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Understanding the experiences of seronegative partners in HIV discordant couples

Naran, Sanjay

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CHAPTER 1 - Introduction

Human Immunodeficiency Virus infection and Acquired Immune deficiency Syndrome (HIV/ AIDS) is one of the biggest challenges facing mankind in the twenty first century. No country or community has been spared from this epidemic. Initially when the HI Virus was first identified in the homosexual communities[1], it was thought to be a disease that would affect this group exclusively. But as time has passed this has proved to be incorrect. While it is still a problem in homosexual groups worldwide, HIV/ AIDS has also ravaged heterosexual communities across the globe[2]. By 1991, South Africa had equal numbers of heterosexual HIV positive cases and homosexual cases[1]. Current statistics show no part of the world to be spared but Sub-Saharan Africa and South East Asia seem to have the highest number of infections[3]. Worldwide there are estimated to be forty million people infected by the HI Virus with Sub-Saharan Africa accounting for twenty five million of these[3]. Of those infected in Africa, less then ten percent are reported to be on any treatment[3]. South Africa's national prevalence rate is estimated to be around 15.83 percent as stated by the South African National HIV and syphilis prevalence survey done in 2006[4]. Countries that have shown recent declines in prevalence include Kenya, Zimbabwe and Haiti and there seem to have been important behavioral changes there, as well with increased condom use, fewer partners and delayed sexual debut[3]. This is encouraging as it suggests that with the correct approach, this epidemic can be controlled.

HIV/AIDS is found in all socioeconomic levels of societies. All racial and ethnic groups are affected. Currently the lowest infection rates can be found in countries like the Philippines, which claims an infection rate of 1 percent of its population[5], but many countries underreport their infection rates. The United Nations has set up the joint United Nations Program on

HIV/AIDS called UNAIDS to assist countries to help those infected and affected by this infection. Various Non Governmental organizations are also involved in the fight against the disease. The William J Clinton Foundation, UNAIDS and the Bill and Melinda Gates Foundation have done tremendous work in helping people from the developing world to gain access to antiretroviral medication. But despite their efforts, most of those in the developing world are still unable to access antiretroviral medication. Countries in Africa are estimated to have less then ten percent of those needing antiretroviral therapy on treatment[2].

Developing countries have been more severely affected and there are various contributing factors for this including lower socioeconomic status, poor nutrition, migrant labour, poor access to health services, malaria, tuberculosis, overcrowding, unemployment, untreated sexually transmitted infections and increased alcohol consumption[6]. However a recent newspaper article in South Africa quoted Professor Carel van Aardt from the University of South Africa's Bureau of Market Research, which found a very high rate of HIV infection in higher socioeconomic groups and the employed population[7]. This is important because it "challenges the belief that HIV is a disease of the impoverished, unemployed and the uneducated." Not only did this study find a high rate in the educated and employed group but the rate has been increasing over the years. This study showed that the epidemic was also affecting the economically active population and this has huge economic implications for South Africa for the future. It also showed that prevention and information messages were not effective enough and would probably need to be adapted specifically for this economically active and productive age group. Until then, this pandemic will continue unabated.

A number of traditional medication regimes exist in different parts of the world and include the African Potato which is claimed to enhance the immune system. Garlic, beetroot, ginger and other foodstuffs have been promoted for the same reason. A Chinese herbal product called

Revivo is also claimed to treat early HIV[8]. This product is claimed to boost the immune system of HIV patients, but the researcher was unable to open links where these claims were reported to be studied and verified. Of those linked websites that were accessible, none of the claims were backed up by scientifically sound studies and thus the researcher is skeptical of these claims! Yoga, Tai Chi and Reiki have also been claimed to enhance the immune system[9], but again these have not been proved.

The South African government has been widely criticized for their approach to HIV/AIDS. President Thabo Mbeki and the health minister Dr. Manto Tshabalala Msimang have often been seen to support the view that HIV/AIDS needs to be treated with nutritional support and untested herbal remedies rather then 'toxic' antiretroviral medicines. Recently, they have often argued that this was not what they meant. Unfortunately, all this arguing has done is to create a controversy surrounding the place of antiretroviral therapy. In an interview done on the radio station 702 in September 2000[10], Minister Tshabalala Msimang refused to acknowledge that HIV caused AIDS. In May 2005 she was quoted as saying "I don't know how many South Africans with HIV would want to take anti-retrovirals". In June of 2005, she went on to say "nutrition is the basis of good health and it can stop the progression from HIV to full blown AIDS…" All of this highlights the various issues that can contribute to confusion and frustration amongst HIV infected individuals and their spouses and families. This in turn is a contributing factor for the continued spread of HIV.

With the ever-increasing number of HIV cases seen by doctors in South Africa and worldwide today, doctors find themselves facing more and more HIV serodiscordant couples who are presenting to them. HIV serodiscordant couples are couples that have different HIV statuses- one partner being HIV positive while the other partner is HIV negative despite exposure to the virus. The opposite of this is seroconcordant couples who find themselves either both being

HIV positive (or negative). A study done in Zambia found 18 percent of partners of known HIV positive patients to be negative[11]. Another study reported a discordant rate of 40 percent[12] while yet another reported a rate of 43 percent[13].

These serodiscordant couples have proved to be extremely challenging to the researcher who works as a general practitioner in a primary care setting. They present with different problems than the traditional HIV concordant couples. The aim of the researcher was to get an in-depth view of what the negative partner in the discordant relationship was going through and experiencing as they went through their lives. He hoped to do this by doing qualitative interviews with these negative partners so that could highlight their problems and experiences. During the interviews the participants were asked two linked questions. The exploratory questions to each participant was -"Tell me about what you have been through since you and your partner have received your differing HIV results." The second part was "What has your life been like since then". The researcher would like to try to get a clearer understanding of what the seronegative partners experience and feel initially and as time goes by. The researcher is hoping that by gaining some insight into this crisis time of theirs, he can highlight issues that need to be addressed by doctors for these negative partners so that they can be helped and that they in turn can then help in the treatment of their positive partners. If we can understand and help them, they may provide the doctor with a most effective family based tool to promote and re-enforce messages that many doctors are often too busy to repeatedly do such as adherence to treatment, encouragement, good sexual practices, health promotion and modification of help seeking behavior. They may, together with the doctor and their positive partners, form a health team[15].

Most doctors are now quite used to treating and assisting couples where both partners are HIV positive. In these situations, the couples seem to go through their challenges together

and they often draw strength from each other or the opposite happens where they split up and deal with things on their own. The SMART[14] (sharing medical adherence responsibilities together) program showed that HIV seroconcordant couples who were involved in this adherence program had improved adherence to treatment with antiretroviral medication. The SMART program also encourages serodiscordant couples to support each other to prevent HIV transmission to the negative partner and also to assist in the positive partner's adherence to medication. This highlights the importance of the doctor understanding the negative partner so that this negative partner can be treated and acknowledged and can thereafter play a more active role in the management of the couple.

The serodiscordant couples cannot rely on the fact that they can go through the illness and its challenges together since they may be experiencing very different emotions like guilt, blame and anger towards each other and themselves.

Family Medicine advocates treating patients within their family setting and using the family in the treatment process since health and illness cannot be separated from a person's physical environment and family influences[15]. A United Kingdom study[16] by King found that more general practitioners are involving family and friends of patients in their care. The researcher has found that this is easier to do in the seroconcordant couples. In the serodiscordant couples, the family medicine approach is something that may be used to great effect. It may lead to a better understanding of both the positive and the negative partner. It may also give insight into the expectations, experiences and needs of the couple, both separately and together. Most doctors focus on the seropositive partner and only involve the negative partner in enquiries about some or other aspect of the positive partner's management. This needs to change since the negative partner is a hidden patient who has been ignored for too long. The concept of the hidden patient was described by Medalie[17], who found that "hidden patients

have various stress-related illnesses: depression, duodenal ulcers, hypertension, migraines, heart attacks, and strokes. Moreover, these and other health difficulties can go untreated."

Most studies done to date have looked exclusively at the HIV positive partner in the discordant relationship. Some researchers have tried to look at both partners but their studies have been very clinically orientated and have focused on trying to find reasons for the couple's discordance and whether there is a cellular protective factor in the negative partner. While this is a very important area of research, it does not address the often forgotten negative partner's psychosocial issues. This partner may be just as scared and confused as the positive partner. Many theories of why the discordant couples remain discordant have been investigated, but none have yielded a conclusive answer yet. An unknown genetic factor or neutralizing antibodies that resist HIV infection in some people has been suggested by a Thailand study[18], but this also has not been proved.

The seronegative partner is a forgotten patient and a forgotten resource, as he/she has the power to help the doctor in the management and motivation of the seropositive partner[14]. This usually forgotten seronegative partner can only be of help in the treatment of the positive patient if the doctor can fully understand and appreciate as well as assist the negative partner with what he/she is going through. They may also be experiencing a range of emotions and feelings such as loneliness and neglect since most of our attention has traditionally been focused on the HIV positive partner.

In the quest for answers to HIV/ AIDS, research seems to throw up more questions then answers. So much has been discovered about HIV/AIDS in the last two decades but there are still so many unanswered questions. This creates a problem for doctors because when patients ask questions, we do not have all the answers and unlike other diseases, where the

doctor can read about the disease or consult with colleagues and later give patients answers, with HIV/AIDS, there are no answers yet for many of the questions patients may pose. This is very frustrating and problematic for the doctor who is treating a disease that is not fully understood.

Little wonder that many patients, dissatisfied with western medicine's lack of understanding of this disease and lack of interest in other aspects of the patient's illness, are turning to unproven and sometimes dangerous traditional medicines and practices. Recently, a BBC report focused on Gambian president Yahya Jammeh who claimed he could cure HIV in three days using secret herbs. Despite widespread condemnation of his claims and the fact that his treatment has not been tested and proven, there have been many people who have turned to him for help. While we often look and wonder about people who go to 'healers' like President Jammeh, we must be able to stand back and analyze what we are doing wrong. If we can identify what he is offering his 'patients', not in terms of treatment of the infection but more in terms of treatment of their psychosocial issues, which we are not doing, we may be able to learn something that will enhance our holistic care of patients! It highlights the need for a patient-centered approach. This approach is an attempt by the doctor to understand the patient's complaints and the signs found by the doctor not only in terms of the disease process, but also as an expression of the patients unique individuality[19]. Subjective aspects are taken into account and the patient's context is also considered important. A treatment plan is negotiated with the patient and the family may also be involved in this.

As doctors, we are not taught to listen to patients. We are made to believe that we must have all the answers and so we need to jump into situations to take charge. If only we would listen to patients, we will find out what they really need when faced with a disease like HIV/ AIDS. Often patients may suffer from psychosomatic problems which can only be uncovered by

listening to the patient and hearing his/her story. Not every patient has a disease that needs a clinical examination and investigations to be treated. Many patients are better off if they are just listened to. Often, by allowing them to relate their ‘story’, they may feel a sense of relief at being allowed to ‘let it out’. They may even find some of their answers themselves while talking about their problem. This is even more true of the seronegative partner. Traditionally we are taught to ignore this partner since they are not the ill member. But, as family medicine has taught us, a person often does not need a disease to be ill[15].

As more family physicians start to realize this and ask family members how they are, and then listen to the answers that are given, the more they are realizing that there are patients who were previously did not even recognized as being patients and in need of help.

CHAPTER 2 -Literature Review

The researcher used the internet sites www.pubmed.com and www.google.com for the literature review. Various keywords were used to find information. These included:

HIV discordant couples.

HIV coreceptors-CCR5 and CXCR4

HIV resistance

Sexually transmitted infections and HIV

Counseling and HIV

Risk factors for HIV transmission

HIV and families

Stigma in HIV

HIV in pregnancy and prevention

HIV and fertility

Microbicides

HIV statistics

HIV treatment

HIV cures

Suicide and discordant couples

Spirituality and HIV

HIV myths

Chronic diseases treatments and adherence

Other sites used were www.avert.org, www.unaids.org, and www.rhru.org

There are an increasing number of researchers looking at HIV discordant couples but very few have focused exclusively on the negative partner and only a few that the researcher has

found have done qualitative studies to get an in depth understanding of what the couples face and go through especially from the negative partner‘s point of view. A Thailand based study focused on caregivers of people living with HIV/AIDS. This study reported themes of fear, stigma, sorrow, empathy, hope and hopelessness as well as a need for more education expressed by the respondents[20]. A further study from Ireland[21] concluded that “caregivers’ needs and perspectives need to be integrated into future service planning and decision making.” This research will see if the results obtained are the same in the South African context. Research from Kenya reported that knowledge on how to deal with discordant couples “leaves a lot to be desired”[22]. There are a few qualitative studies that have involved interviews with both partners. These studies reported mainly on issues that affected the positive partner with very little focus on the negative partner.

Many of the researcher’s discordant patients have asked for reasons as to why one partner remains HIV negative despite their partner being positive. The researcher has been unable to give them an answer as nobody has conclusively proved any reason for this. All this uncertainty about a disease with such a stigma warrants us to look at the couple’s situation from the negative partner’s point of view which may aid in giving the doctor a better insight into the couple’s reaction and level of functioning as well as why they behave as they do especially with regards to risky sexual behavior with each other.

Many research studies have looked at the positive partner while others have tried to uncover reasons for one partner remaining negative in the face of recurrent exposure from the HIV positive partner[23,24,25]. These studies have come up with various possible reasons like resistance to infection due to “major histocompatibility complexes”, cellular immunity and viral characteristics that are responsible for non-transmission of the HI virus. Factors that have been found to increase risk of transmission to partners include anal intercourse, genital

ulceration, advanced AIDS, elevated viral loads and repeated exposure. However, the unknown factor that protects some people still remains a mystery[18,26]. It is known that the HI virus uses receptors to enter CD4 cells. Some individuals have been shown to lack cellular co-receptors and this seems to be a mechanism whereby they resist HIV infection[27].

Bienzle et al[23] looked at possible reason for persistent non-transmission of HIV and concluded that it was a combination of factors including cellular immunity, viral characteristics and co-receptor integrity. What is known is that there are different receptors and co-receptors that are used by the HI Virus to enter cells before it integrates into the host cells nuclear material. The co-receptors that are thought to play a role in viral entry are CCR5 and CXCR4, which are both found on CD4 T cells. These co-receptors are used by the HI Virus to enter cells. Some individuals have been found to have an inherited mutation called Delta 32 CCR5. This mutation changes the co-receptor so that this co-receptor can no longer be used by the HI Virus to enter cells, and it thus seems to offer the person protection from infection[28,29]. Delta 32 CCR5 mutation is associated with HI Virus resistance[30]. This study also looked at the cytotoxic T Lymphocyte activity in seronegative partners from HIV discordant couples and found that they had an increased Cytotoxic T lymphocyte activity compared to their positive partners and this may be due to HI Virus exposure that activates and increases this cytotoxic T Lymphocyte activity which in turn protects from HIV infection and thus seroconversion.

What has been discovered so far is that protection from HIV infection is either due to acquired host immunity or inherited genetic mutations. This acquired host immunity may be activated by HIV infection that then results in immunity preventing the HI virus from establishing itself in the body. The inherited genetic mutation results in dysfunctional co-receptors, which then prevents the HI Virus from entering the cells[31].

There are also other co-receptors that are currently being evaluated. Whether cellular immunity or the inherited genetic mutation is more protective is currently unknown. Some studies[31] have suggested that acquired cellular immunity was more important. The acquired cellular immunity is extremely important as it is hoped that it will assist us in creating a vaccine. If a vaccine can be developed to stimulate a person**'**s immunity, this will help the person fight of any HI Virus that is trying to enter his/her cells. Current research is trying to determine why some people mount a favorable response to the invading virus and how this happens. If we can answer these questions, it will provide us with a vaccine that can potentially save millions of lives by stimulating an immune response in recipients.

Other researchers have looked at trying to change behavior through counseling in an attempt to protect the negative partner**.** A study by Bunnell[32] found that discordance created confusion in the community. The fact that there was no credible reason for the discordance enhanced beliefs in supernatural reasons and witchcraft and also lead to denial about the existence of HIV. This in turn put the negative partner at more risk. Painter[33] found that behavior can be changed in discordant couples through recurrent counseling[34]. These results were also found to be true by a USA based study[35] provided the counseling was repeated. This need for repeated counseling could be a problem for our already overstretched medical system where resources are limited and time constraints on medical personnel do not always allow for repeated counseling sessions. This is where the negative partner can assist if they can be made to feel like part of the team, by reinforcing important messages like healthy living, safe sex practices and treatment adherence.

There are also studies that have looked at discordant couples where the male is HIV negative and the female HIV positive and they have been compared to discordant couples where the female is HIV negative and the male partner HIV positive. This study found that the couples where the male was negative were more likely to use condoms than the couples where the

female partners were negative (17% versus 9,5%)[36]. Studies like this show the need for us to take a closer look at the negative partner so that we can assist and counsel them and they in turn may help in the management of the couple. Females who are the negative partners in the discordant couples face greater challenges then males in the same situation. The risk of forced sex and domestic violence are greater and the female partner is often left with no alternative but to engage in risky behavior[37].

One interesting study found that male to female transmission was 1.7 times higher than female to male transmission[38]. This again shows the need for us to understand both partners so that we can protect the negative partner especially where the negative partner is the female as they are more at risk and they may be pressurized to have unprotected sex.

Different studies have yielded different rates of seroconversion in HIV negative partners exposed to the virus by their HIV positive partners. The study by Quinn et al[39] found a seroconversion rate of 11.8%, with no seroconversions in circumcised males and higher seroconversion rates in those whose partners had a higher viral load. This study suggested that viral load was a main predictor of HIV transmission. A Chinese study[40] found a transmission rate of 11.1 %. They concluded that there was an increased transmission rate with increased vaginal intercourse as well as increased viral load[41] and decreased CD4 count. Untreated Sexually transmitted infections were also found to be a major contributor to increased HIV transmission[41,42].

With all of these unknowns in a disease so common, it is very understandable that patients and their family members will get confused, mislead and disheartened with our medical system and seek answers from traditional healers and witchcraft[32]. The unknowns were also responsible for immense frustration in the researcher as he faced questions from patients

daily at primary care level. The researcher could identify with patients' frustrations and discontent due to the lack of answers.

Microbicides are also currently being extensively researched. Microbicides are products that can be used vaginally or rectally with a goal of preventing or reducing STI's and HIV infection as well as providing contraception. It was hoped that they could be an important tool in the fight against HIV especially in females who often find themselves in a position where they do not have much say or power in response to their partner's demands of not using condoms. Disappointingly, a trial involving the microbicide Ushercell, also known as cellulose sulfate was halted in South Africa, Benin, Uganda and India after it was found that those using the cellulose sulfate had a possible increased risk of HIV transmission as compared to the group using a placebo gel[43]. The ideal microbicide needs to be safe, easy to use, effective, and must not cause viral resistance or disruption of host defenses and must provide contraception at the same time. As yet, the ideal microbicide remains elusive.

Not many doctors have effective counseling skills when dealing with HIV discordant couples[32]. This puts the negative partner at increased risk. Many couples are left with many misconceptions after being counseled by their doctors. Misconceptions include the belief that the negative partner may have a "hidden infection" that is not detectable yet, the belief that gentle sex has protected the negative partner and a belief that this is God's will[32]. These beliefs can give doctors a guide as to what topics must be addressed in the counseling of discordant couples but each case must be handled on an individual basis.

Another big challenge that discordant couples face is negotiating sexual relationships[32]. Some agree to use condoms, some agree to abstain from sex, some sleep in separate beds and others agree to not have sex with their partners but rather with others outside their

relationship. Some couples cease their relationships. This again shows the need for targeted counseling that addresses different issues compared to HIV concordant couples. Their counseling must include topics that "explain discordance, emphasize high risk of transmission and support risk reduction"[32]. What has also been found is that males and females face different pressures if they are the negative partner in discordant couples. Females faced more risk of being forced to have unsafe sex and were at greater risk of domestic violence[37].

Riehman et al[44] looked at ways to help discordant couples and at the same time ensure that the negative partner remains negative. This study found that many discordant couples wanted to remain in a long term faithful relationship with their partner. They suggest that any strategies developed for these couples must take this into account as well as to identify and address high risk behaviour and teach conflict resolution skills.

The effect of voluntary counseling and testing on the behavior of couples was investigated and it was found that before voluntary counseling and testing, less then three percent of couples reported condom use but that after voluntary counseling and testing, more then eighty percent of couples reported condom use[35]. The one problem was that this increased condom use was not permanent and there was a need for ongoing counseling. This is definitely something that needs to be focused on by doctors when they treat HIV discordant couples. The problem is limited time and manpower.

Messages of practicing safe sex seem to be ignored by many people. This is evident by the fact that the HIV pandemic seems to show no signs of abating. We know that there is a need for repeated and focused counseling. An interesting finding was that there was reduced sexual risk behavior after patients were started on antiretroviral medication[45]. There was also reduced risk behaviour with patient counseling and partner counseling[45]. Another study

reported the opposite finding in that there was a misconception amongst some discordant couples that if the positive partner was receiving HAART, then there was no need for safer sexual practices like condom use[46]. These different beliefs show the need for individualized counseling based on every couple's unique situation.

The word "undetectable" to describe the low viral load was found to be dangerous in some couples since they believed that since the virus was undetectable, there was no longer a need for barrier protection like condoms[47,48]. The authors rightfully suggest that the use of the word "undetectable" to describe a very low viral load be avoided as it created the impression that the virus was no longer infecting the positive partner. This was also found to be true by a study from New York[46]. A better word may be "further reduced" as it can encourage the patient to continue to reduce the viral load without sounding as if the virus has disappeared.

Because of the uncertainty around HIV/ AIDS, and the need to provide his patients with answers, the researcher is certain that the issues affecting the negative partner must be explored so they can provide a few answers and assistance to doctors who are faced with these problems almost daily.

CHAPTER 3 - Methods

3a) Aims

To explore seronegative partners' experiences and emotions in HIV discordant couples.

3b) Objectives

Using qualitative interview methods to explore the range of emotions and experiences that seronegative partners in discordant relationships experience at the time of disclosure of the different results and thereafter.

3c) Design

This is a qualitative study that involved interviewing participants using an 'open-ended' method which meant that the participants were not prompted or assisted as they spoke. They were encouraged to say whatever they felt regarding the topic. The researcher did have a list of points that he felt needed to be covered in the interview, but these were to give direction to the interview and not to inhibit the participant from discussing other aspects. The question to each participant was -"Tell me about what you have been through since you and your partner have received your differing HIV results." The second part was "What has your life been like since then".

The researcher used probes as a guide[49]. These probes were chosen by the researcher since he felt that these were the questions that would help the patients present their story as it gave a timeline progression that the patient and their partner probably went through after deciding to test their statuses. However, the participants were not expected to, nor were they repeatedly directed to follow the order of the probes as they were listed by the researcher.
Probes included - What happened at the time of disclosure of the different results**?**

-How did the doctor handle the situation**?**

-How has it affected you life and relationship**?**

-Have you disclosed to family and friends**?**

-how are you coping now**?**

-how do you see your future**?**

-what has helped you most to cope**?**

-what should your doctor offer you**?**

-Is you partner on antiretrovirals and how do you feel about that**?**

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3d) Site of study

General Practitioners from Gauteng were asked to provide participants who fit the inclusion criteria. Three general practitioners provided participants. One practitioner was from the West Rand and he provided three participants. Another general practitioner was from the East Rand and she provided one participant. The last General Practitioner was from outside central Johannesburg and he provided three participants. These practitioners were given an information sheet, which explained the purpose of the study, the methods and the inclusion criteria. The researcher also discussed the proposed study with them and answered any questions they had. There was no standardized explanation that the General Practitioners used when they spoke to their patients about the research. After the General Practitioners gave the patients a brief explanation of the research to be carried out, the prospective participants were then given the researcher's cell phone number to contact him if they were interested in participating in the research. This ensured that the participants were not being forced to participate. The doctor was also asked to let the researcher know by telephone that a participant may call to participate (but not to identify the participant).

3e) Sampling

Purposive sampling was used to select patients who fit the inclusion criteria[49]. Purposive sampling is a type of non random sampling where individuals are selected from the spectrum the researcher is interested in. This provides participants who have been exposed to the same conditions, who can give in-depth accounts of their particular experiences. General Practitioners identified couples who fit the inclusion criteria and they then informed the couples of the study and reasons for it being done. They informed the couples that should they wish to participate, they could call the researcher or give a missed call on his cell phone. All those who phoned and agreed to participate in the study were, together with their positive partner given an explanation of the study and reasons for it. If they agreed to proceed, a time for the interview was agreed upon.

3f) Inclusion criteria: Only serodiscordant heterosexual couples were invited to participate

: Either sex can be the positive partner

: They must speak English.

: The participants must be over the age of 18 years

: The couples must be in a stable heterosexual relationship with one partner.

3g) Exclusion criteria: Anyone below the age of 18 years

: Non English speaking individuals.

: Concordant couples

: Multiple partners

Only heterosexual couples were used as the researcher wanted to focus on this group for the purpose of this study. The researcher felt that if couples of the same sex were also used,

there many have been too many variables, which would have been too extensive for the scope of this study.

The couples were deemed to be in a stable relationship if they were with their same partner only for at least the last year. There was no limit as too how long after diagnosis of the discordance, the patients could be deemed fit to participate in the study.

3h) Data collection

Prospective participants were given an information sheet highlighting the reason and methods of the study as well as information regarding their rights including their right to refuse to participate. Free attitude interviews[49] were carried out with each negative partner at a time suitable to them and the researcher (myself), without the positive partner being present in the interview room**.** The free attitude interviews are used so that the participant may talk on any aspect about the topic. It assists the researcher to get an in-depth view of what the participants feel and experience. These free attitude interviews were carried out by asking the participant two linked questions and then allowing the participant to say whatever they wanted to in response (with minimal guidance/interference from the researcher). Free attitude interviews are open-ended interviews with a core question. Participants were encouraged to say what they really felt and not to worry about whether or not this would be acceptable to the interviewer.

The researcher had done a course at the University of the Witwatersrand Department of Family Medicine titled ‘Qualitative Research Methods Course’ in June 2005 which taught him the skills to do this qualitative research.

Only the negative partner was interviewed, since there is extensive research that has been done to examine the experiences of positive partners. The researcher found very few studies that focused on the negative partner only. Therefore he decided to focus on this group. The interviews were done at a venue of the participant's choice. Six of the seven participants chose to tell their 'story' at their own General Practitioners surgery since they felt there would be less disturbance from family members there. One participant asked the researcher to meet him at his home at a time when his wife was away at work and his child was at school.

Permission to record the interviews was sought and informed consent was obtained in writing. The interviews were audio taped.

The researcher did frequent summarization and clarification[49], to aid in the flow of information from the patient. This allowed the patient to correct anything the researcher may have misunderstood and also by hearing a recap of their 'story', it helped the participant to recall other topics not yet covered by them. The researcher first went through an interview with an HIV counselor in his area to highlight his areas of bias. This involved the counselor acting as the interviewer and the researcher as the participant to see which themes the researcher seemed to favour and prioritize. Interviews were continued until no new themes emerged.

3i) Bias and validity

There is a possibility that patients may have said what they thought the researcher wanted to hear and they may have been afraid of saying anything bad or negative about the doctor and/or partner. This may influence the information offered.

The researcher has preconceived ideas about the topic and did an interview with a counselor to highlight these. The aim of this was to see if the researcher favoured and specific topics or

ideas. Where these were found, the researcher was then aware of his potential bias during the interviews.

Language limitations meant that only a certain group of patients could be selected. Validity was ensured by continuing interviews until saturation of information had been reached and the summarized findings were verbally reported back to individuals for their correction/approval. A different person was asked to do the transcribing. This was done so that the transcripts were not filled with bias as the person doing the transcribing was unaware of the bias of the researcher, which was found during his 'practice' interview and so that there was no unintentional highlighting of certain topics over others.

3j) Ethical Considerations

The protocol was submitted to the University of Witwatersrand Human Research Ethics Committee for approval before proceeding with the research.

The managers or doctors at the relevant facilities were approached to supply participants for this study. These managers or doctors were given an information letter that explained what the study was about as well as criteria for selecting patients.

Dealing with HIV positive patients and their negative partners can lead to participants becoming aware of feelings and emotions that were previously 'hidden' and this can cause problems for the couple. To deal with this, the researcher offered them a debriefing session with a HIV and marriage counselor if needed at no cost to the patient. The researcher made arrangements with a relationship/HIV psychologist who agreed to assist with this if needed. The researcher bore the cost of this.

Confidentiality of all the participants was maintained at all times. This was stated in the signed consent form. The tapes were kept until all information was transcribed and they were then destroyed. This was also stated in the consent form which the participants signed.

All participants were given the right to refuse participation and they were assured that this would not jeopardize their future management by their own doctor. They were assured that their doctor would not be informed as to whether they called the researcher to participate in the research or not. This was also stated in the consent form.

Before each interview, the researcher explained to each participant that their names would not be mentioned but rather, they would be allocated a letter random from the alphabet which would be used to address them with. Since the patients were only identified by this randomly chosen letter in the interview (and they were asked not to use names or surnames while talking) the transcriber, who was a not related to the researcher professionally or by family ties, was not able to identify the participant. The transcriber was a professional legal secretary who was skilled in transcribing dictaphone tapes.

3k) Data analysis

The interviews were audio taped. The contents of the tapes were then transcribed to Microsoft Word. Each participant's interview transcript was then given different coloured fonts. This helped later to identify which participant brought up certain topics. The transcripts were read thoroughly and repeatedly so that the researcher got a full picture of each interview and the issues that were important. This process is also known is comprehending. This process aids in identifying themes. This entire process is called the Grounded theory.

Analytical categories were identified as they emerged from the data and used to form hypotheses from the ground upwards, rather then prior to the research being done[50].

Once the researcher was satisfied that he had a full overview of the participants 'story', he then began to look for recurring words, phrases and ideas within the transcripts. These are called codes[49,50] and the process is referred to as coding. All the codes were initially copied to a separate blank page and then sorted into groups which represented common ideas or themes. From these common codes, themes were identified[49]. Once themes were identified, the researcher put each theme as a heading onto a different blank page in Microsoft Word. The researcher then did a 'Cut and paste'- this involved finding codes which describe and explain and belong to the same themes[49]. Each code represented a different quotation or phrase made by different participants but which fell under a common theme. The different colored fonts assisted in identifying which participant made which statement and how many of them made the same statement on a particular issue. This showed the researcher patterns in the themes and from these patterns, the researcher was able to identify sub themes under each of the main themes. Each of the codes was then further separated according to which sub-theme it fell under. Some codes fell under a few sub-themes and a few different themes. These were then evaluated to see if they could be used to develop hypotheses. A search through the remaining data was then done to see if it supported the hypotheses. The researcher then wrote up the findings of common themes and sub themes based on the analysis. The researcher selected the most appropriate quoted words to summarize and reflect the themes and the meanings found during the analysis process. Thus, each theme had sub themes and under each sub theme there were quotations which backed up and explained the sub theme and ultimately the main theme.

3l) Limitations

This small sample should not be interpreted as numerically representative of negative partners in HIV discordant couples as the participants have been carefully selected to represent the maximum variation of experiences as is appropriate to the aims of this qualitative study.

CHAPTER 4 - Results

Seven interviews were done. Four of the participants were female and three were male. Two of the females had partners on antiretroviral therapy. None of the male participant**s'** wives were on treatment. Analysis of the data revealed four main themes. These were:

4.1) Emotional problems

42) Coping strategies

4.3) Future Plans

4.4) Suggestion for doctors from the participants

Themes	Sub themes	Topics
4.1) Emotional problems	**1A) Expected responses**	**i) Fear and Anxiety**
		ii) Confusion and disbelief
		iii) Worry
		iv) Frustration
		v) Blame and lost hope
		vi)Suicide
		Vii) Disclosure
		viii) Hope and Hopelessness
	1B) Unexpected Responses	**i) Support**
		ii) Focus on Future
		iii) Continued Trust in Doctor
4.2) Coping strategies	**2A) Positive coping strategies**	**i) Communication**

		ii) Support for partner
		iii) Education
		iv) Religion
		v) Disclosure
		vi) Attention from Doctor
		vii) Safe Sex
		viii) Acceptance
		ix) Good news
		x) Social support
	2B) Dangerous coping strategies	**i) Suicide**
		ii) Religious protection
		iii) traditional Medicines
4.3) Future		**i) Children**
		ii)Shattered dreams
		iii)Need for education
4.4) Suggestions to doctors		

Within each theme, there were sub-themes that were identified.

4.1) Emotional Problems

Within the theme of emotional problems, a wide range of responses was given. These were divided into expected reactions and unexpected reactions. The expected reactions were labeled as such since the researcher was not surprised when he heard the respondents expressing those feelings and thoughts. The unexpected reactions were labeled as such

since the researcher was surprised and shocked to hear those reactions, which to him were truly not expected.

4.1A) The expected responses included:

i. Fear And Anxiety

Before doing their HIV test, most respondents expressed fear and anxiety as well as acknowledging that they had a responsibility to themselves and their partners to know their status. A typical response which described the reaction of fear and anxiety was “its was scary, it’s still scary.

After the test, the responses highlighted a range of emotions including fear, disbelief and amazement, unhappiness and loss of hope “When we got the results, and we found out she was positive and I was negative, I was amazed. How could this be? I was scared and confused. Maybe it was a mistake. I felt so heavy in my heart. I did not know what to do at that moment. I think I was stunned and shocked”.

Fear was by far the most common response with all the participants saying they had felt it and some saying they still felt it. “I was very scared” and “its was scary, it’s still scary”.
The fear was not only that their partner had a disease with such a stigma attached to it but also for the uncertain future they faced and the fact that they were unsure whether they had been given an incorrect result.

> One participant said “I was very shocked, scared and unhappy. I wanted to kill myself, so many reasons to commit suicide even if I find that I was negative”. Another said “I’m not sure about the future. Like I said you always wonder how long this is gonna go on”. One male responded about how his future looked so

bleak “I cannot say there is a future – there’s no future”. A female respondent said “I always thinking I see a dim future on my side, my future is doomed”.

The stigma around HIV and AIDS was also a cause of fear with comments like:

“Everything has changed, even at times the way people look at you, or the way you think people look at you – has changed“ and “The stigma is obviously very painful”.

The fear of being incorrectly labeled negative was also expressed by a participant, “I was thinking maybe I was in the waiting period and every time I coughed, I felt maybe I’m positive. When I sweat, I think maybe, the sweating was because of me being positive. I was watching everything”.

ii. Confusion and disbelief

There was confusion about their discordant status and how such a situation could occur. A response like

“To me it’s still a question mark in life and I tend to ask myself why two different results. Is it the act of God or what – I don’t know.” This accurately describes the state of confusion. Participants also expressed how they had never contemplated such a situation, “there was a complete change in our lives, er meaning both my partner and myself did not understand there might be something like that of that nature. We always believed that if one is positive, both will be positive. Here it was a different situation”

A worrying aspect of the confusion surrounding the existence of the discordant state was that none of the doctors included the possibility of them being discordant in the pretest counseling.

> "Even now I keep asking myself, how can this be. I cannot believe how this can be. We were counseled but we were not told that such a result could occur. We were taught about what if we were both positive or both negative, not one positive and one negative. The doctor did not tell us this could happen"

iii. Worry about how their partners would cope.

Participants were also worried about how their partners were going to cope. There were two opposing reasons for this concern. Some of the respondents were worried because they wanted to help their partners and some were worried out of guilt and a sense of being trapped. These two opposing standpoints can be seen form these two responses.

> "I just thought what must my wife be going through at that time" and "right now I'm thinking of so many things, I'm negative and he is positive, if I leave him how is he going to cope without me".

Some respondents complained that they felt their partners were using their HIV positive status to manipulate them and make them feel guilty when they had a disagreement since their partners often brought up the issue of their positive status at such times.

> "And I sometimes withdraw from whatever I am feeling, though I realize that I'm right, then I withdraw just for the sake of her health. The stress affects her CD4 so I must switch of some other issues I wanted to discuss. Sometimes she uses this as a defense mechanism to keep me quiet. She says, "As you know I am like this"…then I must keep quiet. I sometimes tell her I don't like it when you use

your HIV status, to defend your situation even when she is wrong. She must admit if she is wrong and not bring up the HIV status issue".

iv. Frustration

Frustration was also felt when the positive partner refused to maintain communication. Almost all the negative partners continuously said they welcomed ongoing communication with their partners so that they could help them.

"Problem is that she doesn't talk about things, she keeps it hidden. If she is sad, she doesn't say it. I say what is happening. She doesn't open up". Another comment about this situation was, "if I try to communicate with her she doesn't respond so I am not sure if there are problems still.... it affects me negatively".

v. Blame and lost hope

One respondent looked back at her life with regret and wondered what her life would have been like if she had made a different choice in the beginning. This reaction was definitely expected by the researcher but he was surprised that only two respondents felt this way.

"Yes I do hold him responsible for things" Another response was "At times I am angry with him- but it's already late. He could have protected our marriage" This respondent went on to say "I become very disturbed and that maybe at times makes me to hate my partner a lot I'm so hurt when I sit and think about my relationship or my marriage. I said no, you are not faithful-Seems as if there was affair. I don't have a child with my husband but the thing that makes me more bitter. He knew our plans right from the beginning, but he was unfaithful".

What is interesting about these reactions, is that if the positive partner was suspected by the negative partner of contracting HIV during their relationship, then the negative partners

expressed anger and frustration and blamed their partners for what had happened and they were remaining with the positive partner more out of guilt and sympathy. This was the opposite when the negative partner suspected that the positive partner contracted HIV before they got together. These partners commented

> "We have not tried to look at her past to find out where it came from, we are focusing on the future-that is best-It will help us get through things" Another comment was, "I'm not going to be prejudice to her, I'm not going to discriminate her during any time of life and with that situation",

Another interesting observation was that the male respondents all had agreed to support their partners while the female partners were divided on the issue. However, this is not a conclusion that the researcher can accurately confirm as this was a qualitative study with a very small sample but the researcher felt it was something he should highlight.

vi. **Suicide**

A serious but not totally unexpected response that needs to be addressed and will be detailed later on was the threat of personal suicide and also family suicide by two respondents. Whilst the respondents who made these statements insisted that these thoughts were no longer entertained by them, it is an issue that needs to be dealt with and sought by all doctors who treat HIV patients and their partners.

> "I was very shocked and unhappy. I wanted to kill myself, so many reasons to commit suicide even if I find that I was negative". The other said "I sometimes think lets both go to the grave together."

vii. Disclosure

The negative partners all seemed to favour disclosing their situation to family members, feeling that this would assist them by easing the stress on them personally. In all cases, the positive partners opposed this and thus the negative partner did not disclose or did so secretly.

> "I spoke to my partner about telling people, especially our family – he didn't agree to that. Then it was me and him that knew about our status in the house and it was very difficult for me cope, even if I was negative. It was eating me inside, I was very angry that time and I didn't understand why people are not supposed to know about our status in the house, especially our family, our close family. His brother and my close family- that was what was depressing me most…"

viii. Hope and Hopelessness

Some of the respondent's found the situation and their future hopeless while others were filled with hope for the future. Those that had lost hope said

> "I cannot say there is a future – there's no future" Another said "It's not something you forget. You have to live with it everyday so it will be in your mind. In contrast, those with hope said "I want to see the child to be grown to be something better in future." Another said "…you can live a normal, you can get back to where you left off."

4.1B) Unexpected Responses

The reactions detailed above were expected and within the realm of normal human reaction to this type of situation. In contrast to these reactions there were reactions that the researcher felt **were** unexpected. These unexpected responses include the following:

i. Support

Most of the respondents spoke of a need to support their partners and ensuring that they assisted them where possible. They also spoke of putting their partners first. They seemed to harbour no ill feeling towards their positive partners.

> "The first question that came to me is why us– not why her or why me. I tend to show her that even though I'm not infected I'm affected…It has brought us closer to each other, focus on the positive side of life even though sometimes you go down through emotional stress but I keep on telling her, keep your head high". Another said "when we went home, it was terrible, we were both quiet. I did not know what to say. She was afraid. I told her it would not change our situation. I know she was scared. So was I, it was very bad. I told her I accept her as things were….Inside I was scared. I was not sure of our future but I said to myself I must accept the situation and help us both through this". Another participant said "We have not tried to look at her past to find out where it came from, we are focusing on the future - that is best - It will help us get through things".

What is interesting about this is that the two negative partners who had their own chronic disease (diabetes not HIV) both said they were going to support their partners. Whether this was due to them feeling they owed their partners something since their partners had supported them through their diagnosis of diabetes and thereafter or whether it was just their normal response, is unknown.

> "…she showed her real love and her commitment to me and that's when **I** decided this is the time now, I must take my own stand and see to it that I support her all the way like she did during my diagnosis of diabetes". He went on

to add "…Its like both of us are having a chronic disease….we are almost understanding each other on the grounds of, I know that there is a time where I get maybe diabetes complications and she will have to cope with that. And there is a time that she will be getting her own complications from her HIV".

A common response was that the discordant situation had actually brought the couple closer together.

"It has brought us closer to each other". And "I think that also made me a stronger person."

ii. Focus on the future

Another view was that the way to move forward was to focus on the future and not dwell on the past and it was felt that this could be achieved by better communication between themselves and with their doctors.

"It was really, really hard for me to accept, but as time went on, it settled and I'm doing better now." Another said "I'm very supportive" and also "...I tend to show her that even though I'm not infected I'm affected." Yet another response was "We have not tried to look at her past to find out where it came from, we are focusing on the future, that is best, it will help us get through things."

iii. Continued trust in the doctor

Surprisingly, none of the participants felt disappointed or let down by their doctors' lack of a proper explanation for their discordant situation. The researcher was quite amazed at this reaction.

"I accepted that it was something unknown". Another response was "I don't feel bad at all because everybody has limitations…I don't lose confidence in them at all". Yet another response was "I accept that they have no explanation for this".

4.2) COPING STRATEGIES

From the responses, it can be seen that there were various things that the participants and their partners did that helped them cope. The researcher looked for positive coping strategies and negative strategies. The positive strategies were those that helped them cope with their stressful situation while the negative ones were those that put the negative partners at an increased risk of contracting HIV.

4.2a) POSITIVE COPING STRATEGIES

i. Good Communication

Participants felt that good communication between themselves and their partners and themselves and their doctors was vital to them being able to cope with what they were going through.

"Sometimes it has ups and downs but every time we have committed to speak to each other, that's why we can cope". Another added that "It is so important to have more communication. It will make things easier for us. No secrets, so we can move forward." Yet another said "I would talk to him about everything, tell him everything and after talking that to him or telling him that, it's ok."

When there was a lack of communication, the negative partner felt frustrated. One response was

> "Problem is that she doesn't talk about things, she keeps it hidden. If she is sad, she doesn't say it. I say what is happening. She doesn't open up…if we speak we can know how to proceed. Communication is very important…I like to talk and say what I think."

ii. Supporting

Participants felt that by supporting their positive partners, they derived a benefit from this as it eased tension and misunderstanding in the relationship. They said:

> "I think what I've done, which is a positive thing on my side and on her side is I've accepted the status…I was there and I'm still there to support her…The only thing to change it is to accept it and live with it and see the means and ways of how to deal and cope with the situation…my support has helped her a lot…It has brought us closer to each other, focus on the positive side of life…I feel for one thing which is important is the support. I mean if I think she doesn't feel left and because she doesn't feel that way, she tends not to focus on the status." Another said "She needs a positive mind to fight this. I feel I can assist if I keep her mind positive."

Participants also felt a sense of relief at being able to assist their positive partners in their treatment especially with regards to their adherence of medication.

> "He's taking his medication regularly, that helps me"

Many studies have shown the benefit of involving the negative partner in the positive partner's treatment, which leads to improved adherence but the benefit, seems to be for the

negative partner as well, who seems to feel involved and thus helpful. This may give them a sense of relief and is thus an important aspect of treatment not only for HIV but probably for all chronic diseases.

iii. Education

Education was also identified as a coping strategy in that participants felt that they needed to be as educated and informed about HIV and AIDS as this helped them in being proactive with their partners rather then wait for problems like opportunistic infections before learning about them. They seemed to feel that knowledge empowered them and enabled them to anticipate and deal with problems timeously and effectively. When asked what would he like to do, one respondent said

> "I'd say to learn more about the virus itself". Another commented she would like the doctor to "Tell me how to take care of myself. How to handle him if he is sick so that I can care for him but protect myself. I didn't know those things"

Other statements supporting education were:

> "I need to know more about it. The more you know the better." This person went on to say "I have a responsibility to have as much knowledge as possible about this HIV thing. So I learn about it". Another added "I have a lot of knowledge on the topic and this helps me cope." Yet another said "I need information. He (the doctor) must remind us about CD4 and viral load and what the medicines do and any new developments. How to stay negative. How to stay healthy. What to eat. Exercise…This must be repeated every time we visit."

iv. Religion

Religion was mentioned but surprisingly not as often as the researcher expected. Some participants expressed strongly how God and their church had helped them through the crisis. Some said:

> "God will help us; He will do what is right." He went on to add "If it were not for God, we would not have initially met and we would not have got through to now. I know that he will protect us even when we are ready for a baby. I will not take the risk always but at that time my faith in him will protect us. We always forget to thank him but ever since the results I thank him for every day and for looking after us and pray for the future." Another added "the religion issue is-everything has changed after realizing our situation there is a lot of effort going to church". One other said "And I start to pray firstly…I am doing well. God always helps me. ARVs and God help him…I know God is going to protect me…Ja and he is going to be healed if God wants him to, to heal him…God is stronger then HIV." I further response was "God helps me, talking about it to my partner helps, the doctors counseling helps, my mother's support helps…If you are faithful to God and you are asking God to help, he will help you…I have tested twice – it was negative, so that's why sometimes I think God gives me protection"

While religion can play a very important role in assisting infected patients and their partners and families to cope, what these responses show is that some of the negative partners were prepared to put themselves at risk of contracting HIV by not using condoms, because they believed that their faith in God would protect them from contracting HIV as it had done till now. This is an important issue that doctors need to address. It will, be discussed later.

But some only touched on God and religion as a passing thought. This is important since spiritual aspects of suffering are an important focus of family medicine. This aspect may be

more important for the positive partner then the negative participants. This shows the need for individualized counseling.

v. Disclosure

Disclosure to other family members was found to be an important issue but one **on** which the positive and the negative partners differed. While most positive partners were opposed to disclosure, some of the negative partners favored it and felt it may help them to cope by decreasing the stress on them and giving them someone to talk to.

> "I was very angry that time and I didn't understand that why people are not supposed to know about our status in the house, especially our family, our close family...that was what was depressing me most…I like to open up - I'm like that and I want that". Another said "there is a lot of effort going to church and like we are there but we cannot disclose or talk about it." Another view was "But I do believe that if we could, it would ease that pressure of keeping secrets. Sometimes when we are with people, the topic of HIV comes up but I have to keep silent. I do not like that, I like to talk and say what I think. I know about that, to disclose is the only way to relieve stress, but now it's only up to me and my partner, I cannot disclose if my partner is not willing to at the moment".

> In one couple that did disclose, the negative partner commented "We've told family, they know about it. Its better that we told because it reduces the burden of holding secrets."

vi. Attention from the doctor

All the respondents commented on the attention they got from their doctors even when they were not the patients. Those that had been acknowledged by their doctors expressed gratitude for this.

> "she's (patients family doctor) not only there to help you with your illness, she'll ask you about the family and she'll actually take your mind off the thing that you really came for. So in that regard, some of the doctors are really good. They set your mind at ease before you really get to the real thing." Another commented ". The doctors input to me is very helpful and he understands my situation". A third patient commented "Oh they treat me right …I like it when the doctor asks me how I am. It shows he cares. I wish they all did that. It will make me feel as if I am not alone in this battle and there is someone who cares for me". Another comment was "when he (patient's doctor) talks to us he gives us strength. This patient also said "asking us how do we feel, it gives us – a person – individual the oomph to live because if somebody doesn't ask how you are today… Somebody does care." A final statement showing the importance of the doctor acknowledging the negative partner was from yet another patient who recalled "The Dr explains to us and talks to us. I like that he brings up the topic of HIV and our situation. He doesn't ignore the situation…He asks me how I am coping. This shows he care. I like it that he asks me. It is so important. It shows he is concerned about me also, not just her. This is important to me. Not only that he involves me in the treatment of my partner but also that he is concerned of how I am coping. Shows he knows there is stress on me."

Those that felt ignored were adamant that the doctor was at fault for failing to recognize them as potential patients and as resources. They said:

"Involve me in a sense that when you treat my wife as well, I think the doctor must also not forget me." Another comment was "…they must communicate and listen to the negative partner. We trust the doctor and can talk to him. Maintain confidentiality. Allow me to come not cos I am sick but to speak…The doctor must not only focus on the positive one but leave a small space of time for us as well. Sometimes they must see us together and sometimes alone-cos I may not say some things if she is present cos I have to be more sensitive when she is around." Yet another said "I want them must ask me about my stress and problems. Not only him. I feel pain inside also." Another patient said that if the doctor asked her "How am I feeling today…Those few words can make such a difference". She went on to say that she would really appreciate and value a phone call or a home visit from the doctor. "Maybe a phone call from the doctor or a home visit. To come and check on me…there's a bond between you and doctor. Just to expand the bond and to show me that he as the doctor does care for me as the patient. Maybe a short visit for 5 minutes, "how are you, give me a glass of water, I was just passing, said no, let me just come in, it will mean a lot to us."

These are important messages that hopefully all doctors can learn from as they may well improve patient satisfaction which can be so beneficial for future care of both partners. Another patient said "but when he (Doctor) talks to us he give us strength."

One respondent even suggested his doctor should charge him also when the partner is seen so that he can get some attention from the doctor. This highlights how important it is for the

patients, that they receive some acknowledgement and subsequent help from their doctor. He said:

> "There is nothing wrong with my body but something on my mind. I don't have a problem if he charges my medical aid for that, like a consultation. It is important to have your one family doctor who knows you well and knows you life and situation and he understands you"

vii. Safe Sex

Safe sex as an issue was also mentioned. Interestingly and worryingly, where the negative partner was a male, he felt that he would be willing, if not currently doing so, to have unprotected sex with his partner especially when they were ready for a baby.

> "I have tested twice, it was negative, so that's why sometimes I think God gives me protection. Another response was "that is a topic that I am not yet accepting yet. I want children. So does my wife. I cannot accept that we will never have more kids. This is where I have a problem with the condom. I know that I and she want kids and that at some stage we will need to have unprotected sex. I know the risk but I think I am prepared to take it when the time comes-I will deal with things after that. Don't get me wrong doc, I do not believe in taking risks but for this it will be worth it. God will help us, He will do what is right**."** Another male participant said "I know that he will protect us even when we are ready for a baby. I will not take the risk always but at that time my faith in him will protect us." This is a topic that needs to be addressed further and will be discussed later.

There was a misconception amongst some men that if they had remained negative so far, they would always remain negative. This also needs to be addressed by doctors and will be discussed later.

> "Sometimes we use it, sometimes we don't. Because I believe I will not get that disease. God is protecting me like before." Another said "I believe that if – like God has been protecting me before, he has the power to protect me now. God is stronger then HIV**."** Yet another said "I have tested twice – it was negative, so that's why sometimes I think god gives me protection."

Where the negative partner was a female, she was adamant that there had to be condom use if they were sexually active while one respondent refused to have sex with her partner.

> "We never have sex for how long doctor, its now, I'm talking years. This will be the third year now, I'm afraid of him touching me."

Some of the negative males also felt condoms were culturally taboo.

> "In my culture, you use condoms if you do not trust your partner. Not if you are married and love your partner. So that made things difficult"

viii. Acceptance

There was a belief that if there was acceptance of the situation and a positive attitude, it helped the couple cope and move forward.

> "I have accepted the situation as it is, no blaming no accusing. I know that as long as I accept, we can move forward together as a team, instead of blaming and getting nowhere**."** Another said "No I don't get that frustration. I don't get that anger. Like you have heard me telling on the acceptance part of it**."** He went on to add that "the only thing that I've realized is you have to accept your

status and once you've accepted, then you can try and fight the situation. I think what I've done, which is a positive thing on my side and on her side is I've accepted the status even though she didn't in the first place but I mean because I was there and I'm still there to support her… The only thing to change it is to accept it and live with it and see the means and ways of how to deal and cope with the situation…. If you don't accept the situation, you won't be at ease." Yet another said "I know that to move on I must accept things so I can proceed…We have not tried to look at her past to find out where it came from, we are focusing on the future-that is best-It will help us get through things."

ix. Good news about improving CD4 count

Another aspect that helped participants cope better was good new about improving CD4 counts in their positive partner. They said:

"The improving CD4 count gives you hope…it's important that we share. It's important when the positive partner is doing well, we share the information." Another added "last time she went for CD4 test and it was better - we celebrated and it was like as if she was now negative."

x. Social Support

Social support was also identified as a factor that helped them cope better. One person spoke of support from fellow workers, church and keeping herself busy.

She said "Colleagues, even though I am not saying anything, being near them and away from the house helps. I go to church maybe. In the evening there is a meeting somewhere, or keep myself busy with studying- helps me cope." She also said "Being around people, it helps me…keeping busy it helps me not to think about my status… by having lot of social activities, it helps you keep your

mind occupied." Another identified "community work" and the "support group at our church for HIV" which helped her cope. She went on to say "our priest, I spoke to him about it and you gave me like counseling."

4.2B) Negative coping mechanisms

As stated above, these were actions that were identified by the researcher, carried out by the participants in reaction to their situations that put them at increased risks.

i. Suicide

Two participants discussed suicide and family suicide. Both later claimed that they now realized this was not a good thought but none-the-less it is something we need to address. They said:

> "You think of the situation she is in and sometimes you think of family suicide- can I cope when she is sick or should I do family suicide…" It is unfortunate that these participants found themselves in a situation where suicide was even allowed to enter their thoughts. It is an issue that needs to be addressed and will be discussed later.

ii. Religious protection

Another coping strategy that was found to be dangerous was the strong belief in God by many participants. While this belief and faith is not bad, it is dangerous when they believe that they no longer need to use condoms when they are with their partners, since they feel God's protection is adequate. It is a delicate and fragile issue that needs to be approached with a lot of sensitivity and tact. They said,

"Because Dr like I told you first time that this thing of my husband is positive, I was negative, and I don't understand it. God must be helping me. I do not need a condom, God looks after me…" Another said, "When I speak to God, I'm asking God to give me power, to give me strength and that one day he must take my husband's disease away. I have that faith that one day, it will be not there if he tests again. But even now I have that feeling that my husband doesn't have that thing. I have that faith in my heart." Yet another said, "I have tested twice, it was negative, so that's why sometimes I think God gives me protection."

iii. Traditional Medicine

Another dangerous coping strategy was patient's reliance on untested traditional medicines and their belief that certain foods could help them. While none of them said they would rely on these foods only for treatment, it is an issue that needs to be explored and included in counseling sessions. One person said "African potato, they say that it gives you power, strength, everything like that, it a boost to your immune system."

3.3) The Future

i. Children

All the participants raised the topic of not being able to have children. All expressed disappointment that they could not safely have children in the future. Most worrying about this was the response they had to the situation, being that if they could not have children safely, they were prepared to have unprotected sex to have a child. One of the participants said,

"That is a topic that I am not yet accepting yet. I want children. So does my wife. I cannot accept that we will never have more kids. This is where I have a problem with the condom. I know that she and I want kids and that at some stage we will need to have unprotected sex. I know the risk but I think I am

prepared to take it when the time comes, I will deal with things after that." Another said, "If it were not for God, we would not have initially met and we would not have got through to now. I know that he will protect us even when we are ready for a baby."

This issue needs to be addressed by all doctors. All participants must by fully informed of the risks to themselves. They all seemed to be unaware of other options like In Vitro fertilization and other assisted reproductive techniques like sperm washing. Although these are all expensive procedures, it is something that should be discussed with and offered to patients and their partners so that they may make an informed decision.

ii. Shattered dreams and hopes

Shattered dreams and hopes were also highlighted. Many participants spoke of how they had plans and how these were now unreachable. Many felt that they were now in a state of mere survival and could not hope to dream of good things in their future. Some of the comments were:

"I cannot say there is a future, there's no future" Another one added "Inside I was scared. I was not sure of our future." He went on to add "I mean even if I'm working I'm just working for nothing, because there's no family, I don't have children" Yet another said "We still got a very young girl, very healthy and negative and I sometimes wonder are we going to see her grow, are we going to see her 21st birthday".

4.4 Suggestions

From the responses, there were numerous suggestions for doctors which were made by the participants. These include:

1) Doctors need to involve the negative partner in the positive partner's treatment. The doctor also needs to acknowledge the negative partner and talk to them so that they do not feel ignored,

> "The Dr explains to us and talks to us. I like that he brings up the topic of HIV and our situation. He doesn't ignore the situation." One participant would have liked her doctor to say "Hello Mrs. T, you are entering my surgery, how are you today? Are you ok today? But you don't look fine to me. You say you are ok but you don't look ok. Maybe by saying that, it will help me open up." Another had a similar wish for her doctor to ask her" How am I feeling today"? She said if this was done "Those few words can make such a difference." Another response was "He asks me how I am coping. This shows he care. I like it that he asks me. It is so important. It shows he is concerned about me also not just her. This is important to me. Not only that he involves me in the treatment of my partner but also that he is concerned of how I am coping. Shows he know there is stress on me."

2) Another suggestion was that the patients wanted honesty from their doctors. They value this as they realize they can trust their doctor. One participant said "I am happy that my doctor was honest about it and said he doesn't have all the answers. I know that this is still under investigation."

Most participants said they valued confidentiality from their doctors. While many of the participants trusted that their doctors would protect their confidentiality, they were not convinced that the doctor's staff would do so. Some even felt that the doctor's staff had no right to know their details. This is where there will be some difficulty since the staff have access to patients file and they often assist the doctors when the act as translators. So often

doctors think that if they maintain confidentiality, there will be no problems. Most probably do not even consider the staff as problematic. All doctors must discuss this issue with their staff and insist that the staff always maintain this. Some of the comments were:

> ”which means she (receptionist) must’ve read my results. So I don’t think that was too confidential.” Another added “One important thing is the confidentiality. Not of the doctor - of the people that work for the doctor, like the receptionist…They should be sworn to secrecy because they working with the doctor, they are exposed to information. Most of the information leak, if it does leak it will be through the receptionist”

> Another important comment from a participant was “What I don’t like is that the doctor sometimes speaks loud so I tell him please go down a level cos other patients might hear the conversation especially since the walls of his surgery don’t go to the ceiling so people can hear on the other side. So confidentiality is important”

3) Many participants would have liked the pretest counseling to include information on the possibility of them being discordant. They all expressed shock and amazement at their discordant situation.

> “First of all I can say that I was not expecting that you can be negative and partner positive, even after Dr have counseled us…I’m feeling very confused.” Another added “To me it’s still a question”. One final comment on this issue was “both my partner and myself did not understand there might be something like that of that nature. We always believed that if one is positive, both will be positive. Here it was a different situation”

Proper counseling was not given to all patients. Some doctors were too busy and some did not seem to care. This was especially the case when patients did their HIV test at a public hospital.

> "The doctor was not interested on giving me the information, he said you can take this so that you can read up" This lady added "You know they should have talked to me. With this doctor it was different, he ask me why do you want to take the result, I say just to know my status then it ended…He never ask me what if they came out negative or positive, how you going to feel"

4) Most of the participants said they felt that the interview done by the researcher was of benefit to them since it allowed them to say things they did not say before. Most of them were adamant that it would have been better if their partners were present to hear what they had said. Some of the comments were:

> "I benefited as it let me talk about things" and "I think it's important for both partners to be around when such counseling is happening". Another said "I wish this interview could have involved both partners so that when we talk about she/he can hear what the other person is speaking about the whole situation." Another said "I would maybe say it would be better if my partner may be involved then maybe it will relieve something from my side, like stress". He added "she would know what's happening, it would involve her and she would be aware and know how you feel about certain issues as well, which she doesn't know about at present "Another said "I got a lot of things off my chest, I didn't speak to anyone else about…maybe next time if there's anything like this, maybe it involves both of us in discussions. Maybe he won't be afraid to speak out."

However one participant was totally against having his partner present as he felt that it would cause a rift amongst them. This highlights the fact that these negative partners are often ignored and they need to speak to someone to relieve some of their stress. It is important to give them this opportunity to talk and it is important to allow them to decide if they want their partner present at the time.

Doctors must also keep up to date about what is happening in the field of HIV research. Most participants were keen to have their doctors continuously educating and counseling them about HIV and related issues. They seemed to feel empowered with this knowledge and most expected their doctors to give them this information.

> "I need information. He must remind us about CD4 and viral load and what the medicines do and any new developments. How to stay negative. How to stay healthy. What to eat and exercise."

Doctors should also educate their patients and their partners that HIV/AIDS is not a death sentence. The latest research suggests that HIV infected people can live up to thirty five years on treatment. This will allow them and their partners to live a full life and they should be encouraged to continue to dream and strive for their goals rather then sit around and expect to lose their partners. Doctor must also keep abreast of the development with the HIV vaccine as patients thought it was important

One participant said that the doctor must inform him and his partner of her rising CD4 count as it gave them hope. It encouraged them to continue to with their lives and gave them hope for the future.

Another piece of advice to doctors was to give continual counseling to patient and to repeat important messages “Give advice and counseling at every time we see you. Do not forget the negative one and educate us always”

CHAPTER 5 - Discussion

HIV discordant couples face some similar and some different challenges than concordant couples. Their desire for children, risks of domestic violence, fear of separation, social pressures, need for safe sex practices and issues associated with disclosure continuously bother both partners[51].

There was a vast range of emotional problems and reactions that were experienced by the negative partners. While some of these reactions were very understandable given the situation they found themselves in, others were unexpected. The unexpected responses were labeled as such since the researcher was surprised that the respondents would show such responses when faced with their situation. The researcher felt that most people in their situation would not have responded in the same way. While it is very understandable that couples would support one another in good and bad times, the researcher was surprised by the seemingly genuine kindness, compassion and support that some of the negative partners gave to their positive partners. The others supported their partners out of guilt and fear that their partners would not cope without them. This was a far more understandable and expected reaction. The researcher feels that acknowledging and understanding these unexpected emotions and reactions expressed by the negative partners towards their positive partners was of importance in enhancing our understanding of the seronegative partner. While this study is too small to draw conclusions about differences in male and female reactions, it must be pointed out that there seemed to be a trend. When the negative partner was a male, they seemed to fully accept their partner's situation and felt a need to focus on the future, while when the female was the negative partner, she did not accept things as easily.

An article in the Saturday Star newspaper quotes a clinical psychologist as saying that "…blame and anger are secondary concerns. There's more commitment then accusation." She goes on to add that "It's amazing the amount of commitment the men have to their relationship. Their attitude has been: 'This is one challenge among other challenges."[52] One of the negative female respondents blamed her partner and felt "cheated and without hope" but remained with him out of guilt and a lack of other options. These observations need more thorough investigations.

Another observation was that if the negative partner believed the positive partner was infected before they had met, the negative partner seemed to accept the situation and harbored no ill feelings or resentment towards their positive partners. However, if the negative partner believed that the positive partner had contracted the HIV infection while they were together and as a result of the positive partner being unfaithful, there was resentment and anger that the negative partner felt. This also needs more evaluation in future studies. In this case also, the negative partner remained in the relationship out of guilt and due to a lack of other options. This is important as it can guide the doctor when he/she consults with the negative 'hidden' patient. It also shows that this consultation, when it takes place should take place without the positive partner being present so the negative partner can talk and express him/herself freely.

The expected responses included fear, anxiety, disbelief, shock, frustration at their situation and the lack of answers, blaming of their partners for their situation, despair for the future and loss of hope. Most individuals when faced with a life-altering situation would be expected to respond in this way. Elizabeth Kubler Ross' stages of grief include denial, anger, bargaining, depression and acceptance[53]. While not all individuals go through all these stages and in this order, many do. As stated above, these reactions were not surprising. Many patients and

their family members go through these stages of grief after learning of their condition. Patients with HIV infection also fit in this category. With advances in treatment for HIV infected patients, survival times are also increasing. Some experts suggest that HIV infected individuals on antiretroviral therapy can expect to live more then thirty five years[103]. HIV is now like most other chronic diseases. Patients and their families can expect the infected person to live and they need to adjust to this and respond to challenges that arise. While the grieving process is very important in individuals who are faced with crisis situations, it is important that doctors identify HIV positive individuals and their partners and other family members who need assistance. There is the ever-present danger of suicide and depression. It is important to differentiate a normal grief reaction from depression and this is where the challenge lies for the doctor. Grief must never be treated with medication, like antidepressant medication and benzodiazepines and other sedatives which must be avoided if possible or used for a very short period although drugs do have a role to play should real depression set in.

Many studies have found a link between chronic diseases like HIV and depression, not only in the HIV positive patient[54,55,56], but also in the negative spouse[56,57]. A study by Mayer[58] of Alzheimer's patients and their spouses reported, "Repetitive feelings of sorrow and distress appear in caregivers…due to persistent demands caused by the illness." They go on to say that coping skills are needed to prevent the caregiver from being physically, mentally and emotionally depleted. While this study was done on Alzheimer's patients who need a lot more attention then our study population, who were generally still healthy, it does show the potential situation in which our negative partners could find themselves in in the future if their partners do not take antiretroviral therapy when needed and if they reach a stage of HIV multifocal leucoencepalopathy.

Negative partners need constant support from their positive partner, other family members, friends and their doctors. Social support and doctors' support was found to be beneficial to caregivers of HIV positive patients in many studies[59,60,61]. This can be difficult especially if the positive partner refuses to disclose his/her HIV positive status. In this case, the negative partner is left with only the doctor who can provide support. This again highlights the need for doctors to acknowledge the negative partners and to offer them support and help. Too often they are ignored[60,62] and left to deal with issues alone. These stressors can increase their risk of depression and suicide. A study by Rose found that negative partners "value support from professionals based on an acknowledgement and respect for the caregiver's role in the patient's life."[61]

There were numerous reactions from the seronegative partners that were totally unexpected by the researcher. These include total support for their infected partners and a belief that their situation had brought the couple closer together. There was also a belief that the way forward was not to dwell on the past and the details of how and when the positive partner was infected but rather on how to live life to the fullest by both partners. The researcher was amazed at the strength of the negative partners and the compassion they showed towards their infected partners. It is this reaction in the face of such a stressful situation that must be admired and acknowledged. This acknowledgement is perhaps something that all doctors must do, not as a token reward for the accepting, supporting negative partner but as a genuine praise and acknowledgement of a unique and special individual's support, compassion and commitment.

An important lesson that can be learnt from this is that the human spirit can overcome almost any adverse event and triumph over this. The negative partners can be further assisted by acknowledging them, addressing any issues that bother them and by making them feel that

they are part of the team in this fight against the common enemy, which is the HI virus[59,60]. By doing this, we can show that their actions are not unnoticed and they can realize how important they are to their partners in their fight against HIV. It is well documented that HIV infected patients do much better when they have the support of their partners. This was demonstrated in the SMART[14] programme.

All the respondents felt very strongly about their doctor's addressing their issues in addition to their positive partner's issues. They (the negative partners) spoke of how this allowed them to express themselves and how good it made them feel. This is important as it teaches doctors that we often ignore the accompanying partner who is also a patient, but not just any patient, a hidden patient[17]. Family medicine encourages doctors to look beyond the disease and focus on the individual and their family and surrounding. All doctors need to learn this skill since it can be a powerful tool they can use in addressing patients and their family issues, which can then help in treating the presenting patient (positive partner) and the hidden patient (Negative partner).

There are various challenges that discordant couples face including issues around safe sex, fear of loss of their partner due to death or separation, domestic violence, social stigma and victimization and forced sex. These are more often the experiences of the female partner. To deal with these, we need targeted, individualized and repeated counseling sessions that will address these and other issues[51]. Limited resources unfortunately make these repeated sessions difficult and unlikely, but this again highlights the important role the negative partner can play in the holistic treatment of their HIV positive partners, but not before we fully acknowledge and understand them and subsequently give them support as they assist in the management of this chronic disease.

5.1) Beneficial coping strategies

i. Good Communication

The coping strategies highlighted above in the results section were divided up into those that the researcher felt were beneficial and those that increased risks for the negative partner. All doctors can use the beneficial coping strategies mentioned to help the couple to make a plan for newly discovered serodiscordant couples which will assist them as they prepare to face some very difficult issues. One of the beneficial coping strategies was good communication between the positive and the negative partners. Almost all the negative partners commented on the need for honest and regular communication with their infected partners. They all seemed to agree that communication decreased their fear of the unknown, and made them feel like part of the solution. A study from Rwanda[37] found that good communication between the two partners in associated with improved condom use. This was also found to be true by an Atlanta based study[63] and a California study[64]. This again highlights the importance of good communication. The negative partners expressed extreme frustration when there was a lack of communication. While this aspect is difficult for the doctor to include in counseling, it deserves a mention in the pretest and post test counseling session. That doctor may be able to quote literature[37,63,64] that shows the benefits of good intra-couple communication on the future of the relationship and the benefits to the infected patient. It may be an important question that the doctor can raise during consultations which will show both partners the value of good communication and thus enhance their communication levels.

ii. Providing Support

The negative partners seemed to get a lot of satisfaction from being able to support their infected partners. It seemed to give them a feeling of being involved and lending support. This is important since it shows the value of the negative partner who often wants to give

support. It is also well known that positive partners value support from their partners[65]. Unfortunately, the negative partners are often left out and ignored. They can also be used as a very effective tool to promote adherence. HIV needs adherence of over ninety five percent[66] for the medication to be effective and to prevent treatment failure and resistance. The SMART[14] study showed the value of a partner in helping with adherence. The partner does not only need to remind patients of their medication but they can assist in encouraging the patient to continue with treatment. It must however be stressed that it would be unwise for the negative partner to act as a policeman and report to the doctor about the adherence or lack thereof by the patient. This approach can increase resentment and lead to higher rate of defaulting on treatment. An inclusive[56] team approach may be beneficial since it will put the two partners and their doctor on an equal footing and assist in the formation of a partnership[67]. While some doctors may find this type of a situation threatening and intimidating, they may with time get more satisfaction as it will reap rewards in terms of the couple's wellbeing being enhanced.

iii. Education and information about HIV/AIDS

Education was mentioned as a way to cope with the stressful situation. The negative partners felt that they could assist their partners and it empowered them when they had more knowledge about the HI virus and how it infected and affected patients. This is important as it shows that there is a need for doctors to constantly educate the couple (especially the negative partner). Many doctors previously believed that the less the patient and their partners and families knew about chronic life threatening diseases, the less they had to worry about. This is now not an acceptable belief. Informed consent is one of the corner stones of medical ethics. It provides for the patient to be fully informed of his/her condition, prognosis, treatment and alternatives unless they specifically do not want to know this. All patients must be offered this information, so that they can then make an educated decision. Sometime

patients may want their family members to assist with decision making and sometimes they may want the family members not to know what is happening. The right to disclose to family members must always be respected. In HIV infection however, the doctor has the right to disclose to the spouse in order to protect him/her for acquiring the infection. The doctor's aim must never be to supersede the patient's requests and rights. It would be far more constructive to reach a joint decision with the patient. This again shows the need for the patient to have all the facts before he/she can decide. We know that patients often cope better when they have family support. They should never be "protected for their own good" as this is a fallacy. Studies have looked at doctor's disclosure patterns. Doctors largely follow the rule of informed consent, but there are cases where they break this rule. Reasons suggested for them doing this include, the doctors own emotional coping, legal constraints and power relationships amongst patients, doctors and other caregivers[68]. Another study from Cape Town, South Africa found 79 percent of doctors felt it was their duty to ensure informed consent. They all provided legally required information but avoided information on alternate treatments and costs[69].

A qualitative study from Thailand[20] that looked at caregivers of HIV positive patients found that participants wanted "education to improve their knowledge and skills related to care" of their partners. Another study from Canada also reported on caregivers needs "for informational support" from health professionals[70]. Yet another study found that caregivers constantly searched for support and information and were often frustrated by inconsistent and irregular support and lack of information[71].

This patient's (negative partner) desire to be fully informed and educated about this topic requires doctors to have an up-to-date knowledge of HIV and the developments in the fight against this virus. While this may initially cause the doctor to "panic" at the prospect of having

to do more reading and research, it can lead to an opportunity for the doctor to improve his/her skills in practicing evidence based medicine and their use of the internet as tools to improve their patient care. Evidence based medicine integrates published clinical evidence with patient values and clinical expertise to allow informed medical decision making. It requires acquisition and appraisal of clinical information[72]. Evidence based medicine is something all doctors should be familiarizing themselves with as we reach a stage at present where we find doctors swamped with new research and journals to read as well as their being an increasing trend for patients to ask questions and demand their doctors account for what they are doing. Increased litigation has also made evidence based medicine a necessity in the medical profession. With evidence based medicine, comes the need for doctors to learn how to evaluate journal articles so that they can assess which articles are good to read and which are interesting to read. The good to read articles are articles that teach the doctor new things that can improve his/her practice. The interesting articles are articles that the doctor can read if he has spare time that do not teach the doctor new things but that he finds interesting. This art of differentiating the two is important with the information explosion that has occurred and due to the fact that doctors often do not have enough time to read all articles in journals.

iv. The role of Religion

Religion also helped some of the couples cope with their situation[73,74]. The spiritual aspect of patient care and management is increasingly being recognized as vital for holistic patient care[75]. The researcher fully supports patients bringing religion into the equation of holistic care. However, there were a few problems that surfaced around the issue of religion and God which will be discussed below. Spirituality is a component of patient care upon which the doctor has very little control. It may also be difficult for the doctor as it may go against the doctor's own religious beliefs and it may lead to the patient and the family requesting or

rejecting treatment that the doctor thinks is vital. The doctor must approach each patient and situation differently. The doctor needs to try and accommodate the patient's spirituality and beliefs within the treatment framework[76,77]. Where there is a conflict, the doctor must ensure the patient and the family understand the repercussions of their choices and decisions so that they can then make a fully informed decision. As stated earlier, the researcher is a firm believer in patient's right to make informed decisions and the patient**'s** rights to this must be safeguarded as long as the decisions are made with all the information on hand.

v. Benefits and risks of disclosure to others in the family

Disclosure was mentioned as a positive aspect since it was felt that it could ease the burden of keeping secrets from family members. It will however be discussed under negative coping strategies since it was not practiced by most of the couples on the insistence of the positive partners

Therefore, the positive coping mechanisms which the researcher believes can help both partners and keep the vulnerable negative partner safe by reducing his/her risky behaviour with their positive partners included good communication, up-to-date knowledge and information about HIV and AIDS, being allowed to and being acknowledged as offering beneficial support to their partners and religion which helped them make sense of their unique and often confusing situation. A Ugandan based study found that "condom use, abstinence, separation, counseling and reduced frequency of sex were strategies used by discordant couples"[51]. These are important and useful topics that can be addressed in counseling sessions, however their messages must be repeated at each counseling session[32].

All of these positive coping mechanisms make the negative partner feel like they are part of their partner's solution rather then being passive outsiders. This is important as it teaches us to focus on these issues that the negative partners highlighted as being important to them.

5.2) DANGEROUS COPING STRATEGIES

The dangerous coping strategies highlight the issues that we need to address when dealing with serodiscordant couples. These include thoughts of suicide and family suicide, increased beliefs in untested traditional treatments and a belief the God would protect the negative partner from HIV/AIDS and that the fact that the negative partner did not need to practice safe sex since they had remained negative so far without protection.

i. Dangers of depression and suicide

The issue of suicide and family suicide is very important since we can never be sure how true the threat is. While both of the participants who mentioned it later downplayed their earlier statements, such 'threats' should never be taken lightly. Suicide and suicidal ideation have been studied in HIV positive individuals, there are no statistics that focus on the negative family members and spouses. The suicide ideation rate of 50.5 percent was found in a London based study[78]. It may be a common initial thought when faced with bad news and we cannot ignore it. The percentage of those who actually harm them selves and or their families is unknown. All doctors need to actively look for danger signs and ask about these thoughts, perhaps at all visits. If in doubt, the doctor must involve psychologists and psychiatrists. As doctors, we must know our limitations and refer appropriately when needed. These negative partners are also high risk patients for depression especially because of their increased stressors. While most doctors' probably actively look for depression in the positive partner, many probably do not even consider it in the negative partner. Depression must be excluded in all the negative partners from serodiscordant couples. Unfortunately most studies done to

date have only looked for and confirmed a high rate of depression in the HIV positive partner[79,80]. This again shows how the negative partner has been ignored so far in discordant couples. The negative partner who is at increased risk for depression is also at an increased risk for suicide especially of he/she feels ignored and isolated.

ii. Failure to disclose

Failure to disclose to family members was found to increase the burden on the negative partners. Most of the negative partners favoured disclosure to close family especially parents and siblings but the positive partners rejected this out of fear of the stigma that the community holds towards HIV positive patients. While it can be appreciated why the positive partner would want to keep their status a secret, it remains a tricky situation. While not disclosing to anyone may seem beneficial to the positive partner, it is stressful for the negative partner. There should not be any attempt by their doctor to convince the positive partner of the benefits of disclosure, it is a topic that the doctor can bring up for discussion so that the couple can jointly make a decision. The positive partner may think differently when they hear how the burden of not disclosing weighs on the negative partner. However, the negative partner may sometimes be the one who refuses to disclose to close family and friends due to fear of discrimination and victimization. A study reported "negative consequences"[81] associated with disclosure. These include "loss of friends, being sworn and insulted, and being rejected by family." Women in this same study reported being "physically or sexually abused." While these results were seen in the positive partners only, there is no mention of negative consequences directly towards the negative partner. All of this demonstrates that the issue of whether to disclose or not is a very difficult decision, which both partners must jointly agree on. The doct**or's** duty is not to push for either option but to assist the couple to make the decision themselves.

iii. The role of traditional medicines and treatments

There was a mention of traditional medicine by one participant. While the researcher is not against the practice and use of traditional medicine for some illnesses, he is skeptical when they are used to "cure HIV". There are too many healers who till today advertise HIV cures in the newspapers. None of these miracle treatments have ever been shown to work, very few have been scientifically tested and some may even be dangerous when combined with antiretroviral medications. One such case is with Saint John's wort, a herb used to boost the immune system. When used with Crixivan (a protease inhibitor), it has been shown to reduce levels of the crixivan[82]. The researcher acknowledges that traditional healers have a role to play in patient care especially since they provide spiritual and psychological care and support to the patients. Despite this, the researcher feels that with the lack of scientific evidence, traditional healers must take a back seat when faced with an HIV infected person who needs antiretroviral medication after their CD4 count has dropped to below 200. This is something that doctors need to address with both partners. The researcher has treated many HIV positive patients who have spent thousands of rands on miracle treatments without success. Many were left feeling more depressed and cheated and the researcher was left with the task of trying to help them and restore their sense of hope for the future. In the serodiscordant couples, the fact that there are so many unknown factors makes them more vulnerable to seeking alternate treatments. If these are for "HIV treatment or cure", the doctor must address the couple on the danger of this, but if it is for spiritual and ancestral help, them the researcher is in favour of this. Incorporating a patient's beliefs and cultural practices into a treatment plan has been shown to improve patient satisfaction and enhance the doctor-patient relationship. It may even be helpful to mention this in pretest counseling which could be covered in the section on "if the test came back as positive" When discussing this, the doctor would suggest that the couple have the right to choose any treatment method they want, but, the only one that has been tested and proved to work is the antiretroviral

medication. The doctor must not belittle traditional healers and their methods but he/she must point out that these methods are being investigated but thus far they have shown no benefit in the fight against HIV.

5.3) FUTURE PLANS

Various topics need to be addressed that were mentioned in the list of future plans. These include plans for the couples and with their doctors.

i. Desire for parenthood in discordant couples

Most of the respondents brought up the topic of having children. This was also found in the study by Nassozi et al done in Uganda[51]. They all were unhappy with this situation because they were encouraged to practice safe sex, and they realized that this would mean that they could not have children. A worrying aspect of this was that some said they were willing to "be unsafe" to have children. They were willing to take the risk as they felt the benefit of having a child made it worthwhile. Others spoke of God protecting them when they wanted to have children and there was a mention that if the negative partner had remained negative till now, there was no need to use barrier protection as they were "immune" to the disease. These beliefs show the negative aspects of religion on HIV treatment. It is the very religious beliefs that assist the negative partner to cope, that also place them at increased risk when they believe that because of their religious belief, they would be protected by God from HIV infection. The researcher would never tell anyone that God will not protect them, but he does believe that every doctor has a duty to highlight the risk the partner is putting themselves in and how the transmission rate increases with each unsafe act. The patients must know that they are at increased risk if they practice unsafe sex. If they still want to go ahead, the doctor must accept their informed decision. A South African study[83] reported that some HIV positive

individuals avoided pregnancy since they did not want to infect their partner and the baby. This was in contrast to the Ugandan[51] study were most of the positive partners expressed a strong wish for parenthood.

ii. The positive role of religion

In Kenya, the church has been brought in to assist in spreading the message of safe sex. Priests have been educated about safe sex and have started including these messages in their sermons. A program in Burkina Faso looked at educating pastors about HIV/AIDS and mother-to-child transmission. This study showed that the pastors were keen to be taught about these topics but what impact this will have is not yet known[84]. The effectiveness of this approach is still being investigated. In Kenya, an organization developed and launched a project to teach pastors about HIV/AIDS and to encourage them to discuss the subject with their parishioners. Messages of how to prevent HIV infection were highlighted. While the full effect of this project is still being studied, a good start has been made[85]. This progressive approach from the religious leaders must be commended and used as a blueprint for future projects of a similar nature. Most of the participants in this study spoke of their improved relationship with God since their partner's positive result was discovered. With this in mind, it can be seen how important an ally like the pastor of the local church can be in the battle to get people to practice safe sex. However, in predominantly Roman Catholic areas, this approach has been rejected by the church[86]. In practice however, health educators and nurses have been allowed access to catholic schools where they have discussed issues like premarital sex, family planning and HIV prevention. They have also been allowed to distribute condoms to the children. This shows that there is a conflicting view from those at grassroots level to the decision makers in the Vatican.

iii. Addressing myths about safe sex and assisted reproductive methods

Practicing safe sex is an issue that is central in the discordant couple's lives. Safe sex is any sexual activity in which precautions are taken to prevent semen, blood or vaginal fluid from infecting your partner. One hundred percent of condom use is needed to be correctly called safe sex. Condoms provide a barrier that prevents transmission of HIV during sex, provided they are correctly used. There have been attempts to "time unsafe sex" so that it is "safer" by only having unsafe sex at the time of ovulation in the female, provided that the positive partner has a low viral load due to antiretroviral therapy. Mandelbrot et al[87] reported a transmission rate of four percent using this method. This practice must be strongly condemned and avoided as it puts the negative partner in unacceptable risk of acquiring HIV. There have been excellent advances in assisted reproductive techniques in the last few years, especially where the male partner is found to be positive and the female partner is found to be negative. These advances include sperm washing whereby the HIV infected sperms are removed and only the HIV negative sperms that remain are used. If the female partner is found to be positive, the option of adoption can be considered. With these advances, the need to have unsafe sex for procreation is obsolete. Most researchers agree that despite the efficacy of antiretroviral therapy to decrease viral loads to undetectable levels, and the low risk of transmission at these low viral loads[88], there is still no reason to ever practice unsafe sex. Every doctor must explore the couple's understanding of safe-sex practices and emphasize the importance of condom use with water based lubricants. The major problem is that most couples may not fully understand their risks and their options as listed above. Our aim must be to highlight these risks and options. Another problem is that in most of the developing world resources are limited and so the option of sperm washing may not be available to the couple. However, where they do exist, couples must get this information. Doctors must also dispel the myth that the negative partner will remain negative as they had till now without using condoms.

All of these issues need to be addressed by doctors. There are few studies that have quantified the risk of HIV transmission from one partner to the next. Some studies have yielded results of 11.1%[40] risk of transmission in discordant couples. While the researcher strongly advocates patients right to informed consent and educated decisions, he believes that it is every doctor's duty to ensure that their patients are fully educated and informed when they decide on issues like practicing safe sex or not. What the patients need to know is that every unsafe sexual encounter puts them at a cumulative risk. Another study estimated a transmission risk of 0.0011 with each coital encounter[89]. Viral load, existing genital ulcer disease and frequency of condom use have an effect on these rates[40,41]. Another group of researchers calculated transmission rates at different times in the life of the infected partner. Their results concluded that the transmission rate to a non infected partner was much greater in the immediate period following seroconversion. They agree with other researchers that viral load and genital ulceration were the main determinants of HIV transmission in discordant couples[90].

It may also be wise to mention this to couples as well as the existence of the delta 32 CCR5 mutation that seems to protect certain individuals. Whether this provides total protection or not is unknown. It is not known if repeated exposure in these individuals leads to increased risk or if there is absolute protection and immunity. Therefore, their best bet is to take no chances by using condoms.

Serodiscordant couples must not be discouraged from having children but they must be made aware of their options to have children. This was suggested by a study from Nigeria that states this because of "the compelling desire for parenthood" that they found in their study population[91]. The safest of these options is to adopt a child. With South Africa's high numbers

of HIV and AIDS patients, many of whom have not and are not receiving treatment, there are thousands of orphans who need homes and families. In this win-win situation, the orphans would get a loving family and the couple will get a child without putting the negative partner at risk. Despite this large number of orphans, legislation unfortunately makes it very difficult to adopt in South Africa. The television program, Carte Blanche, recently looked at two families, one from South Africa and the other from Washington DC, both of whom wanted to adopt HIV orphans in South Africa. Both families have had to spend large sums of money on legal fees in their battles to adopt children. Both families have not been able to complete the adoption process yet and the South African couple is now looking to adopt a child from Eastern Europe. This highlights the problems that need to be addressed to overcome these problems, which may then make adoption seem like more of an option. Legislation is currently being reviewed with regards to this situation. However, in South Africa, adoption is not widely embraced by most communities as it is in other countries in the world. This is a difficult behaviour to change but all couples must be made aware of this option they have.

iv. Assisted reproductive techniques to consider

"The risk of vertical HIV transmission from mother to child has been shown to be markedly decreased through HIV education, counseling, testing and zidovudine use"[92]. Another option when the female partner is negative and the male partner is positive is to do "sperm washing". This process involves separating HIV infected sperm from uninfected sperms and then fertilizing the ovum from the female partner with this. This process has a good success rate and theoretically has an infection rate of zero. A major drawback of this process is the high price. However, it must be offered to couples wanting children.

Where the female partner is positive and the male partner is negative, a sperm can be fused with an ovum as it is done in Invitro fertilization. But before this is done, the female must

begin antiretroviral medication to increase her CD4 count and decrease her viral load, both of which will decrease the risk of transmission to the baby[93]. She must continue the antiretroviral medication for the full duration of her pregnancy. She will have to deliver the baby by caesarian section as this decreases the risk of transmission to the baby. The baby then needs to start AZT for the first 6 weeks of life and must not be breastfed but rather formula fed. With all of these interventions, the risk of transmission can be lowered from thirty percent to as low as one percent[94]. The couple must realize that there will always be a slight risk since a small percentage of infections occurs while the baby is in the womb.

There is a belief that all HIV positive mothers will deliver HIV positive infants if no treatment is offered to the mothers. Patients were very unaware of the risks to the baby if mother was untreated versus if mother was treated. Patients were also unaware of the treatment options available. This is an area that doctors must address with all HIV discordant couples[95]. We know that transmission rates in HIV positive mothers not receiving any antiretroviral drugs are about twenty five[96] to thirty percent. A rate of 24,2% was obtained in a study from France[97]. With single dose nevirapine, this can be decreased to about half of this. However, there is nevirapine resistance[98] that can occur with single use of the single agent nevirapine but this resistance does decrease with time. The exact amount of time needed for this resistance to disappear is not yet known. With HAART (highly active antiretroviral therapy, which is the preferred regime if affordable), the risk can be brought down even further to about five percent[96]. This can be further reduced by delivering the baby via caesarian section[96], giving the baby a course of antiretroviral medication after birth and finally by preventing breastfeeding and substituting it with formula feeding. This can reduce the risk to as low as one percent[96,99]. Doctors need to be familiar with these statistics so that they can assist the patients in making an informed decision. Doctors must also accept the situation if patients

decide that as a discordant couple they want to have children without medical assistance, as long as their decision is an informed one!

The ethical issues involved in offering HIV discordant couples assisted reproductive techniques was reviewed by Spriggs and Charles and they concluded that this offered more benefits then harms to these couples and violated no ethical principles[100]. Lyerly and Anderson[101] from Johns Hopkins University also suggested that it was "neither ethically nor legally justifiable to categorically exclude individuals from fertility services on the basis of HIV infection". Gilling-Smith et al[102] also challenged the belief that it was ethically unjustifiable to provide assisted reproductive assistance to HIV infected individuals.

v. Shattered dreams

There was also mention by one participant that her dreams were shattered. This reaction is very understandable in light of the couple's situation. It should not be part of the doctor's agenda to try and suppress this feeling; however, it is important that the doctor make the couple aware of the state of treatment and care available to HIV infected patients. All these couples should be informed about the benefits and wonders of properly taken antiretrovirals. A Danish study has suggested that patients on antiretroviral can expect to live up to thirty five years on treatment[103]. This is great news for any serodiscordant couples, many of whom do not know this fact and many of whom believe that their partners will die in a few years form the time of diagnosis. This information will give them hope and it may encourage better adherence.

vi. Unknown reasons for discordance

The results showed that most of the patients brought up the topic of the unknown factor as to why they were negative despite recurrent exposure to the HI virus from their partners. While

most of the positive partners did not lose faith in the medical system because of the lack of answers, they did however want answers. There were a few who accepted that is was due to "Gods will". There has been extensive research that has tried to answer this very question but so far there are no definite answers. The Thailand study[18] reported that it was probably due to an unknown genetic factor and neutralizing antibodies that may have been responsible for protecting the negative partner. Common misconceptions include the concept of a "hidden infection not detectable by HIV tests, belief in immunity, the thought that gentle sex protected HIV-negative partners, and belief in protection by God. Such explanations for discordance reinforced denial of HIV risk for the negative partner within discordant couples and potentially increased transmission risk[32]" and highlight the need for us to address the issue of possible causes as well as the need for doctors to be honest that we do not have all the answers yet. Patients seem to appreciate this honesty.

vii. Sexually Transmitted Diseases

What is important for doctors at primary care level is to look at a few important issues in serodiscordant couples. One such issue is sexually transmittable infections. Both the curable and the incurable sexually transmittable infections must be considered. The researcher is of the opinion that all STI's, both curable and incurable must be sought out in serodiscordant couples. This needs to be done by serological tests. All curable STI's must be promptly treated and the incurable STI's like Herpes must be controlled by long term antiviral drugs[104]. Herpes type 2 infection has been identified as one of the greatest risk factors for HIV transmission[105,106]. A major problem is that many couples are unaware of the existence of an incurable recurrent STI or if they were aware of it, they were unaware of when it was active until it was too late and genital ulcers had already formed.

CHAPTER 6 - Conclusion

This study has highlighted the experiences and the range of emotions that seronegative partners in HIV discordant couples go through. For too long, these partners have been ignored by doctors. This research has shown that these negative partners are also in need of treatment and help from their doctors. By addressing issues affecting these negative partners the doctor can in turn get help from them in treating the positive partner. These negative partners can provide the doctor with a most effective family based tool to promote and re-enforce messages that many doctors are often too busy to repeatedly do such as adherence to treatment, encouragement, good sexual practices, health promotion and modification of help seeking behavior. They may, together with the doctor and their positive partners, form a health team[15]. The research has shown the range of emotions which include those that are expected from a person faced with this type of stressful situation as well as emotions that were unexpected by the researcher, especially in light of the fact that they showed extreme compassion and support in the face of this frightening condition that the couples found themselves in. The research also showed the different coping mechanisms adopted by the participants as they dealt with their circumstances. There were both positive and negative coping mechanisms identified. The research also looked at what the participants thought of their future and which aspects were important to them. Finally, after reviewing the participant's views, experiences, emotions and suggestions, the researcher was able to extract recommendations for fellow colleagues who find themselves faced with couples in the same situation. These recommendations include:

1. Doctors should not ignore the negative partner in discorant couples. They are also patients and in need of help and support. They can in turn help the doctor in future treatment of the positive partner. By just acknowledging them and that they are also

going through difficult times, allows them to bring out their problems and assist in future management.

2. Always discuss the possibility of discordant results before testing a couple. This possibility can be a source of immense stress and confusion to the couple if they have not been alerted to the fact that it can occur.
3. Both partners in the discordant couple must be screened for depression as there is a high rate of this illness in both groups. Too often, this depression is not actively looked for in the negative partner. Doctor's who fail to do this, will be neglecting the wellbeing of the family unit.
4. All discordant couples should be offered ongoing counseling sessions, either separately or together as a couple. This will give the often ignored negative partner an opportunity to air their views and problems, not only to the doctor, but if they participate in the sessions as a couple, they may be able to speak to their partners, indirectly, by speaking to the doctor.
5. When faced with a discordant couple, the topic of future parenthood should be raised by the doctor. If this is ignored, it may force some couples to engage in high risk behaviour without them knowing the repercussions of it. The doctor must present all the options available to the couple, including adoption and assisted reproductive techniques as well as the role of antiretroviral medication.
6. Doctors must keep abreast of the latest developments in HIV and treatment as patients expect them to provide answers. This would include the doctor improving his/her computer skills as well as learning and practicing the art of critical reading so that he/she can access valid information for patients when the need arises.
7. Doctors must pay attention to the setup at their surgeries so that they always ensure privacy and confidentiality. This includes the position of the waiting room in relation to the consulting rooms so that what is discussed cannot be heard by others. The doctor

must also not leave patient records where subsequent patients can see them. Lastly, the doctor must ensure that his staff members, who do see patient records, are informed of their obligations to patient confidentiality.

8. Doctors should avoid using the term undetectable when reporting on the positive partner's viral load. This term may be misunderstood by both partners to mean that the virus was no longer present and thus safe sex practices were on longer needed. A better word to use would be "further reduced" or " in the acceptable range showing good compliance".

CHAPTER 7 - References

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