FACTORS INFLUENCING DISCLOSURE OF HIV POSITIVE STATUS TO SPOUSES AMONG PEOPLE LIVING WITH HIV IN KIRINYAGA COUNTY, KENYA

BY

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DECLARATION

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DEDICATION

I dedicate this thesis to my parents, the late Francis Peter (FP) Mwangi and Loise Muthoni Mwangi. They allowed me space to be me and yet were firm enough for me to feel their love and reminded me “In this family we do it this way…not that way”.

ABSTRACT

HIV status disclosure is critical to HIV prevention and access to health care and treatment. Thus disclosing ones HIV positive status to one’s spouse is crucial in HIV prevention. Failure to disclose one's HIV positive status compromises risk reduction and exposes one’s sexual partner(s) or spouse to infection if theyare not already infected.This study investigated factors influencing the disclosure of HIV positive status to a spouse in Kirinyaga County, in Kenya. The study also investigated the role of perceived communication behaviour of a spouse on disclosure, methods of disclosure, challenges in disclosure and preventive behaviours adopted by the people living with HIV (PLWHIV).The Communication Privacy Management theory was used to provide a guiding framework to understand how individuals manage private information. The research adopted a qualitative approach. The sampleconsisted of both male and female PLWHIV attending selected comprehensive care centres (CCC) in Kirinyaga County. Data was collected from a convenience sample of 98 PLWHIV and seven key informants using semi-structured in-depth interviews. The data was analysed using thematic analysis. The study found that disclosure plays an important role in risk reduction and HIV prevention as most PLWHIV who had disclosed their HIV positive status to their spouses found it easier to discuss HIV prevention and safe sex practices with their spouses. The study found that perceived spousal communication behaviours influenced the decision to disclose or conceal a HIV positive status. The study concludes that disclosure is influenced by different factors which either result in the PLWHIV loosening control of their privacy boundaries and disclosing or tightening control and concealing their HIV positive status. The study recommends that couples should be encouraged to test together thus easing the process of disclosure. It also recommendsincreasing couple communication where couples can increase openness with each other especially in HIV disclosure. A key contribution of this study is the role of spousal communication in disclosure.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CBO	Community Based Organization
CCC	Comprehensive Care Centre
CDC	Centre for Disease Control
CHCT	Couple HIV Counselling and Testing
CL	Comparison Level
CPM	Communication Privacy Management
CSWS	Commercial Sex Workers
HCT	HIV Counselling and Testing
CVCT	Couple Voluntary Counselling and Testing
DASCO	District AIDS and STI’s Coordinator
FBO	Faith Based Organization
FHI	Family Health International
FP	Family Planning
GOK	Government of Kenya
HIV	Human Immune Virus
HTC	HIV Testing and Counselling
IDI	In-depth Interview
KAIS	Kenya AIDS Indicator Survey
KECCS	Kenya Episcopal Conference Catholic Secretariat

KDHS	Kenya Demographic Health Survey
KI	Key Informant
MARPS	Most at Risk Populations
MOH	Ministry of Health
MSM	Men Who Have Sex with Men
NACC	National AIDS Control Council
NASCOP	National AIDS and STD Control Program (Kenya)
OI	Opportunistic Infection
PLWHIV	Person Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
PSI	Population Services International
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIVand AIDS
UNDP	United Nations Development Programme
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

OPERATIONAL DEFINITION OF TERMS

Disclosure refers to a PLWHIV making a decision to reveal their HIV positive status to their spouse. I will use the definition provided by Pearson, Nelson, Titsworth and Harter (2003, p.187). They define self-disclosure as, "the process of making intentional revelations about oneself that others would be unlikely to know and that generally constitute private, sensitive or confidential information".

Spouse refers to people who self-reported as being married or cohabiting.

Private Information refersto the content of what is disclosed (Petronio, 2002, p.5).

CHAPTER ONE: INTRODUCTION

1.0 Overview

This chapter provides background information to the study. It looks at the statement of the problem, research questions, study assumptions and rationale. It also describes the theoretical framework that provides a guide in understanding the interpersonal communication aspect of disclosure to spouses.

1.1 Background Information

HIV/AIDS continue to exact an enormous toll on social and economic development in several countries in the world. According to UNAIDS (2014), in 2013 there were 35 million people living with HIV (PLWHIV) globally with 2.1 million people newly infected with HIV. In the sub-Saharan region there were 24.7 million PLWHIV in 2013 and 1.5 million new HIV infections accounting for 70% of the global total of new infections.

The disease remains a major challenge in Kenya. The first identified case of HIV/AIDS in Kenya was recorded in 1984. In 1999, the government of Kenya declared HIV epidemic a natural disaster. According to NACC and NASCOP (2012) by December, 2011, there were 1.6 million people living with HIV in Kenya (KAIS 11, 2012). Different strategies have been put in place to try and combat the spread of HIV/AIDS in Kenya as in other parts of the world. One of the most acclaimed HIV prevention strategies by experts in the HIV/AIDS field has been CT (Counselling and testing). Whereas, there have been variations in this strategy from Integrated VCT (voluntary counselling and testing), Stand-alone VCT, Moonlight VCT, Provider Initiated Counselling and Testing (PITC), Prevention of mother to child transmission testing

(PMTCT), diagnostic testing, and the Home Based counselling and testing. The key emphasis has been knowledge of one's HIV status and adoption of preventive behaviours.

UNAIDS (2000), argues that knowledge of serostatus through Voluntary counselling and testing (VCT) can be a motivating force for HIV positive and HIV negative people alike to adopt safer sexual behaviour. This would enable seropositive individuals to prevent their sexual partners from getting infected and those who test seronegative to remain negative. According to KAIS (2012, p.xx) 46.9% of adults aged 15-64 years knew their HIV status among HIV infected persons.

The nature of the HIV epidemic is changing thus calling for new strategies. Most prevention programmes in sub-Saharan Africa have targeted what has traditionally been referred to as "high risk" populations. These include: commercial sex workers (CSWs), truck drivers, injecting drug users (Singhal and Rogers, 2003, p.166). Recently, this population has added to it men who have sex with men (MSM). Some of the interventions include free or subsidized condoms, health clinic for STIs and counselling and testing (Singhal and Rogers, ibid. p.165). Spouses have not "traditionally" been seen as a "risk population" since what has been viewed as "high risk" is sex outside the marital union (KAIS 2007, p.18). Zulu and Chepngeno (2003) observe that most preventive strategies emphasize abstaining from sex or using condoms. They argue that these are appropriate strategies for individuals to avoid infection outside marriage but are not perceived by couples to be appropriate within marriage.

Once the epidemic went beyond such core groups to become generalized, many new infections were likely to take place through ordinary conjugal relations (Zulu and Chepngeno, ibid.). Yet even today in countries with high prevalence of HIV, married couples are rarely the primary target of HIV prevention programs. Cleland, Ali and Shah (2006, p.19) observe that studies on young single people have been numerous. “However, the needs of the married population have been neglected by researchers and program staff alike, despite the fact that more than half of HIV infections in the severe epidemic of Southern and East Africa occur in this group” (Hugonnet et al. 2002, as cited in Cleland, ibid.). In Kenya, about two thirds of HIV infected adults report currently being in a union (KAIS, 2007).

Another key element related to the issue of HIV/AIDS is that of discordant couples where one partner is HIV positive and the other is negative. HIV prevalence is increasing especially among the married couples and hence, “marital status is an important risk factor when explaining patterns of HIV transmission” (KAIS, 2007, p. 17). Zulu and Chepngeno (2003) note that, sexually active men who have never been in a union had a prevalence of 2.8 % compared to 7.4 % among men currently in a union. How then do married individuals protect themselves from infection by their own spouses?

Serovich (2001), notes that with advanced therapies, individuals are living longer and healthy without the outward physical manifestations of the HIV/AIDS. This makes it almost impossible for one to know a partner’s HIV status unless they disclose it or until it is too late and the spouse may already be infected. This brings forth the importance of disclosure among spouses.

The importance of disclosure of one’s HIV positive status to a sexual partner(s) is well documented. Disclosure would enable individuals to make informed choices to prevent further infections and protect unborn babies. Whitfield (1998) notes that self-disclosure enables individuals to deal with issues of reducing transmission and obtaining support.

Marks, Richardson and Maldonado (1991, as cited in Serovich 2001) state that "disclosure to at risk partners permits them to play a greater role in either allowing or not allowing unsafe sexual or drug sharing behaviour to occur and hence disclosure could be a pivotal factor in reducing behaviours that continue the spread of HIV".

Self-disclosure is defined as, "the process of making intentional revelations about oneself that others would be unlikely to know and that generally constitute private, sensitive or confidential information" (Pearson, Nelson, Titsworth&Harter, 2003, p.187). The concept of self-disclosure is addressed in greater detail later. It is one of the fundamental ways of making one's information known to others. It consists of information that is intentionally revealed to another person. It goes beyond telling another person about information that is obvious or that is in the public knowledge for instance our obvious physical features. Self-disclosure involves revealing information that touches on sensitive and private issues such as our deepest fears, feelings and values.

After a diagnosis, individuals infected with HIV are faced with the decision of whether to disclose or conceal their HIV status. Self-disclosure is a difficult task that creates both vulnerabilities and opportunities. Disclosing private information makes one vulnerable since information about one's HIV positive status is highly risky. Self-disclosure on the other hand creates opportunities in terms of accessing health care, social and psychological support for the PLWHIV and their family. It may also prevent further transmission of the virus to sexual partners by practicing safer sex behaviours. Therefore, while disclosure may create opportunities for care and support, it may also put the infected person at the risk of stigmatization and discrimination. This may be rejection, isolation by spouse, friends and family and loss of job or income. The fear of being stigmatized, the feelings of shame and guilt among others feed a culture of silence and secrecy about one's HIV positive status.

This study investigates factors that facilitate or hinder disclosure of a HIV positive status to one's spouse. It also looks at whether perceived communication behaviours of a spouse influence disclosure and the challenges faced in disclosing and how they can be overcome. It also makes recommendations on how disclosure can be increased among spouses as a preventive strategy in HIV/AIDS.

1.1.1 HIV/AIDS in Kirinyaga County

The HIV prevalence rate in Kenya is at 5.6% and 4.0 in Kirinyaga County (KAIS, 2012). Like other areas in the country, HIV/AIDS in Kirinyaga has far reaching socio-economic effects. It has led to a high number of HIV/AIDS orphans, loss of family income, high school dropout rates, female and children headed families, loss of manpower, high mortality and morbidity rates (Kirinyaga District Strategic Plan 2005-2010, p.8). The document gives the main method of HIV transmission as unsafe sexual behaviours. Other factors associated with HIV/AIDS transmission include drug abuse especially illicit brew, high levels of peer pressure, ignorance of facts and family breakdown.

Kirinyaga County had 14,557 PLWHIV by the end of December 2011 with 13,077 being adults and 1,480 children (NACC (2016). The spread of HIV/AIDS has often been linked with poverty among other factors. Kirinyaga County is given as the poorest in Central Province with 35.6 per cent of its total population living below the poverty line and 20.64% being described as hard core poor (Kirinyaga District strategic plan 2005-2010). The poorest is indicated as Mwea followed by Kirinyaga West. The Kirinyaga District Plan (ibid.) identifies the HIV/AIDS pandemic as one of the causes of poverty.

Other factors given include; low productivity, poor prices from the sale of farm produce, poor infrastructure, inadequate land, exploitation by middlemen, collapse of cooperative societies, consumption of illicit brews and high costs of farm inputs.

The highest prevalence rates are in the urban and peri-urban centres (see chapter 3) which are mainly agricultural produce markets and commercial centres. According to the Kirinyaga Strategic Plan (2005-2010), about 72% of the total population is engaged in agriculture activities with the rest in commercial and public sectors.

1.2 Statement of the Problem

HIV/AIDS is a major health and development problem in Kenya and other developing countries. About 6.2% of adults between the ages of 15-49 were living with HIV as of December 2011 accounting for about 1.6million Kenyans living with HIV (NACC & NASCOP, 2012, p.2). According to NACC and NSCOP (2012, p.xiii) “the AIDS epidemic has evolved to be one of the central impediments to national health, well-being and development. AIDS has deepened poverty, slowed economic growth, reduced life expectancy and worsened other infectious diseases.”

In Kenya sexual transmission accounts for 93% of new HIV infections with heterosexual sex representing 77% of the infections (NACC &NASCOP 2012, p. 2). Kenya has what is referred to as a generalized epidemic where HIV has spread beyond key populations to affect the whole society. NACC and NASCOP (ibid.) reports that adults in stable seemingly low-risk relationships make up the largest share of new infections.According to KAIS (2012, p.8), heterosexual sex within a union or regular partner accounts for 44.1% of new HIV infections.Yet these groups are rarely the target of HIV prevention programs, most of which focus on condom use and being faithful to one partner and hardly if at all focus on the role of spousal communication in HIV prevention. This is a gap that this study hopes to address.

Studies suggest that “cohabiting couples are at the largest risk group for HIV infection and are experiencing most new infections” (Allen et al. 1991; 1992; Hugonet et al. 2002 as cited in Cleland et al. 2006; Dunkle et al. 2008). NACC and NASCOP (2012, p.2) states “that the number of new infections remains unacceptably high with an estimated 104,137 Kenyans becoming infected in 2011”. NACC and NASCOP (ibid.) observesthat heterosexual sex accounts for 77% of new infections and those adults in stable seemingly low risk heterosexual relationships make up the largest share of new HIV infections. According to KAIS (2007. p.17), “marital status is an important risk factor when explaining patterns of HIV transmission”.

According to KAIS (2012, p.xx) among married or cohabiting partnerships, 4.8% were HIV sero-discordant where one partner is HIV infected and the other is not. This is a high rate of discordance exposing the uninfected partner to risk of infection. Were et al. (2008) indicate that “these couples provide a significant opportunity to impact HIV transmission since in the absence of prevention intervention, 17% of HIV negative partners will seroconvert within 12 months compared to 6% when safer sexual practices are practiced”. Despite these factors, heterosexual cohabiting couples are rarely the focus of HIV prevention efforts (Chiao, Mishra and Ksobiech 2009, p.1). Also NACC (HIV AND AIDS Profile: Kirinyaga County) notes that 73% of those testing for HIV in Kirinyaga County delayed before joining a care and treatment program hence exposing the spouse to risk of HIV infection if not infected.

How then do we protect the uninfected partner? There is need to continue encouraging people to go for counselling and testing (CT) which helps them know their status and hopefully reduce risky behaviour. “The fact that there are twice as many couples that are discordant as couples that are both infected poses an unmet HIV prevention need since the vast majority of these couples do not mutually know their status” (Marum et al. 2003, p.230). The prevalence of discordant couples calls for the need for disclosure as part of HIV prevention. I am convinced by Greene, Parrot and Serovich (1993, as cited in Petronio, 2002, p.217) that “one of the more problematic concerns relates to the unwillingness of infected people to disclose their status even to partners”. I concur with Kalichman and Nachmias (1999, as cited in Sowell, Seals, Phillips & Julious, 2003), that disclosing one’s HIV status to a sexual partner is essential in stopping the spread of HIV infection. Serovich and Mosack (2003, p.2) note that “disclosure of HIV status is important because it permits the partners to be included in the decision making process in either allowing or not allowing unsafe behaviour to occur.”

It is evident from the literature reviewed that disclosure of HIV test results is an important prevention tool. Disclosure of HIV status to sexual partners is an important prevention goal emphasized by WHO (World Health Organization) and CDC (Centre for Disease Control) in HIV testing and counselling (Medley, Moreno, McGill & Maman 2004). As noted earlier, disclosing information about one’s positive status reduces the chances of infecting sexual partners, mother to child transmission and also provides access to medical, psychological and social support. However, it also puts one at risk of stigmatization and discrimination which may drive the infected person to avoid disclosure. HIV positive individuals’ failure to disclose their HIV positive status to their marital partners is a significant factor in the continued spread of HIV as the uninfected partner is exposed to risk. Non-disclosure thus greatly contributes to the spread of HIV and thus constitutes a major barrier to HIV prevention and care efforts and yet it provides the individual with “protection” from HIV related stigma. We need to find ways to break the silence by looking into ways of facilitating for disclosure among spouses. Once the challenges to disclosure are better understood, then recommendations can be made on how to overcome them, facilitate and increase disclosure between spouses.

Although disclosure of HIV sero-status remains an important tool for prevention of new infections and early treatment for HIV positive individuals’ regular sexual partner, studies indicate that many individuals infected with the virus and know their HIV status do not disclose this information to their sexual partners. Kalichman (2000) explains that “as many as one in three PLWHIV engage in unprotected intercourse subsequent to knowing that they have HIV and that continued risk behaviour often occurs with uninfected partners”. This puts their partners at risk of HIV infection and themselves at the risk of re-infection (Stein, Freedberg, Hingson & Samet 1998; Whitfield, 1998).

KAIS (2012) indicates that 65.4% of HIV infected Kenyans who had one or more sexual partners in the last twelve months had disclosed their HIV status to their partner, however 46.4% of them reported not knowing the HIV status of their most recent sexual partner. Temmerman et al. (1990, as cited in Cabrera, Pitt & Staugard, 1996), say that in a study carried out in Nairobi, only 37% of seropositive women who had been counselled in a maternity hospital and advised to tell their partners claimed to have informed them. However, only two of them demonstrated that they had done so by returning with their partners for further counselling.

Also many individuals are not routinely using condoms and other preventive measures to prevent spreading the virus, which points to the need for more efforts aimed at protecting uninfected partners by encouraging disclosure of HIV positive status (Stein et al., ibid.). According to KAIS (2012, p.xx) condom use with sexual partners of unknown HIV status in the last twelve months was low, highest among casual and other partners and lowest among married and cohabiting partners at 2.5% among women and 3.4% among men. This inevitably exposes the partner at risk of HIV infection. In the public health domain there is great interest in finding strategies that can encourage and increase disclosure of HIV positive status. Hence, this study focuses on factors that facilitate and those that hinder disclosure of HIV status.

The importance of spousal communication is often emphasized in FP programs. Several studies indicate that the amount of communication that occurs between partners is positively associated with contraceptive use (Sharan and Valente, 2003; & Bawah, 2002). FHI (2002) notes that "when partners talk, behaviour may change". They add that, "Research suggests that partner communication helps couples improve their reproductive health and that many men and women fail to protect themselves against unplanned pregnancy, STIs including HIV/AIDS in part because they find it difficult if not impossible to discuss with their partner subjects related to sexuality". This resulted in communication interventions designed to target the spousal unit and facilitate communication between couples on FP. Very few studies have paid attention to the role spousal communication plays in HIV positive status disclosure. If spousal communication can increase FP use, then probably it can also help individuals disclose their HIV status to their spouses.

Badr and Taylor (2005, p.674) suggest that couples may overcome conflict and cope with a disease by engaging in open, supportive communication. They observed that engaging in relationship talk helped to reduce social constraints and improve cancer related communication. In addition, couples may benefit from interventions that include a communication component that addresses both the patient's and spouse's needs. Despite the role that spousal communication may play in influencing HIV/AIDS related behaviours, this subject has not received much attention in research in the Kenyan context and none to the best of my knowledge in Kirinyaga County.

In Kenya, the current USAID supported campaign implemented by Population Services International (PSI) on "*mpango wa kando"* (lit: a side arrangement (stay faithful to your partner) is one such effort towards increasing spousal communication on fidelity. However, one may remain faithful but to an already infected partner. A woman seeking advice in a local daily says:

> I…recently discovered that my husband is HIV positive but has kept it from me…I am depressed by the fact that this man knew he was sick but continued to take medication without bothering to share his status with me…(My dilemma, *Daily Nation*, July 20, 2005).

The woman here is expressing her frustration and anger at her husband for not disclosing his status despite knowing he is HIV positive as evidenced by taking medication. The husband had in essence exposed her to HIV infection.

As we saw earlier, the major driver of HIV transmission in Kenya is through heterosexual sex among other modes. Despite heterosexual sex within unions and regular partners being the main mode of transmission of HIV in Kenya, studies addressing factors influencing disclosure and non-disclosure of HIV positive status among spouses especially in rural parts of Kenya and using a theoretical framework are limited. This point to a gap in the studies and programs interventions used in the campaign against HIV/AIDS. This study attempts to fill this gap by investigating factors influencing disclosure and non-disclosure of HIV positive status among PLWHIV to their spouses in Kirinyaga County.

Understanding factors that influence disclosure decisions is significant to HIV/AIDS prevention programs. It is the contention of this study that there is need for research and programs on communication among spouses about their HIV status. It is also important to understand what are the barriers to couple communication on disclosure of HIV positive results and how can we overcome them? What strategies can be used to improve or facilitate spousal communication on disclosure of HIV positive results? In the light of these arguments, this study endeavoured to answer the following pertinent questions:

1.3 Research Questions

1. What motivates PLWHIV who disclose and what deters those who do not disclose their HIV positive status to their spouse?
2. How does the perceived communication behaviour of a spouse influence disclosure?
3. What methods are used to disclose and what challenges are faced by PLWHIV in disclosure of HIV positive status to their spouse?
4. What HIV preventive behaviours do PLWHIV adopt to protect their spouse?

1.4 Rationale

In Kenya, efforts have continuously increased in HIV/AIDS prevention, care and support by different government and non-governmental agencies. As already noted, about 1.6 million people are living with HIV in Kenya (NACC & NASCOP, 2012). This is a problem of concern not only to health care providers whose capacity to provide care and support is overstretched; but also a major economic strain to governments especially in developing countries like Kenya. NACC and NASCOP (ibid. p2) states that, "AIDS remains one of the impediments to national health, development and wellbeing. The problem is more acute in rural areas with fewer facilities and health care providers. Hence, the importance of research focusing on disclosure between spouses to avoid or reduce new infections to partners who are not infected and also for the infected to access care and support.

As seen earlier, the major channel of HIV transmission is through heterosexual sex. There is thus need to address the spousal unit as an intervention for prevention in HIV/AIDS programs. The study focuses on self-disclosure as a specific communication concern due to its important role in the fight against HIV/AIDS. Disclosure may occur in various contexts, for instance in parent-child relationships, spouse-spouse, counsellor-client or patient and health worker. Individuals may also disclose to their non-primary partners or significant others such as parent or sibling. This study focuses on disclosure of one's HIV positive status to a spouse due to the significant potential of HIV transmission occurring in this setting if the infected individual does not disclose to their spouse.

The study aims to understand how we can help PLWHIV increase disclosure to their spouses as a preventive measure in HIV/AIDS. The findings of this study contribute to the knowledge base for future researchers, program planners and policy makers in the area of HIV/AIDS especially on how disclosure of HIV positive status among spouses can be increased. The study is also beneficial to students of communication especially those interested in the area of self-disclosure.

Since there is no cure for HIV/AIDS, prevention is the best option we have for tackling HIV/AIDS. There are measures that can be taken to reduce new infections and re-infection and also help those infected access treatment, care and support. These measures include disclosing one’s positive status to their spouse. Self-disclosure can be an important tool in HIV prevention, care and support hence an important area of study.

1.5 Scope and Limitations

The study was carried out in Kirinyaga County, Kenya among men and women who are HIV positive. This is a qualitative study focusing on disclosure in which an individual reveals private information about their HIV positive status to their spouses. This study addresses itself on disclosure that is intentionally done by thePLWHIV. Private information has an owner and a recipient. In this study the PLWHIV is the owner and has control over the HIV positive status information which they can choose to either conceal or reveal to their spouse. I limitedmyself to the disclosing spouse and not the recipient. The term spouse in this study refers to people who self-reported as being married or cohabiting. Self-disclosure may involve disclosing information about different aspects of the individual. It could be about past sexual experiences, sexual abuse, rape or a traumatic experience. This study however, focuses on the disclosure of HIV positive status to one’s spouse.

Disclosure may occur in many possible arenas. One may disclose to family members, to a sexual partner(s), to children, to an employer or even to a health care provider. This study limits itself to spouses, as the main method of HIV transmission in Kenya is through heterosexual sex (KAIS, 2012; NACC & NASCOP 2012).

HIV/AIDS is a complex issue that has socio-economic and cultural dimensions such as poverty, cultural beliefs and gender disparities. I am also aware that addressing self-disclosure alone would not solve the problem as it may require addressing the cultural and economic issues involved. These include cultural values, beliefs and stigma that propagate the HIV/AIDS epidemic that are beyond the scope of this study. However, these factors will be referred to in the study where necessary.

A limitation of this study is the sensitive nature of the subject matter. The subject of one's HIV positive status is not often openly talked about unless one has disclosed their status to others or it is in the public domain. Even some who have disclosed to their partnersmay not want their HIV status known beyond the spousal boundary. This was a big challenge in getting respondents for the study. I worked with HCT providers and assured the respondents of confidentiality and obtained consent for participation after explaining the nature and purpose of the study. Their names are not used in the study to protect their identity.

Another limitation of this study is the fact that the study focused on PLWHIV in Kirinyaga County and the study results cannot be generalised beyond the County. However, the results can be significant to other PLWHIV who share similar experiences and find themselves in a similar predicament of having to choose either to disclose or conceal their HIV positive status and facing the consequences of either choice. I concur with FHI (2005) that in certain studies such as this one depth takes precedence over eliciting data that can be generalized.

Another limitation is that this study was based on self-reporting of the PLWHIV and I did not confirm with their partner whether this disclosure really happened. The study is that it only interviewed disclosing partner and not the recipient spouse. In some cases, I felt that it might have been helpful if I had spoken to the recipient spouse especially in the area of spousal communication. I had a moral and ethical obligation to keep the PLWHIV identity confidential especially for those who have not disclosed to their spouse. The idea of involving the spouse would have breached our agreement with the PLWHIV. This may be an area for further research to interview both disclosing and the recipient spouse as the dynamics might be different.

Another challenge faced was that of interviewing people who had either had just come from seeing the doctor and were in a rush to go home or engage in other activities. The physical and mental preparedness of some PLWHIV was a challenge. We gave the respondents one hundred Kenya Shillings for transport cost which was appreciated. We had one participant who could not continue with the interview as they felt too weak during the interview and thus it was discontinued.

Funding was a major limitation since the study was self-funded. For instance, the daily transport allowance for the research assistants had to be frequently supplemented in areas which were difficult to access and it costed them a lot more than earlier planned.

1.6 Research Assumptions

The study assumes that:

1. Individuals who perceive high risks of disclosure are less likely to disclose their HIV positive status to their spouses.

2. Individuals who perceive their spouses to exhibit supportive communication behaviours are more likely to disclose their HIV positive status to their spouses.

3. Most PLWHIV disclose their HIV positive status to their spouse directly.

4. Disclosing HIV positive status to a spouse results in adopting safer sex behaviours.

1.7 Theoretical Framework

This study uses the Communication Privacy Management theory (CPM) as outlined by Petronio (2002) to help the researcher understand the data collected. Whereas there are other theories of disclosure, they do not cover key communication aspects of disclosure which CPM covers thus the choice of this theoretical framework. The theory is a practical approach that was found appropriate in the researcher's endeavour to understand the way individuals deal with revealing (disclosure) and concealing (non-disclosure) of private information. The theory helpsthe researcher to understand how PLWHIV manage disclosure or non-disclosure of their HIV-positive status to their spouse.

The theory provides a framework to address issues of privacy and disclosure. In making a decision on whether to tell or not to tell private information such as one's HIV positive status, individuals make choices whether to reveal and let others know about it or conceal it and keep it to themselves. Both disclosure and privacy entail risks and benefits. Petronio (2002, p.2) argues that revealing is necessary yet people value privacy, both of which are important to maintain.

CPM provides a rule based system to examine the way people make decisions about managing disclosure and privacy. The theory makes assumptions that individuals make this decision based on certain criteria and conditions, that privacy and disclosure are dialectical and that individuals believe that they have a right to own and regulate access to their private information.

CPM focuses not just on the disclosing individual but also on the recipients of disclosure who can also influence the decision of whether an individual will disclose or not. Although the main focus of this study is on the discloser (PLWHIV), it is also interested in the role that the spouse communication plays in disclosure. CPM proposes five suppositions and a rule management system for privacy management. The theoretical model is presented in figure 2.1.

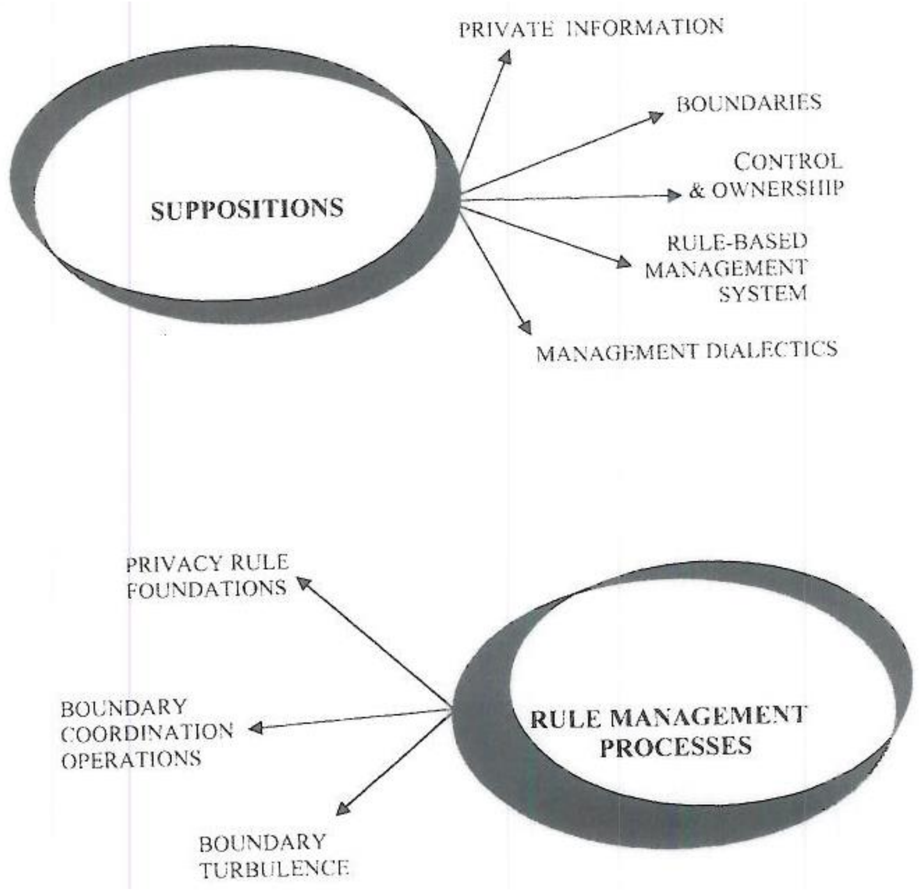

Figure 1.1: Overview of Communication Privacy Management Theory

Source: Petronio, 2002:4.

1.7.1 Theoretical suppositions

CPM makes five suppositions. I will briefly look at each one of them below.

Supposition 1: private information

Private information refers “to the content of what is disclosed” (Petronio, 2002, p.5). Each individual has information that they consider private. Private disclosure is “the process of telling or revealing the contents of private information about others and us. Individuals may reveal private information for various reasons. “They may include intimacy to relieve a burden, gain control, enjoy self-expression or develop intimacy” (Petronio, ibid. p.6).

One’s HIV positive status is considered private information and would be tightly protected. If a PLWHIV decides to disclose to their spouse, the spouse is given access to the private information and henceforth the PLWHIV relinquishes the sole ownership of the private information which they now co-share with the spouse. They can now regulate the dyadic boundary together.

Supposition 2: privacy boundaries

CPM defines privacy as the feeling that one has the right to own private information either personally or collectively; consequently boundaries mark ownership lines for individuals. Personal boundaries are those that manage private information about the self, while collectively held boundaries represent many different sorts of privacy boundary types (Petronio, 2002, p.6).

CPM uses the metaphor of “boundary” to demarcate between what is public and what is private (Petronio, 2002, p.3). What is private is contained within the personal boundary. Individuals erect boundaries around their private information and they can decide to either keep the information private within the personal private boundary where information is only known to the self, or let others in and reveal the private information. According to CPM, individuals regulate the privacy boundary by both opening it andletting others know the information or keeping it closed thus denying them access to their private information. Figure 1.2 shows different boundary types.

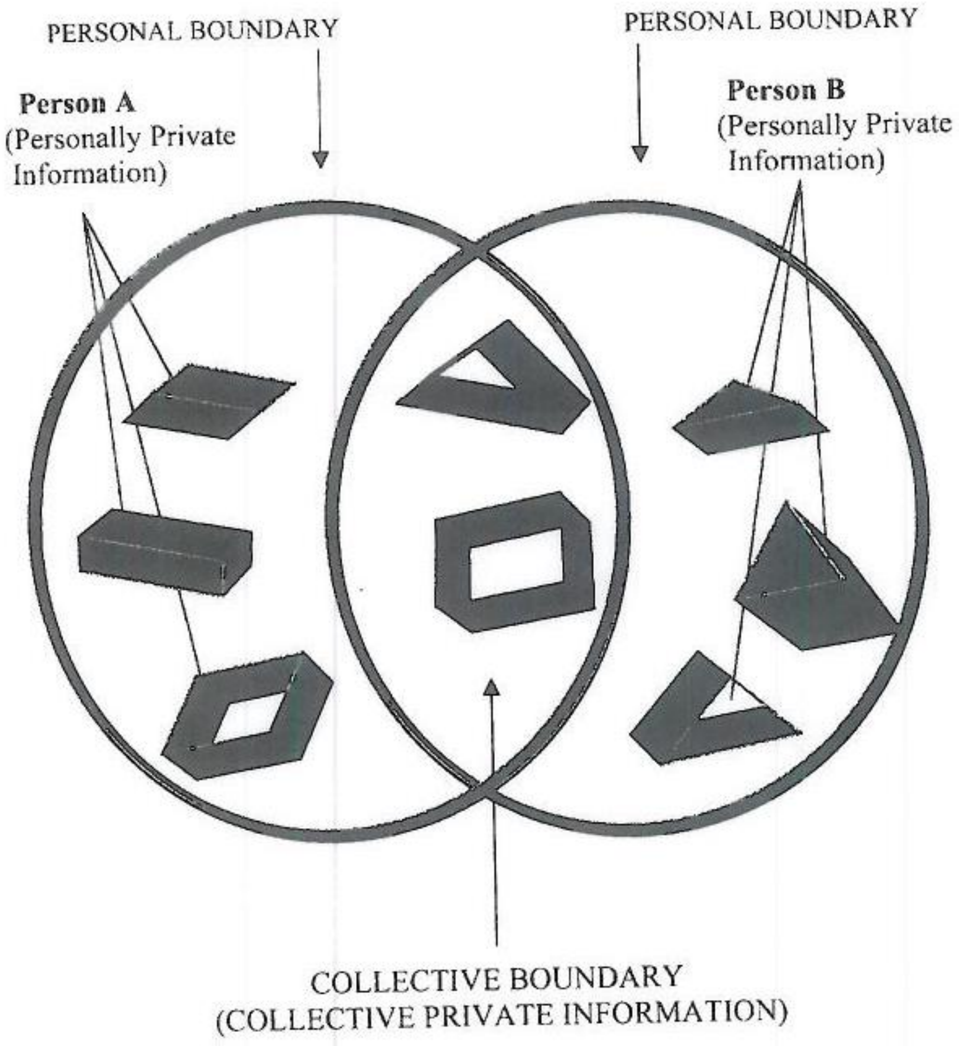

Figure 1.2: Boundary Types: Personal and Collective

Source: Petronio, 2002:7.

Information is either owned singularly by person A or person B. When a PLWHIV reveals their HIV positive status to the spouse or another recipient, they henceforth co-share the information. Hence, the PLWHIV relinquishes their unilateral control and the boundary shifts into co-owned collective boundary. Collectively held privacy boundaries contain information that may be private to a group, family, organisation or society as a whole. For instance, the Freemasons world over are perceived as a “secret society” where members take an oath of secrecy. Masonic rules demand that members support each other and keep each other’s lawful secrets (De Castella, March 9, 2012).

Supposition 3: control and ownership

Schoeman (1984, as cited in Petronio, 2002, p.9) says that privacy is regarded as "a claim, entitlement or right of an individual to determine what information about himself or herself may be communicated toothers."

Individuals believe that they own their private information and should have control over who may have access to it and who may not. Hence, individuals can control whether anyone else gets access to the information, how and when. CPM argues that because people consider their private information as something they own, they then have control to manage how they reveal and conceal the information to whom, when and how? Individuals want control over their private information because there are risks involved when this information is managed by others. Disclosing one's HIV positive status exposes the PLWHIV to risks such as rejection and stigmatization from the spouse, family and community members.

Individuals may own and control personal private information individually or collectively and become co-owners with others. The choice to share or keep private information often hinges on a risk-benefit ratio for those involved (Petronio, 2002, p.10). Revealing exposes an individual to risk and so does concealing. Hence, the possibility of risk heightens the need to control over privacy management. Petronio (ibid. p.10) says, "We feel the need to control our risk-benefit ratio by determining how much vulnerability we are willing to experience."

Individuals may also exercise varying levels of control ranging from very high, moderate to low levels of controls. The boundaries may be thick and hence high levels of control over the private information limiting the accessibility to the private information. Individuals may also employ moderate control where they would have thinner boundaries while others may have very thin boundaries resulting in less control and more openness. Figure 1.3 illustrates the varying control levels.

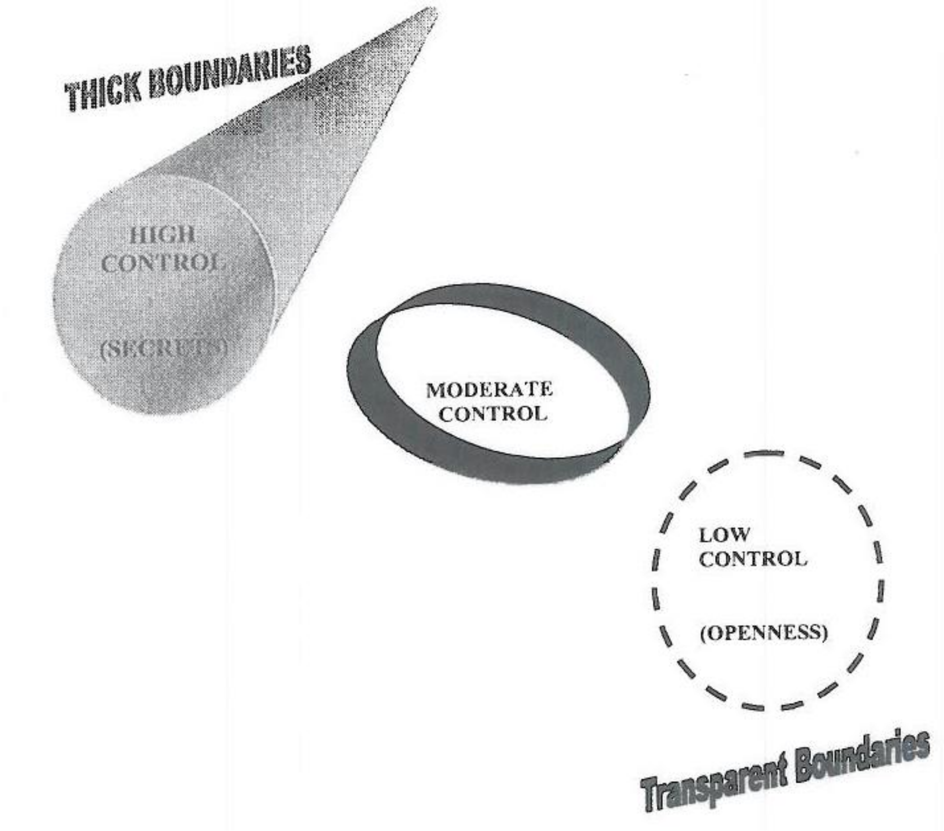

Figure 1.3: Levels of control: Privacy boundaries

Source: Petronio, 2002:11.

Supposition 4: rule-based management system

The rule based management system provides a structure for understanding the way private information is handled. This explains how private information that belongs to individuals singularly or co-owned with other individuals is managed. CPM proposes that once information shifts from personal to collective ownership, it calls for the co-owners to negotiate rules on how to manage the co-shared private information.

Supposition 5: privacy management and dialectics

The term dialectics refers to “the assumption that in social life, people experience tensions between opposites and contradictions” (Petronio, 2002, p.12). The concept of dialectics has been used by different scholars to reflect the different kinds of tensions and forces pulling on either side of different human needs. CPM is based on the dialectics approach including disclosure-privacy, concealing-revealing, openness-closedness and autonomy-connectedness (Baxter and Montgomery, 1996, as cited in Petronio, ibid. p.12). A PLWHIV is faced with the need to be open and disclose to their spouse and at the same time there is a pulling need to be closed and protect themselves.

1.7.2 Privacy rule management process

According to CPM there is a rule management process that regulates the revealing and concealing of private information. According to this theory, “people use rules to regulate the degree of access to or protection of their private information. The rules help an individual to decide, ‘who receives a disclosure, when, how much or how little, where the disclosure occurs and how a person might conceal information” (Petronio, 2002, p.23). Individuals develop rules for boundary management to regulate personal or collective private information. CPM identifies three rule management processes. These are foundations of rules; boundary coordination and boundary turbulence.

Management process 1: privacy rule foundations

The first process focuses on two different aspects namely rules development and rules attributes. Privacy rule development is concerned with the way rules develop. CPM explains that rules are acquired either by learning pre-existing rules or negotiating rules as people formulate new collective boundaries. For example, if an individual joins a club as a new member, they may be instructed or have to learn already existing rules. In other cases, the new members and the old members may have to formulate and negotiate new rules together.

CPM proposes that individuals use five criteria to develop privacy management rules. These are cultural expectations; gender differences; motivations for revealing and concealing; the context of the situation and the level of risk in revealing or concealing.

Cultural criteria: Cultures vary in their privacy needs and individuals are socialised accordingly. Altman (1977 as cited in Petronio, 2002, p.40) explains that "privacy is generic to all cultures but that it differs in terms of the behavioural mechanisms used to regulate desired levels of privacy". Different cultures have different privacy needs, some more individualistic than others. Each person has expectations of privacy influenced by their culture."

Gender criteria: This criterion suggests that men and women have different ways of defining privacy boundaries. Hence, gender may influence one's decision as to whether to disclose or to conceal their private information.

Motivation criteria: This criterion looks at how individuals make decisions to reveal or conceal private information based on the motivation. Different individuals have different motivations in either revealing or concealing their private information. Some may be motivated to disclose by the need to relieve a burden such as guilt while others may be motivated to conceal by the need to protect themselves or their spouse.

Contextual criteria: The context or situation is important in the decision as to whether an individual reveals or conceals their private information. CPM states that the context or situation has two aspects. These are the social environment and the physical setting. The social environment includes contextual factors such as assessing the appropriateness of raising a particular topic in a given situation, changing circumstances and the timing of revealing or concealing.

The physical setting entails selecting a conducive and appropriate environment for disclosure. Kenya online Newspaper, Thursday, February 20, 2014, a prominent radio presenter in the Kenyan Media admitted publicly that he was gay and explained that he had kept this information private for many years because the timing and the context was not right as it would have affected his job.

Risk-benefit ratio criteria: This entails an assessment of risk and/or benefit by individuals as a result of revealing or concealing their private information. CPM employs some core assumptions of Social exchange theory by Thibault and Kelley (1959) where individuals seek to maximize rewards and minimize costs. If an individual perceives revealing their private information as highly risky, then the person develops rules that will help keep the information private and is thus withheld. On the other hand, if the information entails low risk and higher benefits, the individual may reveal it. Individuals weigh the benefits against the risks of either choice and develop rules to maintain the desired level of privacy to either conceal or reveal their private information. Privacy management rules are formed in order to balance the risks and benefits of revealing or concealing private information.

Benefits of disclosure include self-expression, clarification, social validation, relationship development and social control (Petronio, 2002, p.66). On the other hand, risk may be of different types and levels. Private information fluctuates along a continuum from very high risk to low risk levels. When the risk is perceived to be very high, the boundaries are tightly guarded. If the risk is perceived to be low, the private information is guarded by thinner boundaries allowing more openness. Petronio identifies different kinds of risks. They include; security, stigma, face, relational and role risks.

*Security risks:*Individuals may perceive their personal safety or the safety of others to be at risk as a result of revealing private information. For example, a HIV positive individual will assess the perceived risk of losing a job and thus losing economic security or being thrown out of the house by the spouse or family members and risk losing their social security. Thus the perception of a threat to one's security may result in disclosure or non-disclosure for the individual.

Stigma risks: As individuals assess whether to disclose or not, they consider the possible risk of being stigmatised. Some individuals may fear being stigmatised by the family and community members and thus avoid disclosing their HIV positive status.

*Face risks:*Individuals will assess the possible threats to their face such as embarrassment and shame. Some PLWHIV may avoid disclosure for fear of the embarrassment that would be caused by the revelation of their HIV positive status.

Relational risks: These are risks that may affect the relationship between the disclosing individual and recipients of the information. Some people may reveal their HIV status in order to get the spouse's support while others do not disclose for fear of rejection or to protect the relationship.

*Role risks:*Disclosure may affect the roles individuals play in the family and community. Therefore, it is an important factor that individuals would consider in their decision. Disclosure of HIV positive status may risk compromising the role of a "breadwinner" and/or "provider" especially among the male PLWHIV.

The second aspect of privacy rule foundation is privacy rule attributes. According to CPM, privacy rules have two aspects; namely the way people acquire the rules and rule properties. People acquire rules largely through socialization where they acquire already existing family or social rules. Children get to acquire the family rules regarding revealing and concealing private information. Individuals may also acquire privacy rules by negotiating privacy rules when they join a new group. As members of the group, the individuals become co-owners of private information and they need to have rules to manage the private information collectively. These rules will regulate the access of or protection of the collective private information.

The privacy rules may be articulated explicitly or implicitly by the discloser. Explicit rules are stated directly and the discloser is clear on how they expect the recipient to manage the private information disclosed. This includes disclosure warnings which are normally issued before the individual discloses (Petronio, 2002, p.76). This would include statements such as, "don't tell mom..."; "I will tell you something, but you must promise not to tell anyone..."; "It's between you and I..." These statements mark the limits as to who can have access or not access to the information. They may entail a time dimension giving a time limit on how long the information should be kept confidential. Statements such as "Please don't tell mum till am out of town."

Implicit strategies may include hints or prompts on how to disclose or reveal information. They are often unclear and ambiguous leaving room for misunderstandings when the person disclosed to reveals the information without the consent of the discloser because the rules were not clearly stated.

Rule Properties is concerned with the nature of privacy rules described in four ways namely; routinization, orientation, change and sanctions.Routinizationrefers to a situation whereby rules are used routinely and become a basis for revealing and concealing private information (Petronio, 2002, p.79). Often concealing and revealing of private information follows a pattern that is used repeatedly to manage private information boundaries. For example, some people as a matter of habit do not discuss money issues with their spouse while others do not discuss their family issues in public.

Orientation rules have to do with values towards privacy and disclosure. This is as a result of consistent use of the privacy rules across generations or for a long period of time that they have become permanent privacy rules regulating revealing and concealing of private information.

Privacy management rules can also change due two new events which call for establishing of new rules or changing the already existing ones. Petronio (2002. p.80) notes that “an unpredictable situation, a new change in our lives that is unplanned, or a novel event may trigger a new rule or modification of the existing privacy rules”. A PLWHIV who is bedridden may have to change their privacy rules to meet the new demands for physical support.

Individuals are expected to adhere to the privacy rules to manage concealing and revealing private information as agreed by the co-owners. Positive or negative sanctions may be applied to those who have complied and those who have not complied respectively. Positive sanctions would include praise, reward, and approval while negative sanctions would include being reprimanded, not disclosed to in future, given partial information in future or/and warned about their violation, embarrassment, humiliation to reinforce the use of privacy rules.

Management process 2: boundary coordination operations

Individuals have personal boundaries and collective boundaries to manage and therefore coordination is crucial. CPM suggests that there are three management operations used to coordinate privacy boundaries. These are; linkages, permeability and boundary ownership.

Boundary linkages refer to joining or converting one boundary type into another. When an individual owns information singularly, they are responsible for regulating their personal private boundaries. But once they reveal the information to another individual or individuals, they now co-share the private information collectively and one personal boundary is now linked with another personal boundary or boundaries to form a collective boundary. Hence previously personally private information becomes joint co-shared private information. Figure 1.4 illustrates linkage operations.

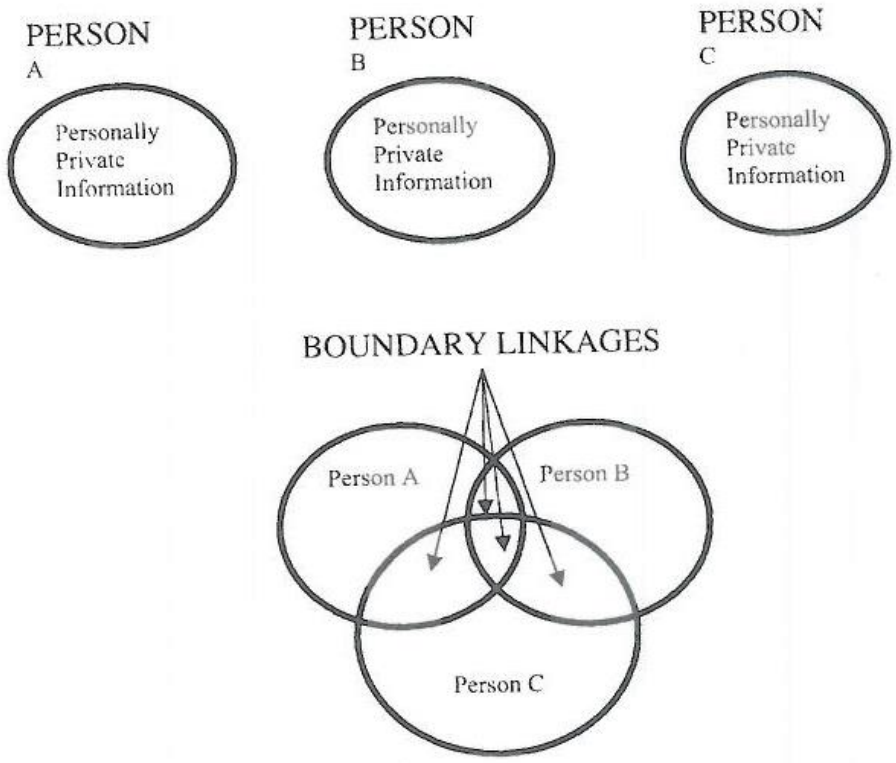

Figure 1.4 Boundary Linkages Coordination Operations

Source: Petronio, 2002:89.

Collective boundaries may be linked in two ways. They may be transformed or appropriated. When someone discloses to a recipient or a confidant, then the personal private boundary can be said to be transformed from a personal to a collective boundary. On the other hand when individuals join groups such as clubs, HIV support groups where members share private information, then the information is collectively managed. The new members learn the privacy management rules of the group. According toPetronio (2002, p. 92) there arefour rules used to link boundaries. These are rules about confidant selection; timing; topic and personal characteristics.

Other individuals form linkages by acquiring private information from others. This includes seeking information from them by probing for information and also by asking direct and indirect questions. Other strategies used to link boundaries include giving permission to encourage disclosure.

The second management operation is boundary permeability. It focuses on "how opened or closed the collective boundaries are once they are formed" (Petronio, 2002, p.99). This concerns how tightly or loosely the privacy boundaries are held. The boundary walls can either be thick or thin affecting the access to and protection of private information. When boundaries are thick, boundaries are tightly controlled affecting the depth, breadth and amount of private information that is communicated. When they are thin, the boundaries are loosely held and there is more permeability of information and openness. These are regulated by privacy access rules and privacy protection rules briefly explained below.

Privacy access rules help individuals to determine who if any person outside the collective boundary can know the private information, the amount of information they can know and when it is appropriate for them to know and how they should be told. CPM proposes that concealing and revealing private information entails assessing and having knowledge about possible confidants. It is critical for an individual to consider the recipient of the private information as it has potential to be harmful and/or making them vulnerable if not managed properly. An individual determines "who, what, when, where private information is disclosed because we own it" (Cline 1982; Derlega, 1993, as cited in Petronio, 2002, p.85).

Privacy protection rules: In addition to privacy access rules, co-owners need to establish privacy protection rules to protect private information and keep it within the boundary. Petronio identifies several strategies that people use to protect access to the private information. These include:

1. Topic avoidance protection rules where individuals protect their boundaries by avoiding certain topics.
2. Taboo topic protection rules where individuals avoid topics that are taboo.
3. Confidentiality protection rules which outline how members need to manage confidentiality in respect to other people's private information.

The third operation is boundary ownership. One of the goals of boundary coordination is to determine and identify the limits of collective and personal boundaries. Boundary ownership has to do with who owns and controls the private information. When an individual owns personal private information, they determine the boundaries and the information is exclusively theirs. They have control over it in terms of access or of protection. When they disclose it to others, then they give up exclusive rights and control to the co-owner(s).

Individuals may use verbal and nonverbal boundary markers to specify the boundary limits. It may also include people using behaviours that indicate that the information is limited to the person and exclude others for instance the use of the palm when whispering, leaning towards the confidant or closing the door, change of topic when another person joins them or stop the disclosure when an "unwanted" individual joins the group (Petronio, 2002, p.108).

Management process 3: boundary turbulence

As we saw in the section above, coordination of collective privacy boundary is crucial in regulating concealing and revealing of private information. However, the boundaries are often not properly co-ordinated resulting in boundary turbulence. Boundary turbulence may result from intentional rule violations; boundary mistakes; fuzzy boundaries; dissimilar boundary orientations; boundary definition predicament and privacy dilemmas. I will briefly look at them below to show how boundary turbulence can occur.

Intentional rule violations refer to situations when people deliberately reveal collectively held private information without following the agreed-upon rules; they violate the rules for regulating privacy boundary. Disclosing information to a third party without the consent of the other individual breaches their expectation and the individual feels betrayed. When an individual makes a person a confidant, they trust them to protect their information. However, often this trust is betrayed.

Unlike intentional disclosures, boundary mistakes are unintentional. They may be a result of errors in judgement, miscalculating the timing and not paying attention to the discloser. For instance, a confidant may reveal private information disclosed to them as they perceive themselves to be honest by disclosing to a third party.

Fuzzy boundaries refer to lack of clarity on boundaries. This happens when the boundary rules are unclear as to who owns or co-owns the private information. For instance, turbulence may result from instances where a family member may disclose information that they co-share with one family member to a third family member in the belief that the other individual is also a family member while the discloser intended the private information to be kept between the two of them.Dissimilar boundary orientations can be attributed to individuals having different orientations to privacy management due to for instance different socialization. When two people come from different privacy orientations, there is likely to be turbulence. One member may be oriented towards being more open while the other member maybe more closed having less permeable boundaries.

It is not uncommon to see couples in conflict because one of them disclosed information which the other spouse perceived to be between “me and my spouse” while the other spouse perceives it to be “a family matter” and discloses it to the brothers, sisters and parents as is the tradition in their family. The two different orientations are likely to result in boundary turbulence.

CPM explains that boundary definition predicament may happen in two ways. In the first case it happens when people treat public space as private and disclose private information inappropriately. This happens when what is supposed to be private information is not kept within the appropriate boundaries. In public transport, one often hears information that is supposed to be private disclosed in public. Also boundary turbulence occurs when individuals such as political figures and celebrities have their privacy compromised by virtue of being public figures.

Privacy dilemmas result in situations where an individual knows that if private information is kept confidential, it has the potential to cause harm and on the other hand if revealed it can also cause harm. The dilemma represents a situation in which the choice is between two equally unsatisfactory alternatives (Neufeldt 1995, p.168, as cited in Petronio 2002, p.200). Whether to withhold or disclose their HIV positive status can be a dilemma to most PLWHIV.

1.7.3 Chapter Summary

This chapter gives an introduction to the study outlining the research questions, objectives, basic assumptions and theoretical framework. The next chapter presents the literature reviewed.

CHAPTER TWO:LITERATURE REVIEW

2. 0 Overview

This chapter reviews literature on the concepts of self-disclosure, importance of self-disclosure, HIV/AIDS and stigma and spousal communication in reproductive health issues including HIV. Works on research issues have been reviewed especially on qualitative research, and ethical issues relating to HIV/AIDS.

2.1 What is Self-Disclosure?

The term disclosure is variously defined. Pearson and Nelson (1997, p.112) define

Self-disclosure as, “the process of making statements about oneself that are intentional and that another person would be unlikely to know or discover”. Self-disclosure can be as unthreatening as talking about a vacation or a favourite sport. It can also be as difficult as discussing one’s sexuality or sexual abuse as a child. According to Pearson and Nelson (ibid.), self-disclosure can be analysed in two dimensions, that is: its valence and amount. In reference to valence they say that we usually give positive information before providing negative information to others.

Stewart and Logan (1993) say that, “self- disclosure is disclosing or presenting one's self by letting others know some aspects of who you are that they probably would not know unless you revealed it to them”. It involves a conscious choice. Grove (1991) suggests that we can choose the level of self-disclosure which can be high, moderate or low level and we can also choose to whom and when to disclose.

Corey (1995, p. 117) says that there are two levels of self-disclosure. One level involves “sharing one's persistent reactions to what is happening in the “here and now”.

The other level entails revealing current struggles, unresolved personal issues, goals and aspirations, joys, hurts, strengths and weaknesses". Corey (ibid.) asserts that a trusting relationship is essential if people are to risk disclosing threatening material. It is the latter level that this study addresses itself to.

Niccolai, King, D'entremont and Pritchett (2006) look at disclosure of HIV in three ways. These are; full disclosure where a partner discloses before engaging in sex, delayed disclosure where one discloses after sex and no disclosure where an individual has not disclosed in both current and past relationships. They also explain passive disclosure where one's partner may know that an individual is HIV positive without the person having disclosed to them directly. This study provides insights into different kinds of disclosure.

Gielen, McDonnell, Burke and O'campo (2000), note that there are three primary mechanisms of notifying a partner about HIV status. These are; health care assisted disclosure, contact tracing programs and self-disclosure. This study focuses on the latter where disclosure is done by the PLWHIV.

2.1.1 Importance of self- disclosure in Interpersonal Relationships

Several writers have written on the benefits of self-disclosure. Pearson and Nelson (1997) say that it allows us to establish more meaningful relationships with others. Self-disclosure facilitates for relationships to grow in depth and meaning. They note that if we use self-disclosure appropriately, our relationships move from being fairly superficial to being deeper and more meaningful. Sharing personal information with another person can build trust and intimacy. An inability to self-disclose can lead to the end of a relationship. Pearson and Nelson (ibid.) cite a common reason for divorce given by women as their lack of opportunity while married to express who they are leading to their marriage break-up.

Self-disclosure can also result in more positive attitudes about others and oneself. You may have disclosed some information to someone and got a feeling of “I am glad I talked to you”. The following statement by Pearson and Nelson (1997) illustrates the benefits of self-disclosure:

> As paradoxical as it may seem, disclosing negative information can also result in more positive attitudes about others and us. When we are able to disclose our negative qualities, shortcomings to others and others are able to do the same with us, we recognize we are fallible and no one is perfect. We become more understanding and forgiving and we develop more positive attitudes about all humankind.

Corey (1995) on disclosure in groups says that the honest sharing of deeply significant personal experiences and struggles binds the group together. In the process of sharing experiences, members identify with others by seeing themselves in others. Group members realize that others have similar issues and the members can help one another work through their issues. This is possible when the group is cohesive enough enabling members to open up and take risks.

Studies show that more psychological harm accrues from the anxiety of not knowing or lies than sensitive, honest disclosure. Doran (2002) indicates that ambiguity leaves patients confused and is a source of distress in itself. Children who know their HIV status have higher self-esteem than infected children who are unaware of their status and parents who have disclosed their positive status to their children experience less depression than those who have not (Lipson 1994).

Another benefit of self-disclosure is catharsis. Corey (1995, p.115) defines catharsis as "the expression or release of pent up feelings" He says that disclosure can be therapeutic in itself as it releases energy that has been used to withhold threatening information. This emotional release normally leaves a person feeling relatively "lighter". Some psychologists believe that cathartic disclosure has real healing power physically as well as psychologically.

Pennebaker (1990) cites several studies where respondents who had disclosed personal information both negative and positive had fewer physical ailments in the months following the disclosure. In a study of two hundred respondents, sixty-five people with an undisclosed childhood trauma were more likely to be diagnosed with various health problems such as cancer, high blood pressure, ulcers, flu, headaches and earache. In the study, the type of trauma was not significant. The only distinguishing feature was that the trauma had not been talked about to others. Bradshaw (1995) reiterates this and says that a lot of energy is expended on hiding the truth. This generates intense anxiety in the person who must be constantly on guard against disclosure and avoiding particular subjects. Bradshaw (ibid. p.48) asserts that "repressed feelings are often the root cause of problems such as premature ejaculation, unexplained backaches, headaches and other psychosomatic disorders".

Rothwell (2000, p.45) classifies the goals of self-disclosure into constructive goals and counterproductive goals. He states that constructive goals are "developing relationships with others, gaining self-knowledge, correcting misperceptions, eliciting reassurance and creating impressions". On the other hand, counterproductive goals for self-disclosure are "manipulation and catharsis". He says that the latter are "me-oriented" rather than "we-oriented".

Derlega and Grzelak (1979, as cited in, Petronio et al. 1993, p.225) cite five reasons for self-disclosure. These are: “expression, self-clarification, social validation, relationship development and social control”. These provide an understanding on the motivations for revealing private information. Davis and Francoi (1987, as cited in Petronio, 2002, p.49) says that individuals are motivated by three needs. These are; “expressive need, self-knowledge need and self-defence”. For instance they note that men avoid disclosure for fear to lose control while women fear personal hurt.

2.1.2 Guidelines for disclosure

West and Turner (2000, p.154) give the following guidelines for self-disclosure.

1. Is the other person important to you?
2. Is the risk of discussing reasonable?
3. Is the amount and type of disclosure appropriate?
4. Is the disclosure reciprocated?
5. Will the effect be constructive?

Rothwell (2000, p.46) give characteristics that act as guidelines for appropriate

Self-disclosure. These are:

1. Trust: This means trusting another person to honour and not divulge what you have disclosed.
2. Reciprocity: This refers to mutual trust and risk taking.
3. Cultural appropriateness: Not all cultures value self-disclosure.
4. Situational appropriateness.
5. Incremental disclosure: This calls for “testing the waters” and gradual disclosure.

6. Desire for intimacy or closeness.
7. Likelihood of constructive outcome. For instance, a stronger relationship makes it worth the risk or preventing a partner from HIV infection.

Some studies show that women placed a higher importance on sender and receiver characteristics than men. Before women can disclose, they need to feel that the recipient will be discreet, trustworthy, sincere, liked, respected, good listener; warm and open (Petronio 2002. p. 45).

Petronio et al. (1993) suggest that disclosure is dependent on two regulators viz. pre-requisite conditions of disclosure and anticipated ramifications of disclosure. They argue that “communication events have a past, present and future”. Hence we rely on our past experiences in deciding whether to disclose to someone and whether we can trust a particular person. This concurs with Bandura’s concept of situation specificity of behaviour and anticipated expectancies and the principles of costs and rewards.

Weaver and Hybels (1995, p.163) concur that “we rely on our past experiences in deciding on whether or not to disclose. From our past experiences we can predict whether we can trust a person to show concern”. Listening, trust, acceptance are important communication skills that facilitate disclosure and thus have a great bearing on this study.

2.2 Self- disclosure and Risk Taking

Self-disclosure entails risks. When we choose to self-disclose information, we have no control of the outcome of the disclosure. The confidant may empathize, provide support, reject, reveal the information to someone, embarrass or hurt the discloser. Higher risk level events often result in shame, threat and severe embarrassment. Bok

(1992, as cited in Petronio, 2002, p.67) says that an example of this is what we often define as a “secret”. HIV positive status is given as one such secret which entails high levels of risk if revealed. Warren and Lashett (1977, as cited in Petronio, ibid.) are of the view that secrets are risky because they have the potential to result in high levels of vulnerability if known by others. There are different types of risks that an individual may have to consider in disclosure. Petronio (ibid.) identifies security risks, stigma risks, face risks, relational risks, and role risks.

Petronio (2002. p.67) argues that “the risks depending on the kind may not completely stop us from disclosing or of keeping information tightly guarded. However, the risk-benefits ratio functions as an important factor in developing norms as a basis for the decision to disclose or remain private”. A PLWHIV would assess the benefits such as spousal support against a risk such as blame or being stigmatized by the spouse or family members. This may result in revealing or concealing their HIV positive status. Greene (2000, Petronio 1991; Yep, 2000, as cited in Petronio, 2002, p.67) explains that “private information changes in degree of risk based on perceived repercussions for revealing and concealing”.

Temmerman et al. (1995) in a study carried out in Nairobi found that out of the women in the study, who disclosed their positive status to their partners, eleven had been chased away from home and or their partner had acquired another wife, seven had been beaten up by their partners and one had committed suicide. This study is important as it shows some reasons as to why women may not disclose their HIV positive status. The current study focuses on both men and women.

Stewart and Logan (1993) note that the risk one takes varies with the communication content, what is presented and the relationship. They say that, intimate content is more risky than impersonal content, that is, it is more risky to talk about "I" than generalizations. Time is also a factor; the past is usually easier to talk about than the present. Topics that are dearer to an individual are more risky to discuss than topics one does not value and negative information is usually more risky than positive information. The relationship between individuals also affects the degree of risk. It is less risky to disclose to someone who has listened to you in the past. An individual would be more willing to disclose high risk content if they are confident that they can trust the other person.

Maman et al. (2001) examines attitudes, beliefs and experiences related to sero-status disclosure and partner violence among women, men and couples who seek VCT (Voluntary Counselling and Testing). They found that the major barrier to HIV testing and disclosure among women was fear of the partner's reaction. However, they also noted that majority of those who disclosed reported support and understanding from their partners.

Medley, Moreno, McGill and Maman (2004) focus on gender dimensions of HIV status disclosure to sexual partners. They look at the rates, barriers and outcomes of disclosure. This provides significant information on barriers and motivations for disclosure, which are addressed in the current study.

Palmer and McMahon (1997) highlight a link between HIV and the defence mechanism of denial. People who are HIV positive can go to great lengths to protect themselves and their loved ones by the defence mechanism of denial. This helps me understand why some people may choose not to self-disclose since disclosing information about one’s HIV positive status is risky and face threatening. Denial about one’s positive status and avoiding disclosure is one way of saving face.

Bradshaw (1995, p.43) concurs that protection is a common motivation for keeping secrets. He says that parents often keep secrets about terminal illness because they think that children cannot handle death and dying. As stated earlier, Palmer and McMahon (1997) say that HIV entails high anxiety levels, great fear and loss. Hence people go to great lengths to protect themselves and their families from what they perceive as dangerous knowledge. Human beings go to great efforts to keep or withhold information, which they believe if known would cause more harm. This follows the script of “*what you do not know does not hurt”.* This provides insights into why some people may not self-disclose.

Corey (1995) looks at barriers that keep us from self-disclosing which are directly relevant to this study. This may be fear of intimacy, avoidance of responsibility and change, feelings of guilt, shame, fear or rejection and cultural taboos. He concurs with Stewart and Logan (1993) and Rogers (1961) that trust helps to overcome these barriers enabling people to risk disclosing threatening material such as the disclosure of HIV positive status which is threatening and involves taking a risk.

Literature on sharing and telling or even receiving bad news shows that, it is never an easy thing. Affleck (1999), notes that it is easier to give bad news through electronic mail than face to face. In her study, she found that negative comments are delivered easily and more accurately as one does not have to "sugar coat" the information or face the recipient, which is stressful. This work is important to this study as it looks at methods of communicating bad news. Disclosing information on one’s HIV status is bad news, and some individuals may avoid face-to-face disclosure. This study may throw light on the need to encourage alternative methods of disclosure. Powell (1969) cites an example in his book where an individual asked a friend, “Why are you afraid to tell me who you are?” The friend answered, “Because if I tell you who I am, you may not like who I am and that is all I have”.

Disclosing personal information makes the person susceptible to hurt by others. The individual weighs the need to disclose against the need to protect their information. According to Barrel & Jourard (1976), whether the balancing tips on or against disclosure depends on expected positive or negative ramifications. They argue that an individual’s reluctance or willingness to disclose depends on his perception of how the disclosure would affect their relationship. Since self-disclosure is intentional, individuals take into account the outcomes of revealing private information before they disclose.

Berardo (1974, as cited in Petronio, 2002, p.6) explains that a person's privacy boundaries changes in their life span. Youniso and Smollar (1985, as cited in Petronio, 2002, p.7) explain that adolescence stage is about individualisation and forming privacy boundaries. The privacy boundaries become more firm and defined during adolescence. These boundaries increase in adulthood but decrease as people get older and require increased support from others to take care of them and their privacy boundaries get thinner. Petronio (ibid. p.9) concludes that “over a life span, privacy boundaries are modified to accommodate private information belonging to the individual”. The PLWHV may have to adjust their privacy boundaries to accommodate their life changes. These texts are important in that they look at how perceived outcomes affect disclosure and they provide further insights into the area of disclosure.

2.2.1 HIV/AIDS Disclosure and Stigma

According to Goffman (1963, p.4), the word stigma comes from the Greek origin referring to "bodily signs designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal or a traitor, ritually polluted to be avoided especially in public places". Goffman (1963, as cited in Brown, Trujulo and Macintyre, 2003, p.49) defines stigma as,

> Undesirable or discrediting attribute that an individual possesses thus reducing that individual's status in the eyes of society. Stigma can result from a particular characteristic such as physical deformity, or it can stem from negative attitudes towards the behaviour of a group such as homosexuals orprostitutes.

Stigma is a common human reaction to disease and other conditions. In different societies, different illnesses, conditions and events have been stigmatised over time. For example, among some African communities the birth of twins was bad luck and the infants had to be abandoned to die. According to Yengo, (2008, as cited in, Cimpri, 2010, p.26), among the Bariba of Northern Benin, infanticide or abandonment of children "abnormally born" continues to date in the belief that the infants will bring misfortune. These abnormalities include premature birth, presentation in any breech position...,face up position during delivery, any physical defect, born with teeth, or who caused the death of the parent are called *gnando* or wizard. Also in recent times there have been several media reports and articles on widespread discrimination and even sale of individuals with albinism in Kenya and in Tanzania. KTN recently aired a story “Prisoner of my skin” which highlighted the challenges faced by albinos in Kenya and Tanzania (Standard Digital News-KT video Albinism).

Brown et al. (2003) says “throughout history many diseases have carried considerable stigma including leprosy, tuberculosis, cancer, mental illness and many sexually transmitted diseases. HIV/AIDS is only the latest disease to be stigmatised”. In the area of HIV/AIDS sources of stigma include fear of illness, fear of contagion and fear of death. Herek and Mitnick (1998), note that these fears are common among the health workers, care givers and the general population.Petronio (2002) says that most individuals must consider the stigma risks before concealing or revealing their private information.

PLWHIV are faced with two interrelated issues that is stigma and disclosure of their HIV status. HIV related stigma is experienced all over the world, although the form and magnitude may vary. HIV related stigma is defined as, “prejudice, discounting, discrediting and discrimination that is directed to people perceived to have HIV /AIDS” (Herek et al. as cited in Emlet, 2005, p.4). PLWHIV experience various physical and psychosocial issues such as feelings of rejection, isolation, shame, embarrassment, guilt, blame and self-hate, which ultimately challenge their face.

Disclosing HIV infection has been an issue of great concern among both the health professionals and the infected. Public fear, ignorance, stigma, discrimination have combined to force HIV positive people into the closet to often cope with the illness alone or with limited support. As HIV/AIDS have made its way into families, PLWHIV are faced with concerns about disclosure of their status, should I tell? Whom and when should I tell and other endless questions on sharing this information.

Bradshaw (1995) notes that HIV/AIDS touch on areas of natural concealment that belong to the realm of the private. It involves what he calls a “dark secret”. HIV /AIDS are closely linked to sex and death, which are major taboo subjects in most Kenyan cultures. This has in turn resulted in guilt, blame, loss, silence and stigmatization of PLWHIV.

Illnesses have both a medical and a social dimension. Some are associated with additional cultural connotations. Various types of illnesses are associated with stigma that results in what Goffman (1963) calls a spoiled identity. A review of literature indicates that PLWHIV worldwide are stigmatized because of their HIV status. “HIV/AIDS is lumped with other physical and medical conditions that have in the past been viewed in moral terms. These include leprosy, syphilis, T.B. and cancer, all of which have been seen as meaning something about the moral status about those suffering” (Dossier, 1988). One of the crucial issues in respect to stigmatization and discrimination of HIV and AIDS is its association by society with behaviours that are deemed as deviant or immoral whether it is homosexuality, drug use or prostitution (Fife & Wright, 2000). Hence the individual is viewed as being responsible and is blamed for the illness.

In Kenya, HIV is mainly transmitted through heterosexual sex (NACC & NASCOP, 2012). Sex in most societies is surrounded by taboos and few people discuss it without making or implying moral judgments or feelings that moral judgments are being made about them (Dossier, 1988). Consequently in Kenya as in many other countries, because of the stigma, PLWHIV are reluctant to disclose their positive status.

Emlet (2005) examines the relationship between socio-demographic factors such as age and social support influence on HIV related stigma and patterns of disclosure. He compared individuals living with HIV/AIDS in Washington in the age group 20-39 and those between 50 and over. The study concludes that individuals regardless of age experience shame, avoidance, real or perceived loss of friends and a sense that people are uncomfortable around them because of HIV. These findings confirm how pervasive HIV related stigma is. Also of relevance to the current study is the finding that disclosure includes an analysis of positive and negative consequences. Although Emlet's study is quantitative and involves comparing two age groups, it provides important insights into issues of HIV related stigma and how people weigh benefits against costs in disclosure. For instance, he found that some individuals disclosed in order to receive formal support through the HIV service network; this outweighed the negative ramifications of disclosure. The current study looks at reasons for and against disclose.

Hastings (2000) is an important work as it investigates constraints of self-disclosure between bereaved parents and civilians. He uses respondent observation in groups for bereaved parents and examines potential constraints to self-disclosure and also how the bereaved parents save face. Although the work is focused on issues of bereavement, it is relevant to our study as it looks at two key concepts relevant to this study viz. self-disclosure and face. Hastings found self-disclosure to be a powerful communication tool for the bereaved in facilitating healing.

Dane in her study on women's disclosure to family and children used a convenience sample of 25 women with the aim of finding out the extent of disclosure of mothers HIV positive status to their children and the effects of the disclosure on the children.

She found that children of HIV positive parents also experience discrimination in social and institutional settings. They are rejected by relatives and at school, relatives may be unwilling to care for them especially if the children are also infected and they may also be rejected by orphanages. This study is crucial as it uses a convenience sample which this study employs.

Sheon and Crosby (2004) in a study of HIV disclosure among men who have sex with men (MSM) in San Francisco wanted to understand the disclosure practices, the risks and attitudes to HIV seroconversion. They carried out a qualitative study using a convenience sample of 150 MSM. They found that HIV negative men did not see the advantage of disclosing to HIV positive casual partners who refuse to use condoms due to fear of rejection. On the other hand the HIV positive men were eager to disclose to avoid responsibility for transmission and facilitate unprotected sex. By avoiding disclosure or not insisting on a condom, a HIV negative man avoids potential rejection and stigmatization by the partner. Sheon and Crosby (ibid.) refer to this as reverse stigma which seems to put HIV negative men at a disadvantage when negotiating safer sex with a HIV positive man. This study is important as it looks at what may make an individual disclose or conceal their HIV positive status. Secondly the study is based on a convenience sample which the current study employs.

Klitzman and Bayer (2005), note that disclosure revolves around moral, social and psychological decision making. It forces the PLWHIV to confront rarely discussed issues about truth, lies, sex and trust. In a New York study of gay and lesbians, 30% of gay men admitted about lying about their HIV positive status. They cited fear of being harmed or injured as reasons as to why they did not disclose. Those interviewed said that decisions of whether one disclosed or not depended on how they perceived theworld. That is, whether the world was perceived to be hostile or hospitable towards those who are HIV positive. The study also found that, the social acceptance of a HIV positive status in a given time and place can affect disclosure. In some societies, there is greater openness about sexuality and HIV than others, hence the perceived attitudes of the society is crucial in self-disclosure. This study throws more insights into reasons for and against self-disclosure.

Self-disclosure which as seen earlier is important to the infected person in terms of accessing health care and support and preventing further transmission of the virus may be hindered by stigma from others or from self or from perceptions that disclosing their positive status will threaten their face. Being HIV positive makes an individual feel ashamed and guilty which threaten the face of the infected person. The issue of self-disclosure is a difficult one especially in a society like ours that stigmatizes infected persons. The fear of being stigmatized and loosing face may make HIV infected persons conceal their HIV positive status.

Goffman (1967, as cited in West & Turner, 2000, p.363) introduced the notion of "face". He saw face as "the image of the self that people display in their conversations with others, it can be maintained, lost and strengthened". Face is a metaphor for self-image (West & Turner, ibid. p.363). It refers to the way we want others to see us and treat us (Griffin, 2000, p.408). Levinson and Brown (1987, p.311) extended the ideas of Goffman to their politeness theory that states that human beings have two types of needs: positive face and negative face needs. Positive face is "the desire to be liked and respected, while negative face is the desire to be free from constraint and imposition" (Pearson, et al. 2003, p.64). Our effort to save face for others is what is termed as politeness. Therefore, the desire to maintain a certain image may influence what is disclosed and whether one discloses or not. The need to maintain a positive face may cause avoidance of disclosure.

2.3 Spousal Communication on Reproductive Health Issues

Research suggests that "partner communication helps couples improve their reproductive health and that many men and women fail to protect themselves against unplanned pregnancy, STIs including HIV/AIDS in part because they find it difficult if not impossible to discuss with their partner subjects related to sexuality" FHI (2002).

FHI (1996) says that communication between partners about sexual concerns, risks and fears leads to better contraception and safer sex. Communication between partners is a key factor in achieving correct and consistent use of barrier methods. Yet in many societies few couples ever talk to each other about reproductive health issues.

2.3.1 Spousal communication and Family Planning

Research has often associated spousal communication with increased contraceptive use. The importance of spousal communication is often emphasized in Family Planning (FP) programs. Several studies indicate that the amount of communication that occurs between partners is positively associated with contraceptive use (Sharan & Valente, 2002). This resulted in communication interventions designed to target the spousal unit and facilitate communication between couples on FP. Salway (1994, as cited in FHI, 2002) says that in Ghana women who had discussed contraceptives with their husbands were twice as likely to use FP as those who had not.

Sharan and Valente (2002) note that individuals who communicate with their spouses, may perceive their spouses as more supportive and feel more in control of their decisions on reproductive issues. Ogunjuyigbe et al. (2009) in their cross sectional study in three states in Nigeria show that marital partners who discuss and take joint decisions on what to do to delay or stop childbearing were more likely to use contraceptives than those who had not discussed it.

Bawah (2002) in their study showed that spousal communication among other factors significantly increases FP use. Other factors that had a significant positive effect were age, level of education, number of children ever born to the woman and whether she had heard a FP message recently.

2.3.2 Spousal communication and HIV/AIDS

Zulu and Chepngeno (2003) in their study examine how men and women in rural Malawi comprehend their risk to HIV and strategies that they consider in marriage to prevent HIV. The study shows that those who have the most reason for concern about contracting HIV and those who have more program and informal social contacts are more likely to communicate. The husbands and wives were found to use subtle and gendered strategies to communicate. For instance in an attempt to encourage fidelity, one spouse may talk about the effects of HIV/AIDS on their children or illness or death of a friend or neighbour.

They also found that most spousal communication about HIV/AIDS risk was as a result of suspicion or knowledge about the spouse’s infidelity. The likelihood that spouses would have talked about the risk of contracting HIV was based on three different factors. The first one is stimulus factors such as exposure to information about HIV/AIDS from radio, health clinic, community health workers or informal networks. The second factor is risk factors. These decrease or increase discussion based on the perceived risk. This is concerned with whether an individual suspects or is worried about the spouse's infidelity. The third factor is marital relationship factors. This is concerned with couple characteristics that may hinder or facilitate disclosure. The study found that the discussion about risk of contracting HIV/AIDS is highest when both spouses are very worried about contracting HIV. Mostly, the discussions are initiated by women and usually when they are worried that their husband is having an affair.

Chiao et al. (2009) examine how demographic and socioeconomic characteristics of cohabiting adults influence their dyadic communication about HIV. The study is concerned about how the position of women in the Kenyan society influences spousal communication. They look at age, education and female participation in household decision making as key factors influencing spousal communication about HIV. The study showed that females with higher levels of education and household decision making are positively associated with spousal communication about HIV prevention. In their study, 60% of couples reported mutual communication, 31% one-sided communication and 8% reported no communication on HIV prevention. Couples with female partners aged 25-34 (66%) were more likely to have mutual HIV communication than in couples with younger or older female partners (55%-57%). Communication was also highest where the female partner has secondary or higher education (76%) and least where the female had no education (30%).

Other factors that were positively associated with mutual spousal communication were female participation in all major household decisions, listening to radio and reading newspapers or magazines at least once a week, type of marriage where couples married by custom or living together were more likely to communicate than marriage by certificate. Muturi (2005, as cited in Chiao et al. 2009) observes that spousal communication about HIV remains limited in rural couples, despite widespread dissemination of information on HIV.

2.3.3 Barriers to spousal communication on reproductive health issues

Fapohunda and Rutenberg (1999) investigated spousal discussion of FP, STDs and HIV/AIDS in Kakamega. They found that while FP issues were sometimes talked about with considerable difficulty, STDs including HIV/AIDS, risks and prevention are rarely mentioned among married couples. Women are not receptive to discussions about FP as they worry about the implication of such discussions on their social status, marital security, well-being and relationship. Men are concerned that they could be suspected of infidelity. Spousal discussion of the risk of STDs including HIV/AIDS is inhibited by the desire to avoid accusations and counter-accusations of marital infidelity between spouses. Almost all respondents stated that such matters are almost never discussed between spouses as they touch on trust. STDs connote unfaithfulness and challenges marital trust.

In the same study, most men and women said that they would not notify their spouses if they found or suspected that they have STDs or HIV/AIDS. Men said that they would be worried that their wives would desert them or get a shock. Women said that they would not notify their husbands about an STD as the men could become violent. But in reference to HIV/AIDS most women said they would notify their husbands so that they could plan for the future. This study provides useful insights into the differences between men and women in terms of communicating on issues of STDS, HIV/AIDS. It also highlights some difficulties in spousal communication on issues of HIV/AIDS. The current study looks at people who are already HIV positive, which offers different dynamics than someone imagining a situation.

Czech and Cage (1998) say that if a woman begins to initiate talks about sexual issues, the husband may feel that *"her eyes have opened"* and the way to keep them closed is through violence. This is confirmed by studies, which indicate that violence compromises HIV protection. Brown (1998) says that women's fear of men's reaction has kept them away from VCT and that fear of ostracism and domestic violence is a key reason as to why pregnant women refuse HIV testing and to return for follows up. Although this study is focused on violence as a factor that makes women avoid attending VCT, it also looks at some reasons for avoiding disclosure. If attending VCT can elicit violence, women anticipating violence may avoid disclosing their HIV positive status.

The lack of discussion of HIV/AIDS has a cultural dimension. Fapohunda and Rutenberg (1999) state that culturally in most Kenyan societies, sexual issues were almost always taboo topics and were never discussed among men and women irrespective of marital status. There is what they call a culture of silence on sexuality. Sex in most African communities is a taboo subject, it forms a part of language and our existence that people do not just talk about, it just happens. In their study, respondents said that they discuss respectable issues not unconventional issues like sexual matters. Some men consider discussing sexual matters with their spouses as relinquishing their power to the spouse and most men do not want to be seen to be taking advice from women.

Nyamwaya (1996) concurs that matters related to sexual behaviour are rarely discussed in public, as sex is a taboo subject in most Kenyan cultures. These texts are crucial to the study as they demonstrate the culture of silence that surrounds issues related to sex and sexuality. They point to some reasons as to why talking about issues to do with sex which is the heart of HIV in heterosexual transmission may pose communication challenges. These are not topics spouses just talk about.

FHI (2002) explain that “in some cultural settings, increased partner communication about sexuality may disrupt power imbalances in intimate relationships, leading to marital discord, suspicions of infidelity and even partner”. These factors may explain why some partners may avoid topics around sexuality including HIV/AIDS. They also note that sometimes when couples communicate they may do so indirectly. In an example from Uganda, although couples said they communicated with each other about whether or not to stop childbearing, they did so indirectly and ultimately ineffective ways. Some indirect communication included, overheard conversations, suggestive remarks, information gathered from a third party or nonverbal channels.

Wolf and Blanc (2000, as cited in, FHI, 2002) based on a study in Uganda suggests that, “because direct communication can generate conflict, it might be best to first promote direct discussions of such sensitive topics by having someone outside of the couple raise them in a public forum”. They found that usually it is the women who are more likely to avoid talking about reproductive health issues because if a discussion does not go well they are more likely to pay the price which could be violence, divorce or losing the opportunity to use contraceptives secretly.

Petronio et al. (1993) describes two strategies that couples use to communicate private information. These are explicit and implicit strategies. Explicit strategies are said to be direct and unambiguous and the message content is clearly articulated while implicit strategies are indirect. He however notes that topic avoidance maybe due to self-protection, relationship protection, partner unresponsiveness and social appropriateness.

Dodoo et al. (2001; Blanc et al. 1996, as cited in, Zulu & Chepngeno 2002) explain that husbands and wives may use non-verbal forms of communication. When one spouse perceives a need to communicate but the other does not, "the topic maybe broached because the other spouse is believed to oppose the issue being considered". Schatz (2002, as cited in Zulu & Chepngeno ibid. p.249) state:

> Couples may avoid direct verbal communication if one or both of them perceive the topic of HIV prevention so sensitive that to broach it would threaten the tranquillity of the marriage. Indeed a number of options exist beyond talking about the risk of HIV/AIDS when one feels that the other is endangering his/her life by indulging in extramarital affairs. One sometimes adopted by women is to discourage the other woman by harassing her or by going to her home and asking "is my husband there?" or even physically assaulting her.

FHI (2002) also looks at communication barriers and why couples are unable to talk about an issue that profoundly affects their quality of life and sexual health. From the Uganda data, they found that discussion about reproductive matters was discouraged by the belief that fertility should be left either to God or to male partners, many of whom were opposed to contraceptives. Another barrier to such discussions on ways to limit childbearing was the belief that discussing such matters raises issues of infidelity or implies that a man wanted to have children outside of the marriage. Hence attempts to discuss FP may raise doubts and thus the topic may be avoided. Straten et al. (1995, as cited in FHI, 2002, p.3) says that married women did not discuss condom use for fear of violence, withdrawal of economic support or suspicion of infidelity. FHI (ibid.) states that for some couples, the subject of sex is just too embarrassing to discuss.

Baxter and Wilmont (1995, as cited in Petronio 2002, p.103) identified six different topics that were off limits for people in opposite sex relationships. These topics include; talking about the state of the relationship, extramarital activities and relationship norms of behaviour in their relationship itself, prior relationships, conflict inducing topics and negatively valenced disclosures about the self."

Other factors that may inhibit spousal communication on FP also include household crowding, fatalism and perceived worthlessness of such discussions and dominance of other relatives such as mother-in-law and embarrassment about discussing FP (Lozare, 1976; Crisol, 1974; Poffenberger 1969; as cited in, Sharan & Valente, 2002).

Grinstead et al. (2001, as cited in FHI, 2002, p.3) indicates that in a US study, race and ethnicity may produce barriers to couple communication about sexual matters. They argue that "persons from different racial and ethnic groups of social networks may have different expectations about gender roles and communication in relationships". This study points to important factors that may affect communication. Other factors include age differences and education. FHI (ibid) notes that differences in age, education or other characteristics may affect communication between partners and power dynamics in the relationship.

Muturi (2005; Bozon, 1991; Cain, 1993; Luke, 2005, as cited in Chiao et al. 2009) argue that poor spousal communication may result from social and cultural norms that create gender imbalances where mostly it is the men who are in dominant positions relative to the women. These gender imbalances can affect the extent of sexual negotiations and behaviours. This would include influencing communication between spouses.

Sheon and Crosby (2003) in their study of MSM found that respondents justified their non-disclosure based on the community norms. According to the study, the gay community norms in San Francisco are that you just do not go asking or disclosing your status. Disclosure was seldom practiced. Although this is a study based on a gay community, it places disclosure within the context of community and social norms.

In an effort to help sexual partners discuss reproductive health matters, FHI developed a tool to help men and women communicate openly with each other about sex and other issues affecting their sexual health. This tool was referred to as *Dialogue*. It was first presented in 1996 in a women's conference. The tool has been used in different parts of the world including Africa. In 1997, the Indian Institute of Health Management Research (IIHMR) tested the tool Dialogue among 400 married men and women. The research showed that discussion about sexual matters barely existed. Interviews conducted after the *Dialogue* sessions showed "a marked change in men's and women's attitudes toward sex and sexuality. Dialogue helped create an enabling environment for a free and open discussion of sex and related issues". Similar strategies may help in disclosure of a HIV positive status.

There are also some cultures that prescribe women's silence and quietness on sexual matters. Silence and passivity in especially sexual matters are attributes of a good woman. In many societies, this culture of silence that surrounds sex dictates that women are expected to be ignorant about sex issues and passive about sexual interactions. This makes it difficult for women to be informed about risk reduction and even when informed makes it difficult for them to be proactive in negotiation of safe sex (Carovano, 1992). This power imbalance that defines gender relations and sexual interactions affects women's access to and use of health services. Kamau (2006, p.189) notes in her study that although girls use reproductive health services more than boys, boys open up more than girls when they have sexual health needs such as condoms and seeking STI services. This may point to differences between male and female disclosure patterns.

Derlega et al (1981, as cited in Petronio, 2002, p.45) note that, men are more willing to disclose about personal information that is perceived to be masculine in nature. This would include private information that reflects the man as successful, a good businessman and manager. This is attributed this to the way men have been socialised to value achievements, competition and success. On the other hand they observe that women tend to be more willing to disclose information that reflects them in a more feminine role. This would include information about marital status and number of children. They attribute this to the way women are socialised to value emotionality and sensitivity. This provides further insights on communication between spouses.

Generally, these works will provide further insights on communication between spouses, barriers to such communication and methods used in spousal communication. In the next section we look at some communication skills and supportive climate that can facilitate disclosure.

2.4 Communication Skills in Interpersonal Relationships

Wahlstrom (1992, p.133) suggests that "effective communication requires certain skills and that although some people are better communicators than others; good communication is a skill that can be learned". He gives the following interpersonal communication skills.

1. Positive self-regard: This refers to feeling worthwhile as a person and feeling good about oneself.
2. Listening: it is an active process that means paying thoughtful attention, or giving a special heed to what one is hearing.
3. Openness to change and diversity: This has to do with the ability to withhold judgement, understanding others and recognizing differences in others.
4. Empathy is the ability to see the world from another's perspective. It is making an effort to hear what a person has to say or feels without imposing one's own values, feelings and thoughts on another person.
5. Assertiveness means to develop a positive voice which affirms your right to be heard but not at the expense of others being heard.
6. Communication competency: This is the ability to tailor messages that are understood and that can accomplish what they are intended to do.

Leary (1957, as cited in, Kiesler 1996, p.57) talks of five levels of communication. Individuals may choose to interact on one level rather than another in their different conversations. The five levels are outlined below.

Level One: Refers to public communication targeting the overt behaviour of an individual. The communication process is objective or public rather than subjective or private.

Level Two: It refers to the verbal content of the statements that the subject makes about interpersonal behaviour of himself or others. It is subjective or private.

Level Three: It refers to private perception or private communication. It includes expressions that an individual makes indirectly about an imagined self or a symbolic world. This includes a person's fantasies, wishes and dreams.

Level Four: refers to those interpersonal themes which the person consistently, significantly and specifically omits in the other three levels. These are themes that are not expressed consciously. They are absent or avoided.

Level Five: Is concerned with values or ego ideals. It refers to the interpersonal traits and actions that the subject holds to be good, proper and right. It is the picture of how one should be and would like to be. It characterises how the person wants us to see their ideas, values they hold and value.

2.4.1 Supportive and defensive climate

Pearson and Nelson (1997, p.176) define a supportive climate as "an atmosphere of openness created when members care about each other and treat each other with respect". They argue that a supportive climate makes individuals feel safe to express themselves because they believe that other people value their opinions. In contrast, when members attack and judge each other, they create a defensive climate. This "is an atmosphere of tension in which members feel they must defend themselves from verbal and psychological attacks" (Pearson & Nelson, ibid. p.176). They also explain that supportive and defensive climates are created by what people say and how they say it.

Gibb (as cited in, Gamble & Gamble, 2002, p.361) identifies six behaviours that cause defensiveness and six contrasting behaviours that reduce the perceived threat which he calls supportive behaviours. These are illustrated in table 2.1.

Table 2.1 Behaviour Characteristics

Defensive climate	**Supportive Climate**
1.Evaluation	1.Description
2.Control	2.Problem Orientation
3.Strategy	3.Spontaneinty
4.Neutrality	4.Empathy
5.Superiority	5.Equality
6.Certainty	6.Provisionalism

Source: Gamble & Gamble, 2002:361.

Evaluation versus description: According to Gamble and Gamble (2002, p.361), individuals will be defensive "if by expression, manner of speech, tone of voice or verbal content the sender seems to be evaluating or judging the listener, then the receiver goes on guard". They state that the anticipation of judgment whether positive or negative hinders open communication climate. On the other hand, descriptive communication involves statements that describe actions without labelling them as good, bad, right or wrong.

Control versus orientation: If an individual perceives the other person as controlling, then it makes one defensive. If one comes across as intending to control or change one's beliefs or values, they are more likely to evoke defensiveness. On the other hand problem orientation communicates cooperation in solving problems and that one is open to new ideas. They are not trying to impose their opinions on others. This makes a person feel that their opinions are valued and they can express themselves.

Strategy versus spontaneity: An individual's defensiveness will increase if they perceive that the other person is having a hidden agenda or is trying to manipulate them. In contrast, spontaneous communication is honest, free of deception and manipulation.

Neutrality versus empathy: Neutrality is an attitude of indifference and lack of interest. An individual communicates that they are not interested thus evoking defensiveness. In contrast empathy communicates care, concern and warmth. The person communicates interest and that they value the other person as a human being.

Superiority versus equality: When a person communicates a sense of superiority the other person easily becomes defensive. This may be communication about their economic, education or social position. Gamble and Gamble (2002, p.362) state that, "when we receive such a message, we tend to react by attempting to compete with the sender, by feeling frustrated or jealous or by disregarding or forgetting their message". On the other hand a person who communicates equality is perceived as "willing to develop a problem solving relationship with us and that any difference between us is not important". Such individual come across as supportive and caring.

Certainty versus provisionalism: Gibb (as cited in, Gamble & Gamble 2002) notes that people who believe that they have all the answers and communicate an attitude of "know it all' make others defensive. In contrast provisionalism refers to an open minded attitude where one is flexible and open to different opinions from others.

2.4.2Core Conditions

Rogers (1961) expresses similar sentiments that people will only self-disclose if they feel safe and supported in a relationship. Rothwell (2000, p.46) emphasizes on the importance of trust in self-disclosure because of the risks involved. Rogers (ibid.)

believed that an individual opens up and is willing to disclose if they perceive a safe environment and relationship. I will briefly look at these conditions below.

Rogers (ibid.) believed that his clients were able to disclose only when an individual perceives safety and support communicated by the confidant in his case a therapist. He described these conditions as the core conditions viz. empathy, unconditional positive regard and genuineness. Griffin (2000, p.45) defines empathy or empathic understanding as follows, "the caring skill of temporarily laying aside our views and values and entering into another's world without prejudice. It is an active process of seeking to hear the other person's thoughts, feelings, tones and meanings as if they were our own". Glassman (1995) defines empathy as the ability to understand another person's perceptions, thoughts and feelings.

Unconditional positive regard means communicating genuine care for the other person and that any behaviour that is overtly or covertly judgmental is avoided (Glassman, 1995). This involves communicating acceptance and that the other person is valued as a human being.

The third condition is genuineness or congruence. Griffin (2000, p.45) says that "congruence is the match or fit between an individual's inner feelings and outer display. A congruent person is genuine, real while a non-congruent person plays a role and hides behind a façade".

Although Rogers is concerned with a counselling relationship in a therapeutic setting, his core principles on relationships are important to all interpersonal relationships in other contexts. People are more likely to disclose information about themselves to people they trust and those perceived to pose minimum risk and to have supportive communication behaviours. These are people who communicate the message and attitude that says “it is okay you can talk to me”. On the other hand, individuals may avoid disclosure to people they perceive to exhibit defensive communication behaviours. This approach throws some light as to why some people may choose to disclose to people they perceive to possess certain communication skills and behaviours and not to others.

2.5 Literature Relating to Theoretical Framework

In this section I have reviewed literature that relates to the theoretical principles of CPM. I have looked at the Social Penetration Theory (SPT) and Cognitive Social Learning theory as I find that they have a great bearing on this study.

2.5.1 Social Penetration Theory

This theory was developed by Irwin Altman and Dalmas Taylor. It describes human relationships between two people in a process they refer to as social penetration. Social penetration refers to “a process of relationship bonding whereby individuals move from superficial to more intimate communication” (West & Turner, 2000, p.148). According to them, intimacy involves physical, intellectual, emotional and shared activities. Also different relationships differ in intimacy levels or degree of social penetration.

The first concept is that of relationships and onions. Altman and Taylor use the analogy of an onion to look at human relationships. They believe that a person can be compared to an onion representing the multi-layered nature of personality. The outer layer represents an individual’s public image (West & Turner, 2000, p. 152). As one discloses more information about the self, they reveal additional layers and penetration deepens from the top layer information that is public knowledge to the next layer and eventually to the inner layer. The top layer may include information about one's physical traits which is in the public domain. Beneath the top layer are other mid layers that eventually lead to the inner core layer.

According to Griffin (2000, p.127), "the inner core is made up of one's values, self-concept, unresolved conflicts and deeply felt emotions and that it is a unique private domain which is invisible to the world and contains some closely guarded secrets". This domain is not accessible to the public or other people unless one chooses to share that information with them. People tend to exchange top layer information frequently and sooner than private deeper layer information. For most people, their HIV positive status is a guarded secret which they may or may not choose to share with others.

A second concept is that of reciprocity. This is "a process in which one person's openness leads to another person's openness" (West & Turner, 2000, p.152). Reciprocity is significant in both established and new relations although it tends to be more especially at the early stages of relationships. Rosenfeld and Bowen (1991, as cited in West & Turner 2000, p. 153) found that marital satisfaction was highest when spouses reciprocated self-disclosure. Some studies have indicated that individuals who know their partners HIV status are more likely to disclose to them.

Brehm, Kassin and Fein (2002, p.333) observe that during first encounters in a new relationship, people tend to reciprocate disclosure at a comparative level of intimacy. Once a relationship is well established, strict reciprocity occurs less frequently.

Another concept is that of breadth and depth of self-disclosure. The theory perceives penetration in two dimensions: breadth and depth. Breadth refers to “the number of various topics discussed in a relationship while breadth time refers to the amount of time that relational partners spend communicating with each other about these various topics while depth refers to the degree of intimacy that guides topic discussion” (West & Turner 2000, p.123). This is concerned with whether issues are discussed at the top layer level or at a more personal deeper level. Breadth without depth describes the typical “Hi, how are you” casual relationships (Griffin, 2000).

The beginning or initial stages of a relationship are characterized by narrow breadth and shallow depth and as a relationship moves towards intimacy, it is expected that a wider range of topics are discussed (more breadth) with more depth (West & Turner, 2000, p. 153). Issues of greater depth such as one’s HIV positive status may thus not be easily discussed as they put the person at greater risk and vulnerability. West and Turner (ibid.) note that trust is an inherent part of the disclosure and reciprocity. Knapp and Vangelish (1996, as cited in West & Turner ibid.) concur that “self-disclosure of intimate information is based on trust”. Griffin (2000, p.129) notes that there is internal resistance and societal norms against telling too much too fast.

Relational costs and rewards is another concept. Social penetration theory is influenced by the Social Exchange Theory principles of costs and rewards. According to this theory, people weigh the costs versus the benefits of a given relationship or situation which then guides their decision accordingly. Relationships are viewed in terms of costs and rewards where individuals seek to minimize costs and maximize profits. In the case of a HIV positive individual, one weighs the costs against the benefits of disclosing their HIV positive status. Pearson et al. (2003, p.182) argue that “every relationship we have has inherent costs and rewards,” West and Turner (2000, p.180), define costs as “the elements of a relationship that have negative value and rewards as those that have positive value”. Gamble and Gamble (2002, p.236) refer to benefits as including “feelings of self-worth, a sense of personal growth, a greater sense of security, additional resources for accomplishing tasks and an increased ability to cope with problems”. They view costs as including “the time spent trying to make the relationship work, psychological and physical stress and a damaged self- image”.

Individuals in a relationship engage in a cost-benefit analysis, weighing the costs against the rewards. Hence, if a relationship provides more rewards than costs then individuals are likely to stay in that relationship. If more costs are perceived, then the relationship is likely to dissolve. The theory suggests that we enter relationships with a comparison level in mind (CL). This is a general idea or standard of expectation of rewards and costs that we should get in a relationship. When the rewards exceed our expectations (CL), then we feel satisfied with the relationship. There is also a comparison level for alternatives (CLalt) which allows individuals to compare rewards in a current relationship with what they think they may get in another relationship. If, for instance, the rewards they are getting from the current relation are so low compared to their expectations, then they may dissolve the current relationship.

According to Altman and Taylor (1973), communicators assess the rewards and costs of the relationship or situation at that moment and can also predict rewards and costs they think can occur later. The decision to disclose or conceal information is based on the perceived rewards and costs. If a person perceives the cost of disclosure as greater than the rewards, then they may not disclose the information. If they perceive the rewards to be relatively higher than the costs, then they will risk disclosure. Individuals strive to minimize costs and maximize rewards. According to Omarzu (2000, as cited in Brehm et. al. 2000), “whether or not to self-disclose, what, when, how much and to whom is a decision that each of us makes based on a consideration of what we stand to gain or lose in a relationship.”

The social exchange principles of costs and benefits predict that the worth of a relationship influences its outcome (Gamble & Gamble, 2002). The theory helps to explain situations in which people may risk or avoid disclosure depending on the perceived costs or benefits of the relationship with their spouses. If individuals perceive more benefits than costs from disclosure, they may be more willing to disclose as compared to those who perceive higher costs. In HIV disclosure, an individual may for instance weigh the cost of rejection against the benefit of protecting an unborn child from HIV infection.

The social penetration process involves different stages as given in West and Turner (2000). These are; orientation stage, **e**xploratory affective exchange, affective exchange and stable exchange. The initial stage of interaction is characterized by superficial, courteous and polite communication which develops to a more friendly, spontaneous and open expression of thoughts in the stable stage.

2.5.2 Cognitive Social Learning Theory

Albert Bandura (1986, 1994 and Walter Mischel (1973, 1995, as cited in Santrock 1997) are the architects of the contemporary social learning theory referred to as the cognitive social learning theory. The theory represents “an approach to socialization and individual development that stresses the process of observation, modelling, imitation, internalization and cognitive or internal thought processes” (DiRenzo, 1990, p. 139). Social learning theorists believe that we are not "mindless robots responding mechanically to others in our environment, but rather we think, reason, imagine, plan, expect, interpret, value and compare" (Santrock 1997, p.413).

According to Bandura's theory, the power of models is a crucial component in modifying behaviour (Brehm et al. 2002). The theory emphasizes that we learn from examples of others as well as direct experiencing. Todd and Bohart (1994, p.349) state:

> Most important human learning is vicarious learning. People do not learn important skills in life by performing trial and error responses until one is reinforced…instead most individuals' important learning is through observation and instruction. People learn through watching other's behaviour, reading books or gathering information from others from other media and receiving instructions. People learn both how to interpret situations and what to do in a given situation.

Bandura believes that much of our learning occurs by observing what others do. This is referred to as observational learning through which we form ideas about the behaviour of others and then possibly adopt that behaviour. Bandura had noted the relationship between being abused as a child and becoming a child abuser in adulthood. As a child one may have learned that a person with more power has the right to abuse or inflict pain on a person with less power. Bandura argues that although no one explicitly verbalizes this behaviour as a rule, the child observes the adult modelling the behaviour. When such a child becomes an adult, they may portray similar behaviour patterns. However, we can regulate and control our behaviour as one can reflect on a situation considering their values and then make a decision. I will look at the theory's key concepts as outlined in Todd and Bohart (1994).

One of its key concepts is Situational specificity of behaviour. Social learning theorists believe that behaviour is situation specific and that behaviour is guided by the expectancies in a specific situation. Behaviour is guided by what one has learned to expect in a specific situation and thus one may act quite differently in a different situation.

Communication has a past, and one can rely on past experiences to make a decision in the present. For instance, if from past experiences a spouse has been supportive when you are in difficulty, you may easily talk to them about a current difficult situation. If on the other hand from past experience, a spouse has exhibited a non-supportive behaviour, then one may withhold information and choose not to disclosure. This may help me understand why some individuals may or may not disclose their HIV positive status to their spouses. Some PLWHIV may disclose their status to certain individuals and not others based on perceived expectancies. Some studies have indicated that women avoid disclosure to avoid violence from their partners (Temmerman et al. 1995 and Maman et al. 2001; Gielen et al. 2000). If individuals perceive a situation to have negative consequences, they may avoid it.

According to this theory, the idea is that the situational specificity is important in predicting what one will do in a given situation. Hence, behaviour in a particular situation is dependent on the perceived outcomes or expectations. As a PLWHIV, one may make a decision on whether to disclose or not based on perceived outcomes or expectations of the disclosure.

Another key concept is self-efficacywhich is “a person’s self-perception of competence to enact behaviour or to handle a given type of situation” (Todd &Bohart,

1994, p.349). It refers to an individual's belief in their own personal ability to do something. One may perceive themselves as not having good communication skills hence they have a perception of low self-efficacy as a communicator. According to Bandura (as cited in Todd & Bohart, 1994, p. 349) low self-efficacy has a number of negative consequences. It leads to:

1. Avoidance as people are likely to avoid situations in which they feel incompetent.
2. Defensive behaviour which is a response to perceived low self-efficacy. One acts defensively when they believe that they cannot handle something.
3. A tendency to give up too soon. As a result a person does not persist long enough to find out if they can master a situation.
4. A tendency to self-monitor in a self-destructive manner as one engages in negative self-evaluation.

From the above, the concept of self-efficacy helps to clarify why some PLWHIV may avoid disclosure because they feel unable to disclose as they perceive themselves as lacking the skills to do so. If this is the case, this study will be interested in finding ways in which the levels of self-efficacy among PLWHIV can be enhanced to increase disclosure. Kalichman and Nachimson (1999) suggest that self-efficacy; beliefs were closely associated with decisions to disclose status to the partners as well as negotiating safe sex practices. They found that low self-efficacy is related to withholding information about HIV status. People may not disclose due to lack of confidence in their ability to disclose.

Another concept is that of social skills training. Related to the concept of low self-efficacy is the idea that behaviour problems may be based on a lack of skills to handle situations. Bandura (1994, as cited in Todd & Bohart, 1994, p.350) argues that "raising the level of perception of self-efficacy is the most potent therapeutic change event and that verbal persuasion is probably the least effective way to do this". Bandura (ibid.) observes that to achieve, "self-directed change, people need to be given not only reason to alter risky behaviour but also behavioural means, resources and social support to do so". Todd and Bohart (1994, p.350) state:

> Performance based therapeutic interventions are more effective than verbal ones. Direct experience is a more potent teacher than words delivered in a therapeutic setting. He believes that therapy must include situations where individuals actually engage in successful mastery experiences and that the therapist must arrange therapeutic tasks so that mastery experiences occur. This can be done with the aid of therapist guidance and modelling or through the use of carefully graduated steps.

Social modelling is based on the idea that people learn vicariously by observing others and people are likely to judge their abilities partly by comparing themselves with others especially in similar circumstances (Hanan, 2009). This may be the thought behind programs such as condom use demonstrations where individuals are shown step by step use of the condom. In 2006, when then Senator Barrack Obama, now the president of the United States of America visited Kenya, he and his wife publicly tested for HIV. This may have encouraged some people to get tested. When Michael Jordan publicly announced his HIV status, people started talking about HIV a little more openly. This can also be noted in the use of support groups for PLWHIV which allows individuals to interact and share with other PLWHIV.Melkote and Steeves (2001, p.133, as cited in Hanan, ibid.) states that the social cognitive theory "is useful in campaigns on HIV/AIDS because of its holistic approach that provides knowledge, skill and confidence to undertake preventive measures against HIV/AIDS."

Most social learning theorists are interested in social skills training programs such as stress management skills, assertiveness training and communication skills programs. A good example of this kind of program is the “Say No” campaign where individuals especially the youth are trained on ways to say “No” for instance to sex. Paul (1991, as cited in, Todd & Bohart, 1994) found that “social skills training programs were considerably more effective in helping hospitalized patients than the typical hospital regimen such as group therapy.”

This theory will help the researcher understand why some individuals disclose while others do not. It could be that some PLWHIV, avoid disclosure because they feel they lack the skills to disclose their HIV positive status despite being told by the counsellor or health care provider of the need to disclose. Are PLWHIV equipped with any skills on how to disclose or they are verbally told to disclose to their partners? The theory provides insights on how individual’s decision to disclose or not is influenced by perceived expectancies and self-efficacy.

2.5.3 Theories of HIV disclosure

Serovich et al. (2008) examine the applicability of two theories of HIV disclosure among HIV positive women. They studied 125 HIV positive women participating in a longitudinal study of HIV disclosure and mental health. The two theories are the Disease Progression Theory and the Consequence theory.

According to the Disease Progression Theory, “individuals disclose their HIV diagnoses as they become symptomatic, it is suggested that as the HIV progresses to AIDS, individuals can no longer keep their HIV status a secret” (Babcock, 1998; Kalichman, 1998, as cited in Serovich, 2008). As the diseases progresses individuals need to explain the frequent hospitalizations, physical deterioration, drug use or need for social or financial support. Holt et al. (1998, as cited in Serovich, ibid.) notes that individuals may disclose as they may need to explain their hospitalization or need additional help to manage their illness. On the other hand some individuals may delay disclosure as a way of normalizing the situation and protecting others from pain (Babcock, 1998, as cited in Serovich, ibid.).

The Consequence theory of HIV disclosure suggests that “disease progression influences disclosure through individuals’ perception of the consequences anticipated as a result of disclosure” (Serovich, 2001, as cited in Serovich, 2008). Hence HIV positive individuals will weigh the costs against the benefits and will disclose if the benefits outweigh the costs of disclosure. These are principles similar to the social exchange principles that we looked at earlier.

Some of the costs for disclosing HIV positive status among women include violence, stigma, parental worrying and rejection, loss of respect and discrimination. Rewards or benefits of disclosing HIV status include acquiring emotional, physical and social support and resources such as help with household chores, medical attention and relief from a burdensome secret. According to Serovich (ibid.) most of the rewards among women were observed to be “other and not self-oriented”. The women’s concern focused on keeping others safe from HIV rather than them.

The study concludes that the Disease Progression theory was not as predictive of disclosure of HIV status as thought while consequences were seen as predictive of disclosure. This work is important to my study as I will be looking at principles of the consequence theory which may help explain why some people may or may not disclose. However, the current study will look at disclosure among both men and women.

2.5.4 The Johari window

One way to describe the process of self-disclosure is to use the Johari window as a model. It is derived from blending the names of its proponents Joseph Luft and Harrington Ingham (Johari). It represents a person in relation to others and explains the value of self-awareness and self-disclosure in human interactions. We all make choices about what information we disclose to others and what we keep to ourselves. The Johari model explains how the process of self-disclosure works in human communication using four quadrants or windowpanes as shown in Figure 2.1.

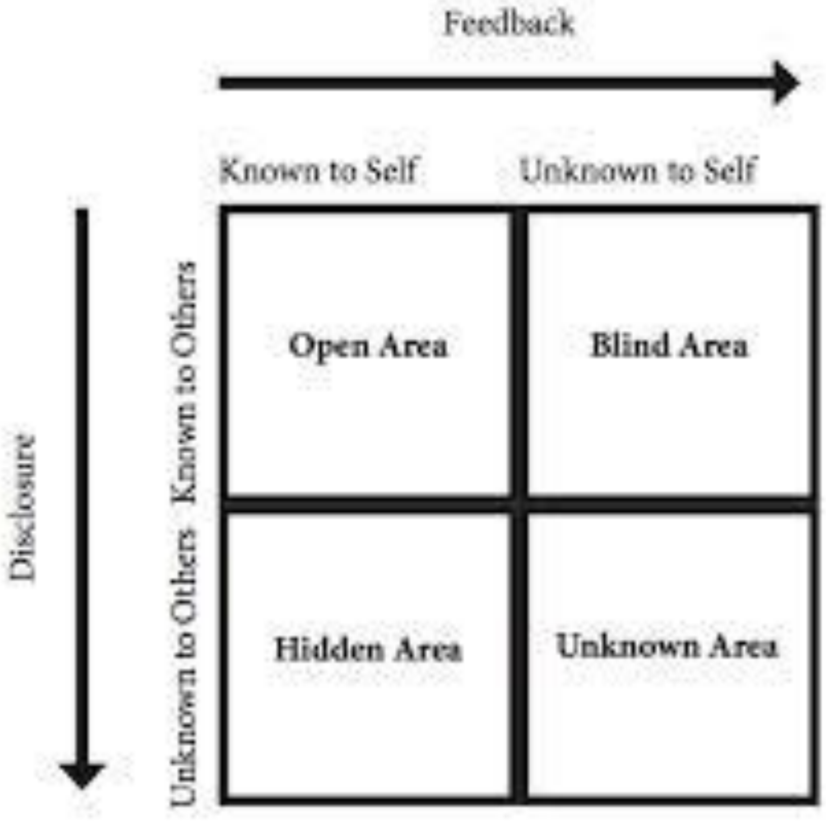

Figure 2.1 Johari Window

Source: Tubbs, 2001:75.

The window has four quadrants or panes, which represent an individual in relation to others. The division of the quadrants is based on the person's awareness of behaviours, feelings and motivations. Sometimes we share information about ourselves with others and sometimes conceal it. Tubbs (2001) notes that, "information, an act, a feeling or a motive is assigned a quadrant depending on who knows about it and that the size of the quadrant changes as the awareness changes."

The Johari window identifies four kinds of information about an individual that play a part in communication (Logan & Stewart, 1993; Tubbs, 2001). Quadrant one, the open pane, involves information about ourselves that we are aware of and are willing to share. This is the kind of information generally referred to as public information. Quadrant two, the blind pane involves information that others know about us but we are not aware of. This may include things we do unknowingly or unintentionally such as, turning one's wedding band when talking or repeating a particular phrase. This is behind many nicknames for teachers in most Kenyan schools.

Quadrant three is the hidden pane. It has information that one knows but they do not want known by others and is unwilling to share it. There are certain things that one knows but deliberately conceals from others. It may be information about one's sexual fantasies, sexual orientation or past occurrences that would rather remain in the hidden panel and unknown to others. Information about one's HIV positive status may be in this pane and one makes a decision to either move it to the open quadrant or withhold it in the hidden quadrant. Moving information from this pane to pane one is self-disclosure. One may keep certain areas hidden from one person but open to another.

Quadrant four or the unknown pane is a non-disclosure area. It entails aspects of a person that neither they nor others are aware of. This kind of information may be revealed in psychotherapy. This may include traumatic experiences that have been repressed.

The panes vary from one relationship to another and also change within the same relationship. When disclosure increases, people not only reveal more information about themselves but are also more likely to discover things about themselves that they had not known before (Weaver & Hybels 1995, p.164).

In self-disclosure, one takes information from the hidden pane and moves it to the open pane. An individual is in control of the third quadrant. What is disclosed is largely up to an individual, though not entirely as sometimes pressure from conflicting forces in all the quadrants may force accidental disclosure for instance, slips of the tongue. Bradshaw (1995; Tubbs, 2001, p.72) observe that “it takes a lot of energy, attention and good imagination to do a good job of keeping information hidden”. Individuals will disclose if they feel safe to disclose.

2.5.5 Application of CPM

I also reviewed works that have used CPM theory. Metzger (2007) looks at how individuals manage disclosure and privacy in e-commerce. She found that online consumers erect boundaries around their personal information and form rules that regulate what information they decide to reveal online. This is helpful study as he is applying the CPM theory although in e-commerce.

Allman (1995, 1998, as cited in Petronio, 2002, p.205) looks at how doctors manage privacy in the area of medical mistakes. For a doctor, revealing a medical mistake jeopardizes his medical career and a possible law suit from the patient or patient’s relatives. Allman (ibid.) found that medical mistakes are “often linguistically revised to take the sting out of the prospect that physicians made poor judgements”. The mistake is framed and presented in a manner that saves face of the doctor”. This study is relevant to the current study as it looks at how privacy is managed albeit in a different context.

CPM has also been used to identify rules that children who have been sexually abused use to manage their privacy boundaries in revealing or concealing the abuse (Petronio, Reeder et. al. 1996; Petronio, Flores and Hecht, 1997, as cited in Petronio, 2002, p.210).

Petronio et al. (ibid. p.211) identified three privacy access rules that the children used. These are tacit permission, selecting the circumstances and incremental disclosure.

CPM has also been used in the area of HIV/AIDS. Greene and Serovich (1996, as cited in Petronio, 2002, p.219) look at the hierarchy of disclosure rules and found that intimate or married couples tend to select each other as the most desired disclosure recipients about HIV status information. Extended family members were the least desirable confidants. Greene at al. (2003) looks at privacy and disclosure of HIV in interpersonal relationships. This is a relevant work to this study as it explains the basic concepts of the theory and their application in HIV disclosure.

2.6 National Guidelines for HIV Testing and Counseling in Kenya

NASCOP (2008) notes that HIV testing and counselling (HTC) is the main entry point to prevention, care and treatment. HTC has been emphasized by health care professionals as a major entry point to HIV prevention, care and support. WHO defines HIV counselling as “a confidential dialogue between a client and a counsellor aimed at enabling the client to cope with stress and make personal decisions related to HIV/AIDS.The counselling process includes evaluating the person’s risk of HIV transmission and discussing how to prevent infection” (FHI, 2004, p.34).

According to FHI (ibid.), HTC plays two main roles. One, is that of preventing HIV infection by promoting behaviour change and two, that of providing psychosocial support for the infected and affected by HIV. The Kenya government in line with the UNAIDS goal of universal access had set a goal of 80% access and knowledge of HIV status by 2010 (NACC, Draft Report, as cited in NASCOP, 2008).

2.6.1 HIV testing and counseling approaches

There are two main types of HTC approaches in Kenya. These are: client-initiated HTC which is commonly referred to as voluntary counselling and testing (VCT) and Provider-initiated HTC (also called PITC) which was previously referred to as Diagnostic HIV testing and counselling (DTC). While DTC was mainly targeting people who are sick presenting with HIV related symptoms, PITC targets all clients seeking services in the health facility. According to NASCOP (2008, p.1), this is "based on the recognition that many HIV positive clients are symptom free and the health facilities can provide an opportunity where they can learn their HIV status".

Client initiated HTC refer "a situation whereby an individual, couple or group actively seeks out HIV testing and counselling at a site where these services are provided and /or accessible" (NASCOP, 2008, p.4). The person wishing to know their status takes the initiative to seek and request for the HTC services. It may be motivated by various reasons such as perceived risk of HIV infection or frequent illness.

According to NASCOP (2008, p.4) provider initiated HTC refers to "a situation in which the HTC service provider, who may be a health care worker or other type of HTC service provider, offers a HIV test to a client or patient regardless of their reason for attending the facility."

There is also self-testing where an individual tests themselves for HIV. In this pproach, the individual does not access the education and counselling component that is part of the other two approaches.

HTC was launched in Kenya in 2001 and started with three pilot sites in government health facilities. By the end of 2007, there were 900 VCT sites in Kenya most of which are in health facilities also called integrated sites while about 15% of them are in community settings often referred to as “stand alone sites” (NASCOP, ibid.). This study will be based on health facility settings in Kirinyaga County.

The HTC approaches in Kenya have witnessed changes from a focus on the primarily client initiated approaches to other approaches. Other models of HTC include mobile, moonlight or door to door HTC. Some HTC service providers target groups with special needs such as the youth or men who have sex with men (MSM).

2.6.2 HIV testing and counselling settings

HTC can be provided in various settings. NASCOP (2008, p.7) gives the following settings. One is the community based settings whose goal is to “strengthen the social elements of HTC prevention, family level counselling and links to support groups” (NASCOP, ibid.). Some examples of community based sites are stand alone, outreach, home-based and workplace HTC.

2.6.3 HIV testing and counseling service

NASCOP (2008, p.15) gives three key components of HTC. These are Pre-test session, HIV test and Post-test session. The pre-test session gives the client wishing to take a test some basic information about HIV, a forum to ask questions and give consent to testing. Some issues to be talked about include information on benefits of knowing one’s HIV status; benefits of couple testing; an explanation of the HIV testing process; the need for consent; risk assessment; referral to support, care and treatment and importance of disclosure to partners and other family members. This is followed the actual HIV test. In most settings, the rapid test is used.

After the HIV test, the HTC service provider must offer post-test counselling based on the HIV test results. The services include risk reduction information, emotional support and referral for appropriate follow-up services. In all the three steps above HTC is guided by three core principles of consent, confidentiality and counselling (NASCOP, 2008, p.19).

Individuals who test positive are advised by the health care provider to start antiretroviral therapy (ART) tailored to their individual needs. NASCOP (2001, p.26) defines ART as "a part of comprehensive HIV care which includes counselling, psychological support and nutritional support, prevention and treatment of OIs (Opportunistic Infections) reproductive health care (including contraceptives where needed pre-pregnancy counselling, PMTCT, STI prevention and treatment to screening for cervical cancer in addition to HIV drug treatment". ART is offered at different health centres across the country. Several government and private health institutions have what is referred to as comprehensive care centreswherePLWHIV can access care and treatment.

2.6.4 Disclosure to a sexual partner or other persons at risk

In regards to HIV disclosure to a sexual partner or others at risk, NASCOP (2008, p.22) explains that:

> HTC workers should encourage and support clients and patients to disclose their HIV status to their sexual partners and other persons at risk. If efforts to encourage individuals to disclose their HIV status fail, and yet they are placing a sexual partner at risk, a medical practitioner may disclose someone's status to their sexual partner or other person at risk. However, persons must be given a reasonable opportunity to disclose their HIV status to sexual partners or other persons at risk, before a medical practitioner intervenes.

Disclosure of an infectious disease is crucial for public health and enshrined in the laws and policies such as the Public Health Act and the HIV prevention and Control Act. The HIV/AIDS prevention and Control bill of Kenya states that, "A person who is and is aware of being infected with HIV… shall take reasonable measure to prevent the transmission of HIV to others and inform in advance any sexual contact or person with whom needles are shared of the fact" (Republic of Kenya, 2003, p. 814). A person who contravenes this commits an offence. This can attract a fine of up to five thousand Kenya shillings or imprisonment for a term not exceeding seven years or both. The national guidelines on VCT states that, "all VCT clients, both HIV positive and HIV negative, should be encouraged to inform their sexual partners of their test results" (NASCOP, 2001, p. 5).

The AIDS epidemic has introduced conflict between confidentiality and the dictates of public interest. On one hand, guarantee of confidentiality encourages people to seek health care and support services. On the other hand this confidentiality compromises public interest, especially when an infected person engages in unprotected sex despite being counselled to notify their sexual partner. There is conflict between the duty or obligation to protect others and the right to privacy. Regardless of what the law may compel us to do or counsellors recommend, disclosing one's HIV positive status remains an agonizing process.

2.7 Chapter Summary

Chapter two looked at the literature reviewed. I looked at literature in the different areas of HIV, disclosure, conceptual framework and methodology. The next chapter outlines the research methodology.

CHAPTER THREE:RESEARCH METHODOLOGY

3.0 Overview

This chapter describes the research design and methodology used in this study. It entails an outline of the research design, study area, sampling procedures, data collection, data analysis and ethical issues. The study is designed to investigate factors influencing disclosure and non- disclosure ofHIV positive status among PLWHIV to their spouses in Kirinyaga County. It will also examine the role of perceived spousal communication behaviours on disclosure and non-disclosure of HIV positive status among PLWHIV to their spouses, methods of disclosure and challenges faced in disclosure and how they can be overcome.

3.1 Philosophical Paradigm

All research is based on some underlying philosophical assumptions. This study is guided by the relativist ontology and the interpretive epistemology. According to Levers (2013, p.3) relativist ontology is the belief that reality is a subjective experience. Hence there is no single universal reality, but multiple realities as individuals' interpret and make sense of their experiences and their world. Nigel and Horrocks (2010, p.9), note that relativist ontology maintains that "the world is unstructured and diverse and that our understanding and experiences are relative to our specific cultural and social frames of reference being open to a range of interpretations". Reality thus is socially constructed through the meanings that human beings associate with their circumstances and experiences.

Benoliel (1996, p.407, as cited in Levers, 2013, p.3) explains that interpretive epistemology views knowledge as relative to particular circumstances, historical, temporal, cultural, subjective and exist in multiple forms as representations of reality by individuals. The researcher seeks to explore and understand the social world through the participants' perspective and explanation (Ritchie and Lewis, 2003).

The current study is concerned with the experiences and meanings that PLWHIV make of their circumstances and experiences. The researcher seeks to get detailed in-depth information from their perspectives. The analysis also uses their accounts. However, to enrichen the study I also use information from different sources such as key informants.

3.2 Study Area

The study was conducted in Kirinyaga County which includes five Sub-Counties namely; Kirinyaga East, Kirinyaga West, Mwea East, Mwea West and Kirinyaga Central. The County is one of the administrative Counties in Central Kenya with its headquarters in Kutus town. It has a population of 528,054 and an area of 1,479 km2 (Kenya Population and Housing Census, 2009). It borders Nyeri and Muranga Counties to the West, Embu County to the South and to the East. Kirinyaga County has four constituencies namely, Ndia, Gichugu, Mwea and Kirinyaga-Kutus (**See appendix iii).**

The choice of Kirinyaga County as the area of study was based on several factors. One is the fact that Kirinyaga is predominantly rural. KAIS (2012) indicates that "prevalence levels in rural areas may be approaching those of urban populations, reflecting an expansion of HIV epidemic towards rural areas". The study also notes that although the prevalence rate is lower in urban areas, the burden of the disease is greatest in rural areas since majority of Kenyans live in rural areas. Hence, there is need for measures to prevent and address HIV/AIDS in rural areas.

A key consideration in my choice of the study area is the fact that Kirinyaga County is not well represented in terms of research on issues of HIV/AIDS and specifically on disclosure to spouses. There is paucity of research on HIV/AIDS issues in most rural areas. Research on HIV/AIDS mostly concentrates in areas seen as having high prevalence rates. These include: Nairobi, Western, Coast and Nyanza. Few, if any studies have been carried out in Kirinyaga County on HIV/AIDS. To the best of my knowledge, I am not aware of any formal research on this subject, and this is the first study addressing HIV/AIDS disclosure in Kirinyaga County. Another reason for selecting the study area is due to proximity as it is my home area. This study is intensive and it requires me to be on the ground a great deal. Hence, selecting Kirinyaga County is cost effective in carrying out the research as the study is self-funded.

The Kirinyaga District Strategic Plan (2005-2010, p.8) gives the highest prevalence rates as being in the urban and peri-urban centres. Those cited with the highest prevalence rates are Kagio, Wanguru, Kagumo, Sagana, Kutus, Kirinyaga, Kerugoya and Baricho. These are mainly agricultural produce markets and commercial centres. According toThe CRA-Kenya: County Fact Sheet (2013), the largest towns in Kirinyaga County are Wanguru in Kirinyaga North with a population of 23,983 in first place, followed by Kerugoya/Kutus in Kirinyaga central with 19,422 and in third position Sagana in Kirinyaga West with a population of 10,551. These are followed by Kagumo with 3,449 and Kagio with 3,357 people. This was a key consideration when selecting the study sites in the three largest towns which also have high prevalence rates. I selected Mwea mission hospital commonly referred to as by the locals as Karira hospital near Wanguru in Mwea East, North; Kirinyaga District hospital in Kerugoya town, in Kirinyaga Central and Sagana health centre in Sagana town in Kirinyaga West. The Pre-testing was carried out at Baricho health centre in Baricho town in Kirinyaga West.

3.2.1 Health facilities in Kirinyaga County

Health can be defined in different ways. The World Health Organization (WHO) definition of health adopted in 1948 defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2003).Cottrell et al. (2002, as cited in Hawks, et al. 2007) explains that health is multidimensional and requires a balance among different elements of physical, emotional, intellectual, social and spiritual health. Each of these contributes to a person's wellbeing. Although some individuals may focus their attention on only one aspect of their health such as physical health by exercising, it is important to enhance the different aspects of health. All the elements are important and work together for the overall health of an individual and the key is to balance the various aspects as each one has an effect on the others. Health is a basic human right.

HIV/AIDS affects the individual's wellbeing emotionally, intellectually, physically, socially and spiritually. The Kenya government in collaboration with other health care providers such as Faith Based Organizations (FBO), Non-Governmental Organizations (NGO) work together in an attempt to meet the health needs of the Kenyan people. The Kenya Vision 2030 has a goal "to provide an efficient and high quality health care system with the highest standards" (GOK, 2007, p.20).

Kirinyaga County has a variety of health facilities both governmental and non-governmental. These include five hospitals, nine health centres, two nursing/maternity homes, 64 dispensaries and 82 clinics. It is also served by 46 pharmacies (District Health Record, Kirinyaga District Health Plan, 2007/2008). This is summarized in table 3.1.

Table 3.1 Health Facilities in Kirinyaga County

Type of Facility	GOK	FBO	NGO	Private	Total
Hospital (Sub/District)	2	2	0	1	5
Health Centre	7	2	0	0	9
Nursing/Maternity Home	0	0	0	2	2
Dispensary	37	27	0	0	64
Clinic	0	0	0	82	82
Private Pharmacies	0	0	0	38	38
Community Pharmacies	0	8	0	0	8

Source: District Health Record, in Kirinyaga District Health Plan 2007/2008:9.

According to the District Strategic Plan, the average distance to a health facility is about 6.32 km. The doctor: population ratio is about 1:79,690. From the list of human resources available contained in the District Health Plan 2007/2008, there is no category for counsellor despite the fact that counselling and testing (CT) services are offered in some of these facilities. This raises the question of who offers the CT services.

3.3 Research Design

The study employs qualitative methods of research. According to Baumgartner et al. (2002, p.209) the term qualitative research is "an umbrella term that refers to several research traditions and strategies that share certain commonalities. They focus on process, on how things happen, attitudes, beliefs, and thoughts and how people make sense of their experiences as they interpret their world". Qualitative research assumes that meaning and reality is situation specific, thus allowing for many meanings none of which is more valid

(Baumgartner et al. ibid. p.24). For example, while one PLWHIV may not disclose for fear of rejection another one may disclose for fear of infecting the spouse or to get support. Similarly, disclosure may elicit support from one spouse and rejection from another.

HIV disclosure revolves around personal choice on whether to disclose or conceal information about one's HIV positive status. It is about an individual's feelings, attitudes and choices which are best understood using qualitative methods of research. Qualitative methods in this study are used to gain more insight into factors that facilitate or prevent disclosure of HIV positive status. Qualitative methods are utilized because they are best suited to getting to the depth and understanding of an issue or idea concerning an individual or a group and why certain views are held, such as the motivation behind their behaviour (Obeng-Quaidoo, monograph 4, KIMC).

Quantitative methods are unlikely to provide detailed explanations for observed patterns of behaviour or a phenomenon such as the perceptions and motivations of the PLWHIV in disclosure. Qualitative methods were used to reveal personal accounts and perceptions of the PLWHIV. FHI (2005) explains that qualitative research is effective in obtaining culturally specific information about the values, opinions, behaviours and social context of particular populations. Due to the sensitive nature of the topic on HIV disclosure, qualitative methods were used.

The strength of qualitative research lies in its descriptive richness and sensitivity as it seeks to gather informants' personal accounts of stories (Palmer & McMahon, 1997). FHI (2005) states that a strength of qualitative research is its ability to provide complex textual descriptions of how people experience a given research issue. It gives meaning to people’s experiences. A limitation of qualitative data is that the results will not be generalized. However, I would concur with FHI (ibid.) that, “although qualitative results cannot be generalized, they can often be extended to people with similar characteristics and that understanding a specific social phenomenon typically takes precedence over eliciting data that can be generalized."

3.4 Target Population and Sampling Procedure

The primary population selected for this study were HIV positive individuals (PLWHIV) in Kirinyaga County. We also talked to HTC service providers and individuals working in field of HIV/AIDS in the County representing government, Community Based Organizations (CBO) and FBOs.These were the key informants. A total of 108 PLWHIV and seven key informants were interviewed. However, ten were discounted and this left 98 PLWHIV, 34 males and 64 females. According to the Kenya HIV County profiles 2016, women in Kenya are more vulnerable to HIV infection compared to men with the national prevalence being at 7.0% for women and 4.7% for men. In Kirinyaga County, the HIV prevalence among women is at 3.1% compared to men at 1.6% (Kenya County Profile, p.73). The study interviewed seven key informants giving a total of 105 interviewees whose data was used for analysis. Data triangulation by collecting data from different sources allows for a broader perspective on the issue of disclosure among PLWHIV and enhances reliability of data (Thomas 2002, as cited in, Kamau 2006, p.74). I used different data sources from PLWHIV and key informants and secondary data. I also collected data from different health facilities.

3.4.1 Selection of study facilities and PLWHIV

The first category of respondents was HIV positive men and women from Kirinyaga County in selected comprehensive care centres (CCC) service outlets. These were Sagana health centre, Mwea mission hospital, Karira and Kerugoya district hospital. The criterion of inclusion was that the respondents were above 18 years, HIV positive, had been tested for HIV and are married or cohabiting (in a formal or informal union and reported being married).

The study sample was obtained from registered CCC centres in Kirinyaga County. These centres also provide the PLWHIV with ART, care and support hence follow up is possible. A total of 28,929 individuals were tested for HIV in Kirinyaga County in 2008. Of these, 16,495 were female and 12,434 were male. VCT services were provided through 80 health facilities.

According to MOH (2011), Kirinyaga has a total of fourteen health facilities offering HIV Counselling and Testing. These are given as Kirinyaga Central with three facilities, Mwea West, three facilities; Kirinyaga East, two facilities; Kirinyaga West, three facilities, and Mwea East having three facilities. Kirinyaga North and Kirinyaga South have since had their names changed to Mwea East and Mwea West respectively. These are listed in table 3.2. It is important to note that HIV/AIDS related services are also offered in other private health facilities in the County.

Table 3.2 Health Facilities Offering HCT in Kirinyaga County

Area/Location	Health Facility Name	Facility Type	Owner
Kirinyaga Central	Kerugoya District Hospital	District Hospital	MOH
	Kagumo Dispensary	Health Centre	MOH
	EcclesiastesGathuthuma Bamako	Medical Clinic	NGO
Kirinyaga East	Kianyaga Sub-district Hospital	Sub-district Hospital	MOH
	Kiamutugu Health Centre	Health Centre	MOH
Kirinyaga West	Sagana Rural Health Centre	Health Centre	MOH
	Baricho Health Centre	Health Centre	MOH
	Gatithi Dispensary	Dispensary	MOH
Kirinyaga North	Mutithi Health Centre	Health Centre	MOH
	Rukanga Dispensary	Dispensary	MOH
	Mwea Mission (Our lady of Lourdes)	Other Hospital	KECCS
Kirinyaga South	Kimbimbi Sub-district Hospital	Sub-district Hospital	MOH
	Difathas Health Centre	Health Centre	MOH
	Kiumbu Health Centre	Health Centre	MOH

Source: MOH 2011, Health-Kenya Facilities, Latest Updates.

I purposively selected those health facilities that had CCC services. I selected one facility from three different areas, namely from Kirinyaga Central, West and North. In Kirinyaga Central I selected the Kerugoya District Hospital, In Kirinyaga West, Sagana rural health centre and Mwea mission hospital from Mwea East. All these facilities have HCT services and provide ART. These facilities also offer a wide range of other HIV/AIDS related services such as TB diagnosis, TB laboratory and TB treatment a crucial component in HIV/AIDS management, FP, home based care, PMCTC and antenatal services. This meant that PLWHIV would come back for ARV, care and support which made it easy for us to access them. In facilities offering HCT only such as Rukanga dispensary then it would have been difficult to follow up PLWHIV since they would have to access follow up treatment and care in other facilities.

Due to confidentiality and bearing in mind the sensitive nature of the study, I could not access information on the HIV status of patients. I sought the help of counsellors and health care providers in the CCC centres to contact their clients and notify them about the study. The service providers have established a working relationship with their clients. I thus used a convenience sample of the PLWHIV. A convenience sample is one that is easily available and is based on the fundamental assumption that the characteristic under study is common to all members of the target population (Fisher et al. 2002; Anderson, 1987). Sheon and Crosby (2004) use a convenient sample of 150 men who have sex with men (MSM) in San Francisco. Essien et al. (2005) conducted a qualitative study on strategies to prevent HIV transmission among heterosexual African American women using a convenience sample. Mariano (2005) used a convenience sample of forty five men and women in a qualitative study on clients' perception of VCT services in Mozambique. Respondents were selected through health care providers and counsellors who identified clients willing to participate in the study.

In this study, a convenient sample of thirty four men and sixty four women who are HIV positive were recruited from the selected CCC centres. I am aware of the limitation of using a convenience sample in selecting the respondents as the results may not be generalized to other populations. Baumgartner et al. (2002, p.133) notes, that a major problem of this approach is that the results are not generalizable beyond the respondents in the study. They add that this does not mean that the results are not accurate or credible; it simply means that the researcher must be cautious in generalizing the findings. However, a convenience sample was a preferred method to facilitate relative ease to access respondents bearing in mind confidentiality and the sensitive nature of HIV disclosure.

The respondents were briefed on the purpose and objectives of the study and those who consented to participate were interviewed. They were assured of confidentiality and that their identity would be kept anonymous. Respondents need to know and feel that the information they have disclosed would not be used to harm them. Palmer and McMahon (1997) are of the view that, "confidentiality is of absolute priority because it is both essential to respect for client autonomy and because assurances of confidentiality maximize personal frankness…".Demographic information of the PLWHIV was collected in addition to being interviewed on questions to help answer the research questions. The research assistants and I got informed consent verbally from the respondents before proceeding with the interview after explaining to them the nature and objectives of the study.

3.4.2 Selection of key informants

Seven key informants were interviewed. These were purposively selected from the health facilities identified while others were community members that the researcher felt that they would provide in-depth insight on the subject of HIV disclosure to spouses. This was after talking to people and some names were mentioned for instance the peer educator and women's group leader. Mugenda (2008, p.196) says that "purposive sampling is a technique that allows the researcher to use cases that have the required information with respect to the objectives of the study and that the researcher must choose the criteria for choosing the cases". Kombo and Tromp (2006, p.82) explain that "the power of purposive sampling lies in selecting information rich cases for in-depth analysis related to the central issues being studied". The goal is to get individuals who "are capable of providing rich information from experience" (Sandelowski, 2000, as cited in Kamau 2006). Table3.3 provides a summary of the demographic information of the key informants.

Table 3.3: Key Informants Demographics

Designation	Age	Gender	Education
Peer educator	51	Female	college
HCT/Peer educator	Not given	Female	Form 4
Clinical officer	35	Male	Diploma
HCT/Nurse/Counsellor	40	Female	Nursing/counsellor, ART certificate
VCT counsellor	27	Female	Secondary
Womenleader/Farmer	Not given	Female	Primary 7
Clinical Officer	26	Female	University

In addition to these seven, the key researcher also consulted with other individuals in the area. These included doctors in private clinics who administer ARV, local church pastor and a youth representative. I was interested in talking to individuals in the community who are knowledgeable and have experience concerning HIV/AIDS issues. Although these were not formal interviews, the discussions were helpful especially at the formative stages of the study.

3.5 Data Collection Procedures

The study used both primary and secondary data. Primary data from fieldwork provided me with an opportunity to interact with the respondents and get in touch with their experiences on the issue of disclosure of HIV positive status to their spouses. I also used secondary data and in addition I gained insights by consulting individuals with expertise in the field of HIV/AIDS and disclosure of HIV test results.

Before the actual field work, I engaged the services of four trained research assistants who have vast experience in qualitative research methods and a wide experience in research on HIV/AIDS issues. They helped in facilitating the in-depth interviews. I had a two day training to familiarize the research assistants with the research instruments. The training emphasized the importance of maintaining confidentiality of the respondents' information and informed consent. Before the commencement of interviews, the respondents were informed about the study briefly and their consent to participate was sought verbally. They were also informed that the interviewer would take notes and record interviews for purposes of reference later.

To maintain confidentiality and anonymity, the respondents' names are not used in the study. I used a code system to safeguard their identity and maintain confidentiality. This starts with a code for the facility, followed by the code for the research assistant and the respondent code. For instance, the code S301, S represents Sagana Health Centre, followed by the research assistant's code 3 and the respondent code 01. In this case the respondent was the first interviewee for the research assistant code 3 at Sagana Health Centre.

I designed semi-structured in-depth interview schedules (IDI) with open ended questions (Attached Appendices) to collect information from the PLWHIV both disclosed and non-disclosed and Key informants. I developed different sets of interview guides for the different groups. The semi-structured interview guide was important in collecting comparable data from the different respondents and sites thus enhancing reliability of the data.

The interviews were face to face interviewer administered which helped to maintain respondent confidentiality. It contained semi-structured open ended interview questions to collect detailed in-depth information on factors that facilitated or prevented disclosure, perception of the spousal communication and its role on disclosure or non-disclosure of HIV positive status and suggestions on ways to increase disclosure among spouses.

According to Bernard (1988), In-depth interviews are good for eliciting information that people feel is too private to talk about in a group. Details that may not initially be brought out can be sought through follow up questions or probes. Nachmias and Nachmias (1996, p.241) says that, "probes help to motivate the respondent on or clarify an answer or to explain the reasons behind an answer, and they help focus on the conversation on the specific topic of the interview. This is an advantage of depth since the researcher can go below the surface of responses to get reasons, motives and attitudes". FHI (2005) explains that "the use of open-ended questions and probes gives respondents the opportunity to respond in their own words rather than forcing them to fixed responses. They elicit responses that are meaningful and culturally salient to the respondents.

I concur with Insite publication(1999) that private in-depth interviews increase the likelihood of candour in discussions about deeply personal and sexual attitudes and behaviours particularly in regard to behaviour that may be perceived as “incorrect”. The in-depth interviews helped me to gain insights and deeper understanding of the PLWHIV experiences, factors influencing disclosure and non-disclosure of HIV and their perception of their spouse’s communication behaviours and if this influences their disclosure decisions.

The first part of the interview guide has a general question as an ice breaker. The interview schedule included demographic information and open-ended questions to help answer my research questions. The sessions were conducted in either Kikuyu or English or a mix of both as deemed appropriate by both the interviewer and interviewee. The interview guide was written in English and a Kikuyu translation was provided. There was also one administered to Key Informants to find out their experiences with clients on disclosure issues and their views on the way forward to help PLWHIV disclose their HIV positive status.

3.6 Validity and Reliability

Reliability is defined by Joppe (2000, as cited in Golafshani, 2003, p.598) as “the extent to which results are consistent over time and an accurate representation of the total population under study and if the results can be reproduced under similar methodology, then the research instrument is considered to be reliable”. In addition, he says that “validity as determining whether the research truly measures what it was intended to measure or how truthful the research results are”.

Brink (1993, p.35) notes that “validity is concerned with the accuracy and truthfulness of scientific findings. A valid study should demonstrate what actually exists and a valid instrument or measure should actually measure what it is supposed to measure”. On the other hand, “reliability is concerned with the consistency, stability and repeatability of the informants accounts as well as investigators ability to collect and record information accurately” (Selltiz et al. 1976, as cited in Brink, 1993, p.35).

The two concepts are surrounded by controversy in qualitative research and some qualitative researchers avoid the terms reliability and validity and use terms such as credibility, trustworthiness, truth, value, applicability, consistency and confirmability (Glaser& Strauss 1967, Lincoln & Guba 1985, as cited in, Brink, 1993).

This study put in place certain measures to reduce bias in the research and ensure rigor and quality of the research findings. One such measure was the use of triangulation of data sources and data collection settings. According to Golafshani (2003, p.603), triangulation is “a strategy for improving the validity and reliability of research or evaluation of findings”. The data in this study was collected from PLWHIV in three different health facilities and also from key informants from the community. I also consulted with some doctors who have clinics in the County offering treatment, care and support for PLWHIV, experts in the field of HIV/AIDS prevention, care and treatment. This way the research is enriched by different experiences and perspectives. Site triangulation also reduces bias from peculiar factors inherent in one site.

The research assistants who carried out the interviews were selected on the basis of their past experience in undertaking qualitative research. They were also given a two day training on how they were to do the interviews, the importance of establishing rapport with respondents, use of probes, need to seek informed consent and maintaining confidentiality. Field & Morse (1985, as cited in Brink, 1993, p.36) recommend that researchers undergo extensive and rigorous training as interviewers before undertaking qualitative stusdies. During the two day training, the research assistants were able to familiarize themselves with the research instruments and review them. This ensured consistency in the way they collected and recorded data. The researchers took field notes and this was backed up by tape recordings which were used to confirm the written notes later for accuracy.

Other measures taken to enhance reliability and validity included explaining to each participant the nature of the study, how the data would be collected and they could opt not to participate in the study. They were also assured of confidentiality. This was an attempt to reduce participant bias, by assuring confidentiality hence they could feel safe to respond to the interview questions as honestly as possible. The interviews were held in private rooms and where this was not possible a quiet private space was used. The information given by the PLWHIV was written verbatim and tape recorded for those who consented. This transcripts and tapes were labelled using codes to keep their identity anonymous. Others measures to enhance validity and reliability included expert and peer review and thick description.

3.6.1 Pre-Testing

I did a pre-test of the data instruments to check on their validity and reliability. This was done at Baricho health centre. The data from this facility was not included in the final study analysis. Mugenda and Mugenda (20003, p.186) explain that the purpose of pretesting instruments is “to ensure that the items in the instruments are stated clearly and have the same meaning to all respondents”. Baumgartner et al. (2002, p.100) outlines the objectives of pretesting below.

1. To determine whether the instruments will provide the needed data.
2. To determine whether or not the subjects understand the content items in the instrument
3. To familiarize the researcher and assistants with the instruments administration procedures.
4. To obtain data for trying out the proposed data treatment techniques.
5. To determine the reliability and validity of the instruments.

The information gathered during the pretesting was used to revise the instruments. For instance, we had a question on norms which most respondents did not seem to understand. After reviewing the question together with the research assistants, we decided to delete it following feedback from the pre-test interviews.

3.7 Data Analysis and Presentation

Qualitative data is analysed inductively. Baumgartner et al. (2002, p. 210) says that the researcher builds concepts, explains processes and develops hypotheses rather than deductive analysis as in quantitative data. The interviews were transcribed verbatim and transcribed to English where Kikuyu may have been used. The research assistants and I made efforts to have the data transcribed on the same day of the interview to allow us remember any details that may have been missed out. Where this was not possible, the data was transcribed on the next day. We also had tape recordings to help fill in any gaps.

Data analysis involved reading through the interview scripts. The data was then analysed and coded into emerging themes from the respondents' discussions using thematic analysis while retaining the richness and originality of their personal experiences

(Hudelson, 1994). Thematic analysis includes data reduction, coding and major themes identified. Braun and Clarke (2006 p.79, as cited in Fereday, 2006) define thematic analysis as “a method of identifying, analysing and reporting patterns within data”. Thematic analysis is “a search for themes that emerge as being important to the description of the phenomena (Daly, Kellehear & Gliksman 1997, as cited in Fereday, 2006, p3). Braun and Clarke (ibid.) identify six steps of thematic analysis to ensure clarity and rigor. These are; familiarizing yourself with your data; generating initial codes; searching for themes; reviewing themes; defining and naming themes and producing the report.

The process involves the identification of themes through reading and re-reading of the data for the researcher to familiarize themselves with the data with the objective of answering the research questions. For instance, some themes that emerged include, private information and pre-requisites conditions for disclosure. The themes are taken from the data or from literature review. These themes describe the different experiences and factors influencing the PLWHIV’s decision of whether to disclose or not to disclose. I concur with Feredy (2006, p.6) that a single comment or statement made by one person is considered as “important” as those that were repeated by several respondents. Braun and Clarke (2006) note that thematic analysis allows for rich, detailed and complex description of data. McCormick and Schmitz (2001, as cited in, Kamau, 2006, p.81) note:

> The coding of open ended questions requires more attention and researcher involvement. Unless the survey is so large as to make it impractical, it is usual for all open ended responses to be listed. The researcher then reviews the list and prepares a set of categories. The categories depend to a large extent on the purpose of the study and the particular question. A question soliciting reasons for using a particular supplier may, for example, in one context have responses reduced to only

> two categories (economic and social reasons) while in another, up to ten categories might be needed.

The results are presented mainly in prose form and where necessary tables or any other appropriate tools are used. I have used excerpts from the data collected to support the findings and discussion.

3.8 Ethical Issues

I acquired a research permit from the National Council for Science and Technology before embarking on the research. I also visited and made verbal requests to the administrators and management in the different sub-county offices and health facilities.

As a researcher, I have an ethical responsibility to the respondents and society as a whole. According to Nachmias and Nachmias (1996, p.81), two key issues of concern to researchers are those of informed consent and privacy. Diener and Crandall (as cited in Nachmias & Nachmias, ibid. p.83) define informed consent as "the procedure in which individuals choose whether to participate in an investigation after being informed of facts that would be likely to influence their decision". This means that the researcher informs the respondents that participating in the study is voluntary and the individual is free to stop participation at any point of the study. Informed consent would only be possible once the respondents are informed about the purpose of the study and any possible risks as a result of participation in the study. Heppner (1992) says that consent refers to "the process of giving the respondents the opportunity to decide whether or not to participate". I did not perceive the respondents to be at any risk as a result of participating in this study.

The researcher and the research assistants explained to the respondents the purpose of the study before the interview started and the consent of the respondents was sought. (see appendix). Each respondent was reminded at the beginning of each session that they may choose to continue or discontinue with the interview. One respondent refused to be tape recorded and the researcher respected the decision. Keith-Spiegel and Koocher (1985) explain that “the goal of ethical research is to develop a fair, clear and explicit agreement so that the decision to participate in the experiment is made voluntarily, knowingly and intelligently”. This means that respondents are not coerced into participating in a study and they can make a decision as to whether to participate or not. All the respondents were 18 years and above. This means that legally they can make decisions on their own.

The issue of privacy is also of concern to this study especially bearing in mind that the respondents are HIV positive clients with the exception of the key informants whose HIV status is unknown. The right to privacy entails “the freedom of the individual to pick and choose the time and circumstances under which, and most importantly, the extent to which their attitudes, beliefs, behaviour and opinions are shared with or withheld from others”(Ruebhausen and Brim, 1966, as cited in, Nachmias & Nachmias, 1996, p.86). Privacy involves being sensitive about information being given, the setting and dissemination of the information given by the respondents. Nachmias and Nachmias (ibid. p.88) describe two ways in which researchers can protect the privacy of respondents. These are: anonymity and confidentiality.

Anonymity means that the respondent cannot be identified from the information given. A respondent is considered anonymous when the researcher or other person cannot identify particular information with a particular respondent. The study assured anonymity to the respondents as their names are not used in the study. We used codes to refer to the PLWHIV as explained earlier.

Confidentiality is “the non-disclosure of research data to third parties or other parties that may use such data for their own purposes” (Mugenda, 2008, p.299). Respondents need to know and feel that the information they have disclosed will not be used to harm them. Confidentiality is of absolute priority because it is both essential to respect for the client’s autonomy and because assurances of confidentiality maximize personal frankness which is essential in counselling (Palmer & McMahon, 1997). The respondents were assured of confidentiality and that any information they disclose in the interviews would only be used for the study purpose and not disclosed to anybody else. It was crucial to reassure the respondents especially those who have not disclosed that we would not disclose their HIV status to anyone. The interviews were conducted on a one to one basis in a private setting within the health centres to protect their privacy. After each interview, the respondents were given an opportunity to ask any question or raise any issues of concern which we did our best to respond to or refer them to persons and facilities that they can get help.

3.9 Chapter Summary

Chapter threedescribes the research methodology. It explains the research design used in the study, study area, target population and sampling procedure. It also outlines the data collection procedures and data analysis. I have also looked at ethical considerations relevant in the study. The next chapter presents the study results.

CHAPTER FOUR: DATA PRESENTATION, ANALYSIS AND INTERPTRETATION

4.0 Overview

This chapter presents the study results from the interviews conducted among PLWHIV and Key Informants in Kirinyaga County. Data was collected from male and female HIV positive individuals who attend Comprehensive Care Centres (CCC) in three health centres. These are Sagana health centre, St. Lourdes Mwea hospital commonly known Karira mission hospital and Kerugoya district hospital.

The chapter starts by giving the demographic characteristics of the respondents, some background information and then the study results. The study results are presented focusing on the research questions that the researcher set out to investigate. The work is presented in prose form pointing out the key themes. I have also used tables to enhance visual presentation of the information.

4.1 Background Information on PLWHIV

A total of a 108 HIV positive individuals were interviewed. Ten interviews were discounted for analysis. Eight of these reported being in a relationship hence not meeting the inclusion criteria. One was in a gay relationship and one was discontinued due to health reasons as he felt weak to continue with the interview. This left a total of 98 respondents on whom the analysis will be based. This comprised 34 males and 64 females. Their demographic data including age, education level, occupation, years in marriage was collected. Out of the 34 males, 30 had disclosed their HIV positive status to their spouses. Among the women, 46 had disclosed while 18had not disclosed.

The respondents varied in their ages. The youngest was 23 years old and the oldest was 59 years old. Majority were in the age bracket between 30 to 50 years. Most of them had basic education up to primary level. 56 of them had primary level education either having completed the primary studies or dropped out before completing. Four had no formal education while 29 had secondary education. Only four had post-secondary education and one had a Masters degree.

Most of the respondents were engaged in small scale farming. Nineteenof the respondents are in small scale businesses such as selling tomatoes, rice and shoe repair. Several of them cited engaging in casual work. Other occupations were, driver, *matatu* conductor, mechanic, self-employed, mason, carpenter, painter, hair dresser, hawker, house help, peer educator and a data clerk. There was a teacher and college lecturer. Some respondents engage in more than one economic activity. For instance, while most engage in farming as the core activity, they may also engage in a small scale business or casual work to supplement their income.

4.1.1 Testing approach

Most of the respondents had been tested for HIV through PITC where testing had been initiated by a health care provider. This accounted for 48 of the respondents. Thirty six had tested through the VCT. Other approaches used were PMTCT, MVCT and couple testing as shown in table 4.1.

Table 4.1: Type of Testing Approach

Testing approach	Total of respondents
Provider Initiated Counselling and Testing (PITC)	48
Voluntary Counselling and Testing (VCT)	36
Prevention of Mother to Child Transmission (PMTCT)	8
Mobile Voluntary Counselling and Testing (MVTC)	2
Couple Testing (CT)	2
Other	2
Total	98

4.1.2 Problems facing PLWHIV

The study wanted to know the general problems that face the PLWHIV in order to gain a deeper insight into the issues affecting them in Kirinyaga County. The respondents were asked to highlight some of the problems that they encounter. Some of the dominant problems given include; financial, health, stigma, psychological and social relationship problems. Another problem was prevention challenges. It is important to note that although I looked at the problems separately, the problems given were highly interrelated.

Most of the respondents pointed out that they experience financial difficulties. They describe how they could not afford to eat a balanced diet as advised by the health care provider. Most reported being lethargic and thus lack energy to work and earn a good pay. One respondent said, *"Generally people look down on you and lack of funds due to the fact that your body is weak and you cannot work"*. They generally talked of lacking funds to buy nutritious food, to meet the basic needs of the family such as education for the children, to pay for rent and meet transport costs to attend clinic. This was echoed by one respondent who said,

> *"We face financial constraints, we are not able to eat a balanced diet as advised, sometimes it becomes a challenge to work without having eaten"* (disclosed male).

Most PLWHIV reported that the main problem for most of them was general body weakness either from not eating well or as a result of the side effects of the ARV. One respondent said that they experienced general body weakness adversely affecting their participation in income generating activities. In addition some respondents said that due to lack of jobs, they mostly relied on *vibarua (casual work).*As one respondent put it, *"lack of jobs, we rely mostly on vibarua, where we work very hard but get very small pay"* (non-disclosed female). Some attributed their financial difficulties to the fact that most of them rely on casual work yet most people in the community did not want to give them jobs especially if their HIV positive status is known. A respondent voiced his concerns as,*"When it comes to casual jobs, the people living with HIV/AIDS whose HIV positive status is known are not given jobs because they are termed as sick or the person may fear that you will leave the job incomplete either due to illness or death"* (non-disclosed male). Lack of finances was seen to be the root cause of a myriad of other problems faced by the PLWHIV.

Most of the respondents also raised concerns about health issues. Some of the health problems cited included lack of appetite, swollen legs, body weakness, *kurwara o uguo* (getting sick just like that) for example coughing, aching joints, frequent illness, nausea, TB, skin infections, rashes, weight gain or weight loss, side effects of ARV, PLWHIV on ARV also taking alcohol, drugs and cigarettes, always taking medication, spouse refusing to take ARV, *miriire* (issues to do with eating) and too weak to take drugs due to lack of food.

Most respondents repeatedly cited not being able to eat nutritional foods as advised by the health care providers in the clinic as we noted earlier. They explained that without eating a healthy diet or just enough food, it affects their health and it means that they are not able to perform certain tasks.

Majority of the respondents cited stigma as a big problem in their communities. Stigma was presented as having different manifestations among different PLWHIV. It was described as:

> Shame; backbiting; gossip; feeling like the odd one out in the community; no one wants to be associated with you; talking bad of you all the time and this results in low self-esteem; people look down on you; people discriminate against you and they will not even share things like basins with you; lack of joy since people keep pointing at you; people do not buy from your shop; job loss as many people will not employ you; fear that others will know your HIV positive status; use of abusive language; being labelled as immoral and some people think we do not deserve to live.

One respondent said, *"when people know your status, they say that you are just waiting to die and discriminate against you"* (non-disclosed female). Most respondents felt that the community views them as immoral and that is why they got infected with HIV as illustrated by the following responses. One says, *"A lot of people stigmatise you saying you are immoral that is why you got infected with HIV"* (disclosed female). The level of stigma was perceived to be very high in the community as illustrated by the following excerpt by a key informant who explained, "*hawapendiata kuonekana hapa. Akiona mtu anajua anaweza enda hivi hivi ata aende kwanza (they do not like to be seen here (clinic), if they see someone who knows them, they can go this way that way or even just* *go away).*

Most of the respondentsalso reported experiencing various psychological problems. Some of the problems cited include:

> "Low self-esteem; not happy or contented with themselves or their lives; physical and emotional abandonment; fear, for example fear to being known to be HIV positive; stress; thinking too much; rejection; feeling not valued and worthless; keeping HIV positive status secret from family; denial; depression; shock; feeling alone; shame and lack of hope, blame and guilt."

A common problem cited was lack of happiness and joy due to gossip, back biting which most respondents frequently referred to as "spreading news". This was seen to be contributing to the lack of joy as people keep pointing fingers at the PLWHIV. This came out clearly in the following respondent's response. *"Talking bad of you all the time, all these result in low self-esteem"* (disclosed male).

Fear was also cited as a key problem. Most expressed fear of others such as relatives and family finding out about their HIV positive status. Others had fear of what will happen to their children, the future of their children and how they will educate them due to lack of funds.

Most respondents seemed to relate their psychological problems to health or financial problems or both. Although most talked about psychological problems faced by PLWHIV, a few pointed out that being HIV positive caused depression among family members. This is seen in the following excerpt*, "depression of the family members due to infection of the breadwinner"* (disclosed male).

Another area of concern was problems affecting their social interactions and relationships within the community. This ranged from problems within the self, with their spouse, family or the larger community. Some of the problems cited included; people looking down on you; people not wanting to be associated with you or someone who is infected; divorce/separation especially among discordant couples; street children as a result of parents separating; avoidance, people avoiding to buy from your shop; abandoned with family responsibilities; bad social relations and staying a long time without a sexual partner. A non-disclosed female simply said,

> *"PLWHIV do not have many friends"*. The social alienation by community members is best summarised by the following concerns, *"We experience a lot of shame from neighbours, some attack us directly, attacking ourchildren, excluding us from responsibility for fear of infecting them"* (non- disclosed female).

Some respondents raised concerns over issues on HIV prevention. Some issues raised include; lack of condoms, lack of pleasure when using condoms, PLWHIV on ARV also taking alcohol, cigarettes and drugs; re-infection because of unsafe sex and false religious beliefs and *wanabi (*prophets) who say that they can pray for HIV positive people to become negative.

Another issue raised was that some PLWHIV engage in risky behaviours such as drug use, use of alcohol, unsafe sex hence exposing themselves to re-infection and their spouses and other sexual partners to infection. A respondent expressed her opinion in the following excerpt*, "Those positive tend to be promiscuous. They "move" (Sic.) with many people and even engage in commercial sex work"* (non-disclosed female).A few respondents felt that there were no problems unique to PLWHIV. Some felt that as long as one takes the drugs (ARV), then there are no problems. This was the view taken by one respondent who said, *"If one adheres to ARV, no problem"* (disclosed male).

4.2Factors influencing HIV Positive Status Disclosure and non-disclosure

One of the research questions was to explore factors that motivate PLWHIV to disclose their HIV positive status and those that prevent PLWHIV from disclosing their HIV positive status to their spouses. This section looks at motivating factors for revealing and concealing one's HIV positive status.

4.2.1 Motivating factors for disclosure

The PLWHIV who had disclosed their HIV positive status cited various reasons as to why they disclosed their HIV positive status to their spouses. The major themes that emerged were, being sickly; wanting the spouse to test; spousal communication and relationship factors, psychological and emotional fear and privacy. Others include advice from the care providers and anger.The main reason cited by most PLWHIV was the fact that they were sickly and had been in and out of hospital several times including admission for some. One PLWHIV expressed that he was so sick that even if he had not disclosed, the spouse would still have known. He explained

> *"I was so sick that even if I had not told her, she would have known since she is the one who was taking care of me. Again she had suspected it when I got T.B"* (disclosed male).

For others, their spouse or both of them were sickly and thus the PLWHIV chose to disclose their status to save the spouse from infection in case they were not already infected. This is illustrated by the following respondent's response, *"Surely I could not wait to see my husband in this state; I had lost weight because of T.B., so I believed the earlier the better, I was trying to save him"* (disclosed female).

Another dominant theme that emerged was fear. The respondents expressed fear of different things. Some expressed fear to infect their spouses and opted to disclose, others feared being "discovered" after keeping the secret, fear of the spouse finding the ARVs and demanding an explanation. For others, they had fear of how to introduce condoms which the health care providers had advised them to use to protect their spouses or a sexual partners. One PLWHIV commented,

> *"I was advised by the doctor to bring her for the test and that we should use condoms. I was afraid because I did not know how to introduce condoms in our marriage so I told her to ease the way for safer sex and to avoid resistance"* (disclosed male).

Another PLWHIV expressed her fears,

> *"I feared what the daktari had cautioned me about infecting him, just in case he was not positive and also I feared that my husband might turn hostile if he realized that I was positive but opted to keep it a secret"* (disclosed female).

Other PLWHIV reported disclosing to their spouses because they perceived them to be having certain characteristics. These included having trust and confidence in their spouse to keep the information confidential or support as the following PLWHIV responded to the question on why they disclosed.

> *"He is my only husband. I love and treasure him, further he was the one supporting me at that time of illness. I have no other hope in life apart from him"* (disclosed female).

Some PLWHIV attributed the disclosure of their HIV positive status to their spouses to anger. This was expressed by some female respondents who expressed anger that their spouses had been unfaithful and having infected them. Others were angry because their spouses knew of their HIV positive status and had been on medication without informing the spouse. One PLWHIV expressed her anger, *"I had pain because he knew that condition but he kept it secret then went ahead and married another woman and they are both taking ARV. So he had left me to die"* (disclosed female).

Some PLWHIV explained that they disclosed their HIV positive status to their spouses in order to ease the burden on themselves or on their spouses. This was cathartic for the PLWHIV. Other respondents expressed the view that they could not do anything about it. The expressed their helplessness as,

> “Yakimwagika hayazoleki (once a mistake has happened you have to live with it).So, I had no option but to tell him and then again he is the only one for me and we share our problems together” (disclosed female). Another respondent said, “I told him because even if I hid it from him, I would not have changed it (probe, meaning?), there was no not need of hiding because I could not change anything since I was already HIV positive” (disclosed female).

The reasons given for disclosing their HIV positive status to their spouses are summarized in table 4.2.

Table 4.2: Reasons for Disclosure to Spouse

Category	**Specific reasons**
Illness	1. Frequent illness for PLWHIV, spouse or both.
HIV Testing Related	1.To get the spouse to agree to be tested 2.To plan to start a family or to get pregnant 3.To help spouse take action early 4. Spouse had insisted on HIV test 5. They tested together 6. Following health care provider's advice
Spousal Communication/ Relationship Factors	1.PLWHIV cares and loves spouse 2. Spouse is supportive 3.To be open 4. To encourage spouse 5.To console and comfort spouse who is also HIV positive 6. PLWHIV saw the need for spouse to know the truth 7.PLWHIV thought the spouse is also infected 8.To discourage spouse from having sex with PLWHIV 9. PLWHIV knew that the spouse would eventually know 10.To see the spouse's reaction 11. The spouse also disclosed
Psychological/Emotional	1.To ease the burden on oneself or on spouse 2.Confusion for instance how to take or hide ARV without the spouse's knowledge 3.To help the spouse accept themselves 4. Guilt 5. Realizing that we are in this together. 6.Pain 7.Anger 8.Stress 9.Denial 10. Loss of control 11.Inability to change the situation of being HIV positive
Privacy	1,Spouse can keep their secret 2.Spouse cannot spread rumours about PLWHIV's status 3.PLWHIV can trust spouse with the secret
Fear	1.Fear of infecting spouse 2.Fear the PLWHIV would die 3.Taking ARV without spouse finding out 4.Spouse asking for sex
Protection	1.Save spouse from similar situation 2.Protect spouse to avoid infecting the spouse in case they are HIV negative
Questions	1.To respond to questions from the spouse 2.To avoid questions from spouse 2.The spouse demanded to know what the doctor had said 3.To confirm rumours about the PLWHIV's HIV status
Others	1.HIV is not something to hide 2. PLWHIV cannot change their status, what has happened has happened 3.Past sexual history

4.2.2 Motivating factors for non-disclosure

Another aim of the study was to find out what prevents PLWHIV from disclosing their HIV positive status to their spouses. Two main themes emerged, that is fear and communication and spousal factors. Other themes were privacy and communication skills.

A dominant theme for concealing their HIV positive status from their spouses was that of fear. An overwhelming majority of the respondents interviewed expressed fear of one consequence or another. They expressed fear of being stigmatised; blamed for bringing the virus home; beaten; spouse's reaction; spouse revenging; separation; spouse leaving or loosing spouse; shame; abandonment; being perceived as immoral; gossip, rumours and fear of information about one's HIV status reaching relatives or in laws.Fear cut across the non-disclosed both male and female respondents. Some respondents expressed more than one fear.

A PLWHIV explained, *"I fear she might leave me, she might know I am the one who brought the disease and decide to take revenge, she might even take the news to my in-laws, I fear that"*(non-disclosed male). A respondent who had previously disclosed to her first spouse was rejected and abandoned and she fears disclosing to the current one fearing to elicit similar consequences. She narrated her fears as follows, *"I fear that I might be faced with the problems that befell me once I disclosed to the first man. Despite that I was telling him to seek for a solution. I feared shame, abandonment, denial, blame. The man hated me and married again. I fear if I disclose, I may carry the same burden"* (non-disclosed female).

This fear was reiterated by most key informants. One KI said,

> *"Most of them do not disclose to their spouses (Probe why?) Most of them have fear of the unknown, ladies fear they will be left by their husbands and as for the men they fear that they will be blamed for being unfaithful that is why they got infected"* (clinical officer).

The other key theme was communication and spousal factors. PLWHIV reported not disclosing to their spouses due to what can be summarized as spousal characteristics and their perceived communication and relationship. For instance, some PLWHIV reported that their spouses were not supportive either emotionally or financially and hence they do not see the need to disclose to them. Others were perceived as judgemental, not concerned about the PLWHIV. One woman remarked,

> *"My husband is just there, most of the time he does not mind what we eat or drink, he's just there, so I do not think it is necessary to disclose to him"* (non-disclosed female).

Other PLWHIV reported not disclosing to their spouses to avoid risking the status of their relationship as one PLWHIV narrated,

> *"I have been desperate for love, so by getting him it was a golden opportunity of which I think I should keep my HIV status as a secret to secure my relationship (pause) although I work towards any step that would make him know that I am HIV positive like requesting him to have a HIV test and discussing about HIV/AIDS"* (non-disclosed female).

The PLWHIV gave some of the following as reasons for not disclosing as summarized in table 4.3.

Table 4.3: Reasons for non-disclosure to spouse

Categories	Specific Reasons
Fear	1. Consequences; blame, stigma, separation, violence, losing spouse, suicide, spouse can ran away from home, gossip.
Spousal Communication/ Relationship Factors	1.Spouse is not supportive 2. Spouse does not listen or want to be told 3. Spouse is judgemental 4.PLWHIV has no confidence in spouse 5. PLWHIV does not trust spouse 6.Spouse not concerned about PLWHIV 7.Spouse is stubborn 8.They are already separated 9. PLWHIV wanted to save their marriage 10.PLWHIV does not want to break spouse's heart 11.The way the spouse talks about PLWHIV as immoral 12. Spouse ran away after PLWHIV said they had gone for test, they did not wait for results.
Privacy	1.Cannot trust my spouse 2.He already tells people I am HIV positive 3.Do not want spouse to tell my in-laws
Communication Skills	1.Not knowing how to start the conversation 2. Spouse has not told the PLWHIV their HIV status
Others	1. PLWHIV does not know the HIV status of spouse. 2. Denial, belief that the PLWHIV is not HIV positive, 3. The doctors are victimizing him.

4.2.3 Expected and actual risks and benefits of disclosureamong PLWHIV

The researcher wanted to find out from the PLWHIV what they expected to happen after the disclosure. The respondents expressed varied expected risks and benefits. While both positive and negative expected outcomes were expressed, majority said that they had expected negative outcomes.

The dominant theme that emerged as an expected risk was fear. Most PLWHIV expressed fear of the spouse running away from home, separation, divorce, rejection, the spouse being angry with the PLWHIV, spouse committing suicide, abuse, insults, being blamed for bringing the infection home, infecting spouse, fear of having infected the spouse, being chased away from home, being doubted or fear of being perceived as immoral. One PLWHIV echoed her fears,

> *"I feared it could be a blame game that I brought the virus into the house. Nimimi nilimletea (it is me who has brought it to him) this could easily bring in fights, blame, rejection, abandonment by my husband"* (disclosed female).

Other expected risks reported by some PLWHIV included expecting problems from the spouse's family; spouse would be angry, mad at me; being accused of unfaithfulness; lack of peace; spouse would not want sex with the PLWHIV; spouse would stop coming home. One PLWHIV described her expectations,

> *"All I expected was that my husband will see me as a woman full of problems. It was T.B., now it is HIV. I have become a bother"* (disclosed female).

The overriding issue of fear was summarized by the key informants. A VCT counsellor said that

> *"Men fear being blamed for bringing the virus home while the women fear being chased away".* Another key informant reported that*"majority fear the consequences of disclosure, some confess they fear shame, separation, fights with spouse, blame is dominant and people prefer to keep it secret to avoid all the above"* (peer educator).

Some PLWHIVs expressed that they had expected positive outcomes. These included benefits such as expecting the spouse to also go and get tested, spouse to accept their status, acceptance, support and understanding. A respondent expressed lacking courage to disclose to the spouse because when he first got tested in 2000, there was no treatment or support being offered by then. But in 2008, he disclosed to her because as he explains *"I knew she would get drugs and continue with her life"* (disclosed male).

Some PLWHIV expected support from their spouses since they had previously discussed with them about HIV testing or the spouse had initiated the discussion on the need for the test as expressed by the respondent below.

> *"Because she is the one who had advised and initiated the need for testing, I was certain that she would support me of which she did"* (disclosed male).

From the study PLWHIV who had discussed their illness or HIV test prior to testing expected support from their spouses.

While some PLWHIV reported anticipating either a positive or a negative outcomes, some respondents reported having no expectations or as they put it,

> *"I was not expecting much", or "whatever happens".* One such PLWHIV said that she expected, *"nothing much, because we had discussed it even before I tested (disclosed female).* Another PLWHIV reported, *"Nothing was in my mind (probe). He is the one was always unfaithful"* (disclosed female).For another PLWHIV, "*all she wanted was to disclose irrespective of the outcome.* She said, *"What he was to do or say was not an issue provided I said what was in me"* (disclosed female).

The researcher wanted to establish the actual consequences of the PLWHIV's disclosure to their spouses against their anticipated consequences. Earlier on they had talked about what they expected, but I also wanted to know what actually happened after the disclosure. As we have seen earlier, most of the PLWHIV had anticipated negative outcomes. Respondents could not always correctly predict outcomes of their disclosure. The data indicated PLWHIV actually experienced both positive and negative consequences.

Some positive outcomes of disclosure cited include; ability to talk and discuss for instance about safer sex such as the use of condoms, ARV and the HIV positive status. Other benefits cited are self-acceptance for the PLWHIV, spouse accepting PLWHIV positive status; the spouse agreeing to go for a HIV test; increased trusting; support and encouragement; planning to have children or not to have any more children, listening; being open; being free; promising love and support and spouse also disclosed their HIV status. A PLWHIV narrated their experience,

> *"After disclosure, I see a lot of support because like in the diet, she makes sure that there is food and porridge ready for me all the time"* (disclosed male).

Some respondents narrated how they were surprised because things turned out better than they had expected. For some who expected negative consequences they reported experiencing positive outcomes after disclosure. One PLWHIV talked of how things with her spouse were so smooth that she was suspicions of his "goodness" and thought that he could also be HIV positive. She narrated,

> *"From the time I disclosed, things became so smooth than I expected even better than before. This made me think that he knows his HIV status but was unable to disclose because he was not shocked to know of my HIV positive status"* (disclosed female).

A few PLWHIV talked of experiencing positive outcomes but were cautioned by the spouse not to disclose to anybody else. A PLWHIV said,

> *"My husband listened and reasoned with me. I did not detect any changes from him but he assured me of total support. He promised to love me the way I am, but urged me not to tell anyone else to avoid tarnishing our names and exposing ourselves to people"* (disclosed female).

Some of the respondents also talked of consequences that started off negatively and ended up positively. For instance, one PLWHIV talked of initial blame, shock but later the spouse changed and started supporting and accepting the PLWHIV.

However, some PLWHIV reported having experienced negative consequences. They cited various consequences including; blame, rejection, spouse being rude and rough, separation or divorce, silence, refusing to eat, insults, shock, worrying, changes in sexual behaviour such as reduced or loss of sexual interest, stress, attempting or contemplating suicide, uncontrollable anger, denial, refusal to accept that PLWHIV is HIV positive, not happy, relocating, spouse refuses to acknowledge that they are sick. A PLWHIV explained her consequences, *"Rejected, he became very rude and rough to me telling me to go die somewhere else not in his homestead. I just stayed there ... where was I supposed to go?"* (disclosed female).

While most PLWHIV reported experiencing either positive or negative consequences, a few talked of experiencing both negative and positive consequences. A PLWHIV explained,

> *"The positive part is that we do things together, like he gives me fare to come to the clinic. On the other side of food he really struggles to make sure there is food. But he got so shocked sometimes I see he is not happy"* (disclosed female).

A few PLWHIV talked of no change or that the disclosure did not impact them in any way. A PLWHIV commented that, *"After testing, this did not sink in our hearts, so we kind of ignored it"* (disclosed male).

4.2.4 Expectedrisks and benefits of disclosure among non-disclosed PLWHIV

The researcher intended to establish the outcomes the PLWHIV who had not disclosed anticipate should they choose to disclose their HIV positive status to their spouses. Most of the PLWHIV reported anticipating risks and a few reported expecting some benefits. As observed among the PLWHIV who have disclosed, fear was also dominant among the non-disclosed PLWHIV. Fear seems to cut across both the disclosed and non-disclosed respondents irrespective of gender.

Most of the anticipated consequences for the non-disclosed can be summed up in one word, fear. The respondents expressed fear of, separation and divorce; being left by spouse; judgment; criticism; gossip, information about their HIV status reaching relatives and in-laws; blame; suicide or a spouse harming themselves or both of them; being abandoned and being perceived as promiscuous. As one respondent narrated, *"I would hate herto take the story to my in-laws. She would also leave me and that would create hatred"* (non-disclosed male). Other negative expected outcomes of disclosure cited include, anger for not having told the spouse earlier.

Only a few respondents said that they would expect some positive outcomes and expressed some hope. This sense of hope was mainly expressed by the women. Some hoped that the spouse may accept the status of the PLWHIV and also go for the test. Others hoped that their relationship may become stronger as illustrated by the sentiments of the PLWHIV as,

> *"I think the relationship will be stronger and we will have better plans for the future"* (non-disclosed female).

A few respondents expressed uncertainty about what would happen and simply said, *"I think nothing much will change because I do not expect much from him on living and family upkeep"* (non-disclosed female).

4.2.5 ActualRisks and Benefits of non-disclosure

I wanted to find out about any outcomes of non-disclosure for the PLWHIV who had not disclosed their HIV positive status to their spouses. Majority of them reported experiencing several negative consequences. They cited consequences such as, lack of trust; burden of lying; depression; non adherence to the ARV; hiding medicine; restlessness; fear of infecting spouse if spouse is HIV negative; guilt; fear of spouse realizing the truth before the PLWHIV tells the spouse; cheating oneself and spouse; confusion; lack of peace and questioning by the spouse about the frequent visits to the clinic or use of medication and carrying the burden of knowing that they are not being honest with their spouses.

Most of the PLWHIV explained that keeping their HIV positive status secret was not an easy task and it came with several risks. In response to the question on the consequences of not disclosing, one PLWHIV remarked, *“Lack of peace due to your conscience especially when we are having sex”* (non-disclosed female).

Some PLWHIV talked of hiding things such as medication and hospital cards. One explained,

> *“Non-disclosure makes me have the burden of hiding things which might make him suspect for instance the hospital documents and drugs. I feel I am not clean to him because I cheat him it is a uterus problem”* (non-disclosed female).

Others reported that non-disclosure affects adherence to the ARV since they have to hide them or take them when the spouse is asleep. Others reported fear of infecting the spouse if they are not already infected. Other consequences included depression and feeling confused as one PLWHIV described her situation,

> *"I am so depressed because I need to have a child since I do not have one. But since I think that I may need to tell him about my HIV positive status before I conceive to protect my baby from infection, thus I feel so down, since I am unable to disclose to him"* (non-disclosed female).

A few PLWHIV were of the view that non-disclosure had benefits. All those who perceived non-disclosure as having positive outcomes expressed the view that because they had not disclosed their HIV positive status to anybody, then nobody knew their status. Therefore, they were "anonymous" and the HIV positive status was their secret and nobody could stigmatise them. They thus avoided any negative outcomes and risks associated with disclosure as one PLWHIV narrates,

> *"By not telling anyone, people do not know about my HIV positive status, thus I avoid being stigmatised and in this case by him not knowing, I avoid his bad temper"* (non-disclosed female).

Another respondent reported that non-disclosure for him has both positive and negative consequences. He expressed the consequences as,

> *"Restless, guilt conscience. I fear to be exposed to the public that I am HIV positive., for the positive consequence is that by now it is only I alone who knows my status, so I feel secure"* (non-disclosed male).

A few respondents expressed the view that although nobody knows their status, they still experiences guilt. One PLWHIV remarked, *"There are many consequences, because my spouse is not considerate but although nobody knows, I still feel guilty"* (non-disclosed female).

4.2.6. Intention to discloseamong non-disclosed PLWHIV

I also wanted to find out from the PLWHIV who had not disclosed their HIV positive status to their spouses if they had any intention of disclosing to their spouses anytime in the future. A clear distinction seems to emerge here between the male and female respondents. Among the men, none of them reported a direct intention to inform their spouses anytime in the future. However, majority of the women reported that they intend to inform their spouses at some point in the future but gave some conditions that must be met by the spouse before they can disclose.

The key theme was an expected change in behaviour and attitude in the spouse and if the spouse behaved in a certain manner. Some PLWHIV expressed the intention to disclose only if their spouses change their behaviour in the following aspects; the spouse becomes supportive, acts like a real man, becomes cooperative, returns home, agrees to be tested, changes their attitude towards HIV and PLWHIV; becomes concerned about the PLWHV, starts loving and wanting to have sex with the PLWHIV. One PLWHIV said,

> *"If he can change for the better and start supporting the family and act like a real man, I can disclose later"* (non-disclosed female).

Others seemed to follow the cliché, *"even Rome was not built in one day and big things start with one step".* One explained that she would like her spouse to know but she is not willing to disclose directly. She hopes that they could be tested together and hence he will know her status. One PLWHIV reported her intention to disclose but fears that it will be "a blame game". She remarked, *"I intend to tell him some day, but I am sure he will put it as a blame game, if he refuses, I will leave it at that"* (non-disclosed female).

Some female PLWHIV who said that they intend to disclose, reported that they would disclose so that their spouses can know their status for their own safety and also start on medication early in case they are HIV positive. One PLWHIV who plans to have a child said, *"Yes, I am hoping to tell him soon so that he can start his medication so that by the time we plan to have children we will be able to protect them from* *infection"*(non-disclosed female).

A few female respondents expressed with absolute certainty that they had no intention of disclosing their HIV positive status to their spouses at all. One categorically said, "No!" to disclosing to the spouse but had already disclosed to the mother and the sister who can give her support

The male respondents expressed no direct intention of disclosing to their spouses as indicated earlier and most were non-committal on their intention to disclose. One pegs his disclosure to the wife disclosing her status, but even then, he may still not disclose. He explained,

> *"Till she tells me hers, I would not tell her. Let her get tested. If she tells me about her status, I will know whether to tell her or not"* (non-disclosed male).

Another male respondent indicated that he would like to take time and even then he would do so indirectly using his friends who take ARV to tell her.

4.3 Communication Behavior between Spouses

Another aim of the study was to investigate the communication behaviours of PLWHIV and their spouses as reported by the PLWHIV and see if their communication behaviour influences disclosure or non-disclosure of a HIV positive status.

4.3.1 Information not considered private between spouses

The researcher wanted to find out what kind of information the PLWHIV shared with their spouses and the information that is not shared. I wanted to have an insight into what kind of issues spouses generally talk about and those that they do not discuss and what they consider to be private information.

The respondents pointed out a number of issues, topics that they share with their spouses. Most of them said that they talk about what they referred to as, “general, those things are obvious, things to do with life”. Most respondents felt that there are things that you generally share with your spouse by virtue of being married. This was echoed by the use of phrases such as, “general issues, issues to do with our lives, family affairs and general talk”. A 43 year old disclosed female says,

> *“We discuss things about our home, those things are obvious, so we talk about them”.* Another one says, *“We discuss life in general and since we are married we talk about everything”.*

The main themes of the topics generally discussed by the respondents included children and family welfare; farming; business and finances; HIV status and positive living; family planning and death and praying.

Most respondents acknowledged sharing information or discussing with the spouses on issues to do with the family’s welfare. Majority reported discussing about the children's wellbeing and upbringing, education and payment of school fees, guiding the children and helping them after completing their secondary studies to get into college. One respondent said,

> *“We discuss on development of the home, bringing up children, like we have a son who is supposed to go to college, so we talk on how to help him”* (disclosed female).

Other than children, respondents also said that they discussed about their parents both maternal and paternal and relatives. They also cited discussing family development such as building a bigger house, buying a plot or buying bulls for ploughing. Other issues discussed include; whether one is going for *kibarua (*casual work) or not, house rent and family life.

Most of the respondents as we saw earlier are farmers. Farming issues are generally shared between spouses. These include issues to do with land preparation, livestock, planting tomatoes in plastic bag for home consumption. Some of the respondents said that they do discuss finances with their spouses for example how much one earned during the day. Others reported discussing investments such as buying cattle or a plot and how to get money. One respondent explained, *"We talk about how we can get money,* how to educate our children. The reason for discussing is to plan for our future" (non-disclosed male). One respondent talked of how they pray asking God to give them a good job. She says, *"We pray to God to help us get a good job so that we can stop hustling to help us get a cure for the virus"*(disclosed female).

While most topics were deemed to cut across both the disclosed and non-disclosed respondents, the topic of HIV was mostly discussed by those respondents who had disclosed their HIV positive status to their spouses. Whereas respondents who have disclosed their status reported discussing issues around HIV, those who have not disclosed generally avoided the topic and when discussed, they focused on the intention to get tested.

Some of the issues discussed include; discussing their illness (HIV positive status); positive living; nutrition; taking ARV and drug adherence; prevention and protecting the spouse from infection or re-infection such as the use of condoms and remaining faithful to each other; need for the spouse to go for HIV test and encouraging the spouse to go on living. One respondent narrated how the spouse encourages him to continue with life. He explains, *"She encourages me and assures me that I will live as long as God wants because for me being infected is like an accident"* (disclosed male).

Most respondents especially in cases where both spouses are HIV positive talked of reminding each other to take their ARV, the need for eating a healthy diet and also discussed about being faithful to each other to avoid re-infection. One PLWHIV explains, *"We usually talk on the need to be faithful to each other to avoid infection from other people, our future and children's wellbeing"* (disclosed male). Among some discordant couples, the topic of testing was discussed with the HIV positive partner encouraging the spouse to go and get tested for HIV. A respondent explains their discussion, *"We usually talk about him being tested frequently to know for real if he is HIV positive or negative. We usually do not talk much because he is in denial"* (disclosed female).

Majority of the respondents who have not disclosed their HIV positive status to their spouses generally avoided the topic of HIV as reported by the following respondent. He explained, *"We talk about business, school fees, we talk about those things, since I got infected I do not like discussing about HIV, there was a time she had asked me to get tested but I refused"* (non-disclosed male).

Most respondents who have not disclosed indicated talking about the intention to go for a HIV test since they cannot acknowledge that they have already been tested and know their HIV status. From the interviews, some respondents seem to "test the waters" by talking to their spouses indirectly about HIV positive status. One respondent described her situation, *“I used to ask him, if I tested and I was found to be sick and he is not sick, what he would do? He used to answer, we will just have to stay together, and that he loves me"* (non-disclosed female).

A few respondents reported discussing about preventive measures and cautioning the spouse or each other. One respondent explained, *“We discuss love affairs and issues to do with multiple partners and mpango wa kando (extra-marital affairs) and the risks involved”* (non-disclosed female). I will look at the discussion on HIV/AIDS in greater detail in later sections.

For those respondents who are still in their childbearing age and would like to have children, the topic of bearing children was discussed. This included issues of Family Panning (FP), fear of infecting the child due to their HIV positive status. A non-disclosed respondent expresses her fears and pressure from her in-laws to get a child. The in-laws feel that she has taken too long to get pregnant. For some, the knowledge that they are HIV positive makes them discuss about avoiding having another child.

The topic of death was discussed among some of the respondents who have disclosed their HIV positive status to their spouses. From the data, the topic of death was not discussed among the respondents who have not disclosed their HIV positive status to their spouses. Some of the issues that were discussed pertaining to death included: the wellbeing or future of the children after the death of parents especially where both parents are HIV positive; issues of inheritance and properties owned and the reality of death.

Those who reported discussing death were of the view that death is inevitable and can happen anytime hence the need to be prepared and talk about it as seen in the following respondent's description of their discussion. Another respondent explained that they discuss death with the spouse so that they can plan for their children. She asks, *"If by any chance we were to die, how would we leave our children?"* (disclosed female).

A male respondent describes how he informs his wife about his properties just in case he dies. He says, *"We usually talk on how we can develop our home. I also tell my wife about my properties so that she can know what to do just in case of my death"* (disclosed male). Some respondents reported praying and asking for God's intervention in getting a cure or helping them to get a better job.

Among the respondents who have disclosed, when asked what information they may not share with their spouses, majority said that there is nothing that they do not share with their spouses. They attributed this to different things; one was trust of the spouse; for others because they are both positive; the spouse had also shared their results or just because they felt that they did not need to keep secrets as husband and wife. One respondent attributed this to his salvation. Some respondents were of the view that as spouses, they should share everything. This was expressed by some respondents as, *"There is nothing I cannot tell him because he is my husband thus I should not hide anything from him"* (disclosed female).

The theme of reciprocity was brought out by several respondents who felt that they shared with their spouses everything including the HIV positive status because the spouses also shared with them. This was the sentiment of one respondent who said, *"There is nothing I cannot share with my husband because there is nothing to hide. He even knows my HIV positive status as well and I also know his"* (disclosed female).

These PLWHIV were of the opinion that once they had disclosed their HIV positive status to their spouses, there was nothing else that they could not share. Some respondents felt that although they shared everything with their spouse, they were not very sure if the spouse was also sharing everything with them. This sense of doubt and uncertainty was expressed by some respondents as *"Nothing, I do trust him although I do not think that this feeling is mutual, because he does not trust me"* (disclosed female).

4.3.2 Private Information

The researcher wanted to find out what the PLWHIV considered to be private information. This may influence their communication behaviour with their spouses and other community members especially in the area of HIV positive status disclosure. The results seem to cut across both the disclosed and non-disclosed respondents. The findings fall into the following major categories of information considered as private information. These are HIV positive status, finances, PIN numbers, sexual issues and others.

Most of the respondents considered their HIV positive status to be private information. Understandably, for the non-disclosed respondents, this is information that they would go to any lengths to keep private and conceal it as they would not want anyone including their spouses to know their HIV positive status. This was mainly attributed to the fact that they have not disclosed and this is a topic that they would rather avoid.

Even among those respondents who had disclosed their HIV positive status to the spouses, the HIV positive status was still considered private information. One respondent explains, *"HIV positive, I cannot just disclose to anyone. It's my big secret* *because watanicheka, wanidharau (they will laugh at me and look down on me)"* (disclosed female). Information about ones HIV positive status was considered private and not to be just disclosed to anyone. Most respondentsdisclosed and non-disclosed referred to it as *"their greatest secret."*

As we saw earlier, PLWHIV cited discussing finances with their spouses. However, certain financial matters are not talked about. Majority of the respondents identified matters to do with their finances as private information. This included for some the amount of money one has in their account(s), personal identification numbers (PIN) for the ATM and telephone and sources of money. Some female respondents also felt that information about their contributions to their merry go rounds and *itati or kiama* (women groups mostly for table banking) is private information.

Some respondents cited information about their sexual lives either with spouse or outside the marriage as private. A PLWHIV explains his private information, *"What I consider private information is money issues, sexual issues and also if I have ampango wa kando, I think it is private"* (disclosed male).One respondent categorically said that for him, certain information he would tell no one except God. He says, *"My affairs outside marriage (extra marital affairs), I would tell God only"* (disclosed male). A female respondent reported that she started being unfaithful when her husband continued having extramarital affairs and this is information that she cannot share with her spouse. She explained, *"Faithfulness, when he started affairs outside our marriage, I had to look for a friend also (laughs) boyfriend, such things I cannot share with him"* (disclosed female).

Other issues respondents cited and considered private information include; family issues such as family conflicts; how they live in the house (issues about the home); one's family and siblings. In addition, a few respondents cited their future plans as private information. A few respondents felt that they have no private information especially after disclosing their HIV positive status.

4.3.3 Confidants to whom PLWHIV reveal private information

When the respondents were asked to identify individuals to whom they would reveal their private information to, most of the disclosed PLWHIV cited their spouse. Majority said that they would disclose their private information to their spouses. This was closely followed by their children especially the first born child, sister, mother and friend in that order of priority.

Of interests to the study is that only those individuals who had disclosed their HIV positive status to their spouses said that they would reveal their private information to their spouse. For those who had not disclosed, only one of them said that they would reveal their private information or secret to their spouse. The respondent explains that, *"I would tell my husband as I have no parents in search of support"* (non-disclosed female).The reasons given for revealing private information to a spouse varied. Some of the reasons cited included; trust the person with a secret; support, they would help if the PLWHIV needs help; the PLWHIV also knows the spouse's secret especially the secret of HIV positive status; the spouse is the next of kin; the spouse can keep my secret; spouse provides; he's my people and love.

Some individuals would not tell their spouses their secrets and would rather reveal their secrets to their children. Some pointed out that they reveal to an older child so that they can relay the information to the other children. In most cases, this was to prepare the older child to take care of the younger ones in case the parent(s) becomes sick or dies. While some PLWHIV indicated that they would reveal their secrets to their spouses, a good number reported that they trust their children more than their spouses. Among the PLWHIV, trust seems to be a key ingredient in revealing private information. This is clearly captured in the sentiments of the following respondents in response to the question of whom they would reveal a secret to. One PLWHIV responded, *“My first born son whom I trust more than my wife. My wife can divorce me but my son remains my son always”* (disclosed male). A second respondent said, *“My daughter because she is the only person that I trust with my secret and also it is her right to know things that are happening to her mother”* (non-disclosed female).

Those PLWHIV who said that they would reveal their secrets to their children gave different reasons. Some of the reasons given were; property, PLWHIV's property belongs to the child or children; creating awareness in the child of the parent’s illness in case anything happens to the parent; trust; right of the child to know; the child would safeguard the secret and not disclose it to anyone else; the child is supportive and understanding.

While some respondents expressed the view that they would disclose their private information to their children, one respondent expressed a different view arguing that he would not tell his children to protect “how the children see me”. They needed to protect their face to their children. From the results, only a few men would tell their private information to their child (ren) as compared to the women. More women both among the disclosed and non-disclosed PLWHIV would tell their children.

Another key group of persons that PLWHIV cited as a confidant was a sister. A clear division seems to emerge. None of the men interviewed said that they would disclose their private information to their sister. But the women irrespective of their disclosure status reported that they would disclose to their sister. Those who said they would disclose to their sister described sisters as; supportive, understanding, good listeners, considerate and trustworthy.

Mothers emerged as another category of individuals who can be confidants that could be disclosed to by PLWHIV from all the sub-categories of disclosed and non-disclosed males and females. Some of the reasons cited for revealing private information to a mother included; she is the one who knows me from childhood; I trust her; I have already told her I am HIV positive; support; she is the only one that can take care of me in case of anything; apart from my wife, she is the only one who knows everything about me; I love her and she is close to me.

A good number of the females interviewed, both disclosed and non-disclosed PLWHIV cited their friends as individuals that they would disclose to. These respondents used phrases such as, “my close friend, my good friend, my best friend” which indicates that it is not just any friend that would be disclosed to private information. Among the males interviewed, only one indicated that he would disclose his private information to a friend.

Some respondents felt that they would not reveal their private information to anyone. Some felt that they would rather remain with it to the end to keep it safe. Some say that they trusted no one and for others past experiences had made them trust nobody as their trust had been broken in the past. One said, *"No, I would not tell my secret to anyone, I should remain with it till the end"* (non-disclosed male). A few PLWHIV seemed to express some regret for having disclosed their secret about their HIV positive status as one narrated, *"If I had a secret today, I would tell nobody. I trust no one. If I tell somebody a secret for example that I am positive then this could lead to rejection, prejudice, evil things. So I had better keep things to myself"* (disclosed female).

Other categories cited as confidants by some PLWHIV included; father; parent, brother, aunt, mother-in-law mother, close family members (relatives) and health care providers such as doctor, clinical officer, peer educators and counsellor. A few respondents explained that the person they would tell would depend on the particular information. Hence it would be one individual or another depending on the issue.

4.3.4 Disclosure of HIV positive Status toother Confidants

The researcher wanted to know if the PLWHIV who had disclosed to their spouses had disclosed to anybody else and if those who had not disclosed to their spouses had disclosed to anybody at all. I also wanted to know the persons to whom the PLWHIV had disclosed to and why? The basic assumption here is that for all PLWHIV, their HIV positive status was known by the care provider or doctors. Most of the respondents who had disclosed to their spouses indicated that they had notdisclosed to any other person.

Some PLWHIV used phrases or expressions to show just how strongly they would want to keep the HIV positive status private. Some emphatically said, "No!" or "No!No!" repeatedly for emphasis. One PLWHIV remarks best summarises the strong feelings about not disclosing to other people. She asserted, *“No! I cannot dare... people will only laugh at you, I hate discrimination and being talked about”* (28 year old disclosed female).

The respondents cited several reasons for not wanting to disclose their HIV positive status to anybody for the non-disclosed or anybody else other than the spouse among those who have disclosed to their spouses. The reasons can be categorized into two broad categories. These are fear and privacy. The specific reasons cited include, fear of other people knowing their HIV positive status, fear of being stigmatised, rejected and of being gossiped about. They did not perceive any benefit of others knowing their HIV positive status. They felt that their HIV status was their personal issue and not a public issue.

For those who had disclosed to somebody else other than the spouse, most of them indicated that they had disclosed to their mother. The second most commonly cited recipient of the PLWHIV’s positive status was a sister; this was followed by children and friends in that order of priority. Other categories of confidants cited include brother, parents, HIV support group members, auntie, cousins, nephews, nieces, church pastor, sibling (without distinguishing between a brother or sister), neighbour, family and relatives. The reasons given for disclosing to these individuals varied. Some of the reasons given can be categorized into four major themes. These are support which could be physical, financial, emotional, psychological support; communication and relationship factors; privacy and questions. The reasons given are summarized in table 4.4.

Table 4.4: Reasons for Disclosure to other Confidants

Category	Specific Reason
Support	1. Confidant provides physical and financial support 2. Confidant takes care of the PLWHIV or their children 3. Confidant encourages the PLWHIV 4. The PLWHIV expects support from the confidant 5. The PLWHIV wanted to help the confidant get tested
Privacy	1. Confidant promised not to tell anybody else 2. To protect the confidant
Spousal Communication/ Relationship Factors	1. Confidant shows empathy to PLWHIV 2. Confidant listens 3. The PLWHIV trusts the confidant 4. They are free and share freely 5. Confidant is worried and shows concern for PLWHIV
Questions	1. To clarify the cause of prolonged illness 2. To pre-empt questions 3. To answer questions
Reciprocal Disclosure	1. The confidant also disclosed to the PLWHIV

4.3.5 Perception of spouse’s communication behavior

The researcher wanted to find out the perception of PLWHIV on their spouse’scommunication behaviours. This provides insight into whether perceived communication behaviours of a spouse influences disclosure or non-disclosure. Two broad categories emerged. PLWHIV either perceived their spouses’ communication behaviour as supportive which was described as being “good” or defensive which was described as “bad”. A few described it as neither good nor bad, somewhere in between.The communication behaviours can be summarized in table 4.5.

Table 4.5: Supportive and Defensive Characteristics among PLWHIV

Category	**Specific behaviours**
Supportive Communication Behaviours	Good listener, non-blaming, encouraging, cooperative, supportive, comforting, humble, polite, sharing, does not shout, discusses issues, considerate. Not abusive, calm, caring, reasoning together, consults, understanding, peaceful, open, free to each other, solving problems together, spending time together, not stressful, not opposing anything the PLWHIV says, providing for PLWHIV (female) and their children, obedient.
Defensive Communication Behaviours	Shouting, not talkative, blaming, thinks ill of me, violent, not supportive, too busy for PLWHIV, not social, ignorant, difficult, does not think, noisy, judgemental, hypocrite, never listens, moody, hot tempered, criticising, does not like to be told, gets angry quickly, evasive, pretending, abusive, dodging issues, talks carelessly, assuming, taking things literally.

The following excerpt illustrates the respondent's perception of their spouse's communication behaviour as good. A respondent explained, *"It is good, he is supportive, and he has never blamed me or discriminated against me since he knew my status. If anything when I am down, he tries to encourage me"* (disclosed female).

While for such respondents, good communication was perceived to be mutual respect, trust and support, for others it was perceived to be good or positive because the spouse obediently follows what they are told to do and do not question the spouse. A respondent explained about his spouse, *"She is very obedient, a good listener and she* *does not oppose anything I say"* (disclosed male). Another explained, *"She is so faithfulto me, I am the one who gives her instructions on what to do and she follows"* (disclosed male).

It is interesting to note that this perception was expressed by both males and females. A few females also thought that their spouse's exhibit good communication behaviour because they did as they were told as one PLWHIV explained, *"It's good, he is supportive and does what he is told to do"* (disclosed female).

Some PLWHIV perceived their spouses' communication behaviour as "bad". The following excerpts illustrate some negative perception of spouse's communication behaviours. One explained about their spouse, *"We used to discuss general things. He was not always ready for me, he used to keep himself very busy and never created time for us to discuss any sensible thing and one would do his or her own thing"* (non-disclosed female). While in the previous section we saw that some spouses perceive their spouses communication as "good" because they do as they are told, a few PLWHIV perceived their spouse's communication as "bad" because they have to be told what to do.

For some respondents, their spouse's communication behaviour is neither negative nor positive. One respondent explained, *"It is in between (laughing), as you know with women they are sometimes rebellious but later she listens to me"* (disclosed male). A respondent explained that their communication was good as long as she did not tell the spouse anything to do with HIV. She asserted, *"Our communication is not bad but if I tell him anything to do with HIV/AIDS, he becomes rough on me and criticizing".* Arespondent summarizes by simply saying, *"Homes are funny"*(disclosed male).

4.3.6 Perception of relationship with spouse

From the results, two main categories emerged. The relationship was either perceived as good or not good. A few respondents described their relationship as in between. Both positive and negative perceptions of the relationship with a spouse were reported among the disclosed males and females and non-disclosed males. Most non disclosed females expressed having a negative perception of their relationship.

The PLWHIV described their relationship with a spouse as good based on the following characteristics. They cited; no fights, sharing confidential information, supportive, peaceful, obedient, financial support, psychological support, caring, discussion of issues, being faithful to each other, comforting, listens, harmony, doing the things I need done, never ran away from home, no domestic quarrels, practice Gods word, not quick to anger, unity, reason together, love, cooperative encouraging, understanding and respect.

A relationship was perceived as “not good” based on the following characteristics that the PLWHIV cited. The spouse; has other sexual partners and extramarital affairs; discriminates children that are not biologically his; not knowing each other’s secret; has another wife; violent; harsh; fights; abandons responsibilities; does not provide financial support for spouse and children; takes so long to see family; does not do things together as husband and wife; shouts; stressful; drinks alcohol; confrontational; not cooperative; does not consult and makes decisions alone and not taking the spouse seriously.

From the findings, the negative and positive perceptions cut across all the different categories of PLWHIV. However, most non disclosed females expressed negative perceptions of their relationships. The following excerpts illustrate negative perceptions of relationships between PLWHIV and their spouses. One said, *"Not peaceful, he does not cooperate, he does things without consultation, he believes very much on his decision (sic)"* (non-disclosed female).

A few respondents could not describe the relationship as either good or bad and felt that they were somewhere in between. Sometimes the relationship is perceived as good and sometimes it is perceived as bad. Some respondents expressed the view that conflicts were a normal part of relationship. Hence despite conflict here and there which they described as "small friction" or "normal" their relationship was perceived as ok. This is explained as "small friction that does not lack in families". Arespondent described their relationship as, *"Relationship ni kujikaza,(accept and live on) it is not stable we used to have a lot of disagreements, fights and even at times we lack basic needs"* (disclosed female). Another PLWHIV used a Kikuyu proverb to describe his perception of his relationship. He says, *"I will go with a Kikuyu saying thatmathanwa meri me kiondo kimwe matingiaga gukongorania (two axes in one basket often knock against each other) meaning some differencesare expected in a relationship but we still manage to solve them by ourselves"* (disclosed male)

4.3.7 Perception towards open communication between spouses

The study aimed at investigating the perceptions of the respondents on open communication between spouses. Two broad categories emerged. One category was those PLWHIV who expressed the view that such spouses are wise and had a good relationship and life. The other group felt that it is unwise and everyone should have private information which their spouse does not know about.

Those who considered spouses who engage in open communication as wise expressed the idea that such individuals enjoyed several benefits such as peace and sharing problems. Some respondents expressed the fact that open communication helps in relieving the burden of hiding the secret of a HIV positive status and also makes adherence to ARV easier as one explained,

> *"I see their life as good because they help each other, because if I did not disclose my status, I would have to look for somewhere to hide my drugs. Sometimes if you do not have fare you will be wondering how you will get to the clinic"* (disclosed female).

A few respondents felt that couples should have open communication by virtue of the fact that they are married. Other respondents felt that disclosing everything to one's spouse is not wise. Most respondents felt that one needs to keep some issues private for several reasons. Some reasons cited include; some spouses are not trustworthy; the information can be used to hurt you later; entitlement to have a secret; knowing each other "inside out" can lead to fights and conflicts; undermining a spouse if you know everything about them; weak relationship and it is good to keep some things to oneself and conceal some things, one cannot reveal everything. Some male PLWHIV were of the opinion that men should withhold certain from their wives because revealing such information can be used later to hurt the individual who discloses the secret. For other respondents, the idea of open communication between spouses is advocated for although sometimes it can have negative consequences.

Some respondents were of the view that it is important to disclose everything to one's spouse as long as certain conditions were met. These conditions include trust and knowing the spouse very well as expressed by the following respondent who said, *"My take on that is that wives are not trustworthy, so if you have to talk everything with your* *wife, you must really trust her"* (disclosed male). Another respondent said, *"It is good todisclose everything to your spouse although one needs first to know him or her better"* (disclosed male). One PLWHIV expressed doubts on the possibility of disclosing everything to one's spouse. He remarked, *"Good, but I doubt how they could discuss everything. Some issues seem a bit sensitive; if you discuss them she might suspect you of being unfaithful"* (disclosed male).

4.3.8 Discussion on HIV/AIDS between spouses

The study intended to find out if the PLWHIV discuss HIV/AIDS with their spouses. This helps the researcher understand their communication on the topic of HIV/AIDS. I wanted to find the answers to the questions, do they discuss the topic or not. For those who discuss, what do they talk about? And for those who do not discuss the topic of HIV/AIDS, why not? Although this topic was briefly discussed earlier, I felt that I needed to address it in greater detail as it is the core of the study.

Majority of the PLWHIV who had disclosed their HIV positive status to their spouses reported that they do discuss issues on HIV/AIDS with their spouses. The key themes of their discussions can be categorized into the following topics; living positively; encouragement; hope and discordance.

Most PLWHIV who have disclosed their HIV positive status to their spouses said that they discuss how to live positively, protective measures and how to prolong their lives despite being HIV positive. Other issues discussed included, taking ARV, adhering to the drug regimen as advised by doctors, eating a nutritious diet, remaining faithful to the spouse and using condoms.

Encouragement was a key issue of discussion. Spouses reported encouraging each other or the spouse to go for a HIV test to know their HIV status for those who had not tested, to start or take their ARV as some spouses were reported to refuse using the ARVs. Another issue discussed was encouraging a spouse to accept the condition and just go on with life. Related to the issue of encouragement above, PLWHIV talked of messages of hope with their spouses.

The concept of discordance seemed a difficult one to comprehend for the discordant couples. Most expressed lack of understanding as to how this could have happened, how one partner can be HIV positive and the other one HIV negative. The concept of discordance was not clearly understood with some questioning “the source” of their infection since their spouse was negative. The complexity of the issue of discordance was echoed by another respondent as, *“We sometimes ask ourselves how and what is discordance? We discuss how to protect one another from infection”* (disclosed female).

Most of the respondents who have not disclosed their HIV positive status to their spouses reported that they do not discuss issues on HIV/AIDS with their spouses. This was more common among the females who have not disclosed their HIV positive status to their spouses. Among the PLWHIV who have not disclosed their HIV positive status to the spouses, they rarely discuss issues on HIV/AID but when discussed, the discussion was mainly focused on two main themes. These are the intention to test and caution.

Since the PLWHIV would not want their spouses to know their HIV positive status or to even know that the PLWHIV has been tested for HIV, most reported discussing the intention to go for a HIV test. This may be for the PLWHIV or for the spouse or both to go and get tested.

Some PLWHIV said that they do not really talk about HIV/AIDS but reported cautioning their spouse or each other about HIV/AIDS. They said that they talk about HIV/AIDS indirectly and in fairly general terms to caution each other to avoid HIV infection. Some PLWHIV discussed HIV/AIDS by focusing not on themselves but on others such as friends and HIV in general. One PLWHIV noted, *"Yes, we usually talk about how people are dying due to HIV and the need to protect ourselves from being infected since he does not know my status"* (non-disclosed female).

While some PLWHIV reported discussing issues of HIV/AIDS with their spouses, others do not discuss the topic. Those who said that they did not discuss the topic with their spouses gave several reasons. The key themes were; fear; belief that there is no point discussing it and lack of time.

Fear seemed to be a key deterrent in discussing HIV/AIDS especially among the non-disclosed respondents but not limited to them. Some PLWHIV avoided the topic of HIV/AIDS due to fear of their spouse's possible reaction to the topic or fear of an unknown reaction. Arespondent explained how he avoids the topic by walking out of the house whenever the spouse starts the discussion on HIV/AIDS. He reported fearing the consequences of such a discussion as the spouse threatens that she would commit suicide if she ever tested HIV positive.

Other PLWHIV expressed avoiding any discussion on HIV/AIDS for fear of being blamed for bringing the virus to the home and thus casting doubt on their relationship. Related to this is the fear of the spouse's reaction. For others it was the fear of not knowing what to say or how to say it. A respondent commented, *"No, I do not know what to tell him or where to start talking about it"* (non-disclosed female).

Some PLWHIV felt that there is no need to discuss HIV/AIDS. Some of the reasons given for this belief included; the fact that the PLWHIV and their spouse already know all they need to know about HIV/AIDS, helplessness, why discuss it, they are already infected and why discuss something that you have no solutions for and cannot change, this will only result in depression. Others expressed the view that HIV is not something good to be talked about now and then because you may end up losing hope and that there is no point in discussing it because as one PLWHIV put it *"I may not tell the origin of the infection, maybe from her past sexual history or mine. So, I do not discuss about it because there is no solution"* (disclosed male).

Some respondents indicated that they did not discuss the topic because they lacked time. This was attributed to mainly the male spouse being busy or acting busy; having no time for me and the children, the spouse being away from home most of the time or when he comes home he would be drunk.

The researcher also wanted to know if the PLWHIV had informed their spouses about going for the HIV test. A clear distinction emerged where for those who had not disclosed their HIV positive status to their spouses, none of them had informed their spouses about going for the HIV test. Among the PLWHIV who had disclosed, some had discussed the HIV test with their spouses prior to going for the test.

For those who had discussed going for the HIV test with their spouse, majority reported that they had been sickly for some time and this prompted them to seek an "answer" to the frequent illness. One respondent explained his situation, *"Yes, I used to get sick frequently. We sat and tried to think about the source of the illness, so we decided to go for the test"* (disclosed female).

Some PLWHIV reported being so sick and had been accompanied by their spouses or relatives or friends to the hospital. These people got to know about the testing even though they had not discussed about it earlier. Other respondents said that they discussed HIV test with spouses because the spouses had already tested and knew their status. Hence the PLWHIV also felt the need to go for a HIV test. Some PLWHIV said that they were encouraged to go for the test after their spouses tested and turned HIV negative.

Some respondents reported that they informed their spouses so that the spouses could also go and get tested. Some female respondents said that they were to start attending prenatal clinic and the spouses knew that they would be tested for HIV as part of the clinic. It is a routine test and is normally carried out in prenatal clinics for pregnant mothers.

As indicated earlier, none of the PLWHIV who had not disclosed their HIV positive status to their spouse had informed their spouse about taking the HIV test. Also some who had disclosed their HIV positive status to their spouses had not discussed going for the HIV test with their spouses. Two categories emerged. The first category is those individuals who did not make a decision about going for the HIV test earlier and the test was provider initiated. The second category was those individuals who had made a decision to go for the HIV test. They went to the health facility specifically for a HIV test but did not inform their spouse. Some of the reasons given by the PLWHIV for not informing their spouses about the HIV test include: test was provider initiated; fear; they chose to know their HIV status first before involving the spouse; they met spouse when already tested and spouse still does not know that the PLWHIV has had a HIV test.

Two key themes emerge among those who had not informed their spouses about the decision to go for a HIV test. These are one, the fact that the HIV test was provider initiated and the PLWHIV had gone to hospital for other types of illness. Most respondents reported having gone for “normal treatment”. Some of the illnesses that respondents cited as prompting them to go to hospital to seek treatment included chest pains, TB, typhoid, boil in the armpit, wound that does not heal, stomach problems, and malaria. Hence as they explained, the HIV test was not the reason that they were seeking health services. Although ill and for some very ill, they had no intention of having a HIV test. The health care provider initiated the idea of the HIV test and thus they had not informed their spouse before the test. One PLWHIV explained, *“No, I did not inform her because I had gone for normal treatment because I was sick and I was requested to come with my spouse to be tested and she also came and tested HIV positive”* (disclosed male). Some respondents had gone to hospital to seek services other than a HIV tests or even “normal treatment”. This included Family Planning (FP) and blood test.

The second theme was fear. Some respondents reported fear of being asked for the results if they had informed their spouses; perceived as unfaithful, confronted, blamed, abandoned and fear of testing positive. One PLWHIV explained theirfears. *“I was afraid to tell her because I thought if I tell her she would definitely think that I have been unfaithful, so I went in secret”* (disclosed male).

Some PLWHIV did not inform their spouses because they either perceived themselves as being at a high risk of HIV infection due to their sexual history or they had information or rumours that a former sexual partner or their spouse was infected. Some reported being suspicious that they may be infected because of the symptoms that they were having which made them suspect that they may be infected with HIV.

Other reasons given for not informing the spouse include impromptu testing where the PLWHIV came across a VCT centre and went for the HIV test; the PLWHIV met the spouse when they had already tested; hospitalization and spouse not at home either due to separation or works away from home.

4.3.9 Information on HIV/AIDS and Disclosure

The researcher also wanted to find out sources of information on HIV/AIDS for the PLWHIV.Majority of the PLWHIV reported getting information from the mass media. Most cited having heard the message on radio and TV. Other types of media cited by a few individuals included newspapers, posters and billboard. One respondent also cited getting information from the internet. Some individuals cited TV programmes such as S*iri*(Populations Service International PSI Kenya, USAID funded soap opera)and*Epuka mpango wa kando* (A public Service Announcement targeting Multiple- concurrent Partnerships).

The second most cited source of information was the clinic and the health care providers at the hospital. These included the doctors, clinical officers, counsellors in the hospitals. Other sources of information cited include; HIV support groups, community health workers, home visits, seminars and training on HIV/AIDS, youth groups which create awareness through drama and talking to people for instance at pool tables and shopping centre, public either in public gatherings, discussion with friends and peers, in church, public transport, schools and reading books and pamphlets. All the respondents interviewed had heard about HIV/AIDS from at least one source. Most of them had heard about it from more than one source.

Majority of the PLWHIV irrespective of the disclosure status indicated that they had heard a message or information on HIV status disclosure. The sources of information were similar to those of HIV/AIDS above.

The key message was the importance of disclosing one's HIV positive status to their spouse. Other messages identified were; encouraging spouses to go for HIV test; notifying the spouse to avoid infection and re-infection; non-disclosure will affect ARV adherence; disclosure helps to prevent the spread of HIV virus; the need for everyone to know their HIV status and let their partner know; need to go for testing, use condoms and be accompanied by your partner to the clinic. A few respondents said that although they had heard a message on HIV status disclosure, they could not remember the exact message. Others could not remember the exact source of the information.

I wanted to find out if the messages that the PLWHIV had heard on disclosure had any impact on them. Most of the respondents interviewed reported having heard a message on HIV disclosure from different sources as seen above. Some said that they had never heard of such a message. For those who reported having heard a message on disclosure, most of them explained that the messages had an impact on them. Two key themes seem to emerge. The dominant one is that the disclosure message made the PLWHIV to go or have the courage to disclose their HIV positive status to their spouse, parent or a friend. Some even were able to request their partners to go and get tested for HIV.

However, most respondents explained that it was not easy to disclose following the message. Some respondents explained their experiences. *“Yes, but a bit hard to disclose. Men are difficult and different. It is hard to disclose to an individual even a spouse. I prefer a couple going for VCT together; they will exchange results”* (disclosed female). For others, the message made them either to go for HIV testing or disclose and requested their spouse to also go for the HIV test.

The second impact can be categorised as impact on their behaviour. Some PLWHIV reported a change in their behaviour. Some changes cited include, adopting safer sex behaviour as in the use of condoms, being faithful to their spouse, reducing or dropping multiple sexual partners and for some not taking alcohol. Some respondents explained, *“Yes, the information changed my life since I used to drink and also had multiple sexual partners. I stopped drinking and dropped all my sexual partners apart from my wife*“(disclosed male).A few PLWHIV reported that the message had no impact on them. For some they had already disclosed by the time they heard the message. For others, life just “went on”.

4.4 Methods of Disclosure and Challenges in Disclosure

One of the research questions of this study was to find out the methods of disclosure used by the PLWHIV and some challenges that they faced during disclosure.

4.4.1 Methods of Disclosure

Some respondents choose to disclose directly while others disclosedindirectly. In some cases, the PLWHIV reported having just informed their spouse about their HIV positive status directly as advised by the health care provider or HCT counsellor. A respondent explained, *"After supper, I obeyed what the doctor had told me. I approached him and told him that I had tested positive despite fearing attack or blame that I had brought the virus into the house, I confronted him"* (disclosed female).

Some PLWHIV disclosed to their spouses directly face to face due to anger as one PLWHIV put it, *"I disclosed to him directly because he is the one who was there when I was discharged. Again he is the one who infected me. He is the one who is unfaithful"* (disclosed female).

Most of the PLWHIV reported disclosing indirectly. They reported that they notified their spouses themselves but indirectly. Various methods were cited including introducing the topic of HIV/ADS or VCT; the spouse enquiring about the visit to the doctor; telling the spouse about their hospital visit; "briefing talks" such as how was your job, business; taking spouses out for dinner, making the evening jovial; sitting together after supper; searching for a suitable moment; giving the spouse a condom; showing the spouse the clinic or hospital card; asking the spouse questions for instance about faithfulness; refusing to have sex or telling a third party.

A common method of disclosure was for the PLWHIV to pretend that they had not been tested and request the spouse to accompany them for a HIV test. This was said to be commonly advised by the health care providers in the hospital as a PLWHIV explained, *"I disclosed to my wife by telling her that we need to be tested, when we went for the test, I pretended not to have been tested previously and we saw each other's results"* (disclosed male). This was also confirmed by the key informant interviews as a strategy that they used to get the PLWHIV to bring their spouses for testing. A key informant explained*, "Yes, we tell them to pretend that they have never been tested but to show the spouse the need and initiate couple counselling"* (key informant, clinical officer).Another method that is reported to be used by the PLWHIV was to tell their spouses that the doctor or health care provider wanted to see them both at the clinic.

Another indirect strategy used was by the PLWHIV was to use questions. They would first enquire for certain information from the spouse or give information about their visit to the doctor. This allowed the PLWHIV to "test the waters" before deciding whether to disclose. A respondent narrated his experience,

> *"I started by questioning her on what she would do if she finds out that she is HIV positive. She said that she would take drugs like other people. I asked her if she knows other people who were taking drugs and she said yes, she knows. Then I requested if we can get tested together to which she agreed and we went for the test"* (disclosed male).

Another indirect strategy was to attempt to create an environment which would result in open communication that could make it easier for the PLWHIV to introduce the issue of disclosure. A PLWHIV describes how he prepared himself. He narrated, *"It was hard for me but I was really encouraged by the providers and I was prepared for anything. I made the evening jovial and generated open communication. I accepted a joke from the whole issue because to realise that she had kept it a secret for some time without really revealing to me. She had known her HIV status and started CCC. So you can be a hypocrite for all that long?"* (disclosed male).Some PLWHIV expressed the view that disclosure required a suitable moment as a PLWHIV described, *"I took him out to dinner, I sweet talked him and I told him in a cunning way that I had been tested and was found to be HIV positive*" (disclosed female).

Other indirect strategies included placing the CCC card at a place the spouse could easily locate, giving the spouse a condom when requested for sex or refusing to have sex. A PLWHIV explained how she disclosed. She said, *"I started by refusing to have unprotected sex with him and when he asked why? I told him that he needed to be tested and wh*en he insisted to know why, that is when I told him about my HIV positive status" (disclosed female).

Some PLWHIV shared the results with their spouses in the presence of the heath care provider. In most cases, the spouse happened to be with the PLWHIV when he or she had tested either because they had accompanied them to the hospital or the PLWHIV was hospitalised. In other situations, the PLWHIV and the spouse had gone for testing together after the PLWHIV requested the spouse to accompany them for testing. Although they tested together and exchanged their results, they had not actually intended to come for couple counselling. Most tested together either because as some PLWHIV put it, they had "tricked" their spouse that they have not tested previously and thus went for HIV test together or the health care provider had requested them to come together.

A few respondents talked of instances where the disclosure of one spouse led to the disclosure of the other spouse. This is illustrated by a PLWHIV response, *"We had gone to a hotel for lunch wherewe talked a lot and made so many promises. He revealed first and I followed suit"* (disclosed female).

Other methods of disclosure said to be used by a few PLWHIV and not commonly used included; the counsellor or doctor disclosing to spouse in the presence of PLWHIV; phone; using a third party such as a mother or sister and unintended disclosure where the PLWHIV meets the spouse at the clinic.

4.4.2 Challenges in disclosure

I wanted to establish some of the challenges that the PLWHIV faced in disclosing or concealing their HIV positive status. Majority of the PLWHIV talked of various challenges. The results revealed challenges of three broad categories. These are psychological challenges, communication challenges and prevention behaviour challenges.Most of the PLWHIV cited challenges of an emotional and psychological nature. These included, stress, self-hatred, hatred for spouse, confusion, anger, fear, thinking too much and denial. One PLWHIV voiced experiencing several challenges as he explained, *"I was in great mental turmoil because she was breastfeeding, so I was afraid she may infect the baby. Some years back* it was very difficult for one to disclose their status, thus I did not have the right words" (disclosed male).

Others reported having challenges related to possible outcomes of the disclosure. This included fear of the spouse's reaction such as the spouse leaving or committing suicide while others expressed fear of how they would be perceived by their spouse. Most predicted negative outcomes which was a challenge.

A few female respondents cited children as posing a challenge for them. Some expressed fear of not knowing what would happen to their children if for instance the spouse chased them away. Some expressed the challenge of the children witnessing the outcome of the disclosure such as violence. One explains how she waited for the children to sleep to protect them from any possible negative outcomes. She narrated her challenge, *"My children, I did not want them to know, so I had to wait until they slept so that they do not* witness the outcome, if I were to be sent away or abused or beaten in their presence" (disclosed female).

Some PLWHIV reported lacking the courage to start the conversation on disclosure with their spouse, not feeling like they had the skills to disclose, lack of the right word and not knowing where or how to start. Some of these challenges were echoed by respondents' responses as illustrated below. One said, *“I did not have the adequate skills on disclosure and I did not know the right words to use. Since she was in denial because of her status, Iwas wondering how she would take it when she learns that both of us are HIV positive”* (disclosed male).

In addition, many PLWHIV talked of the challenge of not knowing how to disclose and yet trying to protect their spouse from being infected. Some expressed feeling inadequate and not being prepared to disclose as one explained, *“Feeling inadequate or like I was not prepared to handle it, I feared he will demand for sex yet I feared I could infect him. I felt like refusing but I gave in to avoid anger and suspicion”* (disclosed female).

Some PLWHIV expressed challenges that were behavioural in nature. These included challenges on adopting safer sex practices such as the use of condoms. Some respondents described the difficulty of introducing the issue of condoms to the spouse or negotiating and convincing the spouse to accept using condoms. This is reflected in the sentiments expressed below. A male respondent describes how he has to use force to use a condom when having sex with the wife since she resists it. He commented, *“Challenges are many, I have to use force to use a condom when having sex with her. Sometimes we fight because I would not want to infect her*” (disclosed male).

4.4.3 Challenges faced by PLWHIV in concealing their HIV positive status

Among the PLWHIV who have not disclosed their HIV positive status, the key challenges cited include difficulty with ARV adherence, finances, communication and psychosocial challenges.

The dominant challenge cited by most of them was “hiding the medicine”. Almost all of the PLWHIV talked about how difficult it is to keep their HIV positive status secret and adhere to the ART. Majority reported that they have to hide the medication, the hospital documents or anything that may point to a HIV positive status including trying not to cough too much when the spouse is around. Others try to hide when taking the ARVs.

A lot of the PLWHIV reported cheating. They either lie about the medication if their spouse asks about them; they cheat about the frequent visits to the clinic or about the frequent illness. One PLWHIV said, *“I cheat him that I attend the gyna (sic.) (Gynaecology) clinic yet I know the truth. Sometimes, I make sure that I take my drugs before he reaches home so that he does not ask for how long I am going to be on the medication. I also cheat him; I tell him that we must use condoms because of my uterus problem”* (non-disclosed female).

These challenges impact on ARV adherence because the PLWHIV only take the drugs when the spouse is not home or is asleep hence interfering with the strict schedule of taking the ARV as one PLWHIV explains, *“I do have a problem with drug adherence, since I only take them when he is not around”* (non-disclosed female). One reported taking the ARV in the toilet which would make one question the issues of hygiene and storage of the ARVs.

Other challenges facing PLWHIV who have not disclosed include financial challenges, communication and emotional challenges. Some challenges cited include, lack of fare to the clinic; being questioned on the frequent visits to the clinic, illness and prolonged use of medication; use of condoms; feeling low, guilt, confused, denial, where to start the conversation and how to start the conversation on disclosure?.

4.4.4Overcoming the challenges

The PLWHIV utilize different strategies to help them overcome the challenges they encounter either in revealing or concealing their HIV positive status. The PLWHIV who have disclosed reported different ways of overcoming the challenges that they faced in disclosure. They can be categorized into three main strategies. These are personal or self, others and communication.Most attributed overcoming the challenges to themselves; others and communication factors.

Most of the PLWHIV reported that their way of overcoming the challenges to disclose was to try and overcome their fear and eventually gain courage to disclose. This fear was either overcome over time, through newly acquired information about HIV /AIDS or through self-encouragement. While some respondents talked of self-encouragement, others talked of encouragement from others such as counsellors, support group members or community health workers. As one explained, *"I was encouraged in the support group therefore I got the courage to talk to him about my status"* (disclosed female).

Other PLWHIV reported accepting themselves and their status and just decided to disclose to their spouses. One man explained his situation using an analogy. He narrated, *"I accepted myself, thus I gathered courage to confront the issue (he pauses) let me ask you? Ungithiigukama ngombe iria riiitike ri, ungika atia tiga uthire ukamituire ringi? (If you went to milk a cow and the milk spills, what would you do other than going back and get cow feed for it again?"* (disclosed male).

Some PLWHIV used indirect approaches to overcome the challenges in an attempt to introduce the issue of disclosure. They brought in the issue of HIV positive status by introducing discussion on HIV /AIDS, or as one PLWHIV put it, by bringing in the issue of the large amounts of money they had used in seeking treatment for the illness.

A few PLWHIV reported resorting to trusting in God and prayer. As one woman put it, *"I prayed to God and I was able to communicate to him humbly"* (disclosed female). For others, it was the realization that they had no other option or choice but to disclose while for others they decided that the spouses needed to know the truth. Others felt that they had no control of the situation and as one respondent put it *"what happened happened". She said, "I knew that what had happened had happened and there is no way back. So I had to tell him to reduce my stress"* (disclosed female). This sense of loss of control is echoed by another PLWHIV using a Kiswahili proverb. He said, "*yakimwagika hayazoleki"* (when water spills, it cannot be collected) (disclosed male). The PLWHIV reported different ways to overcome their challenges. They are presented in table 4.6.

Table4.6: Strategies to overcome Disclosure Challenges

Category	Specific Strategies
Personal	1.Overcoming fear 2.Self-acceptance 3. trust in God and praying 4. Ensuring one always has condoms 5.Gain courage through knowledge, information on HIV 6.Acepting the situation as one cannot change their HV status
Communication	1.Talking and pleading with spouse to accept PLWHIV positive status 2.Talking to a third party 3.Indirect communication such as showing spouse the hospital card to generate discussion 4.Discussing the cost of prolonged illness 5.Deception
Others	1.Assuming the spouse is also HIV positive 2. Responsibility to others and realizing the spouse needs to know the truth. 3. Encouragement from support group, health care providers

As we saw earlier, one of the dominant challenges among PLWHIV who had not disclosed was the issue of how to take ARV without the spouse knowing about it or knowing the exact nature of the illness for which the medication was being taken. Related to this was the challenge of hiding the real reason as to why the PLWHIV went to the clinic frequently or took medicine all the time.

Most of the PLWHIV reported overcoming this challenge by cheating. Cheating was the most commonly mentioned strategy to overcome this challenge. Most reported cheating about the illness, its true nature, the medication, the reasons for taking them, frequent visits to the hospital and frequent illness as we saw earlier. One PLWHIV explained, *"I try to keep my drugs in my pockets so that if the time to take my ARV reaches and we are together, I just pretend to go to the toilet and take them from there"*(non-disclosed female).

Other methods that PLWHIV who had not disclosed reported using to overcome the challenges include, using alcohol, avoiding issues related to HIV/AIDS and talking to other PLWHIV. Others explained that talking to other PLWHIV helps them gain the courage to move on with life.

4.5 Preventive Measures

The study wanted to find out if the PLWHIV knew the HIV status of their spouses and what preventive measures they adopt to protect the spouses from infection if they are HIV negative and themselves from re-infection. I also wanted to know if the PLWHIV is on ARV or belongs to any support group.

4.5.1 Knowledge of spouse’s HIV status

Majority of the PLWHIV who had disclosed reported knowing their spouse’s HIV status. Most of them said that they knew their spouses status either because, they had tested together; the PLWHIV had been tested in the spouse’s presence; the spouse tested in the PLWHIV’s presence; the spouse disclosed to them or because their disclosure resulted in the spouse going for the HIV test and the spouse also disclosed. Two respondents reported meeting their spouses in the support group which made their HIV positive status obvious.

Some PLWHIV reported not knowing their spouse’s HIV status. Most stated that their spouses had never tested; refuse to test or did not know whether they had tested. A few PLWHIV reported that they were not sure about the spouse’s HIV status although some said that they were suspicions of their spouse’s HIV status. The information on the knowledge of HIV status of spouses is presented in table 4.7. I have treated those who say that they are not sure as not knowing since they actually do not know for sure.

Table 4.7: Knowledge of Spouse's HIV Status

Knowledge of Spouses status	**Female**		**Male**	
	Disclosed	**Not Disclosed**	**Disclosed**	**Not Disclosed**
Know spouse’s HIV status	37	1	26	0
Do not know spouse’s HIV status	8	16	2	3
Other	1	1	2	1
Total	**46**	**18**	**30**	**4**

Among the PLWHIV who have not disclosed, only one reported that they knew the spouse’s HIV status. They explained that the spouse had tested and was HIV negative. All the other non-disclosed PLWHIV said that they did not know their spouse’s HIV status. Some reported that their spouse had not tested; did not know if they had tested and others simply stated that they did not know their spouse’s HIV status. A few of them also expressed doubts about the spouses HIV status. This suspicion was based on several reasons such as; the spouse having symptoms that the PLWHIV recognised as HIV related or the spouse had a sexual affair with someone rumoured to be HIV positive.

4.5.2 Protective measures adopted

When the PLWHIV were asked about the preventive measures they take to protect their spouses from HIV infection and themselves from re-infection, almost all them reported the use of condom. This was the case for both the disclosed and non-disclosed PLWHIV. Majority cited the use of the condom only or alongside other measures.

Most reported using condoms following the advice of the health care provider. All the PLWHIV exhibited awareness of why they needed to use condoms and take other preventive measures like avoiding sharing sharp objects like razors and being faithful. One PLWHIV explained, *“ We use condoms to avoid infecting him and also we do not share personal things like razor blades just like we were advised by daktari and peer educators”* (disclosed female).

Among the PLWHIV who have not disclosed their HIV positive status, they also reported using condoms to protect themselves and their spouses. However, since they have not disclosed their HIV positive status, some expressed difficulties in introducing the use of condoms. Some reported telling the spouse to use condoms as a FP method, others tried to convince the spouse to use condoms because both of them had not tested and did not know their HIV status.

The data indicate that although majority of the PLWHIVs both those who have disclosed and not disclosed reported using the condom as a preventive measure, they are faced with several challenges. Some of them reported not using the condom consistently which was mainly attributed to resistance from the spouse. Other reasons given include, the spouse of the PLWHIV believes that they cannot get infected; the PLWHIV has not disclosed their HIV positive status; spouse wants a baby; fear of making the spouse angry; PLWHIV or spouse hates using condoms and that using condoms is quite an involving task. The following excerpt illustrates some of the PLWHIV experiences with the use of condoms. A PLWHIV narrated, *“We use condoms even though he had refused saying that he wants a baby boy. He used to burst the condoms until one day I had an ectopic pregnancy, I became so sick that I was hospitalised. Now he has accepted to use condoms”* (disclosed female).Among the non-disclosed PLWHIV, most attributed the inconsistency of condom use to the fact that they had not explained to their spouse why they were requesting that they use a condom.

Respondents shared other measures they assumed to assist in prevention. These include; not sharing sharp objects and personal items such as bathing products; avoiding body contact when bruised; dropping other sexual partners; avoiding *mpango wa kando* (multiple concurrent partnerships); eating a balanced diet; keeping off sex or refusing to have sex; keeping off men; encouraging spouse to take HIV testing regularly if HIV negative; avoiding alcohol; avoiding spices and processed food and open communication.

A few PLWHIV reported not using any preventive measure as the following PLWHIV explained,*"We do not have any preventive measures, as I said before, we went on with life as before like nothing had happened"* (disclosed male).

4.5.3 PLWHIV in HIV support groups

The researcher wanted to find out whether the PLWHIV were members of any HIV support groups and if they found the groups beneficial or not. I also wanted to find out, for those PLWHIV who are not members of any group, what is the reason for not joining a support group. The PLWHIV can be categorized into two groups, one, those who are members of support groups and those who are not members.

Majority of the PLWHIV reported being in HIV support groups. These included disclosed males and females and non-disclosed females, but none of the non-disclosed males reported being members of a HIV support group.

Some of the PLWHIV both disclosed and non-disclosed males and females stated that they do not belong to any HIV support group. Several reasons were given for not being members. The key reason given was fear by the PLWHIV who did not want their HIV positive status known by others, fear of meeting people they know, gossip and losing customers if HIV status is known. Being a member of a support group carried the risk of other people knowing the HIV positive status of the PLWHIV especially if one met somebody in the group who they recognise. This was felt to be a real risk considering that most of the groups were composed of members from the same area or community. One PLWHIV asserted,

> *"I do not like joining support groups and because my status will be known by many and it will affect my job becausemany people will not agree to hire a sick person for fear the job may be left incomplete"* (disclosed male).

For one PLWHIV, the fear was so strong that she travels from Meru to Kirinyaga, a distance of more than 200 kilometres to pick her ARVs. This way she reduces the risk of meeting someone who knows her. She explained, *"No (probe why?) I fear people will know my status and it is something I cannot live with, that is why I come for my ARVs here from Chogoria"* (disclosed female).

In addition to fear, other reasons cited for not being members of a HIV support group include; support groups are a waste of time; no time, busy at work, farming or with young children, I am new to these things; no support group at my place; do not see their importance, not helpful; lack of funds for registration; no interest; PLWHIV is very weak; lack of knowledge about groups and how to join them; fear of gossip and rumours and the PLWHIV get information needed from other sources such as spouse who attends support group. A few PLWHIV reported having been members previously, but do not belong to any group currently. Some explanations given as to why they are no longer members included relocating, busy with casual work and fear of gossip.

Most of the PLWHIV in support groups reported that the support groups were helpful. The benefits can be categorised into three major themes. These are psychosocial support,financial support, health information and educational support.

Most of the PLWHIV in HIV support groups reported sharing and being encouraged by the facilitators or other group members. They talked of sharing, stress management and sharing experiences such as the use of condoms and side effects of the ARVs as one PLWHIV put it,

> “Yes. I come here and we discuss stories like condom use and many other stories. If one has a problem of a side effect for example, the doctor can change the medication.It also helps because we encourage one another and you get to know that you are not alone taking medication” (non-disclosed female).

Some PLWHIV were of the opinion that the health status of those who are not members of such groups may worsen. One explained,

> *“There is social support, sometimes you find that those who refuse to join the group, their health is worse because they nurse their stress maybe through alcohol or other things and sometimes they even forget to take their medication”* (disclosed female).

Some PLWHIV talked of support groups offering financial support. This was in form of table banking, income generating activities such as keeping chicken, dairy goats, reimbursement for fare and sometimes being given free mosquito nets.Some PLWHIV described their support group as beneficial in terms of educating them and giving them information on HIV/AIDS and related issues. This included information on positive living, eating a balanced diet, safer sex such as the use of condoms.

Majority of the PLWHIV reported being on ARVs. A few of them were not on ARV because as they reported the doctors told them that their CD4 count was still high. In addition to using ARV, some PLWHIV reported being advised by the health care providers to eat well, avoid alcohol and others were put on a special diet.

4.5.4 Discussion on the Need to Disclose During HCT

Majority of the PLWHIV reported that they had been informed about the need and importance of disclosing their HIV positive status to their spouses during the HCT. This was the case for both the disclosed and non-disclosed PLWHIV. Most PLWHIV reported that the HCT or care provider advised them or showed them the need to disclose. Majority also reported having a discussion with the HCT or care provider on the issue of disclosure and other HIV related issues. The dominant message reported in the discussion was the need for the PLWHIV to disclose and the spouse should also get tested in order to know their HIV status. In addition, some reported having a discussion of how they can go about disclosing and were guided on the direction to take.

Most PLWHIV said that they were given advice or freedom to choose to disclose or not to disclose as one PLWHIV put it, *"Yes, I was told that it is my choice to disclose, but if I chose to disclose it will be to my benefit"* (disclosed female). While some reported being given a choice, a few respondents said that the discussion took the form of; you should or must disclose. One PLWHIV described his situation. *"I was told that it is a must I disclose to my wife about my HIV positive status. I was asked for my wife's telephone number so that if she does not come to get tested she can be informed about my status on phone"* (disclosed male).

Other messages in the discussion between the HCT care providers and the PLWHIV during testing include; the need for the spouse to also get tested, positive living, dangers of re-infection; use of condom; balanced diet; personal background such as whether one is married or has children; what one would do if he turns HIV positive; encouragement to go on with life; to disclose before sexual contact, you are not alone. Some PLWHIV expressed challenges despite being advised to disclose to their spouses.

Some PLWHIV acknowledged that they were informed about disclosure during HCT but they have not been able to disclose or were not interested in the topic. Some cheated when asked to bring their partner and said they were not married or were separated. This poses challenges for the health care providers in getting the PLWHIV to disclose to their partners. One PLWHIV reported having mental anguish, they explained, *"Yes, but by this time I was mentally disturbed, I cannot recall exactly what he said to me, all I can remember is that he told me to request my spouse to go for a HIV test"* (disclosed female).A few PLWHIV reported that the HCT provider did not discuss with them the issue of HIV positive status disclosure.

4. 6 Suggestions for Facilitating Disclosure

I asked the PLWHIV to give suggestions and advice on how other PLWHIV who had not disclosed their HIV positive status to their spouses could be helped to disclose. The PLWHIV came up with several suggestions presented in table 4.8.

Table 4.8: Suggestions for helping PLWHIV to disclose

Categories	Specific Categories
Psychosocial Support	1.Counsell PLWHIV on need and importance of disclosure
	2. Encourage couple counselling
	3. PLWHIV to be talked to by other PLWHIV who have disclosed.
	4.Home visits for couples by community health workers
	5. Door to door campaigns to reduce stigma
	6.. Encourage PLWHIV to join support groups
	7. Build confidence in the PLWHIV to get courage to disclose
	8. Use assisted disclosure by health care provider, counsellor
	9. Invoke spirituality
Education/Training	1.Train PLWHIV on disclosure
	2. Educate the community to reduce stigma and accept PLWHIV
	3. Provide more information on the importance of disclosure and consequences of non-disclosure.
	4. Hold couple seminars
	5. Train spouses on effective communication between spouses
	6.Educate PLWHIV, community to remove fear and misconceptions
Communication	1.Talk to family members to accept PLWHIV
	2. Partners should understand, trust each other
	3. Encourage open talks between couples where they share experiences.
	4. Use intermediaries for example an age mate who can disclose to the spouse.
	5. Follow-up of non-disclosed PLWHIV
	6.use of humour
HIV Testing	1.Door to door HIV testing campaigns
	2.Test people at their work places so that everyone knows their status

4.7 Chapter Summary

In this chapter, I have focused on the study results. The study found that some key factors influencing disclosure include; the stage of illness, HIV testing, spousal communication and relationship factors, privacy, fear, protection, psychological and emotional factors and questions asked by the spouse. On the other hand non-disclosure was influenced by fear, spousal communication and spousal factors, privacy and communication skills. The study also found that the decision to disclose or conceal HIV positive status information was influenced by expected risks and benefits. Most PLWHIV loosen control of their HIV positive status information when they perceive trust and support from their spouses. Majority of those who disclosed used direct methods. Nonverbal cues, questions and humour were found to play a crucial role in disclosure. PLWHIV experienced a myriad of emotional, psychosocial, communication and HIV prevention challenges in disclosing as well as in concealing their HIV positive status from their spouses.

In the next chapter, I will discuss the study results. I will also draw inferences to other studies and key disclosure models and theories.

CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.0 Overview

In chapter four, I presented findings of the study. This chapter discusses key findings and relates them to the research questions that I set out to answer. I also relate my discussion to the theoretical framework and related research and theory. The chapter also provides a summary of the study, limitations and gives some recommendations. The chapter addresses facilitating and deterring factors on HIV positive status disclosure, perceived spousal communication behaviours influence on disclosure, communication challenges in disclosure, methods of disclosure and preventive behaviours adopted by PLWHIV after disclosure.

5.1 Discussion

5.1.1Factors Motivating Disclosure and Non-Disclosure of HIV Positive Status to Spouses

One of the research questions of this study was to explore factors that facilitate or prevent PLWHIV in Kirinyaga County from disclosing their HIV positive status to their spouses. From the findings, 30 men and 46 women had disclosed their HIV positive status to their spouses. On the other hand, 4 men and 18 women had not disclosed their HIV positive status to their spouses. DiRenzo (1990, p.192) defines a motive as:

> Motivation is a condition within an organism that impacts behaviour in order to obtain or to avoid a certain end state. Motives may either be biogenic or innate motives or sociogenic which have to do with social or cultural wants.

According to DiRenzo (ibid.), every human being has a set of sociological and psychological needs referred to as basic human needs. Included in these are motives such as social recognition, social acceptance, social security, cognitive clarity, self-esteem freedom from alienation, boredom and sensory deprivation. These needs must be met at least to a minimum level for the psychological balance in human functioning of the individual.

Santrock (1997, p.360), views motivation as involving the question, "why" people behave, think and feel the way they do? He refers to it as "The whys of behaviour". The psychologist Maslow proposes a model that looks at human needs in a hierarchical order ranging from physical to psychological needs. According to Maslow's hierarchy of motives, individual's core needs must be satisfied in the following sequence, physiological needs, safety, the need for love and belonging, the need for esteem, cognitive needs, aesthetic needs and the need for self-actualization (Maslow 1954; 1971 as cited in Santrock, 1997, p.361). According to this hierarchy, people must meet their needs for food first before they can achieve safety and before they can achieve the next higher need. A good number of PLWHIV reported disclosing to their spouse or someone else in order to meet the basic needs such as physical or financial support.

Most psychologists recognise the fact that behaviour is energised and directed by a complex mix of biological, cognitive and sociological processes (Santrock, ibid. p.361). Thus the decision to either disclose one's HIV positive status or withhold the information will be informed by several factors. Petronio (2002) notes that, factors such as culture, gender, motivation, context and risk-benefit ratio can influence one's decision to reveal or conceal private information. Derlega and Grizalek (1979, as cited in Petronio et al. 1993, p.225), cite five reasons for disclosure. These are expression, some clarification, social validation, relationship development and social control.

From our study, respondents cited various reasons for disclosure and non-disclosure of their HIV positive status to their spouses. Some of them disclosed to clarify their continuous state of illness to the spouse, others disclosed to meet the need for relationship development while others for social control. I concur with Derlega and Grizalek (as cited in Petronio et al., 1993) that individuals are motivated by different reasons. For instance, some respondents reported disclosing their HIV positive status to the spouses as they just wanted them to know so that either they could also get tested and/or to get support from their spouses. On the other hand some PLWHIV concealed their HIV positive status due to the need to protect themselves from shame and embarrassment. Others were afraid to disclose for fear of being perceived as immoral or labelled as promiscuous. In the following sections, I discuss some of the key themes that emerged as influencing disclosure and non-disclosure among the PLWHIV.

a.HIV positive status disclosure and stage of the illness

The most commonly cited reason by the respondents for disclosure of HIV positive status to their spouse was the fact that they were sickly and had been in and out of hospital on several occasions without “a solution to the problem”. For some PLWHIV their spouses were also sickly or had been sick for some time. This seems to be in line with Petronio (2002) argument that some life events will result in changes or modification of rule management. When a PLWHIV becomes too sick, often they lose control over their previously tightly held privacy boundaries over their HIV positive status and open it to allow access to their spouses or other individuals disclosed to.

This also seems to be in concurrence with the theory of disease progression discussed in chapter two. The theory of disease progression states that, individuals disclose their HIV diagnosis as they become symptomatic. It is suggested that as the HIV progresses to AIDS, individuals can no longer keep their HIV status a secret (Babcock, 1998; Kalichman 1998, as cited in, Serovich 2008).This may result in the boundaries getting thinner and an individual disclosing their HIV positive status.

This study found that majority of those who disclosed reported being very sickly. The stage of their illness was a motivator in disclosure either to access health care and/or support benefits or for others to get their spouses to also get tested. This is consistent with other studies findings such as Petronio (2002) and Greene et al. (2003). This came out clearly in some of the respondents' responses who cited being sickly as their reason for disclosure.

WHO proposes a staging system for patients infected with HIV. It starts from stage one which is asymptomatic to stage four, the clinical stage in which the patient manifests HIV wasting syndrome and is often bed ridden. The stages are shown in table 5.1.

Table 5.1 WHO Clinical staging for Adults and adolescents

Stage	**Symptoms**
Primary HIV infection	Unrecognised
Stage I	Asymptomatic
Stage II	Moderate weight loss and min or symptoms
Stage III	Severe weight, symptoms
Stag IV	HIV wasting syndrome

Source: NASCOP, 2001:126.

Deribe et al. (2008) in their study on disclosure experiences and associated factors among HIV positive men and women in Ethiopia, found that disclosure of HIV results to sexual partner was associated with knowing one's partner's HIV status, advanced disease stage, low negative self-image, residing in the same house and discussion of HIV testing prior to seeking services.

Almeleh (2006) found that six out of the eleven respondents in their study disclosed when in the symptomatic phase of HIV and AIDS, five were asymptomatic at the time of disclosure. Of the six who disclosed in a state of ill health, five disclosed immediately after diagnosis in order to access health related social support. Their concerns regarding health and mortality superseded fears of rejection and discrimination. Therefore, the perceived potential health benefits outweighed the perceived risks of stigmatisation and discrimination.

In the early stages of HIV/AIDS, one may not tell that their spouse is sick, but with time when one gets to the symptomatic stage of HIV/AIDS, it gets more difficult to hide the illness. It is more like pregnancy; you can only keep it a secret for so long. It soon becomes an open secret. Some PLWHIV described how they avoid coughing "anyhowly" in front of their spouses. However as the disease progresses, one is unable to "control" or hide the symptoms. Some respondents echoed the fact that even if they had not disclosed to their spouses, the spouse would still have known or may have suspected their HIV status.

b.HIV positive status disclosure and fear

Fear was a main factor in influencing disclosure. However, the context of fear was different. As seen in chapter four fear is both a key facilitator for disclosure and also a key deterrent. Fear was reported by most respondents as a key motivator in disclosing their HIV positive status to the spouses. As explained earlier, they expressed fear of several things. These included; fear of infecting the spouse, fear of being “discovered” (spouse finding out one’s status), fear of spouse finding ARVs and demanding an answer, fear of how to introduce condoms among other fears cited.

On the other hand an overwhelming majority of PLWHIV who had not disclosed reported fear as a key deterrent. This was given as fear of being stigmatised, beaten, rejected, abandoned, blamed, spouse’s reaction, separation, losing spouse, shame, perceived as immoral, gossip and rumours and fear of others knowing one’s HIV status. From our findings, fear was the major motivating factor to avoid disclosure among the PLWHIV who have not disclosed. Out of the 22 PLWHIV who had not disclosed, 18 of them reported fear as preventing them from disclosing to their spouse.

According to Lane and Wegner (1995, as cited in Petronio, 2002, p.68), “people keep secret information because there is the fear of real or imagined repercussions that the information would bring with exposure”.

Most respondents expressed fear of the outcome of their disclosure. PLWHIV weigh their situation and ask themselves the question, “do I disclose or do I not disclose?” From our findings, fear is a key driver in this dilemma. The findings indicate that while some PLWHIV reported being motivated by fear to disclose to their spouse, others reported not disclosing due to fear.

Although most literature looks at fear as a barrier to disclosure, fear can also motivate revealing one's HIV positive status. Among PLWHIV who had disclosed, fear was also cited as informing their decision to disclose. For most of them, the fear of infecting their spouse made them disclose to avoid infecting the spouse just in case they were not already infected. PLWHIV talked of "protecting, saving" their spouses. They reported disclosing to their spouse so that they could also go and get tested and know their status. Other PLWHIV were so sick and were afraid of their spouses getting to the stage of illness that they were already in. Disclosing was a way of protecting the spouse and trying to save them. The fear of conceiving and transmitting HIV to the baby (MTCT) influenced some women to disclose.

From the findings, fear plays a major role in the PLWHIVs decision to either disclose or conceal information about their HIV positive status. Fear thus can lead the PLWHIV to disclose not disclose. Fear could result in a PLWHIV loosening control of their boundary surrounding the HIV positive status information and allowing access. For others it leads to a tighter control and thickening of the boundaries and the PLWHIV being more closed and the information is withheld.

Altman and Taylor's theory of social penetration as seen in chapter 2, informs us that as one discloses themselves to another, they are penetrating deeper from the outer core into the inner core of self which contains information that others would not ordinarily know unless we tell them. The inner layer contains information about ones deepest fears among other aspects of information. From the findings, many respondents cited their HIV positive status as information that is highly guarded and as some called it, "my biggest secret". HIV positive status is surrounded by fear. This fear drove some respondents to disclose while on the other hand it prevented others from disclosing.

CPM postulates that individuals will weigh their risk-benefit ratio in their decision to either reveal or conceal private information. One key fear that most respondents cited was fear of "people spreading news". Several PLWHIV especially those who have not disclosed cited fear of their HIV status being known. They feared the gossip. According to Petronio (2002, p.193) gossip message is "about someone else's private information that may not only be partly true or may not be true at all, the content of the gossip is necessarily of a private nature or at least the gossiper tries to make others believe it is restricted to the target's personal boundary".

The fear of gossip was however not limited to only those who had not disclosed, even those who had disclosed did not wish to have their status known beyond the boundary of the spouse or confidant they had disclosed to. This is what Petronio (2002) refers to as boundary management and the individual can decide what information to give up control of and the persons to share it with either jointly with a spouse or collectively with others. CPM as explained in chapter one postulates that individuals develop rules for managing their privacy boundaries (Petronio, ibid.).

Most PLWHIV expressed concerns of fear of their HIV positive status being known or the news reaching their in-laws. They feared being talked about. Ameleh (2004) also noted fear of gossip among his respondents. This fear was cited by several respondents in our study. This fear limited access to only the spouse for the disclosed and for the non-disclosed no one had access.

Fear was cited as a deterrent to disclosure by all the key informants. This included fear to be abandoned, rejected by spouse, fear of the unknown, fear of being discriminated by husband and in-laws among other fears. Thus fear is a key factor in PLWHIV's decision to either conceal or disclose information about their HIV positive status. They can either exercise tight control over the information or allow access and co-share the information with the spouse.

c.HIV positive status disclosure and stigma

There is a lot of stigma associated with HIV/AIDS. As already mentioned, HIV is mainly transmitted through heterosexual sex in Kenya although the virus can be transmitted through other modes. It thus associated with taboo subjects. Stigma is a common human reaction to diseases. Parker, et al. (2002, as cited in Ragimana, 2006, p.23) concurs that HIV/AIDS related stigma and discrimination is closely related to sexual stigma in most parts of the world. This is due to the fact that initially HIV/AIDS affected populations whose sexual practices were perceived to deviate from the norm. Figure 5.1 illustrates the cycle of stigmatisation and marginalisation.

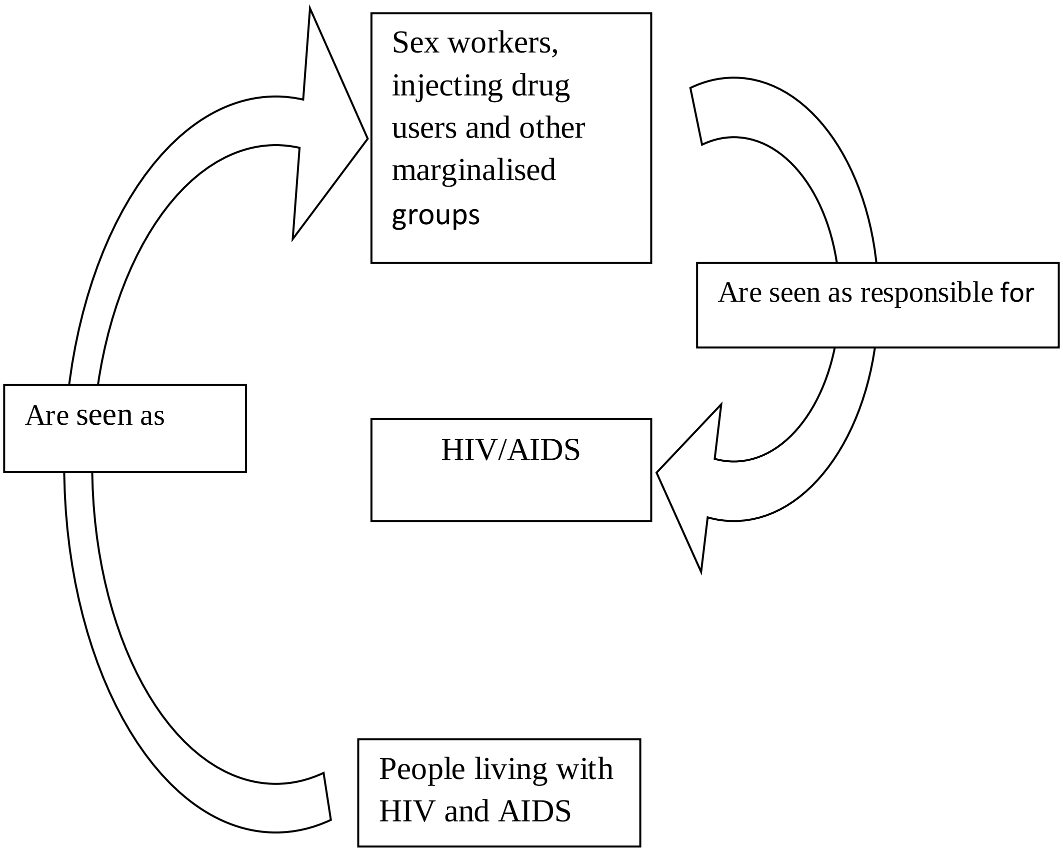

Figure 5.1: The Cycle of Stigmatisation and Marginalisation

Source: Parker & Aggleton, 2002, as cited in UNAIDS, 2005:8.

Sex in most societies is surrounded by taboo. Few people discuss sex without making or implying moral judgments or feeling that moral judgements are being made about them (Dossier 1988). Palmer and McMahon (1997, p. 421) express similar sentiments below:

> *HIV has become the disease of the late 20th century. In so doing, it follows a catalogue of other physical and medical conditions which have in the past been seen in moral terms such as leprosy, syphilis, TB and cancer all of which have been seen as meaning something about the moral status of those suffering.*

From the study some respondents expressed their concerns about HIV/AIDS and the question of moral values. Most talked of being perceived as a “sinner” or “a prostitute”.

Rohleder and Gibon (2005) note that fear of stigmatisation is due to potential negative consequences for being identified and labelled as HIV positive when either accessing treatment or support. As a consequence of these fears, PLWHIV generally keep their diagnosis secret and carry on living as they did previously. The fear of stigma and discrimination discouraged many PLWHIV from disclosing their HIV infection to their spouses and even family members who could be a necessary support system. Even among the PLWHIV who have disclosed to their spouses, they feared disclosing to others for fear of stigma. Cline & Boyd 1993, as cited in Frey, 2004, p.168) point out that:

> The dilemma faced by PLWHIV is, either risk becoming stigmatised by disclosing their condition in order to take a chance on gaining their potential health benefits of social support, or to avoid being stigmatised by engaging in information control and non-disclosure, thereby losing the potential health benefits of social support.

UNAIDS (2005, p.4) explains that stigma associated with AIDS is underpinned by many factors. These are, “ lack of understanding of the illness, misconceptions about how HIV is transmitted, lack of access to treatment, irresponsible media and reporting on the epidemic the incurability of AIDS and prejudice and fears relating to a number of socially sensitive issues including sexuality, disease and death and drug use.”

This study is in concurrence with UNAIDS (ibid.), that HIV/AIDS related stigma undermines prevention efforts by making people afraid to find out whether they are infected or not, to seek out information about how to reduce the risk of exposure to HIV, and to change their behaviour to more safe behaviour less they raise suspicion about their HIV status. Greene et al. (2003) argues that fear of stigma contributes to PLWHIV setting up defensive boundaries around their private information.

The findings from this study indicate that stigma was prevalent and there is need to tackle stigma by increasing understanding on the facts about HIV/ AIDS, educating people about the myths and misconceptions and providing them with factual information. For instance the fear of buying groceries from a shop operated by a PLWHIV as reported by some respondents is borne out of ignorance. It may also require efforts from the media on a change of attitude on the reporting on HIV/AIDS issues. There is need to focus on efforts that combat fear based messages on the media and HIV related campaigns in an effort to change people's attitudes towards PLWHIV. This should be targeted at the community, health care providers, family and the PLWHIV themselves since stigma occurs at all these different levels.

Pryor and Reeder (in press, as cited in Stutterheim 2011, p.5) classify stigma into four types. These are public stigma; self-stigma; stigma by association and institutional stigma. Stigmatisation can occur at the level of the self that is the PLWHIV. They may themselves internalise negative responses and reactions of others, a process referred to a self or internalised self-stigmatisation. Stigma can also manifest itself in the individual feelings of shame, self-blame, worthlessness, self-isolation; withdrawal from society and even suicidal feelings (Stutterheim ibid. p.9). Keeping a secret makes a person feel guilty (Karpel, 1980, as cited in Petronio, 2002. p. 68). These feelings were manifested by several respondents in our study. For PLWHIV, stigmatisation manifested itself in feelings of shame, guilt, self-blame, stress, depression, self-imposed withdrawal and even suicidal feelings.

HIV/AIDS is still considered a terminal illness and being diagnosed as HIV positive is still considered by some as a death sentence. Some PLWHIV explained that their spouse contemplated suicide after disclosure while other PLWHIV feared that their spouse could commit suicide if they disclosed and thus had decided not to disclose.

The stigma associated with HIV/AIDS has muted open discussion, both of the causes and of appropriate responses. According to UNAIDS (2005), visibility and openness about HIV/AIDS are pre-requisites for the successful mobilization of government, communities and individuals to respond to the epidemic. Silence encourages denial that there is a problem that requires open discussion and interaction. We recently saw the withdrawal of *Weka condom mpangoni* (use condom in multiple concurrent partnerships), a public service announcement targeting multiple concurrent partnerships by PSI Kenya.

UNAIDS (2005) argues that stigmatisation poses a barrier to prevention, care and treatment. HIV/AIDS related stigma and discrimination undermines prevention efforts by making people afraid to go for HIV testing and find out whether they are infected, to seek out information about how to reduce the risk of exposure to HIV and to change their behaviour to safer behaviours less they raise suspicion about their HIV status. Therefore stigma and discrimination undermines an individual's ability to protect themselves from HIV infection. It also discourages PLWHIV from disclosing their HIV infection even to family and sexual partners who would provide them with care and support system. Stigma means that PLWHIV are less likely to receive care and support.

The stigma surrounding the HCT centres in Kenya and in many other parts of the world prevents individuals from going for counselling and testing. WHO (2004) indicates that only a minority of African adults will make unsolicited visits to free standing or clinic based VCT centres. People avoid to be seen by their friends or neighbours or people they know.

Comprehensive Care Centres (CCC) provides services where the PLWHIV is made to feel worthy. In Kenya CCC and HIV support groups go a long way in facilitating for this role. However, we find that many PLWHIV will avoid going to the CCC or do not belong to the support groups for fear of being stigmatised or others knowing one’s HIV positive status among other reasons. In Thailand, for example they have HIV friendly temples run by monks who attempt to promote and integrate PLWHIV. The PLWHIV do not want to be seen going there just in case they meet someone who knows them. They will go to great lengths to avoid being seen by people who might know them. Stigma associated with the CCC.s is also confirmed by some key informants who reported that most clients do not like to be seen going for drugs or attending the clinic. Thus some miss appointments rather than risk being seen going to the clinic.

Almeleh (2006, p.137) found that women felt more comfortable disclosing outside their individual communities and in other areas where the possibility of identification was minimal. This minimises the personal risk as seen also among respondents in our study. A PLWHIV narrated how she travels from her residence in Meru to Karira in Kirinyaga where the probability of meeting someone who knows her is low thus minimizing the risk of her HIV status being exposed to others.

d. HIV positive status disclosure and consequences

One of the key assumptions of this study was that the PLWHIV would consider the consequences of their disclosure before disclosing to their spouse. According to CPM, Petronio (2002) explains that individuals erect boundaries around personal information and form rules to decide when to reveal information based on risk-benefits calculation and situation demands. Individuals appraise their situation and the positive and negative possible consequences of disclosure before making the decision to either disclose or withhold information about their HIV positive status. CPM posits that individual's decisions to reveal or conceal private information would be based on the benefit-risk ratio.

The PLWHIV assesses whether the disclosure poses a high, moderate or low risk. The higher the risk anticipated by revealing the private information the lower the probability of disclosure. The basic assumption is that a PLWHIV would weigh the benefits against the risks of disclosure. If the benefits of disclosure outweigh those of non-disclosure then the PLWHIV would disclose and the reverse would hold. In chapter four, we looked at various positive and negative consequences of disclosure.

Studies have shown that perceived negative reactions discourage people from being open about their HIV status (Kalichman et al. 2001; Greene et al. 2003). The study results indicate that most PLWHIV had anticipated negative outcomes. I asked the PLWHIV who had disclosed what they anticipated to happen and what actually happened after disclosure. A good number of disclosed respondents expressed anticipating negative consequences as discussed in chapter 4. Majority of the PLWHIV who had not disclosed also reported anticipating negative outcomes and hence they have not disclosed. Most of the negative anticipated outcomes as seen in chapter four can be categorised as fear of something. This might be fear of the information about their HIV positive status reaching the in-laws, fear of being left by their spouse, fear of gossip, fear of being blamed or fear of being labelled as promiscuous.

Other studies have indicated fear as a factor preventing PLWHIV especially women from disclosing their HIV positive status. According to WHO (2004) for women in particular, confidentiality of medical information including HIV status is essential to the protection of the human rights, because women may find themselves abandoned, subjected to domestic violence, or ostracised if their domestic partners, families or community discover that they are HIV positive (WHO, 2004).

Maman et al. (2001) indicates that fear of disclosure of HIV status is one of the main barriers to women's use of VCT, and that this fear reflects the unequal and limited power that many women have to control their risk of infection. As we saw in the study, fear of violence especially for women also prevents disclosure. Some women reported not using condoms for fear of making their husbands angry. This reflects vulnerability among most women.

Kadowa and Nuwaha (2009) found that among the 139 people who had not disclosed in a Uganda study, 58 out of 139 (42%) cited fear of divorce and violence. Also Gillet & Parr (2010) in their study in Kenya, found that many women in rural Kenya chose not to disclose their HIV positive status for fear of negative outcomes such as blame and rejection.

When the key informants were asked what prevents PLWHIV from disclosing their HIV positive status, six out of seven cited fear. They cited fear of consequences, fear of death of relationship, fear of blame and divorce, fear of unknown, fear of being blamed as the one who brought the virus home, fear of issues of discordance since if one partner tested positive and the other negative it brings chaos in the family.

Most PLWHIV who have not disclosed said that at least “no one knows” and they can “live like normal people”. They protect themselves from the consequences of disclosure by withholding information about their HIV positive status. For some PLWHIV, it is the fear of being subjected to consequences that have befallen others before them and fear to be subjected to similar consequences. According to Rawlins (1983) whenever there is a need to be open, there is a simultaneous need to be self-protective.

Although on one hand concealing one’s HIV positive status is perceived by some PLWHIV as self-protecting, on the other hand, research shows that keeping secrets as opposed to telling may have consequences for the person keeping the secret. Concealing a secret about a traumatic experience such as physical violence toward a child or a sexual abuse may lead to both physical and psychological symptoms associated with bearing the traumatic hardship alone (Kelly & Mckillop, 1996, as cited in Petronio, 2002, p.68). On the flip side, secrets also involve risks and result in higher levels of vulnerability if known by others.

Petronio et al. (1993, p.221) asserts that individuals are often faced with paradoxical demands that require them to manage their need for privacy and autonomy whenever they wish to disclose private information. Disclosure of HIV positive status is associated with negative consequences from either past experiences or having observed others who have disclosed in the community and the consequences they faced. To avoid similar consequences, some PLWHIV opted to keep the information secret and withhold information about their HIV status with the benefit of people not knowing their HIV status.

While majority of the PLWHIV had anticipated negative consequences, a few anticipated positive outcomes. These may include physical, emotional, financial or psychosocial support such as acceptance by the spouse, a strong relationship and having better plans for the future. From the findings of the study, among the disclosed PLWHIV majority reported experiencing positive consequences after disclosure despite having anticipated negative consequences. For some, the positive consequences were immediate while for others it took some time. Some expected negative consequences but were surprised by the actual consequences. They experienced positive consequences. For others, the initial experience was negative but later they experienced positive outcomes as seen in chapter 4. This may persuade some PLWHIV who have not disclosed to weigh the anticipated consequences again.

However, as we have already said disclosure entails taking a risk. Once an individual discloses, there is no guaranteed way of knowing the consequences. After an individual discloses, there is no way of telling what the recipient of the information chooses to say or do. This calls for continued education of PLWHIV, couples and communities who can minimize the perceived costs of disclosure such as rejection and stigmatization of the PLWHIV by the PLWHIV themselves and by other community members. This may include educating the communities at large and family members to reduce stigma, to support PLWHIV in the families and the community and also reduce self-stigma among the PLWHIV. This would minimise the anticipated costs by the infected persons and maximize the anticipated benefits of care and support by family and community members thus facilitating increased disclosure by HIV infected persons. This also points to increased efforts in focusing on measures to reduce stigma.

Some PLWHIV interviewed reported that some members of the community will not buy from their shop if they know that the owner is HIV infected. Despite knowledge of HIV/AIDS reported to be high in Kenya, the fact that people continue to avoid buying from shops run and operated by HIV infected persons points to gaps in the quality of information and education and a need for an attitude change. Although most studies indicate that majority of Kenyans understand the different modes of transmission, most still fear they can get infected by having contact with an infected person even by buying products from their shops. The fear of contagion has also been reported in studies among care providers of HIV positive patients. There is need to provide correct and factual information about HIV transmission and continuously reinforce the message in the media, religious forums in churches and mosques and other places of worship and also through the regular visits to the health centres.

In making disclosure decisions, we found that the PLWHIV in our study were dependent on the self and others such as family and community. These fall into what psychologists refer to as internal locus or external locus of control respectively. That is they will either look into themselves to inform the decision or the decision may be based on what other family or community members may feel or think. This reflects the principle assumptions of the Socio-Ecological Model which recognizes that an individual’s behaviour results from interactions with the community. The model looks at the complex interplay between an individual, relationship, community and societal factors. These factors put people at risk or perpetrate behaviour (CDC, 2014).

From the study PLWHIV’s fear of the in-laws knowing one’s HIV positive status or the information reaching the in-laws made some of them avoid disclosing to their spouses. Therefore the decision not to disclose was based on “others” what Petronio (2002) calls context. Choices are made based on the external locus of control bearing in mind what is acceptable or not acceptable in the community.

Izett and Toubia (1999, p.17) note that in general behaviour reflects a person's knowledge, beliefs and attitudes. The community and individual knowledge, beliefs and attitudes will affect whether an individual discloses or not. However, I am convinced by their argument that complex factors may encourage or dissuade a person from taking action. They say that individuals are surrounded by a circle of family, friends and colleagues which they refer to as social network that influences and reinforces how individuals behave especially in communities structured around the extended family and in such contexts, community choices supersede those of the individual.

I concur with Rossem and Meekers (2004, p.3) that understanding the impact of individual contextual factors on health behaviour is important as it can help inform the design of health programs and enhance their effectiveness. The study points to the need for education programmes targeting the PLWHIV, their families and the community at large.

e. HIV positive status disclosure and self-concept

From our study findings, many PLWHIV defined themselves as, "sick, infected". They label themselves as "the odd ones out", "we have virus", "positives". The respondents also reported that the community members defined them or perceived them as "sinners, immoral, prostitutes, promiscuous, infected, worthless, and valueless", thus affecting their self-concept. In a newspaper column written by Asumpta Wagura who has been public about her HIV positive status for many years, she said that often she would be referred to as “Asumpta *wa* AIDS” (Asumpta of AIDS), (Daily Nation, May 2013).

Santrock (1997, p.415) define self-concept as referring “to an individual’s overall perception of the ability, behaviour and personality”. According to Rogers (as cited in Santrock (ibid.), a person with a low self-concept is likely to think, feel and act negatively. Pearson and Nelson (1997, p.36) explain:

> The self-concept is each person’s consciousness of his or her total, essential and particular being. Included in self-concept are all our physical, social and psychological perceptions about ourselves. These perceptions are as a result of our past and present experiences and interactions with our environment including people in our environment. Self-image entails the roles you see yourself playing, the categories you place yourself within, and the words you use to describe or identify yourself as well as your understanding of how others see you. Self-esteem derives from our failures and success. A favourable perception of oneself yields high self-esteem while unfavourable perception yields low self-esteem.

Most PLWHIV in our study engaged in what scholars refer to as impression management also sometimes referred to as self-presentation. Santrock (1997, p. 466) says “that impression management involves acting in a way to present an image of oneself as a certain sort of person, which might or might not be who one really is”. He says that in most instances we try to present ourselves to look better than we really are. DiRenzo (1990, p.205) explains that “individuals are constantly looking in their societal mirror and making appropriate modifications as necessary”. For instance some PLWHIV reported not coughing “anyhowly” (sic) in an attempt to conceal their HIV status.

Some PLWHIV may have concealed their HIV status to get approval of their spouses and other community members. Some PLWHIV in our study reported not disclosing to avoid being perceived as immoral by the spouse. Vangelisti et al. (2001, as cited in Vangelisti, 2004, p.389) notes that decisions to reveal private information are influenced by beliefs about whether the confidant will still approve the individual after the disclosure and still accept them.

Goffman (1967, as cited in West & Turner, 2000, p.363) uses the term face to refer to the image of the self that people display in conversation with others. Face is a metaphor for the boundaries that people have in their relationships with others. He explains that face can be maintained, lost or strengthened. West and Turner (ibid. 364) explain that face has two dimensions. That is face concerns and face needs. Face concerns relate to one's own face or the face of the other. That is there is a self-concern and concern for others.

In making decisions to either disclose or conceal their HIV positive status, PLWHIV make choices about face concerns and face needs. Some decided to disclose out of concern for others and to protect the face of the others for example their spouse or family members while others decided to conceal their HIV positive status and not disclose because of their concerns for others and themselves. For example, one respondent explained that he had disclosed in order for his family members to stop thinking that he had been bewitched (others concern). Therefore the individual disclosed in order to protect the face of others.

Being HIV positive especially at the last stages of HIV/AIDS as the disease progresses, one may be too sick and weak to do most of the basic things for themselves and they may be hospitalized or too weak thus requiring physical and financial support from others in the family. Also an individual who previously operated a small business or worked as casual labourer is no longer able to do for themselves activities they could do for themselves before hence their negative face is threatened. The symptoms of HIV/AIDS by the late stages are overt and easily visible especially if one is not strictly adhering to the ART regimen and doctor's advice.

Their physical appearance may no longer be what it used to be before the disease progression. These physical changes can affect their body image thus impacting on their emotional and psychological wellbeing. This may expose the PLWHIV to various risks such as insecurity, stigma, face, relational and role risks as suggested by CPM as discussed in chapter one. Thus their privacy and the privacy boundaries are often adjusted to fit with the illness status. Petronio (2002, p.9) explains that "over a life span, privacy boundaries are modified to accommodate privacy information belonging to the individual". The shame associated with HIV/AIDS related stigma affects how people see themselves making them vulnerable to blame, depression and self-imposed isolation (McNeil & Anderson 1998, as cited in UNAIDS, 2005).

The PLWHIV especially the non-disclosed might miss out on the enhanced care that they require. They are also constrained on what kind of food they can eat and also on their sexual behaviours. For example, one needs to eat a special diet, avoid alcohol and other drugs and also use a condom which some reported to be restrictive as already discussed. This affects their ability to be in control of their lives, privacy, autonomy needs hence affecting their face and self-concept.

When the PLWHIV face is threatened, the individual may engage in what Ting-Toomey and Cole (1990, as cited in West & Turner, 2000, p. 367) refer to as face saving and face restoration strategies. Face saving involves efforts to prevent events that can either elicit vulnerability or impair one’s image. Face saving prevents embarrassment. These may include concealing one’s HIV positive status, lying about the illness or attributing the illness to other “socially acceptable” illnesses which do not elicit negative community judgement such as chest problems, skin rash and stomach problems as reported by some PLWHIV. Concealing one’s HIV positive status helps them to self-protect.

Some respondents reported that their spouses or the larger community perceive HIV/AIDS as being caused by wrongdoing on the part of the HIV infected individual. Other studies have found similar views in which the infected person is said to be infected as a result of immorality or wrongdoing. Benoit (1995, as cited in Pearson & Nelson, 1997, p.65) in his theory of image restoration observes that people encounter damage to their reputation because of their own wrongdoing or when they are suspected of wrong doing. Some PLWHIV reported “suspecting” themselves due to their past sexual behaviour.

Benoit (1995, as cited in Pearson & Nelson, ibid.) suggests that people engage in communication behaviours designed to reduce, redress or avoid damage to their reputation. Some PLWHIV reported concealing coughs when the spouse was near them and taking ARVonly when the spouse was away. Others cheated about the illness and attributed it to other causes such as uterus problem, stomach problems or chest problems which the spouse already knew about as seen earlier. Some PLWHIV disclosed their HIV positive status to their spouse or to other confidants and requested them not to disclose the information about their HIV status to anybody else to help the PLWHIV maintain face in the community. This enables the PLWHIV to meet their needs and function as members of the community.

Stewart and Logan (1993, p.50) say that most psychologists concur that there are at least five general needs that influence growth in our personalities and in our relationships. These are identity, inclusion, affection, privacy and power. These may be experienced at different levels of intensity by different individuals at different times. According to Baxter and Montgomery (as cited in, Stewart & Logan 1993, p.415) these needs are expressed as dialectical opposites where the needs operate in a continuum as shown below.

Opposing Needs

Need for identity and Autonomy ______________Need for affection and inclusion
Need for Privacy ______________Need for disclosure and affection
Need for power, control and predictability______Need for change, uncertainty, novelty

Source: Stewart & Logan 1993:415.

Individuals fluctuate along these poles. At times one may feel the need to be with others while at other times they may prefer to be on their own. Similarly there are times we may choose to be open and disclose while at other times we may choose to keep the information to ourselves and keep it under tight control, within our personal private boundaries.

Some of the PLWHIV felt a higher need for privacy and concealed the information about their HIV positive status while others felt a higher need to be open and disclosed their HIV positive status. Individuals make judgements about the degree of privacy and openness that they wish to maintain in a given interaction (Petronio, 2002, p.15). Some may exercise high levels of control over the information about their HIV positive status and conceal the information, while others may exercise low control and allow information to pass to either one other person or more than one. Petronio (ibid. P. 31) says that the levels of boundary permeability which allow information to pass through the boundary vary from open access to closed access. These refer to a thin boundary to a thick boundary respectively.

f. HIV positive status disclosure and Economic Considerations

Most respondents reported facing financial difficulties. This included lack of money to buy food and/or meet basic needs, or even pay for transport to the clinic as seen in chapter 4. International Council of AIDS Service Organization (ICASO, 2007, p.18) notes that economic factors are intrinsic to the HIV epidemic. They include poverty, migration, lack of access to productive resources, education and training which influence HIV vulnerability directly or indirectly. These factors are said to stimulate risky behaviours that are responsible for HIV transmission, create obstacles to prevention and impede efforts to cope with the epidemic.

From my findings, economic factors are both a facilitator for disclosure and also a deterrent. Some respondents especially women reported disclosing to their spouses in order to get financial support. The findings also suggest that poverty and economic status of the PLWHIV are key factors in disclosure of HIV positive status. Some reported that they needed to disclose so as to avoid many questions every time they ask for money to attend clinic. No male reported disclosing due to the need for financial assistance from their spouses (wives). However, one male explained that he had disclosed to his mother and aunt in order to get bus fare to travel back home from his place of work.

Other studies have observed similar predicaments among women. According to Chaturaka and Rajapakse (2010), of the 33,000,000 PLWHIV, 50% of them are women. Majority of PLWHIV are in developing countries and already faced with several financial difficulties in addition to being HIV positive. The need for financial support made some PLWHIV disclose to their spouses or to other confidants in order to get financial support. These reflect the gender inequality and economic dependence of women on their male partners resulting in higher vulnerability to HIV.

Thisstudy suggests that economic consideration affects PLWHIV immensely and one's financial situation can influence their HIV positive status disclosure decisions not only to the spouses but also to family members. Ajzen (2005, as cited in Asari et al. 2014, p.73) asserts that "the more resources and opportunities individuals believe they possess, and the fewer obstacles or impediments they anticipate, the greater should be their ability to control over behaviour". This is similar to Bandura's concept of self-efficacy and CPM assertion that context can influence one's decision to either reveal or conceal private information. Most of the respondents in this study are low income earners from small scale farming and small *jua kali* businesses and/or casual labour and thus may require financial support from the disclosure recipient.

PLWHIV receive free ARV from the government health facilities. However, some still need fare as most are often too weak to walk or have to travel far distances. Majority would need an average of about 100 Kenya shillings for a return journey on a *boda boda* (motorcycle). In addition to this cost they need money to supplement their diet as advised by the doctors and health care providers. These are often challenging for the PLWHIV. Some key informant explained that most PLWHIV experienced financial constraints even buy basic needs for themselves hence some default from taking drugs since they are unable to take drugs on an empty stomach.

In Africa, malnutrition and food insecurity are endemic. Studies have shown a link between malnutrition and suppression of the immune system (Nutrition and HIV/AIDS. Evidence, gaps and poverty Action: sara.aed.org/publications). As we had indicated in chapter four, most of the PLWHIV reported experiencing major financial difficulties. Most engaged in small scale *jua kali* informal businesses and rely on small scale agriculture. These are labour and time intensive activities and often the PLWHIV are weak or away from the business or manual work hence further diminishing their limited resources.

These financial difficulties also cause psychological and emotional effects which increase stress and impact negatively on the PLWHIV and other family members. Some of these include stress, depression, anger and self-hate especially when they can no longer provide for their families.

However, I am convinced by the argument by Lee (2012) that other than just focusing on development of friendly support services and behaviour change communication, there is need to put more resources and efforts on improving the economic situation of individuals and creating an enabling social environment. She argues this is critical in improving reproductive health and minimizing the risk of contracting HIV.

5.1.2 HIV Positive Status Disclosure and Spousal Communication

Another research question was to investigate whether the perceived communication behaviours of the spouse influences disclosure. The study findings noted two broad kinds of information in relation to couple communication. I would categorise them broadly into one; what they called “obvious” that is information not considered private and two, private information. This seems to fit Mcmaster’s model of family functioning (Epstein, Bishop and Levin, 1978) notion that family communication can be categorized into what he refers to as instrumental and affective communication. Affective communication involves the expression of feelings whereas instrumental relates to practical needs which arise within the family (Geldard & Geldard 2008, p.60). They note that some communication is neither affective nor instrumental and it occurs in general discussion.

According to Barker and Chang (2013) instrumental communication concerns the on goings of everyday activities in the family. They add the family communication can be categorized into various types depending on the depth. Communication maybe uninvolved; interest or involvement devoid of feelings in which involvement arises from a sense of duty or need to control; narcissistic involvement, empathic involvement and over-involvement or enmeshment. PLWHIV who perceived empathic involvement from their spouses and affective communication were more likely to disclose than those who perceived their spouses to be uninvolved.

Gabor, Alison and Glick (2009, p.17) note that, “a well-functioning family feels free to discuss issues with each other, are respectful of differences of opinion, address each other directly and express their feelings to each other without fear of retribution and misunderstanding"

a. Information not considered private

Information that was not considered private and was easily discussed between the PLWHIV and their spouses was mainly focusing on issues perceived as obvious general discussions. These are issues that spouses would generally talk about by virtue of being spouses or as some put it by "being married". The topics discussed here include family affairs, children, school fees, family development and farming. Another topic that featured between spouses was the issue of family conflict. As spouses communicate and go on with their day to day activities, they are bound to have conflict. Conflict was perceived by some as normal part of a marriage. One PLWHIV summarizes "relationship *ni kujikaza"* (It takes resilience to remain in a relationship) to reflect the challenges that couples encounter.

The theory of social penetration refers to such topics as issues on the top layer, fairly general information which spouses felt the necessity to discuss. This is information which they do not mind the other spouse knowing. It is what is referred to as public information. All the PLWHIV both the disclosed and non-disclosed reported discussing such issues. The depth of the discussion varies from one spouse to the other although this was not part of the focus of the study.

Research indicates that men and women may also differ in their conversation needs (Cinardo, 2011). Also Harley (2001, p. 64) notes, "I rarely have a man ask me, "Why isn't my wife talking to me?" But I often hear, "why isn't my husband talking to me?" from women". He suggests that men do not seem to have a great need for conversation with their wives as women do with their husbands and that women seem to easily get into conversation for its own sake. Most PLWHIV reported discussing general topics with their spouses.

b. Private information

Gamble and Gamble (2002, p.237) observe that we often have tensions between disclosure and concealment. The authors note that for most people, complete openness is intolerable. On one hand individuals want to share their inner selves with people they care about deeply and on the other hand there are times when they do not feel like sharing and wish to maintain privacy.

From the study, I found that one’s HIV positive status was considered private information by most of the PLWHIV and the privacy boundaries were tightly protected. Those who decided to disclose to their spouses chose to open their private boundaries and share their private information about the HIV positive status with their spouses. This may be dependent on the perceived spousal communication behaviours as being supportive communication rather than defensive, the spouse providing physical or emotional support. These allow the thick boundaries to become permeable and allow disclosure. The spouse is then given access to the private information and henceforth the PLWHIV relinquishes the sole ownership of the private information which they now co-share with the spouse. They can now regulate the dyadic boundary together.

From the respondents’ responses, I realised that some PLWHIV had privacy management rules that reflect how they and their families manage privacy. Some that came out from the interviews state, “we keep family secrets confidential”, “even when we have a conflict, we solve our conflict without involving a third party (outsider).

Bradshaw (1995, p.13) talks of what he refers to as realms of the private. They include; birth, death and dying, intense body suffering, bodily functions, the dignity of the self, success/failure, tangible possessions (money, property) in tangible possessions (values, ideas, opinions), intimacy and sexuality. He calls these the natural areas of concealment.

HIV/AIDS seem to revolve around most of the areas mentioned by Bradshaw above. The PLWHIVs talked about death and dying, intense suffering, pain, side effects of the ARVS, loss of dignity and morality issues around sexuality. All these are areas that affect the individual’s privacy and dignity. In the study, some PLWHIV would rather lie about their HIV positive status than being perceived as dying, immoral, failures and suffering. Such PLWHIV decided to tightly control their private boundaries and conceal the information about their HIV positive status from their spouses.

Stewart and Logan (1993, p.5) explain that humans need to be in control of what others know about them and may not wish to disclose certain information or to share certain experiences they may have had. We want others to respect our privacy. This is the key assumption of CPM, that people believe that their private information belongs to them and they want to control the flow of that information because they believe that they own it and disclosure makes them vulnerable (Greene et al.2003, p.13). PLWHIV repeatedly talked about their HIV positive status as, “My...secret. Most PLWHIV regarded their HIV status as their secret.

According to Bradshaw (1995, p.6) “a secret has two key aspects, namely the content and owner or sometimes called the location. The content can be the feeling, behaviour or fantasy. The second aspect is who owns the secret that is the location”. A secret maybe shared with no one else, or it may be known or confided to another person on the promise that the secret goes no further beyond the agreed upon boundary. Some secrets may be known to the whole group or one or two members.

Warren and Lashet (1977, as cited in Petronio, 2002) say that secrets are most risky because they have the potential to result in a high level of vulnerability if known by others. Lane and Wegner (1995, p.237, as cited in, Petronio, 2002, p.68) note that people keep secrets because there is a fear of the real or imagined repercussions the hidden information could bring with exposure. Some PLWHIV explained that they were cautioned by their spouse not to tell anybody else after disclosing to the spouse to avoid tarnishing their name and exposing them to other people.

Other PLWHIV have disclosed to their spouse or someone else and co-share the information about the HIV positive status as hence refers to it as “our” secret. The privacy boundaries have extended to include the spouse. The spouse is expected to adhere to the privacy rules and keep the co-shared private information within the spousal boundary.Berko et al. (1992, p.210) note:

> We each have a public “I” and a private “I”. The public “I” embodies the qualities, beliefs and personal image we are willing to share with others. The self-concept, ideas and experiences which we choose to withhold to ourselves and make up the private “I”. In communicating with others, we are constantly evaluating what we decide to share and what we choose not to share. Some share more or less ‘everything” while others are very protective of personal privacy. Individuals decide what to share, with whom and under what conditions.

While some PLWHIV take the risk to disclose their HIV positive status for various reasons, others perceived the risk too costly and avoided disclosure. From our findings some clear distinction can be observed between those who have disclosed and those who have not disclosed in discussion on the topic of HIV/AIDS between spouses. Those who have disclosed reported discussing HIV/AIDS and related issues such as drug adherence, clinic attendance, healthy eating and future plans. For details on this see chapter 4. Among those who have not disclosed, the HIV/AIDS topic was not discussed for fear that it could raise suspicion. Petronio (2002) suggests that individuals use topic avoidance as a strategy for privacy protection rule. In addition to topic avoidance, Petronio (ibid.) also identifies taboo topics as another privacy protection rule where individuals avoid taboo topics.

Other studies have suggested similar findings. Fapohunda and Rutenberg (1999) found that Family Planning issues were sometimes talked about with considerable difficulty by couples in Kakamega, Kenya. STDS including HIV/AIDS were rarely mentioned among married couples. They explain that women are not receptive to such discussions as they are worried about the implications of such discussions on their social status, marital security, wellbeing and relationship. On the other hand, men were concerned that they could be suspected of infidelity and extra marital relationships. Most respondents said that such matters are almost never discussed between spouses as they touch on trust. STDS connote unfaithfulness and challenge marital trust and therefore partners avoid accusations and counter accusations.

Other scholars have made similar observations. Zulu and Chepngeno (2003) observed that most spouses avoided the topic of HIV/AIDS. Fapohunda and Rutenberg (1999) note that in most Kenyan communities, sexual issues were almost always taboo topics and were never discussed among men and women irrespective of marital status. Muturi (2005, as cited in Chiao et al. 2009) concurs and says that the spousal communication remains limited among rural couples despite widespread dissemination of information on HIV/ AIDS.

Petronio (1993, p.225) notes that people avoid certain topics due to several reasons. These include self-protection, relationship protection, partner unresponsiveness and social appropriateness. Also Afifi and Guerrero (2000, as cited in Petronio, 2002, p.50) suggest that "people avoid certain topics as a way to guard personal privacy boundaries either with the aim of developing the relationship or de-escalating it". They note that people refrain from disclosing issues that hamper their relationships and avoid discussing topics for fear of bringing up unpleasant issues.

Baxter and Wilmont (1985, as cited in Petronio, 2002, p.103) identify six topics that were off limits for people in opposite sex relationships. They list; extra-marital activities, relationship norms of behaviour in the relationship itself, prior relationships, conflict inducing topics and negatively valenced disclosures about the self. Epstein et al. (2007) asserts that from experience families have difficulties with affective communication while functioning well in the area of instrumental communication.

From our findings, all the PLWHIV who have not disclosed their HIV positive status to their spouses considered their HIV status private information. However, majority of the PLWHIV both disclosed and non-disclosed considered the following areas private and did not discuss with their spouses. These include; HIV positive status for the non-disclosed, source of HIV infection, past sexual history, *mpango wa kando* (infidelity), amount of money one has and PIN numbers. Although the general topic of finances may be discussed, it is important to note that most PLWHIV reported not discussing the specifics of how much money one has in their accounts and the PIN numbers for bank accounts and *Mpesa* accounts as exemplified in chapter 4.

From the topics not discussed with spouses, three of them revolve around sexuality. Individuals seem to avoid topics that reflect them negatively and/or issues that seem to be questioning their morality. Even among those who had disclosed their HIV positive status to their spouses, some expressed their desire to keep the information between the spouses and not to disclose to other people. They wanted the privacy boundary to only extend to the spouse with whom they now co-share the information of the HIV status and not beyond that.

This may point to the need for interventions that would encourage spouses to talk not just about HIV/AIDS but on sexual issues and issues on their reproductive health. Some studies indicate that when couples talk, the uptake of family planning increases. Ogunjuyigbe et al. (2009) study showed that marital partners who discuss and take joint discussions on what to do delay or stop childbearing and are more likely to use contraceptives than those who have not discussed the issue. Sheriff (2012) found that contraceptive use increased with increased communication between couples. Such findings could indicate that discussion on HIV disclosure may increase or change people’s perceptions about disclosure. In the study of Seid et al (2012) they observed that disclosure to family, prior discussion, knowing partner status and relation with partner before HIV testing were independently associated with disclosure of HIV status to the main sexual partner.

From the findings, there is also the need for interventions that empower individuals, the public, spouses in this case not just to wait to be disclosed to by the partner or spouse but also to ask for the spouse's or partner's HIV status information. Individuals need to be empowered to take responsibility in protecting themselves from HIV infection by actively asking spouses and sexual partners about their HIV status. Lucchetti (1999) explores the dialectical tension between practising safe sex and preserving the relationship. She says that, "engaging in safe sex is a goal for many relational partners but being open and honest about one's sexual history may harm a developing relationship making both men and women reluctant to discuss their sexual experiences with potential lovers".

This is a challenge especially in Kenyan society and elsewhere where men and women have unequal power in decision making in the household and sexual matters making it even more difficult for women to ask their partners about the past sexual history. But it must be a challenge we must start tackling in order to prevent and reduce HIV infections between couples. Individuals, both men and women need to take responsibility for their own health by asking questions relating to safe sex and protection against HIV infection.

Partners especially women can be equipped with assertive skills to allow them ask and negotiate for their reproductive health rights. Where spouses feel less empowered, they could use a third party such as a health care provider to disclose to their spouse or initiate and facilitate discussion between spouses as some PLWHIV reported. This is more in line with the traditional set up of seeking, conveying and responding to information. In addition to the health care providers, other third parties used to help inform others on behalf of the PLWHIV from our study include sister and mother. Use of third parties is a common strategy that may be more familiar as a model of communication in our African context. We can note the widespread use of intermediaries in conflict mediation and resolution, in marriage proposals and family disputes. This strategy of passing information through a third party was used by some PLWHIV to help their spouses know their HIV status. It is familiar to them and it can be encouraged among PLWHIV especially in the support groups.

From my findings, a strategy that helped spouses know each other's HIV status was couple counselling irrespective of whether the couple went together or the PLWHIV went first and then "tricked" the spouse to go in for testing and counselling. Couple counselling reduced the burden of disclosure for the PLWHIV as the health care provider or counsellor offered support. Several studies argue that Couple HIV Counselling and Testing (CHCT) has great potential to reduce transmission risks in Sub Saharan Africa (Allen et al., 2003, as cited in USAID, 2010, p.3). CHCT has been shown to be an effective intervention for reducing the risk of HIV transmission among sero-discordant couples (USAID, ibid.). They point out that CHCT may be more effective than individual VCT as a prevention strategy to prevent uninfected couples from infection. Counselling couples together allows the challenge of disclosure to be addressed in counselling.

c. Supportive and defensive communication

As seen in chapter four, supportive communication was characterized by communication behaviours described by the PLWHIV as "good" while defensive communication is generally described as "bad". From my findings, the characteristics of good and bad communication behaviours were similar among all PLWHIV irrespective of their disclosure status. The PLWHIV cited characteristics of a spouse perceived as exhibiting good communication behaviours. They generally agree that a spouse, who listens, understands, does not shout, does not fight, does not blame, provides financial support of PLWHIV and children, is comforting, is supportive and is available, is perceived as having good communication behaviours. On the other hand, bad communication behaviour is characterised by a spouse who does not listen, is quick to anger, shouts, not supportive, is blaming and judgemental to mention a few.

There seems to be a notion among some respondents that good communication behaviour is the same as following instructions, not questioning what the spouse says and doing as one is told. This kind of communication denies the other spouse a voice and participation in decision making in the homestead including decisions on their reproductive health. This points to lack of assertiveness among some spouses. They do as they are told including in areas to do with sexuality and HIV/AIDS. They do not ask questions. The other spouse makes decisions for them and on their behalf. This is in line with the findings from other studies where many men make decisions alone including decisions about sex and reproductive health as we discussed earlier. Greene at al. (2006, p.6) note that "gender inequalities are widespread and that gender roles are strongly reinforced in cultural beliefs and practices and that the social construction of masculinity and femininity profoundly shapes sexuality, reproductive preferences and health practices". Women often assume the subordinate status in most societies.

From my findings, the perceived spouse's communication behaviours can influence disclosure especially where the PLWHIV trusted the spouse to keep their private information safe.

d. Pre-requisite conditions for HIV positive status disclosure

A HIV positive status is highly private information that individuals go to great lengths to protect. For most PLWHIV, the boundaries are so thick as they tightly guard them to protect their private information about their HIV positive status. From the study we established that previously thick boundaries can become thinner and open to allow disclosure thus increasing the collective boundary area if certain conditions are met. Some non-disclosed PLWHIV reported that they would disclose it their spouses for instance became more empathic to PLWHIV and became more supportive.

CPM identifies rules about confidant selection and personality characteristics as factors influencing whether an individual opens up or closes their boundaries through revealing and concealing respectively. The PLWHIV assesses their spouse to determine if they can be disclosed to or not. Certain spouse characteristics or factors emerged as important for one to be disclosed to. From our findings two pre-requisite conditions for disclosure were trust and support. Trust was necessary in the PLWHIV's choice to either disclose or not to disclose. Pearson et al. (2003, p. 284) view trust as meaning:

> That members believe that they can rely on each other. Interpersonal trust means that others are working with the best interest of the group in mind rather than advancing hidden agendas". Pearson (ibid) says that trustworthy "is the degree to which a speaker is perceived as honest, fair, sincere, friendly, honourable and kind. These perceptions are earned. We judge people's honesty by their past behaviour.

Berko et al. (1992, p.212) define trust as "a generalised expectancy that the word, the promise, the verbal or written statement of another individual or group can be relied upon. That is one person expects or predicts that another person will act in a positive way; if the latter person does, trust develops". They also say that because communication takes place in a system dependent on interaction between individuals, trust is the most important element in any communication situation. In addition they say that the inclination to trust or mistrust is learned over a long period of time and it results from cumulative experiences. Trust is cultivated through self-disclosure.

Through disclosure you put yourself at risk. If a PWHV disclosure is met with acceptance, support, trust can be built. If the disclosure results in rejection and not held in confidence then trust is destroyed. As we said earlier, trust is also based on past experiences.

Petronio (1993, p.225) says that communication events have a past, present and future. An individual can self-disclose to another because from experience you know them and you can trust them. We rely on past experiences when deciding on whether to disclose or conceal private information.

Patton and Giffin (as cited in, Berko et al. 1992.) identify four factors that contribute to the development of trust in relationships. These include the confidant being perceived as reliable, having expertise on the matter to be discussed, perceived to have power and having open communication lines.

Trust was given as a key ingredient for the PLWHIV in the study to disclose to their spouses and/or to any other person. Among the respondents this was specified as the ability of the recipient to be trusted with private information, in this case the HIV positive status of the PLWHIV.

Erik Erikson's theory of development as outlined in Santrock (1997) looks at different stages of psychosocial development. He says that the first stage in the cycle of social development is that of trust versus mistrust which occurs during a child's first year of development. Trust is built when the child's basic needs such as the cry for food and warmth are met. The theory suggests that this sets the foundation for what the child expects from the outside world as they grow and that a sense of trust requires a feeling of physical comfort and a minimal fear about the future (Santrock, ibid. p.320).

Most PLWHIV said that they disclosed to their spouses or another person because they trusted them. In addition to trust, other conditions included physical and financial support; promise not to tell anyone, that is to keep the information confidential and /or that the recipient had also disclosed to the PLWHIV. Trust was paramount in most disclosure contexts.

The individuals disclosed to other than a spouse were mothers, sisters, children and friends in that order of priority. Also included by a minority of PLWHIV as recipients of their HIV positive status information were brothers, cousins, aunties, parents, church pastor, nephews, nieces, family members and neighbour.

The confidants were perceived to exhibit certain characteristics which made the PLWHIV consider them as trustworthy to keep their HIV positive status a secret. My findings are consistent with other scholars who have also observed and argued that people will disclose to individuals who exhibit certain traits and not others. People are likely to disclose to individuals they can trust, support them, understand them and can keep the disclosed information confidential.

Knapp and Vangelisti (1996, p.240, as cited in West & Turner, 2000, p, 154) note that "self-disclosure of intimate information is based on trust. And that if we desire reciprocity in disclosure, we must try to gain the trust of the other person and similarly feel trustful of the other person".

Rogers (1961) asserts that people or individuals will only self-disclose if they feel safe in their relationship. Disclosure is only possible when an individual experiences the necessary psychological safety which breeds trust. Rogers argues that if an individual provides psychological safety by creating and communicating what he called core conditions to another individual, then one is likely to disclose. Although Rogers was concerned about a counselling relationship, these principles can be seen to apply to self-disclosure by the PLWHIV as we found in this study. Most PLWHIV reported disclosing to their spouse or to a third party primarily because they trusted that person. Other factors given include that the spouse or other recipient also disclosed some information to the PLWHIV, is a good listener, understands and is supportive.

Rothwell (2000, p.46) also cites trust as necessary for self-disclosure. He says that when one person trusts another to keep the information confidential and not to reveal it to others then disclosure is likely to occur. Stewart (2002, p.302) says that “trust is the essence of which emotional safety serves as the foundation for self-disclosure because trust enables you to put your deepest feelings and fears in the palms of your partner’s hands, knowing they will be handled with care”. Even among those PLWHIV who have not disclosed to their spouses but have disclosed to someone else, trust was key. On the other hand, some PLWHIV decided not to disclose to either their spouse or other persons due to lack of trust.

Some PLWHIV perceived the risk of disclosure too high and avoided it while others took the risk. Some reported experiencing positive consequences such as trust and support from their spouses while others experienced negative consequences such as blame and rejection. Gamble and Gamble (2002,p. 269), say that when one takes the risk to reveal feelings to others, the relationship is likely to reap benefits such as trust and by honestly revealing their feelings, they make it less threatening for the other person to reveal their feelings. This facilitates what social penetration theory refers to as reciprocal disclosure. Some PLWHIV reported reciprocal disclosure where one's disclosure prompted the other spouse to disclose.

Johnson (2002, as cited in, Stewart 2002, p.231) notes that "all our relationships can be classified on a continuum from open to closed". He says that openness means being both open with other people by disclosing yourself to them and openness to others by listening to them and their disclosure in an accepting way. I am convinced by Johnson's (ibid.) argument that because disclosure (openness) is risky, some people prefer to hide from others in the belief that no reaction is better than a possible negative reaction. Some PLWHIV reported that the fact that others do not know that they are HIV positive then they can live like "normal" people. From the findings the level of openness between spouses can be increased to facilitate the sharing of information and disclosure. Galvin and Cooper (1990, as cited in Stewart, 2002) note that lack of trust = reduced likelihood of openness.

Stewart (2002) says that openness is dependent on three factors. These are; self-awareness, self-acceptance and trust. This means that to be open, one needs to be aware of who they are, accept themselves and take the risk of trusting the other person to be accepting of them. Some PLWHIV said they could trust their spouse and this made it easier to acceptthemselves and consequently took the risk to disclose. While some PLHWA expressed denial, some PLWHIV expressed acceptance. One uses the metaphor "birds of the same feather".

Some scholars advocate for disclosure without reserve in marriage (Jourard, 1971, as cited in, Gamble & Gamble, 2002), while others are cautious and talk of selective disclosure. Schnarch (1991, as cited in Stewart, 2002) cites a strategy also used in disclosure which he refers to as, “I will if you will” strategy of disclosure. This strategy is reflected insome respondent’s responses who said they will only disclose if their spouse discloses.

Irrespective of the school of thought, I am of the view that disclosure about HIV positive status to a spouse should not be selective if we have to prevent further HIV infections and re-infections. Disclosure needs to be a key component of HIV prevention strategies and safer sex practice.

Montgomery (1994, as cited in Stewart, 2002) says that while disclosure may have significant impact on close relationships, it does not occur with great frequency even between the happiest partners. This is reiterated by Schwatz (1994, as cited in, Stewart, ibid.) who says that partners lead parallel lives and may never get the habit of sharing their lives with each other. Some of the PLWHIV reported their partners being too busy for them and living or working away from home as some factors that contributed to their not having time to discuss issues.

A PLWHIV suggested that couples can get in the habit of talking even about each other’s daily activities, which may result in more breadth and depth of communication between them. Banski (1993) notes that risk taking communication is not likely to occur frequently within the family life but certain developmental stresses, unpredictable stress trigger personal discussion. Banski (ibid.) suggests that if couples held debriefing conversations and talked about how the day went, they are more likely to experience marital satisfaction; their conversation setting the ground for more sensitive topics.

Ogunjuyigbe, Ojofeitimi and Liasu (2009) in their study found that marital partners who discuss and take joint discussions on what to do delay or stop childbearing and are more likely to use contraceptives than those who have not discussed the issue. This pointsto the need for discussion on reproductive health issues and HIV to be encouraged among couples. If they can start with general issues then discuss deeper not usually discussed topics with time they can build trust.

The current male dominated communication dynamics unearths and entrenches gender dominance in family communication. There is a need to change the perception of what constitutes a discussion from where one spouse gives instructions and the other follows to a discussion where both share issues and make decisions together. This can lead to more involvement and decision making being shared by the spouses bearing in mind cultural challenges and traditional roles of the man as the decision maker in the home.

Chiao et al. (2009) shows that actions such as higher levels of women’s education and participation in household decision making are positively associated with spousal communication about HIV prevention. These points to the need to have programs such as property ownership especially agricultural land which is main means of livelihood for most rural families. The realm of HIV response should address income generating and empowerment programs to make women empowered thus allowing them to participate in decision making and discussion on HIV prevention. This may include assertive skills training and negotiation skills training in the counselling sessions or seminars.

On the issue of trust and open communication the respondents had different views. Some felt that it is ok for marriage partners to conceal certain information and that every individual is entitled to have private information while others felt that when people get married they should share everything.

Some PLWHIV based their arguments on gender. Some male PLWHIV felt that they cannot trust their wives with private information as the women could use it to harm them. Kikuyu language has several sayings cautioning against sharing secrets with women. One such saying is, *Muiya na kihii akenaga kiarua, no muiya na mutumia akenaga akua* (Someone who steals with an uncircumcised boy is happy once he is circumcised but one who steals with a woman is only happy when she dies. (Do not tell secrets to women and boys) (Barra, 1939). On the other hand, some women also expressed distrust in men as exemplified earlier.

Another key pre-condition for disclosure to a spouse was support. Most PLWHIV as discussed earlier, disclosed in order to gain some kind of support from the recipient of the disclosure. This could either be financial, emotional, psychological or psychosocial support. Spouses perceived to be supportive were more likely to be disclosed to than those perceived as not supportive.

The study found that no male reported disclosing to their spouse in order to get financial support, some had disclosed in order to get psychosocial, physical care and support from their spouses. On the other hand, some PLWHIV especially women who had not disclosed cited fear of being abandoned by their spouses if they disclosed and thus risked losing the financial support from their spouses. Ajzen (1991, as cited in

Petronio 2002, p.243) is of the view that “the more resources and opportunities, an individual believe they possess and the fewer the obstacles or impediments they anticipate, the greater will be their control over their behaviour”. Ihave not focused on support in great detail as it has already been discussed in other sections of this chapter.

e. HIV status disclosure and deception

From the findings, for most spouses especially for those who had not disclosed, deception was part of their communication. Even among those who have disclosed, there was deception to some extent on some issues such as faithfulness which in essence would impact on HIV prevention. The spouse may be exposed to HIV virus or the PLWHIV might be re-infected. It also challenges trust between the spouses and we have already seen in the earlier section, individuals are more likely to disclose to people they trust.

Deceptive communication has been defined as “message distortion resulting from deliberate falsification or omission of information by communicators with the intent of stimulating in another, or others, a belief that the communicator himself or herself does not believe” (Miller 1983, p.92, as cited in Petronio, 2000, p.191).

McCornack and Levine (1990, p.119, as cited in Gamble & Gamble, 2000, p.238) define deception as “the deliberate falsification of or omission of information by a communicator with the intent to mislead the conversational partner”. Pearson and Nelson et al. (2003, p. 186) say that deceptive communication is “the practice of deliberately making somebody believe things that are untrue”.

Gamble and Gamble (ibid.) explain that although there are several reasons as to why people lie, two reasons seem to dominate. They suggest that most people lie to gain a reward or to avoid punishment. In our study, we found that most PLWHIV lied to either get some reward such as support from their spouse or the recipient of the disclosure, to "keep" the spouse, avoid separation, and/or avoid punishment such as avoid being thrown out of their marital homes, or being blamed for bringing the virus home. Others conceal information to avoid risking the status of the relationship.

Camden et al. (1984, as cited in, Gamble & Gamble, 2000, p.238) explain that most often when people lie, they may benefit themselves but a percentage of our lies is to protect the person or persons we are lying to and an even smaller percentage to benefit a third party. Bradshaw (1995, p.5) seems to concur with their idea that people lie for protection. He says that "the ability to keep things secret is an essential power that all human beings possess in order to protect themselves". He notes that secrecy is a boundary that protects the individual from the judgement eyes of others. He adds that we live in a culture where openness and rigorous honesty are valued and secrecy seems to be in conflict with openness and honesty.

Petronio (2002, p.190) raises an interesting argument on whether privacy is deception. She argues that concealing information may be a means of protecting one's privacy rather than deception. I am convinced by her argument that the deliberate falsification or omission of information may be the route to privacy as a way to retain ownership of the information. The individual protecting information may not perceive it as deception rather as a means of protecting their private information. In addition she says that if the reason is to protect others, the person expecting the information may perceive it as deception however she argues that if the reason of falsifying or omitting information is to harm the other person by denying access then both parties may perceive deception (p.191). Petronio (ibid.) suggests that the process of boundary management is ongoing as partners decide which feelings and thoughts they are willing to share with others.

Camden et al. (1984, as cited in, Gamble & Gamble, 2000, p.238) says that we use lying as a strategy because lies help us to manage what we perceive to be difficult situations, situations that make us more vulnerable than we would like to be. As discussed earlier, once a PLWHIV told a lie, they had to continue lying in order to safeguard an earlier lie. A PLWHIV who has not disclosed has in addition to lie about a hospital visit or frequent use of medication. To sustain an original lie, we usually need to tell more lies to cover the first one. Camden (ibid.) argues that it is rare to tell someone one lie only. Bok (as cited in Gamble & Gamble, 2002) writes, "The liar always has more mending to do and the liar has to expend a great deal of energy remembering to whom he or she told what and why". A respondent reported on the need to cheat wisely to avoid contradicting oneself.

Stewart and Logan (as cited in Stewart, 2002, p.145) note that deception can range from very direct lies to "softer" more indirect actions such as exaggerations and false implication. Camden et al. (1984, as cited in, Gamble & Gamble, 2000, p.238) say that "we lie to continue to satisfy the basic needs fulfilled by our relationships; increase or decrease desired and undesired affiliations; protect our self-esteem; achieve personal satisfaction and to benefit ourselves or the other person".

Wilmont (1998, as cited in Stewart, 2002) however does not believe that any motive for lying is positive and is of the view that all are self-centred. However, he believes that every day people exaggerate, minimise, and try to spare others feelings or strategically leave out part of the story.

Deception for some PLWHIV in the study had positive results in the sense that no one knows that they are HIV positive and hence they live like everybody else and avoid the risk of facing the consequences of having their status known such as being stigmatised or rejected. They used phrases such as, “feeling safe, secure, nobody knows”. This seems to be in line with what Bradshaw calls lying for protection either of self or other(s).However, the deception also had its negative consequences. This include the PLWHIV feeling guilty, restless, distrust, hiding drugs, burden of hiding things such as medication, hospital documents, feeling depressed, non-adherence of ARV, fear of spouse discovering the lies, fear of contradicting oneself, lack of trust, confusion, lack of peace of mind due to guilt.

Psychologists have linked disclosure with several consequences. Stewart (2002) looks at four benefits of disclosure. These are; it can begin to deepen your relationships at work, school and home; it can increase your self-awareness and understanding of yourself; it can provide a freeing experience; it can help you control challenging social situations; it can help you manage stress and adversities and finally it can fulfil the human need to be known intimately and accepted by others.

On the other hand non-disclosure also has its consequences. Jourard (as cited in, Gamble & Gamble, 2002, p.268) note that “dissembling, concealing or being hesitant to reveal feelings can be a lethal habit. Such people may experience stress, shorter lifespan, experience person and interpersonal difficulties.”

For the PLWHIV, their deception also compromises on HIV prevention and ARV adherence. For those who have not disclosed their HIV positive status to their spouses, they have either to lie about using a condom or not using protection at all for fear of raising suspicion. This is just one lie among the long list we have discussed in previous sections. This indicates the crucial role of disclosure in HIV prevention. It becomes very difficult for individuals especially for women to ask their spouses to use condoms without telling them the reason as to why they are asking the spouse to use them.

Gordon (as cited, in Gamble & Gamble, ibid. p.269), also explain that besides reducing your interpersonal effectiveness, continually bottling up your feelings can cause you to develop ulcers, headaches, heartburn, high blood pressure, spastic colon and various psychosomatic problems.

Psychologists say lying takes a lot of energy and effort. Spouses get caught between the desire for openness and the desire for self-protection or of protection of others as was clearly reflected by some of the PLWHIV responses. A similar suggestion is made by Karpel (1980, as cited in Petronio, 2002, p.68) who notes that keeping secrets makes an individual feel guilty. According to warren and Laslett (1977, as cited in Petronio, ibid. p.68), guilt feelings emerge from keeping secrets because “although there is a right to privacy, there is no equivalent right to secrecy. Secrecy has a negative connotation and is perceived as one is hiding something.”

From the study, some PLWHIV reported feeling guilty, anger, confusion, stress, depression and self- hate knowing that they continued to lie to their spouses. These emotions are likely to have negative consequences to their already compromised immune systems and their relationships with their spouses. They only serve to deteriorate rather than improve the emotional, physical and psychological health of the PLWHIV.

For the PLWHIV, their deception also compromises on HIV prevention and ARV adherence. For those who have not disclosed their HIV positive status to their spouses, they have either to lie about using a condom or not using protection at all for fear of raising suspicion. This is just one lie among the long list we have discussed in previous sections. This points to the crucial role of disclosure in HIV prevention. It becomes very difficult for individuals especially for women to ask their spouses to use condoms without telling them the reason as to why they are asking the spouse to use them.

Other studies have come to similar conclusions. For instance, Catania (1992, as cited in, Chiao, et al. 2009) asserts that if women believe that safe sex negotiation will cause conflict, they may avoid the issue. Cau and Agadjanian (2008) say that cultural norms prevent women from initiative talk on sexual matters with husbands for fear of suspicion of infidelity.

For those PLWHIV who have disclosed, it is easier for their spouses to introduce the topic of condoms as a prevention tool to avoid infecting their spouses and sexual partners and re-infecting themselves. However having said that, from my findings, even among disclosed partners, some spouses and PLWHIV do not use a condom consistently. Others do not use condoms at all.

5.1.3 Methods and Challenges of HIV positive Status Disclosure

Another research question was to find out the methods used by the PLWHIV in disclosing their HIV positive status to their spouses and challenges that they encountered in disclosure. From our findings, the PLWHIV know that they need to disclose their HIV positive status to their spouse. The big challenge is how? Even for those who have disclosed they explained that it was not an easy task.

a.Methods of HIV positive status disclosure

Petronio (1993) talks of direct and indirect disclosure. Catania at al. (1989; 1992, as cited in Chiao et al. 2009) state that a HIV positive person knows exactly what they need to do, that is to notify their partner, not to have unprotected sex and to use a condom. But the challenge is how to disclose this information about their HIV positive status to their spouse. Most PLWHIV reported disclosing directly to their spouse.

Most of the PLWHIV reported disclosing directly face to face and a few called on telephone. Most said that this was in adherence to the health provider's advice. Most PLWHIV said that they were advised to disclose to their spouse, or for fear that the health care provider would inform the spouse, or for fear of infecting the spouse as told by the health care provider. This was no easy task as some PLWHIV talked of preparing themselves mentally by either encouraging themselves or getting encouragement from others such as counsellor or HIV support group.

For those PLWHIV whose spouses knew that they had an illness of one kind or another, the "known" illness gave the PLWHIV a starting point. These included chest problems, uterus, or stomach problems. Other factors that helped the PLWHIV disclose is the spouse accompanied the PLWHIV to hospital, or the couple had talked about the need to disclose prior to the test. These provided the PLWHIV with an opportunity to give feedback about the hospital visit or what the doctor had told them.

Other PLWHIV disclosed indirectly. This varied from the use of a third party such as a counsellor, health care provider, auntie, sister-in-law and mother-in-law. The most common indirect method was to use a health care provider or counsellor. The most frequently used strategy was to pretend that one (PLWHIV) had not been tested and request the spouse to accompany them to the clinic to test or that the health care provider wanted to talk to them both. Two key informants talked about using role plays in showing them how to go disclose to their spouses.

The use of a third party is a commonly used strategy in the traditional set up to convey information and also resolve conflict in most Kenyan communities. Among the Kikuyu of Central Kenya for instance, a young man wishing to marry asked for the girl's and her family's approval through the elders and not directly. The marriage which was a long complex process involved not only the bride and groom but also their friends, village, the grooms father and his friends (Wambugu & Kariuki, 2006, p.115). This strategy of passing information through a third party was used by some PLWHIV to help their spouses know their HIV status. It is familiar to them and it can be encouraged among PLWHIV especially in the support groups.

Using indirect strategies allows the individual options and enables the PLWHIV to save face. They do not have to face the spouse with the information about their HIV positive status.Petronio (2002, p.46) explains that individuals can use incremental disclosure where they can test the waters before actually disclosing. This may also be the case with some non-verbal strategies which can give the PLWHIV options to be vague about their HIV positive status.

Being vague about disclosure of private information to save face allows the disclosing individual the ability to control the amount, depth, breath of information told (Petronio, 2000, p.191). Using indirect strategies to reveal information affords people options of how they want to talk about personal matters or group matters. Also Affleck (1999) found that negative comments are delivered easily and more accurately indirectly such as the use of e-mail than face to face as one does not have to “sugar-coat” the information or face the recipient, which is stressful.

Some PLWHIV reported using nonverbal strategies such as refusing to have sex; keeping the hospital card in a place the spouse is likely to see it or giving the spouse a condom. Although most PLWHIV said that they disclosed by word of mouth verbally, a few also indicated using non-verbal communication alongside. Although non-verbal communication is not the focus of this study, it is important to mention its importance in disclosure of HIV positive status between spouses.

Gamble and Gamble (2002, p. 145) say that “in a normal two person conversation, the verbal channel carries less than 35% of the actual meaning of a message and 65% of the meaning is communicated non verbally”. Hence individuals need to enhance their awareness of non-verbal communication with their spouses. It is possible that many of the PLWHIV communicate or self-disclose without actually needing to verbally self-disclose.

As noted earlier, talking about sex especially across genders is a complex issue in many African societies. Discussion of sex and sexuality openly is viewed as taboo and vulgar. Cultural constraints limit discussion about sex. Dodoo et al. (2000, p.4) argues:

> Although direct discussion between reproductive partners may not occur, there is room for ideas to be communicated from one spouse to the other. Communication occurs without discussion. Cultural bias against cross-gender sexual discussion led to considerable dependence on non-verbal communication. The playing of certain music, the wearing of specific waist beads, certain demeanours and even the cooking of favourite meals may all convey clear unambiguous sex related messages to a partner.

Gamble and Gamble (2002, p, 145) asserts that with practice we can learn to use the non-verbal mode to provide us with "ways of knowing" that would not otherwise be available to us. Hall (as cited in Gamble & Gamble, ibid.) explain that "those of us who keep our eyes open can read volumes of what we can see going on around us".

This may point to the need to promote nonverbal disclosure especially among PLWHIV who find it difficult to disclose verbally to utilise the nonverbal options and this may need follow up and support from a health care provider. Insisting on safe sex or refusing to have sex or even leaving drugs around may be a safer way of disclosing.

Driskell, Salomon, and Safren (2008) observe that using a condom can be disclosure without even saying it. Bird (2010) looks at HIV disclosure in casual sexual encounters among men who have sex with men and found that they leave nonverbal cues including leaving medicine bottles and exposing HIV positive tattoos. This forewarns any potential sexual partner and this way they do not have to talk about it.

A few PLWHIV talked of what I may refer to as coincidental disclosure where for instance one PLWHIV reported finding the spouse at the CCC and then they had to talk about it and disclose.

Some of the PLWHIV reported using metaphors, humour and jokes. For instance one PLWHIV compared disclosure to "a burning charcoal on my head" others used metaphors such as *yakimwagika hayazoleki* (when water spills, you cannot collect it). Pearson et al. (2003 p. 85) defines metaphor as "comparisons among unlike objects or concepts in which a common feature is highlighted. Metaphors are figures of speech that link two dissimilar objects or ideas in order to make a point. A metaphor connects a well-known event or idea with a less known one so that some of your knowledge of the known gets transferred to the unknown. It can add interest and can be very powerful."

Lucas (2001, p. 268) explains that " a metaphor is implicit comparisons between two things that are essentially different yet have something in common, they can add colour to an idea and make abstract ideas concrete, clarify the unknown so as to express feelings and emotions".

Picking the appropriate moment and talking helped to ease the disclosure process. This seems to be in line with CPM suggestion that the social environment and physical setting can influence disclosure. From the study, some PLWHIV reported waiting for the "appropriate context" to disclose. This was crucial in disclosure.

Disclosure is not easy mentally. It takes a lot of energy and courage. Humour, jokes metaphors were used by some PLWHIV as a way to reduce the anxiety and to gain courage to disclose. Though HIV/AIDS is no laughing matter or joke, some PLWHIV used jokes and metaphors when disclosing their HIV positive status. Although a weighty issue, the PLWHIV intends to create a light moment about a difficult subject in a light hearted manner by using humour. Some PLWHIV advised other PLWHIV who have not disclosed to try and use stories, jokes as these would help them to gain courage.

Berk, (2003, as cited in, Stambor, 2006), author of "Professors are from Mars, students are from Snickers, says that humour helps relieve fear and reduce anxiety. He argues that laughing leads to learning. According to Deiter (1998) humour has various physiological and psychological benefits that are associated with laughter and/or humour. Some of these benefits include:

> Muscle relaxation; stimulated circulation; improved respiration and exercise of lungs and chest muscles; increased production of the body's natural pain killers called endorphins as well as lower pulse rate and blood pressure. Humour puts us at ease and helps to relax. It may even help us see life from another prospective.

The use of humour has been recommended as a business management tool that promotes productive work environment, as an effective health care tool and as a possible tool to improve interpersonal relationships ((Kushner, 1990; Clifford, 1996; Sidney, 1994, as cited in Deiter, 1998).

According to Barbato et al. (1997, p.49) "as human beings we have general motives or reasons for communicating with others. We may talk with others just for the fun of it, to escape, affection, to seek relaxation or share thoughts, relax, unwind or take control of others. These motives arise from basic needs to satisfy these needs. Humour use has been recognised as one of the five mature coping mechanisms people use to deal with unfortunate life conditions (Vaillant 1977, as cited in Barbato, ibid.). This is consistent with the PLWHIV who chose to use humour even in their difficult life situation. It can be used to ease one's pain or to help accept the circumstances brought about by life changes.

Disclosure can take on a humorous context when one is disclosing personal information that may be socially undesirable, unacceptable or painful. Through humour, people share their experiences with others and realise that they are not unique and at times not as badly off as they think or as compared to others. Civikly (1983; 1989, as cited in

Barbato et al. 1997) notes that we use humour as an indirect way of communicating and more specifically as a means of communicating difficult information. He also adds that some information may be considered inappropriate if it is not disclosed in a humorous fashion.

From the study, questions play an important role in disclosure of one's HIV positive status. Some PLWHIV disclosed either to avoid, pre-empt or clarify or to respond to a question from the spouse. The common questions were:

1. What did the doctor say? (After PLWHIV returns from hospital)
2. Why the frequent hospital visits?
3. Why the frequent use of medication?
4. Why use a condom?
5. Why the frequent illness?
6. What would you do if I/ spouse tested HIV positive?
7. Have you slept with other women?

According to the Uncertainty Reduction Theory by Berger and Calabrese, individuals have a need to reduce uncertainty about others by gaining information about them. This resonates with the way human beings attempt to manage uncertainty and reduce anxiety. Individuals may use questioning and other information seeking strategies to reduce uncertainty. Littlejohn and Foss (2011, p.181) says that individuals use active and passive strategies for gathering information. He notes that one such interactive strategy is interrogation and self-disclosure.

Some PLWHIV used questions to “test the waters” before disclosing. This helped them assess the spouse's possible reaction should they decide to disclose. Others disclosed to avoid questions such as why one is not breastfeeding or give clarification for instance about rumours that one is HIV positive or their former spouse died of HIV.

While some lied in their response to these questions as we saw earlier, some responded by disclosing their HIV positive status. From our findings, individuals should be encouraged to ask questions and ask for information from their spouses especially in areas of their reproductive health which depends on the two partners such as protection against STIs and HIV. Kibede (2008) also notes the importance of encouraging individuals to ask their partners or spouses their HIV status in addition to disclosing their own.

From our study, questioning seems to play a crucial role in HIV positive status disclosure. Some PLWHIV disclosed to clarify their situation, to prevent and avoid questions, to provide an answer to a question from spouse or others, to respond to questions. It would thus be crucial for HIV/ADS programs to incorporate skills on questioning and empower spouses to seek information from their spouses. For instances couples can ask questions about one's sexual history, unfaithfulness which could inform their ability to protect themselves and reduce risk of HIV infection.

Driskell, Salamon and Safren (2008) note that "many people are unaware of their partners status and make assumptions that they are not at risk for HIV infection because they are married, in relationship, their partner looks healthy or simply because their partner did not use a condom". Research shows that people are often more comfortable disclosing or practising safer sex with partners outside their main relationship.

Other PLWHIV reported disclosing directly due to anger. They just needed to tell their spouses as some put it for the "pain and hurt the spouse had caused them". This is what psychologists refer to as catharsis; get it off your chest. Stiles (1987, as cited in Vangelisti, 2004, p.388) fever model of disclosure suggests that the need to disclose can be so great that it causes the individual anxiety and tension and the only way to relieve that psychological burden is to disclose. A respondent reported that they were extremely angry and could not wait, they disclosed to the spouse on phone while still at the hospital to get it off their chest. Others just needed to tell. Kimberly, Serovich and Greene (1995, as cited in Vangelisti, ibid.) found that catharsis was a primary motivator for disclosure especially among women.

Most PLWHIV even those who have disclosed expressed difficulty on how to disclose. This points to the need for PLWHIV to be properly equipped with disclosure skills in counselling sessions and HIV support groups. The scope of this study did not allow me to find out if the counsellors are equipped with such skills, but from my observation the trained counsellors were few and some nurses and clinical officers assisted in the CCC. There is need for more trained counsellors and even retrain and offer refresher courses for the existing counsellors who may also need to be equipped with skills in order to equip the PLWHIV with the necessary disclosure skills.

b. Challenges in HIV positive status disclosure

Another research question of this study was to find out the challenges that PLWHIV encounter in disclosure. From my findings, both PWLHA who have disclosed and those who have not disclosed encountered several challenges in their decision to either disclose or withhold information about their HIV positive status. The findings from my study indicate that both disclosed and non-disclosed PLWHIV encountered emotional, psychosocial, communication and prevention behaviour challenges as indicated in chapter 4.

The study found that because of the anticipated fears and perceived consequences most PLWHIV cited not knowing how to disclose or even where to start such a conversation or in their own words “lacked words to use”. From the study, almost all the PLWHIVs said that they were aware of the need to inform their spouses about their HIV status. This was reiterated by the key informants especially health care providers and counsellors who reported that they discuss with all clients on the need to disclose to their partners during the counselling process.

From the findings the challenge of disclosure may also be attributed to other cultural, social and behavioural factors such as fear of possible consequences like stigmatisation, rejection by spouse ,denial, being perceived as immoral or a prostitute , being viewed as valueless, “almost dying”. These complex challenges prevent or make it difficult for PLWHIV to disclose their HIV positive status to their spouses. However, some PLWHIV managed to overcome these challenges and were able to disclose. This is important as it can help those who have not disclosed to learn from the experiences of those who have overcome the challenges and disclosed to their spouses.

Some key issues to help them overcome the challenges include encouragement and support of the PLWHIV. This may include encouraging PLWHIV to ask for help from family and community or to accompany them to hospital. From our findings, most PLWHIV disclosed to the individuals who had accompanied them to the hospital whether it is a spouse or a relative. Taking a sick person to hospital, leaving behind chores at home and the farm could communicate to the PLWHIV that the individual understands, cares and is supportive, making the PLWHIV feel that they can trust the individual and disclose to them. Some reported getting encouragement from the health care providers and support groups.

Another area that needs attention is that of HIV support groups. These groups are important as they can equip the PWHIV with the necessary facts and information. It can also boost one’s self-esteem and confidence leading to disclosure. I observed that some nurses were taking on the role of counsellors. There is thus need to increase the number of trained counsellors. Most PLWHIV said that they were aware about the HIV support groups and the benefits of being a member. However, for others especially for those who have not disclosed HIV support groups were reported to increase the risk of exposing them and their HIV status.

Most respondents who have not disclosed, reported a avoiding the HIV support groups for fear of meeting someone that they know who may spread the news about their HIV status. For such respondents, the risk of being a member of a HIV support group is too high despite the benefits that come with being a member such as being equipped with skills, gaining courage and acceptance within the group which can facilitate disclosure for those who have not disclosed. It can also provide information, support and encouragement for the PLWHIV to accept their status and for those who have not disclosed to disclose.

In addition to emotional, psychosocial and prevention challenges that I have discussed in earlier sections, communication challenges prevented some PLWHIV from disclosing and was also a difficult task even for those who had disclosed. Most PLWHIV in the study actually said that the HCT provider discussed with them on the need to disclose to their partner. The big challenge was how to disclose, the skills, and the language limited the disclosure process.

The subject of HIV/ADS is usually associated with the subject of sex and sexuality. I concur with Strong et al. (2002, p.256) that talk around the topic of sex is difficult. They attribute this difficulty to several reasons listed below.

1. We rarely have models for talking about sex. As children and adolescents we probably never speak about it with parents, they discourage it or feel uncomfortable. We learnt that sex is not an appropriate subject of conversation in polite company.
2. Talking about sex matters define us as being interested in sex and interest in sex is often identified as being sexually obsessive, immoral, or bad. If the sex topic is taboo, we risk being labelled bad.
3. We may believe that talking about sex may threaten our relationship. We do not talk about taboo sexual feelings, fantasies or desires because our partners may be repelled or disgusted. We do not talk about sexual problems or difficulties.
4. Sexual vocabulary is a problem. We often use inappropriate language or medical terms, euphemisms, accepted terms and beeps.

According to Bradshaw (1995), as seen earlier certain topics are difficult to talk about for cultural and social factors. Sex belongs to the areas of human conversation surrounded by secrecy and need for politeness. TV programs often beep over words perceived to carry sexual connotations. Parts of the body perceived to connote sex are also obscured. This may explain the difficulty experienced by the PLWHIV in disclosing their HIV positive status which largely revolves around and raises questions about sex and morality especially in the Kenyan context as mentioned severally in this work.

The challenge that most PLWHIV faced had to do with how to disclose as they put it, I lacked words to use, skills, felt inadequate to disclose. There is the need to equip PLWHIV with skills on how to actually go about disclosing to their spouses and other sexual partners. They could for instance be taught skills such as empathy to help them understand their spouses. Disclosure is crucial to prevent the PLWHIV from exposing the spouse or other sexual partners to HIV virus.

Bandura (as cited in Todd & Bohart, 1994) concurs that lack of confidence hinders people from taking action. He calls this self-efficacy. If PLWHIV perceive themselves as inadequate in disclosure skills or having low confidence levels in starting to conversation, they are less likely to disclose. Also Kalichman and Nachimson (1999) showed that low self-efficacy is related with withholding information about one’s HIV status to sexual partners. That is people fail to disclose their HIV status due to lack of confidence in their ability to do so. Some PLWHIV suggested that those who have not disclosed can be taught how to disclose.

All the health care providers (Key informants) talked of the fact that they encourage PLWHIV to disclose and discussed disclosure with clients as they undergo counselling. However, I am convinced by Bandura’s (as cited in Todd & Bohart, 1994) argument that talk alone is not enough (verbal) and that there is need for social skills training for all PLWHIV. He states:

> Performance based therapeutic interventions are more effective than verbal ones. Direct experience is a more potent teacher than words delivered in a therapeutic setting.” Bandura beliefs that therapy must include situations where individuals actually engage in successful mastery of ...This can be done with the aid of the therapist guidance and modelling or through the use of carefully graduated steps.

Only a few health care providers used role playing with clients as illustrated earlier, howeversuch skills training needs to be replicated in all counselling sessions with all PLWHIV. There is need to exploit non-verbal channels of communication and other expressive channels such as art and play therapy in disclosure which may facilitate disclosure especially among those who find verbal disclosure a challenge.

5.1.4 HIV Positive Status Disclosure and HIV Prevention

Another research question of this study was to find out the preventive measures adopted by the PLWHIV to protect their spouses from HIV infection if uninfected and themselves from re-infection.

a. HIV prevention measures

The study findings indicate that all the PLWHIV are knowledgeable on what they need to do in order to protect their spouses from HIV infection if negative and also protect themselves from re-infection. Some PLWHIV reported not knowing their spouse's HIV status (34). They cited various "preventive" measures they take such as the use of condoms, avoiding body fluids, dropping or reducing other sexual partners, being faithful to their spouses, eating a balanced diet, keeping off sex, avoiding alcohol, avoiding spiced and processed foods and open communication.

As seen in chapter 4, all PLWHIV knew or had been advised by the health care providers to use a condom when having sex. However, despite the high knowledge levels of what they needed to do, some had difficulty translating the knowledge into behaviour. This can be explained by cognitive dissonance, resulting in guilt for some PLWHIV (West and Turner, 2000, p.107). The condom was the most widely cited method of prevention by the PLWHIV both among the disclosed and the non-disclosed.

The study found that some PLWHIV still engage in risky behaviours such as drug and alcohol abuse, unsafe sex, commercial sex increasing their risk and exposing themselves and others to HIV infection. Other scholars have made similar observations.Kalichman et al. (2000; 2001) found that one in threepeople living with HIV/AIDS engage in unprotected sex subsequent to knowing that they have HIV and that continued risk behaviours often occur with uninfected partners. Other PLWHIV continued to have sexual partners outside their marriage which in essence compromises HIV prevention and puts their spouse at risk of HIV infection and themselves at the risk of re- infection.

From the findings some PLWHIV reported either having reduced sexual partners outside their marriage or having reduced the numbers of partners. One PLWHIV talked of dropping his other sexual partners in addition to using condoms (disclosed male). Another PLWHIV talked of also finding a “friend” when the spouse started having extra marital affairs. Thus even among infected persons being faithful to one’s spouse is a big challenge to HIV prevention among the PLWHIV and also among the larger population. Also other than having several concurrent sexual partners, we also have cultural and religious practices that may pose a challenge to being faithful to one partner.

Kalichman et al. (2002) argues that HIV infected men are more likely to infect a regular partner than a non-regular one because they are less likely to use a condom with the former. Mishra (et al. 2009, as cited inNACC & NASCOP, 2012, p.22) note that becoming HIV infected is directly correlated with the number of sexual partners.

Also other than having several concurrent sexual partners, we also have cultural practices that may pose a challenge to being faithful to one partner as exemplified by the following excerpt from Dossier (1998, p.59).

> A 35 year old Tanzanian man read a poster explaining that to avoid HIV, one should have sex with only one faithful partner, he bursts outlaughing, "what am I going to do with my other wives".

Most of the PLWHIV demonstrated awareness about the condom and the need to use it in sexual encounters with spouses or with other sexual partners as advised by the health care providers. A good number of the PLWHIV who had disclosed and even those who have not disclosed reported using condoms as a prevention tool. The challenge in HIV prevention lies with the PLWHIV who either do not use condoms at all with their spouses or other sexual partners or use them inconsistently and incorrectly. Hence the condom becomes an ineffective HIV prevention tool. Some PLWHIV reported using condoms "sometimes, not always" for various reasons discussed earlier in chapter 4. Also the heavy reliance on the male condom gives the male an upper hand in the decision on whether or when to use the condom leaving the female vulnerable. There is need to create awareness on the female condom and make it accessible and available.

b. HIV positive status disclosure as a HIV prevention tool

The study found that among the disclosed PLWHIV, 37 women and 26 men knew their spouses' HIV status. Four men and nine women did not know their spouses HIV status. Among the non-disclosed, only 1 PLWHIV knew the HIV status of their spouse. Three respondents said that they suspected the spouse's HIV status but I treated them as not knowing because they do not know for a fact. Hence, only one female knew the HIV status of her spouse out of 17 non-disclosed females and no non disclosed male knew the HIV status of their spouse.

It seems that for those who have disclosed, majority (males, 26) and females, 37) know their spouses HIV status. This would mean that the fact that the spouses know each other's HIV status would enable them to make informed choices about their HIV prevention and safer sex practices. Some PLWHIV reported that once they had disclosed, they adopted safer sex, try to eat nutritious diet, avoid spiced or processed food; throw away sharp objects such as razor blades in the toilet and a great majority indicated that they used condoms as previously discussed.

A key issue with condoms is that for them to be an efficient prevention tool, they must be used correctly and consistently. Although an overwhelming majority of the PLWHIV indicated that they use condoms, some of them reported that they use them sometimes not always, while others reported that they disliked condoms. The inconsistent use of condoms was also reported by the non-disclosed PLWHIV who cited reasons such as not having told their spouse the reason for asking for condom use.

The fact that some of the PLWHIV use condoms inconsistently means that the condom cannot be an effective tool against HIV prevention. As we saw earlier condom use is faced with social, cultural, religious and physical barriers. The biggest challenge is to have PLWHIV and the larger population at large to use the condom consistently and correctly.

Although most respondents reported that they use condoms we did not follow up on the issue of how, in terms of consistency and correct usage of the condoms since it was outside the mandate of the study. There is need for further research on this area.

From my findings condoms were the main method mentioned by majority of the PLWHIV. Also studies indicate that correct and consistent use can reduce HIV transmission. For instance, WHO (HIV/AIDS: Condoms for HIV Prevention) says that "when used correctly and consistently, condoms are effective in preventing HIV and other sexually transmitted infections (STIS). A large body of scientific body shows that male latex condom has an 80% or greater protective effect against the sexual transmission of HIV or other STIs."

To facilitate disclosure of HIV positive status there is need to facilitate discussion of HIV protection and condom use between spouses. This can be achieved through couple counselling and testing, couple seminars and even using media. From the findings, PLWHIV who have not disclosed find it difficult or unable to introduce the topic of condom use hence compromising on protection and exposing themselves to risk of HIV infection. Since there is no cure, consistent and correct use of the condom is the only sure tool of protection from HIV infection among spouses. It will also take us closer to the goal of a HIV free generation.

The study shows that even though the condom may not be used consistently by some of the PLWHIV, disclosure of one's HIV positive status facilitated the couple to discuss and adopt safer sex. The emphasis now should shift from advising PLWHIV to use condoms but to actually reinforce the message of correct and consistent use of the condom alongside other preventive measures.

There is also a need to introduce other HIV prevention methods that are female controlled for instance the female condom which women would have more control overas compared to the male condom. I concur with Okal (2011, p.53) who suggests the need for female controlled methods for HIV prevention.

c. Public Disclosure in HIV Prevention

In the area of public disclosure, most PLWHIV felt that it would be helpful in encouraging people in the community to also test and give other PLWHIV hope. On the other hand, others felt that public disclosure of one's HIV positive status would only expose the individual to more stigmatization in the community. Others do not believe that one can publicly disclose their HIV positive status since even going for the test is not an easy step for many people.

PLWHIV who disclose their HIV status publicly "present the reality of living with HIV, in order to carry out AIDS education, they play an essential role in challenging myths and misconceptions about who becomes infected and making people examine their risk of infection" (Paxton, 1999, as cited in Paxton, 2002). There is thus need to work closely with PLWHIV in the community to educate other PLWHIV and community members. The area of public disclosure and its role in HIV prevention is an area that calls for further research.

d. HIV positive status disclosure and antiretroviral therapy

Antiretroviral therapyisonly effective if the patient adheres strictly to the ARV regimen. Medication must be taken every day for the rest of the patient's life and the correct dose must be taken to avoid developing resistance to drugs.

The study found that HIV disclosure facilitates ART adherence. Adherence to treatment is central to the success of ART including avoiding behaviours which put an individual at risk such as alcohol use. According to (NASCOP, 2001) non adherence can lead to "incomplete viral suppression; continued destruction of immune system and decrease of CD4 cell count; progression of disease; emergence of resistant vital straits and limited future therapeutic options to higher costs for individual's treatment". KAIS II (2012) reported that among those who knew their HIV status and were ART-eligible, 84.5% were taking ART. USAID-Kenya (2013) data indicates that there are over 600,000 Kenyans on ARV treatment as of December 2012.

In the study, PLWHIV who disclosed their HIV positive status reported supporting each other in adherence to the ART. This included reminding each other the clinic dates, time to take drugs, buying fruits, or preparing nutritious diet, being faithful and dropping or reducing sexual partners. On the other hand those who have not disclosed reported challenges in adhering to the ART. This included hiding drugs probably in places that may affect the medication, taking ARV only when the spouse is not at home which can mean that the correct timing is not adhered to. It is crucial for spouses to disclose their HIV positive status in order to increase ART adherence.

Some literature indicates that strict adherence to ART can reduce HIV transmission. For instance, CDC (2013) notes that treatment adherence improves the health and wellbeing of the PLWHIV. Cohen, Chen, McCauley et al. (as cited in CDC, 2013) suggests that ART use by PLWHIV can reduce the risk of sexually transmitting HIV by over 90%. Hence there is a need for HIV prevention strategies to put more emphasis on disclosure which can facilitate ART adherence.

5.2 Conclusion

The study aimed at investigating factors influencing disclosure and non-disclosure of HIV positive status to spouses among PLWHIV. It sought to find out whether the spouse's perceived communication behaviour would influence the PLWHIV's decision to either disclose or conceal their HIV positive status. It also aimed at establishing the challenges faced by the PLWHIV in disclosure and ways of overcoming them. In addition, it looked at methods used in disclosure and preventive measure adopted after disclosing one's HIV positive status. The study was carried out in Kirinyaga County among 98 PLWHIV in CCC in three health facilities and seven key informants.

The study findings shows that all the PLWHIV know and understand the fact that they need to disclose their HIV positive status to their spouses. Even among the PLWHIV who had not disclosed their HIV positive status to their spouses reported being aware of the need for disclosure as they had been advised by the healthcare provider. This was reiterated by the key informants, especially the VCT counsellors indicating that they actually advice the PLWHIV to inform their partners of their HIV positive status.

The study results indicate that disclosure is a mentally, emotionally and socially difficult task hence creating a gap between the knowledge and action (disclosure). This is because although disclosure has benefits that the PLWHIV are aware of, disclosure also entails taking a risk and making the PLWHIV vulnerable to mental anguish, stigmatization, emotional stress, social isolation, rejection and blame from self, spouse and others such as family among other vulnerabilities.

The PLWHIV had to weigh the costs against the benefits of disclosure of their HIV positive status to the spouse before making the decision to either reveal or conceal the information. Those who found the benefits to outweigh the costs disclosed while those who found the risks too high chose to withhold the information about the HIV positive status and did not disclose. The study established that both disclosure and non-disclosure had benefits and costs for the PLWHIV. For some the scale tipped on disclosure while for others it tipped on non-disclosure depending on their cost-benefit analysis. Some of the PLWHIV found ways to overcome and cope with these challenges and managed to disclose while others are still struggling with the decision of whether they will disclose in the near future or never. Majority of those who have not disclosed reported a desire to have their spouses know their HIV positive status, if only they knew how.

The study established that disclosure is dependent on different interdependent factors which influence the PLWHIV to either disclose or not disclose their HIV positive status. We found that a major facilitator and deterrent of disclosure was fear. Fear made some PLWHIV decide to disclose their HIV positive status to their spouses while on the other hand it prevented others from disclosing. For instance, while some feared infecting their spouses and hence choosing to disclose others decided not to disclose for fear of blame, being stigmatized or rejected among other fears. Even among those PLWHIV who have disclosed their HIV positive status to their spouses, they also have fears such as the fear of others knowing that they are HIV positive. This goes to illustrate the uniqueness of human beings.

I am convinced by Izett and Toubia’s (1999, p.17) assertion that complex factors may encourage or discourage a person from taking action and that individuals are surrounded by social networks of friends, family, church, colleagues that influence our decisions. They also argue that in societies structured around extended families, community choices supersede personal choices.

I concur with Hergenhahn (1984) that individuals perceive the world differently and that what they make of their situation is influenced by their subjective world view rather than in a standard manner. This is one of the basic assumptions of the humanistic approach to personality. While fear motivates one PLWHIV to disclose their HIV positive status, it motivates another to withhold the information and prevent them from disclosing. From our study, individuals go to great lengths to protect their private information.

The study concludes that spousal communication and confidant characteristics are important in disclosure. The two main ones were trust and support. It entailed the spouse's perceived supportive communication and their relationship with the PLWHIV. PLWHIV disclose to individuals including spouses who were perceived to exhibit certain characteristics.The confidant has to be perceived as trustworthy by the PLWHIV to keep the information about their HIV positive status confidential or be able to offer support to the PLWHIV. This could either be physical, financial, emotional or psychological support. We found that other than a spouse, PLWHIV often disclosed to their mother, sisters, children and friends among other groups of recipients of disclosure.

The study established that disclosure was mainly done directly by word-of-mouth. However some PLWHIV used indirect methods such as the use of a third party. These included a counsellor, a sister or a mother-in-law. Some PLWHIV also indicated using non-verbal communication alongside verbal communication. This included strategies such as leaving the CCC card and medication on the table where the spouse could easily find it, giving the spouse a condom and this would elicit questions and start the disclosure process. Another conclusion is questions play an important role in HIV positive status disclosure.

The study found that although certain topics are generally discussed between spouses such as farm development and children's school fees, there are other topics that most PLWHIV consider private information. This information is believed to belong to them alone and it is not to be shared even with the spouse. For the non-disclosed PLWHIV, their HIV positive status was private and highly protected to keep the spouse from knowing. Protection rules such as lying, topic avoidance and withholding the information were used.Other issues considered private by most of the PLWHIV included issues about faithfulness, whether one has a "*mpango wa kando",* how they got the infection, past sexual history, PIN number of bank account and *Mpesa* and the actual amount of money one has either in an account, *Mpesa* or *gitati* (table banking).

Another conclusion from the study is that disclosure can facilitate HIV prevention. From the findings, we found that the PLWHIV who have disclosed their HIV positive status to their spouses, find it easier to discuss HIV prevention measures and safe sex such as condom use with their spouses unlike the PLWHIV who have not disclosed. Also more PLWHIV who have disclosed reported knowing their spouse's HIV status than among those who have not disclosed. Therefore, disclosure should be encouraged not just verbally as is the common practice currently but also by inculcating disclosure skills in the PLWHIV during the counselling sessions and in the HIV support groups.

This will enable the PLWHIV to gain confidence within the counselling session and replicate the same in disclosing to their spouse.

The studynoted the use of skills such as role-plays by HCT providers to help the PLWHIV gain the skills and actually practice with a counsellor taking on the role of the spouse and vice versa. This empowers the PLWHIV to go and put into practice what is already familiar having practiced in a safe environment with the HCT counsellor support. This is in line with Bandura's (as cited in Todd & Bohart, 1994) argument that individuals need practical skills to carry out an activity rather than just verbally advising them to go and disclose. Most PLWHIV explained experiencing the challenge of how to disclose and said, "Where do I start such a conversation?", "I didn't have the right words". Such skills like the use of role-plays need to be practised in the counselling session to equip the PLWHIV with the skills necessary for disclosure and also coping with any related disclosure outcomes.

The study established that those PLWHIV who had not disclosed their HIV positive status had difficulties adhering to the ART. This was mainly because they had not disclosed to their spouses and thus had difficulties in observing the schedule recommended by the healthcare provider and also challenges in negotiating for safe sex. As we discussed, some would only take the medication when their spouse was away thus interfering with the strict schedule recommended in using ARV. The benefits of ARV are achieved by strictly adhering to the prescribed regimen in terms of dosage, timing and attending the clinic regularly for care and support services. Strictly adhering to the ARV can have psychological, physical benefits by improving one's immune system and therefore allowing the PLWHIV to live a more productive and healthier life.

This calls for measures to help increase adherence among the PLWHIV especially in low income populations and rural communities.

5.3 Recommendations

The study makes certain recommendations in the areas of policy, practice and further research. The study recommends psychosocial support to be provided to all PLWHIV after testing to increase disclosure. To reduce the window of probability of HIV infection to partners, all tested individuals should be linked with psychosocial support immediately after testing. Assisted disclosure should be offered as an available option for all HIV positive individuals in regular unions. By the time one discloses, they may have already exposed their spouse to HIV infection. I would also suggest allocating resources both human and material on disclosure as an intervention to HIV/AIDS prevention. A lot of funds have been invested and continue to be allocated to the area of HCT.

It is important for program developers in the field of HIV/AIDS to design communication strategies to help spouses develop and improve communication behaviours that create a safe supportive environment that can promote openness in communication and facilitate disclosure of HIV positive status. I would recommend campaigns aimed at strengthening the couple and family relationships and communication.

There is need to increase and facilitate couple counselling and testing. From the study, I established that very few respondents had attended couple counselling and most went for testing alone. Therefore, there is need to address the barriers and challenges that prevent couples from attending couple counselling. There is thus need to organize forums in the community where couples can discuss issues about sexuality, HIV/AIDS, the need to know one’s HIV status and disclose to the spouse and other family related issues.

The study recommends the use of other channels of communication in disclosure such as the use of expressive arts such as play, art and drama therapy. This could also help the PLWHIV deal with stigma, guilt, denial, anger, self-acceptance and blame. I am aware that storytelling, play and art therapy are used to facilitate HIV disclosure to children. This can be modelled and used with the adult population to help them disclose to their spouses and other sexual partners. This would require financial support from the government and other development partners to train care providers with the necessary skills and other related facilities and materials such as play rooms.

The study recommends interventions aimed at expanding social safety nets to cushion or provide psycho-social support even when rejected by the spouse. The PLWHIV could be supported to identify a buddy who can be their support system in the care and treatment process. The buddy would be individuals who have already disclosed. They can be given basic information and awareness about HIV/AIDS by the health care provider to give them the necessary support in their buddy role. This may improve ART adherence and management of any opportunistic infections which eventually can result to increased level of CD4 count and improved productivity for the PLWHIV. It may also reduce the risk of transmission of HIV to their partners.

The study recommends that HIV/AIDS prevention strategies should include empowerment programs which can equip the individuals with the necessary skills to gain self-confidence and feel empowered to make personal choices and seek information. This may include skills such as assertiveness training, as well as income generating activities to empower the PLWHIV economically especially the women. It is crucial to equip individuals with skills and empower them to increase their self-efficacy in different aspects of their lives including risk reduction behaviours for HIV such as negotiating for condom use with spouse or sexual partner and seeking information from health care providers and spouses.

From the study, no respondent including the key informants made mention of the female condom which may raise issues of awareness as well. I recommend the need to introduce the female condom which women would have more control over. However, in comparison to the male condom, the female condom is not clearly understood, not easily accessible and is much more expensive than the male condom which is often distributed for free or sold at a minimal fee depending on the brand. These factors add to the heavy reliance on the male condom which women have little or no control over.

I would recommend the establishment of an organization for PLWHIV similar to the alcoholic anonymous (AA) or similar forums where PLWHIV can meet and share their experiences, challenges, encourage each other and receive information. They can also meet other HIV positive individuals whom they can identify with and learn from each other. This should be meetings held in a location other than within the health centre or clinic as is the case currently with HIV support groups which as we saw earlier can be stigmatizing. This helps to create safety for the PLWHIV and can provide encouragement and support for PLWHIV to disclose.

I would also recommend for HIV program planners in the area of HIV prevention to emphasize disclosure as a prevention strategy. Whereas it is important to advice and encourage PLWHIV to go for HTC and to disclose, it is also important to incorporate practical skills that the PLWHIV can use in disclosing their HIV positive status. I recommend that disclosure programs should focus not just on the PWHIV but the spouse as well.

There is need for education programs to educate PLWHIV to empower them to make personal decisions and maintain their personal choices. This is not without challenges as most of the members of the community have been socialised to make choices which put into consideration community values. Choices are made based on the external locus of control bearing in mind what is acceptable or not acceptable in the community. There needs to be education programmes and empowerment programs that empower individuals and in this case PLWHIV to rely on their internal locus of control which I must admit is a challenge in a community like ours where traditionally the individual comes second after the family and community.

I recommend further research to focus on the role of social and physical context in disclosure of HIV positive status. Research could also look at the depth and breadth of spousal communication and its effect on disclosure. My study makes mention of questions and use of humor by the PLWHIV. Further research can look into the role of questioning and humor in disclosure of a HIV positive status. For students and researchers in the area of gender, they could research on the role of gender in HIV disclosure.

5.4 Contribution to Knowledge

This is the first major HIV/AIDS study in Kirinyaga County since devolution of the Kenya government focusing on disclosure. The study contributes greatly in understanding HIV disclosure in Kirinyaga County and provides a good baseline for other researchers, County Ministry of Health and others in HIV response. Kirinyaga with a prevalence rate of 4% and being sixteenth highest among all Kenyan Counties calls for further studies in the area of HIV/AIDS.

The study looked at spousal communication and its influence on HIV disclosure. It looked at how perceived spouse communication impacts on the control of privacy boundaries. This study aimed at unraveling the nature and potential impact on HIV disclosure to one's spouse. The study established that those who perceived their spouse's communication as supportive rather than defensive were likely to disclose. Thus prior spouse communication influenced a PLWHIV decision on disclosure. It has highlighted that disclosure is not just about the PLWHIV, but the confidant is key in disclosure. The spouse is crucial in the PLWHIV's decision to either disclose or conceal their HIV positive status.

The study points to an area of future research on generic health communication as an intervention for HIV positive status disclosure. Further research is needed in the role of the depth and breadth of communication between spouses on disclosure. This study is of great importance to those who design message campaigns in the area of HIV/AIDS to look at the benefit statement based on what motivates people to disclose.

The study unearthed an uneven pattern of HIV knowledge among the PLWHIV. Some reported revenge as their main motive for disclosure especially those who reported immediately as they were too angry to wait. The anger was targeted at the spouse in the belief that they were the ones who have infected the PLWHIV. HIV exposure was equated with HIV infection based on the basic assumption especially among the women that they were positive because their husbands had infected them. This is not always the case, as they may be discordant couple and the infection may be from other sexual partners other than the spouse. Others reported people not buying from their shops for fear of being infected. Thus it is crucial to address the myths and misconceptions in the community about HIV/AIDS.

Looking at disclosure as an individual responsibility should be questioned as there is evidencethat the level of stigma and openness in the community impacts on disclosure. Disclosure decisions are not only based on personal factors but also on external factors such as community. This study focused on the PLWHIV. However, further research could focus on the role of social and physical context in disclosure of HIV positive status.

Another contribution of this study is the role of disclosure to HIV prevention. We found that PLWHIV who had disclosed were able to adhere to ART and discuss safer sex than PLWHIV who had not disclosed. The study also contributed in the role of questions in disclosure. Spouses need to ask each other questions especially in the area HIV prevention specifically on HIV testing and HIV status of the spouse.

The study contributed in the area of theory application as it applied CPM principles to disclosure among PLWHIV to their spouses in Kirinyaga County. The findings of this study demonstrate how PLWHIV manage their private information about their HIV positive status and use boundary management to either disclose or conceal their status.

5.5 My Thesis

HIV positive disclosure has often been viewed as a personal choice. Though the individual PLWHIV has to make the decision to disclose, that decision largely depends on external locus of control.Disclosure is dependent not just on “self” factors but also on “others”. In our study the spousal communication behaviors is a key determinant as to whether the PLWHIV discloses or not.

5.6 Summary Chapter

This chapter has discussed some of the key findings of the study. Disclosure of HIV positive disclosure to a spouse is influenced by several factors as discussed above. The chapter also provided some recommendations in the facets of policy and further research. It also looks at some contributions that this study makes in the areas of facilitating disclosure between spouses.

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APPENDICES

APPENDIX 1: DATA COLECTION INSTRUMENTS

Name of interviewer/ Code __________________

Name of facility /Code __________________

Date ______________

Time: From: ___________To: _________

BIO-DATA/ BACKGROUND INFORMATION

1. Sex __________ 2. Age _________

3. Education _________ 4. Occupation _________

5. When did you get tested for HIV? _________

6. Have you disclosed your HIV positive status to your spouse? Yes____ No______

Introduction

Thank you for agreeing to talk to me. The information that you give me will be treated with total confidence and will only be used for the purpose of this study. This study is part of a doctoral program at Moi University and its purpose is to gain insights on how to improve community health in this County.

Participation in this study is voluntary and there are no inducements to participate or sanctions for declining to participate. You can opt not to answer any question or terminate the interview at any time. There is no right or wrong response. I would appreciate to hear your opinions on certain health issues.

APPENDIX 1A

INDEPTH INTERVIEW GUIDE FOR RESPONDENTS WHO HAVE DISCLOSED THEIR HIV POSITIVE STATUS TO THEIR SPOUSES

Warm up Questions

1. What are the general problems facing PLWHIV in this area?

(Andũ aria mena mũkingo area ino yanyu ri, ni mathina marikũ makoragwo namo?

After Warm up

1a. what issues do you generally talk about with your spouse?

Ni maũndũ ta mariku ũguo mwaragiriria na mũthuri / mũtimia waku?

b. What information might you not share with your spouse? (Probe: why?)

Ni kũri maũndũ utangimwira?

2a. what do you consider to be private information?

Hari wee ri, ni maũndũ ta mariku ũngiuga ni thiri kana maũndũ maria ũtangienda mũndũ ũngi amenye o uguo? (Korwo ni kurio kaba maundu macio maikare ngoroini yaku ta thiri).

b. If you had secret or private information of any kind who would you tell? (Probe: if they would tell spouse, if yes/no, probe why they would tell?

ũngikorwo na thiri o ya muthemba wothe ri, nu ũkiumbũrĩra? (Uria: kana no aumbũrĩre mũthuri/mũtimia wake? (Uria itumi cia kumumburira na kwaga kumbũra).

c. Have you ever told your spouse a secret? (Probe: which secret and what were the consequences).

ũri woimbũrĩra mũthuri /mũtimia waku thiri yaku? (ũria, gwathire atia? Augire atia kana ekire atia?

3a. what is your perception of your spouse’s communication behaviours? (Probe: for supportive and non-supportive behaviours; he/she perceives spouse as encouraging, listening, supportive, criticizing, and blaming).

Mwenaini wa miario yanyu ri, wonaga mũthuri / mũtimia waku atia? (Ni mundu ũguthikagiriria kana aca, niagũthukaga, ndarekaga njarie, no irumi, gũcinura mundu…).

b. What is your perception of your relationship with your spouse?

Thiini wa muturireini waku na mũthuri / mũtimia waku ri, ũngiuga mũikaranagia na njira ihana atia? (na thayu, haro, ndimwitikitie, twikaga maundu hamwe…).

4a. What is your opinion of individuals who discuss everything with their spouses? (Probe: attitudes toward spouses communicating openly).

Tanjira woni waku iguru ria andu aria mamenyithagia athuri/ atumia ao maundu mothe, matiri thiri? (Mundu na mũthuri /mũtimia wake magiriire kumenyithania maundu mothe kana mangi nimagukirwo namo?).

b. Do you discuss issues about HIV/AIDS with your spouse? (Probe: if yes why they discuss/ if no why they do not discuss).

Nimwaragia uhoro wa mukingo na mũthuri /mũtimia waku? (auga ii, uria gitumi. /auga aca uria niki kigiragia mwarie?).

c. Did you inform your spouse about going for the HIV test? (Probe: if yes, nature of talk, need for testing, prevention measures).If no, probe why?

Niwamenyithirie mũthuri/mũtimia waku ati niurathii guthimwo mukingo? (Uria: aria moiga ii, uria gitumi an aria moiga aca niki kiagiririe amwire).

5a.What is your source of information on HIV/AIDS? (TV, radio, support group)Ndumiriri ikonii mukingo ri (HIV/AIDS) umenyagira ku? (Radio, TV, gikundi kia andu aria mena mukingo).

b. Have you heard of any message on disclosure of HIV status (Probe: where, key message and whether they discussed the message with their spouse or anyone else?).

Uri waugua ndumiriri ikonii kumburira mũthuri /mũtimia kana andu aria maronana kimwiri ati mundu ena mukingo?

Waigwire ku? TV, radio, clinic, mucemanio …)

Ndumiriri yaugaga atia? / Niwariirie mũthuri /mũtimia uhoro wa ndumiriri iyo?

c. (For those who have heard) did the message impact on you in any way? Did it make you talk to your spouse about HIV, adopt safe sex behaviours?).

(Aria maigwite ndumiriri), uria: kana ndumiriri iyo niyakuhutirie handu? (hihi igituma warie na mũthuri /mũtimia, ũthiii ũgathimwo, ũtumire mubira…).

6a.For how long have you known that you are HIV positive?

Ukoretwo wina mukingo ihinda riigana atia? (Wamenyire ri ati wi na mukingo?)

b. When did you disclose to your spouse? (Probe: Duration of disclosure since knowledge of HIV positive status).

Waumbũriire mũthuri /mũtimia waku ri ati wi na mukingo? (Uria: Kuma umenye na riria wamumbũriire ri, ni ihinda riigana atia?).

7a. how did you disclose your HIV positive status to your spouse? (Probe: methods of disclosure, directly or indirectly, face to face).

Wamumbũriire atia ati wĭna mukingo? (wamuikaririe thi ukimumbũrira, ukiandika marua…)

b. Have you disclosed your HIV status to anybody else other than your spouse? (Probe: who and why?)

Tiga mũthuri /mũtimia waku ri, kuri mundu ũngi umbũrĭire ati ũrĭ na mukingo? niki?

8a. why did you decide to disclose your HIV positive status to your spouse? (Probe: reasons for disclosure.

Ni kii giatumire wicirie kumbũrĭra mũthuri /mũtimia waku atĭ wĭna mukingo?

b. What did you expect would happen once you told your spouse that you are HIV positive? (Probe: for anticipated outcomes, both positive and negative)

Atiriri, utanamumbũrĩra ri, hihi weciragia guguthii kana gukuhana atia wamumburira atĩ ũrĩ na mukingo? (Niki giatumaga wone hinya kumumbũrĩra?Weciragia ekuga/agwika atia?

9. What was the consequence of your disclosure? (Probe: for positive and negative consequences or outcomes).

Wamumbũrĩra atĩ wĩna mukingo ri,gwathire atia? (augire atia/ ekire atia, kuri undu wacenjirie)

10a. What challenges/ difficulties did you face in disclosing your HIV positive status? (Probe: language to use, feeling inadequate in skills to disclose).

Ni mihingica irĩku wari nayo ukimumbũrĩra mũthuri /mũtimia waku atĩ wĩna mukingo?

b. How did you overcome the challenges?

Wekire atia nigetha ũhote kumumbũrĩra?

11a.Did you inform your spouse about your HIV positive status before or after engaging in sex with him or her? (If yes/no probe reasons for informing or not)

Ukiumbũrĩra mũthuri /mũtimia waku atĩ wĩ na mukingo ri, nĩ muonanite nake kimwiri kana wamumbũrĩire mutonanite kimwiri?

b. Do you know the HIV status of your spouse?

We niũi kana mũthuri /mũtimia waku niari kana ndari na mukingo? (Niui HIV status yake?).

12. Now that you have disclosed your HIV positive status to your spouse, what preventive measures do you take to protect him or her in the event that they are not infected? (Probe: preventive measures used).

Rĩu tondũ niumbũrĩire mũthuri /mũtimia waku rĩ, kũri ũndũ murageria kugiririria naguo nigetha nake ndakanyitwo ni mukingo?

13a.Do you belong to any HIV support group? (If yes, probe nature of group, activities, does he/she find the group helpful, how?).

(If he/she does not belong to a support group, probe why not).

ũri mũmember wa gikundi kia andũ aria mathimitwo mukingo? (ũria: gikundi kiriku, mwikaga atia mwacemania?

Ni wonaga gikundi kiu ta giguteithagia/ kina umithio?Na njira iriku?

b. Are you taking ARV? (If no, probe why not).

Ni unyuaga dawa cia mukingo (ARV)? (ũria utaranyua rǐ, ũria gitumi)..

14. During the HIV counselling and testing, did the HTC service provider/ counsellor discuss with you the need to disclose your HIV positive status to your spouse? (If yes, probe: content of discussion, what were you told or did in the counselling session?).

Mundu urǐa waguthimire mukingo ri (dagitari, nurse kana counsellor) niakwirire bata wa kumbũrǐra mũthuri /mũtimia kana andu aria angi ungikorwo mungionana kimwiri?

(ũria: akwirire atia?).

15. How can PLWHIV who have not disclosed to their spouses be helped in disclosing their HIV positive status to their spouses?

Andũ aria mena mukingo ri, na matiumburiire athuri kana atumia ao rǐ, mangiteithio atia nigetha nao mahote kumaumburira?

Thanks (Niwega)

APPENDIX 1 B

IN-DEPTH INTERVIEW GUIDE FOR RESPONDENTS WHO HAVE NOT DISCLOSED THEIR HIV POSITIVE STATUS TO THEIR SPOUSES

Warm up Questions

1. What are the general problems facing PLWHIV in this area?

(Andũ aria mena mũkingo area ino yanyu ri, ni mathina marikũ makoragwo namo?

After Warm up

1a. what issues do you generally talk about with your spouse?

Ni maũndũ ta mariku ũguo mwaragiririra na mũthuri / mũtimia waku?

b. What information might you not share with your spouse? (Probe: why?).

Ni kũri maũndũ utangimwira?

2a. what do you consider to be private information?

Hari wee ri, ni maũndũ ta mariku ũngiuga ni thiri kana maũndũ maria ũtangienda mũndũ ũngi amenye o uguo? (Korwo ni kurio kaba maundu macio maikare ngoroini yaku ta thiri).

b. If you had secret or private information of any kind who would you tell? (Probe: if they would tell spouse, If yes/no, probe why they would tell.

ũngikorwo na thiri o ya muthemba wothe ri, nu ũkiumbũrǐra? (Uria: kana no aumbũrǐre mũthuri / mũtimia wake? (Uria itumi cia kumumburira na kwaga kumbũra).

c. Have you ever told your spouse a secret? (Probe: which secret and what were the consequences).

ũri woimbũrǐra mũthuri /mũtimia waku thiri yaku? (ũria, gwathire atia? Augire atia kana ekire atia?

3a. what is your perception of your spouse’s communication behaviours? (Probe: for supportive and non-supportive behaviours; he/she perceives spouse as encouraging, listening, supportive, criticizing, and blaming).

Mwenainiwa miario yanyu ri, wonaga mũthuri / mũtimia waku atia? (Ni mundu ũguthikagiriria kana aca, niagũthukaga, ndarekaga njarie, no irumi, gũcinura mundu…).

b. What is your perception of your relationship with your spouse?

Thiini wa muturireini waku na mũthuri / mũtimia waku ri, ũngiuga mũikaranagia na njira ihana atia? (na thayu, haro, ndimwitikitie, twikaga maundu hamwe…).

4a. What is your opinion of individuals who discuss everything with their spouses? (Probe: attitudes toward spouses communicating openly).

Tanjira woni waku iguru ria andu aria mamenyithagia athuri/ atumia ao maundu mothe, matiri thiri? (mundu na mũthuri /mũtimia wake magiriire kumenyithania maundu mothe kana mangi nimagukirwo namo?).

b. Do you discuss issues about HIV/AIDS with your spouse? (Probe: if yes why they discuss/ if no why they do not discuss).

Nimwaragia uhoro wa mukingo na mũthuri /mũtimia waku? (auga ii, uria gitumi./ auga aca uria niki kigiragia mwarie?).

c.. Did you inform your spouse about going for the HIV test? (Probe: if yes, nature of talk, need for testing, prevention measures).If no, probe why?

Niwamenyithirie mũthuri /mũtimiwaku ati niurathii guthimwo mukingo? (Uria: aria moiga ii, uria gitumi an aria moiga aca niki kiagiririe amwire).

5a.What is your source of information on HIV/AIDS? (TV, radio, support group) Ndumiriri ikonii mukingo ri (HIV/AIDS) umenyagira ku? (Radio, TV, gikundi kia andu aria mena mukingo…)

b. Have you heard of any message on disclosure of HIV status (Probe: where, key message and whether they discussed the message with their spouse or anyone else?)

Uri waugua ndumiriri ikonii kumburira mũthuri /mũtimia kana andu aria maronana kimwiri ati mundu ena mukingo?Waigwire ku? TV, radio, clinic, mucemanio …)

Ndumiriri yaugaga atia? / Niwariirie mũthuri /mũtimia uhoro wa ndumiriri iyo?

c. (For those who have heard) did the message impact on you in any way? Did it make you talk to your spouse about HIV, adopt safe sex behaviours).

(Aria maigwite ndumiriri), uria: kana ndumiriri iyo niyakuhutirie handu? (hihi igituma warie na mũthuri /mũtimia, ũthiii ũgathimwo, ũtumire mubira…).

6a.For how long have you known that you are HIV positive?

Ukoretwo wina mukingo ihinda riigana atia? (Wamenyire ri ati wi na mukingo?).

7a.What prevents you from disclosing your HIV positive status to your spouse? (Probe: Reasons for non-disclosure).

Niki gitumaga wone hinya kumburira muthuri/mutumia waku ati uri na mukingo? (Uria, itumi).

b. Have you disclosed to anybody? (Probe: who and why?).

Ni kuri mundu umburiire ati uri na mikingo? (Uria: nuu na gitumi gia kumumburira)

8a.Do you intend to disclose to your spouse at some point in the future? (If yes, what would prompt you to disclosure to your spouse? any motivating factors, if no, probe why?

Ona akorwo riu ndumburiire muthuri/mutumia waku ri, hihi niurona ta ungimumburira thuthaini?

Angiuga ii uria nikii kingituma amumburire, Auga aca, uria gitumi gia kugiria amumburire).

b. What do you think would happen if you disclosed your HIV positive status to your spouse? (Probe: for anticipated outcomes of disclosure both positive and negative).

Wonaga kana wiciragia ta kungithii atia kana kuhane atia ungimumburira?

9. What are the consequences of non-disclosure? (Probe: both positive and negative

consequences).

Atiriri, kwaga kumburira muthuri/mutumia waku ati urina mukingo ri, ni kuri na wega kana uru waguo?

10a.What challenges/ difficulties do you face in keeping your HIV positive status secret? (Probe: hiding medication, frequent illness, explaining frequent hospital visits)

Ni mihingica/thina uriku ukoragwo naguo kuiga thiri nigetha ndakamenye ati uri na mukingo (kuhitha dawa...).

b. How do you overcome them?

Wikaga atia nigetha ndakamenye ati uri na mukingo? (kunywa dawa kioro, kuhitha dawa, kurega guka thibitari…).

11a. Do you think that you should inform your spouse about your HIV positive status before engaging in sex with him or her?(If yes/no probe reasons for informing or not).

Niukuona ta wagiriirwo ni kumburira muthuri/mutumia waku ati uri na mukingo mbere ya muonane kimwiri?

b. Do you know the HIV status of your spouse?

We niui kana muthuri/mutumia waku niari kana ndari na mukingo? (Niui HIV status yake?)

12. Now that you know that you are HIV positive, what preventive measures do you take to protect your spouse from infection in the event that they are not infected? (Probe: preventive measures).

Riu tondu niui ati uri na mukingo ri, kuri undu urageria kugiririria naguo nigetha muthuri/mutumia waku ndakanyitwo ni mukingo?

13a.Do you belong to any HIV support group? (If yes, probe nature of group, activities, does he/she find the group helpful, how? If he/she does not belong to a support group, probe why not).

ũri mũmember wa gikundi kia andũ aria mathimitwo mukingo? (ũria: gikundi kiriku, mwikaga atia mwacemania?

Ni wonaga gikundi kiu ta giguteithagia/ kina umithio?Na njira iriku?

b. Are you taking ARV? (If no, probe why not).

Ni unyuaga dawa cia mukingo (ARV)? ũria utaranyua rǐ, ũria gitumi.

14. During the HIV counselling and testing, did the HTC service provider/ counsellor discuss with you the need to disclose your HIV positive status to your spouse? (If yes, probe: content of discussion, what were you told or did in the counselling session?).

Mundu uřa waguthimire mukingo ri (dagitari, nurse kana counsellor) niakwirire bata wa kumbũrǐra mũthuri /mũtimia kana andu aria angi ungikorwo mungionana kimwiri?

(ũria: akwirire atia?)

15. How can PLWHIV who have not disclosed to their spouses be helped in disclosing their HIV positive status to their spouses?

Andũ aria mena mukingo ri, na matiumburiire athuri kana atumia ao rǐ, mangiteithio atia nigetha nao mahote kumaumburira?

Thanks (Niwega)

APPENDIX 1 C:

IN-DEPTH INTERVIEWS FOR KEY INFORMANTS

Thanks for agreeing to talk to me. I believe you have a great wealth of experience and knowledge gained working in this community. I would be very grateful if you shared these with me as this will enrich my study greatly. I will begin by asking you…

1. What are the general problems facing PLWHIV in this area?

2. Based on your experience, who do PLWHIV prefer to disclose to? (Probe: whom, why?)

3. Based on your experience, do PLWHIV disclose their positive status to their spouses?

4a.In your opinion what motivates PLWHIV to disclose their positive status to their spouses? (Probe: factors that may influence disclosure).

b. For those PLWHIV who do not disclose to their spouses, what would you say prevents them from disclosing? (Probe: deterring factors).

(Use question 5, 6 and 7 for HIV testing and counselling (HTC) providers only and continue with the rest of the questions, for other key informants go to question 8 and continue to the end of interview guide)

5. As a counsellor/ HTC service provider, do you always discuss disclosure of HIV status to sexual partners with all your clients in the HTC session? (If yes, probe what actually happens, i.e. what do you discuss, tell them or advise them?).

(If no, probe why not?).

6a.How do you encourage your clients to disclose their HIV status to their spouses?

b. What challenges do you face as a counsellor/ HTC service provider in discussing the issue of disclosure to spouses with PLWHIV positive individuals?

c. How do you overcome these challenges?

7. Do you prepare your clients on how to actually disclose to their spouses or is it verbal advice to disclose? (If yes, probe, how do you prepare them? what do you do or say?

8a.Based on your experience, what are the consequences of disclosing one’s HIV positive status to their spouse in this community?(Probe: for positive and negative consequences or outcomes).

b) What are the consequences of non-disclosure of one’s HIV positive status? (Probe: for positive and negative consequences).

9. What preventive measures do you advice PLWHIV to take to protect their spouses from HIV infection? (Probe: preventive measures).

10. In your opinion, how can PLWHIV who have not disclosed their HIV status be helped to disclose to their spouses? (Probe for assisted disclosure, do clients come so that you can disclose to their spouses?).

11. How can HTC services be improved to facilitate increased disclosure to spouses in this area?

12. In your view, does disclosure of ones HIV positive status impact on HIV prevention and HIV risk reduction?

13. Do you have any activities in this area geared towards HIV reduction and prevention? (Probe: type of activities and how they help in HIV reduction).

14. What is the government / Ministry of Health policy on disclosure to sexual partners/ spouses?

15. Is there anything else that can be done to reduce HIV prevalence in this area?

Is there any additional information that you would like to share with me?

Thank you for your time and sharing

APPENDIX II: CONSENT FORM

I agree to participate in the research on factors influencing disclosure and non-disclosure of HIV positive status to spouses in Kirinyaga County. The purpose and nature of the study has been explained to me and I understand that my participation is voluntary. I also understand that I may withdraw from participating at any point during the research. I also understand that my identity will be anonymous but my responses may be quoted in the thesis or subsequent publications without reference to my identity. I have been explained to that the interview will be tape recorded for purposes of the research only.

Tick the appropriate response

I agree to participate __________________

I do not agree to participate __________________

Signed__________________ Date __________________

I give permission for tape recording

I do not give permission for tape recording

Signed __________________ Date __________________

APPENDIX III: MAP OF KIRINYAGA COUNTY

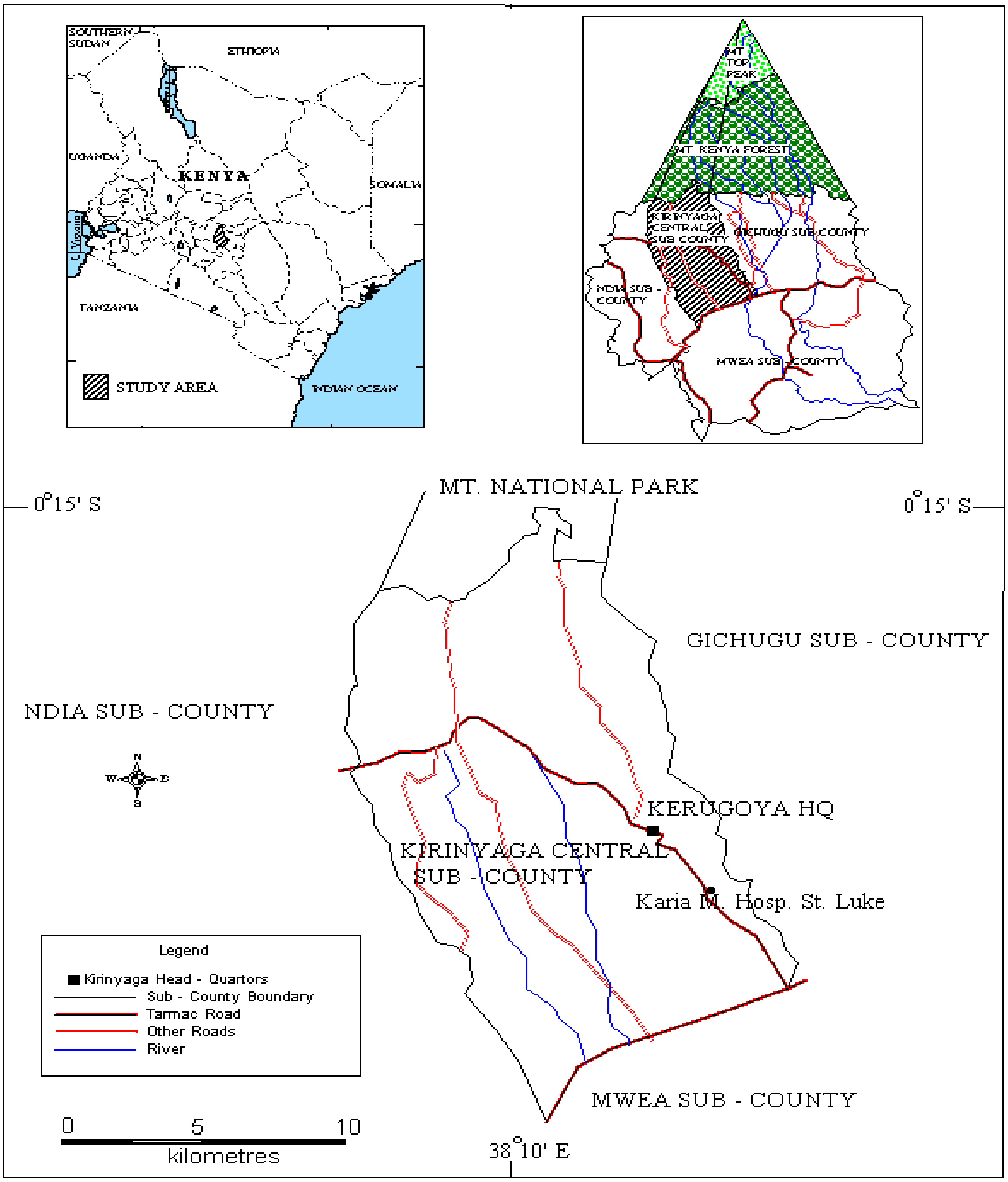
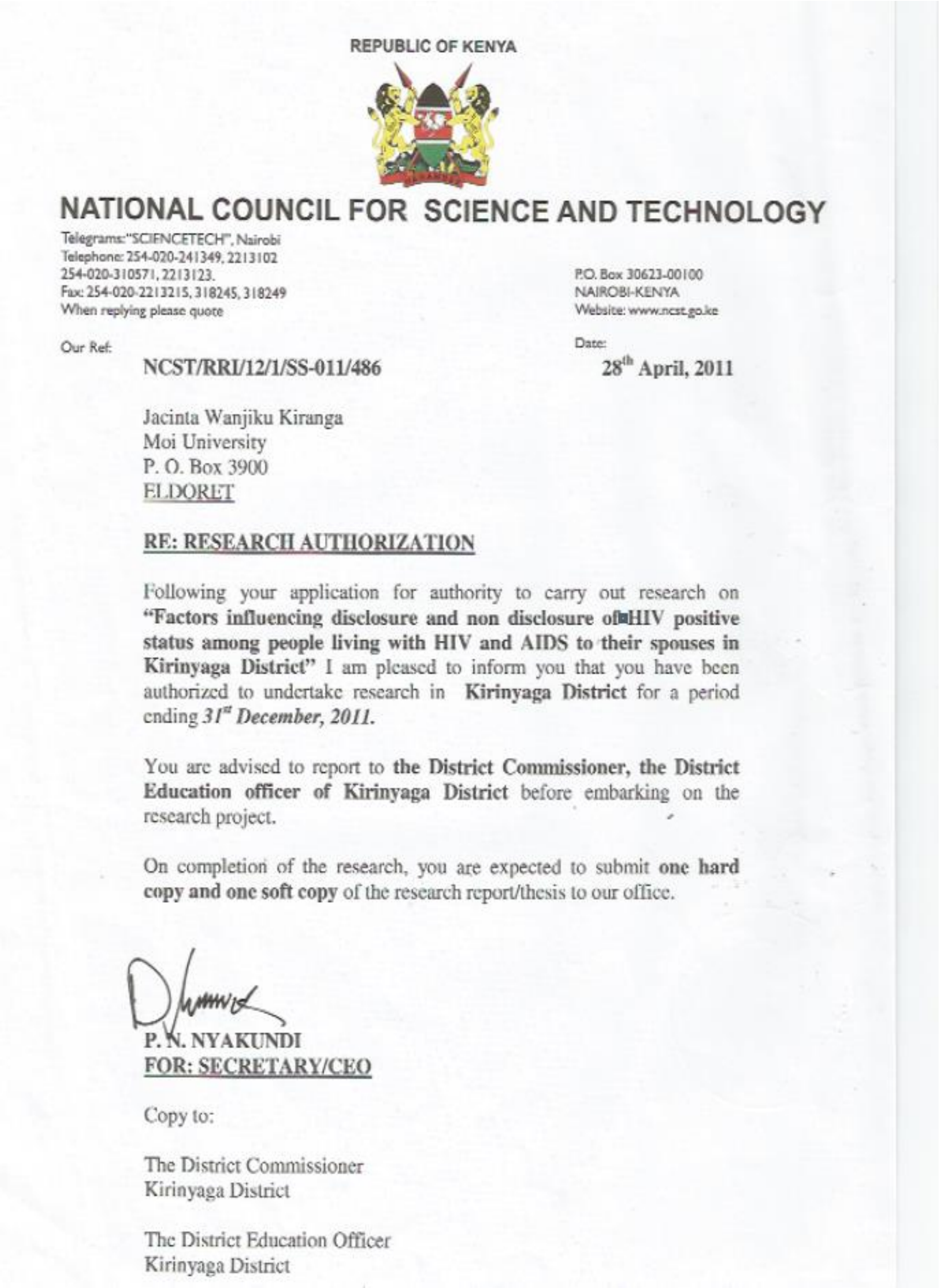


Figure 3.1 Map of Kirinyaga County

APPEDINX IV: RESERCH PERMIT



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NCST/RRI/12/1/SS-011/486

Date:
28th April, 2011

Jacinta Wanjiku Kiranga
Moi University
P. O. Box 3900
ELDORET

RE: RESEARCH AUTHORIZATION

Following your application for authority to carry out research on **"Factors influencing disclosure and non disclosure of HIV positive status among people living with HIV and AIDS to their spouses in Kirinyaga District"** I am pleased to inform you that you have been authorized to undertake research in **Kirinyaga District** for a period ending ***31st December, 2011.***

You are advised to report to **the District Commissioner, the District Education officer of Kirinyaga District** before embarking on the research project.

On completion of the research, you are expected to submit **one hard copy and one soft copy** of the research report/thesis to our office.

P. N. NYAKUNDI
FOR: SECRETARY/CEO

Copy to:

The District Commissioner
Kirinyaga District

The District Education Officer
Kirinyaga District