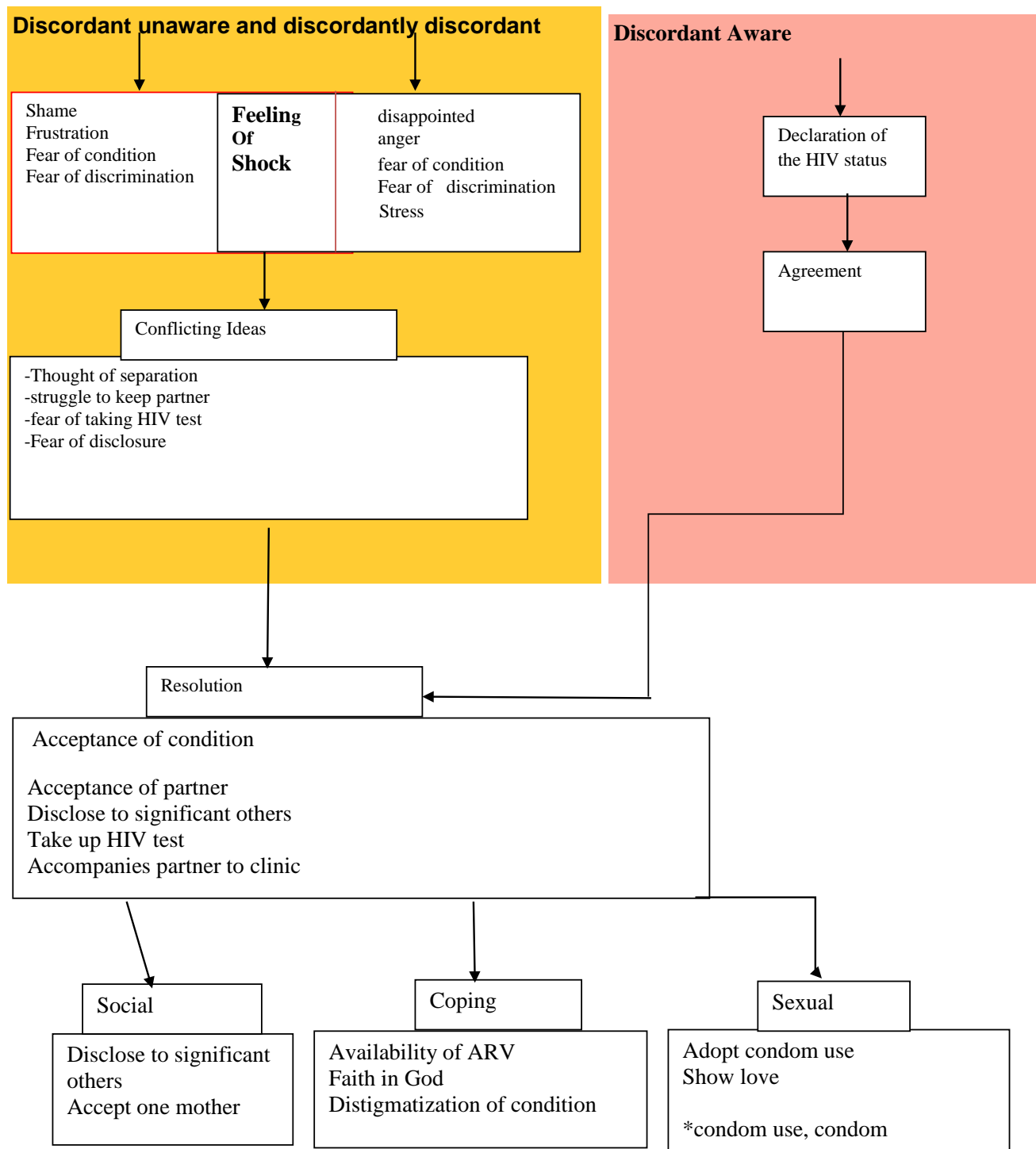
The HIV negative partner only gets to know after discovering suspicious behavior and acts by the other partner and probable signs of AIDS infection. Participants reports that on discovering, the HIV negative partner normally feels betrayed and cheated.

#### **4.4 EXPERIENCING DISCORDANCE**

All participants except discordant aware, reported having unusual experiences following the proclamation of HIV discordance. The experiences caused intense emotional, psychological, sexual and social experiences. The most critical and crucial are the

emotional experience. This is where they will be and when confusion and uncertainty strike between the couple. Couples ordinarily went through three stages of experiencing HIV discordance. These are state of shock, conflicting ideas and resolution. During the resolution stage, the couples start to adjust to life changes socially, sexually and adapt to coping behaviors in order to forge ahead with life. The illustration (figure 4.3) shows the three stages which will further be discussed in section 4.5. During the initial phase of shock, participants reported shame, frustration, disappointment, anger, fear of condition and fear of discrimination.

The second phase of conflicting ideas is characterised by thoughts of separating. Both the infected and the uninfected may feel like separating. The infected thinks of separating because they feel they cannot bear living with the uninfected partner and fear that they might infect them. The infected thinks of separating because they also feel their uninfected partner may not cope living with an infected partner. This stage is also characterised by one partner struggling to keep the other who wants to leave the relationship. The uninfected partner, especially while it is a man fears to go for an HIV test and fear of disclosing the condition to their significant others.



**Figure 4.3 Experiences of HIV discordant couples as they emanated from the study**

As discussed earlier, “the discordant unaware” and “discordantly discordant” would go into the relationship without any clear dual understanding of the discordance. Discovering that they are discordant comes in different ways. One partner narrated her experiences in the following manner:

*“...ahee! Eey, it was in 2007, and 2008, he fell sick. I started caring for him, I sat down and nursed him. He refused to go to the hospital believing in traditional medicine. I continued persuading him ... when I saw his results, I was severely hurt”.*

*“...my girl friend told me that she is HIV infected and I told her that I accept that situation. I even promised her that I will marry her”.*

Another woman who was in a discordant unaware relationship described how they got to know their situation:

*“...actually we both did the HIV test while at work. The Tebelo-pele VTC had come to do their routine testing and counseling. I then went in to get tested. I was in the office. My HIV test results became negative. When he (my boyfriend) came I told him it was his turn to go do the test. I refused to show him my results. He then went on to take the test ... When he came back, I discovered that there was something on his face, he was different, very unstable almost on the verge of crying. I then realised that there was a problem. There was something he was hiding. I then showed him my results and asked him for his. He refused the whole day until we got home in the evening when he disclosed that he is HIV positive.”*

A discordantly discordant couple (man being HIV infected and woman HIV non infected) experience the following:

RESP 025

*“... I used to go for an HIV test and showed him ... one day he wanted us to have sex without a condom, I refused and told him that I cannot agree unless I know his HIV status. He then stopped and said “okay lets forget about that.” I started being suspicious because all the times when I come up with HIV testing issue he says lets forget about it. One day when he was at work I started searching in his room, I searched and I searched. I persistently searched, in secret, doing so because I realised he was also secretive to me. I ultimately found a paper written viral load and CD4 count which was still above 350... I discovered everything, all necessary information. When he came from work, all I*

*wanted was for me and him to part ways because I felt he was a 'sell out', a crook, I got angry and left him for about three (03) months ...".*

Following the realisation of discordance among themselves, couples react in various ways depending on what form of discordance they are. However, the kind of relationship that pre-existed determined how each individual reacted. These reactions form part of the key themes and sub-themes.

#### **4.5 EXPERIENCES OF DISCORDANT COUPLES**

The study aimed to identify the lived experiences of discordant couples. Questions related to psychological, social and sexual experiences and coping strategies emerged out of the interview.

During the data analysis phase, there were recurring themes and sub-themes that emerged from the data. Some of these themes answered the key question for the research, which is, 'Tell me your social, sexual and psychological experiences of being in a discordant relationship. The question has been addressed through the following responses by the participants.

##### **4.5.1 Psychological experiences**

Many subthemes emerged as shock, shame, frustration, fear of condition and fear of being discriminated. These were experienced by the HIV infected partners while the uninfected experienced disappointment, anger, stress, fear of condition and fear of being discriminated.

##### **4.5.2 Feeling of shock**

During the time of breaking the news, most of the discordant couples got shocked. The discordant unaware and the discordantly discordant non-infected are the predominant subjects of shock. Shock came in because they did not expect the news or they did not have a plan of where to or what to do next. The discordantly discordant non-infected get shocked because of the disappointment and the realisation of the deadly secret held by their partners. Shock occurred immediately upon receiving the news that the partner is

HIV infection. More shock occurred when they were told that they were discordant. They become confused especially upon the understanding that they had engaged in risky sexual behaviour. It may be difficult for an individual to acknowledge the truth of the issue, but within each individual, the truth about the situation remains. Shock is interestingly described in differing phrases, some of them being:

- “...o ne a tshidifaletswe” (He felt ice cold)*
- “... o ne a gamaregile” (She was paralysed)*
- “...a tshwara kwa le kwa” (He was confused)*
- “...Ke ne keheletswe” (I was speechless)*
- “... ke ne keitlhobogile” (I had given up)*
- “... ke eme pelo)” (My heart ceased beating)*
- “...ke ne kanna fraa’nyana” (I got frustrated)*

Some respondents narrated their experiences like:

GAB 009

*“... I saw them (tablets). I was shocked more so that they were with his medical cards bearing his name. I asked myself many questions...”.*

RESP 024

*“... actually, I was frightened and panicked a lot especially knowing that we once had unprotected sexual intercourse. I did not believe that she is HIV positive, at one point I thought I was also infected and it’s just that the Tebelo-pele did not do my test properly...”.*

GAB 004

*"I was shocked (my heart stopped beating) I did not know what to say to her ... when I left the clinic my legs could not move, they were heavy. I think we waited (rested) in the corridors for about 20minutes. Tears were eminent, I tried to hold on but to no vain. You know, I have pride that I cannot cry when I am amongst people, but during that moment, I failed”.*

GAB 002

*“ ... I felt like I did not know who I am at first. They tried to counsel me at that time but it was difficult”.*

Following a feeling of shock most participants went on to explain their immediate experiences which are classified as sub-themes.

#### **4.5.1.1 Sub-theme: Feeling ashamed of the shocking news**

Shame has been a major feature for those people who for a long time have thought that they are doing well and the relationship is one of the exceptions, or thought they had found the right person. Most of these partners are in the Discordant unaware and the sero-negative of the discordantly discordant couples. Fourteen out of twenty-three discordant unaware partners explained their experiences as, “I was embarrassed, “it was a shame” “I did not know how to face him” “I felt I could hide myself” or “a shameful situation”. In the Discordant unaware, the individual who ultimately becomes HIV positive feels so helpless in the presence of his/her partner. The positive HIV test humiliates them before their partner especially at the turn of their partners’ negative test result. The discordantly discordant feel ashamed because the secret of concealing their HIV status is revealed. They get pre-occupied with where and how they contracted the virus. Shame prevails especially when they recognise that they may be perceived as having been dishonest in the relationship. Some of the experiences are:

GAB 001

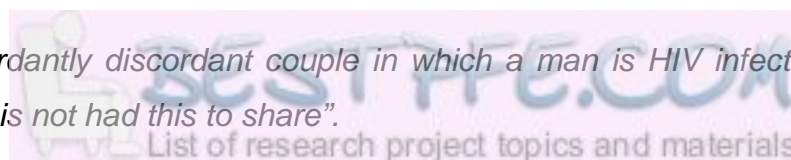
*“... she (my wife) was saying that she is so embarrassed, but I said to her “No, you must not think too much about it ...”.*

GAB 015

*“... I was scared to tell him. I had a belief that he may leave (part ways with) me or maybe beat me. But none of those happened”.*

GAB 009

*“... a discordantly discordant couple in which a man is HIV infected and the woman is not had this to share”.*



*“... Really guilt was with him. He felt so very bad after I have discovered that he is HIV infected. My suspicion is, according to him, I was not supposed to know in a short space of time”.*

For the discordantly discordant, the HIV infected normally hides the results or any evidence that could lead to her/his partner knowing that they are HIV infected. They hide their medical cards, they hide their treatment, and they even don't tell their partners the truth when they go for medical reviews. This turns out to be an embarrassment when the partner gets to discover.

#### **4.5.1.2 Sub-theme: Feeling frustrated**

Frustration is mainly experienced by the discordant unaware negative partners and the discordantly discordant non-infected. Frustration comes in because of shattered trust on the other partner or shaky hopes for the future. Twenty-one negative partners of the discordant unaware and discordantly discordant expressed frustration. They become uncertain of the relationship and whether they will be able to continue in the same relationship with the HIV infected partner. Expressions were like:

GAB 005

*“... The results really hurt me because I felt that he knew he is HIV infected and did not want to tell me that he is living with the virus. I feel he wanted to infect me so that when we come to test we would both have the virus. Again, I wonder how was I going to live with him in such situation, how would I tell my family about that situation!”.*

RESP 027

*“The results came and I was very frustrated ... When he knocked off, I told him my HIV results. I was actually expecting that he will move away or part ways with me because I am HIV infected, but he kept on assuring me that he will stick with me and even promised marriage”.*



#### **4.5.1.3 Sub-theme: Fear of the condition**

During the time of breaking news about HIV discordant, nineteen participants reported fear associated with the condition as they felt they might die. Both the infected and the non-infected thought of death more than anything else. The infected thought that they are going to die very soon, while the non-infected thinks of a difficult life with a sick partner. Death is thought of even by the discordant aware who believe that if the infected partner has to die, they also should die. Nineteen participants explained that they have no life if they are discordant.

GAB 004

*"I felt like I did not have life. The lady who tested us advised me to try and avoid being stressed, but that was something I could not help. Every time, even when I was with my partner I would keep on thinking that I have this HIV infection. Then I would wonder, "will I live long! does she understands what I want! Am I going to be the same person she initially fell in love with! Will she continue to regard me the same way, treating and appreciating me like before?"*

GAB 010

*"... hei, I fell ice-cold. Very scared ... I asked myself, how it happened. To me. It was everything was blocked, darkness in my life ..."*

RESP 27b

*"...that day I cried a lot. I thought of committing suicide, but for the sake of my daughter, I refrained, thinking of the misery I will be causing her... I was wondering what to tell him (my partner) hoping that he would not appreciate me"*

RESP 24

*"... yes he was crying out loud that he is going to die. Crying a lot ... The whole night he could not sleep at all. I took effort to encourage and counsel him. I told him that being HIV positive is not the end of life because there other things like ARVs ..."*

GAB 002

*"At first it was not easy to accept it, wondering how I am going to tell my partner since I was not with him at that time. So I felt like I don't know who I am ...".*

Because of the knowledge that the condition is not easily accepted by others, some HIV non-infected end up struggling to counsel their infected partners so that they may find the best option to live with the condition. An HIV male partner explains how he committed himself to supporting his partner.

GAB 007

*"What came to my mind was that the only thing I should do is to give her support because even though she is positive, I cannot leave her, she may have more problems which may lead either to suicide, or out of desperation give herself to every man in sex, ending up infecting them ...".*

Apart from fear of dying, partners become apprehensive that due to their discordance situation, the society may stigmatise them. Because of the common mode of transmission, that is, sexual intercourse, the discordant partners have a feeling that they will be regarded as being intemperate in sexual matters. Despite so much teachings that the government has done to sensitise the people to destigmatise the condition. Many people still do not appreciate that HIV is not discriminative, hence no one is immune to it. Affected people tend to think that it is a curse to have the virus. When infected they hide. The "affected one", on the other hand always asks questions like: Where did she/he get it from? There are still people, who associate the HIV and AIDS with infidelity, something that though happens everywhere, is shunned by the societies.

Responding participants express fear that their partners, family members and friends would not accept them if they have HIV. The HIV infected is overwhelmed with thoughts that the partner is not going to tolerate the situation. In their battle of emotions, some decide to leave the relationship, while others would very much believe that their partners would leave. Some would not disclose to friends, some to family members some would even take time to disclose to their partners in fear that they would not receive a good treatment from them. Evoked responses were like;

A female partner of the discordant-unaware who is not infected showed how she still doesn't accept the condition by declaring:

GAB 005

*"..... eish, I think there are going to be lots of challenges. ... as I know myself, during the course of our life, if he could try to rebuke me for anything, then I will say ' ooh! What about you who is like this (infected with HIV)'. Even after telling my family members, how are they going to appreciate and regard him! What are they going to think about me! Maybe they will say 'what do you want on that person who may infect you with HIV'".*

RESP 026 who is an infected lady of the discordant aware relationship narrated her conversation with her lover during dating:

*"... Initially I asked him whether he will respect me regardless of my HIV status? ... I mean, will you appreciate my condition, if I am sick will you be considerate that this is a disease like any? He said 'yes I will' ...".*

#### **4.5.1.4 Sub-theme: Feeling stress**

Stress has appeared more frequently to all forms of discordance even the discordantly discordant infected. Stress was the result of unexpectedly erupting discordant phenomenon. No one ever wants to hear that they or their partners are HIV infected. The announcement of the HIV infected status becomes a stressor to any person. For those who are discordantly discordant infected, the stress is the result of revealed privileged information to unintended person.

Most of the people, when they come into a relationship, have an ambition of seeing it grow and succeeding to be a concrete one. When stumbling situations like diseases such as HIV and AIDS occur, the future of the relationship becomes bleak. The HIV non-infected gets disappointed, not only about the future condition of their partners, but also about their faithfulness. Before they are convinced or unconditionally converted to appreciate their partners, they get clouded with questions such as "how come?" "Why", and "Is it real?"

The HIV infected partner, on the other hand struggles, with how to convince the non-infected partner to appreciate them and that the infection is not the result of infidelity. The couples have to fight against all odds that stress them and disrupt their envisaged happiness. Persistent stress may sometimes result in unplanned resources being incurred.

A young man who is infected pointed out:

GAB 004

*“I told my mom. My father is late. I told my mom everything about my girlfriend and she even called her (my girlfriend) but I have trouble with sleeping. I just cannot sleep at night such that I ended up taking 2 sleeping tablets to induce sleep. When I woke up in the morning, I was still overwhelmed by questions ... One thing that pains me more is the plan that we had together with my girlfriend. I keep asking myself if we would achieve any”.*

#### **4.5.1.5 Sub-theme: Feeling of anger**

Anger is predominantly expressed by negative partners of the discordant unaware and discordantly discordant-uninfected. Mainly anger emanates from discovering the untrustworthiness of the infected partner. In these couples, because the infected hides the condition from the uninfected, it denies them the opportunity to take precaution from getting infected. On discovery, the HIV non-infected becomes grossly angry. The infected wonders whether it is the intention of the infected to pass the virus to them. To them it is cruel and inhuman deny them such information. All interviewees felt it is important for their partners to declare their HIV positive status. They would not have any problem in appreciating their partners if told of the HIV status. The discordant unaware non infected become angry because of frustrated hopes and sometimes because of suspicion of infidelity.

The type of anger expressed by those participants was directed mainly towards their partners for being HIV positive. Partners become angry because they find no answer to

why their partners are HIV infected, their anger is also a result of realising that their partners have been knowing and failing to disclose their HIV status.

RESP 25

*“... when he came back from work, I wanted him and I to immediately part ways (separate) because I discovered that he is so bad, he is a crook. I got annoyed and went away for a period of about three (3) weeks. He followed me until he ended up asking the counselors to intervene ... I suspect he knew his status and was keeping it secret to me, I wonder why?. Does it mean the time when he wanted us not to use a condom he was planning to infect me or what! This issue really disturbed me”.*

GAB 003

*“...he was not happy at all. He was asking himself if it could be that I am cheating on him or what?”.*

#### **4.5.2 KEY THEME: Conflicting ideas**

Most of the experiences mentioned evolve out of stress. Stress as described by Potter and Perry (1999:411) evolves out of life events and experiences and ends up stimulating our thinking processes. As the stress of being discordant conflicts on the individuals, they are stimulated to think and during their thinking they look for possible workable options to reduce stress or get out of it. In most cases the immediate and simple option is not necessarily the most appropriate. The individual therefore finds him/herself having to battle to choose between somehow conflicting ideas. The choice of the appropriate option would be influenced by emotional feeling or affection factors, the social factor, benefit of the action and whether the option that one decides upon is socially and morally acceptable or not.

##### **4.5.2.1 Subtheme: Thought of separation**

The thought of separating or moving away as others called it, emerged very frequently on the young ones of age between 21 and 29 years. It was also common on those whose relationships were not very new (less than six months) but not older than two years. The thought of separation was less among those who are married probably

because they are bound by the marital vows as well as societal and moral expectation. It was also less on the couples who have lived together for a longer period of more than two years and have children or share material possessions. However, for the couples who had not been having a steady relationship, characterised by abuse and cheating, thoughts of separation become common irrespective of how old it is or what the couple has.

A four months' relationship of a couple who are not married, and the male is HIV infected narrated their experience:

GAB 004

*"...she has asked me not to push her away. Even just yesterday I was telling her that its better we separate... part of me still wants me to push her because I feel I am going to subject her to suffering. I don't get how two people can be together with different HIV statuses. I think she is just saying that now but naturally she is going to be scared. I don't want to see her suffering".*

A 21 years old woman whose boyfriend is 24 years and has been in the relationship for about two years said:

*"I was asking myself why am I not infected though we started love affair together (him and me at the same time) I then decided to stay at home. I did not check on him. Later on I told myself, 'aahh ..., let me go back to him ...".*

Gab 006, whose nine months' relationship was discordantly discordant and was unstable due to the behaviour of the boyfriend said:

*"It was difficult for me. I could not keep on rebuking an elderly not to keep on taking alcohol while at the same time taking ARV treatment. He would sleep away from home in alcohol bars and I am not even sure maybe he would be with other girlfriends, so I decided it is not working ...".*

#### **4.5.2.2 Subtheme: Showing love, 'breaking the odds'**

Most of the couples have decided to stay in the relationship despite differing HIV status. Reasons for staying together are different, but for the HIV infected partners they stay because of the appreciation they receive from their partners. Appreciating one person has shown how important it is to build a relationship. Most HIV uninfected partners revealed their appreciation through actions and even by verbalising it. Some married partners went to the extent of reciting their marriage vows to show how much they are stuck to their marriage promises. The HIV negative partners would go to an extent of taking risk of acquiring the virus by engaging in unprotected sexual intercourse being a way of showing the other partner how they love them.

RESP 008 claims to love his wife and says:

*"... it is because of love. If you meet a person and claim to love her, it must be true love and not playing with that person's feelings. I love her just as I am sure you can see that she is admirable ... we use a condom, but one time when we were using it. I don't know what happened ... it burst. I don't know maybe it is the foolishness of being a man, I then thought I had contracted the virus ... so I went and took a bath ... I had many thoughts. I was a bit worried but then I ended up accepting and decided to get tested. I also ended up putting away the condom until she conceived'.*

GAB007 whose girlfriend is HIV infected says:

*"... she was not comfortable but I went to an extent of showing her that I need to make her comfortable. I started having sexual intercourse with her without the use of a condom knowing that she is positive".*

#### **4.5.2.3 The challenge of taking HIV test**

Because of the fear of the condition and what it means by being HIV positive, it becomes a big challenge to take a test especially when your partner has tested positive

and you are aware that you have not been using any protection. To many women who were interviewed, taking a test had not been an issue especially when doing it without any knowledge the partner's status. However, women have a challenge in convincing their male partners to take the test. Even when they are sick, most men require energy to be convinced to go for the test. However, as much as is hard to take them for the test, all partners to women who are interviewed managed to go for the test.

RESP 021 whose partner was sick but refused to go for a test narrates:

*“Ehee ... ee, It was 2007 or 2008,he fell sick. I stayed home nursing him. He refused going to the hospital and only preferring traditional doctors...I continue trying to persuade him, telling him I don't despise traditional doctors but we must also go to the hospital”.*

Most of the women could go for the test alone, but most men went accompanied by their partners.

#### **4.5.2.4 Sub-Theme: Fear of disclosure**

Disclosure of the condition to significant others is variant and selective. While some people do not entrust everyone with their condition, majority of the partners prefer to disclose to family members. The most entrusted being the mother, followed by sisters. Both the male and female prefer to disclose to the mothers. The brothers and fathers are less entrusted to be disclosed to. Those who have elderly children prefer not to disclose to them because they do not want to hurt them. Friends are not preferred either for fear that they may divulge information about their condition. One particular participant disclosed to the mother in law.

Disclosure evokes various responses from different people. Most responses have been sympathetic and showed compassion. There has been invaluable counseling from those that the couples disclosed to, ranging from protecting self to keeping the relationship to healthy living.



Some reasons for not disclosing were as follows:

- fear that they may be negative about it
- to safeguard the health of the elderly who may be more hurt
- fear of being discriminated against
- fear that parents may put pressure on them and encourage separation
- having no good relationship with them

The reasons for disclosing to other people are:

- the person is a health worker and is knowledgeable on HIV issues
- have had an opportunity to care for an HIV infected person
- have warm heart and kind
- is a close relative

#### **4.5.3 KEY THEME: Resolution**

In living with HIV discordance, partners struggle with finding workable solutions in order to continue life. After some time they come to a point where they settle and adjust to normal activities. This stage is referred here as resolution. It is the moment when the individual has gained more information about the situations by virtue of having opened up oneself to the reality. The individual begins to express emotions openly realising and recognising that the other partner has really been infected. To them struggling in denial does not help. They end up accepting the situation and the partner.

Couples accept the situation because they have seen other people in the same situation. Partners or couples also accept one another because of the love they have toward each other. Resolution is characterised by:

- (a) Acceptance of condition

Most couples or participants do not have many problems with the situation of being discordant. Though they may not choose to be or they would not like to be in such a



situation, when by any chance they happen to be in such predicament, they simply accept. The main problems that bother them are:

- i) When a partner does not disclose their HIV positive status
- ii) The attitude of other people towards people who are HIV infected

The couples accept the condition because:

- i) The condition is irreversible or not curable, so if it has struck them, then it's done and there is nothing they can do.
  - ii) There is currently treatment that is in use to prolong life and minimise effects of the condition and
  - iii) Having the condition, unlike in the past before the advent of AntiRetro Viral Therapy does not mean you will die soon.
- (b) Acceptance of the partner

Partners are accepted in differing conditions. The discordantly aware are simply accepted for their:

- i) honesty to open up and disclose their status. Most men accept the HIV infected partners because
- ii) they love them and because they fathered their children
- iii) the married couples though there will be other ways like children and material possession, majority felt they have to accept their partners because they have vowed so when marrying

RESP 002

*"...I surrendered to the situation accepting every outcome. I am determined to stand by his side in every eventuality more so that we come from afar through thick and things...I am doing that because he does not have parents, I am almost everything to him. He looks up to me for everything. I feel pity for him and that in marriage we vowed to be separated by death"*

RESP 002

*“Yes, I was shocked because I never expected that. Even though she used to be naughty, I thought the situation is not that far but anyway after discovering that she is infected I gave up and assumed that she has been befallen by a tragedy which can befall everyone”.*

(c) Disclosure to significant others

The issue of disclosure has not found its proper position within the discordant couples. Although some would say they don't want to disclose their discordant situation. Some would say maybe they would disclose to their parent being their mothers or sister. Some do not want to disclose at all while others easily disclose to the family members and even friends. Other members of the couple who have recently been diagnosed, would say they are not sure whether they would disclose in the near of far future. However, many who have disclosed have disclosed received the benefit thereof, and feel it is important for gaining moral and emotional support

(d) Taking up the HIV test

All the participants, including those that initially resisted going for an HIV test ended up taking the HIV test. Those who were initially negative end up agreeing to subsequent testing. Participants wanted to ascertain their negative or positive status. The test is mostly done in the clinics than in Tebelo-pele VTC the reason being the clinics have integrated services, which make it easy for them.

(e) Accompanying partner to clinic

Accepting one another's status seems to have far reaching effects. It proves that couples can bear one another's' load. Most couples have realised an awesome support from their partners following the discovery of discordance among them .The counseling services have bound them together. Even those partners who used not to accompany the spouse are said to be taking part in the health care services of their partners. Most participants say they do so because they have been counseled together. The partners

have also enjoyed the support of their partners such as reminding them about their treatment and sharing the domestic roles such as cooking, laundry and cleaning.

(f) Adoption of coping strategies

Following the dual consensus of living together, the couple agrees on a positive living for all. This seems to have changed the lives of most couples as they mutually agree on what is best for them to lead into longer and productive life.

#### **4.5.4 KEY THEME: Social experience**

Discordant couples have varied social experience, probably because the discordance itself is a social phenomenon. Some of the experiences are associated with the society or community at large, others with the family of the couples; some are amongst the couple itself. Top in the list of the social experience is that the discordant couples are still struggling with the issue of stigmatisation and discrimination.

Some couples feel that having separate porta-camps, dedicated to HIV clients, in clinics as it is the set up in Botswana, discriminates them. To them they should just mix with other clients when they go to the clinics and not have a separate service. The current set up identifies them as people different from others because of their condition. Participants have a problem of disclosing to friends and even family members because they feel that people will not welcome their situation. Some end up bolted alone with their own problems, without anyone to share problems with. Other partners feel that an HIV infected partner should not have a say in the relationship. This shows that the situation is not fully accepted. However, a lot of people believe that discordance is not supposed to be shunned and would advise anyone in discordant situation to accept and continue in it.

The social role of procreation also plays an important part in the way the discordant live. According to African culture, Botswana inclusive, a family exists because of its ability to increase in size. This idea existed right from ancient generations to present date, people still belief in the importance of having children which will definitely impact on the perception of discordant couples in as far as sexuality is concerned. People are still put

under pressure to have children no matter what condition they are having. One lady respondent whose boyfriend was HIV infected lamented this on her social experience:

GAB 009

*“...The other people were advising me that such a situation (discordance) is not a big deal, while others were saying that it might mean I will also end up contracting the virus, and others were advising that I should just pull off and get out of his life. But as for me, to tell the truth, I still love him. I seriously love him. His problem is that he wants a child, but if there was a way that we could have a child without penetration I would not have any problem with the proposal. No problem at all”.*

#### **4.5.5 KEY THEME: Sexual experiences**

Discordance situation has changed the lives of many. Actually discordant couples should be treated as a vulnerable group because if not, it will pose another source of infection. Couples/spouses will be infected through it. This is because most participating partners showed inconsistent use of condoms, while others preferred not to use a condom at all.

From the participant's point of view, discordance has affected them sexually only when the other partner is sick. Ironically after realising that the couple is discordant, after the resolution stage, the couple becomes closer than before. Their sexual performance does not change but because of closeness, they turn to enjoy their sexual act more.

However, during the early stage, immediately after realising the discordance and before the resolution stage, most couples experience intermittent episodes of dryness in sexual life. The reason for this is that some partners are still stiff because of fear of the condition. Later, after the resolution stage most couples enjoy sexual life to an extent of becoming complacent and not using a condom. Quite a number of male partners mentioned that they dedicated sex to their partners in order to make them happy and to express love to them. All the respondents understood and knew the importance of condom use during discordance but many end up not being faithful because they want to please their partner, either they want a child or they yearn to have sex without condom. Some experiences were expressed like:

RESP 25 – an HIV non-infected lady:

*“Actually I don’t have any problem, I have accepted him ... you see the way we are in love it’s so fantastic. It’s too much. I have also discovered that he (my boyfriend) is good in handling a woman during sexual intercourse I appreciate him”.*

RESP 001 – a lady whose husband is HIV positive declares:

*“Ah ... yes ... (laughing with a loud voice) I am not used to constant condom use. Sometimes it’s difficult. The other time I asked him, since we have weaned the baby, why don’t we just once have sex without a condom- o mpharanyetse foo hela? (Just let me have a taste). But he refused and said “no, by so doing I will be killing you my love ... we used to have sex without a condom before he fell sick even when he was, before he tested for HIV and so what has changed or what will change?... is it the test result? But he refused. He says for the sake of the child”.*

#### **4.5.6 KEY THEME: Coping strategies**

Different couples or individual partners use different strategies to cope with effects of discordance. Majority of the couples had been to counseling in the VTCs in the clinics or at Tebelo-pele Testing and Counseling Centers. They testify that the counseling has helped them with enough information to choose appropriate strategies for healthy living. Other couples rely on the Devine power and assistance to cope with the situation. Some partners start to be strong in faith following discordance. Some couples’ source of inspiration is the family whom they disclose to. Others find solace in the warm relationship they receive from their partners.

#### **4.6 DISCORDANT AWARE**

The discordant aware relationship seems to have experiences that are somehow different from those of the discordant unaware and the discordantly discordant. These couples have the opportunity to attend to their difference right from the time of proposal. The HIV uninfected has an informed knowledge to proceed into the relationship that the other partner is infected. They have the opportunity to discuss issues of discordance before they are committed to the relationship. This helps them to take decision under no

pressure from the other party. Couples therefore do not experience “Feelings of shock and conflicting ideas” because they deal with them before getting into the relationship.

#### **4.7 CHALLENGES**

Discordant couples experience challenges ranging from the condition itself to social factors, sexual and psychological factors. Some of the challenges are:

- The continuing stigmatisation of the condition by members of the society
- Pressure from the spouses, parents, community and culture to have children even in the face of discordance
- The segregation made by the health policy of separating the HIV and AIDS services from all other health care services
- The trust that couples have to entrust to those that they disclose to
- The need for children by the spouses who have HIV
- Continued use of condoms because the couple is discordant
- Sometime the refusal to use condom by the other partner
- Having to nurse a cohabiting partner
- Partners who are hesitant (who do not want) to use modern health care services
- Discordantly discordant – positive partners are a problem because they conceal their status

#### **4.8 CONCLUSION**

In this chapter data has been presented and experiences of discordant couples deduce from the raw information. First the demographic characteristics of the respondents have been presented in a summarised form. Lived examples by the discordant couples have been classified into key themes and subthemes to show how they live in the discordant situation.

## CHAPTER 5

### STUDY DISCUSSION

#### 5.1 INTRODUCTION

This chapter intends to further explore and synthesise the findings of the study. The synthesis will be based on the analysis done in the previous chapter to deduce the experience that the HIV sero-discordant couples in Botswana have. The discussion will further link the conceptual framework that is, the Social-Ecological Model with the finding of the study. The discussion is organised in two ways. The first will be concerned with the perception of couples towards HIV sero-discordance and the second part will discuss the couples' needs and challenges.

The need for the study came about because the researcher in his continued clinical practice and interaction with clients who are HIV sero-discordant discovered some couples who are discordant. The researcher got to know this as HIV sero-discordant, an unfamiliar phenomenon that though other couples managed to live with it, but has shaken the relationships of others. Like any other person who may ask, the researcher wondered how does it occur and what factors could explain this phenomenon.

Generally, the HIV sero-discordant phenomenon has received little attention nationwide and still perplexes many. The researcher felt that the HIV discordant could probably be having numerous challenges. During the interaction and counseling of these HIV discordant couples, varying concerns came up. Some of these couples felt comfortable with the HIV sero-discordant relationship, others do not stand the situation at all, while others remain in the relationship because of marital reasons. This therefore prompted an inquiry to find out why others couples are

able to maintain the relationship and why not others? The study sought to explore the experiences (including knowledge, needs, receivability and risk) of the HIV sero-discordant couples.



## 5.2 SUMMARY AND INTERPRETATION OF RESEARCH FINDINGS

This section will discuss the meaning deduced from the data as presented in chapter four. Discussion will include other themes not presented in chapter four and make further interpretation thereof.

The study has evoked diverse experiences by the HIV sero-discordant couples. Experiences were somehow the same for those who entered the relationship not aware (discordant unaware) and for those who entered the relationship with differing motive or attitude (discordantly discordant). However those who entered the relationship aware of one another's HIV states, have different experiences because they are not surprised by realisation of the discordance while already in the relationship.

### 5.2.1 Experiences of HIV discordant couples

After more than twenty eight years following the discovery of the HIV and AIDS in Botswana, still little is in place to address the concerns of couples. It is well known that 'man' is a bio-psycho social and sexual being and as such anything that happens to his environment will affect him physically, emotionally, spiritually and ever sexually. A lot has been done to fight HIV but a very important area, which is paramount in the transmission of HIV occurring in the content of couples, has received very little attention. In Botswana, couple counseling has been introduced but it is based on the assumption that couples will support each other. What and how they experience the discordant phenomenon is not known, scientifically proven or studied. This discussion will hopefully help in addressing the needs of the HIV discordant couples as expressed in their experiences.

#### 5.2.1.1 *Perception of couples towards HIV sero-discordance*

Understanding the discordance is still difficult among the sero-discordant couples in Botswana. Almost all participants in the study (44/46 or 96%) know about HIV. However, how discordance comes about is another unknown topic to many. Some couples still do not understand how it comes about, some attribute it to a protection from God, rough sexual intercourse, while others think it's just a matter of time then the

other partner will test positive, in other words they don't believe it can happen. Some participants gave the following responses:

RESP 001 – a lady whose husband was HIV infected said:

*“... Actually I believe I am already infected. It's just a matter of time for me to be positive. We used to have sex without a condom before he fell sick ...”.*

RESP 009:

*“Ah ... I don't know, I had many questions but no answers”.*

GAB 001 – a husband whose wife is HIV infected said:

*“I accepted it. I never felt hurt. I never had pain about it. I just said no, it's through God's will. If God said we are going to encounter such problems so why should I not accept ...”.*

Exploring couples' understanding of sero-discordance is important because their lack of clarity on HIV discordance could render them highly susceptible to popular myths and misconception about discordance. Interestingly the Batswana's understanding of discordance is similar to those noted by Bunnell et al (2005:1002-1003), who observed that couples explain HIV discordance in many different, yet incorrect ways. According to Bunnell et al (2005:1002-1003), sero-discordant couples believe that it's due to immunity, they believe that the HIV negative partner is actually infected, and that infection only occurs during rough sex. These responses like those ones noted in this study reveal a lot of ignorance among HIV sero-discordant couples.

The belief that God is involved in the realm of discordance has a very strong impact in the couples' health and wellbeing. This may be positive or negative because it is a sign that the positive partner may also be healed from HIV someday” or a “curse from God” and many more. These explanations indicate that the dominant understanding of the discordant phenomena is the spiritual explanations. Such perceptions as spiritual explanations and belief that one is already infected may indicate that couples who believe in them have less drive to further understand their condition and may even have little drive to protect themselves. Understandings like having a strong immunity or a

blood which may not be infected by the virus have also been explained during the study. These results are in congruent with those by Bunnell et al (2005:1003-1005) who purported that in Uganda couples explain the situation as being God's protection and people's strong immunity. The danger with this explanation is that one may continue not protecting himself with the belief that they have "strong blood".

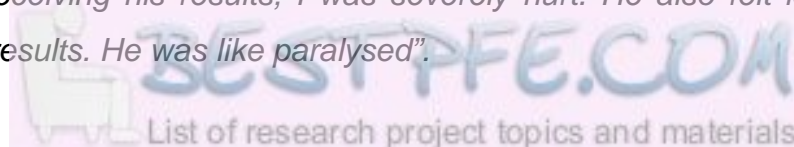
#### **5.2.1.2 Effects of sero-discordance: psychological experiences**

Respondents reported having varied psychological effects ranging from shock as the news of discordant are proclaimed, shame and frustration mainly expressed by the HIV infected partners due to the feeling that they have brought curse to the family or that they are being proven to be unfaithful to their partners. The HIV uninfected partners on the other hand become angry and disappointed by the situation. Some may even think that the HIV positive partner has been knowing and maybe concealing it. Their main disappointment arises from whether they will be able to realise their dreams with the person they have been planning with. These negative experiences brought about stress among discordant.

In a study by Bezuidenhout, Elago, Kalanga, Klazen, Nghipondoka and Ashton (2002:20) it was revealed that the same stress that is felt by the infected is also felt by the affected partners. Bezuidenhout et al (2002:20) revealed that couples are faced with the challenges of loss, fear of death, perceived helplessness, and uncertainty about the future, sadness and anger as well as frustration. The phenomenal stress is described by Smith, Segal and Segal (2013:01) a normal physical response to events that make one to feel threatened or upset balance in some ways. The stress may result in inability to concentrate, constant worrying, sense of loneliness and isolation.

In this research couples felt emotionally disturbed when receiving the announcement that they were discordant. Some responded in anger and show of frustration. Others felt like breaking the relationship, some became emotional to an extend of crying. Some of the feelings were expressed as:

*"... when receiving his results, I was severely hurt. He also felt ice-cold when seeing his results. He was like paralysed".*



*“I had severe dizziness and I was overwhelmed by fear ... I was asking myself how it came about”.*

*“He kept being absent minded for some time, very worrisome. But I encouraged him and I think he is better”.*

These psychological symptoms may have a negative impact in the normal functioning of a person. Effects like absent minded, loneliness and confusion may disturb the normal day to day functions and may lead to complications like suicide and depression. The psychological or internal challenges a person with HIV and AIDS faces vary from individual to individual. Not everyone will experience all of the emotional responses or stages of the emotional responses described. Each HIV and AIDS situation is as unique as the people involved. There are individuals who might face catastrophic changes not only in their personal and job relationships, but in their physical bodies and in their self-images and self-esteem” (Wastein & Chandler 1998:29). As a result of these changes in both working and personal relationships, the behavior of those infected may change. They may become withdrawn, aggressive, and rude to colleagues and friends. This may be because the infected person may feel being victimised. Infected and in some cases affected, people can experience a decrease in self-esteem as they are no longer confident in themselves or what they can achieve. This is likely caused by the stigma within society against infected and affected people. They are seen as lesser persons and are at times devalued. This in itself is of course detrimental to the person’s well-being. Coping with being infected involves confronting fear and denial while maintaining hope.

### **5.2.1.3 Effects of sero-discordance: Sexual experience**

Majority of the participants (24 out of 45, less one who has separated with the partner) feel there is not much negative impact of discordance in their sexual life. It is worth noting however that during the realisation of discordance, the couples experience a decline in sexual activity. This is temporary because after the resolution period there is again a rise or a return to normal libido. The drop in early stage following the HIV test is due to psychological experiences of frustration, stress, fear of infecting the negative partner, anger and shame and disappointment. Some of the experiences were described like:

*“Hei ..., sex is a problem. It is not as easy as before we knew our status. I can tell you that once before we knew, a condom burst, but it was better because we did not know. Now after, aah ... because I am aware. I am ever unsettled and scared I don’t know till when ...”.*

Another lady testifies of her boyfriend who temporarily suspended sexual activity after they discovered that they were discordant:

GAB 009

*“... Really to tell the truth, I am scared. Not through the route that I am aware of .At least it could be through some other route that I am not aware of, but not through sex. We are ever taught about sex and HIV almost every day and that we should protect ourselves. That is why I told you that after he realised our discordant situation he pulled back. Before then we used to communicate like every hour ... After knowing he felt very bad and undermining himself to an extent of shutting down any discussion of HIV and AIDS”.*

*“... ah, sometimes I develop low sexual drive because it is not as interesting as before ... He also has low drive. We sometimes go for two to three weeks without sex. When I ask him he says he is tired”.*

However, the sexual experiences differ from one person to another. It is probably influenced by the internal and external factors within an individual. Some couples take long to resolve and emotionally settle. As a result, they take time to comfortably engage in sexual act. This may end up disrupting the sexual relationship.

There are of course other partners who do not take caution to protect themselves from getting infected with HIV, believing that it is a partners responsibility not to shun their partners because they test HIV positive. This is however a common concern even in Allen et al (2001:733-740) study on sexual behavior of HIV discordant couples after HIV counseling and testing. According to Allen et al, couples continue not to be faithful in condom use despite knowledge of HIV discordant in Zambia. In their study, couples

with HIV negative men had more frequent sex both with and without a condom, compare to couples with HIV positive men.

In this study partners who wanted to discontinue condom use are men. Eleven out of seventeen men discontinued condom use or were unreliable condom users. The results confirm that in other areas where women are not able to negotiate condom use or because of culture they are silenced to take part in deciding issues of sexuality, they are at risk of contracting the HIV because they are at the Mersey of their male counterpart. Men can willingly infect them through unprotected sex. These results also reveal that majority of sero-conversion in families may not necessarily be of the discordant unawareness.

Infected persons are normally in fear because they have to adjust to a new lifestyle. It is not easy to accept that one is infected and thus shock and disbelief, leading to denial, is a frequent initial response. According to Watstein and Chandler (1998:29), there are emotional responses that are symptoms of the psychological effects that people have when infected or affected with HIV and AIDS. Infected persons may be confronted with having to reexamine their sexual identity and the behavioral choices they have made in support of that identity. When one associates HIV and AIDS with what society has traditionally considered immoral, the infected person then has to work through hi/her feelings in order for his/her sexual identity to be reaffirmed in a way that will allow for feeling good about oneself.

Persons with HIV and AIDS may be caused to see themselves as undesirable by other who views them as “contagious”. This in itself is an emotional situation that can cause infected people to withdraw, not disclose their feelings, and become socially isolated. Inevitably this may lead to an emotional breakdown because these feeling continue to be suppressed. The most destructive stressor is that of feeling isolated. This isolation can have many causes, including the loss of support by lovers, family and friends. Additional feelings of isolation may result from the need to change their sexual practices and take more precautions to protect themselves and others.

#### **5.2.1.4 Committing to risk reduction behavior: Condom use**

Almost all (45 out of 46) the respondents understand and believe that condom use is the best way so far to help reduce HIV transmission. Respondents in this study advocated the usefulness of condom, but unfortunately not all were faithful in its use. Seven out of forty-six (15.2%) respondents reported having no problem in using condoms. Two couples (8,7%) reported never ever attempting to use condom despite having been advised during counselling while 35 (76%) struggled with maintaining condom use. Among these people, others were be willing to use it but the other partner was not keen.

The faithfulness in the use of condom depends on gender but age doesn't seem to have any bearing on it. Most of the men are or reported failing to consistently use condom.

GAB 003 who is HIV infected and the boyfriend is not:

*"Sometimes you will try to tell him that we should not do that (have sex without condom), then he will just say 'aahhhh... it doesn't matter' he, men are difficult".*

In other couples the discontinuation of condoms is not discussed, but when it happens no one resists.

RESP 020 –a woman who is HIV infected and the husband not reports:

*"I explained to him right from the beginning that I am HIV infected. He just accepted and said that is a condition for everyone. We agreed that on condom use, but this only took one or so months then we put aside the condom".*

RESP 025 - a woman who is HIV uninfected in a discordant relationship with an infected boyfriend.

*“The baby, I would not refer to the baby as a mistake. It was an agreed thing for us to have sex without condom. I ended up considering that if I am infected then I will enroll in the PMTCT programme”.*

The result shows that a lot of partners still take some uncalculated risks by engaging in unprotected sex despite knowing the possible consequent.

The failure by some of the HIV discordant couples to be committed in condom use may be associated with the perception they have about discordance. In their research Bunnell et al (2005:1005) had indicated that couples' dominant explanations of discordant status has a potential to undermine the motivation of discordant couples to engage in HIV risk reduction behaviors. Their study revealed that if people believe that they are already infected; immune from HIV or has God's protection; then they have little reason to adopt preventative behaviors in the future (Bunnell et al 2005:1005).

Committing to strict condom use is also influenced by other factors, such as knowledge, age, and desire to have children. In a study by Beyza-Kashesya (2010:45), decision-making to use contraceptives may be affected by both internal (personal) and external factors. In her study, 66% of the young people wanted to children despite being HIV infected. 42% of the HIV negative youth do not use condom at all. In this study, the only oldest couple which both man and woman have gone up to primary level at school never used condom although they have been staying together for more than twenty five years still in a discordant situation. Many youth (21 out of 29 that is 72%) aged between 20 and 29 years, in the study struggled with a thought of having to decide on bearing children.

Despite reasons advanced by Beyza-Kashesya (2010), it is necessary to further investigate and determine motivation for engaging in unprotected sex by the partners even after they have been counseled. This will help determine the effectiveness of the clinical counseling they receive and further reinforce where necessary.

### **5.3 NEED FOR COUNSELLING**

Discordant couples in this study found solace in counseling during their quest for finding solution to their psychological, sexual and social needs. Counseling in Botswana Health



care sector is provided by the VTC staff during testing and follow ups. As mentioned earlier, men normally find it difficult to go for HIV testing as compared to their female counterparts. There is also a common belief in men that if the spouse or partner is infected or not infected, the partner also bears the same HIV status as of their partner. For those who go for the test, they testify that the counseling they received helped them a lot. The counseling received is said to have highlighted on the facts about HIV, its transmission and how to prevent it. Couples also are counseled on acceptance of the condition, self-care and adoption of healthy living. They are also encouraged to disclose.

In this study all diagnosis of HIV were made in the government health facilities where there are some structures for counseling. All couples admit having been counseled either by the VCT staff or nurse or doctor. How some couples continue to engage in some risky behavior despite such counseling is a concern to be address in a different perspective.

Counseling is important, particularly couple counseling because it helps to provide same information to the partners and gives them choices of any HIV prevention available, whether they can have children, how to disclose to families about their diagnosis and continue having intimacy, the love that comes with sex so they need to know how to go about it.

#### **5.4 CHALLENGES IN DISCORDANT RELATIONSHIP**

Sero-discordant couples have to deal with many changes and challenges in their life as a result of the discordant status. As mentioned earlier, more than half of the respondents prefer not to disclose to anybody, even the family members because they fear that their status will not be accorded the secrecy they expect. Some of the respondents adopt risk reduction behavior immediately after testing but latter on revert to no condom use, a behavior that puts the negative partner at risk of sero-converting. Some partner are faced with a burden of proving to their partners that they still love them and going to an extend of compromising their own status or health. Other partners have to handle the behavior or the HIV infected in a way to keep the relationship. Some of these and many other challenges are stressing to the discordant couples.

The major challenge discordant couples face is the change in their sexual life. Sexual life is very sensitive to other couples because there is always a risk of infection to the negative partner. This concern has made some couples to reduce the frequency of having sex because though sex drive would be there, the couple or one partner is very uncomfortable due to fear of transmitting or contracting HIV. The findings in this study are related to the findings by VanDevanter, Cleary, Moore, Thacker and O'Brien (1998:42) who discovered that discordant couples ' problems with sexual relationship are related to risk of infecting the HIV negative partner, therefore sex is a constant reminder of the infection and this doesn't make them relax during sexual intercourse. The implication of the discordant status on sexual life therefore affects the emotional and intimate relationships of couples.

Some other partners in this study preferred to be lonely and withdrawn. This behavioral change was observed in some negative partners as well. They avoided talking about their spouse's HIV status thinking that they are being sensitive to their partners' feelings.

## **5.5 DISCORDANCE IN THE SOCIAL-ECOLOGICAL MODEL**

The diagnosis of HIV itself is a concern to any person involved .It can be a stressor to many couples. As a stressor, the diagnosis becomes an entity of the entire environment of an affected or infected partner. How one responds to this stressing environment depends on their intra-personal make up.

According to the Social-Ecological Model (SEM) which forms part of the foundation of this study, the biological and genetic aspects of a person in human development are very vital and need to be taken into account when understanding the person`s perception of development both physical and psychological.

Dahlberg and Krug (2002:32) modified the Social-Ecological Model and contextualised it to a framework for prevention. According to them, the model considers the complex interplay between individual, relationship, community and social factors. It allows us to address the factors that put people at risk for experiencing or perpetrating a phenomenon.

As in the Social-Ecological Model, HIV discordant partners have biological and personal history factors that influence how one experiences the discordance. Such factors are age, education, income or previous encounter with HIV infected person. All partners participating in the study, except one (No 01) have been to formal education. In addition to that, there has been a wide coverage of education in issues of HIV and AIDS and hence majority of Batswana (though no empirical information published) are aware of HIV /AIDS issues. This therefore makes it easier for them to understand the existence of HIV and need to live with it. Majority of participants accepted and acknowledged the situation simply because they know about it and they are not alone in it. Some affirming statements are:

GAB 009

*"Yes, I open up and he also disclosed his HIV status. I just wanted him to let him know that I am aware ..., not for him to go in details until he felt ready to. I mean I have learnt a lot about HIV /AIDS issues. I know everything about them. I always read, I listen to the radios. I have also done a six months on HIV".*

GAB 014

*"Yes, he was awaiting to be enrolled in the ART programmed. He was only laying in what to hear what I will say or what action will I take. When I told me, I explained to him that this condition is the same as any other condition. All that is regarded is for you to take care of yourself".*

The initial experience by the HIV discordant couples are related to psychological factors. The infected experience some frustration and fear of discrimination by the society. On the other hand, the non-infected would also experience fear of being discriminated, disappointed by the situation and to others, by the condition of the infected partner, and angry. These experiences emanate from the interaction with other people in the social environment. The social ecological model described this stage as the second level that examines close relationships. The framework contents that these close relationship of peers, partners and family members influence the behavior of people and may contribute to a large of experiences. It is therefore for this reason that the infected and affected normally consider themselves and not just themselves in isolation from their friends and significant others. As a result they think that what their

significant other would say has a great bearing on how they would behave. This is why disclosure has been too difficult. They believe disclosing to their significant others may put pressure on them to take actions they never plan about.

Although most couples normally come to the realisation of the situation, they often have conflicting ideas. They have conflicting ideas because in their struggle to fight the situation through reasoning and rationalisation, they are aware that ultimately, they have to cool down, swallow their pride and live with the situation. This stage may be equated with the “community” in the social ecological model which explores the settings such as schools, workplaces and neighborhoods in which social relationships occur.

The third stage in dealing with the experiences is the Resolution when an individual accepts the condition and the partner. They decide to take up the HIV test and choose whom to disclose to. This is the point where the couple gives one another support and would even play a reminding role. The couple re-establishes its socially and morally acceptable social and sexual roles. They do these based on mutually agreed coping strategies. In SEM, this stage is synonymous to the fourth or societal factors that help create a climate in which experiences are normalised.

## **5.6 CONCLUSION**

In this chapter some themes which were explored in chapter four have been discussed and impression drawn out of them. The discussion concerned itself with what participants of the study experienced and what other studies have in comparison with this one.

## CHAPTER 6

### PROPOSED GUIDELINES FOR AN INTEGRATED APPROACH OF INCLUDING HIV DISCORDANCE IN THE HEALTH CARE SERVICES

#### 6.1 INTRODUCTION TO GUIDELINES

This chapter aims at providing evidence-informed guidelines for the development of an integrated approach programme within the Botswana health care system which will encompass the HIV discordant couples. Guidelines are a set of proposals that are based on key findings of a research, for this particular ones, the proposals will be based on the findings of the experiences of HIV discordant couples. The study identified certain experiences/challenges that HIV discordant couples face and it is these experiences/challenges that prompted the need for guidelines to address them.

**Table 6.1 Effects of HIV discordance**

Experiences/challenges by the HIV discordant couples	How the experience/challenge affects the couples
1. Fear of discrimination	<ul style="list-style-type: none"> <li>• Fear of being discriminated is closely associated with stigmatisation which still exists among many people. Stigmatised people turn to struggle alone with their problems and fail to seek help. They are bottled up in stress which may ultimately lead them to take inappropriate decisions.</li> </ul>
2. Fear of disclosure	<ul style="list-style-type: none"> <li>• HIV infected partners have a challenge of revealing their HIV status to their partners. They fear that they might be rejected or divorced, sometimes even beaten.</li> <li>• Failure to disclose leads to mistrust when the other partner gets to discover that their partner has been knowingly risking their HIV status, this might lead to conflicts within the relationship.</li> </ul>
3. Need to have children	<ul style="list-style-type: none"> <li>• Discordant couples who do not have children turn to engage in unprotected sex in a quest to have their own biological children. This risks infecting the negative partner. The societal</li> </ul>

Experiences/challenges by the HIV discordant couples	How the experience/challenge affects the couples
	expectation is also such that a married couple must have children.
4. Need for counseling	<ul style="list-style-type: none"> <li>Most of the respondents in the research found counseling very helpful. However, there is very little or no ongoing counseling. Without counseling partners may take decisions some of which are not appropriate or healthy for the relationship.</li> </ul>
5. Having separate services from other clients which exclude them from the normal services of the health facility	<ul style="list-style-type: none"> <li>Being separated from the rest of the clients increases discrimination. Clients are afraid and shy to go to the porta-camps where everyone knows its for the people with HIV.</li> </ul>
6. Other partner (especially men) refusing to go for the HIV test	<ul style="list-style-type: none"> <li>Failing and refusal to take HIV test is by itself a sign of unaccepted situation, fear of stigmatisation and inadequate knowledge. The negative partner who fear to take the test may assume that he is also infected and may not protect himself. The infected one on the other side may not take precaution to protect his partner.</li> </ul>
7. Inadequate knowledge regarding cause of discordance	<ul style="list-style-type: none"> <li>Lack of knowledge may lead to continued myths about the condition which may ill-inform individuals.</li> </ul>

This chapter of the research intends to address these needs from strategic national programme. This programme will be implemented universally, monitored and evaluated to help empower the HIV discordant couples cope with the condition.

## 6.2 INTEGRATED SERVICES: WHAT IT IS?

Seloiwe and Thupayagale-Tshweneagae (2013:60) assert that the word integration stems from the Latin verb meaning complete, where its adjective means organic part of a whole or reunited parts of a whole. According to Seloiwe and Thupayagale-Tshweneagae (2013:60), integration is mostly used to express the bringing together or merging of elements or components that were formerly separated. WHO (2008:24) suggest that service integration means blending either some of the elements of, or all aspects of one service into the regular functioning of another service. WHO (2008:03) redefined the meaning of integration to mean a package of preventative and curative health interventions for a particular population group. Fenton and Morris (2007:66) on the other hand say it's any or combination of; health and social service delivered by a

single organisation, or joint delivery of health and social services by more than one organisation, or services being delivered by multi-disciplinary team in which team members are employed by more than one organisation. From the definitions and description so far, it becomes apparent that integration of services deals with grouping of certain related services to be offered by one service provider. The Botswana Ministry of Health (2009:3) define integration in relation to linking Sexual and Reproductive Health (SRH) and HIV as services or operational programmes that can be joined together to ensure and perhaps maximise collective outcome. These include referrals from one service to another. Integration therefore is central to systems theory and hence central to any organisational design and performance.

WHO (2008:29) contends that many benefits are claimed for integrated health services. The evidence based is limited but there are five main messages from the literature:

- An “always good” versus “always bad” stance on integration is not helpful. On the ground, integration is about practical questions on how to deliver services to those who need them.
- Integration is best seen as a continuum rather than as two extremes of integrated/not integrated. It involves discussions about the organisation of various tasks which need to be performed in order to provide a population with good quality health services. Integrated care looks different at different services levels. In reality, there are many possible permutations.
- Supporting integrated services does not mean that everything has to be integrated into one package. The aim is to provide services which are not disjointed for the user and which the user can easily navigate.
- Managing change in the way services are delivered may require a mix of political, technical and administrative actions. It may require action at several levels, including sustained commitment from the top. Incentives of different form, monetary and non-monetary may be instituted to motivate workers and their managers.
- Integration is not a cure for inadequate resources. It may provide some savings, but integrating new activities into existing system cannot be continued indefinitely without the system as a whole being better resourced.

### **6.3 RATIONALE FOR AN INTEGRATED APPROACH IN MANAGING HIV DISCORDANT COUPLES**

The global call on governments to demonstrate commitment to intensify linkages between sexual and reproductive health and HIV and AIDS at policy and programme level has given the Government of Botswana opportunity review its service provision model and optimise current resources to provide more integrated, comprehensive and coordinated SRH and HIV and AIDS services(WHO, UNDFPA, IPPF & UNAIDS 2005:1).

The Botswana government, in response to this global call adopted the concept of integrated services of health care. One such integration is the SRH and HIV and AIDS linkages of 2012. This integration has been a result of the major conventions and agendas calling governments to speed up actions on addressing the HIV and AIDS epidemic given its critical nature. The integration of SRH and HIV and AIDS in Botswana was primarily based on the Maputo Plan Action which was intended to be a roadmap for member states in achieving the African Union policy framework for promotion of sexual and reproductive health and rights in Africa. The government therefore developed a policy guideline for “Sexual and Reproductive Health Rights (SRHR) and HIV and AIDS linkages Integration Strategy and Implementation Plan” (Botswana Ministry of Health 2012).

Botswana government through the Ministry of Health had earlier on in 2008 undertook a rapid assessment of sexual and reproductive health and HIV and AIDS linkages. The main purpose of the assessment was to:

- Gauge the existence of bi-directional linkages at policy, systems and service delivery levels.
- Identify gaps between the two areas and ultimately develop measures to strengthen and bridge these gaps.

Analysis of the rapid assessment identified the occurrence of linkages at service delivery as opposed to policy level. In addition, there were weak linkages of HIV and AIDS to SRH programmes and services, hence strengthening of bi-directional linkages between HIV and AIDS with SRH were strongly recommended. It is for this reason that



an SRH/HIV linkages strategy together with its implementation plan has been developed.

This strategic document was to guide the implementation, monitoring and evaluation and coordination of SRH/HIV linkages throughout the country. The government of Botswana's SRH policy guidelines and service standards document provides the framework for developing a responsive strategy and an implementation plan for SRH and HIV and AIDS linkages and integration.

The services are guided by the existing SRH and HIV and AIDS linkages, which are:

- Promotion of safer and healthier sex
- Optimisation of the connection between HIV and AIDS and Sexually Transmitted Infections services
- Integration of SRH weakest linkages
- Learn reproductive cancer status and access services
- Promote combination prevention
- Promote abstinence
- Integrate HIV and AIDS with SRH
- Optimise connection between Safe Male Circumcision (SMC)

The importance of integration SRH and HIV and AIDS services was reiterated by the then Mayor of Gaborone Ms. Lesole in 2010 when addressing the 20<sup>th</sup> Botswana Family Welfare Association (BOFWA). The Mayor, who lamented that HIV and AIDS has declared war on mankind yet in some cases it was treated as an isolated problem within the bigger framework of Sexual and Reproductive Health (SRH), (UNDP – Botswana: 2010). The Mayor asserted that SRH and HIV and AIDS are inseparable and integration of the two would position HIV and AIDS prevention, treatment and care within the broader SRH framework. It is believed that integrating the two will increase the cost-efficacy and effectiveness of services, reduce stigma and enable greater service of clients' needs.

For the past three decades since the discovery of HIV in the country, efforts have been concentrated on curbing the spread and managing the HIV infected. The phenomenon

of HIV discordant, though having been in existence from the beginning of the HIV in the country, has not been given enough attention. A move towards integrated services for strategic service plan for managing HIV discordant couples will result in improved health outcomes and strengthened relationships.

The justification for the integration includes the evidence that the majority of HIV infections are sexually transmitted or associated with pregnancy, child birth and breast feeding and the interactions between them are widely recognised. In recognition of the fact that these activities take place between partners or couples, and that HIV discordance is high in the country (17%), there is a strong need therefore to include care of the HIV discordant couples within these existing structures of care. With careful priority setting and judicious programme implementation, the following benefits are expected to be derived:

- Improve access to and update of key HIV and AIDS-discordance and SRH services.
- Better access of people with HIV and AIDS-discordance to SRH services which tailored to their needs.
- Reduced HIV and AIDS-discordance related stigma and discrimination.
- Improved coverage of underserved and marginalised populations, such as injecting drug users, sex workers or men who have sex with men with SRH services.
- Greater support for dual protection against unintended pregnancy and sexually transmitted infection including HIV, for those in need, especially young people.
- Improved quality of care.
- Enhanced programme effectiveness and efficiency.

The change expected in this renewed era of SRHR and HIV and AIDS integration is a comprehensive service provision, that is, provide systematically and proactively to all clients/users in one location by skilled service providers to avoid missed opportunities to avert morbidity and deaths. The integrated service will be delivered by service providers from public health facilities, Non health institutions such as CSOs, NGOs, government ministries and departments, the private sector and the media will play complimentary roles such as creating demand for service in communities and

workplaces, reach the difficult to reach locations and targets, and advocate for policy and legal reform to provide the required enabling environment. This collaborative nature of integration is one of strengths of Botswana's integration strategy. Integrated SRH and HIV and AIDS-discordance services will be provided to the entire population with due attention also to people with disabilities, sex workers, young people including those who were born with the virus. At the preferred models in the health facilities, services will be provided at the same site on the same day. Service providers will be provided with additional skills where there are gaps to deliver the integrated services. A successful integration of SRH and HIV and AIDS-discordance at all levels is expected to contribute to the realisation of the following health outcomes but not limited to:

- Reduction in new HIV infections
- Increase in male involvement
- Reduction in gender based violence
- Reduction in mother-to-child transmissions
- Increase in voluntary couples HIV counseling and testing
- Increase update of SMC
- Reductions in neo-natal and infant deaths

A strong monitoring and evaluation framework to offer strategic guidance ensuring continuous tracking of implementation and goal attainment is essential. The project monitoring and evaluation system will ensouse the principles of integration and seek to harmonise the different programmatic indicators, reduce fragmentation and avoid redundancies. Furthermore, this will form the basis for a systematic documentation of lessons learnt to guide future scale-up efforts.

#### **6.4 SCOPE AND PURPOSE**

The care and management of the HIV discordant couples will entail identification of the partners who are at risk, counselling and testing all those who have infected partners, follow-ups and continuous assessment to identify key critical needy areas. At the center of the integrated programme will be education to empower the couples. Education should encompass both technical and informal training for capacity building. As indicated earlier, Botswana has a pre-existing integrated programme for SRH and HIV

and AIDS. Since HIV discordance is inseparable from HIV and AIDS, the intention of this proposed integrated programme is not to re-invent the integrated approach to services provision, but to strengthen the already ongoing ones through inclusion of HIV discordance. The system will be enhanced through a framework outlining key focal areas for implementation and adoption by all stakeholders.

The guidelines will be designed in accordance with any other guidelines that are evidence based which generally have a role in informing policy maker and programme planners of best practice to improve or change care practice, as well as set standards and to ensure safe and quality care. The guidelines refer specifically to Botswana service delivery and recommends strategies and activities that can be undertaken in the local context. The guidelines should be used as a base for planning and reviewing quality integrated management of HIV discordant couples within the framework of the overall health system.

## **6.5 GUIDING PRINCIPLES**

The integration and implementation of management of HIV discordant care within the already existing services is grounded on the complementary efforts by the Civil Society Organisation to the Governments in the service delivery. These two sectors are the major stakeholders in the implementation of HIV and AIDS programmes. Some guiding principles for the integration of the services are:

- The Alma Ata Declaration of September 1978 which emphasises community participation and partnership building to attain health for all.

The Declaration of Alma-Ata International conference on primary health care suggested:

- Governments have the responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures. A main social target of governments, international organisations and the whole community in the coming decades should be the attainment by all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially

and economically productive life. Primary health care is the key to attaining this target as part of development in the spirit of social justice.

- Primary health care should be sustained by integrated, functional and mutually supportive referral system, leading to the progressive improvement of comprehensive health care for all, and giving priority to those most in need.
- The 50<sup>th</sup> WHO resolution in 1997 as a means of reaching vision of health for all by strengthening partnership or collaboration between governments, WHO and Non-governmental organisation in the health sectors.
- The tripartite partnership meeting that took place in Botswana in September 1998 where a resolution was made to strengthen the government and NGO spartnership in service delivery.
- The policy and service standards objectives of the Ministry of Health to improve the sexual reproductive health of all people in Botswana which among them are to:
  - Improve understanding of SRH by parents, children and youth
  - Control sexually transmitted infection and HIV and AIDS
  - Meet family planning needs
- Family centred and comprehensive approach “that addresses the needs of both adults in a family and attempts to meet their health and social care needs, either directly or indirectly, through strategic partnership and/or linkages and referrals with other service providers” (WHO 2008:16).

Furthermore, the inclusion of management of HIV discordant couples in Botswana is strongly informed by:

- The existence of the National Policy on HIV and AIDS which advocates for a multi-sectoral national response so that the range and projected magnitude of psycho social impact of HIV and AIDS should receive attention from the government ministries and sector of society. The Policy suggests that all sectors and ministries, parastatals organisations, private sectors, and relevant non-governmental and community-based organisations should develop and implement their own HIV.AIDS prevention activities, with initial technical support

from the Ministry of Health (Botswana National Policy on HIV and AIDS, Botswana Ministry of Health 1998:4).

- Sexual activity in Botswana is high and starts early. There is a high level of teenage pregnancy which suggests that there is also high level of unprotected sexual activity in the youths. The youths in this study have been identified as high risks as they still have desire to have children.

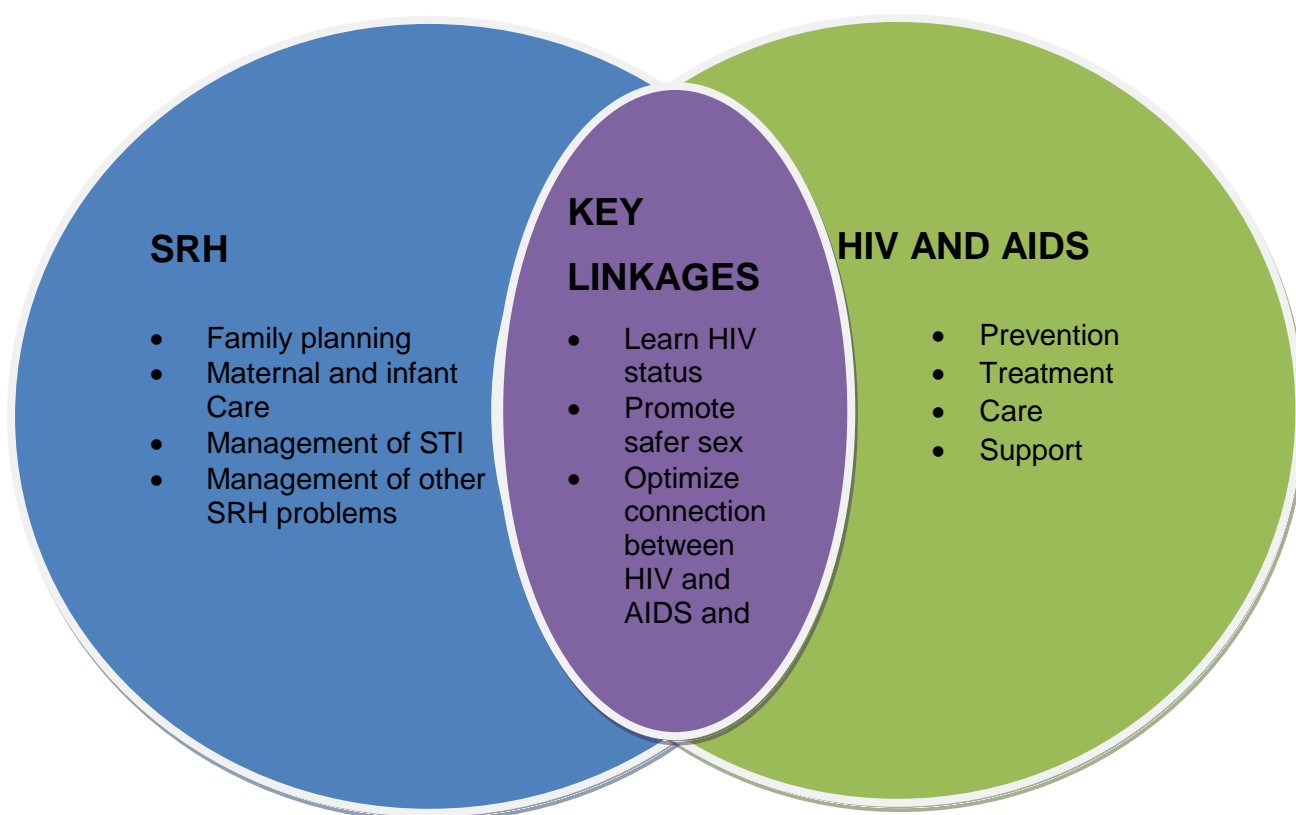
## 6.6 INTEGRATION OF SERVICES

Quinney (2006:38) described integration as “an interdisciplinary, inter-professional, non-hierarchical blending of approaches’ that provide continuum of patient/client-centered care. It employs a collaborative approach, based on mutual understanding and a shared vision. In addition, Seloilwe and Thupayagale-Tshweneagae (2013:56) asserted that it is designed to create coherence and synergy between various parts of the health care enterprise, in order to enhance system efficiency and quality of care, quality of life and consumer satisfaction especially for complex and multi-problem patients or clients’, such as those in HIV discordant relationship. Seloilwe and Thupayagale-Tshweneagae (2013:61) also argued that integration can focus on entire community’s targeted populations (irrespective of health status), vulnerable groups, or patients with specific conditions such as HIV infected or AIDS patients. Integration is broad and varies (Freeth 2007:18). Seloilwe and Thupayagale-Tshweneagae (2013:63) suggested the following types and scope of integration:

- **Functional integration:** the extent to which coordination of key support functions such as management of finances and human resources, strategic planning and information management occurs across all units.
- **Organisational integration:** relationships and networks between health care organisation and institutions.
- **Professional integration:** provider relationships within and between institutions and organisation.
- **Service integration:** coordination of services and integration of care across disciplines and units.
- **Normative integration:** having a shared mission, work values and organisational culture.

- **Systemic integration:** alignment of policies and incentives at organisational level.

The fore discussed scopes of integration help the policy decision to choose and adopt the relevant integration service to be offered. This study proposes the service integration of SRH and HIV and AIDS-discordance which concerns itself with achieving continuity of care over time through incorporation of different services. The integration could mean different things to both the user (client) and the provider (health care provider). To the user, integration may mean health care that is seamless, smooth and easy to navigate. Users want a coordinated service which minimises both the number of stages in an appointment and the number of separate visits required to a health facility. They want health workers to be aware of their health as a whole (not just one clinical aspect) and for health workers from different levels of a system to communicate well. In short clients want continuity of care. For providers, integration may mean that separate technical services, and their management support systems are provided, managed, and evaluated either together, or in close closely coordinated way.



**Figure 6.1** Integration of SRH and HIV and AIDS-discordance



## **6.7 PROPOSED MODELS FOR INTEGRATION**

As mentioned earlier, the government of Botswana through the Ministry of Health already has adopted some integration policies. A number of them, related to HIV are documented and in use. These include, the HIV and AIDS and Sexual and Reproductive Health (SRH) integration policy and Tuberculosis (TB) and HIV and AIDS integration policy. The intention of this study is not to add on to numbers already existing but will be to augment the once in existence with the inclusion of discordance. It is appropriate to consider integrating HIV discordance within the SRH and HIV and AIDS linkage-integration strategy because of the following reasons:

- Both SRH and HIV and AIDS deal with issues of sexuality. The involvement of sexuality in which the couples/partners are involved makes it easier to handle discordance.
- SRH and HIV encompass a larger population which in some cases is not sick and makes it easier to discuss discordance not under duress of ill health.

The Ministry of Health has adopted the following models for integration the SRH and HIV and AIDS integration strategy in which the management of the HIV discordant couples will be incorporated.

### **i. The Mall Model**

In this type of model, different kinds of health services are provided within the same locality. The services may include both the routine and the specialised ones. Service providers are required to provide comprehensive services based on the guideline for linkages and integration. There is interrelatedness of services and collaboration. Within the model, there are referrals and could be team work among the service provides for comprehensive care. The service providers are to be given progressive additional skills. This type of model is idea for use in at primary hospital, district and national referral hospitals.



## **ii. The Supermarket Model**

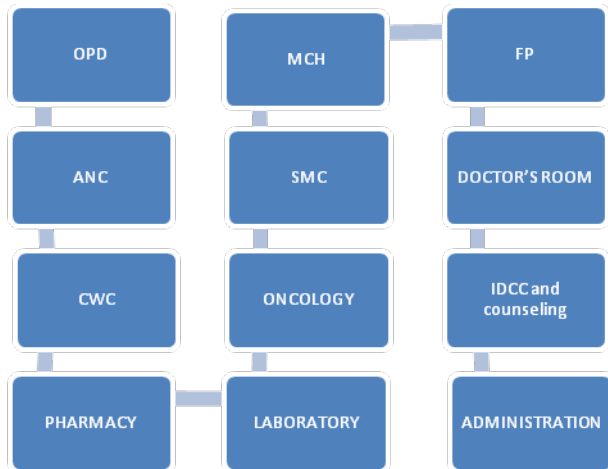
At a lesser scale from the mall model, the supermarket model also operates within the same locality. It does not have departments like in the Mall, but has sections or services may be provided in rooms as compared to department. It may or may not have specialised service providers and has collaborative processes within its functions. It is ideal for clinic set ups in Botswana. Human resource, equipment and supplies need to be assessed and provided accordingly.

## **iii. The Kiosk Model**

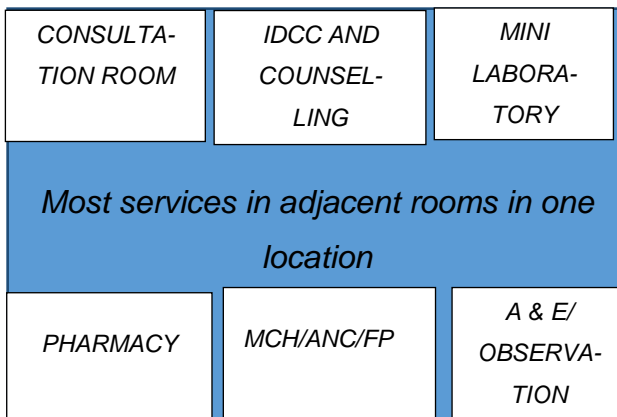
This is a very simplified system that incorporates the integration strategies. It is ideal in the clinics without maternity or health posts. These areas normally have limited space and personnel. Given this limitation, the Kiosk model best fits the arrangement for integration. The service provider(s) is multi-functional at primary level. They offer basic services of all kinds and refer for specialised care.

Figure 6.2 shows the three models with incorporated management of HIV discordant couples.

# FACILITY AND PROPOSED MODELS OF INTEGRATION BY THE MINISTRY OF HEALTH IN BOTSWANA



THE MALL MODEL (IN HOSPITALS)



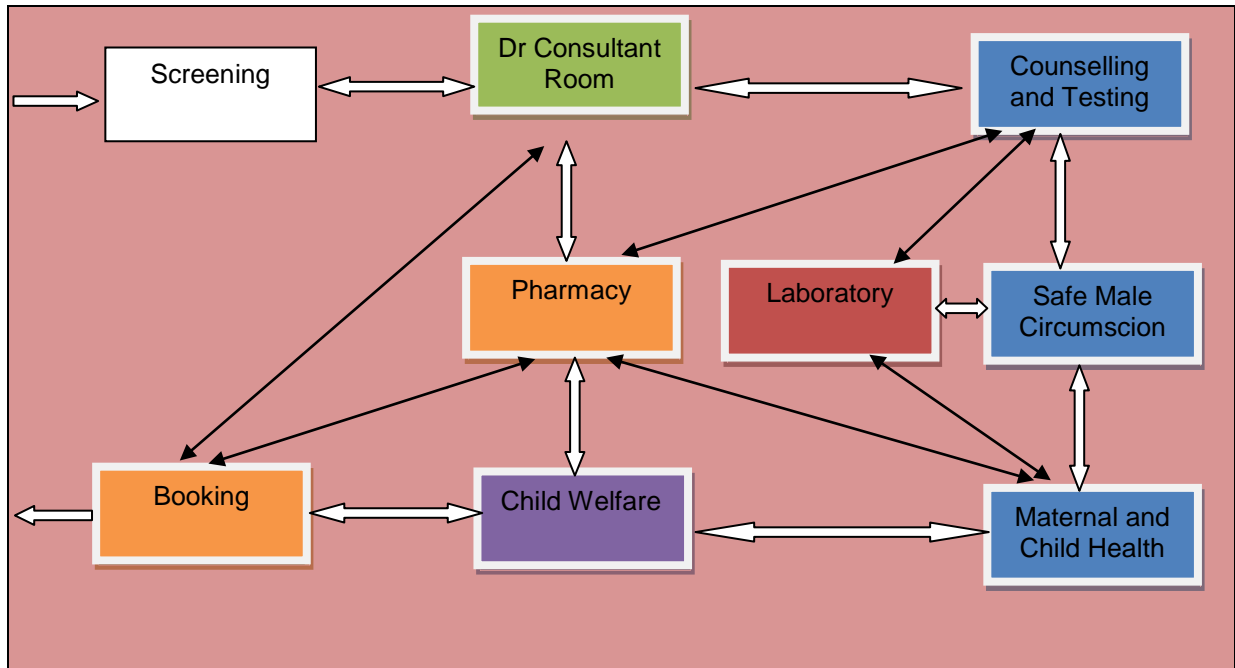
THE SUPERMARKET MODEL:  
PROPOSED FOR CLINICS



THE KIOSK MODEL:  
PROPOSED FOR  
CLINICS/H.POST

**Figure 6.2 Botswana Models of integration**

## 6.8 PROPOSED STUDY MODEL INCORPORATING MANAGEMENT OF HIV AND AIDS DISCORDANCE



**Figure 6.3 The Open Desk Model**

The Open Desk is a modified model to suit the Botswana setup for primary hospitals, clinics and health post. In a situation where there is still a problem of manpower and equipment like Botswana, an Open Desk Model would be ideal. In this integrated approach, different services are offered in the same locality. The model does not have well defined departments but has service rooms manned by professionals. There could be specialised services, but not necessarily specialised personnel.

The screening desk is where everyone comes and is triaged for appropriate service and channeled to meet the appropriate service provider. In the doctor consultation, or discussion room, the couple would come, either because they are accompanying each other or they all come for service. The service provider would have time to discuss all health-related issues with the couple, where appropriate, fertility, HIV and AIDS, HIV testing may be discussed. This is the appropriate room to teach the couple about all issues affecting them as a couple, including HIV discordance. On a busy day, the doctor

would, after assessing the clients refer them to counseling and testing room to be assisted by counselors or social work personnel and be offered voluntary testing. The model is designed to allow referral from one room to another and back to facilitate comprehensive care within the same locality.

## **6.9 BENEFITS OF THE SRH AND HIV AND AIDS-DISCORDANCE**

Stronger linkages between SRH and HIV and AIDS-discordance programmes should lead to a number of important public health benefits. With careful priority setting judicious programme implementation, the following benefits could be expected:

- Improved access to, and uptake of key HIV and AIDS-discordance and SHR services.
- Better access of people living with HIV and AIDS-discordance (PLWHA) to SRH services tailored to their needs.
- Reduced HIV and AIDS-discordance related stigma and discrimination.
- Improved coverage of underserved and marginalised populations, such as injecting drug users, sex workers or men who have sex with men, with SRH services.
- Greater support for dual protection against unintended pregnancy and sexually transmitted infections (STIs), including HIV, for those in need, especially young people.
- Increased knowledge about HIV discordance.
- Increased self-disclosure among HIV discordant couples.
- Improved quality of care.
- Enhanced programme effectiveness and efficiency.

**Table 6.2 Key actions with high potential for public health benefits for integrating management of discordant couples in other health care services**

<b>Key areas</b>	<b>Learn HIV status and access services</b>	<b>Promote safer and healthier sex</b>
Advocacy and policy dialogue	Support legal and policy reform to remove barriers for young people's access to all forms of HIV testing and counselling	Develop policies that support dual protection and advocate for more adequate resource allocation
		Support policy development on comprehensive safer sex services for young women and men , People Living With HIV and AIDS-Discordance (PLWHA)
services	Re-orientate voluntary counselling and testing (VCT) services to better meet the needs of young people, as well as key population	Broaden the SRH services to reach key population, including through outreach
	Provide basic SRH services information and dual protection, counselling and access to condoms in VCT programmes	Promote condom use for dual protection within all family planning and HIV prevention programmes
	Routinely offer HIV testing and counselling in STI services and establish access to comprehensive HIV services	Provide a full range of SRH services, including prevention for and with PLWHA
	Routinely offer couple HIV testing and counselling in family planning and antenatal care services in high HIV prevalence setting	Empower women and girls to negotiate safer sex and to access SRH services
	Provide effective referrals for antiretroviral treatment within VCT programmes in SRH setting	Include the services that address gender-based violence and offer counseling, emergency contraceptive and HIV post exposure prophylaxis to survivors of sexual assault

Other levels of integration for management of HIV discordant couples will be:

- Inclusion in the school curricula; HIV discordance has remained unknown for some time and only caught the attention in recent years. There is need for it to

be taught at both formal schools and even professional training. It is easier for HIV discordance to find place in the training curricula because already HIV and AIDS is incorporated in all the schools syllabuses. Management of HIV discordance could therefore be included within HIV training. Key personnel to be trained are health care providers of all cadres.

- More research on the phenomenon. Research in Botswana is very minimal. Most of the research is done for academic qualification. There is need for the government, NGOs, and even individual to research more on HIV discordance. Researches may cover areas such as, attitudes, perceptions, needs, discordance and culture, discordance and religion among many others.
- The role of media. Media plays an important role in speedily disseminating information. Researchers, and all stakeholders in the fight against HIV/AIDS may take advantage of the media to educate the public about the condition.
- The role of non-governmental organisations. The NGOs have autonomous functions. They should be seen in the forefront of fighting the effects of HIV/AIDS.

#### **6.10 CONSIDERING THE FAMILY/COUPLE AS A UNIT**

- HIV and SRH are often family services. When a person seeking SRH or HIV is identified, it provides an opportunity for other family members particularly the partner to access the services.
- As much as possible health workers should minimise separate clinic visits for different family members – children are often brought to the health center by their parents. Therefore schedule parents for chronic care and HIV testing on the same day as their children's visit.
- It is important to consider scheduling family days on specific days so that families with working parents or children attending school can attend a single visit.
- Alternative opening times for health facilities needs to be considered in order to accommodate working hours of the clients.

Change expected in this renewed era of SRH and HIV and AIDS integration is comprehensive service provision that is provided systematically and proactively to all clients/users in one location by skilled service providers to avoid missed opportunity for

key interventions such as HIV couple testing and counseling, provision of AntiRetroviral Therapy, PMTCT, and adherence support. The integrated services will be delivered by service providers from public health facilities, non-health institutions such as CSOs, NGOs, Government ministries and departments, the private sector and media will play complementary roles such as creating demand for service in communities and workplace.

Miller, Miller, Bowelo, Johnson, Weis, Maribe, Leburu and Maotwe (2008:02) during the rapid assessment of Sexual and Reproductive Health and HIV linkage, made some specific recommendation that will also apply in these guideline as:

- Stronger efforts are required by the department of public health to involve the department of HIV and aids prevention and care in linkage issues. The rapid assessment findings, especially the high demand for HIV services, may serve to stimulate joint discussion between the public health department and donors. This will increase knowledge of the community about HIV discordance.
- Health providers need to be educated about the right of PLHIV to have children, as well as which contraceptives are appropriate for PLHIV who do wish to have children. HIV discordant couples may benefit from this knowledge and be informed on when and how to have a child.
- The ministry of education should review its policies on the distribution in schools of contraceptives for sexually active students. The knowledge about discordance may even be rolled out to secondary school to empower the youth.
- The passage of specific laws to protect PLHIV and HIV discordant from discrimination should be encouraged.
- Communities and clients should be educated about availability of various services at different types of facilities.
- Providers' successful promotion of HIV counseling and testing for males, the promotion of condoms use and with males females, and promotion of family planning services with females should all be recognised. Providers should be encouraged to expand these services to all clients.

## **6.11 APPLYING BEST PRACTICES IN INTEGRATION**

Health centers staff can do a great deal to integrate HIV services. The guidelines are not prescriptive, but give health workers basic principles when reorganising health center for integration services:

- Health workers should be trained to provide multiple HIV services.
  - Deliver multiple intervention or services by a single provider.
  - Health workers should be able to provide key interventions during the same visit for different types of clients.

There would be need for capacity building to the health workers offering these integrated services. It is therefore imperative to do continuous professional development to health worker so that they are informed about current standards.

- Support comprehensive care within the health facility team.
  - Make efficient use of all the health staff to provide all the HIV and HIV related services the patient needs.
  - Focus on providing integrated services to the most common types of clients.
  - Referral of clients with uncommon conditions that require a higher level of care to district hospital, or to another health facility which could best deal with such cases.

## **6.12 GOVERNANCE STRUCTURE AND ROLE DELINEATION**

According to the integrated approach of SRH and HIV and AIDS by the Ministry of Health, the governance arrangement consists of different structures (as shown below) whose responsibilities have been delineated. The same responsibility will apply even with the incorporation of management of HIV discordance. However, the roles below have incorporated the management of HIV discordance.



1. The envisaged role of the Ministry of Health
  - Coordination of the integration at all levels of policy and programme
  - Mobilisation and sustaining resources
  - Advocating of the inclusion of all relevant stakeholders
  - Reporting to donors on the implementation of the integration and sustainability of the entire project
  - Evaluation of the project after the pilot and advising on the direction for the national rollout
  
2. The role of the Reference Committee. This committee may consist of, but not limited to, representative from, Ministry of Health, National AIDS Coordinating Agency (NACA), Clinical services, Institute of Health Sciences, the Public, one of the International Organisations and Attorney General's Chamber.
  - Mobilise the resources to develop and implement an integrated strategy for effective linkages between HIV discordance and SRH
  - Oversee the development and implementation of the SRH/HIV Discordance linkages strategy
  - Ensure coordinated budgeting, planning, implementation, monitoring and evaluation of prioritised SRH and HIV Discordance
  - Contribute to the development and review of policies, guidelines and strategies on SRH and HIV Discordance interventions
  - Coordinate the interagency support to harmonise implementation of SRH/HIV Discordance linkages
  - Oversee the monitoring progress of the implementation of SRH/HIV Discordance like the EU project closely
  - Advocate for human resource development in SRH and HI/AIDS-Discordance to improve linkages at all levels.
  - Represent the country at international SRH/HIV Discordance linkage platforms
  - Approves SRH and HIV and AIDS-Discordance integration and linkage plan and reports
  - Advocate for human resource development in SRH and HIV and AIDS-discordance improve linkages at all levels
  - Support the development of framework plan for monitoring and evaluation and visibility
  
3. Role of the Technical Advisory Committee. The committee may consist of, but not limited to representatives from, hospital services, any of the NGOs dealing

with issues of HIV, clinical services, private practice, health training institutions, pharmacy department, counseling department and public.

- Develop a strategy for SRH and HIV and AIDS-discordance linkages
- Provide technical assistance in planning budgeting and implementation of bi-directional SRH/HIV discordance linkages
- Support the development of the institutional capacity for developing quality SRH and HIV discordance services
- Support the development of an SRH and HIV and AIDS-discordance linkages annual work plan
- Monitor implementation and submit annual reports to the National SRH and HIV and AIDS-discordance linkage Reference Committee for approval
- Document good practices, lessons learned and success stories of SRH/HIV and AIDS-discordance integration and linkages
- Mobilise local and international institutions, private sectors and civil society for technical and financial support
- Advocate for human resource development in SRH and HIV and AIDS-discordance to improve linkages at all levels
- Support the development of framework and plan for monitoring and evaluation and visibility

#### 4. Role of the National Coordinator

- Develop a composite monitoring plan from the implementation plan
- Monitor progress, output and outcome indicators of success
- The implementation of the approved recommendations
- Keep track of the implementation plan and feedback to the Technical Advisory Committee
- Liaise between the Ministry of Health and non-health institutions and ensure their needs are provided
- Keep track of the benefit, needs and expectations of the stakeholders and ensure they are realised
- Write monthly reports on the integration for the Ministry of Health and TAC

#### 5. Roles of the District Focal Person

- Be the focal person in the district for the integration project
- Monitor progress, output and outcome indicators of success
- Liaise with the district facilities and the DHMTs

#### 6. Roles of District Health Management Teams (DHMT)

- Identify appropriate model(s) for each facility for integration

- Agree on its architecture based on the resources available and gaps that can be filled resourcefully (avoiding capital intensive options as much as possible)
- Implement the integration taking into account the findings from rapid assessment done by the ministry in 2010
- Establish indicators of measures
- Monitor and report appropriately

### **6.13 SUSTAINABILITY**

The key factors for sustainability would include:

- Continuous inservice training of service providers
- Periodic reporting to ensure that all service providers are engaged
- Assure funding
- Assured realisation of stakeholders' benefits

### **6.14 CONCLUSION**

This research has identified certain experiences and challenges that HIV discordant couples face. The response to these experiences and challenges prompted the need for guidelines to address them. This chapter therefore provided evidence-informed guidelines for the development of an integrated approach programme within the Botswana health care system which will encompass the HIV sero-discordant couples. The chapter further proposed the integration of HIV sero-discordance services for couples within the already existing structures of integrated services in the Ministry of Health for hospitals, clinics and health post. Some guiding principles for the integration of the services were based on the Alma Ata Declaration of September 1978 which emphasises community participation and partnership building to attain health for all. In the final analysis, the researcher advocates for the OPEN DESK model for integration which may be more suitable for primary hospitals, clinics and health post. This model is recommended for situations where there are human resource and technological constraints like Botswana.

## **CHAPTER 7**

### **CONCLUSION AND RECOMMENDATIONS**

#### **7.1 INTRODUCTION**

This chapter summarises the entire study. It intends to give a brief account of what the study revealed.

The research purpose was to explore the lived experiences of sero-discordant couples in Botswana. This purpose was achieved through the following objectives which were to:

- identify HIV discordant couples living in Botswana and explore their knowledge and understanding of the condition
- explore the psychological, social and sexual experiences of the HIV discordant couples and determine their impact on their lives
- examine the meaning they attach to such experiences and challenges they face as well as their coping strategies

#### **7.2 RESEARCH DESIGN AND METHODOLOGY**

In order to attain the intention of this study, the researcher employed the qualitative phenomenological design. A qualitative design uses a systematic, interactive, subjective approach, which aims at organizing, providing structure to and eliciting meanings from data (Burns & Grove 1997:27; Polit & Beck 2010:463). The research intended to describe human feelings, perspectives, experiences and understanding. The phenomenological approach was preferred because it seeks to discover the experiences of people such as discordance, in the current study. Polit and Beck (2010:267) also content that phenomenology is concerned with extracting essence of the phenomenon as experienced by the informants.

The site for the study was three urban areas in Botswana, namely Gaborone, Francistown and Selibe-Phikwe. These were purposively sampled for their convenience to the researcher, their high rates of HIV prevalence which is assumed to correlate with the HIV discordance. Forty-six participants from the discordant couples were selected. Convenience selection of the actual subjects was done through the guidance of the counselors in the VTC clinics of different facilities. Their experiences were solicited through the use of open-ended questions in oral interviews. All the ethical considerations for such research were observed as cited in chapter 3.

### **7.3 RESULTS OF THE STUDY**

The foremost objective of the study was to identify HIV discordant couples living in Botswana and explore their knowledge and understanding of the condition. According to the results generated from the study, HIV discordance exists in Botswana. Some unpublished information from Tebelo-pele counseling and testing center (2011) revealed that HIV Discordance rate stands at 17%. However, many couples though are HIV discordant do understand what is meant by being HIV discordant, but do not understand how it comes about. Some attribute it to acts or the will of God, while others attribute it to the type of blood group that they have. Others believe that the virus is hiding in the blood and will later show up in the test.

Discordant couples, who have participated in this study, perceive the discordant status mainly through spiritual explanation, even though they still have the curiosity as to how the negative partner remains uninfected while having unprotected sexual contact. There is also a presumption among the negative partners that since their partners are infected, it means that they are as well infected. Therefore it is clear couples understand their discordant status spiritually and some have limited information regarding the possibility of discordant results among couples until it occurs to them. These misconceptions need to be corrected lest the couples will risk infecting the negative partner.

The second objective was to explore the psychological, social and sexual experiences of the HIV discordant couples and determine their impact in lives of the HIV discordant couples. The research determines that there are three types of discordance. First, there are those people who go into the relationship unaware of the HIV results and only come

to learn that they are discordant when they go for the test. These, the researcher called “Discordant unaware”. There are others who go into the relationship already knowing that they are discordant, “discordant aware”. These couples have minimal adverse experience in their lives, because it is through their own willingness to go in such a relationship. There is also another type of discordant named “discordantly discordant”. They are called so because they go into the relationship with different motives. They differ with their HIV status and with their reason to go into the relationship. The HIV infected partner would know that he/she is infected but conceals the HIV results or status. Couples normally allow the relation to go on at the expense of the ignorance of the HIV uninfected. These couples normally have challenges when the other partner gets to realise that their beloved ones are risking infecting them. In this type of discordant, the HIV infected usually is not keen to use protective against HIV.

The first stage following the HIV test is characterised by the HIV discordant couples going through the psychological, sexual and social experiences. The HIV positive go through psychological experiences including stress resulting from thoughts of how it happened, being overly cautious not to infect the negative partner and worry about plans for tomorrow. Shame results from what explanation they will give to the uninfected partner. Couples also have fear of condition. Before the advent of Anti-Retroviral Therapy many people lost their lives and as a result many feared that they might die. There is also fear of being discriminated against by other people resulting from the HIV test. The HIV negative on the other hand experience disappointment because of loss of hope for the future as their partners test HIV positive. There will be anger resulting from disappointment from the infected partner. The uninfected also experiences fear of the condition and fear of being discriminated.

The second stage is characterised by conflicting ideas. Both the positive and negative partners struggle with finding a workable solution to coping with the problem. Some may think of separating with the partner, but wonder as to whom will they find as the next lover, some struggle with keeping the partner who may want to get out of the relationship. The HIV uninfected may want to go for the HIV test but hesitates because of fear that they are also infected and do not want to hear such bad news. Others understand the importance of disclosure but do not trust who they should disclose to.

Disclosure to family members, friends and neighbours is one dilemma discordant couples face. Discordant couples from this study prefer both to disclose and conceal their status. For those who have disclosed their status they received support and care from their families and friends. This will lead to the conclusion that disclosing the discordant status helps in offering support and care. Therefore, in order to avoid struggling alone and being overwhelmed by stress alone, couples need to consider identifying their confidants and disclosing to them. Stigma and discrimination have proven to be a stumbling block to free social self-expression.

It was indicated by the couples that following the resolution stage in discordant relationship, partners establish good communication between themselves. They realize closeness within themselves. These point out that those positive partners have worries and stresses which they need to discuss and have relief. Disclosing, therefore, is important to be emphasised among discordant couples. It helps partners to open up and ventilate, ultimately they will receive advice to deal with their internal feelings so as to avoid stress and strained marital relationships.

Sexual and reproductive issues are some of the challenges for the discordant couples. Some couples indicated that their sexual life has changed. They reported reduced sexual output and frequency. On the other side, other discordant partners reported change only in the first few months (first stage) following the test and knowledge of discordant. After the resolution stage, they experience no change in their sexual life. This leads to the conclusion that HIV discordance may lead to disruption of the intimate relationships of the couples. The desire to have children has also stood out to be a major challenge even among those who have reached the resolution stage.

HIV discordant couples end up identifying coping strategies to help them against all the challenges of being discordant. Some of the strategies adopted include counsel by the health care workers, condom use, spiritual connection, and hope in antiretroviral therapy.

The last, the resolution stage, is whereby the couple comes to terms with the reality of the situation. They accept that the situation exists and there is nothing they could do since the test results are irreversible. The HIV negative accepts the positive one and

even the positive acknowledges the condition to live with. They identify and disclose to those they feel are their confidants and agree to take the HIV test.

## **7.4 RECOMMENDATIONS**

The researcher intends to make the following recommendation for health care service to policy makers, research, training institutes and clinicians. The recommendations are based on the couples' experiences, needs and challenges. They are intended to enhance capacity building to the discordant couples.

### **7.4.1 Recommendation to policy makers**

The HIV discordance should be included in the national HIV and AIDS policy. The discordance in the couples seems to pose a serious threat in the fight against HIV and AIDS. Prevention of couple infection within discordant relationship should be included in the national strategic policies as well as National Development plan.

### **7.4.2 Recommendations for training**

Every government ministry and parastatal company in Botswana has an HIV and AIDS coordinator at decision making level. All these coordinators should be trained on the needs of discordant couples and taught how to counsel them and assist them in living positively in discordance.

The school curricula on HIV and AIDS should include sero-discordance to allow for understanding at all levels. Understanding of such issues would assist in the destigmatising of the HIV and AIDS in general.

### **7.4.3 Recommendations for future research**

Future research to demystify this unknown or misunderstood notion needs to take place in a larger scale and probably using quantitative survey as most researches have been qualitative. The Government, through different ministries and non-government organizations should sponsor researchers to explore discordance in more depth to



understand the phenomenon. Researches may include their needs, their perception in relation to culture, and perceptions within generations.

#### **7.4.4 Recommendation for formation of supportive groups**

The government, private society and international organisations should be encouraged to form support groups for the HIV discordant couples similar to the 'Botswana Network for People Living with AIDS' which will help empower the discordant couples and enhance peer counseling. Clinicians must encourage peer support of HIV discordant couples and where possible continue educating them through workshops and seminars. All these strategies would also assist in the fight against stigma and discrimination of discordant couples and would encourage disclosure to partners and families as support systems.

### **7.5 LIMITATIONS AND STRENGTHS**

The strengths and limitations of the study will be discussed separately.

#### **7.5.1 Limitations**

It should be noted that the research findings of this project are based on a purposive sample. The sample was primarily drawn from Tebelo-pele centre's in towns. The implication is that discordant couples in the wider community including those from rural areas and those that are no longer of child bearing age could have been excluded.

During the interviews, the couples shared many stories with the researcher. However, the volume of data meant that the researcher could tell only some of the stories in this thesis. As a result, this constitutes only partial truths. Although the active voices of the participants were used to construct the report, the quotes were also those chosen by the researcher to illustrate specific themes.

### **7.5.2 Strengths**

The study took place in a setting that the participants were familiar with. All the participants spoke Setswana (the local language of Botswana) all these created a friendly atmosphere for developing relationships with the researcher.

## **7.6 THE STUDY'S UNIQUE CONTRIBUTION TO THE BODY OF KNOWLEDGE**

The study's unique contribution to current literature is that the participants presented very powerful messages regarding being involved in a discordant relationship. It is from this messages that the researcher could deduce from them the three types of couples living in discordant relationships as discordantly aware, discordantly unaware and discordantly discordant. The study further mapped out how each category experiences discordant.

Another unique finding of this study is that the researcher was able to suggest a model that could be used in district hospitals to allow for expressions of thoughts and feelings to couples without the stigma of porta-camps (separate rooms attached to hospitals) for those with HIV and AIDS.

Lastly, the other unique contribution of the study is the development of the counseling guidelines that are inclusive of discordant couples.

## **7.7 CONCLUSION**

There are numerous studies on HIV sero-discordance especially in East Africa. Very few studies on discordance have been done in Southern Africa and this is the first study done on discordance in Botswana. This particular study focused on the lived experiences of HIV sero-discordant couples in Botswana and applied the socio-ecological model. This was timely as couples belong to a family and a society and they each influence one another.



**UNIVERSITY OF SOUTH AFRICA  
Health Studies Research & Ethics Committee  
(HSREC)  
Faculty of Human Sciences  
CLEARANCE CERTIFICATE**

Date of meeting: 31 July 2011

Project No: 41-233-4/6

Project Title: Lived experiences of HIV Sero-Discordant couples in Botswana

Researcher: William Mooketsi Baratedi

Supervisor/Promoter: Prof Gloria Thupayagale-Tshweneagae

Joint Supervisor/Joint Promoter: N/A

Department: Health Studies

Degree: DLITT ET PHIL (Health Studies)

**DECISION OF COMMITTEE**

Approved

Conditionally Approved

**Prof TR Mavundla  
RESEARCH COORDINATOR**

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

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

Ministry of Health



Republic of Botswana

## Application for Approval of Human Research

### Section A: Instructions

1. For research/academic institutions or PHD students attach:
  - a) 14 copies of the Research Application form
  - b) 4 copies of the following:
    - i. Study proposal.
    - ii. Consent/authorization form or a request for waiver of consent/authorization- Setswana, English and back translation where applicable.
    - iii. Questionnaires to be used. Setswana, English and back translation where applicable.
    - iv. Curriculum vitae/ resume of each member of the Research team
    - v. Approval letter from other IRBs
    - vi. Grant approval letter
    - vii. Any other supporting materials i.e. recruitment scripts, brochures, flyers etc
2. For undergraduates and graduates attach one copy of the above listed items/ documents.

### Section B: Application Details

<b>1. Study Title: (Include Version number and date)</b>  <b>THE LIVED EXPERIENCES OF HIV SERO-DISCORDANT COUPLES IN BOTSWANA</b>
<b>2. Date of submission:</b>
<b>3. Type of Research:</b> <ol style="list-style-type: none"><li>i. Basic Science ( )</li><li>ii. Public Health (✓)</li><li>iii. Clinical Research ( )</li><li>iv. Human Biology ( )</li><li>v. Other _____</li></ol>

<b>4. Principal Investigator( Name &amp; Qualifications):</b>  <b>WILLIAM MOOKETSI BARATEDI.</b> <b>(MASTERS OF NURSING SCIENCES)</b>	<b>4(i). Local Contact Details</b> <i>Name:</i>
<b>Postal Address: P. O. BOX 502682 GABORONE</b>	<b>Postal Address:</b>
<b>Phone Number: +267 71729347</b>	<b>Phone Number:</b>
<b>E mail Address: wm_baratedi@yahoo.com</b>	<b>E mail Address:</b>
<b>Name of affiliate Institution/Organization: University of South Africa (UNISA)</b>	<b>Name of Institution/Organization:</b>
<b>Department (If Government):</b>	<b>Department (If Government):</b>

<b>5. Other Investigators /Co-Principal Investigators</b>			
<b>Name:</b>	<b>Organization:</b>	<b>Email:</b>	<b>Telephone Number:</b>
N/A			

<b>6. Key Personnel working with data that may be linked to human subjects:</b>			
<b>Name:</b>	<b>Organization:</b>	<b>Email:</b>	<b>Telephone Number:</b>
N/A			

**Section C: Description of Research**

**1. Brief Description of Study**

The study is part of the requirement to complete Doctor of Literature and Philosophy in Health studies by the University of South Africa. I have chosen the topic because having been working with couples who lived in discordant relationship, I discovered that it is a real challenge. During my interaction with some of the clients I learned that others go through a rough live. Some have separated or divorced, others have kept bonds only for the sake of marriage ties and children. Others seem to be well sustained while others are characterized by seemingly normal relationship with procreation function continuing despite difference in HIV test.

The study therefore intends to explore why there are such varying experiences. Why and how other couples cope while it looks like its difficult for others. For those who cope, I want to find out the source of their inspiration and why others who have travelled the same route would not cope.

The study will be a descriptive qualitative one where experiences of the couples will be analyzed and divided under themes and subthemes to describe the experiences of the couples.

**2. Rationale/Justification** (*Why the need to carry out this study in Botswana*):

This is a requirement for the completion of the Doctorate studies. However, the Researcher found the need for this research as the numbers of the HIV discordant couples are high in the country. According to unpublished statistics from Tebelopele (a national voluntary testing and counseling centre) the occurrence of discordance gets reduced year after year with 20.2%, 17.4%, 14.4% and 8.9% in 2004, 2005, 2006, and 2009 respectively. Despite this scenario, the introduction of AntiRetroviral Treatment may change the situation because when people are on ARV therapy there comes a time after continuous use of the drugs when their virus become undetectable. During this time they are less likely to transmit the virus and hence the uninfected partners may remain uninfected for sometime. Despite this seemingly safe situation, the psychosocial and sexual problems may persist and threaten to weaken or even destroy the relationships. It is important to acknowledge that the family acts as the smallest part, or is a ‘cell’ of the whole society and therefore if a cell suffers then the whole body also suffers.

**3. Study Objectives** (*Both General and Specific*):

The objectives of the study are;

- a. Explore the social and sexual experiences of discordant couples
- b. Describe the meaning they attach to such experiences
- c. Develop a guideline for counsellors and voluntary counselling personnel for counselling discordant couples

**4. Expected Results** (*Both Primary and Secondary endpoints*):

There are three types of the results that are expected. The first type of expected results will be characterized by frustration, discrimination, abuses, threats and rejection or threatened rejection. The HIV victim may also be filled with remorse, emptiness, and isolation.

The second type of expected results could be characterized by support and care, loving partner, a family that copes well with the situation guarding against sero-conversion on the part of the negative one.

Finally, those couples that do not cope will explain why they fail to. Whether it is their type of relationship or differing personal individual characters or it's the Counselors. On the other hand those who cope will explain why they manage to and how.

## **Section D. Methodology**

### **1. Study Design**

This is a descriptive qualitative study method that will be used to explore the lived experiences of HIV discordant couples in Botswana. The study will be guided by phenomenology theory which aims at understanding a phenomenon from the perspective of the study informants who have lived the experience.

### **2. Study sites** (*Districts, Towns, Villages, Health facilities, Schools etc :*

The study will be done in the three cities in Botswana that is Gaborone, Francistown and Selibe Phikwe at the Tebelopele centres which are national voluntary and counselling centres. These cities are being considered because of their high prevalence of HIV Infection and consequently HIV discordant couples according to Botswana AIDS /HIV Impact Survey III (2009: 6).

### **3. Subject Population(s)** (*Clinical condition, Gender, age, and other relevant Characteristics*):

The target population for the study will be sexually active heterosexual individuals who are adults, that is, above the age of 21 years. The research will exclude homosexuals falling in this age category because homosexuality is not yet legally accepted in Botswana and hence their inclusion may bring in extraneous variables.

### **4. Sample size**(*The number of subjects to be involved in the study and how these subjects will be selected from the population*):

The researcher aims to interview 30 discordant couples who will be identified using convenience method. Ten candidates will be selected in each city. Completing the project will depend on the validity of the data from participants and recruitment will cease when no new themes are identified, suggesting data saturation (Gerrish &lacey, 2006:27). Purposive sampling method will be used.

### **5. Subject Recruitment/Sampling Methods** (*Explain all procedures in detail*):

The researcher will train counsellors at Tebelopele centres on how to recruit participants. The counsellors will be asked to identify discordant couples and invite them for the study. The interviews will be done by the researcher. The counsellors at Tebelopele centres work with discordant couples and they know them. The researcher having been involved in a study for HIV disclosure regard this as a more result-oriented recruitment procedure for a study with sensitive issues.



## **6. Data Collection Methods** (*Explain all procedures in detail*)

Interviews will be conducted using semi-structured interview guide. The data from the question will be supplemented by observing participants throughout the interview and noting non-verbal clues. Interviews will be conducted with individuals who have experienced life in HIV discordance. The interview will target both the HIV infected and the uninfected so as to gain insight on both. This will be done in the Tebelelopele centers where participants usually go for counseling and are familiar with the environment. They will be encouraged to talk freely about their experiences and perspectives on HIV discordance. Time allowed will not be predetermined but will go on till the individual feels he/she has said it all. Permission will be sought from participants to audio-tape the conversations. The phenomenological interviews will be in Setswana, the national language of Botswana and would be taped and transcribed.

For each participant, the conversation behavior, facial expressions and participants' reaction to direct and personal questions will be observed. The interviews and content of these observations will be transcribed to create a description for analysis.

## **7. Data Analysis** (*Briefly explain how data will be analyzed*)

Data will be analysed using the method of Giorgi (1985). Giorgi's method of data analysis purports to unearth the meaning of the phenomenon as experienced by participants through the detection of essential themes (Koivisto, Janhoen & Vaissanen, (2002:258). The participants' perceptions will be grouped into a specific description of situated structure and a general description of a situated structure.

## **8. Piloting/Pretesting** (*Explain all procedures in details*)

After granting of permission by the Health Research and Development Committee, the local Tebelelopele testing center (Gaborone) will be approached for the purpose of piloting. Apart from determining the feasibility of the proposal, the intention will also be to refine the collection tool, data collection and analysis plans, as well as the examining the reliability and validity of the research instrument. The permission from the Health Research and Development Committee will be used to request permission and assistance from the local Tebelelopele center to do the piloting. The researcher will sample about three to five couples using the convenience method to check the above mentioned items. Analysis of pilot study will be done through the help of some local experts in Nursing research.

## **9. Protection of Subjects** (*Describe measures to protect subjects from and minimize possible risk of harm, discomfort, or inconvenience*):

The ethical issues most commonly mentioned in qualitative research include informed consent, beneficence, privacy, the researcher's respect to human informants, risk benefit ratio, respect to human dignity and principles of justice (Polit & Hungler, 1999:134).

**Informed consent:** Written informed consent will be given to participants, with clear explanation of the aims of the study. Adequate information about the study will be communicated to participants so that they can make informed decisions. It will be stressed to participants that participating in the study is voluntary and that participants can withdraw from the study at any time with no adverse consequences.

**Beneficence:** Beneficence means to do good. The participants may experience discomfort, anger and despair during the interviews. The researcher will be very

observant to any change and will immediately stop the interview and refer the participants who may experience discomfort to the therapist in Tebelopelo Centres for debriefing.

**Confidentiality:** Confidentiality will be maintained by not using participants' names but codes, the tapes used will be stored in a secure cabinet by the researcher and the transcripts would not bear the participants names.

**Privacy:** The interviews will be held in a private room in the Tebelopele counselling centres. The researcher and the couple interviewed will be the only ones in the interviewing room to ensure that what is being said is known only to the researcher and the couples. The participants will also be assured that information collected during the course of the study will be kept in the strictest confidence. This would be done through anonymity and participants coding.

**Justice:** All participants will be treated equally throughout the study and even after completion of the study. Those who decline during the process will not be given a prejudicial treatment and their decision will not be communicated to the Tebelopelo staff members. All agreements made between the researcher and the participants will be honoured.

**10. Approximate Date Study Recruitment will begin: \_\_ 10<sup>th</sup> October 2011**

**11. Estimated Duration of entire study: \_\_\_\_\_ Two and half Months for data collection ten months from the time data was collected (i.e, 10/10/11)**

## Section E: Subject Information

<p><b>1. Inclusion Criteria</b></p> <p>The research will only include couples who fall in the age group of :-</p> <ul style="list-style-type: none"><li>- 21 years and above</li><li>- Sexually active</li><li>- Mentally sound</li><li>- Have been diagnosed as HIV discordant and been to a VTC or clinic</li><li>- Agreed to participate in the study and have signed the consent form</li></ul>
<p><b>2. Exclusion Criteria:</b></p> <p>The study will exclude all those;-</p> <ul style="list-style-type: none"><li>- Below the age of 21 years because most of them at this age have not established steady relationships.</li><li>- Those who are not mentally sound. Their information may not be reliable.</li><li>- Homosexuals. Homosexual is not legally accepted in Botswana and hence may bring in some extraneous variables.</li><li>- All those who do not have established couples.</li></ul>
<p><b>3. Does the study involve Vulnerable Groups? (Tick all that Apply)?</b></p> <p>Elderly (no )</p> <p>Children ( no)</p> <p>Pregnant women, fetuses, or neonates of uncertain viability or nonviable ( no)</p> <p>Prisoners ( no)</p> <p>Decisionally impaired Persons ( no)</p> <p>Minority and indigenous groups ( may be)</p> <p>Low Literacy ( may be)</p> <p>Economically Disadvantaged ( may be)</p> <p>Other _____ ( )</p> <p>N/A ( )</p>
<p><b>4. Does this study involve any use of a drug? No (NO ) If yes, is the drug registered or given exemption status (IND studies) by the Drug Regulatory Unit in Botswana? If yes attach proof)_____</b></p>
<p><b>5. Reasonably foreseeable risk or discomforts to the subjects (list in detail):</b></p> <p>1. The subjects may be reminded of the worst bitter experiences which may evoke emotionally uncomfortable feelings. (eg, being beaten and insulted by the partner for being HIV positive).</p> <p>2. The subjects may feel uncomfortable due to stigmatization of the HIV</p>
<p><b>6. Who will cover Subject Injury-Related Costs?</b></p> <p>i. Sponsor ( )</p> <p>ii. Third-Party Payers ( )</p> <p>iii. Subjects ( )</p> <p>iv. N/A (✓)</p>

<b>v. Other</b>
<p><b>7. Potential benefits to society and to subjects (do not include compensation):</b></p> <p>The results of the study will also help in policy formulation and strategic management of the clients in HIV discordance relationships. This will be a benefit to the subjects and consequently the society.</p>
<p><b>8. Give details of Botswana based personnel that will be involved (Name, functions and qualifications):</b></p> <p>None, except the Researcher.</p>
<p><b>9. Any remuneration given to subjects? Yes ( ) No ( <input checked="" type="checkbox"/> ). If yes, specify:</b></p> <p>None</p>
<p><b>10. Will the participant incur any financial cost in this study? Yes ( ) No ( <input checked="" type="checkbox"/> ). If yes, specify:</b></p> <p>No</p>

### **Section F: Data Sources**

#### **1. Sources of Data**

- i. Focus Group(s)** ( )
- ii. Interviews** (  )
- iii. Questionnaires/Surveys** ( )
- iv. Census/Public Records** ( )
- v. Human Biological Specimen** ( )
  - Archive ( ) Prospectively Collected ( ) Discharged ( ) Stored Samples ( )
- vi. Medical Records** ( )
- vii. Registers (e.g. TB register and Cancer register)** ( )
- viii. Other** \_\_\_\_\_

**Section G. Study Details**

<p><b>1. Capacity Building</b> (<i>how will the study build capacity in the country</i>)</p> <p>The study will help Doctors, Nurses, Counselors and anybody involved in the care and management of HIV discordant couples, even those who test HIV positive and not necessarily being in a couple relationship to cope with the situation. Experiences of those managed to sustain the relationships could be used in counseling the new testees.</p>
<p><b>2. Dissemination</b> (<i>How will the study findings be disseminated</i>)</p> <p>After the defene and completion of the study the Researcher launch the findings in the presence of all stakeholder so that they can receive information. There will also be a publication of the results with copies given to NACA, Institutes of Health Sciences and University of Botswana.</p>
<p><b>3. Other Ethical Body(ies) Involved in the review of the study</b></p> <p>No</p>

**Section H: Sponsor Information**

**1. Name of Sponsor:** self

**2. Type of Sponsor:**

- i. Government
- ii. Private Foundation
- iii. Industry
- iv. Internal
- v. Other

**3. Sponsor Contact Person:** P. O. Box 502682 Gaborone

**4. Sponsor Contact Telephone:** Cellphone No 717229347

**Section I: Contact Information:**

PI or other researchers for answers to questions about the study or research-related injuries( <i>You must offer at least two contacts</i> ):	The HRDC representative who can answer questions about their rights as research subjects
<p>i).</p> <p>ii).</p>	<p><b>Name</b> _____</p> <p><b>Head of Health Research Unit</b>  <b>Ministry of Health</b>  <b>Private Bag 0038</b>  <b>Botswana</b>  <b>Tel: (+267) 3914467</b>  <b>Fax: (+267) 3914697</b></p>

**Section J: Investigator's Statement**

**INVESTIGATOR'S STATEMENT OF ASSURANCE**

**I promise to abide with existing relevant International Declarations and National procedures and guidelines when undertaking research involving human subjects within the Republic of Botswana and agree to:**

- 1. Ensure that all studies conducted on human participants are designed and conducted according to sound scientific and ethical standards within the framework of good clinical practice.**
- 2. Report to the Health Research and Development Committee any information requested, serious or unexpected adverse events and any information related to national programs.**
- 3. Unless if an emergency treatment for patient care, obtain prior approval from the HRDC before amending or altering the scope of the project or implementing changes in the approved consent form(s).**
- 4. Submit progress reports as required by the HRDC.**
- 5. Maintain all documentation including consent forms and progress reports.**
- 6. Ensure that all members of the research team are aware of their roles and responsibilities in this study.**
- 7. Ensuring, in accordance with the duties outlined for each member, that all members of the team are fully utilized for tasks assigned to them.**

**Principal Investigator's Name: Mr. William Mooketsi Baratedi**

**Principal investigator's Signature:**

**Date:**

**Principal Investigator's Position: Student**

**Local Investigator's Name:**

**Local investigator's Signature:**

**Date:**

**Local Investigator's Position:**

**After Completion**

- 1. An electronic and hard copy of the report should be submitted to the Health Research Unit, Ministry of Health as well as other relevant Botswana Government Institutions/Organizations within 3 months of producing a bound report.**
- 2. All continuing renewals should be submitted at least 6 weeks before the expiration.**

**Section K. For Health Research Unit use ONLY.**

<b>1. Date Received</b>	<b>6. Review Body</b> <input type="checkbox"/> Health Research Unit <input type="checkbox"/> HRDC
<b>2. Final Outcome</b>	
<b>3. Ref No:</b>	
<b>4. Expiration Date:</b>	
<b>7. Continuing renewals extension</b>  <b>Date 1</b> _____  <b>Date 2</b> _____  <b>Date 3</b> _____	
<b>8. Final Report Submission</b>  <input type="checkbox"/> Yes <b>Date</b> _____ <input type="checkbox"/> No	

Telephone: (267) 363200  
FAX (267) 353100  
TELEGRAMS: RABONGAKA  
TELEX: 2818 CARE BD



MINISTRY OF HEALTH  
PRIVATE BAG 0038  
GABORONE

REPUBLIC OF BOTSWANA

REF NO: PPME-13/18/1 Vol VII (158)

20 October 2011

Health Research and Development Division

Notification of IRB Review: New application

Mr William Mooketsi Baratedi  
P.O.Box 502682  
Gaborone

Protocol Title: **THE LIVED EXPERIENCES OF HIV SERO-DISCORDANT COUPLES IN BOTSWANA**

**SPONSOR:** N/A

**HRU Review Date:** 19 October 2011  
**HRU Expiration Date:** 18 October 2012  
**HRU Review Type:** Full Board HRDC  
**HRU Review Determination** Approved  
**Risk Determination:** Minimal risk

**Dear Mr Baratedi**

Thank you for submitting a new application for the above referenced study. This approval includes the following:

1. Application Form
2. Proposal
3. Supporting Documents

This permit does not however give you authority to collect data from the selected sites without prior approval from the management. Consent from the identified individuals should be obtained at all times.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.



Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health within 3 months of completion of the study. Copies should also be submitted to all other relevant authorities.

If you have any questions please do not hesitate to contact Mr. P. Khulumani at [pkhulumani@gov.bw](mailto:pkhulumani@gov.bw), Tel +267-3914467 or Lemphi Moremi at [lamoremi@gov.bw](mailto:lamoremi@gov.bw) or Tel: +267-3632464

#### **Continuing Review**

In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Form for Approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health Research Division Office (HRDD), Office No. 9A 10 or Ministry of Health website: [www.moh.gov.bw](http://www.moh.gov.bw) or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: [kgmotlhanka@gov.bw](mailto:kgmotlhanka@gov.bw) As a courtesy, the HRDD will send you a reminder email about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Report form.

#### **Amendments**

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No. 9A 11 or Ministry of Health website: [www.moh.gov.bw](http://www.moh.gov.bw) or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: [kgmotlhanka@gov.bw](mailto:kgmotlhanka@gov.bw) . In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".


#### **Reporting**

Other events which must be reported promptly in writing to the HRDC include:

- Suspension or termination of the protocol by you or the grantor
- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects.

Do not hesitate to contact us if you have any questions. Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours sincerely

  
P. Khulumani  
**For Permanent Secretary**



P. O. Box 502682

Gaborone

06<sup>th</sup> June 2012

The Deputy Permanent Secretary

Clinical Services

Private Bag 0038

Gaborone

Dear Sir/Madam

**REQUEST TO CONDUCT A STUDY**

I am a Nursing student reading for Doctor of Literature and Philosophy with the University of South Africa (UNISA). As a requirement for the fulfilment of my degree, I have to embark on a dissertation which is related to the field of my study. I have therefore decided to study "Live Experiences of HIV Discordant couples in Botswana".

The aim of this study is to explore and discover the experiences of couples who are HIV discordant in Botswana. This will help Beneficiaries understand the needs and challenges that HIV discordant couples go through and ultimately help in the care and management.

The study will be done in Gaborone, SelebiPhikwe and Francistown. Purposeful sampling method will be used to identify participants because of the sensitivity of the condition. They will be identified through the help of facilities managers or care Givers/counsellors. The rights and confidentiality of every client will be observed at their strictest level.

This letter therefore serves to request your kind office to allow this project to go on.

Attached are letters from the University and Health Research and Development Committee in the Ministry of Health approving the conduct of the research.

Thanking you in anticipation.

Yours faithfully



.....

William Mooketsi Baratedi (Mr.)

O mang 207111309

Please note the change in para that says

‘Before embarking on the actual research, the researcher further **obtained** permission from the clinical service department in the Ministry of Health to use the clinics in sampled site. **(Appendix E)**’.

*The word **obtained** has replaced **asked***

**SAVINGRAM**

**FROM:** Deputy Permanent Secretary  
Clinical Services

  
M. Galeemelwe /For DPS

**TEL:** 3832565

**FAX:** 3121327

**TO:** DHMT Heads:  
Gaborone  
Francistown — PP  P. 2011  
Selebi-Phikwe

**Reference:** DCS 13/18 II

6<sup>th</sup> June 2012

**PERMISSION FOR CONDUCTING A STUDY**

The Department of Clinical Services has given permission to Mr William Mooketsi Baratedi to conduct a study in some of your health facilities during the month of June and July 2012. He is expected to start in Francistown on 11<sup>th</sup> June 2012. Mr Baratedi is studying a PHD programme in the University of South Africa.

Mr Baratedi's study is focused on a very fascinating, but sensitive topic of "the lived experiences of HIV sero-discordant couples in Botswana". This department has approved of his request to conduct the study in your facilities because he has the approval of the Health Research Committee from the Ministry of Health.

Thank you.

Mr Victor Letshabete to attend. 71720415

Clinics to be visited are:

Masego — Sedimo

Kapologing — Jorosi

Arenw — Mosekane/kepitwile

Gereld — Motshobeng

... the Community registers



**SAVINGRAM**

**FROM:** Deputy Permanent Secretary  
Clinical Services

  
M. Galelemelewe / For DPS

**TEL:** 3632565  
**FAX:** 3121327

**TO:** DHMT Heads:  
Gaborone  
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**6<sup>th</sup> June 2012**

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Thank you.

*Approved & to see MR Mooketsi (Baratedi) of RHT  
in action*

The clinic will be visited are:

1. Tapologo Clinic
2. Botsabetsi Clinic
3. Kagiso Clinic

*In name  
26-06-12*





**SAVINGRAM**

**FROM:** Deputy Permanent Secretary  
Clinical Services

  
M. Galeemotwe /For DPS

**TEL:** 3632566  
**FAX:** 3121327

**TO:** DHMT Heads:  
Gaborone  
Francistown  
Selebi-Phikwe

**Reference:** DCS 13/13 II

6<sup>th</sup> June 2012

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Mr Baratedi's study is focused on a very fascinating, but sensitive topic of "the lived experiences of HIV sero-discordant couples in Botswana". This department has approved of his request to conduct the study in your facilities because he has the approval of the Health Research Committee from the Ministry of Health.

Thank you.

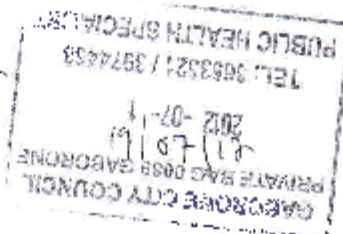
*Permission granted*

*type for DHMT*

*to be conducted*

*The clinics visited are as follows*

1. Bonteng ✓
  2. Old Naledi ✓
  3. Kagiso "2" Clinic ✓
6. BTA  
7. Ext 2 Clinic ✓



## Consent Form

I .....hereby agree to participate in an interview carried out by Mr. William Mooketsi Baratedi for the purpose of the research.

I agree that my participation in this research project is voluntary but not binding and that I may withdraw from the project at any time if I wish to do so without any penalty and this will not jeopardize my future treatment by my doctors, nurses, counsellors, or any care provider/advisor who will not be informed of my decision.

I have been informed of the purpose of the study and have understood it. I have been informed that participation in the study is voluntary and every attempt will be made to keep my details confidential.

I agree that my interview will be recorded in the audio tape and this will later be transcribed into paper, after which the audio tape will be destroyed. I have been informed that my responses will only be used for this research project.

I have been informed and assured that whether I choose to participate or not in this research, care providers will not be informed of my decision.

Signed. .... on. .... day of .....(Month) .....Year.



# Tumalano

Ke le ..... Ke dumalana le go tsa karolo mo potsolosong e e dirwang ke rre, William Mooketsi Baratedi yo o dirang di-patlisiso.

Ke dumalana gore go tsa karolo ga me mo dipatlisisong tse ke ka itlhophelo, ga go patike, mme ebile ke ka boela maikutlo a me morago fa ke sa kgone, le gore seo ga se kake sa mpakela kotlhao kana sekgoreletsi mo isagong mo thusong kana kalafi e ke e bonang mo Ngakeng, Baoking, Bagakolodi, kana mang fela yoo lebaneng le go nthusa.

Ke boleletswe ka maikaelelo a patlisiso e, ebile ke a tlhologantse. Ke boleletswe gore go tsa karolo mo ke ga Itlhophelo mme ebile maiteko otlhe a tlaa dirwa go sireletsa le go boloka se ke se buang e le sephiri.

Ke dumalanye gore potsoloso e, e tlaa gatsiwa ka sekapa mantswa, mme e tlaare morago puisanyo e e fetolelwe mo mokwalong, ere morago, sekapa mantswa se sutlhwe, kana puisanyo e senngwe. Ke boleletswe gore puisanyo e, e tlaa dirisiwa fela mo patlisisong e, eseng gope gape.

Ke solofeditse gore le fa ke tsa karolo kana ke sa e tsee mo patlisisong e, botlhe ba ba ntseng ba mpha thuso kana le ba ba tlaa e mphang mo isagong, ga bana go bolelelwa ka tshwetso epe yame.

Monwana. .... ka. .... letsatsi .....(kgwedi) .....ngwaga.

## **Experiences of HIV discordant Couples in Botswana**

### **Questionnaire to the Infected partner.**

#### Introduction.

1. The following are questions which will guide us to understand your experiences of discordant HIV situation.
2. You are requested to answer appropriately and in details according to your own understanding and experience
3. Please say out your experiences in your own language. In case the interviewer wants clarification in some context, you are requested to freely supply information in an acceptable language.
4. As an Interviewee, you are free to or not to participate in this research, you are therefore not to pressurise yourself if you don't feel comfortable to, and this will not prejudice your care in any way nor will you be penalized for not taking part.
5. This information will only be used for the purpose of this research only
6. For the sake of time this interview will be recoded into an audio tape and the audio will later be transcribed to script/paper. The audio information will not be kept but destroyed after transcription.
7. You are assured of absolute confidentiality, that non of your information can be divulged to any person unless you allow so. Nevertheless the results of the research will be published and these will be the results of the whole research and no identity of any person will be revealed.
8. Thank you

DEMOGRAPHIC PROFILE FOR THE INFECTED.

Site. ....

1. Age
  - a. 21 – 24 years
  - b. 25 – 29 year
  - c. 30 – 34 years
  - d. 35 – 39 years
  - e. 40 – 44 years
  - f. 45 – 49 years
  - g. 50 years and above
  
2. Sex
  - a. Male
  - b. Female
  
3. Educational level
  - a. Never been to school
  - b. Primary school
  - c. Secondary school
  - d. Post secondary school
  - e. University

4. Marital status

- a. Single
- b. Married
- c. Divorced
- d. Widowed

5. State of the relationship

- a. Courtship
- b. Married
- c. Cohabiting
- d. Visiting partner

6. Employment

- a. Unemployed
- b. Self employed
- c. Casual /temporary employment
- d. Full time employment

7. Nationality.

- a. Motswana
- b. African
- c. Non African

## **B. Social and sexual history**

8. How long have you been with your present partner?
9. Before meeting the present partner, did you have any and how long did the relationship last? Why did the relation end?
10. Before having any sexual relationship/intimacy with your partner, did you know each other's HIV status?
11. Do you use any birth control or STI prevention method? Which one do you use?
12. Is anyone, between you and your partner taking any drugs? If yes, what for?
13. Are you or your partner circumcised?
14. Have you ever disclosed your situation to anybody? If yes , to who and why?
15. Are you or did you receive any counseling? If yes, from whom?

## **c. Experiences of the HIV infected partner**

16. Where did you go for HIV testing?
17. Did you receive any pre and or posttest counseling? How did you feel about it?
18. Could you please explain in your own words how you felt when you were told of the results? Why did you feel that way?
19. How long did it take you to tell your partner? And why?
20. How did your partner take your words of being infected? Explain your impression of his/her overt and covert reactions.
21. Why do you think she/he reacted so?
22. After your partner has tested negative, how did you feel, and why?
23. Why did you think results differ?
24. Do you think you need any help in this situation?
25. Have there been any changes in your relationship (socially, emotionally or sexually) ever since you were told your partner's results differ from yours? Explain the changes.

26. What kind of good words or encouragement have you received from your family members, and close friends?
27. What are the challenges that you have encountered regarding the HIV discordant situation?
28. What do you think have been your major achievement in your situation?
29. How do you think HIV discordant couples could be supported?

## Experiences of HIV discordant Couples in Botswana

### Questionnaire – Uninfected

Introduction.

1. The following are questions which will guide us to understand your experiences of discordant HIV situation.
2. You are requested to answer appropriately and in details according to your own understanding and experience
3. Please say out your experiences in your own language. In case the interviewer wants clarification in some context, you are requested to freely supply information in an acceptable language.
4. As an Interviewee, you are free to or not to participate in this research, you are therefore not to pressurise yourself if you don't feel comfortable to, and this will not prejudice your care in any way nor will you be penalized for not taking part.
5. This information will only be used for the purpose of this research only
6. This interview will be recoded into an audio tape for the sake of time and the audio will later be transcribed to paper. The audio information will not be kept but destroyed after transcription.
7. You are assured of absolute confidentiality, that non of your information can be divulged to any person unless you allow so. However the results of the research will be published and these will be the results of the whole research and no identity of any person will be revealed.
8. Thank you

## DEMOGRAPHIC PROFILE FOR THE INFECTED.

Site. ....

### 9. Age

- a. 21 – 24 years
- b. 25 – 29 year
- c. 30 – 34 years
- d. 35 – 39 years
- e. 40 – 44 years
- f. 45 – 49 years
- g. 50 years and above

### 10. Sex

- a. Male
- b. Female

### 11. Educational level

- a. Never been to school
- b. Primary school
- c. Secondary school
- d. Post secondary school
- e. University



12. Marital status
  - a. Single
  - b. Married
  - c. Divorced
  - d. Widowed
  
13. State of the relationship
  - a. Courtship
  - b. Married
  - c. Cohabiting
  - d. Visiting partner
  
14. Employment
  - a. Unemployed
  - b. Self employed
  - c. Casual /temporary employment
  - d. Full time employment
  
15. Nationality.
  - a. Motswana
  - b. African
  - c. Non African

## **B. Social and sexual history**

16. How long have you been with your present partner?
17. Before meeting the present partner, did you have any and how long did the relationship last? Why did the relation end?
18. Before having any sexual relationship with you partner, did you know each other's HIV status?
19. Do you use any birth control or STI prevention method? Which one do you use?
20. Is anyone, between you and your partner taking any drugs? If yes, what for?
21. Are you or your partner circumcised?
22. Have you ever disclosed your situation to anybody? If yes , to who and why?
23. Are you or did you receive any counseling? If yes, from whom?

## **C. Experiences of the HIV none infected partner**

16. How did you learn that your partner has contracted HIV?
17. Could you explain your reaction to such news.
18. Why do you think you reacted the way you did?
19. Did you go for the test?
20. Did you go alone to the test or with your partner? Why?
21. What was your expectation of your own test?
22. Did you require any counseling before and after the test? Why?
23. What have been your greatest concerns or worries?
24. What has been your hardest thing about coping with the situation?
25. What has been your source of hope?
26. What do you consider to be the most trying moment of the HIV discordant situation?

27. What advice or suggestion would you give to a couple that experiences HIV discordance?

28. Tell me what you and your partner's life has been before knowing that you are discordant and what changes (if any) have emerged.

29. What are your future plan regarding child bearing?

30. Do any of your family members or close friends know about you situation?

31. What has been their reaction?

**OBSERVATIONAL TOOL**

Client Code .....

- 1. Sex. Male/Female
- 2. Comfortable with the environment. ....
- 3. What kind of character is he/she? .....

Reserved . ....

Open and talkative. ....

- 4. Non verbal clues

Frowning .....

Smiling .....

Stresses points .....

Exclaims at other questions .....

Hesitant to answer other questions .....

Body expression;

Nodding. ....

Shaking head. ....

Uses shoulders to acknowledge .....

- 5. Level of concentration .....

- 6. Health of the participant .....

- 7. Emotional Expressions

Expresses anger. ....

Expresses compassion. ....

Laughs incongruent to the situation.....

Expresses sorrow. ....

Expresses regret. ....