

**AN EXPLORATORY STUDY OF THE PSYCHOSOCIAL
IMPLICATIONS OF HIV SERODISCORDANCE IN
MARRIED HETEROSEXUAL COUPLES**

BY

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ABSTRACT

There is limited knowledge on the psychosocial implications of HIV/AIDS in serodiscordant heterosexual couples in sub-Saharan Africa. Several studies have indicated that there is an increase in the number of such couples on the African continent, yet there are minimal or no services offered to support such couples.

The aim of the study was to explore the psychosocial challenges faced by heterosexual serodiscordant couples who were married. Ecosystems and biopsychosocial approaches were used as a framework to guide the study. A qualitative study was conducted in Durban, South Africa. Purposive sampling was used, comprising of four married couples and two individuals who were married but participated individually and not as a couple. Semi-structured interviews were undertaken. Both inductive and deductive approaches were carried out to analyse interview transcripts.

None of the participants had received satisfactory explanations of their serodiscordant results. The discovery of serodiscordance resulted in difficulties with disclosure to families and children, maintaining safer sex, achieving intimacy due to lack of communication and bearing children due to fears associated with infection. Serodiscordance resulted in positive partners constantly fearing that their negative partners would leave them.

Participants in discordant relationships had difficulties dealing with the changes that discordance brought into their lives. This resulted in enormous stress in their relationships including feelings of isolation, confusion and despair. Acceptance of serodiscordant status and support from family members were positive coping mechanisms used by discordant couples to alleviate stress. Avoidance was a negative coping mechanism used by some couples in dealing with the challenges of discordance.

Factors contributing to the negative participants remaining in the relationship included love and companionship, children, commitment to the relationship and acknowledgement of the existence of HIV. The findings also indicated that none of the participants received on-going counseling and there were no programs catering for serodiscordant couples.

This study supports the view of other researchers who believe that there is a dire need for service provision for serodiscordant couples. Based on the findings of this study, micro, mezzo and macro intervention strategies are recommended.

DECLARATION

The work described in this dissertation was carried out in the School of Social Work and Community Development, University of KwaZulu-Natal, under the supervision of Prof Carmel Matthias.

This study represents original work by the author and has not otherwise been submitted in any form for any degree or diploma to any tertiary institution. Where use has been made of the work of others, it is duly acknowledged in the text.

Uschi Babalwa Dano
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This study is dedicated to:

My late grandfather Lunika Nondumo and my grandmother Welekazi
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and

all serodiscordant couples, may love flourish in your lives and give
you strength to pull through.

LIST OF ACRONYMS

AIDS: Acquired immuno deficiency syndrome

ARVs: Antiretrovirals

DSI: Donor sperm insemination

IgA: Immunoglobulin A

IUI: Intrauterine insemination

IVF: In vitro fertilization

PWA: People living with HIV/AIDS

PEP: Post exposure prophylaxis

HIV: Human immuno virus

SI: Self insemination

CHAPTER ONE

INTRODUCTION AND THEORETICAL FRAMEWORK

CHAPTER ONE

CONTEXTUAL AND THEORETICAL FRAMEWORK OF THE STUDY

1.1 Introduction and motivation for the study

More than 60% of people infected with human immuno virus (HIV) / acquired immuno deficiency syndrome (AIDS) are on the African continent, with South Africa being the epicentre of the global AIDS epidemic. Dorrington et al (2006:2) estimated that 5.4 million South Africans were living with HIV/AIDS.

Dorrington et al (2006:27) contend that people who are infected with HIV/AIDS in South Africa are mainly between the ages of 20–64 years and this is also the age group that comprises a significant portion of the country's labour force. In their study it was estimated that 2.8 million women of child bearing age (15-49 yrs) were living with HIV/AIDS. Across all adult age groups there were more women than men living with HIV/AIDS in the country. An exception was noted when comparing the provinces of Free State, KwaZulu-Natal and the North West where the prevalence of women infected was lower than that of males. In Dorrington et al's (2006:28) study, the prevalence rates in provinces were also reviewed with KwaZulu-Natal being the highest, with 28.7% of people living with HIV/AIDS, and the Western Cape being the lowest, with 5.4% infected people.

The above statistics show the high prevalence of HIV in the country and particularly in the province of KwaZulu-Natal. HIV/AIDS has ravaged the societal strata leaving children without parents, high mortality rates, increased numbers of tuberculosis cases and absenteeism in the workplace. The stigma and discrimination around HIV has caused numerous psychosocial challenges for people who are infected and affected by HIV/AIDS. Some of the psychosocial issues include disclosure of HIV/AIDS, HIV testing, emotional stressors related to HIV and difficulties in practicing safe sex.

There is an exceptionally high prevalence of HIV/AIDS amongst sexually active heterosexual individuals in South Africa. Many infections have occurred

in individuals who are in stable relationships or who are married. Maxwell & Boyle (1995) found that many long term relationships are not monogamous and that safe sex is not practised. There is therefore a risk of HIV in stable relationships and in married couples. This is due to the fact that many individuals who are married and in stable relationships are under the impression that they are safe from HIV and do not use condoms. They believe that their relationships are based on trust and for some of them it is difficult to introduce the use of condoms after long periods of unsafe sex, as this may be interpreted as questioning the trust in the relationship (Painter, 2001 and Maman et al, 2001).

According to Bunnell et al (2005), high proportions of HIV infections in sub-Saharan Africa occur among married HIV discordant couples, yet few interventions target these couples. The prevalence of HIV discordance among married and cohabiting couples in Africa is high, ranging from 3-20% in the general population to 20–35% among couples in which one partner seeks HIV care services (Bunnell et al., 2005; Hugonnet et al., 2002 & Painter, 2001).

Hendricks (www.cpa.ca/phase/families,friends&partners.pdf) described a serodiscordant couple as “a couple where one partner tested HIV positive and the other tested HIV negative”. He stated that this definition assumes that both partners have been tested and have disclosed their serostatus to each other. Mattison & McWhirter (as cited in Hendricks) (www.cpa.ca/phase/families,friends&partners.pdf) described the following types of serodiscordant couples: -

- “The first refers to those partners who were together before the HIV test was available. When they were tested, for various reasons, only one partner tested positive,
- The second type is where one partner seroconverted during the relationship and the other did not,
- The third type is where both partners knowingly entered the serodiscordant relationship”.

The increasing number of serodiscordant couples poses a challenge in that both partners (either negative or positive) need an explanation and information with regards to their difference in status. Painter (2001:1398) states that “couple relationships have not been given adequate attention in social/behavioral research in sub-Saharan Africa”. He maintains that an understanding of how couples manage HIV risks as well as HIV prevention is unknown. Interventions to support couples in HIV prevention efforts have remained underdeveloped.

Painter (2001) and Palmer & Bor (2001) maintained that there has been very little research done to investigate the psychosocial dynamics experienced in these types of relationships. These authors also argued that there are no policies in place to deal with the needs of these couples. They view this as a political and social constraint in these types of relationships, as they are not socially accepted and not seen as true partners.

I also found in my social work practice that there was an increasing number of serodiscordant married couples seeking assistance. In trying to assist these couples I found that little information existed and there were no programs catering for serodiscordant couples. I also became interested in understanding how discordant couples coped with the challenges arising from their relationships. This research stems from the curiosity generated by my experience in working with serodiscordant couples. This study was undertaken in Durban in the province of KwaZulu-Natal. The research was conducted in the Durban area since it was geographically accessible and I had developed relationships with practitioners who were working in the HIV field.

1.2 Problem statement

With the reported increase in HIV infection among the general public, the numbers of serodiscordant couples are most likely increasing in our society. However, limited or no support is given to these couples because most interventions are directed to HIV positive couples. The HIV/AIDS counselling

guidelines that are in place in South Africa do not incorporate discordant couples. Knowledge, policies, programmes and interventions do not address the issue of discordant couples, especially those who are married. This also poses a challenge to therapists or service providers who undertake couple therapy or HIV/AIDS work. I therefore felt that there was an urgent need to explore the challenges faced by married discordant couples in order to intervene in an appropriate manner.

This area has not been researched sufficiently and there is limited literature on the psychosocial implications of HIV on heterosexual serodiscordant couples in South Africa. Although some work has been done, especially in Western countries, the concentration has been on homosexual serodiscordant couples. This study focused on heterosexual couples because of the high HIV prevalence rate among heterosexuals in South Africa. It also focused on married couples because of the limited number of research studies on HIV/AIDS and married couples.

1.3 Research aim

The aim of the study was to understand the biopsychosocial challenges faced by serodiscordant heterosexual couples who were married.

1.4 Research objectives

- To explore how couples have dealt with challenges arising from their serodiscordant status.
- To ascertain the need for services for couples who are serodiscordant.
- To provide recommendations on what should be incorporated in HIV/AIDS counseling guidelines, policies and programs.
- To contribute to the body of knowledge on heterosexual serodiscordant couples.

1.5 Research questions

- How do couples deal with issues of disclosure, intimacy, finances and adherence to medication?
- What are the psychosocial implications of being in a heterosexual serodiscordant relationship?
- What are the factors contributing to the partners remaining in the relationship?
- What services are utilised and needed by the respondents in the study?

1.6 Value of the study

This study will add to the body of knowledge on serodiscordant relationships. This aims to add to the limited research and information currently available on serodiscordance, especially within the African context. The findings will also help healthcare workers such as psychologists, social workers, counsellors, nurses, psychiatrists and doctors to better understand psychosocial challenges faced by serodiscordant couples and how serodiscordance impacts on different levels of the ecosystem. Furthermore, findings would also be useful in the development and designing of new intervention programmes and a training manual on how to counsel serodiscordant couples. This study will also identify gaps in service delivery, thereby guiding provincial, national and continental policy makers on services that need to be rendered to provide a holistic intervention in dealing with HIV/AIDS issues. The findings would hopefully encourage and advance research in the area, thereby generating an informed understanding of psychosocial challenges faced by serodiscordant couples and their families.

1.7 Theoretical framework guiding the study

The biopsychosocial approach and ecosystems approach was used in understanding the psychosocial challenges faced by serodiscordant couples in this study. These approaches emphasise viewing every aspect of life in a

holistic manner and that every problem is interconnected biologically, psychologically, socially and culturally. They also emphasise that interventions should be encompassed by a biopsychosocial understanding at different levels of ecosystems.

1.7.1 The biopsychosocial approach

The biopsychosocial approach views an individual's health as holistic, that is, psychologically, physically, culturally and socially as connected (Berger et al, 1991). Health and illness are a natural part of life. They both exist within the course of an individual's lifetime. Gilbert (2002) stated that the biopsychosocial approach addresses the complexity of interactions between different domains of functioning and argues that it is the interaction of domains that illuminates important processes.

HIV/AIDS has been seen as a health or biomedical issue undermining the fact that it impacts not only on the biology of an individual but affects all other spheres. These include psychological functioning and the social environment where individuals interact with others. In understanding serodiscordant couples the approach will assist in providing an understanding of how the biopsychosocial implications of serodiscordance affect couples.

For a holistic understanding of serodiscordant couples, it is vital that various biopsychosociocultural issues that impact on the couple's relationship be understood and integrated. At a biological or physiological level the couples firstly become involved in a diagnostic test of HIV which on its own is associated with feelings of enormous anxiety and fear of the outcome of the results. In many cases individuals test for HIV while they are sick or have symptoms that lead them to suspect that they might be infected. After the diagnosis there's lifestyle modification that includes paying close attention to diet, exercise and use of condoms that couples need to adhere to. Prevention of opportunistic infections and issues related to drug therapy such as adherence to treatment and resistance becomes necessary.

Social implications of the HIV disease such as stigma, isolation and discrimination become part and parcel of everyday life of the serodiscordant couple. Such stigma and isolation could lead to serodiscordant couples finding it difficult to disclose their difference in serostatus to their families, friends and children. Zeakes (2003) states that social support from family is needed as social isolation and hopelessness are major factors in depression and contributors in the progression of a terminal illness.

There are also cultural factors that impede in serodiscordant couple relationships. Bernstein & Van Rooyen (1994) describe culture as the system of information that codes the manner in which people in an organized group or society or nation interact with aspects of the social and physical environment in which they live. Rogers (2000) also described culture as an important influence on HIV/AIDS behaviour and as the total way of life of a people, composed of their learned and shared behaviour patterns, values, norms and material objects.

In understanding the challenges facing serodiscordant couples it is important that we understand the cultural environment that modify couple's behaviour and thinking. Rogers (2000) contended that cultural appropriateness in health promotion refers not only to the individual but also to the context that nurtures the individual and his or her family and community.

The biopsychosocial approach allows for serodiscordant couples to be understood from a holistic perspective that is encompassed by examining the biological, psychological, social and cultural factors that impede on the couples' relationship. This will allow for a comprehensive assessment and intervention/s that are tailor made for a broad spectrum of needs of serodiscordant couples.

"What is gained from a biopsychosocial approach is a holistic approach to treatment. People are more than mere biology and to treat a disease from that perspective is to ignore other aspects of an individual. The Biopsychosocial approach allows for biological treatment, psychological

healing and understanding and permits others to participate and support an individual". (Zeakes, 2003:2)

1.7.2 Ecosystems theory

Ecosystem theory "views the person as developing within a complex system of relationships affected by multiple levels of the surrounding environment" (Berk, 2001:25). This approach moves away from linearity and focuses on the wholeness, interdependence and complementarity of living organisms. A system can be defined as a whole made up of mutually interdependent parts where a change in one part has an impact on the other parts (Potgieter, 1998). Systems merely represent a way of thinking and a way of understanding observations and the data that are elicited from observations. Individuals, families, small groups, organizations, communities, societies and cultures can be viewed as systems. Each of these entities affects the others.

A systems approach provides a model that focuses on multiple levels of phenomena simultaneously, for example, families, the workplace, and community life. A systems view helps social work practitioners to understand behaviour in context and suggests a means by which units of varying size and levels of complexity can mutually influence each other. To analyse problems, persons, and situations, to plan remedial interventions, and to implement appropriate techniques requires an adequate grasp of practical theory and knowledge about human behaviour in the social environment (Hepworth, et al., 2002).

Ecosystems approach places emphasis on the person in the environment, claiming that a human being is a biopsychosocial being whose behaviour is influenced by the environment he/she lives in. If the environment is not conducive enough it becomes difficult for human beings to function. Ecosystems approach will help in understanding the changes that occur in serodiscordant couples' subsystems and how these changes affect the larger

systems. This will also help social workers or health care practitioners to identify interventions needed at different levels of the systems.

The following systems referred to are micro systems level, mezzo systems level and macro systems level.

1.7.2.1 Micro systems level

According to Fiedeleley (in Naidoo 2004), the micro systems level refers to “the smallest ecosystem within which the person interacts or performs most of his/her work, as well as the elements of the larger environment, such as the family, in the person’s life”.

In this study the microsystem refers to the married couples themselves and their children. Changes commence from the moment one partner receives his/her HIV positive diagnosis. This on its own brings about change in the relationship of the couple. These changes may include condom use, diet, financial implications, reproductive decision making and disclosure to family and children, and therefore affects the whole family system.

A family is seen as a social system composed of people who interact with each other in patterned ways. A system perspective views the members of a family not as isolated units but as interacting units. The ways in which they interact are determined by cultural expectations, socially structured situations and the biological characteristics of the family members themselves. Theorists also use a systems perspective to consider families from the point of view of the roles of their members. If roles are unclear or disrupted, family functioning breaks down (Berger et al., 1991:73). This then requires social workers, when assessing the families of discordant couples, to examine the different roles that each member of the family plays, for example a child can play a role of care-giver to a sick parent.

1.7.2.2 Mezzo systems level

This is also known as the level of environment, and includes the communities within which people function (Bernstein & Galloway, 1992). The family is located geographically and socially within a neighbourhood and community. These entities can also be viewed as systems that interact with the individual and the family system.

At this system level the serodiscordant couples could be functioning within an environment that is not responding to the needs of the couple, and which is characterised by stigma towards people who are infected with the disease. Normalising HIV is still a battle in our communities and becoming sexually involved with a partner who is HIV positive is taboo and also seen by some as abnormal.

1.7.2.3 Macro system level

The macrosystem includes national values, legislation, policies, prevailing ideologies and funding patterns. It also refers to the broader environment, consisting of systems with which the family members do not have direct interaction, but nonetheless influence the family greatly (Naidoo, 2004; Kasiram 1995).

At the moment in South Africa, existing HIV/AIDS counselling guidelines, campaigns and policies exclude serodiscordant couples. These couples are treated as if they do not exist. Understanding the needs of the serodiscordant couples at this level would allow for appropriate interventions in policy making and program formulation.

1.8 Operational definition of terms

Adherence: “Adherence means taking the recommended dose, at the recommended time and in the recommended way” (Brouard, 2005:71).

Cohabiting: to live together as a man and wife, especially when not married.

Marriage: state of being legally joined as husband and wife in civil or customary law.

Disclosure: refers to sharing of HIV status and serodiscordance.

Pneumocystis carinii pneumonia (PCP): The most common infection in people with AIDS.

Safer sex: any sexual activity in which there is no exposure to another person's body fluids.

Seroconversion: occurs when people exposed to an infectious agent such as HIV develop antibodies to that agent.

Serodiscordant couples: refers to those couples where one partner tests HIV positive and the other tests HIV negative.

Stable relationship: individuals who have been in a constant relationship for longer than six months.

Resistance: it is the consequence of genetic changes (mutations) that emerge when there is ongoing HIV replication in the face of inadequate concentrations of antiretrovirals agents (Miller, 2002:32).

1.9 Presentation of contents

The remaining chapters of the research are outlined as follows:-

Chapter Two provides a literature review on explanation of serodiscordance and psychosocial challenges faced by serodiscordant couples.

Chapter Three describes the research methodology adopted in the study. The research procedure, sampling techniques, the sample and data collection methods are elucidated. Ethical considerations and the limitations of the study are discussed.

Chapter Four analyzes and discusses the data collected in relation to the following major categories:- the psychosocial challenges faced by serodiscordant couples in their lives; couple differences in HIV serostatus and emotional reactions; practitioners explanation/s on the differences in serostatus; impact of serodiscordance on marital relations and sexual practices, disclosure to family, friends and children, reproductive decision making, ARVs and adherence and services needed by discordant couples.

Chapter Five concludes by discussing the findings on the needs and challenges faced by serodiscordant couples and proposes a way forward. Recommendations on future research and interventions are discussed.

CHAPTER TWO

LITERATURE REVIEW

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

In reviewing the literature in this chapter the researcher will examine previous studies conducted with serodiscordant couples regardless of sexual orientation. The first part of this chapter deals with explanations of serodiscordance. Thereafter, the challenges faced by serodiscordant couples reviewed in this chapter include disclosure of HIV infection to family and friends, dealing with the emotional and sexual intimacy in the relationship, reproductive decision making, ARV knowledge and adherence, the negative partners' care-giver role and provision of services to serodiscordant couples.

2.2 Understanding serodiscordance

In serodiscordant relationships one partner has tested HIV positive and the other has tested HIV negative. In explaining the biological causes of serodiscordance, some researchers argue that unsterilised injections are a possible explanation for individuals becoming infected with HIV. Gisselquist et al (2002) in their study on HIV/AIDS in sub-Saharan Africa state that there is something more than simply heterosexual sexual transmission involved in HIV infection in Africa. They state further that the significant numbers of HIV positive African adults cannot be explained on the basis of current knowledge about sexual and vertical transmission hypotheses. They believe that iatrogenic transmission could be an explanation for some infections occurring in Africa. "Iatrogenic infection means an infection inadvertently introduced through medical procedures" (Gisselquist et al., 2002:3). They concluded that the possibility of transmission through unsafe injections and other unsterile medical procedures is one of the causes of unexplained infections in Africa.

Immunoglobulin A (IgA) antibodies are seen as another explanation for understanding serodiscordance. According to McCook (2003:1) "men who

have sex with HIV positive women but remained virus free carry relatively high levels of antibodies that specifically fight HIV infection in the tissue that first encounters the virus". McCook (2003) reported that in a study of 14 HIV negative men whose female partners were HIV positive, 11 of these 14 men were found to have high levels of IgA antibodies that specifically target HIV in seminal fluids. Scientists, according to McCook (2003), have shown that IgA helps protect the body against HIV by changing its shape and barring its entry into target cells. IgA's were not found in men who were HIV positive. These findings did not explain what caused women to remain HIV negative when their male partners are HIV positive. Neither did the study confirm whether the IgA antibodies were only found in men, nor give the reasons why three of the men who had no IgA remained HIV negative.

Although little information exists about why some people become infected and others do not, the above studies present possible explanations. It is evident from the above reviewed findings that there is no conclusive biological evidence why some people remain HIV negative after they have sex with HIV infected persons. This certainly confirms that there is a need for further research on this subject.

2.3 Psychosocial reactions after HIV and Serodiscordance Diagnoses

This section explores the psychosocial reactions of individuals and couples after the initial diagnosis of an HIV positive and serodiscordant status. The discussion will also focus on the stages that HIV positive individuals go through after the initial diagnosis together with the effects of the diagnosis on the relationship.

When individuals are faced with life threatening diseases such as cancer, heart disease and HIV/AIDS they suffer from psychosocial stresses such as dealing with loss, fear of illness and death, perceived helplessness, uncertainty about the future, anxiety, sadness, anger, anticipatory grief, financial worries and interpersonal stress (Lego, 1994). As much as HIV positive individuals experience the above-mentioned psychosocial stresses,

Hendricks (in www.cpa.ca/phase/families,friends&partners.pdf) maintains that there are unique stressors to HIV individuals such as isolation, shame, guilt and lack of support.

Aronstein & Thompson (1998:65) and Lego (1994:4) discuss the roller coaster of emotions that HIV infected individuals go through. These include panic, anger, shock, fear, shame, denial, suicidal thoughts, loss of control and changes in physical appearance. These are expanded on as follows:-

Panic: Panic is brought about by the fear of not knowing how long one will live.

Anger: Anger is said to be associated by the HIV positive individual with feelings of "Why me, Why now?" believing that life has been stolen away from them. Some individuals will act out by infecting others out of revenge.

Shock: Shock is experienced especially when an individual was expecting that his/her results would be negative and discovers to his/her surprise that the results are positive.

Fear: HIV infected persons may at this point begin to fear incapacitation, physical and mental deterioration, deformity and pain, especially if they have witnessed the illness and/ or death of friends, family and relatives.

Shame: A sense of shame, self - blame and fear of stigma often occurs. The knowledge that one has a terminal disease is always devastating, especially when others view the disease as a punishment for bad behaviour.

Denial: This is a reaction where HIV positive individuals will ignore the diagnosis through a process of dissociation and then go on having unsafe sex.

Suicidal thoughts: Suicidal thoughts may occur after the person has accepted the diagnosis. The HIV positive person may want to protect family and friends

from the pain of a prolonged illness and death, or may fear dementia or a painful death.

Loss of control: It is natural for a person to feel out of control as the virus progresses. An individual who is experiencing opportunistic infections might consider it to be the beginning of the end.

Reduction in Self-esteem: Chronic illness often causes people to feel less important. The reason for this is that illness may restrict individuals from receiving benefits from the strongest sources of self - esteem in society such as work and love. Illness can drastically alter a loving relationship, producing strains and burden on the care-giver and shame and guilt for both the ill person and the care-giver.

Changes in Physical Appearance: Changes in physical appearance nearly always occur in an HIV infected person. The most common is the progressive wasting away of body fat and muscles. These changes are difficult for most people to bear, especially those who have always taken pride in their appearance.

Individuals confronted with a diagnosis of HIV/AIDS experience enormous emotional turmoil in their lives (Pomeroy et al., 2002). Not only does the HIV diagnosis bring stress to individuals but also to a couple's relationship. Research has shown that couples in discordant relationships face a heavier psychological burden. In a study conducted by Smith (1996), 75 discordant couples showed elevated levels of depression, anxiety, hostility, hopelessness and demoralization after the discordant diagnosis. Similarly, Johnston (1995) found that shock and surprise of a discordant result throws a couple into a precarious position. It is therefore vital to explore stresses associated with serodiscordant relationships.

In his study Johnston (1995) found that negative partners experienced conflicting emotions after the discordant results were received. They were happy that they tested negative and also disappointed and angry that they

were not HIV positive like their partners. On the other hand, the HIV positive partner felt relieved that he/she did not infect his/her partner, but felt guilty that the partner would feel obliged to look after him/her while sick.

The challenges that are experienced within a discordant relationship differ for the positive partner and the negative partner. Seropositive partners face the challenge of “living in the present”. Some positive partners live with a sense of urgency arising from not knowing how much time they have left (Johnston, 1995). Johnston warned that this sense of urgency could destroy the relationship as partners would not be living at the same pace. Seropositive partners also wanted to ensure that their partners were provided for financially after their death and had actively sought out methods of doing so by paying off their debt/life insurance. Furthermore, seropositive partners had recurrent fears that the seronegative partner would meet someone else who would replace them after their death (Johnston, 1995).

Pomeroy et al (2002) and Johnston (1995) found that as couples became more familiar with an HIV diagnosis they settled down to a more normalized relationship. However even though normality returned to the couple system they continued to experience a roller coaster of emotions including uncertainty, shame, guilt, sense of responsibility, fear, stigma and shame. These emotions were coupled with a lack of communication about the illness or death.

2.4 Disclosure of serodiscordant status to family and children

Ever since the AIDS epidemic began the question of whether, and when, to disclose has been one of the hardest decisions that PWAs (Persons living with AIDS) have to make. There are various reasons for disclosure of HIV status, such as feelings of responsibility, acceptance of their status and when PWAs are symptomatic ([Http://archives.healthdev.net/stigma-aids/msg00132.html](http://archives.healthdev.net/stigma-aids/msg00132.html)). Most individuals disclose their status in order to receive emotional support from their families. Also PWAs who have developed support networks find it easy to disclose. When PWAs are considering

disclosing their status, they are forced to reflect on their ability to handle the prejudice and stigmatisation that often accompanies being known as someone living with HIV/AIDS.

Discrimination against HIV positive people takes many forms: loss of jobs, evictions, refusal of insurance cover, refusal of public services, denial of or delay in provision of health care services. Discrimination and prejudicial attacks have been found to have a profound social and psychological effect on individuals who have disclosed their HIV status. This prejudice has resulted in PWAs not disclosing their status because they fear discrimination and isolation (Aronstein & Thompson, 1998).

Disclosure is often associated with disclosure of HIV positive status but in serodiscordance relationships it refers to disclosure of both an HIV positive and negative status. Disclosure is often difficult for couples, as they fear that they will be rejected or judged. They often prefer to keep the presence of HIV a secret.

The section below will review challenges faced by serodiscordant couples when they have to disclose the difference in their serostatus to their families, friends and children.

2.4.1 Disclosure to family

For every person infected with HIV, there is a family and a social support system that will also be affected. Therefore family becomes an integral part of the couple, especially in African societies. Family refers to “whomever a person or persons define as their family. This can include biological parents, children, siblings, heterosexual/homosexual lovers/partners, friends and co-workers” Hendricks (in www.cpa.ca/phase/families,friends&partners.pdf). How a family copes with illness, including HIV/AIDS depends on both the nature of the family organization and the belief system that governs the family's response to illness in general (Walker, 1991).

Even though families are so important, the couple is still left with a decision of whether or not to disclose. This review explored some of the reasons for disclosure, who couples disclosed to, and the reactions of family members.

In the Palmer & Bor (2001) study, participants reported that the reason for not disclosing to their families was to protect their relatives from the emotional pain and a shift in family dynamics. Chandra et al (2003) found that stigmatisation, fear of discrimination and disgrace were the main reasons found in their study for non – disclosure to family. On the other hand, those who disclosed did so to gain support of their family members. Chandra et al (2003:213) found that people disclosed with expectations of emotional and material support, which was referred to as “self focused reason to disclosure”.

In Johnston's (1995) study one negative partner disclosed his partner's positive status to the family, and the family accepted the partner's status and found it easy to disclose to friends and others. In contrast to the above, another respondent had difficulties with her family accepting her partner's HIV positive status. The family could not understand why she would choose someone who is HIV positive and put herself at risk of becoming infected. Similarly in a study of homosexuals it was reported that families and friends wondered why someone who was HIV negative continued to be in a relationship with someone who was HIV positive therefore putting themselves at risk of death or dependence (Smith,1996),

Johnston (1995) also reported that those couples or HIV positive individuals who did disclose chose to disclose to mothers and sisters rather than fathers and brothers. Palmer& Bor (2001) argued that the reason for this could be the role mothers play as care-givers and nurturers within a family system.

According to Hanson (2000) some women who are seronegative in discordant relationships are denied the right to disclose by their husbands. In addition, women who have children and grandchildren and who are seronegative in discordant relationships are faced with further complexities and anxieties (Hanson, 2000). These anxieties include feeling tied culturally,

socially and financially to marriage and family. They fear divorce and separation as this will require explanation to their extended families, children and community and this adds to the burden of silence, lies and secrecy that HIV infection has become part of their lives. They fear stigma and shame that the diagnosis will bring to their families. They remain silent, married and supportive of their husbands while they are unable to find support and care for

It is clear from the above that couples would have to weigh the benefits versus the costs in deciding whether to disclose to their families. Their serodiscordant status remains a secret until they feel comfortable in disclosing it. This secrecy can cause emotional strain in their relationships.

2.4.2 Disclosure to children

Disclosure to children is challenging. According to Sheckter (2002) parents struggled to find the best time and the right words to communicate the sensitive information on their HIV status to their children.

The studies reviewed (Waugh, 2003 & Lewis, 1999) showed that the decision to disclose to children was a difficult one to make, especially when parents were not sure of the appropriate age for disclosure. Sheckter (2002:8) conducted a study in Canada with 57 parents (both heterosexual and homosexual) and their children aged between 2 to 23 years. He found that mothers were not disclosing to their children in order to give them a “normal life”, whereas fathers delayed because they felt that children would not understand. Those parents who disclosed were said to have viewed children as autonomous and self sufficient and believed that children deserved to be told. On the other hand, some parents viewed children as innocent and vulnerable and needing to be protected from painful information (Sheckter, 2002:9).

In the same study, Sheckter (2002) found that some parents disclosed immediately while for others it took as long as nine years to begin to think about disclosing to their children. While some parents prepared for disclosure

by discussing it with someone whom they trusted, other parents believed that prayers helped them in preparing for disclosure (Chinouya, 2006 & Sheckter, 2002). More women than men prepared by reading information on HIV/AIDS. The decision to disclose to children varied depending on the age of the child and the health status of parent and child. Mothers tended to disclose earlier than fathers and more often to their daughters than their sons (archives.healthdev.net/stigma_aids/msg00132.html).

In a study by Johnston (1995) one couple only disclosed their serodiscordance status to their child when the father was hospitalised. The mother had to explain to the child about HIV and discordant results and also reassure the child that she would do everything in her power to remain negative. This couple shared their frustration with regards to being unable to communicate further on the subject with the child.

2.4.2.1 How to disclose to children?

Sheckter (2002:9) stresses the importance of a trusting relationship in disclosure, and recommends the following:

- “That parents develop a level of trust and be willing to tell their child or children; this level of trust included: parents trusting in themselves, trusting in their child, trusting in the parent - child relationship and trusting in the family as a whole.
- That they know their child and treat each child as an individual.
- That they build a strong parent – child relationship prior to disclosure.
- That they introduce information gradually
- That they ensure that their children understand that other family members are not at risk of becoming infected from living in the same household as the person infected.
- That parents should deal with their feelings of fears first and be hopeful, positive, truthful and honest”.

The literature reviewed indicates that parents had difficulties in disclosing to their children. The difficulties resulted from the fear of not knowing how a child or children will react after disclosure. Also parents do not know what to say and how to say it. However, the literature reviewed showed that there are parents who disclose despite the difficulties mentioned.

In concluding this section on disclosure it must be noted that most of the studies reviewed regarding disclosure focused on HIV positive individuals with little reference to serodiscordant couples. Only studies by Palmer & Bor (2001) and Johnston (1995) had relevance to serodiscordance. The studies reviewed showed that there is limited theory available covering the disclosure processes undertaken by serodiscordant couples to their families and friends. The findings of this research study are intended to add to the body of knowledge of how and when serodiscordant couples disclose to their children and their families.

2.5 Emotional and sexual impact of serodiscordance on the relationship

Most heterosexual HIV transmission between individuals in sub - Saharan Africa occurs in long term and stable relationships. In high prevalence areas of Africa, cohabiting couples make up a large proportion of groups at risk of HIV infection (Bunnell et al, 2005). The greatest HIV risk for women in these relationships is their husbands or stable partners. Effective protective action against HIV/STD infection within a couple's relationship requires communication, agreement and above all, cooperation between couple members (Painter, 2001). Apart from this, Skurnick et al (1998) contend that couples in stable partnerships may have greater difficulty in changing well established patterns of sexual practices.

HIV poses a constant threat within a discordant couple's relationship because it can be sexually transmitted (Palmer & Bor, 2001). Fear of infecting or being infected by the other partner raises concerns and this touches the most intimate aspects of the relationship. Smith (1996) found that couples lacked any sense of what should constitute "normality" for them. In his study he found that couples hardly ever communicated and ceased being sexually intimate.

One of the challenges faced by serodiscordant couples is to practice safe sex. This includes issues of mind altering during sex, being carried away by passion, misinformation, desire to join the infected lover, and the inability of

the non- infected partner to insist on safer sex due to fear of physical or emotional abuse. Palmer & Bor (2001) in their study found that the negative partners often insisted on practising unsafe sex with the hope of getting infected. They interpreted this as a way for negative partners to redress the imbalances in the relationship, such as loss of intimacy in sex.

In the studies reviewed there were challenges that prevented partners in practicing safer sex all the time. Firstly, Skurnick et al (1998) found that unemployment of the female partner was seen as a contributing factor in being unable to practice safe sex. It was found that these women were five times more likely not to use condoms. Secondly, Skurnick et al (1998) also found that reverting to unsafe sex was more common when the women were in their 30's and 40's. Lastly, Palmer & Bor (2001) found that couples who had a history of unsafe sex in the past were more vulnerable to returning to risky behaviour, possibly because of feelings of hopelessness about their future and difficulties in communication with their partners.

Due to the risk involved and the fear of seronegative partners getting infected in discordant relationships, certain sexual practices emerged. Studies by Smith (1996) & Johnston (1995) found that some couples do not have sex with their partners, some have sex that does not involve penetration, and some have sex with penetration using condoms. One of the respondents commented that her partner had problems maintaining an erection due to the fear of infecting or getting infected.

For the couples who found it easy to adapt to the regular or long term use of condoms, it was evident from studies reviewed on prevention interventions that there were low rates of seroconversion where partners both knew their status. Also condom use was reported to be more frequent and consistent, especially where men were HIV seronegative (Painter, 2001 & Skurnick et al., 1998).

Various studies have discussed the negative impact of severe illness on partners and the intimate relationship. The illness can cause severe

psychological distress, particularly where partners have to fulfill the role of care-givers (Van Devanter et al., 1999). When PWAs learn that they are or have been exposed to HIV or have been diagnosed with AIDS related medical conditions, it is almost certain to affect an individual's sexual life. When an individual has been diagnosed with HIV initial reactions are shock, fear, anxiety or depression, which may lead to a person completely shutting down sexually (Shernoff, 1991).

Illness also impacts on interpersonal relationships. There seems to be a definite correlation between the quality of the relationship and the ability of the person to cope effectively with the illness. Also, for someone who is becoming increasingly symptomatic it is highly likely that their interest in having sex will decrease and eventually disappear. When some PWAs lose weight, they no longer find themselves attractive and they avoid being intimate. On the other hand, Shernoff (1991) found that one reaction to the onset of a personal health crisis is to become extremely sexually active, either with one partner or many.

The progression of the illness threatens the stability of the relationship and this brings about psychosocial strain. Palmer & Bor (2001) argue that this is a challenge that can strain or strengthen the relationship. They suggest that couples need to be able to adapt the relationship to the changes illness may bring on a continuing basis as the disease progresses towards possible death. Psychosocial strain also contributes to loss of libido in the seropositive partner. Apart from this, the bigger challenge is the difficulty in discussing the issue of sex with the partner. Despite the libido problems that a couple may encounter, the imbalances in a relationship may also be caused by one partner's unwillingness to discuss the illness itself. It is suggested that strong social support also correlates with better quality adjustment to illness in the long term, although couples affected by HIV may experience a greater degree of social isolation (Palmer & Bor, 2001).

It was evident from the studies reviewed that even though partners experienced difficulties with their sexual life there were benefits in remaining

in the relationships. In Palmer & Bor's (2001) study, HIV negative participants mentioned that they felt safe or more comfortable in a relationship where they knew their partners' status even though it was positive. Participants claimed that being in serodiscordant relationships made it easier to adapt and maintain safer sex practices.

Kasiram et al (2003) discuss some of the factors that improve or weaken couples' relationships that therapists should consider while providing therapy. Factors that improve couple bonds and personal adjustment include: good communication, honesty and openness, being sexually responsible, finding fulfillment in other areas of life, identifying new forms of intimacy, satisfying oneself sexually, growing through adversity, clarifying one's values or goals and working as a team to deal with HIV/AIDS.

Factors that weaken couple relationships and poor personal adjustment include: feeling negative about oneself, being unsure about the other's true feelings, loss of joy of life, communication problems, feelings of guilt, fear of disclosure, loss of trust, lack of intimacy, impotence, blaming sex for HIV, feelings of fear or rejection, stress, gynaecological problems and partners who refuse to use condoms.

Dealing with the emotional and sexual impact on the relationship is vital in serodiscordant relationships. Palmer & Bor (2001) propose that redressing imbalance and the desire for normalization of a relationship after HIV diagnosis are important considerations for sexual risk behaviour both within and outside the relationship. They have suggested interventions that alleviate psychological stress that may decrease couples' vulnerability to relapse from safe sex, and also counselors to help couples adopt and maintain safe sex practices while continuing to have satisfying sexual relations.

In relation to interventions on promoting safer sex, Painter (2001) suggests that media messages are more concerned with technicalities of safe sex than with processes of communication and negotiation that affect HIV risk and prevention efforts by couples. He also mentioned that Voluntary Counseling

and Testing (VCT) facilities are infrequently attuned to couples' needs and that few couples present together for VCT. Also VCT services are provided to individual clients not couples. Couples need to work together in understanding and coping with the effects of illness, and this mutual understanding is said to be essential for the survival of the relationship (Palmer & Bor, 2001).

Most partners find it difficult to communicate openly around issues of intimacy. Some avoid discussing HIV out of fear of causing distress to their partners. Some also avoid discussing negative emotions that form part of everyday life. Feelings of guilt related to discussion of problems and conflicts within the relationship were also reported (Kasiram et al, 2003). In order for couples to have a healthy relationship, despite the HIV factor, it is important for both parties to communicate openly and honestly about their feelings. It is crucial for couples to discuss their needs and be honest about their feelings regarding changes that are happening in their relationship (Kasiram et al, 2003). Better communication in a relationship can also lead to emotional needs being met by a partner.

2.6 Reproductive decision making for serodiscordant couples

Sauer (2002:1) succinctly states that the "reproductive drive is incredibly strong, and patients are known to take risks in order to have a baby beyond what may be reasonable". This is perhaps particularly true for those couples who have no children and who are in their peak reproductive years. Chen et al (2001) in their study on fertility desires and intentions of HIV positive women and men, found that 28-29 % of 1421 HIV infected men and women desired to have children at some time in their lives. Some infected participants in that study felt that raising a child was a way of giving meaning to life and women felt that pregnancy and childbirth was a way of regaining their sense of womanhood and sexuality.

Besides the reproductive drive, most infected individuals experienced family and societal pressure to bear a child. Sewpaul (1999) correctly maintains that in African communities, bearing a child is seen as an essential part of being a

woman and of achieving success in one's life. Sewpaul (1999) further states that in African societies, for a couple not to have children is not only seen as a crisis, but regarded as a tragedy or a disaster by the community, because children are not only seen as "children" but as "generations". The inability to have children can thus result in stress and / or depression in couples who are infected or in serodiscordant relationships. In their study, Grieser et al (2001:226) refer to "childbearing as the rite and passage into the spiritual world for the parents, and those who die before having children are considered to be spiritually impure and, as a result, may end up as restless, harmful spirits".

Grieser et al (2001) investigated how reproductive decision making is made in the midst of the high HIV infection rate in Zimbabwe. They found the following in relation to whether or not people chose to have children. The reasons for having children included assisting parents in old age, continuing the name of the clan, providing joy or entertainment in the home, companionship for the parents or for other siblings, having a child is important in proving one's fertility; securing the bond between husband and wife and women strengthening their relationships with the in-laws. The reasons for not having children included rising costs of bringing up children; the AIDS epidemic causing them to limit their childbearing (this is associated with the fear and emotional pain of child death) and fostering or taking care of children of their relatives who have passed away.

Grieser et al (2001) concluded that reproductive decision - making is strongly influenced by cultural norms, such as the value of children in a particular society and the specific roles of men and women. Given the above reasons for individuals or couples desiring to have children it is highly likely that couples in serodiscordant relationships would want to take a risk and have a child or children despite the fact that the other partner could become infected.

With regard to reproduction and prevention of HIV conversion, most attention has been given to vertical transmission (mother to child). This is directed to women who are already pregnant and there is less attention or no information

given to couples who want to bear a child. The review below examines some of the reproductive choices available to couples who desire to have a child. These choices include assisted reproductive techniques

2.6.1 Assisted reproductive techniques

Assisted reproductive techniques discussed in this section include artificial insemination, self insemination and timed intercourse.

2.6.1.1 Artificial insemination

Artificial insemination includes donor sperm insemination, intrauterine insemination, in vitro fertilization and intracytoplasmic sperm injection. Thornton et al (2004:63) suggest that the use of assisted reproductive techniques decreases the chance of horizontal transmission to almost negligible rates, which provides HIV infected couples with the possibility of pregnancy while minimizing the amount of unprotected exposure necessary to conceive.

2.6.1.2 Donor sperm insemination

This is insemination using seronegative donor sperm. This is regarded as the safest method, as it eliminates the risk of transmission of the HIV virus to uninfected women wishing to conceive a baby. According to Eriksen (2001), although this is a perfectly safe method, it is not the option of choice for most serodiscordant couples because a child born using this procedure will not have the genetic resemblance of the other partner.

2.6.1.3 Intrauterine insemination (IUI)

In serodiscordant couples, washed intra-uterine insemination is one of the methods considered for conceiving, especially when the male partner is HIV positive. This procedure eliminates the need for intercourse and the subsequent risk of HIV transmission. In this procedure, special techniques are

used to separate the spermatozoa from the seminal fluid. The sperm are then placed directly into the uterus after accurately assessing the time of ovulation (Eriksen, 2001). Eriksen (2001) further suggests that when using the IUI procedure it is vital for washed sperm to be tested for HIV using the PCR before the insemination.

Sauer (2002) found that washed sperm preparation and intrauterine insemination demonstrated safety, with no seroconversion occurring in women or their offspring. However, he stated that it is difficult to ensure that all CD4 receptor cells are washed free in the preparation. Pasquier et al (2000) also maintains that the selective isolation of motile spermatozoa should minimize transmission during artificial insemination. Medically assisted conception using spermatozoa tested for HIV is a much safer alternative than condom free intercourse during ovulation.

In a study where 29 serodiscordant couples underwent 59 insemination attempts, this resulted in 18 pregnancies. Of the 18 women inseminated, none of them seroconverted after 18 months of follow up (Sauer, 2002).

2.6.1.4 In-vitro fertilization (IVF)

This method is considered when IUI is not feasible or was unsuccessful. With HIV it is mainly used when the male partner is positive. In this type of technique the woman's oocytes (eggs) are harvested after undergoing ovulation induction, and the male's sperm is isolated. The intracytoplasmic sperm injection technique involves fertilizing each egg with one sperm instead of exposing the egg to millions of sperm as is done in IUI. Once several eggs have developed into embryos, they are then transferred back to the uterus and the woman is monitored using a blood pregnancy test to determine if implantation was successful. Intracytoplasmic sperm injection (ICSI) is commonly used to address male factor infertility. The success rate of ICSI in a woman under the age of 35 is 45%-50% per cycle which is interpreted as being a high rate of pregnancy (Eriksen, 2001:4-5).

Sauer (2002) used invitro fertilization with intracytoplasmic sperm injection to reduce the risk of transmission from HIV infected men to HIV uninfected women. Thirty four women underwent 55 treatment cycles, resulting in 25 pregnancies and 17 deliveries. During this study there were no seroconversions noted in the 34 women who participated or in the 25 infants who were delivered. Also multiple gestations were noted in 6 of 17 delivered pregnancies. Although this procedure has a high rate of conception, it is also considerably more expensive than other procedures.

2.6.1.5 Self insemination

This is one of the methods that can reduce the transmission of HIV to a negative male partner. Self insemination is said to be a viable, low cost alternative for serodiscordant couples. With this method women can inseminate themselves with freshly ejaculated semen using a syringe (without needle) or a disposable plastic Pasteur pipette (Thornton et al, 2004 & Sauer, 2002).

2.6.1.6 Timed intercourse

Thornton et al (2004) reported that 80% of HIV infected couples who had previously conceived had engaged in unprotected intercourse to achieve pregnancy. Timed intercourse is suggested for couples who want to undergo this route of conceiving. This procedure involves a timed ovulatory intercourse, which is to engage in unprotected intercourse during the fertility period. The fertility period is described as "the specific days relative to ovulation during which a woman is most likely to conceive" (Thornton et al 2004:64).

A study by Gilling-Smith (2000) also describes timed intercourse using ovulation detection methods. He found a 4% transmission rate in 92 serodiscordant couples, with seroconversion restricted to partners who reported inconsistent condom use outside the fertility period. In couples where one partner is on antiretrovirals, they will need to have a viral load that is

undetectable and their CD4 levels must be above 400p/ml for them to be able to minimize the risk of infection to their partners.

2.6.2. Pre-Conception Assessment

Wilde (2002:1) maintains that “couples who decide to proceed with either timed ovulation or artificial insemination with washed sperm should undergo fertility assessment and genital tract infection screening”. These assessments are to ensure that pregnancy is possible and also that there are no infections.

Fertility assessment is done in both males and females. In males, semen analysis is performed. The minimum criteria are a sperm count greater than 20million cells per ml with greater than 50% of the sperm being mobile. If the sperm has abnormalities, IVF or timed ovulatory intercourse should be considered.

In females, open fallopian tubes and a normal uterine cavity could be assessed by either a specialist X - ray called a hysterosalpingogram or laparoscopy combined with hysteroscopy. A normal ovulation should occur with females in order for them to be able to conceive. (Wilde, 2002:3)

Wilde (2002:3) also recommends that both males and females undergo a thorough sexual health examination and screening for concurrent sexually transmitted infection (STI).

2.6.3. Reproductive decision making counseling

Chen et al (2001:144) maintain that the fact that many HIV infected adults desire and expect to have children has important implications for prevention of vertical and heterosexual transmission of HIV. There is a need for counseling to facilitate informed decision making about childbearing and child rearing, and the future demand for social services for children born to infected parents.

Prior to planning any pregnancy, couples should assess their readiness to have a child. This includes considering their emotional, physical and financial well - being. In the case of HIV infected couples, health status is of utmost concern. Assessing their anticipated life expectancy is important, particularly if one or both partners are on treatment, not adhering to treatment or failing treatment. They should seek expert medical advice about potential medical complications due to HIV.

Chen et al (2001:153) list some issues to be covered during counseling for HIV positive men and women who desire to have a child:

- "Family planning counseling
- Clear treatment guidelines for HIV positive women during pregnancy and dissemination to obstetricians in a timely manner
- Follow up of a new born until maternal antibodies disappear and HIV status can be ascertained
- In addition to prenatal and delivery care, that they help plan for a future closely linked to medical and social support, particularly given the competing care-giver responsibility of a parent living with infection.
- Children of infected parents will need social services and other support to plan for a life with parental illness including counseling to cope with any stigma of growing up with an HIV infected parent.
- Women who become pregnant unintentionally will need services that aid in decision making to plan the outcome of their pregnancy. These should include; help in coping with unintended pregnancy, exploring negative or positive attitudes towards childbearing, consider the consequences of bearing a child or pursuing alternatives such as adoption".

2.6.4 Limitations of reproductive techniques

Thornton et al (2004:63-64) cite the following limitations of reproductive techniques:

"Although assisted reproductive technologies seem to provide a possible alternative for HIV affected couples who desire reproduction, many remain unconvinced that these are entirely risk free procedures. Assisted reproductive techniques are expensive and thus many couples find them very exclusionary."

It is evident from the above information that even though there are some options for serodiscordant couples the techniques remain expensive leaving people with only the one affordable option of self insemination and timed intercourse. According to Sauer (2002:3) “women need to understand that none of the procedures are risk free and all carry a small possibility for infection”.

In conclusion, studies by Thornton et al (2004), Sauer (2002), Wilde (2002), and Eriksen (2001) indicated that although the risk of heterosexual transmission is relatively low, the rate of male to female transmission per contact is significantly greater than the risk of female to male transmission. Thus the above mentioned techniques give more attention to male HIV infected partners. This also confirms that conceiving and reproduction decisions are easily made when the female partner is positive because there is less risk of infection than when the male partner is HIV positive.

Many of the reproductive techniques mentioned above are expensive and do not guarantee conception at any stage, and this could lead to couples opting for timed intercourse. The information on these types of techniques are not accessible to the people who most need it, and consequently even couples who may have money for such techniques will not be in a position to access information. Sauer (2002) argues that serodiscordant couples should receive information about all reproductive options and that reproductive counseling should be non-directive and supportive of the patient's decision.

2.7 Antiretrovirals and adherence

Antiretrovirals are drugs used to prevent the HIV virus from reproducing inside the body, allowing the immune system to recover. ARV treatment has brought hope to individuals with incurable HIV diagnoses in order to sustain their lives. Hope comes at a price because individuals who are on treatment have to cope with the side effects of the treatment. There are also issues of adherence and resistance. Taking the ARVs is a lifetime commitment that

requires psychological readiness from the person taking medication and support from the family to help an individual to adhere to treatment (Miller, 2002).

For these drugs to be effective patients are required to adhere to the drug regimens given to them. ARV adherence is essential to maintain long-term health benefits and avoid development of drug resistance. "Adherence means taking the recommended dose, at the recommended time and in the recommended way. It refers to the degree to which a patient follows a treatment regimen which has been designed in the context of a partnership between the client and the health care worker" (Brouard, 2005:71).

Resistance to treatment means that medicine used to destroy a virus is no longer effective to fight against the virus. This becomes a strain on patients since it is associated with treatment failure and limits future treatment options. It is an important factor in the choice of therapy. Resistance is a serious problem in patients as it reduces treatment options for people with HIV and also resistant strains of the virus can be passed on to other people through unprotected sexual intercourse, thereby limiting their treatment options (DOH,2004).

Adherence is a problem for patients to achieve as sometimes they miss taking their medication or find it difficult to cope with the side effects of the medicine. Studies by (Brouard, 2005; Oggins, 2003; Miller, 2002 & Palmer & Bor, 2001) mention treatment regimens, side effects, the patient - doctor relationship, clinical settings and medication as a reminder of HIV and lowered individual spirit as factors inhibiting adherence.

Adherence to medical care and medication presents a challenge to discordant couples as development of drug resistance can compromise the health of the HIV positive partner and through unprotected sex transmit a drug resistant virus to the negative partner (Remien & Stirrat, 2002). The effect of ARVs on positive partners could also cause disequilibrium in the family system and problems in the couple system. Palmer & Bor (2001) found that with the

participants in their study there was a sense of frustration and disillusionment with the use of antiretroviral medication from both partners. Positive partners complained about side effects that lasted longer than expected, disrupting their routine and causing detrimental effects both physically and socially.

A negative partner who provides support to the positive partner normally balances disruption and disequilibrium in the relationship. Palmer & Bor (2001) found that treatment provided seronegative partners with a focus for their commitment to give support to their partner. They found that seronegative partners encouraged their partners to continue taking medication and also took the time to seek out relevant literature and other sources of information to keep up to date with medical procedures and interventions. Seropositive partners found their enthusiasm for drug therapy more difficult to maintain over a long period of time, and their partner provided support in coping with this.

In conclusion, the studies reviewed showed that in taking ARVs, positive partners have to be able to adhere to treatment. Several studies reviewed have shown that the effects of ARVs have a negative impact on the relationship, including the possibility of transmitting a drug resistant virus to a negative partner through unprotected sex. It was evident that negative partners played a supportive role in assisting their HIV positive partners in adhering to treatment (Brouard, 2005; Oggins, 2003; Miller, 2002 & Palmer & Bor, 2001).

2.8 A care-giver role played by negative partners

It has been noted in the previous studies that the difference in serostatus introduces an imbalance in a relationship. Palmer & Bor (2001) and Johnston (1995) argued that imbalance is significant where the negative partner becomes a care-giver. Negative partners have to deal with feelings of helplessness whilst also trying to lead a normal life. On the other hand, the positive partner is facing the threat of an untimely death.

D'Cruz (2005:588) found that wives cared for their sick husbands through actual care giving tasks related to personal care, emotional care and medical treatment, as well as supporting the entire household through the assumption of family roles and responsibilities, including earning following their husbands' inability to perform their roles. In her study she noticed the gender division in care giving where the care-giver role was played by women only and positive women did not receive physical or emotional assistance from their husbands.

The findings in these studies are interesting, although limited knowledge was available on the role played by the negative partners. There was no literature covering psychological effects of caring for others in these studies. Due to the roles played by negative partners in their serodiscordant relationships, it is imperative that there is further research that will explore whether the care-giver role provided does provide a balance in the relationship.

2.9 Service delivery for serodiscordant couples

There seems to be a lack of services for serodiscordant couples. In the Palmer & Bor (2001) study it was noted that respondents were frustrated with the lack of services provided. They felt that services provided were for their positive partners, excluding them (Palmer & Bor 2001). According to Palmer & Bor (2001) negative partners felt that the roles they played as both care-givers and partners were not recognized by health professionals. Thus there were no services that focused on their needs.

In all the studies reviewed the authors made recommendations based on their findings about what service delivery for serodiscordant couples should entail. Palmer & Bor (2001) stated that psychological services need to be located outside traditional healthcare settings and in community based settings.

D'Cruz (2005:590) in his study recommended gender sensitive intervention programs, claiming that women are not only burdened by their care giving and support roles but also experience acute distress. In the gender sensitive programs D'Cruz (2005:590) recommends provision of emotional support,

respite care, material and financial support, support with regard to treatment and shelter and planning for the future, employment, training, assistance with care giving and attention to health needs. Dane (1999) proposed programs that provide opportunities to talk about the isolation and shame that is endemic to living with HIV, the impact of grief on parenting and disclosure outside the family. He recommends services that can meet the many challenges of living with HIV/AIDS.

2.10 Conclusion

In conclusion, the literature reviewed on serodiscordance has shown that there are growing numbers of serodiscordant couples in sub - Saharan Africa. The difference in serostatus results in confusion for both health care workers and affected couples. This confusion is caused by a lack of understanding of the causes of serodiscordant results. In understanding serodiscordant results, two views were presented in the review. One study by Gisselquist et al (2002) explained that people who tested HIV positive with unexplained infection in Africa was a result of transmission through unsafe injections and unsterile medical procedures. Another study by McCook (2003) found that there were IgA antibodies that led to some individuals not being infected with the HIV virus. Both these studies explored the issue from different angles but there was no conclusive evidence as to what causes serodiscordance. This issue requires further research.

Psychosocial reactions to serodiscordance were reviewed. Findings were mostly focused on positive individuals and there was little information available on serodiscordant couples. Studies noted the fact that there was little attention given to serodiscordant couples in the HIV programs. With disclosure, studies reviewed showed that there is limited theory covering the disclosure processes undertaken by serodiscordant couples to their families and friends. The gap revealed in this review on disclosure information such as how children, families and friends react after learning about discordant results will be explored in this study.

Studies (Painter, 2001; Palmer & Bor, 2001; Smith, 1996 & Johnston, 1995) on the emotional and sexual impact of serodiscordance on a couple's relationship concluded that couples had difficulties in maintaining safe sex, that illness does impact on sexual and interpersonal relationships and that couples avoided discussing HIV. There was no evidence in the literature on why some couples were able to sustain safe sex, while other couples could not. There were also no studies that reviewed cultural beliefs and norms that propelled serodiscordant couples to practice unsafe sex. It was evident that, irrespective of HIV status, individuals had a desire to bear and raise children. Different reproductive techniques were discussed. It was concluded that reproductive techniques are expensive and do not guarantee conception at any stage and are not risk free. There is no literature on whether serodiscordant couples use these different types of techniques in conceiving a child or whether they have knowledge of these procedures.

ARV adherence and its effect on the relationship and services provided to serodiscordant couples were also reviewed. Furthermore, the literature reviewed stipulated a need for services that were directed to serodiscordant and recommended that there should be policies and programs in place in Africa that catered for serodiscordant couples. The following chapter discusses the research methodology, including the method of data collection and analysis.

CHAPTER THREE

RESEARCH METHODOLOGY

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter describes the research methodology used in the study and how the study evolved from its conception to the final product. It also addresses data analysis, ethical concerns and limitations of the study.

3.2 Research Method

The nature of this research study was sensitive and there was limited knowledge on the psychosocial implications of serodiscordant couples. To adequately uncover the implications of HIV/AIDS and challenges faced by serodiscordant couples an in-depth qualitative approach was used. Terre Blanche & Durrheim (1999) state that qualitative methods allow the researcher to study selected issues in-depth, openly and in detail as they identify and attempt to understand the categories of information that emerge from the data. When using qualitative methods, the researcher collects data in the form of written or spoken language and analyses the data by identifying and categorising themes.

A qualitative approach was used to enable the researcher to obtain rich, in-depth data on a relatively unexplored area of study. Also the qualitative approach allowed the researcher to explore perceptions and experiences of serodiscordant participants. Qualitative research also provided participants with opportunities to share their views openly.

3.3 Research Design

Since limited research has been done in this area, an exploratory design was used. Exploratory studies are used as preliminary investigations into relatively unknown areas of research (Terre Blanche & Durrheim 1999). Wisker (2001) and Rubin & Babbie (1997) indicate that exploratory research employs an open, flexible and inductive approach to research as it attempts to look for

new insight into phenomena. This approach blended well with the qualitative method.

3.4 Sampling

Sampling can be defined as a technical accounting device to rationalise the collection of information; to choose, in an appropriate way, a restricted set of objects, persons and events from which information will be drawn (Mouton and Marais 1990:75). Sampling is an important aspect of research because the type of conclusions that can be drawn from the research depend directly upon those whom participated in the research study (Terre Blanche & Durrheim, 1999). There are two broad categories of sampling. They are: non-probability sampling and probability sampling (Rubin & Babbie, 1997).

Probability samples are selected based on principles of statistical randomness. For probability sampling, the researcher has to have a sampling frame and also a random selection procedure to select individuals off the sampling frame for inclusion in the sample (Terre Blanche & Durrheim, 1999). This allows for the results to be generalized to the larger population. Probability sampling was inappropriate for the study and the researcher opted for non-probability sampling.

Non-probability samples are selected according to principles of convenience or accessibility (Terre Blanche & Durrheim, 1999). They are used when:

- There is no available sampling frame.
- The cost of probability sampling in terms of time and money is too high.
- There is in-depth qualitative research.

Since this research study was an in-depth qualitative study and because of limited access to a pool of serodiscordant couples, non-probability, purposive sampling was used.

Participants in this study were drawn from referrals by therapists and doctors. I presented information on the research study to HIV/AIDS service providers. An information sheet detailing the procedures of the research, information about the researcher and an informed consent letter were also distributed to health care practitioners. Those patients who were willing to be involved were referred to the researcher. At this point, purposive sampling was used. Terre Blanche & Durrheim (1999:281) describe purposive sampling as a method that is used in selecting a sample that is exceptional, selected with a specific purpose in mind and having populations that are difficult to reach. This type of sampling is also based on the researcher's knowledge of the population.

The following sampling criteria were used:-

- Participants who had been tested for HIV and had serodiscordant results.
- Heterosexual couples.
- Partners who knew each other's status.
- Couples who were married or cohabiting for more than a year. Married and cohabiting couples were included in order to explore in-depth the challenges posed by differences in their HIV statuses in long term relationships.

Difficulties were experienced in obtaining the sample. One of the major difficulties was accessibility to the participants. Many medical doctors in particular were reluctant to refer patients claiming that the study was too sensitive. This is what Terre Blanche & Durrheim (1999:136) term gate keeping in research. According to them, gatekeepers are people who have a say over who is let in and who is not. This gate keeping led to some participants being excluded from the study without them making their own informed decision on participation. This was thus, one of the problems experienced in acquiring a sample.

Participants were between 30 and 49 years old. The sample in the study comprised four married couples and two individuals who were married but participated individually and not as a couple. In the latter two cases the

researcher had already interviewed the participants before discovering that their partners were not available. One partner was out of the country and the other, after initially agreeing, decided not to participate. Because of the rich data collected in these single partner interviews I decided to include them in the final sample. They met the sampling criteria.

3.5 Data collection

3.5.1 Data collection method

Qualitative data were collected using semi-structured interviews with serodiscordant couples. Data collected in qualitative research has the following characteristics; rich in description of people, places and conversations and not easily handled by statistical procedures (de Vos, 1998). Also, qualitative research is concerned with understanding behaviour from the subjects own frame of reference. Interviews enable face to face discussion with human subjects and this also involved developing a relationship that is encompassed by trust (Wisker, 2001). Rapport building with serodiscordant couples was crucial as sensitive and emotional issues were discussed during interviews.

According to Welman & Kruger (2001:159)" semi-structured interviews offer a versatile way of collecting data. This type of interview can be used with all age groups". Semi - structured interviews also allow the interviewer to use probes with a view to clearing up vague responses, or to ask for elaboration of incomplete answers. Semi - structured interviews can be considered when:

- The topic is very sensitive in nature.
- The respondents come from divergent backgrounds; and
- An experienced and expert interviewer is available to conduct the interviews.

In understanding the challenges experienced by serodiscordant couples, semi-structured interviews were conducted, using an interview guide. In using semi-structured interviews the researcher used predominantly open - ended

questions. Semi-structured, open-ended questions manage to address both the need for comparable responses and the need for the interview to be developed by the conversation between interviewer and interviewee (Wisker, 2001:168). Also, open - ended questions allowed the researcher to understand what participants' lives, experiences and interactions.

An interview schedule was developed for this particular study. The interview schedule consisted of closed and open - ended questions (Appendix 2). An interview schedule is used in semi-structured interviews (Welman & Kruger, 2001). It involves a list of topics that have a bearing on the given theme that the interviewer should raise during the course of the interview. The interviewer may adapt the formulation, including the terminology, to fit the background and educational level of the respondent while asking questions.

The following section discusses the processes followed in this qualitative study.

3.5.2 Data collection process

Pre - interviews were conducted with the participants to discuss pragmatic issues. Participants were informed of what the research entailed and also to assess whether the participants met the sample criteria. This was done telephonically and face to face.

In-depth interviews were conducted either in the couples' homes or the researcher's office. Each partner was interviewed separately so that they could freely express their views. Informed consent forms were given to participants to read and sign before the commencement of the interview. The consent form detailed the objectives and procedures (this included the use of a tape recorder) of the research (See Appendix1). Confidentiality and anonymity were ensured. Voluntary participation, the possibility of sharing the results of the study with other helping professionals and possible publication were discussed.

The interview took an hour to two hours per person. A tape recorder was used. According to Burns (2000) tape recording increases accuracy of data collection, and allows the interviewer to be more attentive to the participant as the interviewer does not have to write down responses, while responding appropriately to the participant. The researcher explained further about the types of questions and their sensitivity. The participants were given the choice of not answering questions with which they were uncomfortable. At the end of the interview, those participants who needed debriefing were debriefed or referred for counselling.

3.6 Data analysis

A content analysis method was used. This method involved classifying text into significantly fewer content categories (Struwig & Stead, 2004). All interviews were tape recorded, transcribed and translated by the researcher. Transcribing each tape took a minimum of seven to a maximum of ten hours depending on the length of the interview. This was the most time consuming exercise in the research but it helped me to be more objective about the data collected. This was achieved by listening to the whole interview to gain a complete sense of the participant's responses and then delineating units of meaning which were relevant to each question.

The taped interviews were transcribed into transcripts. Both inductive and deductive approaches were used to analyse the interview transcripts. A deductive approach involved constructing general themes that had been derived from reading literature and through my involvement in counselling serodiscordant couples. These were built into some of the interview questions. Some of these formed the main themes. Other main themes and sub-themes emerged directly from the data and this allowed for the use of an inductive approach.

Interview material was categorized into various themes. This process involved sorting out transcripts into the broad themes or sub themes used in the guide and adding new themes from the interviews. This procedure ensured that

scattered information on the same sub-themes were put together for a complete review. Each category was labeled using an appropriate heading. Analysis included identification of key themes and comparison of responses according to gender and HIV status.

3.7 Validity and reliability

Vithal & Jansen (1997:32) described validity as an attempt to “check out” whether the meaning and interpretation of an event is sound or whether a particular measure is an accurate reflection of what you intend to find out. Marshall (1986: 197-198) in Sewpaul (1995) described the following reflective checklist to be used in assessment of validity in qualitative research:-

Questions pertaining to how the research was conducted:

- Was the researcher aware of his/her own perspective and influence?
- How did the researcher handle himself or herself?
- Did he/she challenge himself/herself and accept challenges from others?
- Was he/she open to new encounters?
- Did he/she tolerate and try to resolve the chaos and confusion?
- Has the researcher grown personally through the experience?

Questions pertaining to relationship to data:

- Is the level of theorising appropriate to the study and to the data?
- Is the theorising of sufficient complexity to reflect the phenomena being studied?
- Are alternative interpretations explored?

Questions pertaining to the contextual validity:

- How does the conclusion relate to other work in the area?
- Is the researcher aware of relevant contexts for the phenomena studied?
- Is the material useful?

The above questions on validity are very relevant in assessing qualitative research as they provide guidelines and indeed a reflective checklist. Most of the questions above were dealt with in this research.

Reliability is about the consistency of a measure, score or rating (Vithal & Jansen, 1997). Sewpaul (1995:48) suggested the following be used in checking for reliability in qualitative research:-

- “Reliability is enhanced through proper documentation of the methods of data collection and through recording reliable data.
- Reliability should also be enhanced by presenting as much of the original data as possible in the research document. “

From the above check list I would regard this research as a reliable study, as every effort has been made to document the methods of data collection and present the original data which did not infringe the privacy of the participants.

3.8 Limitations of the study

There were various challenges I faced during the preparation of the study and during collection of data. These challenges included: a lack of literature on serodiscordant couples, obtaining a larger sample than the one used and practitioners' attitudes towards the study.

There is lack of theory on psychosocial challenges faced by serodiscordant couples in the South African region and African continent. The theory that is available is from western countries and focuses predominantly on homosexuals. The literature that is available gives attention to sexual behaviour and prevention of seroconversion between couples who are serodiscordant and pays little attention to other challenges presented in serodiscordant relationships.

The small sample size limits the generalisability of the results. However, since this was a qualitative study, the purpose of the study was not to generalise the findings but to gather rich data.

The attitudes and gate keeping of medical practitioners and some therapists had an impact on accessing participants. What intrigued me was the fact that medical practitioners who found the study interesting were eager and made an effort to look for couples. The practitioners who showed no interest at all in the study were very reluctant to accept the information provided to them though they mentioned that they saw many couples who were discordant in their practices. Their concerns were related to issues of confidentiality and they also claimed that the study was too sensitive to research.

Furthermore, the participants who participated in the study were geographically from Durban in KwaZulu-Natal, were mainly Africans and were all employed. The findings might differ in another province, with another race group and also different socio - economic backgrounds.

3.9 Ethical considerations

Ethical clearance was obtained for this research study during the proposal phase. Due to the sensitivity of the study; confidentiality, privacy and anonymity were preserved in the study. In the reporting of the results, the researcher has not provided a complete profile of the participants. In addition, quotations that would identify participants' responses have not been used in order to ensure confidentiality.

Informed consent was obtained from participants and voluntary participation was ensured. Permission to use a tape recorder and the safe keeping of the tapes and transcripts were discussed. Participants were informed that they would not receive payment for participating in the interview.

Some of the questions in the interview triggered suppressed or repressed emotions. These were addressed after the interview through debriefing.

Participants were referred to other service providers for help but given support whenever they needed it. Three of the participants followed up on the offer.

At times my role as a researcher overlapped with my professional role as a therapist during interviews. Because I was aware of this predicament I tried to separate the two, thus debriefing and referrals were conducted after the interview.

Days after the interview participants praised the researcher for the interview as it made them recognise certain issues that they were taking for granted. This was evident in the case where one participant called me after the collection of data and said, *"I do not know what you have discussed with my partner during the interview but there have been good changes in our relationship"*.

There is a possibility that certain issues were overlooked regarding ethics of the research. Every effort was made, to ensure that the study was carried out in accordance with strict ethical codes and not to compromise the participants in any way. In the following chapter, the results are analysed and discussed in seven major sections.

CHAPTER FOUR

ANALYSIS AND DISCUSSION OF FINDINGS

CHAPTER FOUR

ANALYSIS AND DISCUSSION OF FINDINGS

4.1 INTRODUCTION

This chapter contains the results of the study. It describes, discusses and analyses the in-depth responses of serodiscordant participants who are married. A qualitative approach was adopted in understanding the experiences and the challenges faced by these couples in their discordant relationships. The nature of this study required empathy from the researcher and rapport building as repressed or suppressed information was brought to the surface during interviews.

Participants in this study were drawn from referrals by therapists and doctors. At this point, purposive sampling was used. Participants' responses are analysed according to their HIV status and to some extent their gender. The themes that emerged are identified and discussed. For purposes of preserving confidentiality and anonymity the researcher has not provided a complete profile of the couples. In addition, direct quotations are not always included to ensure that participants would not be able to identify their partners' responses. For the same reason individual participants' responses have been provided instead of couples' responses.

This chapter is divided into seven major sections. The sections are grouped according to their subject areas and do not follow the sequence of the interview guide. In section A, demographic information is provided. In section B, couples' differences in serostatus and explanations given by health care workers for serodiscordant results are presented. Section C presents the data on disclosure to family, friends and children. In section D, the impact of serodiscordance on marital relations and sexual practices are discussed. In section E, the challenges faced by serodiscordant couples in reproduction decision - making are presented. In section F, ARV adherence and the caregiver role played by negative partners and children are discussed. Lastly

section G, describes the services recommended by serodiscordant couples in meeting their needs.

SECTION A

4.2 DEMOGRAPHIC CHARACTERISTICS OF THE PARTICIPANTS

Participants were between the ages of 31 and 49 years old. The participants in the study comprised four married couples and two individuals who were married but participated individually and not as a couple. In the latter two cases the researcher had already interviewed the participants before discovering that their partners were not available. One partner was out of the country and the other, after initially agreeing, decided not to participate. Because of the rich data collected in these single partner interviews I decided to include them in the final report since they met the sampling criteria.

In the following table, demographics of the couples are provided. As explained earlier, very limited identifying information will be provided.

TABLE 4.1 Demographic information

Participants	Duration of marriage	Number of children	Desire to have a child or children	Year of serodiscordant diagnosis
Couple A	21 yrs	3	No	2002
Couple B	4yrs	2	No, pregnant at the time of study	2004
Couple C	1yr & cohabited for 10yrs	1	Yes	2001
Couple D	2yrs	1	Yes	2002
Individual M	6yrs	3	No	2000
Individual F	8yrs	2	No	2001

As can be seen in table 3.1, the couples were all married for more than a year, with one couple married for 21yrs. This suggests that HIV infection can occur even in stable and long term relationships. These findings challenge the notion that marriage is a safety net from AIDS.

The question about the number of children that participants had was asked to ascertain couples' needs in relation to reproductive decision making. All the couples had children. However, two couples had no biological children of their own. The negative partners in these unions had a child from a previous relationship. Three couples had children before they got married. One participant described the situation as follows:

“we had a child before we were married and after we were married we had two other children.”

Table 3.1 above also shows that the couples received the discordance diagnoses between the years 2000 and 2004. Only one couple knew the difference in their status before they got married. The rest of the couples learnt their HIV status a long time after being married or cohabiting. Therefore the possibility exists that some participants were infected after they were married and others were infected long before they were married.

The narratives of two female positive participants illustrate the latter. The two HIV positive female participants shared a common story about their marital relationships. They described the story of their relationships as follows:

“I met my husband when I was still studying. After finishing my high school we started going out together. ...I was pregnant with the first child. After I told him I was pregnant he disappeared. He came back when the child was two years old and apologized. We got back together and eventually got married”.

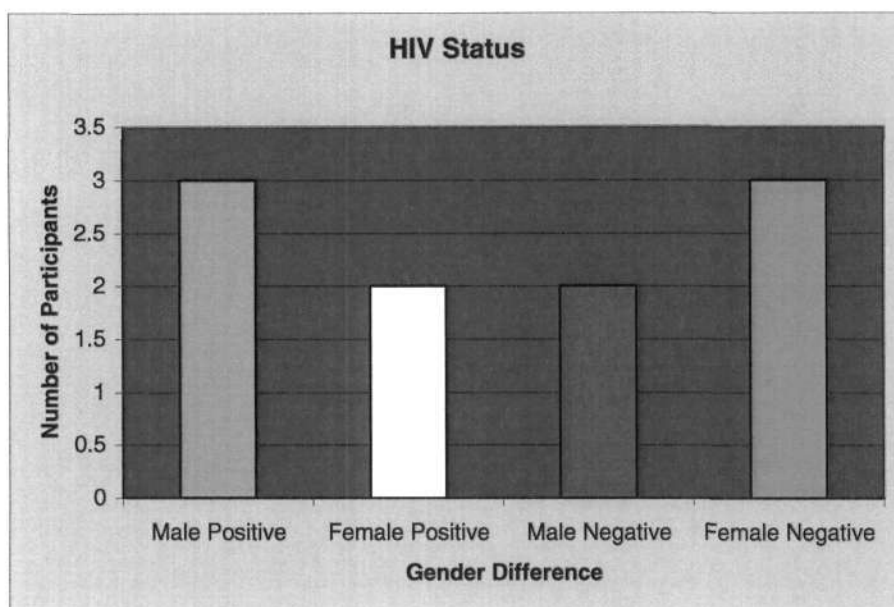
“We started going out when I was young. Then we broke up after having the first child. I then had a child with someone else. My husband then came back after seven years and we got married”.

Both women were confused about why their husbands did not contract HIV after having unprotected sex with them. Bennetts et al (1999) also found that

women in serodiscordant relationships with negative partners were infected outside their current relationship.

All participants were black Africans except one couple who were coloured. Five participants had secondary school education and five had completed tertiary education. All participants were employed at the time of study with three participants holding managerial positions, one participant being self employed, three working in sales and marketing, and the other three doing technical jobs. All, except one couple, were on medical aid insurance.

Figure 4.1 HIV status of participants



The graph above represents the number of HIV positive and negative participants in the study and divides them according to their gender. Three male participants were HIV positive while two females were HIV positive. Three females were HIV negative while two males were HIV negative. There were five positive participants and five negative participants.

In the following section the psychosocial challenges faced by the participants in this study in coping with their serodiscordant status is discussed.

SECTION B

4.3 COUPLE DIFFERENCES IN HIV SEROSTATUS AND EXPLANATIONS GIVEN BY HEALTH CARE WORKERS

This section describes the reasons participants tested for HIV/AIDS, their emotional reaction to the serodiscordant results, how participants coped with the difference in serostatus, and factors contributing to the negative partners remaining in the relationship. In addition, the information given by health care workers (doctors, counselors), reasons and beliefs held by negative participants for testing HIV negative and whether or not on-going counseling was received are discussed.

4.3.1 Factors that influenced the decision to test for HIV

Desire to find reasons for ill health, applying for an insurance policy and encouragement from HIV positive partners were found to be reasons that influenced participants to test for HIV.

Desire to find reasons for ill health

Four of the positive participants were ill and hospitalized. Of these four participants, two participants were suffering from PCP pneumonia, one with suspected TB and one with an undiagnosed illness. Participants were asked to test for HIV by their doctors. The following comments illustrate how some of the participants found out their HIV status:-

"I went for a TB check up. They told me that I have no TB. I have a slight mark on my lungs. Then I got sick. I went to Addington hospital. I was then hospitalized. That is where they asked me if I could have an HIV test done. I agreed to the test. So they found out I was positive."

"I was in and out of hospitals. So in hospital the doctor told me that the symptoms that I had were similar to HIV symptoms. So he suggested that I get tested. So I was tested positive."

"I was very sick in hospital and I was diagnosed with PCP pneumonia and they advised that I do an HIV test."

Applying for an insurance policy

One couple applied for an insurance policy. The insurance company asked the one partner to consult a doctor. She described their situation as follows:

“We were applying for an insurance policy and when the results came back, they declined me the policy and allowed my husband the policy. Then they advised that I see my doctor. I then went to the clinic. It’s when I tested HIV positive”.

Encouraged by HIV positive partners

Four of the positive partners encouraged their partners to test for HIV. The four partners tested for HIV and their results were HIV negative. As described by one participant:

“He told me that he tested HIV positive so I must also go and check my status”.

The above findings on factors influencing the decision to test are similar to the studies of Mahlaya & Osei-hwedie (2005) & Maman et al (2001). They found that reasons for testing were primarily motivated by being pregnant, testing as a means to confirm positive status, sickness, death of a child or partner, and encouragement from partners. Couples who are in long - term relationships or who are married are often not encouraged to test for HIV. This is postulated by Bunnell et al (2005:1009) as follows:

“...most HIV prevention messages, and even definitions of HIV/AIDS knowledge, have focused on risk in the context of casual partnerships and relationships outside marriage. This focus has caused many interventions to either explicitly or implicitly portray marriages as a safe haven, usually without emphasizing the importance of HIV testing before marriage or within established couples who have not previously been tested”.

4.3.2 Disclosure of HIV positive status to partners

Disclosure of an HIV positive status to a partner was found to have no negative consequences except in one incident where a positive partner was physically abused. Positive participants disclosed their status because they thought that their partners were also HIV positive.

Two positive participants reported that they were with their partners when the tests were done. Two other participants disclosed to their partners immediately after the diagnosis and one participant disclosed a week after receiving the results. Some of the responses were as follows:

“I told her immediately and probably she thought that I was joking.”

“Immediately after the doctor told me in hospital I informed my partner but she assumed that since I was positive she’s also positive.”

“A week after they told me the results. The doctor organized for counseling and I disclosed in hospital. Initially he blamed me for the positive results. He said I knew about my results before we got married ...so he thought I married him while knowing I’m HIV positive for security. ...and that’s when he started abusing me emotionally and physically.”

The findings indicate that three of the positive participants disclosed their HIV status because they thought that their partners were also infected. One positive participant informed his partner before they got married. One informed her partner because they had applied for life insurance together.

A further finding was that only one participant indicated problems at the time of disclosure. A female participant indicated that upon disclosure of her positive status to her husband, she was physically abused. These findings are similar to those found by Maman et al (2001). They found that with serodiscordant couples, testing and disclosure processes of serostatus was generally a very positive experience. He also reported that women were more likely to experience negative consequences after serostatus disclosure, including physical violence.

4.3.3 Emotional reactions to differences in HIV status

The discovery of serodiscordant results brought about mixed feelings that included confusion, disbelief, relief for the couples and fear of rejection by positive partners. The following discussion describes the emotional reactions presented by participants. In the following discussion, results are presented for the eight participants who learnt about their serodiscordant status after marriage. As noted in section 4.1 above, one couple knew their serodiscordant status before marriage.

Relief: Both negative and positive participants experienced relief after discovering that they were discordant. Four negative participants were relieved because they were not infected with HIV. As described by one participant:

“...relieved that I was not infected, but there were times when we got emotional and there was a lot of blaming.”

On the other hand, two positive participants were also relieved because they had not infected their partners. As one participant stated:

“I was very relieved that I did not infect her. I thought that she was definitely going to be infected because at that time I did not know that one could not get infected.”

Disbelief: Two negative participants could not believe that they tested HIV negative as compared to their partners who tested HIV positive. They could not believe how it happened. As a result they repeatedly went for HIV testing but their results remained HIV negative, as described by the following participant:

“I did not believe that I was negative, so I went to check after three months but my results were still negative, and I have tested four times but continued testing negative even after the condom broke.”

Two positive female participants echoed their disbelief when they tested HIV positive while their husbands tested HIV negative. One positive participant expressed the following:

"I could not believe that I tested HIV positive and he was negative. I could not understand how I could be infected and he is not, after having sex without using condoms."

Confusion: The serodiscordant results did not only bring disbelief, but also confusion. Participants could not understand how one partner could remain uninfected after having sex without a condom. This was expressed by all eight participants who did not know their statuses before marriage. One participant constantly echoed her confusion throughout this section of the interview as follows:

"Frustrated, shocked, angry and confused. Actually I'm still confused."

Bunell et al, (2005) and Johnston (1995) also found in their research that the majority of the participants reported being confused by their HIV discordant results.

Fear of rejection: Four positive participants also experienced feelings of fear of rejection. These positive participants, after discovering that they had differences in HIV status, were scared that their partners would blame them for being diagnosed with HIV. As explained by one participant:

"I was scared that he was going to leave me or divorce me."

Also, three negative participants expressed that their positive partners were expecting them to leave since they did not want them to bear the burden of being involved with someone who was HIV positive, especially when they were ill. The following illustrates this:

"He thought that I would leave him... I felt it would be unfair of me if I were to leave him just because he's in trouble. He used to be worried thinking that I

would leave him saying that there's no person who would stay with someone who is HIV positive after it was him who was cheating."

The findings discussed above show that all participants experienced some form of emotion. The overwhelming feeling was one of confusion about the differences in HIV status and fear that the negative partner would leave the relationship. Hanson (2000) and Johnston (1995) also found that seropositive partners had recurrent fears that the seronegative partners would leave them and meet someone else who would replace them after their death.

4.3.4 Trust versus infidelity¹

The discovery of serodiscordance raised questions regarding trust and infidelity in the relationship. As much as negative participants voiced mixed feelings (confusion, happiness, disbelief, anxiety and numbness) after they tested negative, questions on how the partner got infected with HIV were raised as illustrated in the following statement:

"I did raise questions as to how my partner got infected though that's not something that we always talk about. Each time I raised this question we ended up pointing fingers and blaming each other...we just left it like that without resolving it. Life goes on."

When infidelity was explored, participants were reluctant to discuss it and felt that it was no use going back to the past. One participant mentioned that she thought there were many reasons why her partner may have tested positive such as through a blood transfusion. The issue of infidelity was left hanging to maintain the equilibrium in the relationship. Although participants mentioned that HIV was not an issue and that they simply wanted normalcy in their lives, a lack of trust and unanswered questions on the positive diagnosis, seriously affected the relationship.

¹ Parts of this section have been published in Dano (2006:48).

4.3.5 Coping mechanisms used by couples

There were two types of coping mechanisms which emerged in this study: negative and positive coping mechanisms. Positive coping mechanisms included support and acceptance, and the negative coping mechanism was avoidance.

Acceptance: Three negative participants mentioned acceptance of the other partner's status as a way of dealing with the confusion of the serodiscordant status. Accepting that the situation would not change, irrespective of the answers, was a mechanism for adapting to change in the relationship.

“...because we have both accepted the situation about our difference in status so there's no problem.”

Support: Three female negative partners were more supportive of their HIV positive partners as opposed to the two negative male partners. As described by one negative participant:

“Initially I was so supportive. I was surprisingly very supportive of him. I just wanted to help him.”

Hanson (2000) found that seronegative women remain silent, married and supportive of their husbands while they are unable to find support and care for themselves.

Avoidance: Participants mentioned that they did not want HIV to dominate their lives. They wanted to live normal lives. What constituted normalcy was to forget about the existence of HIV in their relationships. One negative participant mentioned that she wished she could live her life without being reminded that HIV/AIDS existed in their relationship:

“I just wish I could live my life without being reminded of HIV/AIDS all the time.”

Acceptance and support were significant findings on how participants really coped with their feelings and adapted to changes in their relationships. What was more interesting is the fact that negative women participants were more supportive of their positive husbands. What was not explored was whether acceptance and supportiveness was related to the fact that women accept that married men have extra marital affairs.

4.3.6 Factors contributing to the negative partners remaining in the relationship

Negative partners were faced with a crucial decision on whether or not to stay or leave their marriages after their partners tested HIV positive. All negative partners made the decision to remain in the marriage. The themes which emerged were: remaining in the relationship because of love and companionship, children, commitment to the relationship and acknowledgement of the existence of HIV everywhere.

Love and companionship: Two negative participants in the study mentioned love and compassion as reasons for them remaining in their serodiscordant relationships. They felt that their love for their partners could not be changed by their difference in status as echoed by the following participant:

“... HIV should not affect or change the way people are living their lives/ relationships.”

Acknowledgement of the existence of HIV: Three negative participants mentioned that it was not necessary to leave their marriages since HIV was everywhere. They commented that it was better to stay with someone that you knew was HIV positive than leave the relationship. They felt that the risk of infection was high in a relationship where the one partner was negative because of the chances that he/she might be unfaithful and be infected at a later stage. This may be related to the high HIV infection rate that exists in

South Africa that led to the participants deciding that it was safer to be in a known discordant relationship. As two participants stated:

"The devil you know is better than the devil you don't know because you can deal with it."

"For me it felt like anyone could be HIV positive and it is better to know what is happening than not knowing."

Similarly Palmer & Bor (2001) found that HIV negative participants mentioned that they felt safe or more comfortable in a relationship where they knew their partners' status even though it was positive. Participants claimed that being in serodiscordant relationships made it easier to adapt and maintain safer sex practices.

Children and commitment to the relationship: Two negative participants also mentioned that they had been together for a long period with their partners and had older children, thus leaving was not an option.

"We have been together for a long time and I have older children who have children of their own, especially my elder son."

Hanson (2000) noted that women who have children and grandchildren and who are seronegative in discordant relationships are faced with further complexities and anxieties. These anxieties include feeling tied culturally, socially and financially to marriage and family (Hanson,2000). Although Hanson discusses anxieties, it appears that in this study staying was not due to anxieties but rather due to commitment to the relationship.

4.3.7 Explanations given to participants by doctors/ counselors on their differences in serostatus

Participants were given various reasons for their discordant results. In analyzing the results the following themes emerged: being seen as lucky, that some people are immune and that there was no explanation whatsoever.

Seen as being lucky: Four participants reported that the doctors told them they were lucky for not being infected, without giving any further medical or biological explanation. This was illustrated by the following comment:

“The doctor said she was one of the lucky people, there were no further explanation as to what were the causes.”

Some people are immune: Two participants (one couple) reported that their doctor told them that some people do not get infected or are immune to HIV/AIDS. The doctor also informed the negative partner not to bother to test for HIV again as she will not be infected. The same couple visited another doctor who used the example of fertilization to explain the process of how one partner did not get infected. Both partners were confused after they were given these explanations. This was described as follows:

“But one doctor told me that I must never get tested again in my life, giving the reason that I won’t be infected. So this confuses me more because what I know is that with no protected sex there’s a chance that I can get it even afterwards.”

“They explained that the fluids or sperm they rub in and they mix up something similar to conceiving a child. Some people they don’t get infected like when other sperm do not fertilize the egg. We just assumed...I don’t know what we were assuming. Some people are very easy to contract it others are not. Even doctors they can’t explain how it happens.”

No explanation given: Five participants mentioned that their doctors could not explain the reasons for their serodiscordance.

An interesting finding was that couples tested more than once and went to different doctors with the hope that there would be an explanation given to them for their serodiscordant results. Also they thought that maybe the results would change. Lack of information on causes of discordance leaves couples confused and uncertain about what to believe. The above comments demonstrate clearly that more research needs to be done in relation to explaining the causes of discordant results to couples. Also there is a need for counseling guidelines, policy or protocol for health care workers to be informed on what to say during counseling. According to Bunnell et al, (2005:1000):

“Immunological research has suggested that cellular immunity and viral characteristics may be associated with HIV discordance, but the biological implications and the magnitude of the effect on risk of transmission are not well characterized. While some solid scientific evidence exists, additional research is underway to provide translation of this evidence into meaningful messages and this for patients is challenging.”

All the participants were dissatisfied with the explanation given to them by health care workers. Some of the participants conducted their own research on discordance but they were still not satisfied. The following comments illustrate this as follows:

“We were told that this just happens. No clear explanation was given and this made me more frustrated. “

“There was no explanation so I decided to do my own research on the internet. There was no better explanation whatsoever...”

“I was seeking an explanation and answers. They said one in a million doesn’t ever contract it. Bottom line was that I was negative.”

“Actually he couldn’t explain the reason why and just told me that it’s rare situation.”

This is similar to Bunnell et al’s (2005:4) observation that “very few clients and counselors provided accurate information about why HIV discordance existed”. They further explained that a minority explained discordance using scientifically established factors associated with risks of HIV transmission, including circumcision, length of relationship, frequency of sexual encounters and presence of STDs.

4.3.8 Beliefs held by participants for testing HIV negative

Three of the negative participants felt that their ancestors and God were looking after them and they were the lucky ones or the chosen ones. Two of these three participants reported the following feelings about the differences in their status:-

“... it could be that my ancestors are looking after me and also God is giving me protection.”

“I just felt that I’m the chosen one, because I’m a true believer and I have faith in God and this shows that our lives are in somebody else’s hands.”

Bunnell et al (2005) stated that in their study the negative participants gave the following reasons for not being infected; ordained by God, inaccurate tests, gentle sex, chance/ luck or belief that they were immune to HIV. Even though participants felt that they were lucky, they clearly wanted more scientific knowledge and evidence that explained the causes of discordant results. Most of them went the extra mile in doing their own research in trying to find out the reasons for discordant results.

4.3.9 Information on on-going counseling

Only two of the positive participants received on-going counseling especially on treatment readiness. None of the negative partners received on-going counseling. The two positive participants who received counseling mentioned that the focus was on information on treatment, nutrition and use of condoms and nothing on discordance.

Negative partners felt that they should have received counseling to discuss their own concerns. The frustration in this regard is echoed by one participant as follows:

“After they have given him the tablets there was no counseling at all. But there was nothing for me as a negative partner”.

It is clear from the above finding that there was only information giving and no therapy given to participants on how to deal with psychosocial issues and concerns arising from their difference in status. This suggests that there is a need for referral systems to be put in place to enable couples to deal with their concerns.

In summary, reasons for testing, emotional reactions to differences in serostatus and explanations given to participants by doctors or counselors on their difference in status were explored in this section. The following section discusses disclosure of serodiscordant status to family, friends and children.

SECTION C

4.4 DISCLOSURE OF SERODISCORDANT RESULTS TO FAMILIES, FRIENDS AND CHILDREN

Disclosure of HIV status is usually a process that involves only HIV positive individuals, but in serodiscordant relationships it involves both HIV positive and negative partners (Van Der Straten et al, 1998). This section explores the processes involved and psychosocial reactions after the disclosure of serodiscordance by the participants to their families and friends. The findings will be discussed according to difference in HIV status and to some extent, gender.

The table below illustrates the disclosure patterns of serodiscordant status to family, friends and children.

Table 4.2 Disclosure of serodiscordant status

DISCLOSURE	FAMILY		CHILDREN		FRIENDS	
	Positive	Negative	Positive	Negative	Positive	Negative
DISCLOSED	4	2	1	2	4	3
DID NOT DISCLOSE	1	3	4	3	1	2

4.4.1 Disclosure of serodiscordance to family members

Only two couples disclosed their status to their families while the rest of the participants disclosed individually or did not disclose at all. Four positive participants disclosed their serodiscordant status to family members. One positive participant did not disclose. Two negative participants disclosed and three negative participants did not disclose their discordance status to their families. The disclosure was either done to a sibling, parent or an extended family member. Six participants disclosed and four did not disclose.

Of the four positive participants who disclosed, two were males and two females. Males that disclosed did it involuntarily, resulting from their illness and admission to hospital at the time of disclosure. On the other hand, females disclosed voluntarily to their family members.

4.4.1.1 Reasons given by participants for not disclosing

Three negative participants communicated the fear that their relationships would not be accepted by family members and that they would be pressurised to divorce or leave their positive partners. Linked to the above reason, another fear was associated with the fact that their family members would not understand why they wanted to remain in such risky relationships. One positive participant feared that his parents were not psychologically and physically fit to deal with the news.

The following quotes illustrate the above:

“I haven’t told my family because I know how they are. They would have asked me to leave him”

“I don’t think it is important that we disclose to them. It’s better to leave other people stress less, you know, because the problem with disclosure is you are causing them more stress. They will start thinking when are you going to die, worrying and give you more worry. Then they will start thinking and asking, are you taking more precaution (sex wise)? They start putting unnecessary pressure for nothing that is why we must take things as they come. So why worry about Jo’burg when you have not reached Jo’burg.”

“No, I don’t want to disclose because there’s no need for it, they will not understand why I have to remain in this relationship.”

“My mother is not well, so I’m scared that she might get sick after I disclosed.”

Their fears were thus associated with prejudice and the intense pressure that would be exerted on them by their families. As a result they felt that disclosure could result in strain and enormous stress on their families. It appears from the study that the decision not to disclose was taken in order to preserve family relationships and ties. In addition, one positive partner had fears about the consequences for the parent if he disclosed. The results of this study are

similar to the study of Palmer & Bor (2001) where the reason for participants' non-disclosure of their status to their families was to protect their relatives from emotional pain and prevent a shift in family dynamics.

4.4.1.2 Reactions of family members to discordance disclosure

Families of positive participants were at first devastated that their family members were suffering from HIV/AIDS. They were also concerned about the deterioration of their health since they were ill at the time of diagnosis. All positive participants reported that their families accepted their positive status and were supportive. Two participants described the following:

"I initially told my mom and she was fine with it. I am more upfront with her. She then disclosed my status to the rest of the family. My family was supportive."

"I disclosed to my sister. She was shocked and wondering how does it happen that he was not HIV positive. But she is supportive of me."

In contrast families of negative participants were relieved and happy that their family members were HIV negative but angry with the positive partner. This was described as follows:

"This happened in two stages, both families were traumatised after they had found out that my husband was positive and after my results were negative my family was very relieved. One of my brothers was very angry with my husband."

One positive partner reported that the family of the negative partner was not only angry, but insisted that the negative partner file for divorce and threatened to remove the children away from the positive partner. The participant described this as follows:

"At some stage my husband's family was trying to take the kids away from me claiming that I'm going to die one day so the kids needed to get used to the idea that I'm not going to be around...I was the bad person in the family. They were not talking to me."

The families of negative participants were also worried that the negative partners would get infected in the long run and pressured the negative partners not to have sex with the positive partner as evidenced below:

“...and she said to me, I hope you are not having sex with him anymore”.

The data presented above shows that upon disclosure of serodiscordance, the positive participants were accepted and supported by their own families and generally not accepted by their negative partners' families. Although all families shared disbelief and shock after learning about serodiscordance, the responses by negative participants' families were devastating. The reactions within these family systems are also a reflection of what occurs at the mezzo level around HIV/AIDS and serodiscordance. Smith (1996) reported that families and friends wondered why someone who is HIV negative would continue to be in a relationship with someone who is HIV positive and risk HIV transmission, death or being dependent on someone else or having someone else dependent on them. In addition, van der Straten et al (1998:538) found that:

“...disclosure was problematic because support was sought not only for the partner living with HIV, but for the potentially high risk sexual relationship of mixed serostatus. While for some, close relatives were the main source of emotional support, awkward and unsupportive responses from family and friends were mentioned by many of the participants when the differing serostatus in their relationship was disclosed.”

It was also interesting to note that sisters and mothers in the study were most often reported as the individuals to whom the disclosure was presented. Palmer & Bor (2001) also found that study participants who disclosed their serostatus chose to disclose to mothers and sisters. These authors attributed this to the role of women as care-givers and nurturers within the family system.

4.4.2 DISCLOSURE OF SERODISCORDANCE TO CHILDREN

Disclosure to children was not done as a couple but as individuals. None of the male participants, irrespective of their status, disclosed to their children. Only three female participants disclosed the serodiscordant status to their children. Two of the participants were negative and one was HIV positive. Therefore, in three families children were not told about the HIV status of their parents nor the serodiscordance.

4.4.2.1 Reasons given by participants for not disclosing to children

Participants who did not disclose to their children shared their fears and concerns as follows: sex was not easy to discuss with children and they feared not knowing what to say or how to say it. In addition, participants feared the possibility of a child judging the positive partner. This was associated with the attitudes and prejudices that people hold about HIV infected people, such as that they are promiscuous. The other issue was that participants did not know how they would answer questions if the children asked them. They also feared that the children would reject them.

The fear that disclosure would have a negative impact on the psychological and emotional functioning of the child was also reported. As stated by one participant; *"I do not want them to be worried about my status"*. All three participants shared the same sentiments of being worried about the negative consequences of disclosure and how children would cope with the news.

Two participants claimed that the ages of their children were not appropriate for disclosure. As mentioned by a participant; *"They are still too young to understand. When they start asking a lot of questions, questions like why and when ...that will be the right time to tell"*. Although these parents mentioned age appropriateness, some of them did not have a clear idea of what the appropriate age for disclosure was.

4.4.2.2 Procedures followed by participants in disclosing to children

The following describes the procedures followed by the three female participants who disclosed their serodiscordant status to their child/children. Disclosing to children has been found to be the most frightening and most daunting for parents, as they do not know what to say and do while disclosing. The following describes how participants disclosed the discordant status to their children.

One of the participants mentioned that she started by educating her children about HIV/AIDS before disclosing:

“...it took me a long time to disclose to my kids. I always wondered how am I going to tell them and how are they going to react. What I did with the big one I use to sit down with him and try to find out what he knows about HIV. I will then correct the myths and misconception. So I started educating him ...”

She further indicated that:

“I educated my kids about HIV/AIDS and thereafter I decided to disclose before they knew/ learnt about it from someone else and I have also prepared my kids for public disclosure.”

She mentioned that she did this to ascertain information children had about AIDS and to correct the myths while ensuring that they have a clear understanding of what HIV/AIDS is all about.

The second participant mentioned that her sibling disclosed on her behalf. She stated that:

“My sister informed my children...”

The third participant stated that her child started asking questions when he saw the positive partner presenting symptoms of AIDS. It was at that point when the disclosure was made;

“They were learning about HIV/AIDS in school so while he was sick he said to me mommy I think daddy has AIDS because of the symptoms his presenting with. I also think he saw his tablets because he was taking treatment at that

time. And then he asked if I did do a test and what were my results. I then told him .He then asked if I was sure that they were negative... What helped was that we made him part of the decision making (fetching tablets)".

It is evident from these findings that disclosure to children occurred because certain events occurred, it was not done voluntarily except in one case.

4.4.2.3 Reaction of children to disclosure

After participants had disclosed their serodiscordant status, children manifested feelings of sadness and worried that the positive parent was going to die. One participant described the reactions of her children as follows:

"My sons were crying and devastated. You know when you have told someone that a person has died, they were like that. They were worried, thinking that their father was going to die. But they are sensitive to people who are saying negative things about HIV positive people."

Children were also supportive and reminded the positive parent to take their medications regularly. One participant reported that her young children were concerned about whether they were also HIV positive and wanted to be tested. Although children were relieved that one parent was negative, they were confused about the serodiscordant status of their parents. The third participant described how his son could not believe that it was possible that after the length of time his parents had been together, the mother was not infected:

"Before he believed that I was negative he was very worried and even said that before I get too sick I must ensure that I have left money for him to continue with his education."

The findings suggest that one of the main reasons given by parents for delaying disclosure was associated with the child/children's age and fear of causing emotional stress. Stein (2004) found that HIV positive mothers often indefinitely delay disclosure to children on the grounds that children are too young to understand. This is seen as an attempt to protect children from painful information and from becoming overwhelmed (Sheckter, 2002).

The silence on HIV/AIDS by parents is universally accepted, as the disease is associated with death and promiscuity, leaving parents ashamed about disclosing their status to children. Stein (2004:17) postulates that it is the stigma associated with AIDS, rather than its nature as a terminal or chronic disease, which often underlies non- disclosure to children. He further argues that there is a need for parents to be empowered to deal with their feelings of guilt and shame when discussing HIV with children.

Data presented in this study also illustrates that the children who knew their parents' status often protected their parents from others. Children who were informed of their parents' terminal illness showed significantly less anxiety than children who were not told. Children responded to the diagnosis by being closer and protective or appeared confused, tearful and scared (Stein, 2004 & Dane, 1999).

The disclosure of status occurred at home except in the case of one child where it took place in the car. One participant disclosed immediately, the other participant disclosed after three years of knowing their serodiscordant status and one child found out after seeing symptoms and reading the labels on tablets. This suggests that disclosure may not have happened if participants were not on medication. Parents used different strategies in disclosing their status, including educating the children about HIV/AIDS before the disclosure and seeking help from a sibling to disclose on behalf of the participant. Serodiscordance brought hope to children that they still had one parent who was not infected.

4.4.3 Disclosure of serodiscordance to friends

Four HIV positive participants disclosed their serodiscordant status while one did not disclose his status and three negative participants disclosed their serodiscordant status while two negative participants did not disclose. In total, seven participants disclosed and three participants did not disclose. An interesting finding is that all of the participants disclosed the serodiscordant

status individually and not as a couple. Another finding was that three HIV negative participants disclosed to friends and not to their family members.

4.4.3.1 Reasons for disclosure and non-disclosure to friends

One of the reasons mentioned by participants for disclosure to friends was that they disclosed with the hope that their friends would provide support and understanding. Two participants mentioned that they wanted to encourage friends to test for HIV before they became ill.

Three participants who did not disclose feared that their friends would not understand and they would start telling the news to everyone. The following was described:

“We agreed that it would be our secret; no one else will have to know about it. I haven’t told my friends because they might not be able to keep a secret.”

“I felt that it was necessary that we don’t share our statuses with other people because before you know it they will be gossiping in the whole town.”

After disclosure, friends reacted with shock and confusion but they were supportive. They also wondered about the difference in status. The following describe their reactions:

“It was a shock at first, they could not understand that kind of thing. At the beginning you know the myths around HIV they become distant and they have come around slowly. But I explained to them.”

“Shocked and supportive for both of us”. They have never asked or had comments about the difference in our status but while I was reflecting with them as to how could such a thing happen they were also interested in reasons, just like me.”

“Well I guess my friend was shocked after knowing that my husband was positive...this has also helped me to have someone to talk to whenever I’m having concerns”.

Data presented shows that three negative participants disclosed to their friends as compared to their families. Friends were shocked after learning that their friends were serodiscordant and one positive participant reported that his

friend's initial reaction was to become distant after the disclosure but that s/he had provided support to the participants. Therefore friends became an important support system.

In summary, fear of stigma and rejection remains a barrier to effective disclosure of a serodiscordant status, resulting in individuals keeping it a secret. For negative participants the fear that their families and friends would judge them for remaining in risky relationships prevented them from disclosing. One positive participant feared that his parents would be psychologically affected by the news. 70% of the participants disclosed either to family members, friends or children.

The following section describes the impact of serodiscordance on marital relations and sexual practices.

SECTION D

4.5 IMPACT OF SERODISCORDANCE ON MARITAL RELATIONS AND SEXUAL PRACTICES²

This section explores the intimate relationship of participants after the diagnosis of serodiscordance. The findings will be presented in two sub-sections: marital relations and sexual practices after the serodiscordance diagnosis. This was the most sensitive section of the interview, as it required participants to reveal their sexual practices.

4.5.1 Marital relations after the diagnosis of serodiscordance

This section on marital relations focuses on the changes that occurred after the diagnosis of serodiscordance. All participants indicated that the presence of HIV and differences in HIV status had detrimental effects on their relationships. Feelings of insecurity, feeling betrayed, physical abuse and neglect and lack of communication were themes that emerged. These were reported by participants to have threatened the stability of the couple system.

² Parts of this section have been published in Dano (2006)

Feelings of insecurity: Four of the five positive participants expressed insecurities in the relationship. They felt that their negative partners were going to leave. One negative participant mentioned that her positive partner was jealous and had unfounded suspicions that she was cheating. This resulted in quarrels. She stated that:

“He has been jealous and he started doing funny things such as suspecting that I’m involved in an affair.”

According to Forbes (in Wasson, 2007:77) “jealousy is a mental cancer; it spreads quickly and can be fatal to a relationship”. It appears that the vulnerability of a positive partner leads to insecurity and constant fears of abandonment. Aronstein & Thompson (1998:195) postulated that “the fear of being abandoned and dying alone rushes in, adding to the intensity of the infected partner’s distress.” The findings suggest that HIV intrudes in the couple system evoking anxiety and paranoia in the positive partner. It can be argued that this is a normal reaction when there is a threat to the relationship.

Feeling betrayed: One positive participant expressed her disappointment about how her husband treated her unfairly. She stated that he made no attempt to understand her illness and what she was going through. She felt betrayed by her husband, claiming that she had been a loyal wife and did not understand why he was not supportive. She expressed the following concern:

“Things were not the same. The main thing I felt he did not understand the whole HIV thing ... the fact that he could not understand my sickness, could not understand what I was going through. I was also thinking that I have been the loyal wife all my life and he’s treating me badly, not giving me the treatment that I deserved.”

Physical violence and neglect: One positive partner experienced physical abuse and neglect after the husband blamed her for bringing HIV into the home. This has caused enormous strain in the family system as children were affected by this conflict.

The positive partner was feeling betrayed by the husband for not supporting her and this could be associated with the fact that the husband was still

blaming her for being HIV positive and for possibly having committed adultery. It could be that the negative partner was feeling betrayed and was thus unsupportive. Aronstein & Thompson (1998:185) also observed “the rage, despair, and often deep sense of betrayal in the wake of a partner’s failure to respond in times of distress.” These authors further argued that “there is a tendency on the positive partners’ part to expect the negative partner to modulate and respond to distress rather than tend to it on an individual basis through support groups or psychotherapy. The negative partner may pull back in the face of such pressure, leaving the positive partner feeling abandoned in the face of his/her distress”.

Lack of communication: All participants found it hard to communicate openly about their fears and concerns in relation to their discordance and HIV/AIDS. Reasons given by two negative participants were that they were protecting the positive partner from getting hurt by avoiding the topic.

“There’s no specific communication about him and the disease but the general public and the disease. It has become a fallen topic. I don’t want him to become uncomfortable.”

“All I can say is that me and my husband we have never sat down and discussed about HIV in relation to our lives. We just discussed when he was fetching his tablets and that was it. I would like to talk more about his concerns and how he feels. I would like to talk about different issues but I am scared that he will think that I think he’s dying.”

Aronstein & Thompson(1998) maintained that the “negative partner may also fear that by sharing the extent of his distress that he will only be further burdening his already burdened partner”. On the other hand, positive participants felt that they did not want to become a burden to their partners. One participant illustrated this as follows:

“No, sometimes I feel I don’t need to create a sense of panic. When I’m sick I keep it to myself until it then gets worse.”

Participants in the study were very reluctant to discuss concerns in the relationship. However they would discuss: HIV management (check up and

appointments); nutrition and HIV (type of food they ought to eat) and treatment issues (what type of treatment they are taking).

As noted above, the communication focused on general issues in relation to HIV/AIDS and was not specific to feelings of each individual within the couple dyad. These findings are consistent with those of Smith (1996) who found that the couples in his study hardly ever communicated verbally and also ceased being sexually intimate. He argued that as much as couples faced a future of living with HIV, they lacked any sense of what should constitute "normal" for them as a couple.

In contrast to the negative comments above, two participants were more positive about their relationship as discussed below:

Acceptance and trust: Two participants expressed that trust in their relationships had made it easy for them to continue with their lives and they understood each other better. Acceptance of the presence of HIV in the relationship has also made it easy to keep the marriage intact.

"Things are just the same, there's no difference. Because we have both accepted the situation about our difference in status so there's no problem."

"I think it is the way we communicate and the fact that there has always been that trust between us. Trust has made our relationship stronger...we understand each other better now than before."

These two participants found that acceptance and trust was a remedy for making serodiscordant relationships work. These participants appear to have realized that trying to find answers to the unknown would not change the fact that they are serodiscordant and acceptance is taken as a sign of moving on with life.

Even though results have not been analysed in terms of couple responses (because of confidentiality issues) it was evident from the findings that participants had differences of opinion and perceptions about what constituted normalcy in their relationship. One couple at the time of study was recently

diagnosed. The positive partner was quite emotional during the interview though she mentioned that everything was fine. The themes discussed above will need to be covered in counseling guidelines with serodiscordant couples.

4.5.2 Sexual practices after serodiscordant diagnosis

The following two themes emerged: changes in sexual desire and ability and inability to maintain safer sex practices. In the discussion that follows these themes and the sub-themes will be discussed.

4.5.2.1 *Changes in sexual desire*

All participants' felt that their sexual life changed drastically, for better or worse. Three participants noted positive changes in sexual desire and seven participants noted negative changes in their intimate relationship. Positive changes included themes such as partners becoming closer to each other and reality of death drawing partners together; and negative changes included themes such as frequency change, loss of interest in sex and positive partner being highly sexually active.

Becoming Closer: Two participants mentioned that the serodiscordance diagnosis resulted in them feeling closer to each other. As indicated by one of the participants:

“We explore more things now ever since diagnosis, I think we appreciate sex now, more than ever”.

Reality of death: One participant stated that she and her partner realised that they did not have much time left with each other. The partner expressed the same sentiments when interviewed. Both indicated that the serodiscordance diagnosis had drawn them closer and improved their sexual intimacy. The negative partner expressed the following:

“Once a week, I think the reality of death has made one to discover or appreciate life more than ever. Maybe the fact that he won't be around forever I look more to please while the other person is still alive.”

The reality of living in the present was evident in this study leading four participants to appreciate their lives. Tallis (1997) also found that an HIV positive result can put life into perspective and highlight the value of being alive.

Frequency change: A drastic change was noted by couples in the frequency of making love. One participant shared her frustration as follows:

“...changed from everyday to twice a week to absolutely nothing.”

In contrast, four participants reported improved sexual intimacy from unsatisfactory to fulfilling levels and from once a month to almost everyday. This shift has led to couples having a healthy sexual relationship.

Loss of interest in sex: Loss of interest in sex was reported as the factor that caused the most tension in the couple and family system. Four participants mentioned that they fight about anything and everything, and also they do not talk to each other for days. One participant mentioned that his partner always had excuses for not wanting to have sex. Expressing his frustration he mentioned that he understands why men cheat as follows:

“ When I ask for the reasons she will say girls are different from guys... she will have headaches all the time....now I even understand why men cheat... this causes more tension in the house.”

Bunnell et al (2005) postulated that sexual relations posed the most formidable challenge for couples, particularly women. Also many HIV positive participants had lost interest in sex completely due to their serodiscordant status.

Two positive female participants expressed how uncomfortable they felt when making love. These participants associated this with the fact that their partners were refusing to use condoms. As a result of loss of libido one of these two participants encouraged her partner to have sex outside their marriage. This was described as follows:

“I have just lost interest in sex...I have asked him to get another girlfriend because I don't feel comfortable having sex with him.”

Bunnell et al (2005) reported a case of one couple who wrote a contract in which the man agreed that the woman could look for an HIV negative sexual partner outside their relationship, provided they continued to live as a couple.

Being more sexually active: One positive partner was reported by his negative partner as being more sexually active than before and also having extramarital sex. This was described as follows:

“After diagnosis he has become more active in sex even outside our marriage “.

For those who reported a negative impact, a picture emerged in this study. Women participants reported having problems with libido and did not feel comfortable having sex as compared to male participants. When they were asked for the reasons for such a change, participants were not sure what was causing the change. They felt that the change was brought about by tension in their relationships. Negative female participants, after further probing, expressed that their lack of libido could be associated with fear of being infected and fears that the condom may burst. On the other hand, the positive participants' fears could be associated with fear of infecting the other partner and also blaming sex for being infected with HIV. These findings are consistent with studies conducted by Palmer & Bor (2001), van der Straten et al (1998) and Shernoff (1991) who found that managing emotional and sexual intimacy could be challenging in serodiscordant relationships due to transmission concerns, the burden of initiating and maintaining safer sex and the health status of the infected partner. These authors maintain that all of these factors could contribute to changes in sexual desire and increases in psychosexual problems.

The reason for the positive partner encouraging the negative partner to have extramarital sex could also be associated with feelings of fear of rejection and being lonely, and therefore trying to create balance in the relationship. This

balance would be achieved by having the sexual needs of the other partner satisfied while he is still part of the couple system.

4.5.2.2 Ability and inability to maintain safer sex practices

“Added to the pressure on couples is the need to practice ‘safer sex’ at a time when intimacy and closeness is most needed but often difficult to achieve” (De Matteo et al., 2002:273). The ability and the inability of couples to maintain safer sex continues to be a core concern, leaving couples with a sense of guilt after engaging in unprotected sex. In the section below the sub-themes are discussed.

Ability to maintain safer sex practices

Two participants mentioned that the adjustment to using condoms consistently had not been easy since they had not used them before the diagnosis. One couple managed because they knew their serodiscordant status before they engaged in a sexual relationship. Participants mentioned being compelled to use condoms as they feared the risk of infection and felt that they had no other choice in attempting to prevent infection. For the participants who knew their discordance after marriage, use of condom was a logical decision rather than one that was discussed or negotiated. Participants made the following comments:

“The reason for introducing condoms in our sexual life was mainly based on the fact that we use condoms in order to avoid infection... we have to use condoms because we were told to use condoms and we therefore do not have a choice.”

“I don’t have problems though at first it was a problem in getting used to them. Just because I have to take care of my health I do use them. I think he was insisting on using condoms because the doctor told him that he would go back and get sick if he doesn’t use condoms. Though we have had some problems at first as it was not easy to use condoms but we are managing.”

For couples who eventually managed to consistently use condoms, the following pattern was evident: couples started with the inconsistent use of condoms → this led to arguments and conflict about safer sex → this resulted

in not having sex at all→ and culminated in practicing safe sex. What was unclear, was what led couples to have protected sex again as they had minimal communication and negotiation about their sex lives. There is a need for this pattern to be explored further.

Inability to maintain safer sex practices

All couples felt that it was difficult for them to maintain safe sex. The following sub-themes emerged: condoms were a constant reminder of HIV/AIDS; they spoilt the natural fun and passion; there were difficulties in becoming accustomed to the use of condoms and the negative partner refusing to use condoms since they previously did not seroconvert after unprotected sex.

Difficulties in becoming accustomed to the use of condoms: Three participants mentioned that they had difficulties in getting used to condoms. They related this to the fact that they had not used condoms for a long time and adjustment was difficult to reach. They mentioned that they get carried away by passion and they found condoms uncomfortable to use. One participant stated that:

“It’s not easy. Even now I get carried away now and again and we engage in unprotected sex. You know that kind of stuff and she will get upset afterwards. She will be complaining but it’s not that very often. It’s difficult to get used to condoms after a long time of not using them.”

Condom as a constant reminder of HIV/AIDS: Four participants mentioned that each time they are intimate and having fun, they have to stop and prepare to use condoms. For participants this becomes a constant reminder about the existence of HIV/AIDS in their lives. They felt that they cannot escape from being reminded all the time that there is HIV in their lives. One participant described this as follows:

“Oh God. I still find it a problem though we have to use them, but still I cannot get used to them. It is a constant reminder of what is going on. It’s like you can’t live without thinking about AIDS because each time you want to have sex you are reminded of what is going on.”

Condoms spoil sex: One participant mentioned that she felt that condoms spoiled passion and the intimate moment they shared as a couple. This was expressed as follows:

“He does not mind though at times we fight because he doesn’t use it. I think he just doesn’t wanna use it, it spoils the fun of sex.”

All the above mentioned findings on inability to maintain safer sex are similar to the findings of Remien, et al (1995) although their study investigated homosexual partners. Aronstein & Thompson (1998:193) argued that “we are faced with having to believe in the concept of safer sex in order to maintain a sexual life, we are also faced with constant, and at times highly disruptive, intrusion of the horror of HIV into fantasies that are often highly charged with excitement, vitality, and the desire to connect with another person”.

Negative partners refusing to use condoms: two positive female participants mentioned that their negative male partners did not want to use condoms even though they knew that their partners were HIV positive. The two positive participants expressed that their partners felt that using condoms was unnecessary. The following are the comments made by the two female participants:

“He doesn’t want to use condoms despite that he knows that I’m positive. He felt using condoms was not necessary since we have not been using condoms and he’s not infected. But I told him that he’s blaming me already that I brought HIV at home and I don’t want a situation where he will get infected and blame me for it.”

“It has not been easy for him to use condoms, actually he doesn’t want to use condoms since he is not infected.”

The above findings are in contrast to the findings of Skumick et al (1996) and Painter (2000) who found that condom use was reported to be more frequent and consistent especially where men were HIV seronegative. However, Palmer and Bor (2001) found that the negative partners often insisted on practising unsafe sex with the hope of getting infected. They interpreted this as a way for negative partners to redress the imbalances in the relationship, such as loss of intimacy in sex. There were no indications in this study to

suggest that negative partners wanted to join the positive partner. As opposed to joining the infected partner, it would seem that the negative partners in this study wanted closeness during intimacy. The positive participants stated that their partners had expressed that they had not got infected and were unlikely to get infected in the future and therefore it was not necessary to engage in protected sex.

Another significant finding from this study was that female participants expressed dissatisfaction with the use of condoms. This is in contrast to the perception that it is generally males who refuse to use condoms. Most HIV studies view women as powerless and in need of being empowered to negotiate safer sex (Abdool Karim, 1998; Tallis, 1997). These studies have overlooked the fact that at times, not using condoms is not always related to power dimensions between men and women but to issues of emotional closeness and passion. Therefore there is a need when dealing with couples to acknowledge the difficulties they face in constantly using condoms and to develop ways and means of promoting safer sex.

In summary, this section explored and discussed the findings on the impact of serodiscordance on marital relations and sexual practices. The following section will report the findings on reproductive decision making in serodiscordant relationships.

SECTION E

4.6 REPRODUCTIVE DECISION MAKING AND SERODISCORDANCE

This section explores the challenges faced by serodiscordant couples who contemplated having a child/children. Two couples and two individuals in the study had already had children with one participant pregnant at the time of the study. The couples who already had children, did not want to have more children, indicating that the number of children they had was sufficient.

This section therefore focuses on the two couples who still wanted to have children. In both these relationships the males were positive and the females were negative and of childbearing age. One couple had disclosed their discordant status to the positive partner's family while the other couple had not disclosed. The following section discusses the themes and sub-themes of unwillingness of the positive partner to have children, the need to bear children and family pressure for couples to bear children.

4.6.1 Unwillingness of positive partners to have children

Both positive partners did not show interest in having a child even though they were childless. One positive partner did not specify reasons for his unwillingness while the other positive partner mentioned fear of child death and not being financially ready as his reasons for his decision. It appears that the fear, pain and trauma he experienced after his child from another relationship died, left him unwilling to bear a child again. This is what the participant had to say about the issue:

“...especially about my other child who passed away. I have seen how she suffered so I don't want that to happen again ...”

Although there have been developments around parent to child transmission to prevent new borns from getting infected with HIV, the positive partner still remained unwilling to have a child. The emotional turmoil that the participant had gone through left a scar that would take time for him to overcome. Grieser et al (2001) also found that the reasons for not having a child or limits to childbearing were associated with fear and emotional pain of child death, rising costs of bringing up children and the AIDS epidemic. It was interesting to note that despite the fact that childbearing is associated with manhood, these two partners were not keen on bearing a child. This could also be associated with the fear of infecting the negative partner and the sense of guilt that they will have to live with throughout their lives if their partners become infected. Also the fact that the negative partners had children with whom they

lived gave them the sense of fatherhood and temporarily closed the gap of childless living.

4.6.2 The need to bear children³

Both negative female partners showed enthusiasm for childbearing although their positive partners did not reciprocate this interest. The following were the sub - themes that emerged regarding the desire to bear children and challenges thereof:

Preserving and strengthening marriages: Both participants who wished for a child expressed the need to preserve and strengthen their marriage bonds. As one partner explained:

“...also this would help our marriage to be strong”.

Mbiti (as cited in Mathekga & Sekudu, 2006:229) argued that in some African societies marriage is not fully recognized or consummated until the wife has given birth. The first pregnancy therefore becomes the final seal of a marriage and is the sign of complete integration of a woman into her husband's family and kinship circle.

Womanhood: The need to please was also evident and taking pride in giving a child to a husband. This was seen by one partner as a sign of womanhood and a sign of love. The following illustrates this:

“My husband doesn't have kids so I thought I could make him happy.”

Similarly, Sewpaul (1999) found that in African communities, bearing of a child is seen as an essential part of being a woman and of achieving success in one's life. In addition, Mathekga & Sekudu (2006) maintain that culturally, the status of being a mother is a central element in the definition of a normal adult female and it is commonly accepted that females should produce off- spring.

³ Parts of this section have been published in Dano (2006)

Conceiving versus HIV infection: Both negative partners despite the fact that they were keen and willing to have children were afraid of getting infected. The fear was overwhelming and perceived as a stumbling block between them and fulfilled happiness in their marriage. As echoed by one partner:

“....but I’m scared that I might contract HIV.”

Use of artificial insemination: The negative partners were interested in gaining more information on artificial insemination as this process would assist them in bearing children while also it might take care of their fears of getting infected. As discussed by one partner:-

“Well we have discussed about it but we need more information on how can we prevent infection or use modern ways of conceiving a child.”

It appears from the findings that artificial insemination was seen as an alternative by negative partners and the only hope for them to conceive a child without the risk of infection.

It was evident from the findings that even though negative female partners had their own children, it was imperative for them to seal their marriages and bear children. It was also clear that in the presence of HIV, making a decision as to when and how to bear a child was not easy, especially if the male partner was HIV positive. It caused stress in the couple system with negative partners exerting pressure on their positive partners irrespective of their unwillingness.

4.6.3 Family pressure for couples to bear children

Childbearing is often seen as a gift from God, surety that the next generation and name will continue; a sign of fertility and the link between ancestors and the living (Mathekga & Sekudu, 2006; Grieser et al, 2001; Sewpaul, 1999). The following discusses the role played by family members in putting pressure on couples to bear children in order to meet cultural and societal expectations. The themes which emerged in this section were:

Hopes for a grandchild: The couple who did not disclose their status expressed how the male positive partners' parents harboured hopes for a grandchild. They shared that their family was interested in knowing when they would bear children. This made the couple uncomfortable when the issue was raised since they did not know what answers to give to parents. This was illustrated as follows:

".. My mother was always making comments about a grandchild..."

"His mother always commented on my weight and making remarks that she will soon be having a grandchild."

Bunnell et al (2005) found that couples who had not disclosed and had few children, commonly experienced pressure from relatives to have more children.

Inheritance: In contrast to the above, despite the family knowing about the discordance, they insisted that the negative partner should bear a child. The reason for this family insisting on a child was that the negative partner ought to bear a child for her to earn the inheritance. The negative partner's motives in remaining in the relationship were also questioned by the family and this pressured her to have a child. This was illustrated as follows:

"...yes there is family pressure because his family thought it's better for me to bear a child... so that my child could inherit..."

Whiteside (1998) argued that fertility/childbearing is an issue firmly rooted in culture, and children represent a woman's best claim on family resources. In the same vein, Grieser et al (2001) maintained that securing the couple bond and the wife strengthening her relationship with her in-laws, were reasons for having children despite the presence of HIV. Bernstein and van Rooyen (1994) contend that the value placed on children is sometimes higher than that placed on the marital relationship.

It is evident from the above findings that decision making regarding child bearing was surrounded by pressure exerted firstly by family members of male participants and secondly by negative female partners on their positive

partners. This pressure resulted in enormous stress for couples adding to their psychological turmoil in dealing with serodiscordance. Apart from this, female partners had to conform to child bearing expectations irrespective of their emotional readiness, due to family and societal pressure. This pressure is precarious as it might lead to couples conceiving and risking infection. It was clear that the pressure was placed more on wives than husbands along with the need to maintain and preserve the marriage. This could be related to the cultural role women play in African societies.

The findings of the study also indicated that there is a need for couples to be informed regarding different reproduction techniques and other options available for them to make informed decisions on child bearing. Reproductive counseling is suggested in this regard as discussed in chapter 2 of this report.

In the following section factors that influence and hinder ARV adherence and the role that is played by negative partners and children in promoting adherence are discussed.

SECTION F

4.7 ARV ADHERENCE AND CARE-GIVER ROLE

All positive participants in the study were on ARVs. This section explored participants adherence to treatment, the care-giver role played by different members of the family system and economic implications of HIV diagnosis in the couple and family system.

4.7.1 ARV ADHERENCE

Taking of ARVs is a lifetime commitment that requires psychological readiness from a person taking medication and support from family to help an individual to adhere to treatment. The issue of adherence to treatment is an important aspect as it determines the future of the HIV positive individual and also minimizes possibilities of resistance to treatment. "Adherence means

taking the recommended dose, at the recommended time and in the recommended way. It refers to the degree to which a patient follows a treatment regimen which has been designed in the context of a partnership between the client and the health care worker" (Brouard, 2005:71).

Positive participants were interviewed on their level of adherence to medication and how their partners assisted them in taking their medication regularly. Three participants were taking their medication regularly, while two participants admitted that they did not take their medication regularly. The following themes emerged in relation to factors promoting adherence and factors negatively affecting adherence:

Factors negatively affecting adherence

Working conditions: Participants mentioned that the type of work they did prohibited them from taking medicine regularly. One participant mentioned the following in this regard: *"I'm always on the road driving so at times I forget to take my tablets"*. Since types of work people do could be detrimental to adherence, it is vital for health practitioners to advise patients accordingly when giving medication. In addition it is important to ascertain how patients are going to fit the medication into their daily schedule.

Use of Alcohol: One participant mentioned that he is afraid to take his medication when he has been consuming alcohol and as a result he misses the doses that he is supposed to be taking. He explained it as follows:

"It's only when I have taken alcohol. I normally drink on Fridays so I won't take tablets on Friday & Saturday morning depending on how drunk I was the previous night. I don't leave a big break in between. I don't take tablets after drinking because I'm scared that alcohol would have an effect on tablets".

This suggests that after consumption of alcohol patients do not take their medication due to a fear of the effects of alcohol on medication and other reasons. It is thus important that patients who consume alcohol be educated

on the effects of alcohol on treatment and the danger that is posed to non - adherence by their behaviour.

Side effects: Three participants mentioned that the side effects were unbearable and as a result it was difficult for them to continue taking medication as required. One participant described it as follows:

“the tablets used to make me worse and more sick, to a point that I once felt like flushing them down the toilet...I used not to take them regularly... but I’m used to them now.”

It appears that side effects play a big role in participants not adhering to treatment. It is important for health practitioners to ensure that they share strategies on coping with side effects with their patients.

Forgetting of tablets: This was associated with feelings of being well and feeling better after being sick. As mentioned by one participant as follows;

“... I think now I’m feeling normal unlike before so I think I’m taking advantage of that and it gets easy to forget treatment.”

Mostly participants commenced their treatment while they were ill. To some degree they thought that they were dying. Taking medication and feeling better led to some participants having reduced feelings of anxiety about their illness that caused them to forget their medicine. Forgetting to take tablets and also the types of jobs that the participants were doing played a big part in non-adherence.

The data presented in this section suggests that working conditions, use of alcohol, side effects and forgetting of tablets were factors affecting adherence. Similarly Oggins(2003) found that perceptions of the disease and treatment regimen, side effects of medication, not knowing how medication works and people who are accustomed to take medication immediately after getting ill did not understand the need to take medication for prolonged periods, were factors that affected adherence.

Factors positively influencing adherence

Support from negative partners and children were seen as the main factor which influenced adherence to treatment. Three male positive participants mentioned that their partners played a big part in helping them remember to take their medication. In contrast to this, two positive female participants noted that their partners were not helping them, instead children were seen as playing a big role in reminding their parents to take medication especially those children who knew that their parents were infected. Similarly Palmer & Bor (2001) maintained that seropositive partners found their enthusiasm for drug therapy more difficult to maintain over a long period of time, and their partners provided support in coping with treatment. The following are some of the comments made by participants whose partners were supporting them while taking their medication.

“I take my medication at 7pm all the time, so she reminds me all the time to take my medication or my daughter because they are so worried.”

“She always reminds me to take my tablets or she will pack them for me if we are going somewhere.”

For the two participants whose negative partners were not giving them support while taking medication, the following comments on how or what they expect from their partners were made:

“My partner should stop telling me about the side effects but support me with what I’m going through. He must remind me to take my medication...”

“Partner needs to be educated about side effects, adherence, and resistance etc.”

The above could be related to the fact that men are not usually care-givers. There is also the possibility that these male participants were still trying to make sense of the discordance result and thus found it difficult to provide support.

4.7.2 Care giving and changing roles within the family system

Three of the negative partners played a significant role in reminding their positive partners to take their medication everyday and on time. One of the participants even mentioned that she fetched the medication for her husband. The second participant made a comment that reminding her partner to take medication had become a part of her life. Similarly Palmer & Bor (2001) noted in their study that treatment provided seronegative partners with a focus for their commitment to give support to their partners and they encouraged their partners to continue taking medication. They also took time to seek out relevant literature and other sources of information to keep up to date with medical procedures and interventions. The following are some of the comments made by the participants in this regard:

“...Nevertheless I always keep on telling him to take his tablets (“the tablets awareness”). This has also become part of me.”

“Well I think he has put his faith in me, I’m the one who is always reminding him of his tablets. I’m totally responsible for everything. I even go with him to doctors visits so when I have some questions I get to ask them during that time. I have to make sure all the time that he has taken his tablets.”

Living in serodiscordant relationships creates new and sometimes unexpected roles for individuals within the family system. The traditional role of women being spouses, mothers and care-givers was evident in this study. HIV related tasks with couple relationships such as seeking information and giving support, developing social contacts and monitoring health often fell to women even when it was the man who was HIV positive (van der Straten et al; 1998).

Besides the role played by negative partners, children also played care-giver and protector roles and reminded parents to take their medication regularly. Three couples mentioned that their children played a very significant supportive role in assisting with the ill positive parent and taking care of them while they were sick. They have also played a role in ensuring that they take their treatment regularly. This was associated with fear and anxiety that the positive parent will die. They also protected their parents from negative gossip

from their neighbors claiming that anyone can be HIV positive. As described by the two participants:

“...but they are sensitive to people who are saying negative things about HIV positive people.”

“When neighbors started spreading rumors about my husband that he was positive my son was sad and confronted them. He told them that they are not so sure of what they are talking about so they should leave us alone.”

None of the negative male participants played a role of care-giver to their partners. This is related to patriarchy in South African society. It was clear in this study that non-supportive husbands contributed to the psychosocial stresses of positive females who, despite their positive status, had continued to provide care and support in their families.

4.7.3 Economic implications of HIV diagnosis for the couple system

All participants in the study felt that HIV had not brought about any financial strains in relation to buying medication. Three couples had medical aid insurances. The other two participants with no medical aid were receiving treatment at an NGO that distributed free ARVs. Two couples felt that the only strain was to spend more on a healthy diet since their lives had changed and they had to eat healthier. The responses illustrated this as follows:

“At the clinic they give us free treatment so it’s easy that way other than that I don’t get sick so I don’t need to use Medical Aid.”

“He doesn’t get sick so we really don’t feel the need. The clinic is paying for everything, the tests, tablets so we don’t feel it that much.”

“Well there are no other financial strains because the medical aid is having chronic cover.”

Participants in this study had not felt the financial constraints because they were all working and on medical aid or getting ARVs for free. This may not be a true reflection of the reality in South Africa where there are high levels of poverty and unemployment. Thus we cannot generalize that HIV diagnosis does not have financial implications.

The following section is the last section of the analysis chapter. It discusses recommendations made by participants regarding service delivery that is holistic for serodiscordant couples in meeting their psychosocial needs.

SECTION G

4.8 SERVICES REQUIRED BY SERODISCODANT COUPLES IN MEETING THEIR NEEDS

After discussing the enormous challenges faced by discordant couples in their relationships, the following section discusses the services identified by participants that would assist them in coping better with discordance challenges. These services included: counseling, education, reproduction information, testing and gender based interventions. Findings from both negative and positive participants will be combined. These findings are listed in the table below:

Table 4.3: Recommendations with regards to service delivery

Theme	Sub-theme	Frequency
Counselling	Ongoing Counseling	09
	Couple Counseling	06
	Grief Counseling	02
	Disclosure to children	05
	Family therapy	07
	Alcohol Abuse	01
	Support groups	06
	Telephone counseling	04
	Support for HIV negative partners	02
Education	ARV and adherence education.	10
	Educational campaigns on discordant relationships.	04
Reproductive Issues	Artificial insemination	06
	Data-base of service providers	01
Testing and HIV Management	PEP for couples	04
	24hr service centre	03

4.8.1 Counselling

Nine participants felt that it is imperative that couples be referred for on-going counseling to assist them in coping with their difference in serostatus. Six participants felt that in couple counseling, issues such as dealing with practicing safe sex and ability to be intimate irrespective of differences in status, promoting communication between couples and discussing fears and concerns about HIV infection needed to be incorporated. Two participants felt that there was a need for them to grieve. This, according to participants

included dealing with fears of the positive partner being ill and dying, preparing children and negative partners for the death of the positive partner and bereavement.

Family Therapy was identified by seven participants as a crucial intervention. This they felt should include children, siblings and in-laws of the couples. This was seen as a way of increasing support for the couple and educating the family about HIV and discordance. Participants also felt that this was vital, as it would allow children and immediate families to express and deal with their concerns and fears. A topic that one of the participants felt needed to be covered during family therapy was alcohol abuse.

Five participants felt that they were experiencing problems of how to disclose to their children. In addition, the negative participants expressed the difficulties that they were experiencing in disclosing to their families. Issues on when and how to disclose to children and families were identified as crucial matters that needed to be dealt with during counseling. Two participants felt that it was necessary to have services that would also cater for the negative partner, while four participants felt telephonic counseling was another interventive tool that could be used by serodiscordant couples. The following quotations illustrate these points:-

“...psychosocial support for couples because at the moment what we have doesn’t begin to meet the needs of the couple, look at issues of people who are interested in having kids, what I’ve seen other people going through in their family structures is not funny, probably they need some family intervention. How to deal with an HIV positive person, issues of women being care-givers (you’re positive and have kids who are positive, sometimes a partner who is positive). Interventions that are taking care of women, teach women some form of techniques of helping themselves, issues around gender issues need to be reviewed such as women need to ask from their in-laws to attend a clinic. We can all be HIV positive but circumstances differ from one another.”

“Programs that will focus on communication between couples especially to discuss couple fears because there are fears, but a program that will prepare one when the partner is ill.”

“Interventions on what or how to prepare for your child before and after you have died.”

"Communicating with children on how to disclose and deal with issues arising after disclosing. Counselling for children and education on HIV."

"...because they are left out, because there's no support for the family in terms of understanding the trauma around difference in HIV status."

"...support system such as ongoing counseling, where you can phone at any time and ask for help."

'...there's lack of support for HIV negative individuals. It's like if you're negative stay out of our way we have a lot of work to do. I just feel like an intruder this is the biggest challenge I have faced."

Also, van der Straten et al (1998) found that HIV negative women particularly expressed a need for individual support that was not centered around their positive partners. Although the management of HIV was a couple issue, few opportunities existed to have couples participate together, as most services focused only on infected individuals.

Six participants felt that joining a support group would assist them with sharing the information and minimise the burden for each couple and they preferred a group of couples. This is illustrated as follows:

"A group of couples will be better so that we could learn from each other."

"... probably it would enlighten couples that they are not alone, the more they get to share their own issues the more they will be able to cope."

Van Der Straten et al (1998) found that feeling connected to the other couples in a real or virtual way helped partners to deal with HIV by combating stigma and alleviating isolation in a support group.

4.8.2 Education

All participants felt that there was a great need to be educated on ARV treatment. This included types of regimen, side effects, how resistance occurs and how to promote adherence. This education should also be given to children. Educational campaigns on discordant relationships were mentioned

by eight participants as a tool to destigmatise and promote acceptance of discordant relationships,

“ARV education on adherence, side effects and all those things, issues around reproduction. Drugs that are good for women and men.”

“Education for the couples and families. The uninfected also need to be educated on how to cope with diagnosis.”

4.8.3 Reproduction issues

Six participants recommended information on childbearing, this included the costs of artificial insemination, list of doctors or service providers who are experts in dealing with artificial insemination and HIV/AIDS.

“Reproductive issues are more important, on procedures, costs and referral. Doctors who know what are you there for instead of explaining all over again.”

4.8.4 Testing and HIV management

Four participants felt that there was a need for making PEP (Post Exposure Prophylaxis) service delivery accessible to couples. Also three participants in addition to this, mentioned a need to have 24hour service for couples where they could make a call at any time and ask for help.

“A place where when you've got questions you can go to as a couple or if you have few things which are secretive that you want to discuss (eg breaking of a condom at night). There should be services where we could call in. Info on PEP is needed for most couples and places that offer services for 24hrs and they should be easily accessible.”

According to Bunnell et al (2005:10) “we must ensure that optimal prevention activities, including partner testing and targeted interventions for discordant couples, are an integral component of the rapidly expanding care and treatment programs. Detailed guidelines on how to educate and counsel HIV discordant couples are urgently needed in Africa”.

In conclusion, understanding of serodiscordant couples needs to go beyond avoiding HIV transmission but to understand the complex and dynamic psychosocial challenges that serodiscordance status bring in the marital relationship of couples. This chapter has presented the findings on psychosocial challenges faced by married serodiscordant couples. The following chapter will provide a summary of the main findings and recommendations based on these findings. In addition, future research, information for policy makers and practitioners are discussed.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

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5.1 Introduction

In this chapter a summary of the main findings, conclusions drawn from the findings and recommendations are discussed. In addition, suggestions for future research studies are provided. The contribution that the study has made to social work theory and practice are also discussed.

The aim of the study was to understand the psychosocial challenges faced by married serodiscordant couples. The objectives of the study included exploring how couples dealt with the challenges arising from their serodiscordant status and ascertaining the need for services required by couples who are serodiscordant. The aims, objectives and the key questions contained in chapter one will provide the framework for the discussion in this chapter.

An exploratory qualitative study was undertaken. The theoretical framework of the study was the biopsychosocial and ecosystems approaches. Purposive sampling was used. In-depth interviews were personally conducted and analyzed by the researcher. The sample comprised of four married couples and two individuals who were married but participated individually and not as a couple. Five participants were HIV positive and five participants were HIV negative. Participants were between the ages of 30 and 49 years old. All couples were married at the time of study. The couples in this study were all married for more than a year, with one couple married for 21 years. The couples received the discordance diagnoses between the years 2000 and 2004. All the couples had children. However, two couples had no biological children of their own. The negative partners in these unions had children from previous relationships.

5.2 Summary of main findings and major conclusions

In the discussion that follows the summary of the main findings and the major conclusions are discussed in an integrated manner.

5.2.1 Couple differences in HIV serostatus and emotional reactions after the diagnosis

Participants' reasons for testing included a desire to find out why they were ill, applying for an insurance policy and encouragement from positive partners. All the negative partners only tested after their partners' positive HIV diagnosis was revealed. It was evident that participants assumed that if their partner tested HIV positive, they would also be HIV positive. It is necessary in HIV/AIDS education that this assumption is corrected to prevent further new infections. A major conclusion therefore, is that none of the participants tested voluntarily for HIV/AIDS. Voluntary counseling and testing for married couples should be encouraged.

The findings indicated that three of the positive participants disclosed their HIV status because they thought that their partners were also infected. One positive participant informed his partner before they got married and one informed her partner because they had applied for life insurance together. Disclosure of HIV status to partners was reported to have a positive outcome, except in one instance where a positive woman was physically abused by her husband after disclosure.

The discovery of serodiscordance raised questions regarding trust and infidelity in the relationship. Even though negative participants voiced mixed feelings (confusion, happiness, disbelief, anxiety and numbness) after they tested negative, questions of how the partner got infected with HIV were raised. When infidelity was explored, participants were reluctant to discuss it and felt that it was no use going back to the past. Therefore, the issue of infidelity was left hanging to maintain the equilibrium in the relationship.

The factors that contributed to the negative partners remaining in the relationship were: love and companionship, children and commitment and feeling safe in serodiscordant relationships. Most of the negative participants felt that it was not necessary to leave their already positive partners as it was highly likely that they might again meet someone who was also HIV positive. Fear of being rejected by the negative partner was a constant fear that positive partners had to live with. This was one of the implications of living in a serodiscordant relationship.

In dealing with the issues of difference in serostatus, participants used acceptance and support as positive coping mechanisms and avoidance as a negative mechanism. A major finding of the study was that none of the doctors and counselors provided a bio-medical explanation on the causes of serodiscordance and this resulted in confusion and dissatisfaction. Doctors and counselors need to be informed and taught how to communicate serodiscordance information to couples.

Another major finding was that none of the couples had been referred for on-going counselling. Only two HIV positive partners mentioned that they had been referred or attended counseling after the diagnosis and there was no counselling offered to HIV negative partners. The counseling they received only focused on treatment readiness, nutrition and use of condoms. Their serodiscordant status was not discussed. Negative partners indicated that they felt like intruders because no attention was given to them when they accompanied their partners and also there were no programmes or support systems that catered for their needs. It is imperative that in HIV/AIDS counseling both partners be included during counseling and the psychosocial implications of difference in serostatus be dealt with.

5.2.2 Disclosure of serodiscordant results to families, friends and children

The four positive participants who disclosed their HIV status to their families disclosed because they were ill at the time of diagnosis and their family

members needed to know what was wrong with them. Sisters and mothers were reported to be the people to whom the disclosure was presented and they were supportive. Positive participants who disclosed were all supported by their families.

Both the positive participant and the negative participants who did not disclose felt that it was not necessary as disclosure could lead to people worrying. The one positive participant who did not disclose was afraid of how his parents would react and the impact this would have on their health. Negative participants were afraid that their parents would not understand and force them to leave their marriages. In fact, those negative participants who did disclose experienced problems with their families not accepting their positive partners. They were asked to leave their marriages and not to have sex with their positive partners. Three of the five negative participants chose to disclose to friends rather than family members. Friends were found to be supportive.

Being in serodiscordant relationships made it difficult for negative partners to disclose due to the fear that their relationships would not be accepted and understood. The negative partners who disclosed had to live with the pressure exerted by their families to leave their serodiscordant relationships. On the other hand, it was evident that at a micro system level positive participants received support from their families. However, the research data would seem to suggest that the focus of attention of the positive partners' family was on the positive partner only. There is a need for families and communities to be educated on serodiscordance in order to deal with the stigma and challenges associated with being in a relationship that is affected by HIV/AIDS.

The findings indicated that parents found it very difficult to disclose to their children. Three female participants disclosed their serodiscordance status while the rest of the participants were unable to disclose. Only one participant disclosed immediately. The other children found out after seeing symptoms and reading labels on tablets. This suggests that disclosure may not have happened if participants were well and not on medication.

The explanations given for not disclosing were associated with fear of how children would cope with emotional stress. Age was another factor cited by participants. They felt that children were too young to understand. In addition participants indicated that they did not know what to say, how to say it or how they would respond to some of the questions raised by children.

Parents used different strategies in disclosing their status, including educating the children about HIV/AIDS before the disclosure and seeking help from a sibling to disclose on their behalf. A conclusion that can be drawn from the results is that parents need help with disclosure to their children. For those who did disclose, serodiscordance was viewed positively by the children because they felt that they still have one parent who was not infected.

5.2.3 Impact of serodiscordance on marital relations and sexual practices

Marital relations changed after diagnosis of the serodiscordance status. Changes included feelings of insecurity, betrayal, physical abuse and lack of communication. Participants found it hard to communicate openly about their fears and concerns in relation to their discordance and HIV/AIDS. Some of the reasons given by the negative participants were that by avoiding the topic they were protecting the positive partner from getting hurt.

After the diagnosis of serodiscordance, participants felt that their sexual life changed drastically. Positive changes in sexual desire included becoming closer and the realization that they did not have much time left with each other and this had drawn them closer and improved their sexual intimacy. Negative changes included loss of interest in sex and in one case a positive participant encouraged her partner to have extra-marital relations.

Participants had difficulties in adjusting to the use of condoms for the following reasons: condoms were a constant reminder of HIV/AIDS; they spoilt the natural fun of sex and passion and because the negative partner refused to use condoms since they had not seroconverted after unprotected sex. The

inconsistent use of condoms was an issue that caused a lot of conflict, guilt and anxiety in the relationship, leaving the positive partner feeling neglected and isolated. The issue of partners not seroconverting also posed a great deal of confusion in relation to the use of condoms. For example this led two male negative partners to believe that they were immune to HIV and that they therefore did not need condoms.

For those couples who eventually managed to consistently use condoms, the following pattern was evident: couples started with the inconsistent use of condoms → this led to arguments and conflict about safer sex → this resulted in not having sex at all → and culminated in practicing safe sex. What was unclear was what led couples to have protected sex again as they had minimal communication and negotiation about their sex lives. There is a need for this pattern to be examined further.

The conclusion drawn from these findings is that couples experienced problems with intimacy due to lack of communication and a constant fear of infecting and being infected. This also resulted in them having difficulties in maintaining safer sex practices.

5.2.4 Reproductive decision making in serodiscordant couples

Couples who already had children in the study were not interested in having any more children. Negative participants in two relationships wanted to have children even though their positive partners did not reciprocate this interest. One of these participants gave no reasons and the other maintained that he was not financially ready and he was still grieving over the death of his previous child. The reasons given by negative female partners for wanting children were associated with strengthening the relationship between them and their spouses and that giving birth was a sign of womanhood.

Childbearing was a challenge to serodiscordant couples as it was not easy to conceive a child with HIV present. Couples endured pressure from their families who harbored hopes for a grandchild. In addition, despite one family

knowing about the discordance status of the couple, they insisted that there should be a child. The reason for this family insisting on a child was that they felt the negative partner ought to bear a child in order to earn the inheritance.

The two couples who were interested in having children had difficulties in obtaining information on reproductive techniques. The difficulties mentioned were lack of knowledge of people who rendered the service especially for serodiscordant couples and information on costs involved in doing the procedure. The findings also indicate that couples in the study were not keen on fostering or adopting a child.

The three major findings which emerged in relation to reproductive decision making were: family pressure to bear a child, pressure exerted by the negative partners and the fact that it was not easy for negative female partners to conceive a child because of the risk of HIV/AIDS transmission. It was evident that despite the presence of HIV/AIDS, participants wanted children. It is vital that reproductive counseling be included in HIV/AIDS guidelines together with information on artificial insemination (see chapter 2).

5.2.5 ARV adherence and the care-giver role

All positive participants in the study were on ARVs. Factors found to affect adherence were: working conditions, abuse of alcohol, side effects and forgetting to take tablets. The support provided by negative partners and children were found to be the core factors influencing adherence. Negative female partners played a big role in assisting their husbands with adherence as they were fully responsible for reminding them to take their tablets. Positive male partners mentioned that their wives were supportive and reminded them to take medication all the time. In contrast to this, positive female partners mentioned that their husbands were not providing support.

Living in serodiscordant relationships created new and sometimes unexpected roles for individuals within the family system. The traditional role of women being spouses, mothers and care-givers was evident in this study.

Children also played a care giving role in supporting and reminding their parents to take their tablets. All participants in this study were on medical aid insurances. There were no financial strains reported as a result of HIV/AIDS except that they had to spend more money on healthy food.

ARVs had an impact on the physical and psychological well being of the individual and it was observed that support received at a micro level ensured that the positive partners did adhere to their medication. It is imperative that negative partners be involved in HIV management of their partners and be informed of all the processes involved.

5.2.6 Services required by serodiscordant couples in meeting their needs

Participants were asked to make recommendations on services they needed based on the challenges they faced in their serodiscordant relationships. All participants felt the necessity for counselling and saw it as a crucial intervention that they needed at different levels. They mentioned counseling for children, family interventions, on-going counseling, couple counseling and dealing with alcohol abuse.

In addition to this, other interventions recommended were: testing and HIV management, ARV education on adherence, HIV negative partners' education on how to cope with the disease/illness. Further suggestions were: support systems for couples (where they could make a call at any time and ask for help), a 24 hour drop-in centre where discordant couples could call at any time for PEP, information on childbearing including the costs of artificial insemination, a list of doctors who are experts in dealing with artificial insemination and HIV, a list of service providers, gender specific programs and programs to prepare a negative partner for a period during which the positive partner will be ill or dying.

5.3 Recommendations

On the basis of the findings of this study the following recommendations are made. The ecosystems approach is used in differentiating interventions at different levels.

5.3. 1. Micro level

Therapists should demonstrate acceptance and acknowledge the difficulties of serodiscordant couples such as the inability to normalize relationships after the diagnosis of HIV/AIDS. The following are recommendations made with regard to counseling.

Communication and negotiation: It is crucial that couples learn to communicate and prioritise their needs and be honest about their feelings regarding changes that are happening in their relationship. Communicating with love and warmth can create an environment that is conducive to discussing sensitive issues. Timing is also important when discussing sensitive issues. Teamwork is essential as it sets the stage for negotiation and change.

Couple therapy: This is vital in accepting discordance and explaining the causes and meaning of discordance. Couples need to discuss how they will deal with issues of trust and honesty in their relationship. Dealing with the illness and care giving and psychological stressors related to these, need to be explored and dealt with. Therapists would need to assist couples in separating HIV issues from normal relationship issues.

Sex therapy: It is recommended in dealing with serodiscordant couples. Difficulties associated with condom use need to be acknowledged and therapists need to assist couples in developing ways and means of maintaining satisfying safe sex. Alternatives need to be explored such as

micro biocides, non-penetrative sex and use of sex toys to enhance intimacy. Issues regarding post exposure prophylaxis (PEP) need to be discussed.

Family therapy: In assisting couples disclose to family and children, family therapy can be used. It is essential that disclosure becomes a process that involves both partners instead of this being a role played by females. Appropriate disclosure strategies need to be discussed and couples need to be educated through role play and enactment.

On-going counseling: Medical doctors need to be encouraged to refer couples for counseling. In order to eliminate the “intruder feelings” that negative spouses experience, there is also a need for incorporating services for negative spouses. Issues of death and dying need to be integrated in on-going counseling. Also dealing with issues of fear of being positive and adjusting to the unknown would assist serodiscordant partners.

Reproductive counseling: Childbearing is a crucial issue especially for couples who do not have children. There is a need to develop a data base of service providers who have knowledge and experience in artificial insemination/ in vitro fertilization, especially in relation to HIV/AIDS. It is vital that accessible and affordable artificial insemination procedures be performed in assisting couples. There is also a need to educate couples on the different options available such as self insemination if the male is negative, adoption and foster care. Where couples are forced by relatives to have a child, it is critical that counseling is offered to prepare them in decision making. For couples who decide to take the risk of unprotected sex in conceiving a child, education about risks, checking for sexually transmitted diseases and viral load of the infected partner, are necessary. Therapists should remember that irrespective of whether they agree with the decisions couples take, they need to support them.

5.3.2 Mezzo level

At the mezzo level, recommendations are made in relation to testing and difference in status, community responses, reproductive techniques, gender based intervention and support groups.

Testing and difference in status

The following describes recommendations relating to HIV testing and serodiscordance.

- HIV/AIDS and VCT awareness campaigns that also target married couples.
- Promote and mobilise people to test for HIV as this will assist them in knowing their status early rather than getting to know when they are ill.
- There is a need to integrate information on serodiscordance on HIV/AIDS pre and post test counseling guidelines. Also develop a manual that would provide information to practitioners on serodiscordant relationships.
- Promotion of ARV readiness programs that fully involve negative partners.

Community Programs

Families and communities need to be educated on serodiscordance to promote understanding and reduce stigma. There is a need for community mobilisation on issues around the destigmatisation of HIV/AIDS. It is recommended that awareness and intervention programs target serodiscordant, married couples. One such program could focus on early identification of these couples during HIV testing. Couples need to be encouraged to test together. Condom use campaigns should also target married couples and not single persons only. Communities need to be educated on serodiscordance to assist them to understand and accept these types of relationships.

Reproduction techniques

There is limited access to information relating to reproduction techniques and other options that serodiscordant couples could undertake. Service providers and social workers need to develop policies and implement services that are going to attend to reproductive needs of serodiscordant couples.

The psychosocial challenges that compel women who are in serodiscordant couple relationships to bear children needs to be taken into consideration. There is a great need to empower women in decision making with regards to their reproduction. Empowerment will be brought about by educating couples, especially women, on different options available for them in order to make informed decisions without the risk of HIV infection. Social workers need to lobby and advocate for accessibility and affordability of artificial insemination.

Gender based interventions

Community based efforts must be undertaken to address women's limited capacity to initiate preventive health behaviors. Also there should be programs designed to help them as they play a care-giver role in their families. Programs targeting men are also needed in helping them to deal with issues arising from serodiscordance.

Support groups

Serodiscordant couples are isolated and stigmatized and this can cause stress. A support group can serve as a support system to these couples where they could meet with other couples who share the same challenges and victories as them. Groups can serve as a stress reliever, educator, promote a sense of togetherness and become a platform to share strategies.

5.3.3 Macro level

Policies and protocol development

Provincial, national and international policies, programmes and counseling guidelines on serodiscordant couples need to be developed, as presently in South Africa, none exist. These couples are treated as if they do not exist, yet by gaining knowledge and understanding, these couples can normalize and de-stigmatize HIV/AIDS. It is through these couples that individuals, practitioners and communities can understand how seroconversion may be prevented in long term relationships and how the use of condoms can be encouraged.

Funding of programs

Funders play a big role in influencing decision making in program development and service delivery. Funders need to be encouraged to prioritise serodiscordance in the programs that they are funding.

5.4 Applications for social workers, clinicians and trainers

Serodiscordant relationships are seen as “abnormal” because there is a stigma associated with being in such a relationship. The implication is that people in these relationships have a choice about leaving and not exposing themselves to HIV/AIDS. When they decide to stay, they remain in a shell surrounded by discrimination and isolation. The complexity of the challenges faced by these couples needs to be understood by practitioners who provide counselling.

Therapists need to be mindful of being non-judgmental and having positive regard, warmth and empathy. Although these permeate everyday practice especially in social work, there is a need to be in the “couple’s shoes” and practice being non-judgmental. Acceptance, openness, warmth, empathy and positive regard will help in shaping and changing attitudes, fears and

concerns while assisting these couples. Clients will thereby be helped in challenging and changing their own thinking and behavior in an environment that is supportive.

There is a great need for social workers and other health care professionals to include information on serodiscordance in their HIV/AIDS curriculum training. It is evident from the results of this study that there is limited or a lack of information regarding serodiscordance and there is little that practitioners know about these couples. In addition there is a need for a counseling manual to address issues from a biopsychosocial approach, designed by a multidisciplinary team.

5.5 Recommendations for further research

The study was exploratory in nature and focused on a small sample of serodiscordant couples. There is a need for further research on a larger scale using a larger sample in investigating the prevalence of serodiscordant couples in the country. Research studies in other geographical areas, including participants from different socio-economic status and race groups is also recommended.

There is also room for investigating the impact of serodiscordance on family systems. This could include interviews with the members of the family system in ascertaining their views on the issue of discordance and how it impacts on them.

There is limited scientific knowledge and evidence that explains discordant results even after partners continue having unprotected sex. There is a need for further research on this aspect and provision of answers that would reduce the level of confusion among couples.

5.6 Dissemination of recommendations

One of the objectives of the study was to add to the body knowledge on HIV/AIDS and inform practice. Participants in the study were informed that their experiences would be used to help improve service delivery and knowledge regarding serodiscordance.

The following steps will be taken to disseminate the findings:

1. Articles will be submitted to journals and newsletters.
2. Findings will be presented at conferences and other forums.
3. A training manual for health care workers will be developed in this regard.
4. Meeting with policy makers and key role players to discuss the implementation of findings for policy and service delivery.
5. Lobby advocacy organisations to ensure that policy makers address the issues regarding serodiscordance.

Conclusion

“In sickness and in health, till death do us apart”

This is the vow that couples took during marriage and they continue living this despite the challenges that serodiscordance brought to their lives. To ensure that these couples live meaningful lives, it is important that couple counselling, intervention programmes, policies and guidelines in working with serodiscordant couples be developed in Africa. Normalising HIV/AIDS and serodiscordant relationships is also crucial as this would destigmatise HIV/AIDS and provide an immediate opportunity to prevent HIV transmission and gain social acceptance. Serodiscordance remains a mystery and it is vital that further research be done in this area (Dano, 2006:52).

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APPENDICES

APPENDIX 1: INFORMED CONSENT

To whom it may concern

Dear Sir/Madam

You are hereby invited to participate in a study of married or cohabiting couples where one partner tested HIV positive and the other tested HIV negative. This study aims to understand the challenges faced by these couples and how they deal with such challenges. The research study will cover issues such as disclosure, knowledge of HIV and antiretrovirals, financial challenges, interaction and intimacy, reproductive decisions, coping mechanisms and services available to couples.

Participants will be required to participate in an interview that will take approximately an hour. A tape recorder will be used to tape the interview so that the researcher can concentrate on listening rather than writing. The interviews will be held at a place that is comfortable or convenient to the participant or in the researcher's offices (City centre/Westville). Partners will be interviewed separately from each other. All information from the interview will remain confidential and will not be discussed with your partner or anyone else except, discussed with participants concerned. The tapes will be destroyed after use. Participants will remain anonymous and have a right not to inform the researcher of their real names.

Participating in this study will make a significant contribution to other couples in the same situation, as this will inform counselling guidelines and services needed for serodiscordant couples to make their lives easier.

There will be no payments made for participating in the study. The participants have a right to withdraw from the study at any stage and for any reason.

I _____ the undersigned hereby understand the contents and conditions of participating in this research.

Signed at _____ on this day _____ month _____
year _____.

APPENDIX 2: INTERVIEW SCHEDULE

SECTION A

DEMOGRAPHIC INFORMATION

1. Age

2. Gender: Male or Female

3.

MARITAL STATUS	Tick	DURATION
Married		
Cohabiting		
Separating		
Divorced		

4. Educational level

Primary	
Secondary	
Trade/ Technikon	
Tertiary	
Other(explain)	

5. Current Employment:

6. Number of children and their ages

Number of children	Age

7. HIV status of respondent?

Positive		Negative	
----------	--	----------	--

SECTION B

DIFFERENCES IN SEROSTATUS

1. How did you find out about your HIV status?
2. When did you find out about your HIV status?
3. After receiving your results how long did it take you to disclose to your partner?

PARTNERS REACTION

Positive partner:

4. How did you react to your partner's negative results?
5. How did you feel about being HIV+ whilst your partner is negative?

Negative Partner:

6. How did you react to your partner's positive results?
7. How did you feel about being HIV- whilst your partner is positive?

SECTION C

INFORMATION RECEIVED FROM DOCTORS/COUNSELLORS

Question directed to participants who have had unprotected sex and still remained with different status.

Positive Partner's Response:

1. Did your doctor/counselor explain why you are HIV+ and not your partner?
2. Were you happy with the explanation? Yes or No (Please elaborate)
3. Did you receive any on-going counselling?

Negative Partner's Response:

1. Did your doctor/counselor explain why you are HIV- and not your partner?
2. Were you happy with the explanation? Yes or No (Please elaborate)
3. Did you receive any on-going counselling?

SECTION D

INTERACTION AND INTIMACY

1. Can you briefly explain about the history of your relationship?
2. What has worked well and what has not?
3. Do you find it easy to communicate with your partner about your fears and concerns, feelings and needs in your relationship?
4. What is not being spoken about both generally and HIV specifically?
5. Were you engaging in unprotected sex before diagnosis?
6. If yes, are you still engaging in unprotected sex?
7. How do you feel about the use of condoms?
8. How does your partner feel about the use of condom?
9. How was your sex life before diagnosis?
10. How is your sex life now?

SECTION E

DISCLOSURE

FAMILY MEMBERS

Positive partner:

1. Have you disclosed "your" status to any of your family members?

Yes		No	
-----	--	----	--

2. If yes, what was their reaction to this?
3. If no, give reasons for not disclosing your status.

Negative partner:

4. Have you disclosed your partner's status to your family?

Yes		No	
-----	--	----	--

5. If yes, what was their reaction to this?
6. If no, give reasons for not disclosing.

FRIENDS

Positive partner:

1. Have you disclosed your status to any of your friends?

Yes		No	
-----	--	----	--

2. If yes, what was their reaction to this?

3. If no, give reasons

Both partners:

4. Have you disclosed your partner's status to your friends?

Yes		No	
-----	--	----	--

5. If yes, what was their reaction to this?

6. If no, give reasons for not disclosing.

CHILDREN

1. Have you disclosed your/ partner's status to your children?

Yes		No	
-----	--	----	--

2. If yes, what was their reaction to this?

3. If no, give reasons for not disclosing

4. How did you go about disclosing your status to your child/children?

5. What were the fears and concerns presented by your children?

6. What is your current relationship between you and your children?

SECTION F

REPRODUCTIVE DECISIONS

1. Since your statuses have been known have you had a child after your diagnosis?

Yes		No	
-----	--	----	--

2. If yes, which method was used?

3. If no, are you planning to have a child?
4. If yes, how are you planning to get pregnant and avoid getting infected?
5. What other reproductive options are you aware of in getting pregnant?
- 6, Whose decision was it to have a child?

Mutual Decision	Positive partner	Negative partner
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6.1 What was this decision based on?

7. Is there by any chance that the decision was due to family pressure?

SECTION G

KNOWLEDGE OF HIV AND ANTIRETROVIRALS

KNOWLEDGE ON HIV

1. What do you understand about HIV/AIDS?
2. PROBES
 - 2.1 What concerns do you have about your partner's status?
 - 2.2 What knowledge do you have on prevention?
 - 2.3 What knowledge do you have on progression of HIV to AIDS?

KNOWLEDGE OF ANTIRETROVIRALS

- 3 What do you understand about Antiretrovirals?
- 4 Do you think you need special education on Antiretrovirals?
- 5 If yes, what aspects would you like to know so that you better understand the use of Antiretrovirals?

POSITIVE PARTNER

6. Are you taking antiretrovirals?
7. If yes, do you take your treatment regularly?
8. If sometimes, what prevents you from taking medication regularly?
9. How did you deal with side effects of treatment?
10. Does your partner help you to adhere to your medication?

Yes	No
-----	----

Explain

11. If no, how would you like your partner to support you with regards to your medication?

NEGATIVE PARTNER

12. Is your partner taking Antiretrovirals?
13. If yes, is he/she taking treatment regularly?

14. What do you think is your role in helping out your partner in adhering to medication?

SECTION H

FINANCIAL IMPLICATIONS

1. What are the financial challenges that you are faced with ever since the diagnosis?

PROBES

2. Do you have Medical Aid?
2.1 If no, how do you cover your medical expenses?

SECTION I

CHALLENGES AND COPING STRATEGIES

POSITIVE PARTNER

1. What other challenges does the different HIV status pose in your lives?
2. How do you deal or meet such challenges?

NEGATIVE PARTNER

3. What other challenges does the different HIV status pose in your lives?
4. How do you deal or meet such challenges?

SECTION J

SERVICE/S REQUIRED IN MEETING THEIR NEEDS

1. If there was a program designed for serodiscordant couples, what type of programmes would you like to be in place/ implemented?
2. If a support group is formed would you participate?
3. If no, please explain.