

**UNIVERSITY OF NAIROBI**  
**INSTITUTE OF ANTHROPOLOGY, GENDER AND AFRICAN**  
**STUDIES**

**TO DISCLOSE OR NOT: WOMEN'S EXPERIENCES WITH HIV-  
POSITIVE STATUS DISCLOSURE TO SEXUAL PARTNERS: A  
CASE STUDY OF NAKURU, KENYA**

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**A Project submitted in partial fulfillment for a Masters Degree in  
Gender and Development**

**December, 2007**

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**Declaration**

This is my original work and has not been presented for a degree by any other university.

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This research project has been submitted for examination with my approval as University Supervisor, Institute of Anthropology, Gender and African Studies, University of Nairobi

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## **Dedication**

I would like to dedicate this project paper to several people. First and foremost is to Grace Muthoni Gichuhi, my mother, who was my first 'gender' teacher. She inspired me to see myself as whole and complete and to never limit myself. She remains my role model.

I also dedicate this project paper to a very dear friend, Jennifer Liku who encouraged me to pursue my dream and has been with me every single step of the way. Without her friendship and support, this would not have been possible. She is also my role model.

Lastly, I would like to dedicate this paper to one more person who must remain unnamed. He has been a friend, brother, cheerleader and mentor all rolled into one. He has taught me to have confidence in myself and my abilities and never ceases to make me laugh. Thank you.

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## **ABSTRACT**

The prevention and control of HIV infection depends on the success of strategies to prevent new infections and treat currently infected individuals. Within HIV testing and counseling programmes emphasis is placed on the importance of HIV status disclosure among HIV infected clients, particularly to sexual partners. Disclosure may motivate sexual partners to seek testing, change behaviour and ultimately decrease transmission of HIV. In addition, disclosure may facilitate other health behaviours that may improve the management of HIV. For example, women who disclose their status to partners may be more likely to participate in programmes for prevention of HIV transmission from mothers to their infants. Through disclosure of her status, a woman may receive support from her family or others in her social network and may also be able to access available support services. It has been recognized however, that there are a number of barriers that HIV infected women may face in sharing their test result with sexual partners. This report aims to identify the major barriers and outcomes of HIV positive disclosure to sexual partners. In addition, women's experiences with HIV positive status disclosure to sexual partners is documented and the support mechanisms they employ in order to disclose their status with minimal negative consequences reviewed. The report ends with a section on recommendations for ways to move forward to increase disclosure rates among women to their sexual partners.

# CHAPTER ONE: BACKGROUND TO THE STUDY

## 1.1 INTRODUCTION

Disclosure in the context of HIV/AIDS occurs when a person's HIV test result is revealed to another (USAID, 2003). 'Disclosure' means telling someone your HIV status. In this era of HIV/AIDS, every effort must be made to encourage everyone infected with the disease to be open about their HIV-positive status. Voluntary Counseling and Testing (VCT), a testing model which is mostly used in Kenya, generally tests patients individually and informs the testee individually of the result. Great emphasis is placed on confidentiality of the whole process. Nowhere in this model, is disclosure of the test results to those concerned highlighted. However, the importance of disclosure cannot be overemphasized. It is the gulf that stands between survival and certain death from the disease; between productive life and unproductive and eventual extinction from the face of the earth. This is because it is only those who have disclosed their HIV status who are able to have access to health facilities for care, concern, and cure (UNAIDS, 2006).

In the context of the HIV/AIDS epidemic, gender plays an integral role in determining an individual's vulnerability to infection. Gender is a social construct that differentiates the power, roles, responsibilities and obligations of women from that of men in society (UNIFEM, 2000). Across cultures, there is a difference between women's and men's roles and decision-making authority. For physiological and biological reasons, women have always been more susceptible to contracting the HIV virus than men. Biological factors include: the higher viral concentration in semen compared to vaginal fluids, larger exposed surface area and longer viral contact among women (WHO, 2002b). However, biological vulnerability alone does not account for women's experiences with the HIV/AIDS epidemic. The larger socio-cultural context, in which women find themselves, has a major role to play in their susceptibility to infection and their experiences once infected. It also affects their ability to access care, support or treatment, and the ability to cope when infected (UNAIDS, 2006).

Gender norms greatly affect women's and men's sexual behaviour and attitudes and how they cope with HIV/AIDS once infected (UNAIDS, 1999). Hence, in addition to increasing the vulnerability of women to HIV, the power imbalance that defines gender relations of sexual interactions also affects women's ability to disclose their HIV-positive status to their sexual partners. For example, fear of violence means women may hesitate to be tested or fail to return for the results. This is because they are afraid that disclosing their HIV-positive status may result in physical violence, expulsion from their home or social ostracism. Research undertaken in Sub-Saharan Africa has shown these fears to be well founded (WHO, 2003).

Emotional and physical abuse upon disclosure of HIV-positive results are some of the outcomes that are a reality for many women. In a study done of Voluntary Counseling and Testing (VCT) services in Dar es Salaam, Tanzania, in 1999, it was found that only 57 percent of women who tested HIV-positive reported receiving support and understanding from sexual partners (Maman et al, 1999). Women may also be more affected by stigma and discrimination than men because of social norms concerning acceptable sexual behaviour in women and because women are more often economically vulnerable than men (UNIFEM, 2000). HIV stigma is a 'process of devaluation' of people living with or associated with HIV and AIDS which includes identifying and labeling differences, associating differences with negative attributes, separation of 'us' from 'them' and status loss and discrimination (Nyblade;Field 2000). This is the unfair and unjust treatment of an individual based on his/her real or imagined HIV status or on the basis of belonging of being perceived to belong to a particular group. HIV-related stigma is therefore compounded for women who are already disempowered.

Stigma includes issues such as loss of social standing, being teased/insulted. Physical assault, abandonment and threats of violence are also related to stigma and discrimination. HIV-positive women, therefore, bear a double burden: they are infected and they are women. Stigma is unnecessarily tied to disclosure or lack of it for many women. Disclosure and stigma are, therefore, very topical issues when dealing with HIV/AIDS for women (UNAIDS and WHO, 2000). This is because women are more

affected by stigma and discrimination arising from HIV/AIDS. For example, a study conducted in Zambia and Tanzania, in 2000, found that women were more likely to suffer stigma compared to men (Nyblade and Field, 2000). In the research, 63.1 percent of women were reported to be experiencing stigma as compared to 49 percent of the men. In the same study, 49 percent of women and less than 10 percent of the men interviewed, reported being threatened with violence after disclosure of HIV – positive results.

A number of barriers that HIV-infected women face when sharing their test results with sexual partners have, therefore, been recognized by researchers (UNAIDS, 1999, WHO, 2002, Weiss et al, 1998). In addition, there are marked differences in the HIV-positive status implications HIV for men and women. The distinct roles and behaviors of men and women in a given culture dictated by that culture's gender norms and values give rise to gender differences (UNAIDS, 1999). Some of these differences result from biological differences in sex between men and women. However, more of these differences result from socially defined gender differences (Hays et al, 1993). For example, gender norms encourage women to remain ignorant of the facts of sexuality and HIV/AIDS because they are not 'supposed' to be sexually knowledgeable. Similarly, men may remain 'ignorant' because they are 'supposed' to be sexually all-knowing. Women may want their partners to use condoms (or to abstain from sex altogether) but may lack the power to make them do so. Women (who are often more socially, economically and physically vulnerable than men) may also be unwilling to learn and/or share their HIV status for fear of violence and/or abandonment if results turn out positive (Weiss et al, 1998).

Sexually active women are also discouraged from discussing sex too openly with their own partners, since women are encouraged to be ignorant and inexperienced (UNIFEM, 2000). This means that women are unlikely to communicate their need for safer sex with sexual partners. In Kenya, for example, a study conducted in Kisumu in 1997, revealed that young women felt that they did not have control over their sexuality - instead girls learned that sex was something that happened to them. It was not something they could initiate or actively participate in (Balmer et al, 1997).

For many women, the decision to tell their sexual partners their HIV- positive test results is often a very difficult process made even harder because of their subordinate status in society. This is because of the fear of experiencing negative consequences which is very real. They may be blamed for bringing AIDS into the family and are often seen as to blame for their infection (WHO, 2002b). Discrimination within the family, abandonment and even violence are some of the real consequences that they consider when deciding whether or not to disclose their HIV-positive status to their sexual partners (Maman et al, 2001). Loss of child custody and stigma are also some negative consequences that they may consider in deciding whether or not to disclose their HIV-positive status to their sexual partners (De Bruyn, 2005).

## **1.2 STATEMENT OF THE PROBLEM**

Society prescribes to women and men different roles in different social contexts. There are also differences in opportunities and resources available to men and women and in their ability to make decisions and exercise their human rights. These include those related to protecting health and seeking care in case of ill health (UNIFEM, 2000). Gender roles and unequal gender relations interact with other social and economic variables resulting in different and sometimes inequitable patterns of exposure to health risk. These differences in turn have clear impact on health outcomes especially in the case of the HIV/AIDS pandemic (WHO, 2002).

The power imbalance that defines gender relations of sexual interactions has increased women's vulnerability to HIV infection (UNAIDS, 1999). This has also affected women's ability to disclose their HIV-positive status to their sexual partners. The risk of HIV infection for women is increased by socio-cultural and economic forces that define gender relations. Women lack control in matters of sexual relations within relationships, with men's needs taking precedence. They therefore, face increased risks of infection by virtue of their social position, unequal life chances, rigid and stereotypical gender roles and poor access to education and health services. The social and economic vulnerability and gender inequality of women lies at the root of their experiences in coping with stigma and discrimination associated with HIV-infection and disclosure of such status

((UNIFEM, 2000). In many societies, being socially ostracized, marginalized and even killed are very real potential consequences of exposing one's HIV status. Studies have shown that women who test HIV-positive are more likely to be abandoned by their partners (Maman et al, 1999; UNAIDS, 1999).

An increasing proportion of people affected by the HIV/AIDS pandemic are female (UNAIDS, 2006). Therefore, there is considerable interest in finding strategies to encourage disclosure of HIV-positive status especially among women. The importance of disclosure for women cannot be overemphasized. Kalichman (1999), points out that indeed, disclosure of one's HIV status to sexual partners is essential in stopping the spread of the disease. It facilitates access to care, as only those whose problems are known are very likely to receive attention and assistance – ARVs, VCT, treatment and prophylaxis for opportunistic infections. It also encourages healthy attitudes as partners and friends come to understand and appreciate the sexual preferences – abstinence, keeping to one partner only and condom use - of their spouses (WHO, 2004). This prolongs the lives of the infected and affected as all the above work in synergy towards promoting their relevance and productive participation in daily activities, in their families and the society.

HIV testing and counseling is critical to prevention and treatment in order to control the HIV pandemic (Chesny et al, 1999). Prevention of new HIV infections and treatment of currently infected individuals are the keys to the prevention and eventual control of the HIV pandemic. Within HIV testing and counseling programs, emphasis is placed on the importance of HIV status disclosure among HIV-infected clients, particularly to sexual partners (Norman et al, 2005). Disclosure of HIV status is very important for a number of reasons. First, disclosure may motivate sexual partners to seek testing, change behavior and ultimately decrease transmission of HIV (Galvan et al, 2000). At the same time, disclosure may facilitate other health behaviours that may improve the management of HIV/AIDS like the prevention of HIV transmission from mothers to their infants. Finally, through disclosure of her status, women may receive support from her family or others in her social network and may also be able to access available support services (UNAIDS and WHO, 2000).

Focusing on gender and HIV/AIDS is, therefore, of crucial importance in the prevention of new infections and access to treatment for those infected. Even though gender has as much to do with men as it does with women, the focus of this study will be on women because of their subordinate status in society as compared to that of men and the unique problems that they face because of their status in society when dealing with the HIV/AIDS pandemic.

This study, therefore, seeks to answer the following research questions:

1. What barriers do women face in relation to disclosure of HIV status to sexual partners?
2. What are the outcomes that are associated with disclosure of HIV status to sexual partners for women who are HIV-positive?
3. What are the experiences that women go through in deciding whether or not to disclose their HIV status to sexual partners?
4. What support do women need in order to disclose their HIV status to sexual partners without negative consequences?

## **1.3 OBJECTIVES**

### **1.3.1 Overall Objective**

To explore the barriers and outcomes that HIV-infected women face in sharing their results with sexual partners in Nakuru town, Nakuru district.

### **1.3.2 Specific Objectives**

1. To identify the barriers that women face in regard to disclosure of their HIV status to sexual partners
2. To examine the outcomes that are associated with disclosure of HIV status to sexual partners for women who have tested HIV-positive.
3. To explore the experiences that women go through in deciding whether to disclose their HIV status to sexual partners.
4. To establish the kind of support that women need in order to disclose their HIV status to sexual partners without negative consequences.

## 1.4 HYPOTHESES

1. Women face barriers with regard to disclosure of HIV status to sexual partners
2. Women face negative outcomes associated with disclosure of HIV status to sexual partners
3. Women employ positive strategies in regard to disclosure of their HIV status to sexual partners.
4. Women require positive support to disclose their HIV – positive status to their sexual partners with minimal negative consequences.

## 1.5 RATIONALE OF THE STUDY

The experiences of women with disclosure of HIV status is the focus of this paper since gender plays a very significant role in women's inability to disclose their HIV positive status to sexual partners. Women comprise an increasing proportion of people living with HIV/AIDS and of new infections worldwide. In Sub-Saharan Africa, women represent 6 in 10 (57%) of people living with HIV/AIDS (WHO, 2002). There are major barriers to disclosure of HIV status for women – usually the fear of negative outcomes. Women who currently disclose do so selectively based on how they anticipate that their partner will react (WHO, 2004). Fleischmann (2005) argues that in coping with HIV and AIDS, women face more harm, discrimination and stigma compared to men. It is therefore, not just the serostatus that is key to altering women's lives, but equally (and at times more) important their spouse/partners response to the new crisis in the family. As a result many women hesitate to test for HIV and to disclose their HIV-positive status even to their husbands/partners (USAID, 2003).

It is, therefore, important to find strategies that allow women to maximize on the beneficial outcomes and minimize the harmful aspects of disclosing their HIV serostatus to their sexual partners (Fleischmann, 2005). A lot needs to be done to increase the ease, safety and readiness of disclosure of HIV status for women to their sexual partners. This study will shed light on women's experiences with disclosure and the factors they consider in deciding whether or not to disclose their HIV status to sexual partners. This is information which can be used in designing gender specific counseling messages that can



be targeted at women. Adequate counseling time to addressing the potential means and outcomes of disclosure to better prepare women can also be considered.

There is an increasing recognition that disclosing one's HIV status is an essential part of behaviour modification required to reduce the spread of HIV/AIDS (UNAIDS, 1999). Voluntary Counseling and Testing (VCT) for HIV is widely promoted as an important first step in behaviour modification. However, without disclosure, few of these benefits can be realized (Maman, 2001). HIV-positive women are unable to initiate negotiations of sexual practices that would reduce the risk of transmission. This is because the intricate manipulation of sexual relations that are necessary for women to engage in in order to survive economically in deprived circumstances that are present in resource poor settings of Sub-Sahara Africa. This study will therefore explore this issue by examining the support structures that would encourage women to disclose their HIV status to sexual partners. Support mechanisms for women who experience negative outcomes can therefore be established using the findings of this study.

Disclosure of one's HIV status is an essential part of behavior modification, access to HIV treatment and management programs and for decreasing levels of community stigma. The creation of an enabling environment for HIV disclosure holds the potential to form a cycle whereby individuals are more likely to disclose (Norman, 2005). Disclosure is also fundamental in managing HIV especially in terms of adhering to complex treatment regimens. The study will help to better understand the impact of HIV status disclosure on women by exploring the outcomes that they experience. This knowledge can inform program design that increases positive outcomes of disclosure for women. Gender inequity within many communities in Sub-Saharan Africa is at the root of many negative outcomes of disclosure. Some of these negative outcomes of disclosure are fear of being physically assaulted or even being threatened with violence by their partners. Women may also fear abandonment by their partners or even having property taken away from them. This study further aims to document how women are dealing with disclosure in order to gain insights into how to strengthen ongoing counseling and support services so as to encourage and facilitate disclosure.

Disclosure can be a very stressful process because it makes one vulnerable to stigma from family, friends and the community. Stigma has been identified as a barrier to disclosure and access to health care and social support (UNAIDS, 2006). However, the strategies individuals use to negotiate the fear of rejection and isolation have been vastly underreported. The ways each person experiences and copes with the infection is reflected in the choice of whether, how and to whom to disclose their status (Antelman et al, 2001). Describing and analyzing the internal dialogue of pre disclosure and the event of disclosing itself is an essential step in designing effective interventions that will facilitate disclosure among women. This study hopes to explore women's experiences with disclosure. It is envisaged that this will assist in the development of more effective 'screening' tools that counselors can use to identify women least likely to disclose and those most likely to experience negative outcomes as a result of disclosure.

Many studies examining disclosure have been undertaken in developed country settings (WHO, 2004, Antelman et al, 2001, Maman et al, 1999). Considering the prevalence rates of HIV in Sub-Sahara Africa, there is a dearth of research on the complex process of HIV disclosure in the region and in Kenya in particular. Information on women's experiences with HIV status disclosure is still largely anecdotal (UNAIDS, 2006). Research data on disclosure of HIV status to sexual partners is therefore still needed and this study hopes to add to the knowledge gap in this area. In addition, as understanding of disclosure by women and its implications increases, donors, the community, program designers and managers become better placed to support this important work.

## **1.6 SCOPE AND LIMITATIONS**

This aimed at documenting women's experiences with HIV status disclosure. It will be carried out in the Nakuru Provincial General Hospital in Nakuru district. It examined the barriers, outcomes and processes of HIV status disclosure by women to sexual partners. It also identified the support that women need in order to disclose their HIV status to their sexual partners safely.

The study did not include an investigation into the rates at which women disclose their HIV status to their sexual partners. The HIV/AIDS related stigma is also limited the study since some women were reluctant to talk about the disease.

## **1.7 ETHICAL CONSIDERATIONS**

Studying of human behavior raises many ethical issues. The researcher complied with the principle of informed consent to ensure that the subjects knowingly agreed to participate in the research. The Informed Consent explained the nature, purpose and procedures of the interviews and focus groups. Data collected was kept confidential at all times. This was done through the use of pseudonyms and code numbers to conceal the identity of respondents for their safety, dignity and privacy. Confidentiality was therefore protected for all subjects involved in this study. To further protect confidentiality, paper records and audio tapes of recorded interviews and focus groups were kept locked at all times. Only the researcher had access to the tapes or transcripts. Rapport was developed before the study commenced and the researcher was flexible enough to avoid misconceptions.

The researcher also sought government approval at local and national levels to conduct the study.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Introduction**

This chapter is divided into two parts, namely, literature review and theoretical framework. In literature review, an overview of women's experiences with HIV positive status disclosure to sexual partners is presented. The review also addresses the barriers and outcomes of HIV positive status disclosure to sexual partners in addition to the support that women need in order to disclose their HIV positive status to sexual partners without negative consequences. On the other hand, the theoretical framework highlights the theoretical orientation that guided the study.

### **2.2 HIV Status Disclosure: An Overview**

An estimated 38.6 million people were living with the HIV virus by the end of 2005. An estimated 4.1 million became newly infected with HIV and an estimated 2.8 million lost their lives to HIV/AIDS in the same year (UNAIDS, 2006). Stigma and discrimination against people with HIV remains pervasive. Women's social and economic vulnerability and gender inequality lie at the root of their painful experiences in coping with the stigma and discrimination associated with HIV infection. In many countries, being socially ostracized, marginalized and even killed are very real potential consequences of exposing one's HIV status (UNAIDS, 1999). Yet HIV testing is a critical ingredient to receiving treatment. As a result, many women are reluctant to test for HIV and to disclose their HIV positive status even to their husbands. So once infected, women are unable to protect their sexual partners from contracting the virus. For example, in a study undertaken by the United Nations in Africa, in 2006, only 27% of those women who tested for HIV disclosed their status to their sexual partners (UNAIDS, 2006).

HIV infected women experience higher rates of discrimination when compared to men (UNIFEM, 2000). The implication of this is further marginalization of HIV positive women. Women are also reluctant to come forward for testing as well as treatment and support for fear of exposing their status. In 2001, survey conducted in Kenya by the African Union, more than half of the women surveyed who knew that they were HIV

positive, had not disclosed their status to their sexual partners (ECA, 2004). They feared that disclosure would expose them to violence or abandonment. These adverse consequences of disclosure have been documented in other settings. Women who disclose their status are often accused of extra marital affairs and they receive lower levels of support (Maman et al, 1999).

In another study, conducted by the Population Council, in Tanzania in 2001, it was found that disclosure to partners by HIV-positive women though it had increased over time was still significantly less than for HIV-negative women. Only 27% of HIV-positive women, who were tested as individuals, disclosed their results to a partner within six months of being tested. Overall, the major reason for non-disclosure (52%) cited by the women interviewed was fear of the partner's reaction and principally the fear of abuse and abandonment (Population Council, (2001).

Along with these benefits however, HIV-positive status disclosure to sexual partners has a number of potential risks for women. These include loss of economic support, blame, abandonment, physical and emotional abuse, discrimination and disruption of family relationships (WHO, 2004). Consequently, many HIV negative persons are unaware of their partner's status or risky behaviours and may make assumptions that they are not at risk for HIV because their partner looks healthy. In addition, HIV is a condition that is often mistakenly associated with careless sexual behaviour. Research has also shown that people are often more comfortable disclosing to partners outside their main relationship (Maman et al 2001).

Disclosure has a number of public health benefits, such as increasing social support for people who are seropositive, increasing untested partners' awareness of the risk of HIV infection, and increasing the opportunities for risk reduction. Disclosure can also improve access to care and support programs for infected individuals. Promoting HIV disclosure by women however, leads to concerns about negative social outcomes including physical violence and abandonment of women in many settings. Service providers, therefore, need

to address the issue of negative outcomes during counseling while at the same time promoting disclosure which is a big contradiction.

### **2.3 Benefits of HIV Status Disclosure to sexual partners**

In addition to the public health benefits of disclosure that include expanded awareness of risk that may lead to decreased sexual risk-taking and ultimately decreased transmission of HIV, there are also potential benefits to the individual who chooses to share his/her results with her sexual partner. Disclosure of HIV status to sexual partners may first lead to increased opportunities for instrumental and expressive social support (WHO, 2004). Secondly, it may lead to increased access to necessary medical treatment and care. Thirdly, it may lead to increased opportunities to discuss and implement HIV risk reduction with partners and finally it may also lead to increased opportunities to plan for the future carefully and thoughtfully (Antelmann et al, 1999). Disclosure also helps create a sense of closeness in family relationships and helps to reduce feelings of anxiety and isolation. In addition, disclosure helps to build social support networks and relieves the burden of living with the secret of being HIV-positive.

### **2.4 Risks of HIV Status Disclosure to sexual partners**

There is an increasing recognition by researchers who have studied the issue of disclosure that disclosing one's HIV status is an essential part of behaviour modification required to reduce the incidence of HIV (Antelman et al, 1999, Norman et al, 2005, UNAIDS, 2006). However, disclosure can be an extremely stressful process because it makes one vulnerable to stigma by family, friends and community. The individual benefits that women may receive from sharing HIV results with their partners need to be balanced against the potential risks that an individual women may face if she discloses. The potential risks of HIV status disclosure to sexual partners include the loss of economic support, blame, abandonment and physical and emotional abuse. In addition, these women experience discrimination and disruption of family relationships (WHO, 2004).

Another potential risk of disclosure is the possibility that children may face violence or abandonment as a result of their parent's disclosure of the positive status whether or not

the children are also HIV-positive (UNAIDS, 1999). Emotional distress, rupture of relationships, decreased sexual satisfaction, and violence from partners are also potential risks to disclosing HIV status to sexual partners by women. The low rates of HIV disclosure by women has therefore, limited the effectiveness of HIV prevention programs (WHO, 2002a).

## **2.5 Barriers to HIV Status Disclosure to sexual partners**

Women face certain barriers when they want to disclose their HIV status to sexual partners. In a study conducted in Tanzania, 49% of women surveyed reported that their partner was supportive and understanding of their disclosure. However, 10% of them reported blame from their partner, 6.1% reported abandonment and 4.3% reported physical violence (Maman et al, 2003). While the proportion of women experiencing negative outcome of serostatus disclosure in this study was small, some of the negative outcomes these women face can be quite severe. When women attending a VCT clinic in this study were interviewed three months after testing, fear of their partner's reaction was the reason most often cited for not disclosing their HIV status. Fifty two percent of women who did not disclose cited this reason. The reaction that was most feared was the loss of economic support. These women's fears were grounded on experiences they had had with their partner before testing (Maman et al, 2001). These experiences included threats of abandonment and violence and being blamed for bringing HIV into the home. Although the major barrier to disclosure is the fear of negative outcomes, women are in the best position to know when it is best to disclose. While a relatively small proportion of women report negative outcomes in general, this may represent a large absolute number of women as more women learn that they are HIV-positive and disclose their status to their partners.

Although there has generally been an increase in disclosure rates among women, the decision to disclose remains a difficult one for many women. The major barrier most often cited by women on disclosing HIV test results to sexual partners is fear of partner's reaction. Another related barrier to disclosure among women, was the lack of communication with their partner about HIV testing. In a study conducted on voluntary

counseling and testing (VCT) services in Tanzania, it was found that disclosure rate was significantly higher for couples who discussed HIV testing prior to the woman getting tested (Maman et al, 2001).

### **2.5.1 Fear of abandonment**

Fear of abandonment is a major barrier that women face in disclosing their HIV status to their sexual partners. This is closely tied to fear of loss of economic support from a partner. In resource poor settings of developing countries, resources are extremely scarce and women's access to resources independent of their partner is uncommon. It is not surprising, therefore, that fear of losing instrumental support from a partner is a major consideration when deciding whether to share results or not. The absence of social security and health insurance in most African countries also make women dependent on their partner and family for health care. Women may, therefore, choose not to disclose their HIV status in order to benefit from family support (Antelman et al, 2001). Many women also fear abandonment. This is because it also means that their children are also abandoned. This is, therefore, further fuelling the HIV epidemic because women do not feel safe enough to disclose their status to their sexual partners.

### **2.5.2 Fear of rejection/discrimination**

In addition to fearing abandonment and loss of economic support, fear of social isolation and discrimination is another important barrier to disclosure of HIV status by many women. Women fear discrimination and social isolation from family members and from the wider public (UNAIDS, 1998). Fear of discrimination can be further defined as fear of social discrimination leading to social isolation and loss of support and fear of socioeconomic discrimination which may lead to problems with jobs, housing, insurance and other practical socioeconomic considerations. Fear of loss of confidentiality and exposure is also closely tied to the fear of discrimination.

Due to concern over disclosure of HIV-positive results, it is often difficult for HIV-positive women to find one another and establish peer support networks. 'The reason why a man blames a woman is because he is the one who has power over the woman'. This is



a response given by a respondent in a study carried out in Zambia (UNAIDS and WHO, 2000). Women are blamed and shamed as ‘dirty’, ‘immoral’, and ‘misbehaved’ when they disclose HIV seropositivity. As a consequence, they keep quiet and are not able to draw support from each other and from their families.

### **2.5.3 Fear of Violence**

HIV/AIDS and violence are two of the major health problems affecting the lives of millions of women worldwide. (Population Council, 2001). Women who disclose their serostatus to their partners may be at increased risk for violence and that the threat of violence may play a key role in deterring women who wish to disclose their serostatus to their sexual partners. (UNAIDS, 1998).

Violence against women or gender-based violence is any “act that results in or is likely to result in physical, sexual or psychological harm or suffering to women including, threats of such acts, coercion or arbitrary deprivations of liberty, whether occurring in public or private life (UNIFEM, 2000). Male partners may react violently to disclosure of HIV status. Violence is a form of enacted stigma and HIV/AIDS is used to justify violence against women who do disclose their HIV status to their husbands or partners (Maman et al, 2001).

Fear of violence is a major barrier to disclosure for many women. In a study carried out in Tanzania in 2001, 10% of women reported fear of violence as a barrier to HIV status disclosure (Kilewo et al, 2001). In another study carried out in Kenya, 51% of women indicated that the fear of violence was a major barrier to sharing HIV test results. (Rakwar et al , 1999). In yet another study carried out in Burkina Faso in 2001, fear of domestic violence was the only identifiable reason why women chose not to share test results with their partner (Nebie et al, 2001). Women also felt that their husband’s anger was aggravated when they resisted abuse by defending themselves.

Partner violence is, therefore, a serious problem for many women wanting to disclose their HIV status. In a study undertaken in Tanzania in 2001 on disclosure, the researchers

found that if a woman underwent the test without her partner's consent, conflict frequently arose (Maman et al, 2001). In one case, a woman's partner threatened to abandon her if she was tested and found to be HIV-positive.

#### **2.5.4 Fear of upsetting family members**

Concern for others is also another barrier that prevents many women from disclosing their HIV status. Protection of the family from shame, protection of the family from obligation to help, and avoidance of communication about highly personal information are all linked to the fear of upsetting family members (WHO, 2004). The fear of burdening or disappointing others is therefore a major barrier with most women feeling that the family would be shamed. From the study in Tanzania, 17% of the HIV-infected women studied reported that their reason for non-disclosure was the desire to avoid upsetting others (Antelman et al, 2001).

#### **2.6 Negative Outcomes of Disclosure**

Negative outcomes of disclosure, though less common, often include blame, abandonment, anger, violence, stigma and depression. The negative aspects of disclosure are harsher for women because women are more socially and economically vulnerable and often dependent on their partner's economic status. In many instances, women may disclose their status expecting support from their partners but find themselves abandoned (WHO, 2004). Some women encounter rejection and discrimination and stigma. For these reasons, the risk of disclosure of a HIV-positive test result is significant and many women resist disclosing their status to anyone. Gender norms and inequality create the 'enabling' environment for stigma and violence against women who do disclose their status.

In a study carried out in Tanzania in 2001, 56% of a sample of people living with HIV reported experiencing some form of stigma in the past year (Maman et al, 2001). While men also experience stigma, the proportion of women who experience stigma is far higher. This is because the unequal power balance in gender relations favours men even when it comes to outcomes of HIV – positive status. For example, 22% and 15% of men

reported losing social standing, 36% of women and 27% of men reported being teased or insulted. In addition, 42% of women and 32% of men reported being gossiped about while 19% and only 7% of men reported being excluded from social gatherings (Maman et al, 2001). This data shows that more women are more likely to suffer negative outcomes of disclosing their status than men. This is a big hindrance to women who want to get tested for HIV and consequently to disclose their status. 'More often I see it's a woman who is more likely to be ill-treated because a woman has no voice' (Maman et al, 2001: pg18).

In the same study conducted in Tanzania, women reported to experience some severe forms of HIV related stigma from disclosing their HIV status as compared to men. For example, 9% of the women reported being physically assaulted by their spouses as compared to only 1% of the men surveyed. Further, 18% of the women reported being abandoned by their spouses as compared to 7% of the men. A large number of women (49%) reported being threatened with violence by their spouse and 24% had their property taken away as compared to only 3% of the men surveyed (Maman et al, 2001). These severe forms of stigma related to HIV are therefore likely to be experienced by more women as compared to men.

## **2.7 Gender and vulnerability**

Stereotypical gender roles place young women, and to a lesser extent young men, at heightened risk of HIV infection. Young women in many parts of the developing world have little control over how, when and where sex takes place. In perhaps the majority of countries, there are strong pressures on young unmarried women to retain their virginity (UNIFEM, 2000). Consequently, the social pressure to remain a virgin can contribute in a number of ways to the risks of Sexually Transmitted Infections (STIs) and HIV which women face. In some contexts, young women may engage in risky sexual practices, such as anal sex, as means of protecting their virginity. The high social value placed on virginity among unmarried girls may pressure parents and the community to ensure that young women are kept ignorant about sexual matters. Female ignorance of sexual matters

is often viewed as a sign of purity and innocence, while having 'too much' knowledge about sex is a sign of 'easy virtue' (UNAIDS1998).

This emphasis on 'innocence' prevents young women from seeking information about sex or services relating to their sexual health. Sexually active young women are also discouraged from discussing sex too openly with their own partners, since women are encouraged to be ignorant and inexperienced (UNIFEM, 2000). This means that young women are unlikely to communicate their need for safer sex with partners. In Kenya, for example, a study in conducted in Kisumu 1997, revealed that young women felt that they did not have control over their sexuality - instead girls learned that sex was something that happened to them. It was not something they could initiate or actively participate in (Balmer et al, 1997).

In addition to the emphasis widely placed on remaining 'chaste', girls are commonly socialized to be submissive to men. Girls are often pressured by boys to have sex as a proof of love and obedience. Not surprisingly under conflicting pressures, girls have little influence over decision-making or the use of contraception and even on the important matter of disclosure of HIV status to sexual partners (WHO, 2004). Even where sexually active young women are aware of HIV/AIDS and measures to protect against infection, rarely do they have the power to ensure that condoms are used.

While dominant ideologies of femininity promote ignorance, innocence and virginity, dominant versions of masculinity encourage young men to seek sexual experience with a variety of partners (UNIFEM, 2000). In some cultures, boys are actively encouraged by both their peers and family members to use their adolescent years to experiment sexually (WHO, 2002). So while for girls, public disclosure of sexual activity leads to dishonor, bragging about sex is common for boys. Whereas gender norms dictate that girls and women should remain poorly informed about sex and reproduction, young men are expected to be more knowledgeable, often as an indication of their sexual experience (USAID, 2003). Therefore, young women risk their sexual health because they must appear to be ignorant and so cannot openly seek information, young men risk their sexual

health because they must appear to be knowledgeable and so cannot openly seek information either.

The HIV/AIDS epidemic has served to further entrench some gender inequalities and has placed women at increased risk of HIV infection (UNAIDS, 1998). Central among these is the tendency for some older men to seek partners who are less likely to be sexually experienced or, in their eyes, infected by HIV. This places young women at increased risk of becoming infected by older men who may have wide sexual experience (De Bryun, 2005). It is important to recognize that many young women who have HIV infection have had one sexual partner. Furthermore, families affected by HIV/AIDS may seek economic security by marrying off their daughters prematurely to older men (USIAD, 2003). Not only may this have serious implications for the sexual and reproductive health of the young women concerned, it may cut short their education and hold back social development.

Women in sexual relationships find it difficult to know when to disclose their HIV status. It is also important to note that women are at risk of violence when disclosing their HIV status. In sexual relationships, studies show that living with a secret, such as HIV, can be more emotionally harmful than the rejection that could result from disclosure. Many women who have kept a secret for a long time feel a sense of relief after telling. Community based organizations and AIDS clinics can offer resources to guide women through the disclosure process.

## **2.8 THEORETICAL FRAMEWORK**

### **Socialization Theory**

Socialization is the process by which individuals acquire the knowledge, skills and dispositions that enable them to participate as effective members of the society (Brim, 1966). In this process, the individual learns the values, attitudes, norms and other attributes of his culture and the end result is a social being. Socialization starts during childhood and continues through the entire life as people learn everything through the social experience. The assumption behind the socialization theory is that social behavior

is to a large extent governed by societal and cultural rules. Through it, an individual learns the types of interactions that are defined as legitimate and those that are considered illegitimate within his/her group. The individual also learns the positive and negative sanctions that can be brought to bear as a consequence of the actions that he/she takes (Tallman et al, 1983).

The theory also holds that socialization may either take place through direct or indirect means. Direct socialization is the conscious effort to teach manners, values and beliefs that are thought to be appropriate for a particular position. However, it is more likely that socialization takes place indirectly as individuals learn through interactions with each other. This is for example how children learn without any form of formal instruction or teaching.

Through socialization, social identities are formed and in this way individuals learn the expected behaviors associated with a particular social position. This happens when an individual demonstrates the behavioural skills, values, attitudes and feelings associated with that identity. For example women learn their appropriate identity through the socialization process. The identity of the individual, therefore, positions them in the social system (Tallman et al, 1983). The social aspects of identity refer to the broad social categories that are used to distinguish people and to establish behavioral expectations. Gender, religion, status in society, occupation and so on are social identities that distinguish individuals.

There are various agencies of socialization that make it possible for socialization to take place. Agencies of socialization are structured groups or contexts within which significant processes of socialization occur. Socialization can hence be divided into primary and secondary socialization. Primary socialization occurs in infancy and childhood and is the most intense period of cultural learning. During this phase, the family is the main agent of socialization. Secondary socialization takes place later in childhood and continues into maturity. The main agents of socialization during this phase include schools, peer groups, organizations and mass media. All these settings

provide educational experiences to the individual through which behavior and attitudes are influenced. Through socialization, which is a lifelong process, individuals learn how to process information, generate ideas and evaluate the consequences of their actions (Tallman et al, 1983).

The socialization theory however, has some limitations. Human beings are portrayed as mechanical creatures who do not think and reason. They are portrayed as creatures that are consequently not responsible for their actions. This is because all actions are attributed to how one was socialized and therefore, actions are not attributed to individual agency. Further, the socialization theory is too general. It does not account for individual personality development but rather portrays human beings as easily controlled through the socialization process. Additionally, the theory may lead to many conflicts since what is taught in one culture may be totally different from what is taught in another hence leading to unresolved differences and conflict.

The socialization theory was used by Margaret Mead, an anthropologist, to document the socialization process in different societies. This was in the early 1950's. She conducted extensive field studies of early socialization practices in six different societies across the world. She found out that socialization practices varied from one society to another leading to vast differences in what was socially acceptable from one society to another. Secondly, she found out that socialization practices are however, generally similar among people of the same society. Human beings therefore, socialize their children the way they themselves were socialized.

### **2.8.1 RELEVANCE OF THE THEORY**

It is through the process of socialization that girls learn from a tender age what is expected from women in society, including learning about their sexuality. This knowledge is deposited in each woman in the form of schemes of perception, thought and action. Women's experiences with disclosure of HIV positive status is greatly influenced by cultural norms and habits acquired through socialization.

Boys and girls are treated differently from the time they are born and in addition, there are different expectations for them as they mature into adulthood. This gives rise to gender relations where males are seen to be superior and in charge and women as inferior. Boys and girls are consequently treated differently in matters of sexuality. This promotes certain behaviours and self images that recreate the preconceived cultural stereotypes about gender. Since we fit into society as gendered individuals, this has therefore curtailed women's ability to take the leading role in matters of sexuality.

In a man's world there are certain things that are not questioned or talked about – the mistakes, love, hesitations, social failures and weaknesses. These are often associated with femininity. Matters of sexuality and love, therefore, have deep roots in the socialization process. Customs and ideas about sexuality are relevant to women's ability to discuss issues like HIV/AIDS and how to protect themselves and their partners and even to disclose their status once infected. Asymmetrical ideas of men's and women's sexuality hence end up encouraging unsafe sex and hinders access to information and services. There is also a strong belief in men's sexual initiative and women passivity in sexual matters. Men, therefore, do not take an active role in reproductive health issues generally since this is seen to be a woman's responsibility.

The rules that govern society that are learnt through socialization, influence an individual's sexuality. The power relations underlying all sexual interactions favour men over women. Power is fundamental to both sexuality and gender. The unequal power balance in gender relations, therefore, favours men. Men have greater control than women over when, where and how sex takes place. An understanding of individual sexual behaviour, male or female, thus, necessitates an understanding of gender and sexuality as constructed by a complex interplay of social, cultural, economic forces that determine the distribution of power. Research conducted by researchers worldwide has identified the different ways in which the imbalance of power between women and men in gender relations curtails women's sexual autonomy and expands male sexual freedom thereby increasing women's and men's vulnerability to HIV/AIDS (De Bruyn, 2005, Gupta, 2000, Weiss et al, 1998).



Women, due to socialization, are therefore, vulnerable in a number of ways. First, in many societies, there is a culture of silence that surrounds sex. This makes it difficult for women to be informed about risk reduction, and even when informed, makes it impossible for them to be proactive in negotiating for safer sex.

Apart from this, the traditional norm of virginity for unmarried girls that exists in many societies paradoxically, increases women's risk of infection because it restricts their ability to ask for information about sex out of fear that they will be thought to be sexually active.

We may also say that because of the strong norms of virginity and the culture of silence that surrounds sex, accessing treatment services for sexually transmitted diseases can be highly stigmatizing for women.

Furthermore, in many cultures, because motherhood, like virginity, are feminine ideals, using barrier methods or non-penetrative sex as safer sex options presents a significant dilemma for women.

At the same time, women's economic dependency increases vulnerability to HIV. Economic vulnerability makes it more likely that they will exchange sexual favours for money, less likely that they will succeed in negotiating protection and less likely that they will leave a relationship that they perceive to be risky.

Finally, violence against women which is a disturbing form of male power contributes directly and indirectly to women's vulnerability to HIV and the experiences they go through once infected (De Bruyn, 2005, Gupta, 2000, Weiss et al, 1998).

The unequal power balance in gender relations it must be noted, however, also increases male vulnerability to HIV infection.

The vulnerability of women to HIV can therefore, be understood in the broader context of deeply embedded social and gender inequalities which lie at the heart of women's inability to deal effectively with the needs and risks created by the epidemic. Cultural values, rights and attitudes and the needs of women are inevitably intertwined. There are therefore, social and cultural determinants to HIV and AIDS infection among women because they relate to the role of women within relationships, families and communities

which in turn determines the nature and patterns of sexual activity and other patterns that place women at heightened risk for HIV infection. HIV infection is preventable. But powerlessness and dependency strip women of the ability to protect themselves and even to access care and support once infected.

Damaging gender and sexual stereotypes that are learnt through socialization are therefore, at the root of women's vulnerability to HIV and access to and use of treatments. Cultural norms create damaging, even fatal, gender disparities and roles. There is an irresponsible image of male sexuality and the fostering of women as powerless victims in relation to sexuality. Disclosure of HIV-positive status for women is therefore an issue that is pertinent as it is directly related to attitudes and behaviours that are taught through the socialization process. Gender equitable attitudes and behaviours can however, be taught through the socialization process

## **CHAPTER THREE: METHODOLOGY**

### **3.1 Introduction**

This chapter describes the research site, study design, the population and the unit of analysis. The chapter also describes the sample design and sampling procedure. In addition, the chapter explains the methods of data collection and data analysis and problems encountered in the field.

### **3.2 RESEARCH SITE**

This study was carried out in Nakuru town (Municipality) in Nakuru district. Nakuru district is in the Rift Valley Province of Kenya. According to the census figures, Nakuru district had a population of 1,520,005 persons by 2001. Nakuru town (Municipality) has a high population (163,982) because it is the commercial and industrial centre of the entire province. It is also the administrative headquarters for the province. The rapid population growth rate poses major challenges and pressure in the provision of services like water, housing, health and education. Nakuru district is one of the seventeen (17) districts in Rift Valley province. It lies within the great Rift Valley and borders eight other districts namely; Kericho and Bomet to the West, Koibatek and Laikipia to the north, Nyandarua to the east, Narok to the south west and Kajiado and Kiambu to the south (Ministry of Planning and National Development, 2001).

#### **3.2.1 RESEARCH DESIGN**

The study was cross sectional and descriptive. A cross sectional study is a one time, snapshot study where people are interviewed for their perceptions and then you leave. It is a bird's eye view of a problem in a population at a single point in time (Baker, 1999). It is therefore, short. The study was descriptive hence it investigated women's experiences with HIV status disclosure to sexual partners in Nakuru town, Nakuru district. The nature of the data sought was both quantitative and qualitative. Therefore, both quantitative and qualitative methods of data collection were used. Structured interviews, in-depth interviews and focus group discussion were conducted. The Statistical Package for Social Sciences (SPSS) was used to analyze the quantitative data which will then be presented in

tables of frequencies and percentages. The qualitative data was analyzed qualitatively and is presented in verbatim texts and selected comments.

### **3.2.2 THE POPULATION**

Population refers to an entire group of individuals, events or objects having a common observable characteristic (Mugenda and Mugenda., 1999). In this study, the population included all women attending Maternal and Child Health (MCH) services that have been tested for HIV and have disclosed their status to sexual partners in Rift Valley Provincial General Hospital. The unit of analysis was individual women.

## **3.3 SAMPLE DESIGN AND SAMPLING PROCEDURE**

### **3.3.1 Sample Design**

Sampling is the process of selecting a number of individuals for a study in such a way that the individuals selected represent the large group from which they were selected (Mugenda and Mugenda 1999). It takes less time to study a sample than a whole population. Data was collected at Rift Valley Provincial Hospital among women attending MCH services who had already been tested for HIV.

### **3.3.2 Sampling Procedure**

The study targeted women attending Maternal and Child Health (MCH) services who have previously been tested for HIV and attending Maternal and Child Health (MCH) on the particular day (the In-charge of MCH provided this information). Purposive sampling which is a non-probablistic sampling technique was used. Purposive sampling was used in this case because the cases that have the required information with respect to the objectives of the study (women who have tested HIV – positive) was used. The final sample was selected using systematic sampling which is a probabilistic sampling technique. Systematic sampling was therefore used by selecting every Kth sampling unit to determine the sampling interval. Thus every Kth unit was interviewed until the required number of women had been interviewed. ( $K=N/n$ ). These sampling methods were used for the structured interviews.

## **3.4 METHODS OF DATA COLLECTION**

### **3.4.1 PRIMARY DATA COLLECTION SOURCES**

#### **3.4.1.1 Structured Interviews**

In this type of interviews, the interviewer records responses from respondents. Informants were asked to respond to an identical set of questions using a standardized questionnaire (Appendix 1). The interviewer-administered questionnaire had both closed and open-ended questions to allow respondents to provide further details on some of the issues raised. This method was chosen to allow for the quantification of data. The questionnaire consisted of basic socio-economic information and questions related to women's experiences with disclosure of HIV positive status to sexual partners. 50 structured interviews were conducted.

#### **3.4.1.2 Focus Group Discussions**

Focus group discussions are held with groups that are systematically selected according to defined criteria, for example, gender, age, occupation, etc., to discuss a specific topic of interest. The focus groups are limited in size (6-12 people) in order to allow full interviewee participation in the discussion while providing diversity of perceptions and opinions. Focus group discussions stimulate new perspectives and ideas among participants, elicits complementary views and opinions and activates forgotten details (Rudqvist, 1991). They are also economical since they are carried out by few persons during relatively short periods in the field. This method was chosen in order to elicit, confront and mutually check different perceptions and opinions. An interview guide composed of a minimum set of questions was used. (Appendix 2). Focus group discussions allow for verification of information obtained from the structured questionnaires although they do not yield quantitative data. Two focus group discussions were held with the women who were recruited. Each group was composed of 8 women and was tape recorded. The selection of the respondents for the focus group discussions was done through a simple random method among the 50 respondents who had earlier been exposed to the structured interviews.

### **3.4.1.3 In-depth Interviews**

In-depth interviews allow for the discussion of key issues that could be overlooked in the focus group discussions but this time on a one on one basis with the interviewee. They also delve into issues that may be too sensitive to discuss in a group forum. In-depth interviews are also the best format for obtaining individual in-depth reactions to different issues. These issues could be personal or culturally sensitive. In in-depth interviewing, the respondents were therefore, able to express their opinions without any fear. This method was chosen because the data produced is relevant and timely. Confidentiality is also maintained because it is just the interviewer and the respondent present. This is a very key issue when discussing sensitive issues like HIV and AIDS. An interview guide composed of a set of questions was used (Appendix 3). The interviews were recorded through detailed note taking. 8 In-depth interviews were conducted

### **3.4.2 SECONDARY DATA SOURCES**

Documentary materials such as journals, books and articles were used particularly at the formulation stage of the research. Relevant literature on gender dimension of HIV status disclosure were reviewed to provide background information for the study. The results from the study will be used to add to the information already documented by other researchers.

### **3.5 TECHNIQUES OF DATA ANALYSIS**

Since data collected was both quantitative and qualitative, different methods of data analysis were used. Data from focus group discussions and in-depth interviews was organized, summarized, and presented in verbatim quotes and selected comments. Data from structured questionnaires was analyzed quantitatively using Statistical Package for Social Sciences (SPSS) and results presented in tables of frequencies and percentages.

### **3.6 PROBLEMS ENCOUNTERED AND SOLUTIONS USED**

During the study, several problems arose. Some respondents were at first reluctant to be interviewed. To solve this problem, the researcher introduced herself and stated clearly the purpose of the research. The researcher also went through the informed consent

process before interviewing the respondents. The possible respondents were also given a chance to ask questions before they could be interviewed.

## CHAPTER FOUR: DATA PRESENTATION

### 4.1 Introduction

This chapter presents the research findings. The data from questionnaires was analyzed using the Statistical Package for the Social Sciences (SPSS). Data from in depth interviews and focus group discussions is presented in verbatim quotes and reported speech.

### 4.2 Socio-Economic characteristics of the study population

A total of 50 women with ages ranging from 18 years to 44 years (mean 26.12) were involved in the study. 43% of the respondents were between the ages of 21 and 25 years. 20% of the respondents were between the ages of 18 and 20 years and almost a similar number (21%) were between the ages of 26 and 30. In addition, 14% of the respondents were between the ages of 31 and 35 years. Only about 5% of the respondents were aged 40 and above.

Among the respondents, Christianity was the predominant religion (97%). Islam on the other hand accounted for almost 2% of the respondents while the remaining professed to no religion at all or practiced traditional religions. The majority of the respondents were in married relationships (72%) while 15% were single women. Those living with someone accounted for 5% of the respondents while those divorced or separated accounted for 3% of the respondents. The rest were either in committed relationships or widowed.

The majority of the respondents (78%) had between 3 and 5 children while 20% had two children or less. All the respondents had at least one child.

#### 4.2.1 Level of Education

All the respondents interviewed had at least primary education (75%). Those with secondary school education accounted for 23% of the respondents while those with higher education accounted for 2% of the respondents. Table 4.1 shows the distribution of the respondent's level of education



**Table 4.1: Distribution of respondents' level of education**

Education Level	Frequency	Percentage
None	0	0
Primary	75	75
Secondary	23	23
College/University	2	2
Total	100	100

#### 4.2.2 Source of Income

The respondents interviewed were involved in different occupations in order to earn a living. There were varied ways that the respondents earned a living including farming, home makers, day labourers and more formal occupations with salaried incomes. Others were entrepreneurs or owned their own businesses. Those involved in farming accounted for 32% of the respondents while those in entrepreneurial or owned their own businesses accounted for a further 29%. The businesses they were involved in were many and varied including selling second hand clothes and vegetables, retailers of communication services and selling food in informal structures. On the other hand, home makers depended on their spouses for their livelihood and accounted for 12% of the respondents. Those involved in day labour accounted for 5% of the respondents. Those in more formal occupations with salaried incomes accounted for 18% of the respondents and were involved in professions like teaching, civil service or retail shop assistants.

Those earning an income of less than 2000 shillings accounted for 15% of the respondents whereas those earning between 2001 and 4000 shillings were 37%. A further 35% earned a salary of between 5001 and 10000 shillings. Only 13% of the respondents earned more than 10000 shillings. Table 4.2 shows the respondents income distribution per month.

**Table 4.2: Respondents' Monthly Income Distribution in Kenya Shillings**

<b>Income per Month</b>	<b>Frequency</b>	<b>Percentage</b>
Less than 2000	15	15
2001 – 5000	37	37
5001 – 10000	35	35
Over 10000	13	13
Total	100	100

### **4.2.3 Sharing of HIV Test Results**

The respondents involved in the study gave various reasons for being tested for HIV. Top among these reasons was the fact that their partner was sick or had died. 26% of the respondents gave this reason for being tested for HIV. 25% of the respondents however, got tested because they were planning for their future and so they wanted to know their status so as to know how to move forward. A further 18% of the respondents were tested for HIV because of their partner's past sexual behaviours. They felt that this had exposed them to the virus. In addition 12% of the respondents said that they were sick and that is why they had decided to get tested for HIV. Those who were planning to get married and those for whom premarital counseling was required by the church accounted for 2% each of the respondents.

Virtually all the respondents interviewed except one got their HIV test results immediately after being tested. This can be explained that presently all HIV testing is done by rapid test. This means that the results are available after a few minutes and one does not have to wait for days or even weeks to get their results. However every testee has the option not to receive the test results immediately and can request for more time to prepare themselves for the news. The only respondent who did not get her test results immediately decided that she was not yet ready to receive the news and needed further counseling to prepare herself for the results. She came back after 2 weeks to retake the test and this time she was ready.

75% of the respondents interviewed had discussed the decision to get tested with their partner before they went for the HIV test. The other 25 percent decided to get tested without telling their partners. Among those who discussed getting tested with their partners before going for testing, half reported their partner being supportive of them. 8% of the respondents reported that their partners had volunteered to also go for testing. 12% of the respondents reported that their partners had showed no reaction while 4 % reported their partners being sad. 11% of the respondents reported that their partners had blamed them for being HIV positive. 2% reported being physically assaulted on disclosing their test results to their partners while 1% reported being thrown out of the house and the partner leaving the house respectively. Among those who reported adverse reactions from their partners, 60% reported that their partner's reaction had not changed over time.

Among the respondents who did not discuss testing with their partners before they went for testing 62% told their partner their test results while 38% had not told their partner their test results yet. Among those who reported telling their partners their test results only 5% reported them showing support and understanding. 18% of the partners showed no reaction while only 1% felt sad. 15% of respondents reported being physically assaulted by their partners while 8% were thrown out of the house by their partners. A further 10% reported that their partners had left the house while only 4% reported that their partner had panicked. Virtually no respondent reported their partner volunteered to also go for testing. Various other reactions were reported after the respondents told their partners their HIV status.

38% of the respondents reported not telling their partners their HIV test results. Various reasons were given for not doing these. Chief among these reasons was the fear of abandonment on disclosure of HIV test results. Another reason given for not disclosing test results was the fear of rejection/discrimination and the fear of violence. Fear of upsetting family members especially children was another reason given for not disclosing test results to sexual partners. The respondents therefore choose to stay quiet about their HIV positive results until they judged the environment to have improved enough for them to feel safe enough to disclose their status

When asked whom else (apart from their partner) they had told about their HIV positive status, the majority (60%) reported telling their parents. A further 20% reported telling a sibling or a cousin. The reason given for telling family members was that the respondent could access mental and psychological support as well as calling upon them to assist them in carrying out daily chores like baby sitting and cleaning. Surprisingly 10% of the respondents reported telling their employer about their HIV positive status. The reason given for this was that they would need to access some benefits due to their condition. These benefits included insurance cover for themselves and their children if their children were also HIV positive. Another reason given for telling employers their HIV positive status was that they may need to take time off due to illness or to access ART drugs. 5% of the respondents reported telling a friend and a similar number reported telling no one about their status. Those who reported telling no one about their HIV positive status gave the reason that they did not want to be pitied or looked at differently

There were various reactions by partners about the decision of the respondents to get tested for HIV. 32% of the respondents interviewed reported that their partner was supportive of their decision to get tested while 38% reported their partners being unsupportive of their decision to get tested. A further 15% did not care either way while 6% of the respondent's partners advised them to get tested.

On disclosure of HIV test results to sexual partners, 61% of the respondents had told their sexual partner their HIV test results while 38% had not. Among those who had disclosed their HIV test results; various reactions were recorded from the partners on first hearing the HIV test results of the respondents. About half of the respondents reported sexual partners showing support and understanding after disclosing their HIV positive test results. Table 4.3 shows various reactions shown by sexual partners for those who had discussed getting tested with their partners before tested and the reactions of partners for those who had not discussed testing with their partners before getting tested.

**Table 4.3 Partners' Reactions on Hearing About HIV Test Results**

Partners Reactions	Told About Testing Before (%)	Told About Testing After (%)
Showed support and understanding	50	12
Partner volunteered for Testing	8	1
No Reaction	12	18
Felt Sad	4	2
Panicked	8	4
Blamed me	11	18
Physically assaulted me	2	16
Threw me out of the house	1	9
Left the house	1	10
Other Reactions	3	10
Total	100	100

From the above table we can see that discussing getting tested with your partner before you went for HIV testing was likely to yield more positive results. Half (50%) of the respondents who had done this reported their partners showing support and understanding. In comparison, only a negligible 5% of respondents who had not discussed testing with their partner before getting tested reported similar results. 16% of these also reported being physically assaulted by their partners compared to only 2% of the former group. 9% of the latter group were also thrown out of the house as compared to only 1% of the former. Asked whether their partner's reaction (whether positive or negative) changed over time, 65% reported change over time while 35% reported no change at all in their partner's reaction to their HIV positive test results. Among the change of reactions was that the respondents grew closer to their partners, others grew distant while some reported separating over time after their partner knows their HIV positive test results.

Several reasons emerged as to why respondents did not tell their sexual partner's their HIV positive test results. Most of those who did not disclose their HIV test results cited fear of violence as their reason for not disclosing. Fear of abandonment and rejection were the other reasons given for not disclosing HIV positive test results.

An overwhelming 90% of the respondents reported belonging to a support group for people living with HIV/AIDS. They considered these groups to be a lifeline for them. Most of these groups meet at least once a week. In addition the respondents are visited by a community health worker right in their homes whenever they had a problem or needed assistance with anything. In these support group meetings they encourage each other, pray, sing and keep each other updated on services available to assist them for example free drugs, food and counseling services. They also share experiences with coping with stigma. A further 9% of the respondents reported belonging to groups that are income generating. These included 'merry go rounds' or farming projects that are restricted to those living with the HIV virus. Only a negligible 1% of the respondents reported belonging to no group or organization that have regular meetings outside their home

Respondents were unanimous in needing counseling and support services in order to be able to disclose their status to their partners. Most said that they needed some before they could disclose their status. Yet others said that the experiences of people living positively with HIV results were crucial in encouraging them to also disclose their status. From such people, they got useful tips on the process of disclosure in order to minimize negative reactions

## CHAPTER FIVE: DATA INTERPRETATION (IMPLICATIONS OF FINDINGS ON OBJECTIVES)

### 5.1 Introduction

This chapter presents the research findings. Included in this chapter is the interpretation of the data and the implication of the findings on the objectives.

### 5.2 Barriers to HIV Positive Status Disclosure to Sexual Partners

The respondents interviewed in the study identified several barriers regard to disclosure of HIV positive results to sexual partners. Fear of physical violence was the reason most identified by the respondents. Overall 39% of the respondents reported being physically abused by their partner. Those respondents who had not told their partners about their HIV testing were more likely to experience physical violence compared to those who had told their partners that they were going to be tested. One 32 year old woman had tried to discuss testing with her partner and he had reacted very badly'. She said 'Oh, we argued for 3 or 4 months. I told him I am going to test and he said 'What are you sick from?' So I went and told him 'I have already gone and the card is there'. He yelled 'Didn't I tell you don't go there? I am going to leave you'. This woman's experience of trying to raise the issue of disclosure before testing presents a barrier to sharing her results with her husband. A 38 year old respondent reported 'when I informed him about the results, there was endless violence in the house'.

The major perceived barrier to HIV testing for the respondents was fear of a partner's reaction. Several women choose not to inform their partners of their intention to get tested because they feared their reaction. For many of the women who talked to their partner about testing, this discussion was often tense and hostile. The decision to get tested was one that women often fought hard to defend. According to a married 31 year old woman respondent, 'We exchanged words when I was thinking of coming for the test. I was telling him that I was coming to test and he kept refusing. I told him I must go now even if you refuse. He kept asking me 'for what reason are you going to test? Don't go. Why should you go to test'? If a woman underwent a test without the consent of her

partner, conflict often arose. In one case, a woman's partner threatened to abandon her if she was tested and found to be HIV positive.

The tension that was described about the decision to disclose HIV status to a sexual partner was strongly influenced by the extent to which the partner was aware of and involved in the HIV testing experience. Several respondents mentioned the importance of communication prior to testing. Although the ideal would be to talk to a partner before testing, many women could not achieve this ideal. If a woman underwent testing on her own without informing her partner, she risked being blamed as the source of infection. For women who either did not inform their partners they were going to be tested, or whose partners were not supportive of their decision to be tested, HIV serostatus disclosure therefore sometimes led to verbal and even physical abuse. A respondent said 'It took two weeks to tell him. He told me 'you know who has brought it' I told him, 'if you are blaming me then blame me but you are the one who has brought it'.

Fear of abandonment was also another barrier identified as a cause of non-disclosure of HIV positive test results. This is because many of those interviewed were financially dependent on their partner so they did not want to lose their support. This fear of losing economic support from their sexual partner is closely tied to the fear of abandonment by their partner. 52% of the respondents interviewed cited this as their reason for not disclosing their status to their sexual partners. 'He didn't know I came for the test' (Why didn't he know?). 'I don't live with him. I feared annoying him because he is very brutal. If I tell him, he may become brutal. He will decide to leave me and stick to his wife'. Yet another respondent (29 years) said 'he had decided that we get separated but I think it is because of the disease. He wants us to leave each other and me to go away and die'.

All the respondents expressed a fear of rejection or abandonment by their sexual partners as barriers to disclosure. While some women experienced rejection and abandonment from partners, in almost all cases where rejection and abandonment occurred, there were alternative sources of support through family members, support groups. The majority of respondents disclosing their HIV positive status to their sexual partners and other people.



could access support, both materially and emotionally from them. As one respondent stated 'when you yourself are open, you can access the relevant people in order that they can help you access resources'. Another respondent actually claimed that her overall support from her partner had improved.

There was concern about whether a sexual partner will remain in a relationship on disclosure of HIV positive results. HIV positive status disclosure is therefore a test to verify the partner's commitment to a relationship. Emotional concerns were also cited as a barrier to HIV positive status disclosure. These concerns include the fear of emotional abuse which was cited by 56% of the respondent as a barrier to disclosing their status. There was also the fear of being viewed as having had many sexual partners and that was why someone was HIV positive. This view is expressed in society in general.

### **5.3 Outcomes of HIV Positive Status Disclosure to Sexual Partners**

For many of the respondents interviewed, disclosure of HIV positive test results was often associated with less anxiety, fewer symptoms of depression and access to social support services. Positive outcomes of HIV positive status disclosure to sexual partners were also experienced as well as the negative outcomes. Positive outcomes included increased support, acceptance and kindness. Disclosure was also associated with decreased anxiety, strengthening of relationships and increased social support. Disclosure to sexual partners caused the respondents to feel closer to them. Negative outcomes reported included blame, abandonment, anger, violence, stigma and depression. Negative outcomes (particularly abandonment) were a reality for many women who choose to disclose their status to their sexual partners.

Many respondents disclosed their status to their sexual partners expecting some benefit but the expected benefits did not always occur. Some would disclose their status to their partner expecting support but instead find themselves abandoned. Some women encountered rejection and discrimination and were even accused of infidelity. Despite health education messages about HIV/AIDS, sexual partners developed avoidant behaviour with their HIV positive partners. For these reasons, the risk of disclosure of a

HIV positive test result is significant and many women resist disclosing their status to anyone. Only those women who actually felt safe enough to disclose did so.

#### **5.4 Experiences Associated with HIV Positive Status Disclosure to Sexual Partners**

For all respondents, disclosure was not a one-time event but was experienced as a process. They used certain tactics in order to maintain relationships with their sexual partners while at the same time ‘feeling out’ the impact of an HIV positive status would have on their relationships. This reflects the uncertainty about how a partner will react to news about a HIV positive diagnosis. Tactics were also utilized in order to find alternative ways for partners to find out, rather than the respondents having to disclose their status themselves.

Indeed she told her husband she was going to the clinic because she thought she was pregnant. She was trying to find a way to draw him to the clinic (she was not actually pregnant). She wanted someone else to tell him she was HIV positive, not her.

In another case the respondent was in a relationship with a man but did not feel ready to disclose her status to him. She had asked him to be tested but he said that he had been to the clinic and his results were lost. She believed that he was probably ‘in the same boat’ as her and was also afraid to disclose. At the time of the interview she was planning to take him to the clinic so that they could both be tested and that she could then act surprised. For many of the respondents, the negotiation of the disclosure allowed for a certain level of management over one’s status and the ability to make decisions.

Nearly all of the respondents experienced a period of struggle before disclosure and had taken a period of time to disclose to their sexual partners. During this time, some individuals described the guilt of this burden because they had not yet disclosed to their sexual partners. One respondent stated that ‘when you haven’t disclosed, you are always worried’. The daily reality of keeping their status a secret was a very difficult and onerous process. All the respondents interviewed eventually disclosed their HIV positive status to someone (friend, parent, and sibling) even if not their sexual partner. Because

the knowledge of a HIV positive status is too heavy for most, the experience of disclosure was liberating. One respondent described the following:

She told her partner about her status after a month. Before she told him, she was very stressed out, depressed and lost weight even though she was pregnant at the time. After she told her partner, she felt *free*.

For others, not only did the experience of disclosure unburden them, but by disclosing to other HIV positive people, they were able to join a community where this process is shared with people who are going through similarly difficult experiences.

She is a member of the Catholic Church support group. When she began attending, she says that she was very depressed but that when she went and spoke with the other women, she felt *lighter*.

This correlates directly to Paxton's (2002) description of the paradox of coming out openly as an HIV positive person is that by facing AIDS-related stigma, one finds psychological release-liberation from the burden of secrecy and shame. 'The very thing that seems to be the most dangerous to do, openly confronting stigma and facing possible rejection ultimately can be the most liberating' (Paxton, 2002). It is widely accepted that holding back ones feelings results in stress which leads to physical illness. For the respondents in this study, the process of unburdening this weight allowed for both the release of psychological stress and the potential to access social support.

### **5.5 Support Mechanisms Associated with HIV Positive Status Disclosure to Sexual Partners**

Consistently family members were the most supportive group in terms of accessing both material services and emotional support. This is important because satisfaction with social support cushions one against depression and experience psychological well-being. This source of support was essential to the well-being of all the respondents interviewed. Disclosure is also a catalyst for accessing necessary support of ART (Anti Retroviral

Therapy) therapy and Prevention of Mother to Child Transmission (PMTCT) services. In addition key sources of institutional support included NGOs, hospitals and government grants. Support groups were easily accessible and were successful in mitigating some of the psychosocial effects of a HIV positive diagnosis. 'it has provided me with emotional support and a place where I can talk about the daily experiences with this disease'. (Respondent from the Catholic Church Support Group).

Support groups are an essential part of living positively with HIV/AIDS. This is a resource that was accessed by virtually all the respondents interviewed. Some even took a positive leadership role and acted as role models for others. Beyond informal support, disclosure also brought about the opportunity for them to educate others in the community about the disease.

Some respondents mentioned support from friends and family members and other community members such as priests, as a factor that helped them disclose their HIV serostatus. In one case a woman who tested HIV positive tried to encourage her partner to get tested. When he refused, she called upon their priest who counseled him to agree to the test. The priest also helped the woman through the entire process of sharing her HIV results with her partner and also coming to terms with the results.

## CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

### 6.1 Introduction

This chapter concludes the implications of the research findings and gives recommendations on the ways forward so that disclosure of HIV positive test results to partners can be increased.

### 6.2 Conclusion

This study paper indicates that decisions to test for HIV and to share test results with a sexual partner are weighed by considering a number of factors. Women perceive HIV testing as a way to plan for the future. The primary barrier to HIV status disclosure to sexual partners was fear of conflict with their partners. This study shows that women who have communicated with their sexual partners about testing beforehand are significantly more likely to share their HIV test results than women who have not talked to their partners prior to HIV testing. The major reason for non-disclosure was fear of a partner's reaction. Disclosure of HIV positive test results by women to sexual partners is important to both preventing the spread of the disease and enabling persons to access treatment, care and support. It is crucial to increase the ease, safety and acceptability of disclosure of HIV status for women

Fear of abandonment was the major barrier that was mentioned more often by respondents as the reason why they did not disclose their HIV positive status to their sexual partners.

### 6.3 Recommendations

Findings from this study suggest a number of recommendations that could reduce the barriers women face in disclosing their HIV positive status to their sexual partners.

#### **Encourage couple communication about HIV testing.**

The benefits of couple communication about HIV testing are evident from this study's findings. Efforts should therefore be made to highlight these benefits. This may make it easier for couples to get tested together and for individual women to share test results

with their sexual partners. Promotion of couple counseling is an important step to facilitate positive outcomes and minimize negative outcomes. In addition, involving men in the process of HIV testing and counseling of women may help to bypass many of the barriers associated with disclosure and may also facilitate sustained behaviour change among couples due to the fact that men generally have more control over the sexual decision-making within couples. Targeting men and recruiting couples for HIV testing and counseling can only help to increase positive outcomes of HIV positive disclosure to sexual partners.

**Train HIV counselors to ask questions about partner violence and to encourage disclosure of HIV positive test results when appropriate.**

Counseling of clients on disclosure can only be a positive thing for many couples. However, despite an emphasis on counseling, counselors do not ask clients about their experience with partner violence. Counselors have an important role to play in helping clients develop safe disclosure plans. Counselors therefore need to be trained in how to ask sensitive questions about violence and use this information to foster but not force clients to disclose their status to their sexual partners.

Ensuring that clients are the ones to make decisions about partner notification of test results should be encouraged. A client referral approach in which counselor discuss disclosure plans with clients needs to be considered instead of the present approach where there is total silence on this issue.

**Ongoing counseling and HIV support groups**

Repeated opportunities for counseling on disclosure is another strategy that can be used in HIV/VCT programs to try to increase rates of HIV disclosure to sexual partners. Antelman G. (2001) found that the rates of HIV status disclosure to sexual partners increased with the number of times that a health official at the HIV clinic where a person received care discussed the issue of disclosure. At a minimum, raising the issue of disclosure during both pretest and the post-test counseling session is necessary in order to work through the barriers and develop a plan for disclosure to sexual partners. During

the pretest counseling session, the counselor can help the client to think about the potential reaction of the partner, develop answers to potential questions that partners may have and to think about when and under what conditions results will be shared with partners. Pretest counseling can also be used to help clients think about the consequences of failing to disclose including infecting their partners, perinatal transmission and difficulty in accessing medical and social support. During the post-test counseling session, counselors can discuss additional barriers and develop a specific disclosure plan. In situations where ongoing counseling may be an option, the opportunity to continue working with clients after the standard post-test counseling session is important. The development of support groups for infected women provides another avenue for ongoing support that may help women work through their disclosure processes. In addition to providing ongoing emotional support, such groups may provide a supportive environment for those who have already disclosed to share their experiences and strategies with peers, thereby providing a forum for openly discussing fears, benefits, anticipated outcomes, and real outcomes of disclosure.

### **Broader community-based initiatives**

Recognizing that some barriers women face in sharing HIV test results with their partners have their roots in underlying discriminatory gender norms and social attitudes about HIV/AIDS, there is need to address these broader issues. Until the underlying power differentials in gender relations are addressed, the specific problem of HIV and violence will continue. Programs that target young men and boys to promote more equitable relational development are important. These programs can provide young men with strategies for alternative sexual behaviour.

Women's empowerment programs are another means to try to shift gender norms and ultimately facilitate HIV status disclosure to sexual partners. Micro credit programs are another empowerment approach that may enable women to access independent sources of income. Access to resources may provide women with more latitude to challenge male decision-making within their relationships because they are not completely dependent on financial support from their partners. Fear of abandonment and loss of financial support

were the major reasons women cited for not sharing HIV test results with their sexual partners. Therefore, if women have access to independent sources of financial support then fear of financial loss should become less of a barrier to disclosure.

Community based programs to reduce stigma associated with HIV/AIDS is another approach that need to be taken in conjunction with other efforts in order to encourage HIV testing and facilitate HIV status disclosure. Women are often at risk for both HIV and violence because of the behaviour of their sexual partners.

#### **6.4 Areas for Further Research**

More research is needed to identify disclosure factors associated with negative outcomes of disclosure so counseling tools can be developed to identify individuals least likely to disclose and counsel them accordingly. Counseling tools also need to be developed to identify individuals least likely to disclose and counsel them accordingly.

Research similar to this one needs to be conducted to examine the relationship between male and female client's HIV serostatus, the rate of disclosure to partners and the incidence of negative outcomes of serostatus disclosure.



## REFERENCES

- Antelman, G. Smith Fawzi, M.C., Kaaya, S. Mbwambo, J. Msamanga, G.I., Hunter, D.J. (2001) *Predictors of HIV-1 Status Disclosure: A Prospective Study Among HIV-infected Pregnant Women in Dar es Salaam, Tanzania*. AIDS, 15 14:1865 - 1874
- Antelman, G. Smith Fawzi, M.C., Kaaya, S. Mbwambo, J. Msamanga, G.I., Hunter, D.J. (1999) *Factors Related to Disclosure of An HIV-Positive result to a Sexual Partner or any other Confidant in Dar es Salaam, Tanzania*
- Baker, T.L. (1999) *Doing Social Research*, Boston: McGraw-Hill College
- Benard, H. R. 1994. *Research Methods in Anthropology: Qualitative and Quantitative Approaches*. 2<sup>nd</sup> edn. London: Altamira Press
- Brim, O.G. (1966) *Socialization through the Life Cycle*, New York: Willey
- Chesney, Margaret. A. and Smith Ashley, W. (1999) *Critical Delays in HIV Testing and Care; The Potential Role of Stigma*. Am Behav. Scientist 1999; 427: 1162 - 1174
- De Bruyn Maria (2005) *Women, Gender and HIV/AIDS – Where are We Now and Where Are We Going – Hivos*, The Hague,-Netherlands
- Economic Commission for Africa (ECA), (2004) *Gender and HIV/AIDS – Discussion Outcomes*, ECA, Addis Ababa, Ethiopia
- Fleischmann, J (2005) *Strengthening HIV/AIDS Programs for Women: Lessons for US Policy from Zambia and Kenya*. Washington D.C, Center for Strategic and International Studies

Geeta Rao Gupta – Plenary Address XI International AIDS Conference, Durban, South Africa (2000). *Gender, Sexuality, and HIV/AIDS; The What, the Why, and the How*, ICRW, Washington D.C, USA

Maman, S.J. Mbwambo, J. Hogan, N.M., Kilonzo, G.P., Sweat, M.(2001) *Women's Barriers to HIV-Testing and Disclosure: Challenges*. AIDS Care 13(5); 595 – 603

Maman, S.J., Mbwambo. M., Sweat, N., Hogan, T. and Kilonzo, G. (1999) *Women's Barriers to HIV Testing and Disclosure; Challenges for Voluntary Counseling and Testing*. Oral presentation at XI Conference on AIDS and STDs in Africa. Lusaka, Zambia

Ministry of Planning and National Development: Nakuru District Development Plan (1997 – 2001) Government Printer, Nairobi, Kenya

Mugenda, Olive and Mugenda, Abel (1999) *Research Methods: Quantitative and Qualitative Approaches*, Acts Press, Nairobi

Nebie, Y.M.N, Leroy V, Maandebrot L, Seydou Y, Sombie I, Cartoux M, Tienderebevyo S, Dao B, Ouangre A, Nacro B, Fao P, Ky-zerbo O, Vande Pierre P, Dabis F. (2001) *Sexual and Reproductive life of Women Informed of Their HIV Seropositivity; A Prospective Study in Burkina Faso*. JACquir Immune Defic Syndro. 28: 367 – 372

Nyblade, L. and Field, M.L (2000) *Women, Communities and the Prevention of Mother-to-child Transmissions of HIV; Issues and Findings from Community Research in Botswana and Zambia – International Centre for Research on Women (ICRW)*, Washington D.C

Norman, Amy, Chopra Mickey and Kadiyala Suneetha (2005) *HIV Disclosure in South Africa: Enabling the Gateway to Effective Response*, International Food Policy Research Institute, Renewal, Washington D.C

Population Council (2001) *HIV and Partner Violence: Implication for HIV Voluntary Counseling and Testing Programs in Dar es Salaam, Tanzania*, Population Council, Washington, D.C

Rudqvist, Anders (2001) *Fieldwork Methods for Consultations and Popular Participation*, Department of Social Anthropology, Stockholm University

Tallman, I., R. Morotz-Baden and P. Pindas (1983) *Adolescent Socialization in Cross-Cultural Perspective: Planning for Social Change*, New York, Academic Press

UNAIDS. 2006. *Report on the Global AIDS Epidemic. Executive Summary*. UNAIDS Press Service, Geneva, Switzerland

UNAIDS (1999) *Gender and HIV/AIDS: Taking Stock of Research and Programs*. Geneva, Switzerland

UNIFEM (2000) *Progress of the World's Women 2000; UNIFEM Biennial Report*, UNIFEM, New York New York

USAID (2003) *Women's Experiences with HIV Serodiscordance In Africa: Implications for VCT and PMTCT* USAID, Washington, DC

UNAIDS (1998) *AIDS Epidemic Update*, Geneva, Switzerland

UNAIDS and WHO (2000) *Opening Up the HIV/AIDS Epidemic: Guidance on Encouraging Beneficial Disclosure, Ethical Partner Counseling and Appropriate Use of HIV Case Reporting*, Geneva, Switzerland

Weiss, E. and Gupta Rao G. (1998) *Bridging the Gap: Addressing Gender and Sexuality in HIV Prevention*, International Centre for Research on Women, Washington D.C

World Health Organization. 2004. *Gender Dimensions of HIV Status Disclosure to Sexual Partners; Rates, Barriers and Outcomes-A Review Paper*. WHO Publications. Geneva, Switzerland

World Health Organization (2002) *Integrating Gender Perspectives in the Work of WHO – WHO Gender Policy*. Geneva, Switzerland

World Health Organization (2003) *Gender and HIV/AIDS*, Department of Gender and Women's Health, Geneva, Switzerland

World Health Organization (2002a) *World Report on Violence and Health*, Geneva, Switzerland

World Health Organization (2002b) *Integrating Gender into HIV/AIDS Programs – A Review Paper*, Geneva, Switzerland

Zulu, E.M., and Chepngeno Gloria (2003) *Spousal Communication About the Risk of Contracting HIV/AIDS in Rural Malawi*, <http://www.demographic-research.org>

## Appendix 1

### QUESTIONNAIRE FOR STRUCTURED INTERVIEWS

#### INTRODUCTION

Good morning/afternoon. My name is Mary Gichuhi. I am a Master of Arts student from the University of Nairobi. I am undertaking a study for my degree on women's experiences with HIV – positive status disclosure to their sexual partners in this area. I would like to know what barriers and outcomes women experience when they disclose their HIV – positive status to their sexual partners. I would also like to know what support mechanisms, if any, women feel are necessary in order to disclose their HIV – positive status with minimum negative consequences to them. I would be grateful if you agree to answer the following questions. However, you are free to withdraw from the interview if you feel uncomfortable. Taking part in this study is therefore voluntary. All the information that you give will be kept strictly confidential and I am the only person who has access to it. Do you have any questions? Can we go on?

Date of Interview /--/--/2007

Code Number -----

#### A) BACKGROUND QUESTIONS

N	Questions	Responses	Codes	Go to
1	How old are you?	Age	/--/--	
2	What is your marital status	Single, not in relationship In a committed relationship Married Living with someone Divorced/separated Widowed No answer	1 2 3 4 5 6 7	
	<b>READ OUT</b>			
3	Do you have any children?	Yes No	1 0	If 0 – Q6
4	How many children do you have?	Number	/--/--	
5	What is your religion?	None Muslim Catholic	1 2 3	

		Protestant	4	
		Pentecostal	5	
		Other (specify) -----	6	
6	Have you ever been to school?	Yes	1	If 2 –
		No	2	Q8
7	What is the highest level of schooling that you have attained	Primary	1	
		Secondary	2	
		Higher	3	
8	How do you currently earn a living?	Unemployed	1	
		Homemaker	2	
		Student	3	
		Farmer	4	
		Day labor	5	
		Public sector employee (Occupation-----)	6	
		Private sector employee (Occupation-----)	7	
		Entrepreneur/own business	8	
		Other (specify) -----	9	
10	What is your approximate income per month	Below Ksh 2000	1	
		Between Ksh 2000 and 5000	2	
		Between Ksh 5000 and 10000	3	
		Over 10000	4	

#### B) SHARING TEST RESULTS

No	Questions	Responses	Code	Go to
11	What were the main reasons you had for being tested for HIV?	Your past sexual behaviors	1	
		Your partner's past sexual behaviors	2	
		Your partner told you to get tested	3	
		Your partner is sick or died	4	
		Your exposure to HIV at work	5	
		You had a blood transfusion	6	
		You just wanted to know your HIV status	7	
		Your are sick	8	
		Your workplace required testing	9	
		You are planning to get married	10	
		Premarital testing required by church	11	
		You are planning to have children	12	
		You are planning for the future	13	
		Other(specify)-----	14	
		Declined	15	
12	How long did it take you to collect the results after being tested?	Immediately	1	
		Days	2	
		Weeks	3	
		Months	4	
		Years	5	

		Other (specify)-----	6	
13	Did you discuss getting tested with your partner before you went for HIV testing	Yes	1	If no – 15
		No	2	
		Decline	9	
14	How did your partner feel about your decision to go for HIV testing?	Supportive	1	
		Unsupportive	2	
		Did not care either way	3	
		He advised me to test	4	
		Other (specify)-----	5	
		Decline	9	
15	Have you told your partner your test results?	Yes	1	
		No	2	
		NA	9	
16	How did your partner react at first on hearing your HIV-positive test results	Showed support & understanding	1	
		Volunteered for testing	2	
		No reaction	3	
		Felt sad	4	
		Panicked	5	
		Blamed me	6	
		Physically assaulted me	7	
		Threw me out of the house	8	
		Left the house	9	
		Other (specify) -----	10	
		Decline	11	
17	Did your partner's reaction change over time?	Yes	1	If No – 19
		No	2	
18	How has your partner's reaction changed?	-----		
		-----		
		-----		
		-----		
		-----		
		-----		
19	Why did you not tell your partner your HIV test results?	-----		
		-----		
		-----		
		-----		
		-----		
20	Whom else have you told about your HIV positive status?	No one	1	
		Friend	2	
		Sibling/Cousin	3	
		Mother	4	
		Father	5	
		Other (specify) -----	6	
		Decline	7	

- |    |  |  |   |
|----|--|--|---|
| 21 | Do you belong to any groups or organizations that have regular meetings outside of your home? (Multiple responses possible)  | Civic/political<br>Social work/charitable<br>Income generating<br>Credit groups<br>Women's organizations<br>Support groups for PLWHA<br>Religious clubs<br>Other (specify) -----<br>None<br>Declined | 1<br>2<br>3<br>4<br>5<br>6<br>7<br>8<br>9<br>10 |
| 22 | What kind of counseling & support services should be offered to women who have tested HIV – positive to be able to disclose their status to their partners?                            | -----<br>-----<br>-----<br>-----<br>-----<br>-----   |   |
| 23 | What is the best way to promote disclosure of HIV results in your community?   | -----<br>-----<br>-----  |   |
| 24 | Can you think of any <b>positive</b> consequences of disclosing HIV – positive test results to partners ?  | -----<br>-----<br>-----<br>-----   |   |
| 25 | Can you think of any <b>negative</b> consequences of disclosing HIV – positive test results to partners ?  | -----<br>-----<br>-----<br>-----   |   |
| 26 | On a scale of 1-4 can you tell me how much you agree with the following statement: <b>I feel that my marriage or relationship has been harmed because of my HIV – positive status.</b> | 1. Strongly agree<br>2. Agree<br>3. Disagree<br>4. Strongly disagree<br>8. Declined<br>9. Don't Know   |   |
| 27 | What are the problems that HIV – positive women are likely to face after disclosing their status to their partners?  | -----<br>-----<br>-----<br>-----   |   |



## Appendix 2

### INTERVIEW GUIDE FOR FOCUS GROUP DISCUSSIONS

#### INTRODUCTION

Good morning/afternoon. Welcome to this focus group discussion. My name is Mary Gichuhi and I will be your facilitator today. My partner's name is Jane and she is here to help to record the conversation that we will be having. A tape recorder will also be used to record our conversation so as to be able to capture everything said. The tapes from this discussion are only accessible to me. I have asked everyone to choose either a number or a false name to be used during the discussion. Please let me say that anything that is said in this group is confidential. I will not be sharing your answers with anyone, and the recordings of this conversation will not have your names attached to it. You should feel free to say whatever you think. There are no right or wrong answers so please share your point of view even if it differs from what others have said. I am very interested in all your experiences. If you are uncomfortable with a question, you can decide not to answer it. Can we begin?

1. What does your community think about the importance for someone to know if they have HIV/AIDS? Why?
2. Should partners tell each other about their HIV status? (Give reasons for your answer).
3. Should women be encouraged to be open about their HIV – positive status to their partner (s)?  
Why?  
Why not?
4. What, in your opinion, might keep women from telling their partner(s) about their HIV – positive status? (Probe to explain in detail).

5. What were your experiences when you told your partner about your HIV – positive status? (Probe to get details)
6. What might encourage women to tell their partners about their HIV-positive status?
7. Can you think of any negative consequences that you experienced after disclosing your HIV –positive status to your partner(s)?
8. Can you think of any positive consequences that you experienced after disclosing your HIV – positive status to your partner(s)?
9. How should women inform their partner(s) that they are HIV – positive?
10. What would motivate couples to stay together after disclosure of HIV – positive results?
11. Do men and women differ in their experiences if they themselves are HIV – positive? How? Why?
12. What can be done to help reduce the negative reactions women may experience once they disclose HIV – positive status to their partner(s)?
13. What can couples do to help their relationship once the woman has disclosed her HIV – positive status?
14. What kind of counseling and support services should be offered women who test HIV – positive to be able to disclose their status to their partners?

## Appendix 3

### INTERVIEW GUIDE FOR IN-DEPTH INTERVIEWS

#### INTRODUCTION

Good morning/afternoon. My name is Mary Gichuhi. I am a Master of Arts student from the University of Nairobi. I am undertaking a study for my degree on women's experiences with HIV – positive status disclosure to their sexual partners in this area. I would like to know what barriers and outcomes women experience when they disclose their HIV – positive status to their sexual partners. I would also like to know what support mechanisms, if any, women feel are necessary in order to disclose their HIV – positive status without minimum negative consequences to them. I would be grateful if you agree to answer the following questions. However, you are free to withdraw from the interview if you feel uncomfortable. Taking part in this study is therefore voluntary. All the information that you give will be kept strictly confidential and I am the only person who has access to it. Do you have any questions? Can we go on?

1. Is HIV/AIDS a problem in your community? (Yes/No)

Probe for reasons for answer (Why/Why Not?)

2. How does the community view people living with HIV/AIDS?

(Probe to expand on answers)

Why does it have this view?

How does that affect the community?

When do you see these views in daily life?

Where is this evident in your community?

3. When and Why did you decide to get tested for HIV? Probe to find out whether it was strictly voluntary, coerced or mandatory testing.

4. How soon after getting your test results did you share them with your partner? If not yet disclosed, why not?

5. What motivated you to disclose your HIV – positive test results to your partner?  
What is stopping you from disclosing your HIV – positive status to your partner?
6. What, in your opinion would stop a woman from disclosing her HIV – positive status to her partner?

**I'd like you to think about the actual time you disclosed your HIV – positive status to your partner. Take a moment and remember everything you can about it and tell me the whole story. (Clarify any points that come up as the interviewee describes the episode and then ask the following questions)**

6. How did your partner react at first on hearing about your HIV – positive status?
7. Did anything change in your life? What happened?  
If yes, explain what changed
8. Do you attend a support group? If yes, in what way is the group helpful or not helpful?  
If No, why not? In what way do you think you would benefit (or not benefit) from a support group?
9. What more, in your opinion, do you think can be done to help women who wish to disclose their HIV-positive status to their partner(s)?
10. What kind of counseling and support services do you think should be offered to women who test HIV – positive to be able to disclose their status to their partner(s) with minimal negative consequences?