A study on Factors associated with non-disclosure of HIV positive status to sexual partners by adult patients attending the VCT clinic at Nhlangano health centre, Swaziland.

By

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# DECLARATION

This dissertation is submitted to the University of Limpopo (MEDUNSA Campus) in accordance with the requirement for the degree of M. Med (Fam. Med) in the Department of Family Medicine and Primary Health Care. It has not been submitted for any other degree or diploma of any examining body. Except where specifically acknowledged, it is all the work of the author.

**Dr Michael Legasion** 

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## ABSTRACT

A study on Factors associated with non-disclosure of HIV positive status to sexual partners by adult patients attending the VCT clinic at Nhlangano health centre, Swaziland.

**<u>Aim</u>**: To describe the factors associated with non-disclosure of known HIV sero-positive status to sexual partners by adult patients attending the VCT clinic at Nhlangano health center, Swaziland.

**Design**:- Cross-sectional study using questionnaire administered by a trained research assistant.

**Setting**:- Nhlangano health center VCT clinic, Nhlangano town in the Shiselweni region, Southern Swaziland.

<u>Study population</u>:-<u>All adult patients above the age of 18 years who had undergone HIV</u> testing, who knew their positive HIV status and had follow up visits at the VCT clinic of Nhlangano health centre, from November 2005 (when the centre started rendering VCT service) till the beginning of the data collection, in September, 2008.

**<u>Results</u>**:-The vast majority (89.1%) disclosed their positive HIV status to their sexual partners and 94.6% believed that letting their sexual partner/s know about their HIV status was very important. In terms of knowing the HIV status of their partners, 55.4% knew the HIV status of all of their sexual partners and 44.6% knew only the status of the regular partner/s. With regard to condom use, 96.7% believed that using condoms helps them to prevent transmission of HIV and 91.3% expected that letting their partners know about their HIV status would help them use condom more frequently. Only 53.3% said they would insist on condom use even if their partner is not willing to use.

### <u>Conclusion:-</u>

- The rate of positive HIV status disclosure to sexual partner found in this study compared to many studies done in other settings is considerably high. This is encouraging especially considering the existing very high prevalence of HIV infection in the country. Despite this though, knowing partner's HIV status was relatively lower. Therefore, people are more likely to share their HIV status with a partner than insist that the partner does the same.
- Even though the study was done only amongst patients attending VCT, it is important to note that the majority of the patients had positive attitudes about HIV status disclosure to a partner, and believed in the importance of letting their sexual partner/s know about their HIV status. Patients understood the unethical nature of engaging into sexual intercourse without disclosing their positive HIV status to their partner. It is possible to conclude that factors which contributed to these positive results should be implemented at a larger scale, namely creating awareness, health education, good counseling and follow up of treatment.
- Awareness of the importance of condom use in preventing HIV transmission (including the fact that disclosure of HIV status to a partner enhances its better use) was impressively high amongst almost all participants. But it is worrisome that only half of the participants said they would insist on condom use irrespective of their partners' willingness to use it or not.

• The variables that were found to be independently associated with disclosure to a partner comparing those who disclosed with those who did not were gender, age, marital status, education, number of sexual partners, and stage of the HIV condition.

# TABLE OF CONTENTS

DECLARATION	I
ACKNOWLEDGEMENT	II
ABSTRACT	III - IV
TABLE OF CONTENTS	V
LIST OF ABBREVIATION	VI
CHAPTER 1: Introduction	1 - 7
CHAPTER 2: Literature review	8 - 37
CHAPTER 3: Methodology	38 - 43
CHAPTER 4: Result	44 - 62
CHAPTER 5: Discussion	63 –72
CHAPTER 6: Conclusions and recommendations	73- 76
REFERENCES	77 - 89
APPENDIX 1: Protocol	90 - 101
APPENDIX II: Consent form	101 - 103
APPENDIX III: Clearance certificate	104

# **ABBREVIATIONS**

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal care
ARVs	Antiretroviral drugs
ART	Antiretroviral Therapy
AVERT	Antivirus and Vulnerability Emergency Response Team
CDC	Centre for Disease Control and prevention
COE	Centre Of Excellence
FDC	Family and Community Health (FCH)
GWH	Department of Gender and Women's Health in WHO
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
IPPF	International Planned Parenthood Federation
MEDUNSA	Medical University of southern Africa
MSF	Medicins Sans Frontieres / Doctors without borders
PMTCT	Prevention of Mother-to-Child Transmission
PSI	Population Services International
OVC	Orphans and Vulnerable Children
SDHS	Swaziland Demographic and Health Survey
SEC	Scientific and Ethics commitee
SNAP	Swaziland National AIDS Program
UNAIDS	Joint United Nations on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV and AIDS
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

# CHAPTER 1

# INTRODUCTION

# 1.1 BACK GROUND OF THE RESEARCH PROBLEM

The Kingdom of Swaziland is a small landlocked country of 17,363 Sq kms located in southern Africa with a population of 1.1 million. It is bordered by South Africa in the north, south and west and Mozambique in the east. The Swazi nation has a strong culture centred around the monarchy. The country is homogenous in terms of culture and language. Both siSwati and English are official languages in Swaziland. The country is divided into four regions and further divided into 55 political constituencies known as Tinkhundla, each Inkhundla is made up of several chiefdoms and is headed by an elected individual known as Indvuna. The chiefdoms are made up of clusters of homesteads forming communities. These are headed by the chiefs who are appointed by His

Majesty the King, who delegates authority to them based on heritage.

Swaziland is amongst the sub-Saharan countries hardest hit by the HIV/AIDS pandemic having the highest prevalence in the world (UNGASS, 2008). The productive segment of the population is affected most, which has a negative social and economic impact exacerbating the existing poverty. More than two-thirds of the population lives below the poverty line. HIV/AIDS is a significant burden on the health system. Everyday at almost every health care facility throughout the country, enormous numbers of patients seek medical attention for various complications of HIV and related opportunistic infections. The government of Swaziland has placed a national programme; SNAP (Swaziland National AIDS Programme) to fight the pandemic. There are also a number of other non governmental organizations which have come into action collaborating to mitigate the impact of the ever increasing pandemic. In 2003 the government launched its strategy to provide free nationwide <u>antiretroviral treatment</u> (ARVs). Other initiatives for <u>HIV prevention</u> implemented included condom distribution, behavior change campaigns, prevention of mother to child transmission, and early diagnosis by testing (Avert.org, 2009).

Most Swazis live in rural areas and there are several socio cultural factors in the country that increase vulnerability to HIV. These include including polygamy, widow inheritance, multiple

female

partners, and extramarital relationships. Poverty and gender inequality aggravate the problem. Women's subordinate status in Swazi society remains a major barrier to their health. Swazi women

tend to be poorer than their male counterparts, in part because they constitute less of the formal

workforce and have limited rights to own and inherit property and land (Country Report of the United Nations Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa). The rate of teenage pregnancy is considerably high. Swazi men migrate to South Africa looking for jobs and stay away from their family which predisposes them to extramarital affairs.

The control of HIV infection depends on the success of strategies to prevent new infections and treat currently infected individuals. Disclosure of HIV status to a sexual partner is a very fundamental and crucial issue in the prevention and management of HIV/AIDS. Despite this tangible fact, risky sex without disclosure of HIV status is common among people with HIV (WebMD health news, 2003). Hence, delving into this crucial issue and analyzing the possible factors that could affect disclosure is vital to salvaging Swaziland from this relentless pandemic.

## **1.2 MOTIVATION FOR THE STUDY**

The researcher got the inspiration based on his own observation at the health centre where he is

working. There is a significant discrepancy of answers given on the issue of disclosure of HIV status to sexual partners among the patients coming to the HIV clinic, either to be counseled, initiated on or to refill antiretroviral treatment. Some let their partners know of their HIV status

#### and

others do not inform their partners about their HIV status or that they are taking antiretroviral treatment. Others do not know the status of their partners. Hesitancy to discuss HIV status can have a negative effect on the treatment adherence, condom use and so on.

There has been a large number of studies done around HIV and AIDS. Little research has been conducted to understand the factors that influence disclosure of HIV status to sexual partner/s

in

Swaziland. The social, cultural and economic factors that propagate the disease, could have an

adverse effect on disclosure. This merits a scientific based study to reveal the extent and consequences of the problem and possible factors related to it.

### 1.3 SETTING

The study was conducted in Nhlangano, which is the main town of the Shiselweni region in Swaziland. The other three regions are Hhohho, Manzini, and Lubombo. The name Nhlangano means "meeting place". It is geographically located in the Southern part of Swaziland about 130 kilometers from Mbabane, the country's capital, and approximately 15 kilometers from the Mahamba South African border. According to the 2007 census, the total population for the whole of Shiselweni is 202,686 and that for Nhlangano is close to 10,000.

Nhlangano health centre was inaugurated in 1986. It is situated roughly 2 kms from the town centre on the Nhlangano - Makhosini road, adjacent to the Ngwane College. Nhlangano centre provides primary health care services. There has been increasing demand on the health center as more people services related to HIV/AIDS.

Correspondingly, there has been an increase in the staffing and structures of the centre to meet the need. It is currently operated by 4 government employee doctors including a dentist, 1 ART

doctor, 3 volunteer Cuban doctors, MSF doctors, a matron, 4 nursing sisters and over 40 staff

nurses and nursing assistants, paramedics and other ancillary hospital staffs. The main departments of clinical work in the centre are outpatient, serving 200-300 patients everyday, a ward with 60 beds including Maternity, Public health unit (includes PMTCT), VCT and TB departments.

The VCT programme in the centre (including provision of antiretroviral therapy) became fully operational in November, 2005, roughly 2 years after the national ART programme had started, and the ARV supply was being rolled out all over the country. A separate new building was built for it in the health centre by an Italian corporation in 2007 which has helped to enhance the service and making the work more conducive. The newly built centre where this research was conducted has a doctor's consultation room, nurse consultation room, 2 counselor's room, drug storage room, data clerk office and reception. Currently, it is operated by 1 ART doctor, 3 full time assigned government employed nurses, 2 data clerks, 3 expert clients, counselors. MSF Switzerland having signed memorandum of understanding with the Government of Swaziland, is helping in the HIV and TB programme in the Shiselweni region and doctors from MSF also come to see patients on certain days of the week.

## **1.4 HEALTH CARE SYSTEM AND OTHER REGIONAL FACILITIES**

Health care service in Swaziland is not only offered through the modern / western method, but also

through traditional medicine practiced by traditional healers/herbalists, etc. The western / modern

health care system is decentralized into the four administrative regions of the country. Each region coordinates its activities, however all the regional activities are coordinated at the central level. The country has both private and public health facilities distributed around the country. The country's health care delivery system is divided into three main levels; the clinics, the health center/Public Health Units, and the hospitals.

There is a regional hospital at a distance of about 30 kms from Nhlangano health center, Hlathikulu government hospital. It is one of the biggest hospitals in Swaziland and serves as a referral hospital for three health centers, Nhlangano, Matsanjeni and Sitobela. Matsenjeni health centre is located around 70 kms distance further south of Nhlangano on the road which goes to the Lavumisa border. It is similar to Nhlangano health centre in its infrastructure and capacity. Sitobela health centre is in the Lubombo region but uses Hlathikulu hospital as a referral centre. There are around 6 clinics under Nhlangano health centre Gege, Mashobeni, Mahlandle, Mhlosheni, Zombodze, and Dwaleni. These clinics use Nhlangano health centre as their referral centre. There are 7 clinics under Hlathikulu and 4 under Matsanjeni. MSF is decentralizing the

distribution of Antiretroviral treatment (ARVs) to the clinics for greater accessibility to the indigent and to alleviate the load on the bigger centers. Doctors from the Baylor Center of Excellence based in Mbabane also work at the centre once a week to attend to pediatric HIV patients.

# CHAPTER 2

# LITERATURE REVIEW

# 2.1 INTRODUCTION

In this chapter, literature was obtained by submitting requests to the resource centre at the department of Family Medicine and Primary Health Care, University of Limpopo (Medunsa Campus). Internet searches using search engines like "Google scholar", "Yahoo", "Pub-Med" and "Medscape" were done. Over seventy articles relevant to the topic on different web sites were reviewed which yielded important information. Key words used were "Disclosure of HIV to Sexual partner", "Impact of HIV", "Sexual Ethics", "Rate of HIV disclosure", "Factors" AND "HIV disclosure", "Factors" AND "HIV disclosure of HIV", "Benefits of HIV disclosure", "Barriers of HIV disclosure", "Law" AND "HIV disclosure", "Criminal sex", "HIV disclosure outcome", and "Meta analysis". Recommended books of family medicine were also reviewed.

# 2.2 IMPACT OF HIV GLOBALLY AND IN SWAZILAND

#### 2.2.1 GLOBAL IMPACT OF HIV

HIV/AIDS is a global problem affecting human kind with no exception of age, race, gender, sexual orientation, profession or socioeconomic status. Since its identification the pandemic

has exceeded all expectations in severity and scale of impact. It was first recognized in the United States in 1981. HIV was isolated from a patient with lymphadenopathy in 1983, and by 1984 it was demonstrated clearly to be the causative agent of AIDS (Fauci A S and Lane. C H, 2003). Since 1981, according to the world wide HIV and AIDS statistics on AVERT.org (2009), more than 25 million people have died from AIDS.

UNAIDS and World Health Organization AIDS epidemic update (2007) showed that in 2007 globally 33 million were living with HIV (22 million being in sub-Saharan Africa) and 2.7 million people were newly infected with the virus in the same year. About 2 million people died of AIDS in 2007 of which 76% occurred in sub-Saharan Africa. AVERT.org (2009) report states that women accounted for 50% of all adults living with HIV worldwide, and for 59% in sub-Saharan Africa at the end of 2007. Even though UNAIDS report (2008a), showed that the global epidemic has levelled off in terms of the percentage of people infected (prevalence) and that the new HIV infections rate declined from 3 million 2001 to 2.7 million in 2007, the total number of people living with HIV has increased globally with nearly 7,500 new infections each day. According to AVERT.Org (July,2009), young people (under 25 years old) account for half of all new HIV infections worldwide which shows that the AIDS epidemic is not over in any part of the world.

The impact of HIV/AIDS on children and young people is also a severe and growing problem. UNAIDS report (2008b) showed that in 2007, 420,000 children under age 15 were infected with HIV and 290,000 died of AIDS. In addition to the estimated 2.1 million children living with HIV/AIDS, about 15 million children have lost one or both parents due to the disease, 11.6 million of whom live in Africa.

Comparing the difference in the level of the pandemic spread across the globe, Global health council report (2007) pointed out that HIV infections and AIDS deaths are unevenly distributed geographically and the nature of the epidemics vary by region. Epidemics are abating in some countries and rapidly increasing\_in others. More than 90 percent of people with HIV are living in the developing world. The epidemic in Africa is one of the greatest health care challenges facing the world today.

Elaborating on the multisectoral impact of HIV/AIDS in depth, The Henry J Kaiser family foundation (2007) discusses the socioeconomic impact of HIV/AIDS from different perspectives and explains why the impact of diminished productivity is felt in many sub Saharan countries on a national scale. HIV/AIDS causes debilitating illness and premature death in people during the prime years of life and has devastated families and communities. Further, it has complicated efforts to fight poverty, improve health, and promote development by diminishing a person's ability to work and provide for his or her family. At the same time, treatment and health-care costs related to HIV/AIDS consume household incomes. The combined effect of reduced income and increased costs impoverishes individuals and households. It also deepens socioeconomic and gender disparities. Women are at high risk of infection and have few options for providing for their families. Children affected by HIV/AIDS are less likely to receive an education due to their illness or the need to leave school to care for ailing parents and orphaned younger siblings. Community resources are strained – hospitals, social services, schools and businesses. Health care workers, teachers, and business and government leaders have been lost to HIV/AIDS.

#### 2.2.2 IMPACT OF HIV IN SWAZILAND

Swaziland is among the countries hardest hit by the HIV/AIDS pandemic since the first HIV case was reported in Swaziland in 1986. The general mode of HIV transmission remains heterosexual sex, with some new infections occurring as a result of mother-to-child transmission (UNGASS, 2008). The HIV epidemic in Swaziland rapidly increased in the late 1990s and was declared as a "national disaster" by his majesty King Mswati III in 1999. The HIV prevalence among ANC pregnant women has increased from 3.9% in 1992 to 42.9% in 2004 (Sentinel Surveillance Report, 2004). However, according to UNGASS (2008) the 10th sentinel surveillance (2006) showed a slight drop to 39.2%. HIV prevalence in the 15-24 age group remained steady at 39.4% between 2002 and 2004 and showed a decline to 34.6% in 2006. A consistent decline in the HIV prevalence among the 15-19 year age group (from 32.5% to 26%) was recorded between 2002 and 2006.

According to the 11<sup>th</sup> National HIV serosurveillance report, (2008), the overall HIV prevalence in the population aged 15-49 is 26% with women (31%) more likely to be HIV positive than men (20%). The prevalence of HIV infection among pregnant women was 42% according to this survey report in 2007.

Tsela S and Odido H (2007) reported on the Swaziland HIV Estimation and Projections, that the number of people living with HIV/AIDS was estimated at 185,005 (with uncertainty range from 176,701-192,794). The estimated number of people living with HIV/AIDS that are in need of combined ARV treatment also has increased from approximately 43,157 in 2004 to 58,250 in 2007.

Discussing the HIV and AIDS condition in Swaziland, AVERT.Org report (2009) pointed out that the HIV prevalence rate of 26.1% reported in 2007 is still one of the highest in the world even though it has significantly dropped compared to the previously reported prevalence rates. Average life expectancy in Swaziland has dropped from 57 years to just 31 years as a consequence of the pandemic. As elsewhere in sub-Saharan Africa, the huge number of people dying from AIDS exacerbates existing poverty rates, which in turn leaves individuals vulnerable to the adverse effects of HIV. When those of productive age die from AIDS or are too sick to work, there is less income and therefore less food for families. Lack of adequate food and nutrition leaves individuals less able to cope with HIV if they are infected, as effective treatment depends on a good diet. Poor and vulnerable women are more likely to engage in transactional sex, where they have limited power to negotiate condom use.

UNGASS (2008) mentioned that there has been remarkable progress in prevention of the spread of HIV infection in Swaziland through behaviour change campaigns which target issues like having multiple sexual partners, intergenerational sex, and also scaling up of the Prevention of Mother to Child Transmission (PMTCT). However, prevention efforts have continued to be hampered by limited behaviour change in the population at large. In addition, HIV testing is not widely utilized, with only 15 percent of the general population between 15-49 years old, having tested. More women than men are tested for HIV (SDHS, 2006/7).

One of the major impacts of the HIV and AIDS epidemic on Swaziland is the increase in the

number of orphans and vulnerable children. The Swaziland government is addressing this through policy and the development of the National Action Plan for Children. Despite the considerable efforts made to mitigate the impact of the HIV/AIDS epidemic on orphans and vulnerable children (OVC) by providing education, food, health, psychosocial support and shelter, only 42% of OVC reported to have received at least one type of support (SDHS, 2006/7)

In general, critical challenges remain in Swaziland's response to HIV. Vulnerability to HIV infection continues to be high due to the combined effects of poverty, gender inequality and some harmful cultural practices. Furthermore, the drivers of the epidemic which include multiple concurrent partnerships, intergenerational sex, low condom use, low HIV testing and disclosure levels, and high prevalence of sexually transmitted infections, are yet to be fully strategically addressed. The success of prevention and control depends on the strategies to prevent new infection and treat currently infected individuals. It is predominantly the unsafe sexual practice of HIV positive individuals with the HIV negative ones that fuels the HIV/AIDS epidemic. The enormous importance of disclosure of HIV status to prevent new infections cannot be over emphasized.

#### 2.3 WHAT IS DISCLOSURE?

The word disclosure means "the act of disclosing, uncovering, or revealing; bringing to light; exposure" (Webster's dictionary). It can also be said "the release of information about a person

or entity" (yourDictionary.com). In the context of HIV/AIDS, disclosure refers to the act of informing any individual or organization (such as a health authority, an employer or a school), of the serostatus of an infected person. It can also refer to the fact that such information has been transmitted, by any means, by the person him or herself, or by a third party, with or without consent (UNAIDS, 2000). In this particular research, an individual is said to have disclosed to a sexual partner if he has made his partner aware of his HIV status. Sex without disclosure would be any penetrative unprotected sexual intercourse.

Voluntary Counseling and Testing (VCT) is an entry point to prevention and treatment services which places a lot of emphasis on HIV status disclosure among HIV-infected clients, particularly to their sexual partners UNAIDS (2001). International organizations like the Centers for Disease Control and the World Health Organization emphasize the importance of HIV status disclosure. CDC (2002) and UNAIDS (1997).

Disclosure is a major decision that can have consequences for the person living with HIV and those around him (IPPF, 2002). UNAIDS best practice collection (2000) explains that people everywhere have great difficulty in openly facing issues involving sex, disease and death. In many countries, the stigma and discrimination surrounding HIV/AIDS prevents many people who are HIV positive from informing spouses, lovers, family, friends, colleagues – and even health care providers – about their status. There is every incentive to keep their HIV status a secret. In resource-poor countries, particularly, the fear of stigma, lack of treatment options, and the very limited access to voluntary counseling and HIV testing have led only a small number of people voluntarily to test for HIV and disclose their status. The fact that only a small number of people know they have HIV, and an even smaller number disclose that they

are HIV positive, has added to the difficulty faced by governments and communities in creating greater awareness of the HIV/AIDS epidemic, thereby preventing further HIV infections and accurately monitoring HIV and AIDS on an ongoing basis.

Disclosure is a multifaceted issue that may be influenced by an individual's perception of the social, psychological, and material consequences of informing others (Michael Stein MD et al, 1998). The HIV-infected individuals remain sexually active long after they become aware of their infection. Disclosure requires personal responsibility. Not only past partners but potential partners need to be informed. Even though this is a challenge to all relationships, it will remain central to limiting the spread of the acquired immunodeficiency syndrome.

#### 2.4 ETHICAL AND LEGAL ASPECTS OF HIV DISCLOSURE

Efforts to prevent transmission of HIV have focused on educating the general public about the risks of HIV transmission. Nondisclosure of HIV status has been condemned as both a moral and a legal offense subject to both civil liability and criminal prosecution (Wein M, JAMA, 1989). In many countries, the intentional or reckless infection of a person with HIV is considered to be illegal according to criminal transmission of HIV (Avert, 2009).

It is difficult to identify a more charged issue in AIDS prevention than that of nondisclosure of positive HIV status to sexual partners (Ciccarone et al, 2003). People who do so can be charged with criminal transmission of HIV, murder, manslaughter, attempted murder, or assault. Regardless, as stated by the Henry J Kaiser family foundation report (2003), HIV

positive individuals' failure to disclose their HIV status to sexual partners either intentionally or unintentionally is a "significant but underreported factor in the continued spread" of HIV not only in the developing countries but also in the developed ones like the United States (). Some countries have created laws specific to HIV, and others use existing laws to prosecute specific incidences of intentional transmission. As of 1999, 31 states in the US had statutes making sexual contact without disclosure a criminal offense (Shriver et al, 2000, Ciccarone et al, 2003). Other countries like the United Kingdom charge under the existing laws.

Intentional transmission is considered the most serious form of criminal transmission Avert.org (2009). Some cases have involved individuals (both HIV positive and HIV negative) who have used needles or other implements to intentionally infect others with HIV. Others cases have been based on HIV positive people who have had sex with the primary intent of transmitting the virus to their partner. Intentional transmission can also take place when a negative partner has an active desire to become infected with HIV but this is unlikely to lead to prosecution, as both parties consent.

Reckless transmission is transmission that takes place as part of the pursuit of sexual gratification rather than an intentional act. If for example, a person who knows they have HIV has unprotected sex with a negative person, but fails to inform him/her of the risk involved, this could be classified as reckless transmission in court.

Accidental transmission is the most common way that HIV is passed on. A person is generally said to have accidentally transmitted HIV if they were unaware that they had the virus, or if they were aware of their HIV positive status and they used a condom during sex, but the condom failed in some way.

Though it is a criminal offence for an HIV infected individual to fail in revealing to a sex partner that he or she is HIV infected, (Tebas P, 2001) on "THE BODY and Web MD" health news (May 23, 2009), highlighted that many HIV infected individuals do not disclose to their sexual partners, and a significant proportion of them continue to engage in high risk behaviors. Kalichmann and Nachimson (1999a) also indicated that up to one third of individuals diagnosed with HIV infection continue to have unprotected sex, at times without informing their sexual partners, who may be of negative or unknown serostatus.

In the context of HIV/AIDS, UNAIDS and WHO encourage "beneficial disclosure" of HIV/AIDS status (UNAIDS best practice collection, 2000). This is explained as a disclosure that is voluntary; respects the autonomy and dignity of the affected individuals; maintains confidentiality as appropriate; leads to beneficial results for the individual, his/her sexual and drug-injecting partners, and family; leads to greater openness in the community about HIV/AIDS; and meets ethical imperatives so as to maximize good for both the uninfected and the infected. In order to encourage beneficial disclosure, an environment in which more people are willing and able to get tested for HIV, and are empowered and encouraged to change their behaviour according to the results should be created. This can be done by: establishing more voluntary counselling and testing services; providing incentives to getting tested in the form of

greater access to community care and support, and examples of positive living; and removing disincentives to testing and disclosure by protecting people from stigma and discrimination.

With regard to partner counselling (partner notification), UNAIDS and WHO encourage ethical partner counselling. Such partner counselling is based on the informed consent of the source client, and maintains the confidentiality of the source client, where possible. However, it also takes into account the serious possible consequence of not counselling partners.

HIV counselling and partner counselling programmes should involve strong and professional efforts to encourage, persuade and support HIV-positive persons to notify their partners. In the few cases in which a properly counselled HIV-positive person refuses to disclose to his/her partner, the health care provider should be able to counsel partners, without the consent of the source client, after there has been an ethical weighing of the potential harms involved, and appropriate steps have been taken. These steps involve repeated efforts to persuade the source client to counsel partners, informing the source client that partner counselling will occur, keeping his/her name confidential if possible; and ensuring social and legal support for the source client and other relevant parties (spouses, partners, family members) to protect them from any physical abuse, discrimination and stigma which may result from partner counselling.

The World Bank Legal aspects of HIV/AIDS (2007) also states that many countries authorize physicians or counsellors to conduct partner notification. It also states that partner notification usually should be voluntary, but occasionally can be done without the consent of the index

patient. A physician's duty to disclose a patient's HIV status to the patient's partners who may be at risk of infection emanates from the legal concept of "duty to warn."

In order to warn the partners of an HIV-infected patient, the physician may be authorized under law to obtain the partners' names from the patient, confidentially tell the partners they may be infected, and provide the partners with HIV counselling and access to testing and other services. Physicians and other health care providers must conduct partner notification in a confidential manner to avoid violations of their patient's right to privacy and reduce possible stigma and discrimination.

It is generally agreed that there are four major guiding principles in medical ethics: respect for autonomy, beneficence, non maleficence and justice. Adamson and Joseph, (2004) say that appropriate consideration of all these principles is crucial to ensure an effective struggle against HIV. Matters regarding autonomy (self-governance or personal freedom, confidentiality and disclosure; and the best interests of patients) feature more prominently in HIV/AIDS case management than in many clinical situations.

Partner notification offers a chance to increase the number of people who will seek testing and counseling for HIV, and to get more people into treatment (legal aspects of HIV on The World Bank, 2007). The partner notification process encourages (and sometimes obligates) a person to disclose his or her HIV status to sex and/or needle-sharing partners or to take efforts to reasonably protect partners from avoidable health risks. Partner notification has become a common practice around the world in HIV prevention efforts. Public health professionals justify

partner notification programs as a method for prevention and to increase access to treatment. In many cases there appears to be an ethical duty to disclose one's HIV status to partners who may be at risk of infection. This duty is grounded in the obligation to do no harm to others and the concept of a partner's "right to know" about the risks he/she may face. Similarly, Ciccarone et al, (2003) put emphasis on this ethical issue saying that failing to disclose HIV-positive status might be considered "morally indefensible because it precludes the partner's ability to exercise informed choice about the level of risk he or she would like to assume". In this respect, the duty to disclose is grounded in the need to prevent further infection.

### 2.5 BENEFITS OF HIV DISCLOSURE

Disclosure of HIV status is an important public health goal for a number of reasons and there is increasing recognition that it is an essential part of behaviour modification required to reduce the incidence of HIV (Collins NL and Miller LC, 1994). Self-disclosure of sensitive information is generally thought to have beneficial effects on an individual's physical and psychological health. In the case of HIV/AIDS, individuals who disclose their status are in a better position in terms of reproductive choices as well as psychosocial support. (Derlega et al: 2004) also stated that negative emotional reactions, including depression and HIV related worries are inversely related to disclosure.

Disclosure is fundamental in managing HIV, especially in terms of adhering to complex treatment regimens and also facilitates other behaviors that may improve the management of

HIV (Amy Norman et al, 2005). For example, HIV-positive people have reported that they sometimes skipped doses because they could not take a prescribed medication without being observed doing so (Chesney and Smith: 1999). It was also indicated by (Waddell and Messeri, 2006) that individuals who disclosed their results have better adherence to ART treatments. (Medley et al, 2004) found that women who disclose their status to their partners may be more likely to participate in Prevention of Mother To Child Transmission (PMTCT) programs.

Disclosure may motivate sexual partners to seek testing, change behaviour and ultimately decrease transmission of HIV. The exchange of information about one's HIV status with a prospective partner is associated with safer sexual practices. (Larkins S et al, 2005).

A mathematical modeling analysis by Pinkerton and Galletly (2007) showed that serostatus disclosure reduced the risk of HIV transmission by 17.9% to 40.6% relative to non-disclosure. Increasing the disclosure rate from the base-case value of 51.9–75.7% produced a 26.2–59.2% reduction in risk.

Even though voluntary counselling and testing for HIV is widely promoted as an important first step in behaviour modification, without disclosure, few of the benefits can be realized, one of the primary benefits being protecting the non infected partner. Most new HIV infections in Africa now occur in cohabiting couples many of whom do not realize that only one may be HIV infected (Susan Allen et al, 2003). The prevalence of serodiscordant couples in populations varies. In sub-Saharan Africa studies have found rates of 3–20% of serodiscordance in the

general population, and higher rates of 20–35% of serodiscordance has been observed in studies of those presenting to voluntary counselling and testing (VCT) services (Bunnel, et al, 2005). In a longitudinal study of couples in Tanzania by (Hugonnet S et al, 2002), it was found that the risk of HIV for a seronegative partner in a serodiscordant couple was several fold higher than that of partners in seroconcordant HIV negative couples (RR 57.9, 95% CI 12 to 244). Similar increased risk was seen in the another cohort study done in Uganda by (Serwadda D etal,1995), where females in serodiscordant marriages are reported as having twice the infection risk of males.

Collini P and Obasi A (2006) found five prospective cohort studies conducted in resource poor settings assessing the rate of condom use before and after VCT among serodicordant couples. The studies were conducted in Zambia, Rwanda, Zaire and Haiti. The results showed that the rates of condom use before VCT were uniformly very low and rose to around 50–70% after VCT in most of the studies.

Ijumba K et al (2004), in South Africa showed that knowing someone with HIV was associated with condom use at last sexual contact and negatively associated with multiple and casual sex partners. People with HIV are also at greater risk for contracting sexually transmitted infections due to compromised immune systems. Thus if disclosure of HIV status results in condom use (or other protective behaviors) it will be a direct health benefit to the discloser. Even couples in which both partners are positive can infect each other with modified HIV strains (Valerian J, 2003).

Disclosure has a number of other potential benefits for the individual including increased opportunities for social support, improved access to necessary medical care including

antiretroviral treatment, increased opportunities to discuss and implement HIV risk reduction with partners, and increased opportunities to plan for the future. Disclosure of HIV status has become an entry criteria for many treatment programmes in resource constrained settings.

However, disclosure does not always mean, individuals will use the information to protect themselves or others; in fact, some will knowingly place themselves at risk of infection. (Serovich JM and Mosach KE, 2003) concluded that it is erroneous to assume always that disclosure would lead to safer behaviours or lead to lowering of risk all the time. They found out that even when individuals overcome the barriers to disclosure and reveal their serostatus to sexual partners, there is no guarantee of their subsequent sexual safety. Marks G and Crepaz N (2001) expressed a similar viewpoint, explaining that some HIV-infected individuals may disclose their serostatus but then deliberately ignore or avoid protection (what they termed "informed exposure"), possibly to attest to their commitment to the relationship or because of the effects of substance use prior to sexual activity. They also stated that similarly, nondisclosure does not necessarily lead to unsafe sex always. Some HIV-infected individuals may refrain from divulging their HIV serostatus to protect their privacy and avoid the negative consequences of disclosure, such as stigma or rejection. However, they may engage in protected sexual activity, perhaps out of a sense of personal responsibility toward their partners. They labeled this strategy "uninformed protection". Kalichman SC et al (1999b) also have found inconsistencies between disclosure and sexual safety that the fact that one has disclosed of the positive HIV status to his or her partner may not necessarily always imply that there will be safer sex.

#### 2.6 BARRIERS TO HIV DISCLOSURE

HIV status disclosure has many potential risks and there are a number of barriers that HIVinfected individuals face when sharing their test results with friends, family and sexual partners. Disclosure can be an extremely stressful process, because it makes one vulnerable to perceived stigma of friends, family or the community (Paxton, 2002). Even though results from different studies indicate that in the majority of the cases, support and understanding are the outcomes from partners upon disclosure of HIV test results (Maman S et al, 2003). Disclosure can also incur negative consequence, making the decision to disclose a dilemma for individuals infected with HIV (Gielen AC, 1997).

The most common barriers to disclosure that were mentioned on the WHO Document Summary (2004) included, fear of abandonment, fear of loss of economic support from partners, fear of rejection/discrimination, fear of violence, fear of upsetting family members, and fear of accusations of infidelity. Women's fear of abandonment was closely tied to fear of loss of economic support from a partner.

In settings where resources are extremely scarce and women's access to resources independent of their partner is uncommon, it is not surprising that fear of losing this instrumental support from a partner is a major consideration when deciding whether to share HIV test results or not. Stigma has been identified as a barrier to health care, social support, and disclosure (Letteney et al: 2004).

#### 2.7 RATES OF HIV DISCLOSURE

Researches done at different times and in various settings on the issue of HIV status disclosure to sexual partners have indicated that HIV positive patients do not always disclose their serostatus and may be ignorant of their sex partner's serostatus. There was a wide range of discrepancies and inconsistencies in the reported rates of HIV disclosure from the different studies done.

Adamson S and Joseph M (2004) reporting on the prevalence of disclosure, found there to be wide variability depending on serostatus, gender, and population group. A meta analysis by Simoni JM and Pantalone DW (2004) to determine whether there is an association between disclosure and sexual safety summarized the different rates of disclosure from the results of 15 different. They found the rate of disclosure was having a wide range from 30 to 93%.

Also according to WHO Document Summary (2004), the disclosure rate ranged between 42 and 100%, depending in large part on the type of partner to whom the person disclosed. The lowest rates of disclosure were reported among past partners or current casual partners.

The rates of disclosure in studies from developing countries were notably lower than rates reported from the developed world. In a meta analysis by (Medley A, et al, 2004) which summarized 15 studies on the rate of HIV disclosure among only women in developing countries of which 14 of the studies were conducted in sub-Saharan Africa, the disclosure rate

ranged from 16.7% to 86%. A review done by (WHO/FDC/GWH, 2004) states that studies done on disclosure rates among women only showed that rates of disclosure to sexual partners are higher among women in the developed world (average 71%; range: 42%-100%) compared to women in the developing world (average 52%; range: 16%-86%). The lowest rates found in this review were among pregnant women tested in antenatal care (ANC) settings in sub-Saharan Africa (16.7%-32%). In addition, larger proportions of studies from developing countries reported women that did not share their HIV test results with anyone (10%-78%) as compared to women in developed country studies (3%-10%).

The review further analyzed that even though there is a considerable variation across different studies in the timing of disclosure measurement, studies from both developed and developing country settings commonly found that disclosure rates to sexual partners tend to increase over time from initial diagnosis. The studies in the review reported a substantial increase, in some cases a doubling, of disclosure rates over time. Therefore, when comparing the rates of disclosure across studies there is a need to take into account the time frame since diagnosis. (Antelman G et al, 2001) found that disclosure to sexual partner among women attending an antenatal clinic increased from 22% within two months of diagnosis to 41% after nearly four years.

Other important findings from both developed and developing countries settings include discrepancies between intention to disclose and actual disclosure behaviour, with actual disclosure rates lower than intended disclosure rates. Women in both settings often disclose to

multiple categories of people and there are also cultural factors that influence the patterns of disclosure to sexual partners and other members of social networks (WHO Document Summary, 2004).

The results of individual studies done in different settings also demonstrate the magnitude of the problem of non disclosure. For instance, (Perry SW et al, 1994) found that almost one third of HIV-seropositive men and women did not disclose their HIV serostatus to past or present sexual partners. Also, (Stein MD et al, 2003) found that 40% of sexually active men and women living with HIV in a community sample had not disclosed their serostatus to their sexual partners. Similarly, in another study by (Kalichman SC and Nachimson D, 1999a) it was reported that 41% of HIV positive persons had not disclosed their HIV serostatus to their sexual partners.

In a study by Marks G and Crepaz N (2001), involving 206 HIV positive men of mixed sexual orientation, 48% had not disclosed their serostatus to their sexual partners. A number of studies have also documented that many people with HIV have partners who are HIV negative or of unknown serostatus Kalichman SC and Nachimson D (1999a) found that 42% of HIV positive men and 42% of HIV positive women reported at least one instance of unprotected sex during a six month period, frequently with partners with unknown or seronegative HIV status. Similarly among 48 respondents, Ciesla JA, et al reported that 31.1% of HIV positive patients reported unprotected vaginal or anal intercourse with a partner of negative or unknown HIV status.

In sub-Saharan Africa, the primary mode of transmission is heterosexual contact and studies have shown that the rates of infection and transmission of HIV are increasing among married persons making disclosure very important (Olley BO etal, 2004). In South Africa for instance, the rate of HIV infection among married heterosexual couples cumulatively increased from 5% in 1999 to 12% at the end of 2002 (Abdool-Kareem Q and Abdul Kareem S, 2002).

Another study done in South Africa to examine HIV serostatus disclosure and its relationship to risky sexual behaviours in 69 sexually active, heterosexual, married (62%) or cohabiting (38%), in patients recently diagnosed to be HIV positive, showed that 78% had not disclosed their HIV status to their sexual partners and 46% had no knowledge of their sexual partner's serostatus (Olley BO, 2004). Compared to those who disclosed their serostatus, those who did not disclose were more likely to be male, did not use a condom during their last sexual encounter, used alcohol heavily before sex, had multiple sexual partners, and engaged more frequently in sexual intercourse preceding the study.

In a cross sectional survey done by Wong LH etal (2009) in Soweto and the Kwazulu natal, that measured the rate of disclosure of HIV status and factors associated with disclosure, HIV disclosure was reported by 87% of participants and among those who disclosed, 93% disclosed to boyfriends or girlfriends. Following disclosure, 82% requested that their partner be tested and 81% reported that they wanted to limit sex to one partner; 64% stated using condoms for all sexual encounters.

Stein MD et al, 2003 also agree that non-disclosers are not more likely to regularly use condoms than disclosers and hence sexual partners of HIV-infected persons continue to be at

risk for HIV transmission.

#### 2.8 OUTCOME OF HIV DISCLOSURE

In most studies from both developing and developed country settings, HIV status disclosure to sexual partners was associated with positive outcomes including increased social support, acceptance, kindness, decreased anxiety and depression, and strengthening of relationships (WHO, 2004). While fear of negative outcomes was a major reported barrier to HIV status disclosure, most individuals who choose to disclose reported experiencing positive social outcomes as a result of their disclosure including support and understanding from partners. (Medley A et al, 2004) in their analysis of 17 studies from peer-reviewed journals, found that the negative outcomes were fewer than initially feared and infrequently led to divorce or separation.. On the contrary, in the long run, disclosure turned out to offer positive outcomes in most instances. However, a woman may find herself vulnerable to blame, anger, stigma, depression, abandonment, family disputes, social embarrassment, violence and exile. Although the negative outcomes are not frequent as expected, they can be very substantial and should not be overlooked.

The serostatus of the male partner is an important aspect that was not discussed. Male partners who knew of their own seropositivity, and did not disclose their serostatus, would probably have been the most receptive to their partner's disclosure. Even those male partners who considered themselves to be at a high risk of acquiring HIV infection, or later tested positive, might have been receptive and supportive. This is particularly important in settings where the prevalence of HIV infection is high.

Negative outcomes included blame, abandonment, anger, violence, stigma, and depression and were less commonly reported among those who disclose than positive outcomes. However, it is important to note that those who choose not to disclose may well be those who are most likely to experience negative outcomes due to the disclosure. In studies that looked at violence as an outcome of HIV status disclosure for women who chose to disclose, violent outcomes were reported more often by women in sub-Saharan Africa (3.5% to 14.6%), than by women in USA studies (0.4%-4%). The highest rates of disclosure-related violence were reported among women in ANC. HIV-infected women in sero-discordant couples were the most likely to experience violence as a result of disclosure.

Though the focus of this research is on disclosure of HIV status for the sexual partner, as stated on the legal aspects of HIV on The World Bank (2007), disclosure of information about HIV is not only needed for the partner and significant others alone but may also be required for public health surveillance, for the provision of appropriate medical care, and for certain non health purposes such as law enforcement or insurance. On the process though, it can reveal intimate details about an individual's health status and other personal information that an individual may wish to keep private. It therefore can damage the privacy of persons living with HIV or AIDS and have other negative consequences such as stigma, discrimination, violence, and social isolation. It may also lead to serious economic harm, including loss of employment, insurance, or housing.

#### 2.9 FACTORS INFLUENCING HIV DISCLOSURE

Factors that motivated people to disclose to partners, family and friends included sense of ethical responsibility/ concern for partner's health, failing health/severity of illness, and need for social support to cope with diagnosis to alleviate the stress associated with non-disclosure, and to facilitate HIV-preventive behavior (WHO, 2004). Multiple opportunities for disclosure counseling are important to provide ongoing support throughout the disclosure process.

In their study of disclosure experience and associated factors in Southwest Ethiopia among HIV positive men and women Deribe K et al (2008) discussed the numerous factors that have been associated with HIV status disclosure. They reported that living in the same house with the partner, having a prior discussion with a partner before testing, knowledge of the HIV status of one's partner, low levels of negative self-image and advanced clinical stage of disease are the factors that they identified to be associated with HIV disclosure to a partner. These findings were consistent to what was found by other similar studies. (Niccolai LM, 2006) has demonstrated that "main/steady/close/regular" partnerships are more likely to involve disclosure than"other/casual/unfamiliar" partnerships which goes in line with the report by Medley A et al (2004) and WHO (2004) that the lowest rates of disclosure were reported among past partners or current casual partners. Mansergh G, et al, (1995) discussed factors beyond partnership can influence disclosure as well. Specifically, illness severity and length of time since HIV diagnosis have been shown to be positively correlated to disclosure.

The longer the length of the time from the diagnosis and the more advanced the clinical stage of the disease, disclosure would be more likely.

HIV-infected individuals are more likely to disclose to a partner whom they know is HIV-positive than to an HIV-negative or of unknown serostatus (Rosa CJ and Marks G, 1998). Concurrently (Sigxaxhe T and Matthews C, 2000) states that awareness of HIV transmission and social configuration has immense importance in determining HIV serostatus disclosure. The authors further explain that awareness of HIV transmission and HIV prevalence within the community could perhaps be the most important determinant of a woman's willingness to disclose her serostatus. Prior communication about HIV testing with a partner has a positive impact on disclosure of the result after testing. A study done in Tanzania by (Maman et al, 2003) found strong association between prior communication about HIV testing with a partner and HIV serostatus disclosure. Another study conducted in Tanzania by (Antelman G et al, 2001) showed that short duration of relationship, polygamous marriage, working out of one's home, not knowing someone with HIV and low income were negatively associated with disclosure. In the same study it was found that women who had greater than 6-lifetime sexual partners were less likely to disclose their status.

Peterson SH et al (2006) also says women who chose not to disclose were more likely to report unsupportive and threatening sexual relationships which might impede their ability to safely disclose their serostatus, negatively affecting their health and that of their sexual partners. Also women who do not disclose have shorter, less committed relationships more sexual partners, and hold less faith in their main sexual relationships.

(Kalichman SC and Nachimson D,1999) report that self-efficacy as a key determinant of HIV status disclosure. Having not disclosed to sex partners was closely associated with lower self-efficacy for disclosing. (Antelman G et al, 2001) also found that women with higher education are more likely to disclose their result to their sexual partner than women who are illiterate.

Progression of HIV might precipitate disclosure due to visible signs of disease or an urgent need for emotional support. (Serovich JM and Mosack KE, 2003) agrees with this but mentions that HAART has caused HIV infection to become a chronic condition allowing people to remain healthier for longer, thus diminishing the need to disclose HIV status due to illness. In a cross sectional survey in the Caribbean region conducted by Bouillon K et al, (2007) in which the authors found that almost one third of persons living with HIV/AIDS had not told anyone that they were HIV positive, time since diagnosis, health status and disease progression, age (both of the HIV-infected person and of the potential confidant), education, and gender have been mentioned to be correlated with disclosure. Cultural factors have also been identified as influencing disclosure. An anonymous survey done in Cape town, South Africa by Simbayi L.C et al, (2007) showed that HIV-related stigma and discrimination are associated with HIV transmission risk behaviours. The authors recommended that interventions are needed in South Africa to reduce the AIDS stigma and discrimination and to assist people with HIV to make effective decisions on disclosure.

Akani C I and Erhabor O, (2006) in a study done in Nigeria found that females were more likely (59.7%) to disclose their HIV serostatus compared with males (40.3%). The authors found that HIV infected mothers were twice as likely to confide in (65.6%) than in fathers. Married respondents were more likely to disclose their status. Better-educated respondents with tertiary education were more likely to disclose their HIV-serostatus. Expectation of economic, spiritual, emotional and social support was the major reason for disclosure.

#### 2.10 HIV DISCLOSURE IN SWAZILAND

Paradoxically, most of the studies on disclosure were done in developed countries with low HIV prevalence (Olley BO etal, 2004) and only limited data is available from developing countries like Swaziland. The researcher came across two relevant studies that were done in Swaziland on the issue of HIV disclosure to sexual partner and rate of condom use after knowing the status.

In a cross sectional study done towards the end of 2004 at Mbabane government hospital by Borgsund C and Stureson A (2005) on "sexual risk behaviour after HIV testing and starting of antiretroviral treatment", the authors discovered that from the 206 participants included in their study, almost half of the participants have told their partner that they are HIV positive and about half of the partners that were informed have tested for HIV. The results of the tests were mostly positive (82%). They also found that amongst those who disclosed their status, the majority of the patients preferred to disclose to their partner (47%) rather than their relatives or friends (40%).

There was only a slight increase in disclosure after the respondents started treatment leading the authors to conclude that "ART does not increase disclosure significantly". Seventeen percent of the participants had not told anyone about their status. Condom use before and after testing was assessed. The authors found an increase in condom use after testing HIV-positive and a further increase in condom use after start of treatment.

In another cross sectional study done at the VCT centres of Mbabane Government Hospital and Raleigh Fitkin Memorial Hospital by Ericsdotter A and Skånberg A (2005) on the treatment of HIV in Swaziland , found out that from a total of 134 participants, 61% had disclosed to their partner. However, only 65% of the patients had a partner, which means that most of the patients who had a partner had told him or her about their status. A total of 3% of the patients had not disclosed to anyone despite being on treatment. Similar to the above study, both male and female respondents were more likely to disclose to their sexual partners. The disclosure to people other than the partner was reported to be low which was thought to be due to stigma. Initiation of treatment in this study also did not increase the disclosure rates significantly. In this study also the use of condoms with temporary partners as well as in steady relationships increased after HIV diagnosis which is consistent with other studies cited in this literature review.

#### 2.11 RELEVANCE TO FAMILY MEDICINE

HIV and AIDS counseling in primary health care is one of the key roles a family physician can play including encouragement on HIV disclosure to a sexual partners. Ian R. Mcwhinney (2004) on his book "A Text book of family medicine" outlines these responsibilities.

## "Family physicians are committed to the person rather than to a particular body of knowledge, group of diseases or special technique".

Having a broader bio-psycho-social approach rather than focusing only on a particular disease condition alone is one of the distinctive features of a high quality family practice This would enable the family physician to address issues beyond the mere HIV infection or clinical mishap the patient has presented and further probe into the patient's idea, fear, expectation, beliefs and so on. Pertaining to the issue of disclosure of HIV status to a partner, the reasons for not disclosing, concerns, fears, anxieties, and expectations of the patient that he/ she may think will come across upon disclosure should be addressed which will positively influence the patient to disclose.

#### "The family physician seeks to understand the patient into the context of the illness".

Issues of disclosure needs to be seen in the context of the personal life of the patient, the family, sexual relationships and social context as stigma is one of the big deterring factors

around disclosure. Assessing the patient's social support financial status issues of partner violence would be considerably important. Understanding community beliefs about HIV and attitude towards disclosure of serostatus is of huge importance also.

# "The family physician sees every contact with the patient as an opportunity for prevention or health education".

This has a very high impact understanding the relevance of disclosure. The family physician has the responsibility to teach his/her patients on every possible encounter or consultation possible. Patients with HIV have to be taught to have a good awareness of how non-disclosure could negatively affect the health of their partner and themselves.

#### "The family physician views his or her practice as a population at risk".

Disclosure is very important in terms of reduction of HIV transmission. Considering instances of serodiscordancy, children of infected mothers and all the partners involved in case of multiple sexual partners, the family physician should extend their views into the population at risk as a result of non disclosure.

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# CHAPTER 3

## METHODOLOGY

## 3.1 AIM OF THE STUDY

To describe the factors associated with non-disclosure of known HIV sero-positive status to sexual partners by adult patients attending the VCT clinic at Nhlangano health center, Swaziland.

## **3.2 OBJECTIVES OF THE STUDY**

- To determine the rate of disclosure and non-disclosure of known HIV sero-positive status to sexual partners
- To identify the factors associated with non-disclosure of known positive HIV serostatus to sexual partners.
- To compare condom use between patients who have disclosed to their partners with those who have not

## **3.3 STUDY DESIGN**

This was a cross-sectional study using a questionnaire administered by a trained research assistant. The questionnaires were self designed, extracted and organized based on the literature reviewed as well as findings of other similar studies. They were prepared both in English and SiSwati languages, to be administered in the preferred language of the patient. They were also made simple and straight forward. The study population consisted of all adult HIV-positive patients who knew about their positive HIV serostatus and visited Nhlangano Health Center's VCT clinic between November 2005 and September 2008.

## **3.4 STUDY POPULATION**

#### 3.4.1 STUDY SAMPLE

Based on the study population of 2300 by the time the research started, using a 95% confidence level, power of 80% and confidence interval of 10%, the sample size was calculated to be 92.

## **3.4.2 INCLUSION CRITERIA**

All adult patients above the age of 18 years who had undergone HIV testing, knew their positive HIV status and had follow up visits at Nhlangano Health Centre, VCT clinic.

## **3.4.3 EXCLUSION CRITERIA**

- Patients with advanced HIV disease according to WHO staging (Stage IV) whose health condition could not allow them undergo the process.
- Patients who are critically ill or mentally incapacitated.
- Patients with co-existing psychiatric conditions.
- Stable patients who were transferred from the Health Centre to the clinics to get their treatment refills at a clinic level due to HAART decentralization programme and hence did not attend the health centre for refills.

## **3.5 DATA COLLECTION**

## 3.5.1 DATA COLLECTION ARRANGEMENT

Random sampling was used to obtain 92 names out of the 2300 patients registered at the Nhlangano Health Centre VCT. The data clerk then made a separate list of these randomly selected patients and identified their files to be kept in a separate file cabinet. She was responsible to follow the patients who came every week and connected them with the nurse who was trained to conduct the interviews. The interviews were to be conducted only after obtaining a written informed consent. The patients were also fully informed of their right not to partake in the process of the study if they did not want from the outset and also that they could

withdraw out anytime they wanted to, which was also clearly stated on the consent form.

Participants were interviewed in either English or Siswati based on their stated preference. The interviews were conducted either in the nurse consultation room or the counselling rooms in the VCT department to ensure privacy.

#### 3.5.2 PERIOD OF DATA COLLECTION

Data was collected from September 8, 2008 to April 09, 2009. Several factors slowed the pace of data collection. There were not enough contact addresses or phone numbers documented on the patients' file to schedule appointment on specific dates. Those few who gave their telephone contact address (whether their own or for the person they wanted to be contacted through), were contacted and could come early. Some of the patients missed their appointments on the expected date of their visit or sent other people to collect their refill. Sometimes the research assistant nurse was requested to see patients in other departments and patients were unable to wait for her return, thus delaying their interview time until they came on another visit.

Reselection had to be done using a similar method of random sampling in cases where the selected patients were deceased, or were stable patients already transferred to their nearest clinic to continue their HIV treatment refills according to the ARV treatment decentralization project to the clinic levels started by MSF.

## **3.6 DATA ANALYSIS**

The data collected was analyzed using statistical software SPSS 17.0 All variables are presented as frequency tables and bar charts.

Cross tabulations were also done to determine the relationship between the predictor variables and the response. Chi-square tests were calculated and p-values of less than 0.05 were determined for statistical significance.

## 3.7 BIAS

- Selection bias was minimized by the use of systematic random sampling in selecting the sample population for the study. The participants were selected from the total list of the study population in a completely random manner.
- Inter-observer bias was reduced by having only one research assistant administer the same set of questions in the one of the two patient's preferred language (either in SiSwati or English). In the unfortunate event of the interviewer not being around, the patient was given another appointment time and a transport fees were provided for those who could not afford to come.

## **3.9 ETHICAL CONSIDERATIONS**

Confidentiality and anonymity of subjects were maintained by non-inclusion of names and analyses of data were done as group data. Written Informed consent was obtained from each subject prior to enrolment in the study (signing the consent form), after the aim and objectives of the study were explained.

Permission to proceed with the study was obtained from the following:

- a. Chairperson of the management committee, Nhlangano health centre, Swaziland
- b. Head, Regional health office, Shiselweni
- c. Permission to conduct the research was obtained from the Scientific and Ethics Committee (SEC) for Swaziland.
- d. The departmental research committee, Department of Family Medicine and Primary health care, University of Limpopo (Medunsa Campus), Pretoria
- e. The Medunsa Research and Ethics Committee (MREC), of the university of Limpopo (Medunsa Campus), Garankuwa. (Clearance certificate no. MREC/M/77/2008: PG).

## **CHAPTER 4**

## RESULTS

## 4.1 DATA ANALYSIS

The findings of this cross sectional study are shown in this chapter. Results were determined by analyzing data collected from the randomly selected participants. Selected participants completed a questionnaire administered by a trained research assistant. There were a total of 28 questions included in the questionnaire (see appendix II).

Data was collected only after the aim of the study was explained to potential participants, and after written informed consent was obtained. Each participant was interviewed privately. A total of 92 participants were reviewed yielding a response rate of 100 %.

The results were analyzed using statistical software SPSS 17.0. The information gathered are presented as frequency tables and bar charts for all the variables in order to determine the distribution of the variables. Cross tabulation was also done to determine the relationship between the predictor variables and the responses. Chi-square test and t-test were calculated for the variables and the results with p- value less than 0.05 were determined to be statistically significant.

### 4.3 MEASUREMENTS

## **4.3.1 SOCIO DEMOGRAPHIC INFORMATION**

A total of 35 participants (38.0%) were in the age range of 26–35 years, while 29 (31.5%) were between the age of 36–45 years, 20 (21.7%) between 46–55 years, 4 (4.3%) between 18–25 years, 3 (3.3%) between 56 – 66 years and only one (1.1%) above 65 years. There were more female participants, 60 (65.2%) compared to male participants of 32 (34.8%). According to their marital status, 36 (39.1%) were single, 35 (38.0%) were married to one wife, 2 (2.2%) were in polygamous marriage, 16 (17.4%) were widowed, 2 (2.2%) were divorced, and 1 (1.1%) was cohabiting.

The highest level of education for majority of the participants with a number of 50 (54.3%) was secondary school. 25 (27.2%) had only primary level and 6 (6.5%) high school as their highest level of education. 7 (7.6%) had no educational level (never been to school), and 2 (2.2%) did not respond. All the 92 participants interviewed were Swazis.

## Table I. Socio-demographic information of all participants (n=92)

CHARACTERISTICS	NUMBER	PERCENTAGES (%)
AGE (in years)		
18 – 25yrs	4	4.35
26 – 35yrs	35	38.04
36 – 45yrs	29	31.52
46 – 55yrs	20	21.74
56 – 65yrs	3	3.3
Above 65	1	1.1
GENDER		
Male	32	34.8
Female	60	65.2
MARITAL STATUS		
Single	36	39.1
Married	35	38.0
Married (polygamy)	2	2.2
Divorced	2	2.2
Widowed	16	17.4
Cohabiting	1	1.1

EDUCATIONAL LEVEL	NUMBER	PERCENTAGES (%)
Primary	25	27.2
Secondary	50	54.3
High school	6	6.5
Tertiary	2	2.2
None	7	7.6
No answer	2	2.2

### Table I (cont). Socio-demographic information of all participants (n=92)

#### 4.3.2 HIV CLINICAL AND IMMUNOLOGIC STAGING

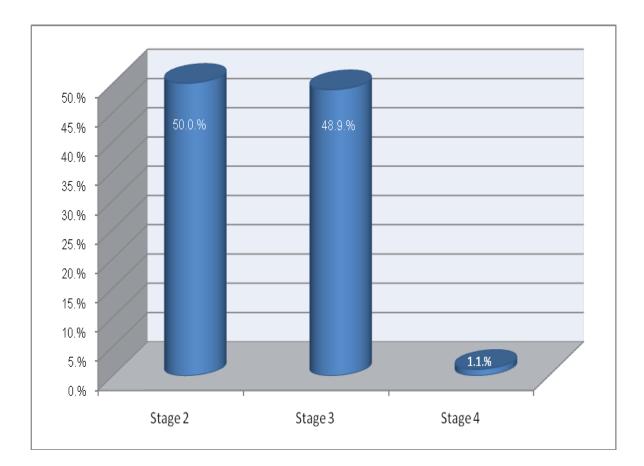
The HIV/AIDS disease progress or severity amongst the participants was assessed based on the condition of the patient at the time the research was conducted using both the WHO classified clinical staging method which has 4 stages (stage 1-4) and immunologic staging methods using their most recent CD4 level.

Almost all the participants were found to be in clinical stage 2 and 3. 46 (50.0%) were in clinical stage 2, followed by 45 (48.9%) who were in clinical stage 3 and 1(1.1%) was in clinical stage four.

Based on the assessment done using the immunological staging method (using CD4 level), it was found that majority of the participants with total number of 78 (84.8%) had their CD4 count level below  $200/\mu$ I, followed by 6 (6.5%) who had their CD4 level between  $200 - 500/\mu$ I, and 2 had above  $500/\mu$ I.

For 5 participants (5.4%), their CD4 count results were unavailable and for 1 (1.1%), there was no response. All the participants were already initiated on the highly active antiretroviral treatment (HAART) by the time they were recruited into the research process.

Figure 1. Distribution of the participants based on the WHO clinical staging.



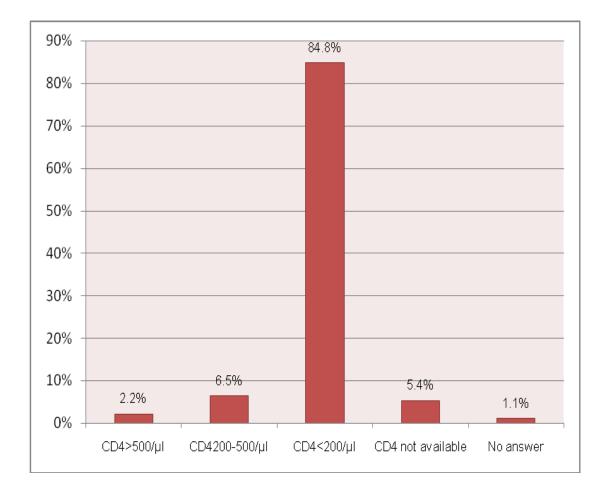


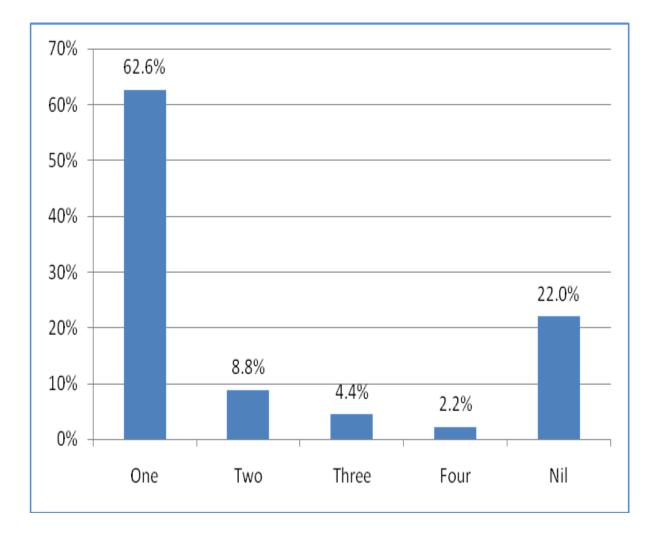
Figure 2. Distribution according to the WHO immunologic staging method for the participants.

#### 4.3.3 ANALYSIS OF VARIABLES

On assessment of the number of sexual partners the partcipants had in the previous 12 months, it was found that majority, 57 (62.6%) had only one partner. Twenty participants (22.0%) had no sexual partner in the previous 12 months. Amongst the 14 participants who had more than one partner in the previous 12 months, 8 (8.8%) had two partners, 4 (4.3%) had three partners and 2 (2.2%) had 4 partners. One (1.1%) did not respond to this question.

Amongst the participants who had more than one sexual partner, 8 (57.1 %) were men and 6 (42.9 %) were women. 5 (35.7 %) of them were married and 7 (64.3 %) were singles. Amongst those who had no sexual partner over the previous 12 month 4 (20%) were men and 16 (80%) were women.

Figure 3. The graphic distribution of the number of sexual partners the participants had in the previous 12 months.



It was also assessed how many sexual partners the participants had since the time they were first told or discovered about their positive HIV status. The majority of respondents 55(59.8%) had one partner when they learned their HIV status, 8(8.7%) had two partners, 6(6.5%) had three to four partners and 16(17.4%) had none partners and 1(1.1%) did not respond.

Figure 4 below depicts the graphic presentation of the distribution of number of sexual partners after knowing the HIV disagnosis.

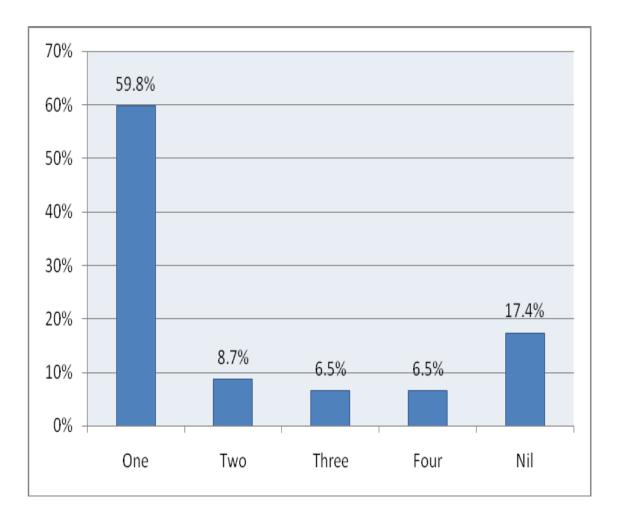


Table II displays the responses given by the research participants to questions about sexual partners and HIV status disclosure.

The largest proportion of the participants with the total number of 87 (94.6%) did believe that letting their sexual partner/s know about their HIV status was very important, 1 (1.1%) did not believe it was important and 4 (4.3%) were not sure. On the issue of informing sexual partner, majority of the participants answered that they had informed all of their partner/s 82 (89.1%) and 10 (10.9%) did not inform any one of their partner/s. Eighty three (90.2%) of the participants had the intention to disclose to all their partner/s in the future about their HIV status, 4 (4.3%) had no such plan and 5 (5.4%) were not sure (Refer to Table II).

Most participants were of the opinion that close friends or family members would help them disclose their positive HIV status to their sexual partner/s. Seventy nine (85.9%) had such opinion, 5 (5.4%) responded no and 8 (8.7%) responded that they were not sure of its significance. Amongst those who had disclosed their HIV status to their partner/s, sixty six (71.7%) said that the presence of such people has helped them significantly to disclose their status to their partner and 22 (22.8%) were not sure if it has helped them significantly.

Majority of the participants with total number of 79 (85.9%) agreed that it would be improper and unethical not to let their partners know about their positive HIV status, 5 (5.4%) did not agree and 8 (8.7%) were not sure. In terms of the assessment done to know whether the participants knew the HIV status of their sexual partners, 51 (55.4%) said they knew the HIV status for all their sexual partners and 41 (44.6%) said they knew only for the regular

partners. Inquiring if the participants would think letting their sexual partner/s know about their positive HIV status would make them feel better and comfortable, 68 (73.9%) said they were of the opinion that it would make them feel better and comfortable, 17 (18.5%) said no and 7 (7.6%) responded that they would feel better if they tell only some of them (Refer to Table II).

# Table II. <u>HIV status disclosure variables in relation to</u> sexual partner/s (n=92)

Variables						
	<b>Yes</b> Numbers	%	<b>No</b> Numbers	%	I'm not s Numbers	ure %
Importance of letting partner/s know about own HIV status	87	94.6%	1	1.1%	4	4.3%
sexual partner/s informed about positive HIV status prior to getting engaged in sexual intercourse	82	89.1 %	10	10.9%		
Plan of telling all partners in the future about positive HIV status	83	90.2%	4	4.3%	5	5.4%
Think the presence of significant people help disclosing HIV status to partner	79	85.9%	5	5.4%	8	8.7%
For those who had already disclosed their HIV status to their partner, if they think the presence of significant people to them helped them to disclose to their partner.	66	71.7%	4	4.3%	22	23.9%
It is improper and unethical not to let your partner know about your positive HIV status	79	85.9%	5	5.4%	8	8.7%
Know the HIV status of sexual partner						
* For all partners (A)	51 - <b>(A)</b>	55.4%				
* for regular partners (R)	41 – <b>(R)</b>	44.6%				
Think Knowing the HIV status of sexual partner would make them feel better	68	73.9%	17	18.5%	7 (for some)	7.6%

The largest proportion of the participants with total number of 89 (approximately 96.7%) believed that using condom helps them prevent transmission of HIV and 84 (approximately 91.3%) think that letting their partners know about their HIV status will help them use condom better. Majority of the respondents 80 (87.0%) did not agree that it should be the man's decision whether to use condom or not. When asked about whether or not they would insist on condom use even if their partners are not willing to use one, 49 (53.3%) said they would but 36 (39.1%) said they would not. The remaining participants, 7 (7.6%) were not sure.

## Table III. Variables in condom use

/ariables			No		l'm sure	not	
Believe using condom helps preventing transmission of HIV.	No. 89	% 96.7%	No. 1	% 1.1%	No. 2	% 2.2%	
Letting your partner know about your HIV status will help you use condom better.	84	91.3%	6	6.5%	2	2.2%	
Should be the man's decision whether condoms are used or not	8	8.7%	80	87.0%	4	4.3%	
Would insist on condom use even if partner does not want	49	53.3%	36	39.1%	7	7.6%	

Table IV. Condom use i	in relation	to HIV	disclosure
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Variables	Already disclosed to partner(No.&%)	t-test	95% CI	P- Value	Not yet disclosed to partner(No.& %)
Using condom helps to prevent HIV		2.6	1.57-0.55	0.000	
Yes	80(87.0%)				9(9.8%)
No	1(1.1%)				0(0.0%)
I'm not sure	1(1.1%)				1(1.1%)
Letting a sexual partner know of HIV status will		2.5	1.53-0.11	0.000	
help use condom better.	75(81.5%)				9(9.8%)
Yes	5(5.4%)				1(1.1%)
No	2(2.2%)				0(0.0%)
I'm not sure					
It Should be the man's		-1.2	0.08-0.54	0.072	
decision that condoms are used					
Yes	0/0 70/)				0(0.09/)
No	8(8.7%) 71(77.2%)				0(0.0%) 9(9.8%)
I'm not sure	3(3.3%)				1(1.1%)
Insisting on condom		2.2	0.08-0.54	0.001	
use even if partner is					
not willing to use					
Yes	44(47.8%)				5(5.4%)
No	33(40.2%)				3(3.3%)
I'm not sure	5(6.1%)				2(2.2%)

Statistical analysis was performed using t-test to compare condom use between patients who were aware of their HIV positive status and have disclosed to their sexual partners with those who have not disclosed their status to their sexual partners. P-value of less than 0.05 was determined for statistical significance.

Out of the total of 92 participants included, 82 have disclosed their HIV status to their partner/s. Amongst them 80 (87%) believed that condom helps prevent transmission of HIV, 1 (1.1%) did

not believe that condom help to prevent HIV and 1 (1.1%) was not sure. Amongst the remaining 10 participants who did not disclose their HIV status to their partners, 9 (9.8 %) believed that condom was helpful in preventing HIV transmission and 1 (1.1 %) was not sure. (t-test 2.6, Cl 1.57-0.55, p=0.000).

Amongst the participants who disclosed, 75 (81.5 %) said that letting their partner know of their positive HIV status would help them use condom better, 5 (5.4%) said it would not help and 2 (2.2%) were not sure. In comparison from those who did not disclose, 9 said letting their partner know of their HIV status would help them use condom better and 1 said it would not help (t -test 2.5, CI 1.53-0.11, P=0.000).

Comparing the belief between the two groups whether it should be the man's decision to use condom or not, 71 (77.2 %) of the participants amongst those who disclosed said no, 8 (8.7%) said yes and 3 (3.3 %) were not sure. Amongst those who did not disclose 9 (9.8%) said no and 1 (1.1 %) was not sure. (t-test -1.2, CI 0.08-0.54, p=0.072).

Amongst those who disclosed, 44 (47.8 %) said they would insist on condom use even if their partner is not willing to use, 33 (40.2 %) said they would not insist and the other 5 (6.1 %) were not sure. Amongst those who did not disclose, 5 (5.4%) said they would insist, 3 said they would not insist and 2 said they were not sure (t-test 2.2, CI 0.08-0.54, p=0.001).

The other variables that were assessed which could affect disclosure were fear of being left alone or abandonment, fear of physical abuse or assault, economic dependence on the partner and fear of going into serious financial shortage. On analysis of the obtained data, it was found that 33 (35.9%) participants said they had a fear that their partner would walk out or them should they have known about their HIV status, 33 (35.5%) did not have such fear and 26 (28.3%) were not sure. The majority of the participants 77 (83.7%) did not fear that their partner would physically abuse them if they informed them about their HIV status, 10 (10.9%) were not sure and 5 (5.4%) did have the fear of being physically abused.

The majority of the participants, 55 (59.8%) were not financially dependent on their partner's income. 30 (32.6%) were dependent on their partner's income and 5 (5.4%) were dependent partially. Most participants, 82 (89.1%) did not have any fear that they would be facing financial problems if they let their partner know about their HIV status.

# Table V. Shows some of the challenges in HIV status disclosure to sexual partner by the participants

VARIABLES			No		ľm n	ot sure
Fear that your partner will walk out on you if he/she knows about your HIV status	No. 33	% 35.9%	No. 33	% 35.9%	No. 26	% 28.3%
Fear that your partner will physically abuse you if you inform him your HIV status	5	5.4%	77	83.7%	10	10.9%
Financially dependent on their partner's income	30	32.6%	5	5.4%	55	59.8%
Any fear that you will be facing financially problems if you let your partner know about your HIV status.	3	3.3	82	89.1	6	6.5

The variables found to be independently associated with disclosure to a partner comparing those who have disclosed with those who have not were gender, age, marital status, education, number of sexual partners, clinical stage of 2 and 3, and immunological stage with CD4 < 200 /µl. Statistical analysis was performed for each variable using t test, confidence interval and p value. p–value of less than 0.05 was determined for statistical significance.

From those who disclosed 53 (64.6%) were female and 29 were male (31.5%) compared to 7 (7.6%) females and 3 (3.3%) men from those who did not disclose. (t test 2.1, Cl 0.01- 0.66, p= 0.04). 33 participants (40.2%) between the age of 26-35, 26 (28.3%) between the age of 36-45 and 17 (18.5%) between the age of 46-55 years have disclosed compared to 2 (2.2%), 3(3.3%) and 3 (3.3%) of similar age group respectively among those who did not disclose.

Thirty three (40.2%) were married, 33(40.2%) were single and 13(14.1%) were widowed amongst those who disclosed compared to 3(3.3%) married, 2(2.2%) singles and 3(3.3%) widowed amongst those who did not disclose. (t-test 3.1, CI 0.42-1.92, p=0.003). From those who disclosed 20(24.4\%) were having educational level up to primary school level and 47(57.35\%) up to secondary school level as compared to 5 (5.4\%) in primary 3(3.3\%) in secondary from those who did not disclose. (t-test 3.5, CI 0.32-1.16, p=0.001).

Variables	Disclosed N (%)	t-test	95% CI	P- Value	Non disclosed N (%)
Gender		2.1	0.01-0.66	0.04	
Male	29(31.5%)				3(3.3%)
Female	53(64.6%)				7(7.6%)
Age		8.4	1.17-1.89	0.000	
26 – 35yrs	33(35.9%)				2(2.2%)
36 - 45	26(28.3%)				3(3.3%)
46 – 55	17(18.5%)				3(3.3%)
Marital status		3.1	0.42-1.92	0.003	
Single	33(40.2%)				3(3.3%)
Married	33(40.2%)				2(2.2%)
Widowed	13(14.1%)				3(3.3%)
Education		3.5	0.32-1.16	0.001	
Primary	20(24.4%)				5(5.4%)
Secondary	47(57.35%)				3(3.3%)
Clinical					
Stagell	42(51.2%)	7.3	0.87-1.5	0.000	4(4.3%)
Stage III	40(48.8%)				5(5.4%)
Immunological					
CD4<200/µl	70(85.4%)	10.1	1.28-1.91	0.000	8(8.7%)
Sexual partners					
One	51(56.0%)	3.7	0.45-1.52	0.000	4(4.4%)
More than one	30(33.0%)				6(6.6%)

Advancement of the HIV condition was assessed according to the WHO clinical and immunological staging criteria and was also found to be independently associated with disclosure. 42(51.2%) were in clinical stage 2, 40(48.8%) in clinical stage 3 amongst those who disclosed as compared to 4(4.3%) in clinical stage 2 and 5(5.4%) in clinical stage 3 amongst those who did not disclose.(t-test 7.30, CI 0.87-1.5, p=0.000). CD4 level was below 200/µl for 70 (85.4%) amongst those who disclosed compared to 8(8.7%) from those who did not disclose.(t-test 10.1, CI 1.28-1.91, P=0.000).

Amongst those who disclosed, 51(56.0%) had only one sexual partner and 30 (33.0%) had more than one sexual partner. In comparison from those who did not disclose 4(4.4%) had only one sexual partner and 6 (6.6%) had more than one sexual partner (t-test 3.7, Cl 0.45-1.52, P=0.000).

## Table VII. Variables that were found to have statistical significance

	Yes	0.5		% CI	P-Value
Variables Believe that it is important to let your partner/s know about HIV status	Mean 1.3	SD 1.5	Lower .95	Upper 1.6	.000
Have you been informing your sexual partner/s about it prior to getting engaged in intercourse	1.15	.49	1.00	1.29	.000
Plan of telling partners in the future about positive HIV status.	1.44	.79	1.23	1.55	.000
Think the presence of significant people to them will help them in disclosing their HIV to their partner if they had not do it so far	1.00	1.20	1.83	1.98	.000
If they had disclosed their HIV status to their partner, did they think the presence of sig. people to them helped them to disclose to their partner.	1.46	.82	1.23	1.58	.003
It is improper and unethical not to let your partner know about your positive HIV status	1.45	.49	1.29	1.49	.000
Believe using condom helps preventing transmission of HIV.	1.05	.31	.94	1.07	.002
Letting your partner know about your HIV status will help you to use condom better.	1.11	.38	.98	1.13	.001
Should be the man's decision whether condoms are used or not	1.83	1.98	.90	.23	.062
Insist on condom use if your partner does not want to use one	154	.64	1.36	1.62	.000

The variables that were found to be statistically significant with p value less than 0.05 are shown on table 7. Belief in the importance of letting a sexual partner/s know about the HIV positive status was significant (mean = 1.3, SD = 1.5 and p=0.000). Informing sexual partner/s about the positive HIV status prior to engaging in sexual intercourse and planning to tell all partners in the future about positive HIV status were found to be statistically significant (p=0.000). The presence of one's significant people in helping disclose HIV status to a partner was found to be statistically highly significant (mean = 1.00, SD=1.20 and p=0.003).

The presence of significant people in helping disclose HIV status to a partner/s was also found to be statistically significant for those who had disclosed already. Thinking that it is improper and unethical not to let a partner know about the positive HIV status was also significant.( mean =1.45, SD =0.49, p=0.000).

Variables of condom use were also found to be statistically significant. Belief in using condom to prevent transmission of HIV, letting one's partner know of the HIV status to increase condom and insisting on condom use whether the partner wants or not were all found to be statistically significant (p= 0.000). The p value of 0.062 for the variable "it should be the man's decision whether condoms are used or not" shows that it is not statistically significant with (mean = 1.83, SD = 1.98 and CI (0.90,-0.23)) In other words, participants do not think that it should be the man's decision to use or not use condoms.

## **CHAPTER 5**

## DISCUSSION

## **5.1 INTRODUCTION**

This chapter describes and further discusses the results shown in chapter 4. The results obtained in this study were also compared against findings from similar studies. This chapter will also outline the possible conclusions that can be drawn from the analysis of the obtained results. The limitations that were discovered on the process of the study as well as the recommendations made thereof are also highlighted.

#### 5.2. General information

The age range for most of the participants in this study was 26-45 (69.5%). This is in line with the 2008 national survey report which stated that there was a steady increase of the HIV prevalence in the age group of 25 to 39 since 1992. According to the 2006–2007 DHS, women aged 25 to 29 had the highest prevalence of either sex at 48.9 percent, and among men, the prevalence was highest among 35- to 39-year-olds, at 44.9 percent.

There were more female participants than males (65.2 % Vs 34.8 %). This also holds true for the general population as Swaziland's HIV epidemic is reported to be feminized; according to the 2006–2007 DHS, 31 percent of women are infected compared with 21 percent of men. . There could also be other reasons – for example, women tend to seek medical attention more frequently than men.

Education for most of the participants was limited. 54.3% listed secondary school as their highest level of education and 27.2% listed primary level as their highest level of education. Most of the people coming to the centre also have low socio-economic status though the amount of monthly income for the participants was not checked. Some publications reviewed showed that a higher educational level was associated with an increased disclosure rate. For instance, Antelman G et al, (2001) found that women with higher education are more likely to disclose their result to their sexual partner than women who are illiterate.

According to their marital status, the participants who were single (39.1%) were comparable in number to those who were married (38.0%). Of the married male participants, most were married to a single wife and only 2.2 % were in polygamous type of marriage. This finding was lower than the researcher's expectation. The divorce rate was low (2.2%).

Both clinical and immunologic staging methods of the World Health Organization (WHO) were used to assess the progress of the HIV/AIDS condition of the participants. According to the clinical staging, 50.0% were in stage 2 and 48.9% were in stage 3. Most of the participants (84.8%) had CD4 level below 200 (Immunologic AIDS). This could be due to the fact that

most patients wait until they are experiencing physical symptoms before seeking testing and treatment come to be tested and get treatment. More emphasis has to be given at a national level to increase the number of people that undergo VCT while they still are asymptomatic, as low HIV testing is one of Swaziland's challenges on the fight against HIV/AIDS.

In other studies, advancement of disease status is positively correlated with disclosure of HIV. Presumably, the reason for this is that when patients have visible signs of disease which are difficult to hide from the partner. But this may not be true I, partners will already suspect positive HIV status. This may not hold true for patients who initiate HAART early. In such patients, HIV is a manageable chronic condition in which individuals live healthy lives for longer period of time, thus diminishing the need to disclose HIV status due to illness (Serovich JM and Mosack KE, 2003). All the participants recruited into the study were already initiated on the Antiretroviral (ARV) treatment. But being on antiretroviral treatment on its own was not shown to have increased disclosure significantly in previous studies in Swaziland.

### 5.3. Rate of HIV disclosure and non disclosure

There is a wide range of discrepancies and inconsistencies in the reported rates of HIV disclosure from different studies done worldwide. In general, the rates of disclosure in studies from developing countries are notably lower than rates reported from the developed world. The average rate of disclosure for developing countries is 49%. This rate is well below the average rate reported from studies conducted in developed countries (79%).

The level of disclosure of HIV status to sexual partner found in this study was high. Eighty two out of ninety two participants have disclosed their HIV positive status to their sexual partner/s giving disclosure rate of 89%. This is higher compared to the previous studies done in the country by Borgsund C & Stureson A, (2005) at Mbabane Government Hospital and Ericsdotter AC & Skånberg A, (2005) at Mbabane government and Raleigh Fitkin Memorial Hospitals which also assessed the rate of disclosure of HIV to sexual. In the former, it was reported that almost half of the participants have told their partner that they are HIV positive. In the latter, it was found that 61% had disclosed to their partner (but only 65% of the patients were reported to have a partner by then).

Corresponding with the high disclosure rate found in this study, it was also observed that most of the participants were having positive attitude towards HIV status disclosure to a partner. Most participants (94.6%) believed that letting their sexual partner/s know about their HIV status was very important and 85.9% said that it would be improper and unethical not to let their partners know about their positive HIV status. According to (Sigxaxhe T and Matthews C, 2000), such high level of awareness of HIV transmission and HIV prevalence within a community could perhaps be the most important determinant of a woman's willingness to disclose her serostatus.

The disclosure rate found in this study was also higher than what was reported in other studies done in developing countries. For example, according to the meta analysis by (Medley, et al, 2004) which reviewed 15 studies from different developing countries, the reported range of disclosure was 16.7% to 86% compared to most of which, the disclosure rate in this study was

higher. The high disclosure rate in this study is comparable though to what Wong Van and Modiba (2009) found in Soweto and the Kwazulu natal in South Africa for which the reported disclosure rate was 87%. (Deribe et al, 2007) also found disclosure rate of 90.8 % in their study which was done in Jimma, south west Ethiopia. (only 9.2% did not disclose their result to their current main partner as compared to 10.9% in this study). The high rate of disclosure in this study might be attributed to the rigorous pre HAART adherence counselling sessions all the participants had to undergo before they were initiated on the antiretroviral treatment (since all were on HAART) which also puts huge emphasis on the importance of partner disclosure. Feeling of responsibility towards their partner could as well be another possible explanation.

Though it was clearly shown from other studies that there are discrepancies between intention to disclose and actual disclosure behaviour, with actual disclosure rates being lower than intended disclosure rates, the intention of disclosing the positive HIV status among the participants to all partners in the future was also significantly high amongst the participants with 90.2% saying that they were going to disclose to all their partner/s in the future.

Knowing partner's HIV status was found to be associated with the disclosure of one's own status to a partner whereas the reverse is true for having multiple partners. The more the number of sexual partners, the lower becomes the rate of disclosure. It was also noted from other studies that people tend to disclose more to their current and steady partners rather than to their casual or previous partners. One of the reasons given for this was a difference in the sense of responsibility. In this study, 62.6% of the participants had only one sexual partner and 22.0% had no partner since the previous 12 months. Since having known of their HIV status, 59.8% had only one partner which could have motivated the participants to disclose more.

The duration it took for the participants to disclose their status to their partner since the time they knew of their HIV diagnosis was not assessed though. This would have been vitally important as time since the diagnosis of the HIV condition is one of the factors that potentially influences the rate of disclosure (Bouillon K et al, 2007). The longer the duration from the diagnosis, the higher the rate of disclosure. This has another benefit in that it enables one to assess exposure risk to the the partners over time.

When asked about whether or not participants knew their partner's HIV status, 55.4% knew the HIV status of all their partners in the previous 12 months and 44.6% knew only for the regular partners (22.0% reported to have no partner in this period). Most participants (73.9%) believe that knowing the HIV status of their partner would rather make them feel better. The sero-status of the partners in particular was not checked. Assessment of partner HIV status could have been very helpful in terms of assessing the number of sero-discordant couples. Among those disclosed to their partners, 40.2% of were married and 40.2% were singles.

#### 5.4 Condom use and disclosure

One of the key steps in the prevention of HIV/AIDS pandemics at a national level is educating people about condom use, and ensuring that condoms are widely distributed for easy accessible. VCT services rendered in every health care facility in Swaziland shares this responsibility. It has been shown in studies done in other resource constrained settings by

Collini P and Obasi A (2006) that VCT services make a significant impact of increasing condom use by 50-70%.

The results in this study demonstrate that the majority of the participants believe that condoms prevent HIV transmission (96.7%). This high level of awareness among the participants is probably due effective health education at the VCT center. It should not be inferred that same level of information is given to the general population.

Consistent with the high rate of HIV disclosure in this study, most of the participants (91.3%) also think that it is important to inform their partner of their HIV status in order to promote condom use within their sexual relationships. This finding was also similarly high amongst the participants who did not disclose. Nine out of the ten participants who did not disclose their status to their partner/s fully agreed on the above point. The fact that disclosing and non-disclosing participants from VCT in this study had positive attitudes towards should not automatically imply that condom behavior changed.

Studies have shown the positive impact of disclosure on safer sex. For instance, a South African study by Ijumba K et al (2004) showed that knowing someone with HIV was associated with condom use at last sexual encounter and negatively associated with multiple and casual sex partners. But the reverse could also be true that it does not always mean, individuals will

use the information to protect themselves or others; in fact, some will knowingly place themselves at risk of infection. (Serovich JM and Mosach KE, 2003) concluded that it is erroneous to assume always that disclosure would lead to safer behaviours or lead to lowering of risk all the time. They found out that even when individuals overcome the barriers to disclosure and reveal their serostatus to sexual partners, there is no guarantee of their subsequent sexual safety.

Some HIV-infected individuals may disclose their serostatus but then deliberately ignore or avoid protection, possibly to attest to their commitment to the relationship or because of the effects of substance use prior to sexual activity (Marks G and Crepaz N , 2001). They also stated that similarly, non-disclosure does not necessarily lead to unsafe sex always. Some HIV-infected individuals may refrain from divulging their HIV serostatus to protect their privacy and avoid the negative consequences of disclosure, such as stigma or rejection. However, they may engage in protected sexual activity, perhaps out of a sense of personal responsibility toward their partners. Kalichman SC et al (1999b) also have found inconsistencies between disclosure and sexual safety that the fact that one has disclosed of the positive HIV status to his or her partner may not necessarily always imply that there will be safer sex.

The other striking finding in this study with regard to the issue of condom use in line with the findings discussed above is that despite the high level of awareness of the importance of condom in use HIV prevention, participants had relatively low confidence in their ability to insist on using condoms irrespective of their partner/s wishes.

Only 53.3% said they would insist on using condoms even if their partner did not want to. Only 39.1% saying they would not and 7.6% saying they were not sure. Only 44 out of the 82 participants who disclosed, and only 5 out of the 10 participants who did not disclose, said they would insist on condom use even if their partner does not want to use condom. This finding can not only be attributed to the subordinate status of women (65% of the participants were women) in Swaziland since that the majority of the participants (87%) did not agree that it should be the man's decision whether to use condom.

Based on these findings, it is difficult to conclude that disclosure of HIV status increases condom use among the participants. This study did not measure specific comparison condom use before and after HIV disclosure. Such an investigation, especially as it relates to the sero-discordant couples, should be considered for later analysis.

#### 5.5. Factors influencing disclosure

The rate of HIV disclosure found in this study was much higher than the researcher expected. Possible reasons for non-disclosure assessed amongst the participants are fear of abandonment or being left alone, fear of physical abuse or assault, economic dependence on the partner and fear of going into serious financial hardship. In the context of the subordinate status of women in Swaziland, the researcher believes that these factors are likely to exert a detrimental effect on disclosure.

Contrary to the researcher's opinion prior to the study, fear of physical abuse was not found to be a major problem with most of the participants. Only 5.4% said they had that kind of fear. However, 35.9% expressed the fear of abandonment by their partners. In spite of the fact that majority of the participants were women, only 32.6% were economically dependent on their partners. Facing financial problems if they let their partner knew about their HIV status was not reported as a problem by the majority (89.1%) of the participants.

Economic independence has a positive influence on disclosure. This could have contributed to the high rate of disclosure found in the study as self-efficacy was reported to be a key determinant of HIV status disclosure (Kalichman SC and Nachimson D,1999). The majority of those who participated in the research could have either good relationships or reliable social support. The presence of significant people was mentioned by 71.7% of the participants as an important factor that would help one to disclose his or her positive HIV status to a sexual partner/s. In line with this point, Peterson SH et al (2006) in their study said that women who chose not to disclose were more likely to report unsupportive and threatening sexual relationships which could impede their ability to safely disclose their serostatus, negatively affecting their health and that of their sexual partners.

The factors that were found to be independently associated with disclosure using statistical analysis (t-test, 95% CI and p value) were gender, age, marital status, educational level, advanced stage of disease and the number of sexual partners (see table 6 in chapter 4). Some of these factors were also reported in other similar studies to be associated with disclosure (Bouillon K et al, 2007 and Deribe K et al, 2008).

# **CHAPTER 6**

# **CONCLUSIONS AND RECOMMENDATIONS**

# **6.1 CONCLUSIONS**

The following conclusions could be made about adult patients attending VCT at Nhlangano

health centre from the findings of this study;

- The considerably high rate of positive HIV status disclosure to sexual partner found in this study compared to many studies done in other settings is very much encouraging especially in the context of the existing very high prevalence of HIV infection in the country. Despite this though, knowing partner's HIV status was relatively lower which needs to be put on emphasis. This needs to be addressed.
- Even though the study was done only amongst patients attending VCT, that the
  majority of the patients were found to have positive attitude about disclosing HIV status
  to a partner, believed in the importance of letting their sexual partner/s know about
  their HIV status, possessed a background understanding of the unethical nature of
  engaging into sexual intercourse without disclosing their positive HIV status to their
  partner extremely positive. All contributing factors in terms of creating awareness,
  health education, good counseling and follow up of treatment that could possibly have
  positively influenced the participants in this study to have such, should continue be
  implemented at a larger scale nationally to achieve even better results.
- Awareness and belief in the importance of condom use in preventing HIV transmission

including the fact that disclosure of HIV status to a partner enhances its better use was

impressively high amongst almost all participants. But it is worrisome that only half of the participants said they would insist on condom use irrespective of their partners' willingness to use.

 The variables that were found to be independently associated with disclosure to a partner were gender, age, marital status, education, number of sexual partners, and stage of the HIV condition.

## 6.2 LIMITATIONS OF THE STUDY

- Even though the disclosure rate was found to be high in this study, the study did not examine the duration of time the participants took to disclose their HIV positive status to their partners. This would have been important to examine in order to understand the risk of exposure for the partners and to assess whether necessary protective measures were taken during such period. The length of time to disclose is also an important factor in disclosure of HIV status as studies from both developed and developing country settings commonly found that disclosure rates to sexual partners tend to increase over time from initial diagnosis.
- Though most of the partners in this study knew the serostatus of their partners, especially for their regular partners, the actual serostatus of partners was not collected. This would have been important to know to understand sero-discordant couples.

- The issue of partners communicating with each other prior to getting tested for HIV
  was not properly assessed. The extent to which partners communicate with each other
  prior to testing could pose a significant impact upon partner disclosure. Prior
  communication before testing might help individuals to anticipate a partner's reaction
  and would give them an opportunity to raise the issue again and disclose their result.
- The issue of stigma in disclosure of HIV status is a commonly encountered challenge and need to be explored in more depth.
- The researcher feels that more exhaustive lists of possible reasons for non-disclosure and socio demographic factors like income level for the participants should have been included in the questionnaire.
- Condom use prior and after the disclosure of HIV status was not specifically compared.
   This information could enable one to better understand the effect of partner disclosure on condom use.
- The findings of the study are limited to Nhlangano health centre and may not be generalized to all the other health care facilities in Swaziland.

### 6.3 RECOMMENDATIONS

- The importance of this research topic was increasingly felt by the researcher through the process of the study. Even though the HIV disclosure rate to a sexual partner found in this study was much higher than the researcher's own expectation and the results of other similar studies, the finding was among patients who have regular follow up at a VCT. The researcher feels that a similar research should be repeated at a larger scale amongst the general population, not only limited amongst the VCT patients who had repeated counseling so that the results are not overestimated.
- One of the most important benefits of HIV disclosure is that it is believed to enhance partner protection. But as has been discussed, there is no guarantee that disclosure always results in safer sexual practice. Hence, specific comparison on the rate of condom use before and after disclosure of HIV status to a partner need to be strongly considered.
- HIV status disclosure studies should not only assess the rate of disclosure, but also the presence of delay in disclosure and also whether there has been prior communication between the partners before testing. This would have impact directly both on the disclosure rate as well as on the partner risk assessment.
- Knowing of the sero status of participants partners' should be assessed as it has enormous implications on disclosure rates and helps in the assessment of risk and promotion of preventive methods especially amongst sero-discordant couples.

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