



UNIVERSITY OF NAIROBI

FACULTY OF ARTS

DEPARTMENT OF SOCIOLOGY & SOCIAL WORK

**AN EXPLORATION INTO THE BARRIERS AND OPPORTUNITIES
EXPERIENCED IN DISCLOSING HIV STATUS AMONG SPOUSES IN
KOROGOCHO INFORMAL SETTLEMENT IN RUARAKA SUB
COUNTY, NAIROBI COUNTY - KENYA**

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**A Research Project submitted to the Faculty of Arts, University of Nairobi, in
Partial Fulfilment of the Requirements for the Award of the Degree of Master of
Arts in Sociology (Counseling)**

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DECLARATION

This Project is my original work and has never been presented for a degree in any other University.

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DEDICATION

I wish to dedicate this work to my loving parents, the late Bethuel Nyaribo Tinega and Omong'ina mama...Mrs.Pauline Mandere Tinega. For their inspiration, love and encouragement to become the best I could be in life! I salute you.

I also wish to dedicate this work to my dear loving wife...Mrs. Lucy Bosibori Osoro for the untiring effort and support throughout my studies

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I wish to thank the almighty God for giving me this opportunity to realize my academic dream; all glory and honor be unto him.

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LIST OF ABBREVIATIONS

AIDS - Acquired Immunodeficiency Syndrome

ART - Anti-Retroviral Therapy

ARVs - Anti-Retroviral Drugs

CBO – Community Based Organization

CDC- Centre for Disease Control

CTC - Care and Treatment Centre

HCP - Health Care Provider

HIV - Human Immune-deficiency Virus

KI - Key Informant

MOHSW - Ministry of Health and Social Welfare

MSF – Medicines San Frontier

MTCT - Mother to Child Transmission

NACP - National AIDS Control Programme

NGO - Non-Governmental Organization

PLWHA - People Living With HIV/AIDS

PMTCT - Prevention of Mother to Child Transmission

PTCs- Post Test Clubs

SCT - Socio-Cognitive Theory

SSA - Sub-Saharan Africa

TB -Tuberculosis

UNAIDS - Joint United Nations Programme on HIV/AIDS

UNGASS - United Nations General Assembly Special Session

USAID - United States Agency for International Development

VCT - Voluntary Counselling and Testing

WHO - World Health Organization

ABSTRACT

The devastating impact of Acquired Immune Deficiency Syndrome (AIDS) in the world – especially in sub-Saharan Africa- has led to unprecedented global efforts to ensure access to antiretroviral (ARV) medicines that moderate the effects of the disease. In order to ensure further reduction in the prevalence of HIV as well as lower the resistance of the disease to ARV medicines, it is essential that an effective disclosure support process should be an integral part of any treatment programme. Failure to tackle this will jeopardise the future of treatment programs and may result to failure of the immense global and national efforts to provide hope for people living with HIV.

This study explored the barriers and opportunities experienced in disclosing HIV status among spouses in korogocho informal settlement in Ruaraka sub-county, Nairobi county. The study applied both probability and non-probability methods of sampling to get the calculated sample size of 24 respondents. Non-probability method of sampling was used to get Focus Group Discussions and key informants. Purposive sampling was used to identify the key informant and FGDs participants. The qualitative data was transcribed and presented in detailed descriptions of the interviews and focus group discussion findings.

The study findings indicate that experiences of HIV status disclosure vary among spouses. The key barriers to disclosure identified include Fear, gender inequalities, Stigma, discrimination, disempowerment and poverty. These barriers cripple an individual's coping mechanisms with the HIV infection and subsequently affect their ability to disclose. Respondents felt the need for unconditional acceptance and support from the entire community, health care providers for them to be able to curb the barriers to disclosure and explore more into the opportunities for disclosure. The study established that counselling is an important point of contact that can be used to address barriers to HIV status disclosure. However, it was revealed that there is need for improvements in the level of and type of counselling offered when providing test results.

The study recommends the mainstreaming of culturally appropriate counselling strategies in the on-going counselling practice, introduction of community based programs to reduce stigma associated with HIV and AIDS, strengthening of Post Test Clubs (PTC's) in order to provide a platform of sharing information and experiences and the promotion of couple counselling in order to minimize negative outcomes of disclosure. It is anticipated that besides adding to the empirical body of knowledge on the barriers and facilitators of HIV status disclosure, the results from this study shall equip policy makers with the data and evidence to inform decision making at county and national level. It shall also furnish scholars in the social arena with information on existing research gaps that require support for further investigation.

CHAPTER ONE: INTRODUCTION

1.1 Background to the Study

The devastating impact of Acquired Immune Deficiency Syndrome (AIDS) in the world – especially in sub-Saharan Africa- has led to unprecedented global efforts to ensure access to antiretroviral (ARV) medicines that moderate the effects of disease in every country where HIV is a threat. According to Akileswaran et al. (2005), to ensure that AIDS can continue to be reduced, it is essential that the effective disclosure support process should be an integral part of any treatment programme. Failure to tackle this will jeopardise the future of treatment programs and may result to failure of the immense global and national efforts to provide hope for people living with HIV (PLWHIV) through the provision of treatment to those in need. This research is a wakeup call to the risk of treatment failure and the development of wide spread ARV resistance unless all patients are given continues support they need to achieve full adherence to ARVs. This can be fully achieved if people disclose the HIV zero-status to their sexual partners without minimal negative outcomes. This will promote safer sex practices hence avoiding re-infections.

According to UNAIDS (2012) on statistics of the HIV/AIDS , more than two-thirds (69 percent) of all people living with HIV, 23.5 million, live in sub-Saharan Africa—including 91 percent of the world’s HIV-positive children. It further posts that in 2012, an estimated 1.8 million people in the region became newly infected and an estimated 1.2 million adults and children died of AIDS, accounting for 71 percent of the world AIDS deaths in 2012.

With the rapid expansion of access to HIV voluntary counselling and testing (VCT) throughout sub-Saharan Africa (UNAIDS, 2008), the behavioural response to learning one's HIV status becomes an increasingly important factor in determining the course of the AIDS epidemic. One such response to VCT is the extent to which individuals disclose their HIV Zero status to others after VCT. Disclosure of HIV positive status gives any potential or current sexual partners the opportunity to adopt behaviours that protect them from HIV infection. Equally if HIV positive individuals do not share their HIV test results, sexual partners are instead forced to rely on subjective assessments of a spouse or potential partner's HIV status, and these assessments are often unreliable (Anglewicz et al., 2009).

HIV status disclosure between spouses is particularly relevant for the spread of HIV/AIDS in sub-Saharan Africa (SSA). HIV discordant couples now represent the majority of HIV-infected couples in SSA (Corno et al, 2007), and a large proportion of new HIV infections in this region occurs within discordant couples in long-term stable partnerships (Hudson, 1996). Because HIV is often transmitted between spouses, communication of HIV test results between spouses is critical for individuals to be fully aware of their risk of HIV infection and have the opportunity to take action to prevent infection.

Disclosure is also important for health of HIV infected individuals. It is often necessary for HIV positive men and women to inform others of their condition in order to receive necessary emotional and physical support (Antelman et al., 2001). For some, it is necessary to disclose an HIV positive status to a spouse in order to facilitate access to anti-retroviral HIV treatment (Farquhar et al., 2000). Also, the act of disclosure itself may also have beneficial effects for

individuals, as depression is higher for some HIV positive individuals who have not disclosed their status (Bennetts et al., 1999)

The barrier to disclosing HIV test results is often generally described as “fear”. However, the specific fear of disclosure varies across settings. Divorce is higher among HIV positive individuals (Keogh et al., 1994; Porter et al., 2004), and fear of divorce or abandonment precludes HIV status disclosure in some instances (Antelman et al., 2001; Mamman et al., 2001; Medley et al., 2004). Gender-based violence is often closely associated with HIV risk for women in SSA (Dunkle & Jewkes, 2007), so it is not surprising that fear of physical abuse prevents women from sharing their HIV status (Antelman et al., 2001; Kumar et al., 2006). Stigma, either real or perceived, also inhibits disclosure, as some fear social isolation and discrimination that could result from sharing one’s HIV status (Antelman et al., 2001). While fear of the consequences may inhibit disclosure in some cases, the decision not to share one’s HIV test result could also simply be a matter of a “need for privacy” (Wong et al., 2007).

1.2 Problem statement

Most people living with HIV do not want to transmit HIV and believe that either safe sex practices or disclosing their HIV-positive status to their sexual partners, or both, is the right thing to do. But disclosure is an intensely personal and difficult undertaking. Whenever a person discloses intimate details about his or her personal life, emotions are engaged. Disclosing intimate personal information may involve thoughts, memories, feelings and sensations. People faced with a stressful situation may remember other stressful situations, feel scared or feel like “running away,” their heart may beat faster, or they may feel sick to their stomach. Disclosing

one's HIV status to a sexual partner means talking honestly about sex, sexual orientation, sexual acts, possible drug use, disease and possible death. All of these are often taboo subjects that are at very least difficult to talk about openly and honestly amongst most couples.

Even for the most self-affirming, self-confident person, these are difficult subjects to talk about. Vulnerabilities surface: self-image, self-perception and self-esteem are all involved. Researchers need to be aware of all the powerful psychosocial factors that influence a person's decision to disclose or not disclose his or her HIV-positive status, including the fear of rejection, stigma, discrimination, potential criminalization, violence and death.

In spite of these fears and barriers, disclosure of HIV status to sexual partner has been emphasized by WHO and the centre for disease control and prevention (CDC). Disclosure of HIV /AIDS status to partners is associated with less anxiety and increased social support among many partners. Additionally, HIV status disclosure may lead to improved access to HIV prevention and treatment programs, increased opportunities for risk reduction and increased opportunities to plan for the future of the family. It has been clearly documented that risk behaviours changed most dramatically among couples where both partners are aware of their HIV status.

Disclosure of HIV status to partners also enables couples to make informed reproductive health choices that may ultimately lower the number of unintended pregnancies among HIV positive partners. This study therefore aims at exploring the barriers and opportunities of disclosing HIV/AIDS status among PLWHA at Korogocho slum of Nairobi County.

1.3 Main Research Question

What are the barriers and opportunities in HIV/AIDS disclosure among spouses in Korogocho informal settlement Ruaraka Sub-county, Nairobi County?

1.3.1 Specific Research Questions

- i. What factors hinder spouses from disclosing their HIV positive status to each other?
- ii. What factors facilitate disclosure among HIV positive spouses?
- iii. What are the effects of disclosing HIV status among spouses?
- iv. What is the role of counselling in status disclosure among HIV positive spouses?

1.4 Objectives of the study

1.4.1 Main objective

The broad objective of the study is to explore the barriers and opportunities in HIV / AIDS status disclosure among spouses in Korogocho informal settlement in Ruaraka Sub-county, Nairobi County.

1.4.2 Specific objectives

- i).To investigate the factors that hinder spouses from disclosing their HIV positive status to each other.
- ii).To examine the factors that facilitate disclosure among HIV positive spouses.
- iii).To determine the effects of disclosing HIV status among spouses
- iv).To find out the role of counselling in status disclosure among HIV positive spouses

1.5 Study Justification

HIV status disclosure of PLWHA to partners and others is of vital significance to HIV prevention. Thus, the issue of HIV status disclosure needs to be addressed to prevent the spread of HIV infection, promote accessibility to care and treatment programs, attain psycho-social support for patients from relatives and friends, reduce stigma, adhere to treatment and promote safer health behaviour. Tremendous efforts have been made to increase HIV status disclosure rate as one of HIV prevention strategies. However, little is known on the barriers and opportunities to disclosure of HIV and AIDS status among couples especially in areas such as Korogocho where the prevalence of HIV infection is relatively high. This study therefore aimed at exploring the barriers and opportunities of disclosing HIV and AIDS status among couples. The study will contribute in filling the existing knowledge gap hence suggest proper intervention measures for promoting disclosure in the society, which, in turn, will reduce the spread and transmission of HIV and AIDS

1.6 Scope and Limitations of the Study

This study was purposive only targeting spouses in the informal settlement of Korogocho in Nairobi County. The target population comprised those spouses who are living with HIV and AIDs and have disclosed or have not disclosed their status to their partners. The study only examined the barriers and opportunities of HIV/AIDS disclosure among spouses in Korogocho. The results of this study can therefore not be generalized to other HIV and AIDS spouses in formal and rural settlements across the country.

CHAPTER TWO: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1. Introduction

HIV/AIDS remains a global public health problem worldwide. By the end of 2010, it was estimated that 34 million people in the world would be living with HIV, with 2.7 million being newly infected (WHO 2010). The number of AIDS related deaths has been noted to decrease worldwide from 2.2 million to 1.8 million from 2005 to 2010 respectively. However, the rate is increasing in Eastern Europe and Central Asia from about 7,800 to 90,000 and it is twice in East Asia from 24,000 to 56,000 (UNAIDS 2011). In Sub-Saharan Africa, it is estimated that 22.5 million people are living with HIV, with 2.3 million being children, while a total of 14 million are orphans from HIV/AIDS (UNAIDS, 2011).

HIV/AIDS in Kenya has a long history and serious efforts and several interventions have been made to reduce its impact, including the establishment of Voluntary Counselling and Testing services (VCT) whereby in 2009, it was estimated that 44% of PLWHA were on ART (Ministry of Health 2009). The HIV/AIDS prevention strategies that include abstinence, being faithful to one uninfected partner, condom use, nutritional education, psychological support and Prevention of Mother to Child Transmission (PMTCT) have been promoted.

VCT was first introduced in 1989 along with establishment of Care and Treatment Centres (CTC) as a strategy to prevent new infections and treat already infected individuals. The rise of VCT and CTCs in Kenya has raised the number of HIV positive diagnoses and counselling services, of which among others, the issue of disclosure is discussed.

Disclosure can either be beneficial or harmful. It is beneficial when it encourages people to access HIV prevention and care services and harmful when it brings adverse consequences. In this case, HIV status disclosure is an important strategy for HIV prevention as it enables HIV positive individuals to access HIV care and treatment programs, creates the awareness of HIV risk to sexual partners and practice safer sex behaviour. It also enables couples to make informed reproductive health choices which can reduce unwanted pregnancies hence reduce the risk of MTCT. In addition, it may enable individuals to receive care and socio-economic support from sexual partners, family and the community.

Disclosure to sexual partners is one of the key strategies in HIV prevention as it promotes safer sex practices, prevent new infections to partner, reduce the risk of MTCT, increase social support and reduce depression. However, in spite of the benefits mentioned above, the disclosure rate in some developing countries remains low as it ranges from 16.7% to 86% (United Nations, 2012).

On the other hand disclosure is harmful when it brings adverse consequences. Negative consequences such as stigma, discrimination, rejection, divorce, blame, shame, and abandonment, among others, are major hindrances of disclosure because they reduce the pace of HIV prevention.

In many countries, disclosure of one's HIV status is done by the patient himself/herself to a person whom he/she preferred to tell. However, in some countries, health care providers are the ones who decide who are first to reveal the status to, whether the patient him/herself or family members (spouse, parents or children). It is then becomes the family's decision whether or not to tell the patient the truth or to hide it for the sake of patient's best interests. However, in spite of the good intention of involving family members in HIV disclosure, in some families, revelation has resulted in discrimination and psychological stress. Women suffer more from such negative consequences than men (Schoepf, 2010).

HIV positive status disclosure is a very sensitive phenomenon. HIV infected persons need to outweigh the benefits against the harm before disclosing their status. This reality necessitates an understanding of barriers and opportunities of HIV status disclosure and associated factors among people living with HIV/AIDS who are attending care and treatment centres.

2.2 Disclosure in the developed world

Among the fifteen studies based in the USA that report HIV status disclosure rates to sexual partners, 6 reported on samples of women only, 3 reported disclosure rates among heterosexual men and the remaining 6 studies included both men and women in their sample (Simon et al 1995). 14 of the 15 studies recruited their participants from clinic- based settings. All 15 reported disclosure rates to sexual partners. And some studies included multiple categories of sexual partners such as current, past, casual and steady partners. The period of time that lapsed between diagnosis and assessment of disclosure ranged from 2 months to 3 years. There was also the

study from France that looked at HIV status disclosure to sexual partners among HIV – positive patients attending treatment services at an HIV clinic in Paris, France. The disclosure rates to sexual partners were high, ranging from 42% to 100%, depending to a high degree on the sexual partner whom the person disclosed. The lowest rates of disclosure were reported among past partners or current casual partners. Among the studies that reported disclosure rates to current and or steady sexual partners the average rate of disclosure was 79%. There was variation in rates of HIV status disclosure to sexual partners among different ethnic groups in the USA and in France. Armistead et al (1999) reported a relatively lower % of women who disclosed to partners (56%) as compared to women from a study by Simon (89%) and men from a study by Levy, A et al (2009). In a study among ethnically diverse HIV- infected women, Simon et al (2005) found that Spanish – speaking Latinas reported lower rates of disclosure than English –speaking Latinas, African-Americans and Anglo- Americans. In a study from France, Bungener et al (2000) found a similar trend with 69% of HIV –infected women of European descent informing at least one member of their family of their status as compared to only 38% of women of Africa descent. This suggests that there may be important cultural factors that impact on the partners of self-disclosure to sexual partners.

Levy et al (2009) found that among the patients from an outpatient clinic in Paris, France, less than half (42.5%) disclosed to their partner immediately after diagnosis, 21% disclosed within one month after diagnosis and 24% waited more than one year to disclose. Women tended to share their result with their sexual partner immediately after diagnosis more than men.

Across the study there remained a percentage of individuals who reportedly did not share their HIV test results with anyone since the time of their diagnosis. Gielen et al (2007) reports and, Kilmarx P, Hamers F, Peterman T.(1998) reports 11%, Simoni et al (2000) 10% and Lester et al (2005) reports that 67% of individuals in his sample had not disclosed to any friend and 25% had not disclosed to any family member.

2.3 Disclosure in the Developing Countries

Studies of HIV status disclosure rates to sexual partners from the developing world include 11 studies from Sub- Sahara Africa (1 from Burkina Faso, 2 from Kenya, 3 from Rwanda, and 5 from the United Republic of Tanzania). One reporting disclosure rated from multi-country study in –Kenya, Tobago, and United Republic of Tanzania. There were no published studies from other regions of the developing world that reported rated of HIV status disclosure to sexual partners.

Six of the studies reported rates of disclosure among women who were enrolled in HIV prenatal transmission trials and remaining three studies reported rates of disclosure among other clinic based populations. The assessment of disclosure ranged from 2 weeks to almost 4 years.

The rates of disclosure among the studies from the developing world were notably lower than rates from the developed world. Among the studies that reported disclosure rates to current and or steady partners the average rate of disclosure was 49%, considerably less than the average rate reported from studies conducted in the developed world (79%).

Only a few of the studies reported on disclosure rates at multiple assessment points. The study from United Republic of –Tanzania by Antelman G et al (2001) found that disclosure to sexual partners increased from 22% within two months of diagnosis to 41% after nearly four years. MacNeil JM, Mberesero F, Kilonzo G (1998) reports that disclosure rate to sexual partners increased from 5.8% at baseline to 18.8% six months after diagnosis. Van der Straten et al (1995) reports that 77% of the HIV – positive women shared results with their partners within one year of diagnosis and this increased to 70% among women followed two years after diagnosis.

A large proportion of individuals from the developing world studies reported that they did not share their HIV status results with anyone as compared to developed world studies. 10% of women from Thailand had not shared results with anyone Simoni JM et al (1995). Similarly, 17% of HIV positive women from a VCT clinic in –Tanzania Bungener et al (2000), 50% of HIV positive women from rural South Africa. Gielen et al (1997), 16% of participants from rural Tanzania Hays R et al (1993) and 77% of the HIV positive women from urban Tanzania Kilewo et al (2001) had shared their results with anyone.

2.4 Barriers to HIV status disclosure

In our society, stigma is often associated with having any disease, particularly a serious disease that can be passed from person to person. HIV is now a chronic and manageable condition when people have proper access to treatment and enjoy the personal circumstances that enable them to adhere to this or that prescribed treatment. Some progress has been made in terms of shifting the

public's perception of HIV since the beginning of the epidemic. But, despite that progress, PLWHAs continue to be particularly stigmatized worldwide (Supra, 2009)

Although there are laws in Kenya that can protect PLWHAs from discrimination, discrimination remains common and disclosure can expose them directly and indirectly to discrimination in housing, employment or access to health and social services. A. Gielen, et al (1997) states that disclosure can also lead to rejection by family, friends and community, and can even result in the disclosed being subjected to violence.

HIV also disproportionately affects individuals who are already marginalized. These people risk being further marginalized if they disclose their HIV-positive status.

(Baltimore 2003) argues that fear of violence and rejection can have a strong impact on the decision to disclose or not, particularly among some HIV-positive women who fear potential reactions of their male sexual or drug-injecting partners. People may also fear that their partners may reveal their status to others. Social exclusion and isolation can also play a role.

According to a study in the U.S.A, gay and bisexual men have demonstrated that internalized homophobia, isolation from the gay community, lack of familiarity with the majority culture, and being "in the closet" can have a negative impact on some men's decision to disclose to sexual partners. (R. Wolitski et al.1998)

The criminalization of HIV non-disclosure can also make disclosure to sexual partners more challenging for PLWHAs who may fear being subjected to false accusations and/or prosecution if they tell their partners they have HIV. This is of particular concern for PLWHAs in abusive relationships or after a bad breakup. Researchers should be aware that fear of criminal prosecutions can also hinder a person's capacity to talk openly about their disclosure or sexual practices with their Researchers since information provided to a Researcher can be compellable as evidence in a criminal investigation. (Soc Sci & Med 2011)

The ability to disclose one's HIV-positive status can be related to the degree to which an individual has accepted his or her HIV diagnosis. It is often most difficult to disclose soon after diagnosis, when a person is grappling with the initial impact of his or her HIV-positive status. A person's ability to disclose his or her HIV status can also be affected by the physiological and psychological changes brought on by sexual arousal, drug use or drug addiction. The release of chemicals in the body during erotic arousal can change perception, cognition and boundary-setting. An intense pre-orgasmic state may strongly impact a person's ability to disclose. Both the psyche and the body are in harmony and focused on building sensuality and not necessarily on rational or ethical thinking. People who use drugs may also experience the same type of blurring of their rational and ethical vision. Disclosure may be easier before intense erotic arousal or when the physiological and psychological need for drugs is not so great.

The criminalization of HIV non-disclosure may also have an impact on the ability of a PLWHA to disclose his or her status to a partner with whom he or she has already had sex, especially if no

condom was used, as disclosure may result in potential accusation and prosecution for not disclosing HIV-positive status before the first sexual encounter (Adams et al.2008).

Disclosure may be easier or more difficult depending on the context in which it takes place. In many cases, due to fears of rejection and breach of confidentiality, disclosure to potential sexual partners may be more difficult than disclosure to trusted friends or family. Disclosure may be less common with casual partners or in a commercial sex setting, especially if condoms are used. In the environments where anonymous sex takes place, serious conversations about HIV status usually do not occur. People may also engage in sexual acts on the basis of non-verbal disclosure signals, assumptions, or underlying physiological and psychological factors. For example, an individual, who is HIV-negative, may assume that a partner who wants to have unprotected sexual intercourse is also HIV-negative.

Disclosure in the context of a long-term or committed relationship may also be extremely difficult. Relationships may not always be based on trust, honesty, openness, safety, or good communication. PLWHA may fear their partners' reactions. They may fear losing his or her partner, children, financial security and sometimes immigration status, or be subjected to physical and emotional violence. HIV- positive women in longer-term heterosexual relationships, may also face specific challenges affecting disclosure and safe sex practices due to norms of discontinuing condom use once a relationship becomes "serious," expectations related to childbearing, or assumptions about women's sexuality that may vary from one community to another.

2.5 Opportunities/ Motivators for disclosure

With the rapid expansion of access to HIV voluntary counseling and testing (VCT) throughout sub-Saharan Africa (UNAIDS/WHO, 2008; WHO, 2007), the behavioral response to learning one's HIV status becomes an increasingly important factor in determining the course of the AIDS epidemic. One such response to VCT is the extent to which individuals disclose their HIV zero status to others after VCT. Disclosure of HIV positive status gives any potential or current sexual partners the opportunity to adopt behaviors that protect them from HIV infection. Conversely, if HIV positive individuals do not share their HIV test results, sexual partners are instead forced to rely on subjective assessments of a spouse or potential partner's HIV status, and these assessments are often unreliable (Anglewicz et al., 2009).

HIV status disclosure between spouses is particularly relevant for the spread of HIV/AIDS in sub-Saharan Africa (SSA). HIV discordant couples now represent the majority of HIV-infected couples in SSA (de Walque, 2007), and a large proportion of new HIV infections in this region occurs within discordant couples in long-term stable partnerships. Because HIV is often transmitted between spouses, communication of HIV test results between spouses is critical for individuals to be fully aware of their risk of HIV infection and have the opportunity to take action to prevent infection. (Hudson, 1996; Robinson et al., 1999)

Disclosure is also important for health of HIV infected individuals. It is often necessary for HIV positive men and women to inform others of their condition in order to receive necessary emotional and physical support (Antelman et al., 2001). For some, it is necessary to disclose an HIV positive status to a spouse in order to facilitate access to anti-retroviral HIV treatment (Farquhar et al., 2000). Also, the act of disclosure itself may also have beneficial effects for

individuals, as depression is higher for some HIV positive individuals who have not disclosed their status (Bennetts et al., 1999).

To counterbalance the barriers, some studies also reported on the factors that motivated individuals to disclose to their partners and to other members of their social network. The reasons for disclosing differed depending on the individual to whom the person was disclosing. Simoni et al (1995) found that ethical responsibility and concern for partners' health was the major reason cited for disclosing to sexual partners, whereas seeking social support was the primary reason for disclosure to friends and family.

Increased social support was also mentioned as a major reason for disclosure to partners, family, friends and medical providers in the study by MacNeil JM, Mberesero F, Kilonzo, G (1999).

2.6 Outcomes of disclosure

Disclosure of HIV status to sexual partners is an important prevention goal emphasized by the World Health Organization (WHO) and the Centres for Disease Control and Prevention (CDC) in their protocols for HIV testing and counselling. Disclosure offers a number of important benefits to the infected individual and to the general public. Disclosure of HIV test results to sexual partners is associated with less anxiety and increased social support among many people. In addition, HIV status disclosure may lead to improved access to HIV prevention and treatment programmes, increased opportunities for risk reduction and increased opportunities to plan for the future.

Disclosure of HIV status also expands the awareness of HIV risk to untested partners, which can lead to greater uptake of voluntary HIV testing and counselling and changes in HIV risk

behaviours. It is clear from the literature that risk behaviours change most dramatically among couples where both partners are aware of their HIV zero status. In addition, disclosure of HIV status to sexual partners enables couples to make informed reproductive health choices that may ultimately lower the number of unintended pregnancies among HIV-positive women (UNAIDS; 1997)

2.7 The role of counselling in Disclosure

In addition, to social factors that may play a role in motivating individuals to disclose, a couple of studies also reported on the role that counselling might play in facilitating disclosure.(De Rosa et al,1998) found that rate of disclosure increased with the number of times that a health professional discussed issues of disclosure at the HIV clinic where they received care. Men who were counselled both at post- test counselling and their current HIV clinic were nearly likely to have disclosed to all sexual partners than men not counselled at both sites. In a qualitative study conducted at a VCT clinic in Tanzania, Mamam et al (2002) found that men and women mentioned the important role Counsellors played in their decision to disclose.

There are number of factors which promote HIV status disclosure. Taking ARV is one of the determinants of disclosure, PLWHA who are on ARV are more likely to disclose their status compared to those who are not on ARV. This is due to the fact that before starting ARV, they receive ARV adherence counselling in which among other things, they emphasize on disclosure so that they can be assisted especially by being reminded to take their medication (ARVs) or to

be helped to pick the medications from the centre once the patients cannot do by themselves for a strong reason.

HIV counselling promotes disclosure of one's HIV status. Counselling encourages the HIV infected persons to disclose their HIV positive status to others. Counselling can be done during pre-test and post-test counselling sessions or during the routinely clinic visit for care and treatment programmes. The study reports that clients who received on-going counselling at every clinic visit are more likely to disclose, this is due to the fact that clients are coupled with benefits of disclosure. A Tanzanian study Mamam et al (2002) reports that counselling has influence on disclosure

2.8 Theoretical framework

This study adopts the theory of planned behaviour, social cognitive theory and theory of reasoned action. These perspectives played a fundamental role in guiding the entire study including interpretation of research findings.

Kerlinger (1964) defines a theory as a subset of interrelated concepts, definitions and propositions that present a systematic view of phenomena by specifying relations among variables, with the purpose of explaining and predicting phenomena. Nachmias and Nachmias (1996) concur with the same by noting that theories help us explain and predict phenomena of interest and in consequence, to make intelligent and practical decisions. Credible theory, they say is the conceptual foundation for reliable knowledge. The theory of planned behaviour and

social cognitive theory lay suitable framework to help examine and explain the barriers and opportunities of HIV/AIDS disclosure amongst spouses in Korogocho informal settlement.

2.8.1. Theory of Planned behaviour

The theory of planned behaviour is heavily influenced by Ajzen and Fishbein in 1980. It suggests that a person's behaviour is determined by his/her intention to perform the behaviour and that this intention is, in turn, a function of his/her attitude toward the behaviour and his/her subjective norm.

The best predictor of behaviour is intention. Intention is the cognitive representation of a person's readiness to perform a given behaviour, and it is considered to be the immediate antecedent of behaviour. This intention is determined by three things: their attitude toward the specific behaviour, their subjective norms and their perceived behavioural control. The theory of planned behaviour holds that only specific attitudes toward the behaviour in question can be expected to predict that behaviour. In addition to measuring attitudes toward the behaviour, we also need to measure people's subjective norms – their beliefs about how people they care about will view the behaviour in question. To predict someone's intentions, knowing these beliefs can be as important as knowing the person's attitudes. Finally, perceived behavioural control influences intentions. Perceived behavioural control refers to people's perceptions of their ability to perform a given behaviour. These predictors lead to intention.

A general rule according to this theory is that the more favourable the attitude and the subjective norm, and the greater the perceived control the stronger should the person's intention to perform the behaviour in question. It is on the basis of this that this theory was chosen to explain what

hinders and motivates spouses to disclose or not to disclose their HIV and AIDS status to their partners.

2.8.2 Social cognitive (or learning) theory

The evidence of the social cognitive or social learning theory (SCT) states that new behaviours are learned either by modelling the behaviour of others or by one's direct experience. Social learning theory focuses on the important roles played by indirect, symbolic, and self-regulatory processes in psychological functioning and looks at human behaviour as a continuous interaction between cognitive, behavioural and environmental determinants (Bandura, 1977). Central tenets of the social cognitive theory are self-efficacy – the belief in the ability to implement the necessary behaviour (“I know I can insist on condom use with my partner”). Outcome expectancies - beliefs about out-comes such as the belief that using condoms correctly will prevent HIV infection. Programmes built on SCT integrate information and attitudinal change to enhance motivation and reinforcement of risk reduction skills and self-efficacy

Specifically, activities focus on the experience people have in talking to their partners about sex and condom use, the positive and negative beliefs about adopting condom use, and the types of environmental barriers to risk reduction. A meta-analysis of HIV risk-reduction interventions that used SCT in controlled experimental trials found that 12 published interventions with mostly uninfected individuals all obtained positive changes in risk behaviour, with a medium effect size meeting or exceeding effects of other theory-based behavioural change interventions (Greenberg, 1996). It is on the basis of this that this theory can be used to explain the barriers and opportunities of disclosing HIV/Aids among spouses.

2.8.3 Theory of reasoned action

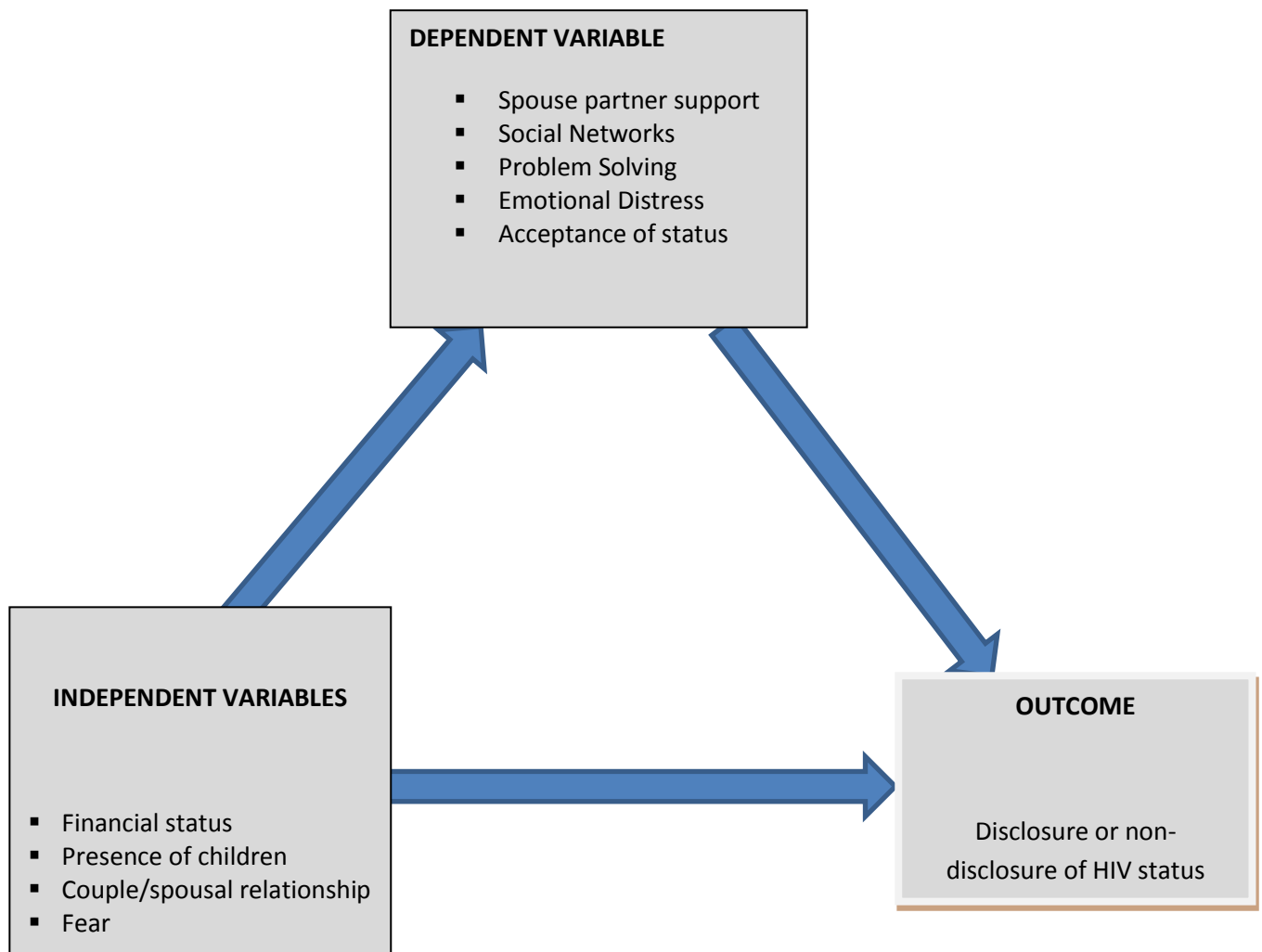
The theory of reasoned action, advanced in the mid-1960s by Fishbein and Ajzen, is based on the assumptions that human beings are usually quite rational and make systematic use of the information available to them. People consider the implications of their actions in a given context at a given time before they decide to engage or not engage in a given behaviour, and that most actions of social relevance are under volitional control (Ajzen, 1980). The theory of reasoned action is conceptually similar to the health belief model but adds the construct of behavioural intention as a determinant of health behaviour. Both theories focus on perceived susceptibility, perceived benefits and constraints to changing behaviour.

The theory of reasoned action specifically focuses on the role of personal intention in determining whether behaviour will occur. A person's intention is a function of two basic determinants: attitude (toward the behaviour), and 'subjective norms', i.e. social influence. 'Normative' beliefs play a central role in the theory, and generally focus on what an individual believes other people, especially influential people, would expect him/her to do. For example, for a person to start using condoms, his/her attitude might be "having sex with condoms is just as good as having sex without condoms" and subjective norms (or the normative belief) could be "most of my peers are using condoms, they would expect me to do so as well". Interventions using this theory to guide activities focus on attitudes about risk-reduction, response to social norms, and intentions to change risky behaviours

2.9 Conceptual framework

The framework presented here (see figure below) illustrates how various factors (enablers and barriers) experienced by couples may contribute to the ability of either spouse to disclose HIV status either directly or indirectly. The framework reflects the general importance of context as well as specific aspects of context that may be particularly relevant to couples.

CONCEPTUAL FRAMEWORK



The study conceptual framework shows the interrelationship between the dependent and independent variables and their expected outcomes with regard to disclosure or non-disclosure of HIV status among spouses.

The independent variables discussed below shows the interrelationships of these factors;

Financial stability of a partner determines various aspects including partner support whereby they support each other financially and may not depend on well-wishers while the contrary, financially unstable individuals may tend to depend on well-wishers for financial support. The latter will tend to disclose in order to obtain the much needed financial support.

The presence of children as an independent variable may determine social support from a partner/spouse and acceptance of status. A HIV positive individual may readily accept their HIV status in order to receive the much needed medication (ARVs) in order to live long enough to care for their young.

A couple's relationship type will determine various aspects including problem solving and emotional distress/ coping mechanisms. Couples with a good/warm relationship are able to solve their problems more readily and openly. They have higher chances of HIV disclosure unlike in cases of strained egalitarian relationship couples.

Fear as an independent variable determines an individual's ability to disclose and cope with their HIV status. Fear of discrimination, violence and stigma from society and peers may affect an individual's social networks that may lead to emotional distress and subsequently lack of disclosure

Spouse partner support could act both as an enabler or disabler of disclosure. A supportive spouse acts as an enabler to disclosure and vice versa.

Social Networks of an individual will most often enable disclosure because they form part of a larger social coping mechanism of an individual. Family, friends and colleagues that are open and embracing HIV positive persons will more than likely encourage an individual to disclose. On the contrary hostile social networks will discourage an individual from disclosing for fear of stigma, isolation and/or desertion.

Problem Solving skills of an individual will influence their ability to disclose or in-disclosure. An individual with good problem solving skills will more than likely disclose their HIV status because they are confident of their ability to cope with the perceived health problem at hand. An individual with poor problem solving skills will feel inadequate or ill-prepared to solve or face the health challenge and therefore may not disclose their status to spouse or significant other

Emotional Distress caused by knowledge of one's HIV status may act as an enabler or hindrance to disclosure. An emotionally distressed person may confide in a close friend for help or empathy. This may act to support disclosure. On the other hand, an individual may choose to not disclose because of the stressors associated with the disease and its social implications.

Acceptance of status by an individual is a strong indicator and precursor to disclosure. An individual who has accepted their HIV status has the ability to disclose their status without fear of any repercussions. An individual that is still in denial will not accept their status and therefore may not disclose their status to anyone

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter presents a brief description of the methods which were adopted in this study. It looked at the research design, the study site description, the target population, the sample size, the sampling procedures, methods of data collection, the research instrument, data analysis methods and presentation.

3.2 Research Design

The research design is a scheme, outline or plan that is used to generate answers to research problems (Orodho, 2003). This study adopted the descriptive survey design. The descriptive survey design was chosen because the study collected information about people's attitudes, opinions, and habits. This allowed the researcher to generate accurate information concerning the study. The study was concerned about the barriers to and opportunities for HIV-positive status disclosure among spouses living in Korogocho informal settlement in Nairobi.

3.3 Site Description

The study was carried out in the MSF-Belgium Korogocho clinic that serves Korogocho informal settlements and is located in Ruaraka Sub-County, Nairobi County. The clinic was purposively selected because of its large catchment area and presence of well-established Post Test Counseling Clubs (PTCs). Korogocho informal settlement was estimated to be the fourth largest slum in Nairobi, after Kibera, Mathare Valley and Mukuru kwa Njenga (Kenya Census 2009). The majority of residents were originally migrants from rural Kenya who were seeking work and better life in the city. Housing is self-built and improvised: shacks and makeshift

dwellings made from found and recycled materials. There is no central sewage system, clean water supply or street lights. Households in the slum lack access to clean water, sanitation facilities and sufficient living area (Mutua et al,2007).The slum has approximate area of 1.5 square kilometres, population density of 63,318 people per square kilometre and estimated total population between 150,000 to 200,000(KNBS, 2010).

3.4 Study Population

Study population is defined as that population the researcher wants to generalize the results of the study, events or objects to which a researcher data wishes to generalize the results of the research (Mugenda and Mugenda, 2003). According to the Kenya national census (2009) Korogocho slum had about 200,000 people. In the context of this study, the populations included married men and women who are living with HIV/AIDs. This target population was purposively selected because it provided the characteristic information required by the study i.e. Persons living with HIV and AIDS in an informal settlement.

3.5 Sample Size

The study used both probability and non-probability methods of sampling to get the sample size of respondents for the study sample. For probability method of sampling, stratified random sampling method was used to get the three PTC from the five PTC.The 3 clubs comprised a total membership of 111 i.e. Club A had 37, club B had 41 and club C had 33 members. The researcher used proportionate to size sampling to get the required number of respondents from each of the three PTC clubs. The calculated number of respondents from club A was 8, from club B was 9 and from club C the researcher sampled 7 respondents as detailed below

Club A: $37/111 * 24 = 8$ (4 men and 4 women selected)

Club B: $41/111 * 24 = 9$ (4 men and 5 Women Selected)

Club C: $33/111 * 24 = 7$ (4 men and 3 Women selected)

Total Number of study respondents = **24**

The 24 respondents included both those who have disclosed their HIV status to their spouses and those who have not disclosed their status to their spouses.

Non-probability method of sampling was used to get FGDs and key informants. Purposive sampling was used to identify the key informant and FGDs. The researcher purposively sampled six FGDs where two from each stratum for men and women separate. Four key informant were also purposively sampled and they included the health centre in charge, social worker/ Researcher, NGO health person and community development officer.

3.6 Sampling Techniques

The 3 selected PTCs from the 5 PTCs are based in MSF Belgium clinic in the village of Kisumu Ndogo in Korogocho slum. The leaders of these 3 PTCs were purposively sampled and invited to participate in the study. These PTC leaders conduct health talks in the MSF-Belgium Korogocho clinics and hence were easily identifiable to the Researcher. To identify PTC members who had not disclosed, purposive sampling was used whereby PTC leaders of the 3 selected PTCs in Kisumu Ndogo were requested to identify members in each PTC who was known have disclosed their status and those have not disclosed their status to their partner. These potential study subjects who had disclosed their status were asked to attend a meeting with the Researcher to be explained the purpose of the research in detail, and to request their assistance in identifying

members of their PTCs who had not disclosed about their HIV status and who they thought would be willing to participate in the study.

Purposive sampling was done when identifying the leaders of Post Test Clubs (PTC) whose characteristic is that they must have disclosed their HIV/AIDS status to their spouses. Purposive sampling was used to identify the key informant and FGDs. The researcher purposively sampled six FGDs where two from each stratum for men and women separate. Four key informant were also purposively sampled and they included the health centre in charge, social worker/ Researcher, NGO health person and community development officer.

3.7 Unit of Analysis

The unit of analysis in this study was the barriers and motivators of HIV/AIDS status amongst couples. Disclosure can either be beneficial or harmful. It is beneficial when it encourages people to access HIV prevention and care services and harmful when it brings adverse consequences. In this case, HIV status disclosure is an important strategy for HIV prevention as it enables HIV positive individuals to access HIV care and treatment programs, creates the awareness of HIV risk to sexual partners and practice safer sex behaviour

3.8 Units of observation

The main units of observation were the spouses who have and have not disclosed their HIV and AIDS status to their partners in Korogocho slum of Nairobi County. Members of post-test Clubs (PTCs) were interviewed. They included 12 men and 12 women. 6 of each gender had disclosed their status to their spouses while the other 6 of each gender had not.

3.9 Research Methods

This study used the following research methods:

3.9.1 In-depth interviews

An in-depth interview is qualitative data collection method which enables a researcher to get appropriate results. An in-depth interview provides the opportunity to capture rich, descriptive data about people's behaviors, attitudes and perceptions, and unfolding complex processes about the current phenomenon the researcher is investigating. In-depth interviews are normally carried out face to face so that good relationship is created with respondents which enable the researcher to obtain relevant information. Successful in-depth interviewers listen rather than talk to enable the respondent to answer and express all his/her views.

3.9.2 Focus Group Discussions

Focused group discussions were used to get information on the topic of study. They were guided by the researcher to participate in lively and natural discussion amongst on the conceptualization in an exploration into barriers and opportunities experienced in disclosing HIV/AIDS status among spouses in Korogocho informal settlement in Kasarani District, Nairobi County. Focus group discussions explored the meaning of survey findings that cannot be explained by use of statistics. A total of 6 FGDs were conducted with men and women separate.

3.9.3 Key informant interviews

Key informant interviews was conducted to a specific key resourceful individuals in the community who were having valuable insight and resourceful specialized knowledge on regarding the topic of study. Key informants fill the information gaps that a research may have

with regards where he/she is supposed to be in community to observe. The key informants were source of firsthand knowledge in given study community, they provide honest information, sensitive and confidentiality issues which cannot be discussed in focus group discussion. In this study 4 Key Informants interviews was conducted on; the health centre in charge, social worker/ Researcher, NGO health person and community development officer.

3.10 Research Instruments

The researcher used the following research instruments to collect data:

3.10.1 In-depth Interview Guide

An In-depth interview guide is a tool or a research instrument consisting of a series of questions and is made up of open- ended questions with specific response categories. The open- ended questions helped the researcher to elaborate to respondents on questions in depth manner in order to express their feelings, attitudes and even perception. The researcher used in-depth interview guides to obtain information from respondents from the three selected PTC.

3.10.2 Focus Group Discussion Guide

According to Mugenda and Mugenda (2003), a focus group discussion is a form of group interviewing in which a small group – usually 10 to 12 people – is led by a moderator (interviewer) in a loosely structured discussion of various topics of interest. The focus group discussions guide is a series of questions that facilitates discussion for focus group discussion. The guide directs a moderator on how to ask specific question and what will follow. The guide provides familiarity on the topic of discussion and ability to speak.

3.10.3 Key informant interview guide

The interview guide approach is more structured than informal conversational interview although there is still quite a bit of flexibility in its composition (Gall and Borg, 2003). Key informants interview guide is a research tool and are series of questions on key informants in order to gather information, was administered on key informants. It enables them to fill the information gaps that a research may have with regards where he/she is supposed to be in community to observe. It's in form of confidential to key informants and gives a particular perspective on specific problem in the particular group in community.

3.11 Data Analysis

Qualitative data which included recorded interviews was transcribed and edited. Transcripts were demarcated with segments of texts that represented the main issues that emerged during data collection. Each segment was labelled with a "code" – such as ‘feelings about rejection’, ‘stigma’ in line with research questions and objectives. After coding was complete, a summary was created of the common/recurring codes, taking into account the similarities and differences in related codes across the entire transcripts, distinct original sources/contexts, or comparing the relationship between one or more coded. The emerging themes and main concepts were used to answer the study research questions.

CHAPTER FOUR: DATA ANALYSIS, PRESENTATION AND INTERPRETATION OF FINDINGS

4.1 Introduction

This chapter presents the analysis of the data collected, presentation and discussion of the findings in relation to the objectives and the aim of the study. This chapter covered background information, experiences of knowing HIV positive status, barriers to disclosure, opportunity/facilitating factors of disclosure, the outcomes of disclosure and experience of counselling in HIV status disclosure.

4.2 Response Rates

The study targeted 24 respondents, 6 FGDs and 5 Key informants in order to collect the required data for this study. The researcher achieved 100% response rate by interviewing all 24 respondents, having 6 FGDs and interviewing 5 Key informants.

4.3 Demographic Characteristics of Respondents

The demographic characteristics of respondents information in this study was used to show an in-depth understanding of the respondents. Demographic characteristics of the respondents included gender, Age bracket of the respondents, Level of education, occupation and religion. The findings of the study are discussed in the subsections below.

4.3.1 Age Group of the Respondents

The researcher sought to find out the age bracket of the respondents in order to ascertain their contribution to the study. The results are shown in Table 4.1

Table 4.1: Percentage distribution of respondents by age

Age in years	Frequency	Percentage
21-30	4	17
31-40	10	41
41-50	6	25
Over 50	4	17
Total	24	100

Source: Researcher (2015)

From the findings, majority of respondents 41% were aged 31-40 years old, followed by 25% who were 41-50 years old. Further findings revealed that 17% of the respondents were aged between 21-30 years old and those are over 50 years old. The most affected are aged 31-40. This corresponds with the age bracket with the highest number of married respondents.

4.3.2 Gender of the respondents

Further the study sought to find out the gender distribution of the respondents in order to establish the number of men and women participated in this study. The results are shown in Table 4.2

Table 4.2: Percentage distribution of respondents by gender

Gender	Frequency	Percentage
Male	12	50
Female	12	50
Total	24	100

Source: Researcher (2015)

From the findings the gender distribution of respondents is 50% for male and female. The findings have the equal gender distribution since the study was involving 12 men and 12 women.

4.3.3 Education Level of the Respondents

Further the study sought to find out the education level of the respondents in order to establish how the level of education affects their lives. The results are shown in Table 4.3

Table 4.3: Percentage distribution of respondents by education level

Education level	Frequency	Percentage
Primary	4	17
Secondary	14	58
College	6	25
Total	24	100

Source: Researcher (2015)

The findings found that 58% of the respondents had reached secondary school level, 25% had college level education and 17% of the respondents had primary level education.

Majority of respondents have reached secondary level education since most of them moves to city to look for green pasture after form 4. Also few had attained college level since they earn wages which could enable them to pursue further education.

4.3.4 Religion of the Respondents

Further the study sought to find out the religion of the respondents in order to establish their religion. The results are shown in Table 4.4

Table 4.4: Percentage distribution of respondents by religion

Religion of the respondents	Frequency	Percentage
Christian	16	67
Muslims	6	25
Others	2	8
Total	24	100

Source: Researcher (2015)

From the findings majority of respondents 67% are Christian followed 25% who are Muslims, finally 8% who are from other religions.

In informal settlement there are many Christian sect and cults and this make larger of entire population to be Christians. Also some sects and cults don't allow their members to go for HIV testing since they term themselves holy people.

4.4 Experiences of knowing HIV positive status

The findings from those that have not disclosed their status indicate that there is a lot of pain connected to HIV/AIDS especially for faithful partners learning about their HIV positive status for the first time when they least expect. Most of the respondents indicated that they were very sick and went to Hospital as a normal thing and in most cases were diagnosed TB positive and were advised by the Doctors to go for a HIV Test and the results indicated were HIV positive. All the respondents indicated that they were stressed up and felt that the world has come to an end. It took them time to accept their status and they were real confused with life and most of them their families started to experience a lot of problems and challenges.

Data from FGD indicated that most women they didn't want to go for HIV testing, they were forced to do the same during the time they were pregnant as a requirement for Anti-natal clinic.

One woman indicated as follow:

“I knew I was so faithful to my husband and I was always treating him well and I knew he loved me. I learnt of my HIV status when I was pregnant with our third born in 2003 through the Anti natal clinic. I cried that day and could not believe it. I denied that it was true until I gave birth. I went for another test after delivery and confirmed that I was indeed HIV positive. I was really stressed and feared telling him because he would accuse me of unfaithfulness”

Due to fear of false accusation by their spouses, respondents like the one above may choose to not disclose their HIV status to their partners.

The findings from the disclosed group were different from those of undisclosed group. They said it was more of a relief they indicated that their experience of knowing their HIV status was a relief for them and it was an end to a long journey of worries and so many other problems they encountered because of the opportunistic infections we had had. So to them now it was a relief and they felt actually it was the right time for them now to start another second chance in their life.

The finding further established that knowing their status was a relief because it gave them answers to a lot of questions and problems they had had which they did not realize the cause of. Their experience of knowing their HIV status actually; before they learnt of their HIV status they had a multiple infections that could not be treated, but now they went freely went to the clinic for treatment.

Data from FGD indicated the same that knowing their HIV status help them, it was a relief in their life which make them to lead a positive life.

Data from FGD (A Man) said:

“Knowing my HIV status helped me modify my life. Formerly, I was not behaving very well. When I was told I did not get shocked until when I got home. I was counselled then I was referred to Kenyatta National Hospital. I did not believe that I had the Virus because I am very faithful.”

Those who know their status lead a positive life since have been in many workshops which encourage them to live positively. Also some are shocked when they learn they had the virus since are always faithful to their partners. This is due to married people having secreted affairs without their spouses knowing it.

The findings from the undisclosed group show that they expressed the sense of helplessness and hopelessness on discovering they were living with the HIV virus. They expressed that was the worst day in their life, they will never forget. They thought are not going to live but here they are. They wondered how will live, will they live longer or short. If they die, what will happen to their families thereafter? Some didn't feel or rather find the reason to work hard at all because after all, were dying and people would scramble for their property.

All respondents reported that the circumstance under which the test or diagnosis was done is what affected them most. The undisclosed respondents were not expecting to be tested at all, so they were deeply shocked and pained. This is both physical pain which is from opportunistic infections and emotional pain which is from learning the HIV positive status for the first time. All these experiences offended the clients and may opt to withdraw themselves from the community

4.5 Barriers to Disclosure

The study established four factors that hinder spouses from disclosing their HIV positive status to each other. These barriers to disclosure include ; Fear where respondents discussed the various forms of fear including fear of abandonment, fear of rejection/ discrimination, fear of violence, fear of upsetting family members, fear of accusation of infidelity, fear of loss of economic support from partners. Also there were Myths and misconceptions where some respondent reported that they don't even believe in the existence of AIDS. There was Stigma which was found to be a cross-cutting barrier presented by all respondents. Respondents discussed discrimination by family and community as a real threat to their ability to disclose. Children from HIV positive parents had experienced stigma at school and this knowledge prevented some spouses from disclosing their status to their mates. Insufficient social support through counselling was identified as a barrier to disclosure. One respondent mentioned that the counsellor's involvement needed to be more engaging over time in order for them to overcome their fears and concerns on disclosure

The data from FGD reflect these barriers. They indicated that a person with myths and misconceptions does not believe AIDS exist. They knew would stay with the secret. They give them the best when encouraging our children to work hard because anytime they could die .This worries them, would be hurt inside but they won't know.

Data from FGD (woman) said as follow:

“He will kill me I tell you the truth. Because one day we were talking and he said: “if I go to hospital with a woman and test positive all of us will find our graves” I got scared and knew he could kill me.”

When the women learns they are HIV positive they real fear to disclose to their husbands since most of them the time they discover they are HIV victims they will kill the entire family this hinders women to disclose their status openly.

The study found out that most women didn't disclose to their husband their HIV status since their men wererough. Also the study established from the findings that others didn't want to disclose because they don't want their children to suffer.

Counselling helps a lot but not on disclosure, I have not got enough courage because I have not managed to disclose so far. When counsellors tell you that just go and disclose don't fear that is all, but this is your wife you can sleep with you know, it's not a stranger in the house. This is the most important person in my life it's the mother of my children the woman I have known for my all life. It is not as simple as the counsellors may put it. We don't have enough counselling support we need and this has been big challenges in disclosing our status.

Further, the study revealed that the fear was about what will happen to their marriage if they disclose. So the fears were all inclusive including what will happen to their children once they know that their parents are HIV positive. Finally was perception of the community members to my children that they are HIV positive.

Data from FGD (A woman) said:

“Obviously after the disclosure there are bound to be questions about why me, where did it come from, I feared that I would be blamed for having the HIV status.”

When one discover he/she is HIV positive they intend to question themselves why them, it's not an easy thing to accept that one has virus.in present society still there is stigma where people with HIV virus are termed as lose and morally decay and in most cases like from man side they blame the woman responsible for HIV virus and infected their son.

The findings found out that it was very difficult on the issue of denial or the aspect of it can't be, it can't be in the family, it's not for me it's for those people it can't be me or my wife.Furthermore, those with poor discernment will discriminate this patient either wife or anyone else who disclosed his/her HIV status is in the family like they did to leprosy patients in old days. They think a HIV infected person does not deserve to live in the community. Children coming from a HIV infected family who are in school are discriminated by fellow children thinking that the family of that child was not a decent one.

Data from KI (chief) indicated as follow:

“To couples, if a wife discloses her HIV status to her husband and the husband goes for test and finds he is HIV negative, divorce will follow because he will think that his wife was not faithful. The revelation will therefore be the source of marriage breakdown. They think a HIV infected person does not deserve to live in the community and this lead to discrimination denial hence short life for victims.”

The moment the man discover that the wife she is HIV positive and him he is HIV negative it brings a lot of conflict in family where the woman she is regard as immoral, unfaithful and not

worthy to be a wife. Because in Africa still the patriarchal mentality is at peak, the women she is condemned completely and chased away or divorced completely. But for the man if is discovered that he is HIV positive nothing is done even in most cases they force their wives to be intimacy and in process they also infect them since its regarded that a man owns a woman and she has no right even in controlling their lives because most women in slums are not empowered and aware of their rights.

The findings above indicate that the most common barriers mentioned by undisclosed respondents included the Fear of abandonment. This was the major barrier that was mentioned most often by women. It was closely tied to fear of loss of economic support from partners especially in these settings where resources are extremely scarce.

The absence of social security and health insurance in most African countries also make women dependent on their partner and family therefore women may choose not to disclose so they get these benefits.

Fear of rejection, stigma and discrimination was found to be another barrier. HIV/AIDS related stigma remains one of the greatest obstacles to people living with HIV being able to fulfill their human rights. Stigma is a major barrier to creating and implementing HIV programmes. Clients feel belonging to an “undesirable” minority group due to discrimination.

Stigma has concrete repercussions for people living with HIV. The respondents who had full blown AIDs had faced open stigmatization and discrimination due to their infection. They therefore chose not to share with anybody about their disease because if they did it will make them feel isolated and the sense of loneliness will increase.

The clinician supported these sentiments and said that most of the clients whom they attend to feel the same way during their first experience of the diagnosis. They even warn them against calling their names with the files in the outpatient department waiting bay.

Socio-economic discrimination was also mentioned by respondents. This is especially when it came to disclosure to people that the respondent felt had power over some of their aspects of life like work or resources.

Fear of upsetting family members is another barrier to disclosure. Respondents reported that undisclosed to them will protect the family from shame, from obligation to help and avoidance of communicating about highly personal information. All these are associated with high levels of worry about HIV/ AIDs and cultural attributes associated with the disease.

4.6 Opportunities/ Facilitating Factors of Disclosure

Knowledge is vital in disclosure and the undisclosed group cited lack of it from the counsellors had hindered their disclosure.

4.6.1 The Undisclosed

The findings from the study show that the undisclosed they all expressed the desire to disclose however they didn't know how. Some their desire to disclose is due to have gotten treatment literacy training and they wish their couples knew. Most request to collude with counsellor to pretend that you do not know them and that are testing for the first time with him so that when they come they test together.

Data from FGD (man) indicated as follow:

“The only way out is for a counsellor to help. I am aware that I need to protect her from infection and myself from re-infections. But you see, I can’t use a condom because how will I explain the reason for using the condom?”

In most cases, those partners who were unfaithful to their spouses and are infected with HIV virus it’s hard to reveal to their partners. AS much as they try to protect their partners they can’t do so since they fear to use protective as they lack explanations to their partners. Also for women they can’t tell their husbands to used protective since a man will need to know why to use a protective. In this manner partners pretend going to hospital and in process they agree to be tested after counselling where are told to accept the outcomes. But the affected already had agreed with counsellor on how to help other partner to understand their status.

Further the study established that the respondents requested the counsellor to talk to the Doctor to write for them a letter asking their couples to come with me to the clinic so then the Doctor to recommend that both need to test for one to get the medication. Then when they come are sent to the counsellor for couple counselling and testing as if they have never tested before. When this happens they may not blame each other. This the only way out otherwisethey don’t know how else to go about it.

Data from KI (a victim woman) said:

“When he will fall sick then he will be tested. I will just wait until he is very down to a level he can’t support himself then he will be told. Then I will disclose to him that I knew long time but

because of his big head. I know he will be too weak to run after me or beat me up. Then we will be counselled over safe sex then he can't escape testing if he dares, then I will threaten to leave him. Then am sure he will agree to test oh! That is the only way out for me."

The issue of women telling their men that they are infected with HIV virus is tricky since most men intend to be violent on women even chasing them around and beating them by blaming them for infecting them even if are the one infected their wives. Women are first one knowing their status because generally women have many complications in their metabolic life and in most cases they found themselves in hospital, also women are good listeners and can be easily influenced by counsellors to be tested compared to men. Since women know that if they inform their husband will beat them even chasing them away, they wait until when their husband are weak to inform them that have been HIV positive for long time, here men are weak they can't beat nor chase their women but real needs them to take good care of them. Hence men are advised and counselled on how to live positively.

From the respondents there was tendency of blaming each other by others saying that now you can teach me because am unable to do so. Another way for them to think is looking for somebody to come to the house to counsel them to get information then the counsellor will gauge because have never been counselled. Once I know how to start especially through counselling, I may know how to go about it.

The respondents gave different factors that motivated them to disclose to their partners and to other members of their social network. The reasons for disclosing differed depending on the individual to whom the person was disclosing. Ethical responsibility and concern for partners' health was the major reason cited for disclosing to sexual partners, whereas seeking social support was the primary reason for disclosure to friends and family. Increased social support was also mentioned as a major reason for disclosure to partners, family, friends and medical providers in this study. In addition, to social factors that may play a role in motivating individuals to disclose, counselling also plays a role in facilitating disclosure. The study found that rate of disclosure increased with the number of times that a health professional discussed issues of disclosure at the HIV clinic where they received care. Men who were counselled both at post- test counselling and their current HIV clinic were likely to have disclosed to all sexual partners than men not counselled at both.

4.6.2 The disclosed

Form the findings the respondents indicated that ittook themtime more than 2 years to disclose their HIV status to their partners.Also it took them time before they disclosed since they feared that their partners could go away and leave them.

Data from FGD indicated that onmost side they revealed say counselling has really helped them. It is one of the main factors that helped them to disclose their HIV status.

“For me, the strongest factor was education. Once I received education and basic facts about HIV AIDS its infection and transmission, I realized that it was up to me to take charge of my health.... also after going for some workshops trainings I was able to disclose.”

Awareness about HIV/AIDS and what it entails it's of essence through workshops and other trainings enables the HIV victims to lead healthy life and are more concerned to minimize infections and transmission. Also awareness helps persons living with HIV take charge of their health and this enables them live long enough to care for their families.

After knowing their status they realized they had a family as a parent they realized had duties to their children.it was Important to disclose to them because they love them and still need them. They had to disclose it avoiding re-infections and all that and use of the condom. Further data from FGD one woman said:

“... for me, going public especially in community outreaches through clinic health talks helped me to disclose that I am HIV positive. It also enabled me to disclose even to the family was that I was living with HIV. This has really helped me to reduce new infections.”

Presently in informal settlement, many HIV victims and doing community outreach through clinic health talks and this help many HIV victim to disclose their status in public and through this other are encouraged and disclose their status too. Mostly CBOs and other NGOs support them and as others see this decide to disclose too and in the process they reduce infections.

When the respondents in the FGD where asked to share about the factors that motivated them to disclose, the responses varied depending on the relationship that existed among the partners. These included: Time factor; it took quite more than 6 months of diagnosis among all disclosed respondents before they disclosed their status,

Major supporting factors for disclosing mentioned included: Counselling, education and commitment to significant others.

Among other key factors mentioned included the need to reducing the infections/ re-infections, community involvement, past experiences of HIV in the family, need to save the lives of others, to counter stigma and the need for family planning.

4.7 The Outcomes of Disclosure

Most respondents especially women indicated that the outcome after disclosing to their spouses was that they walked out on them. According to respondents most men used that as a tool of holding the kids from them because they knew that in a few days their wives would be dead. Further the study established that disclosure helped everyone become open about their status, now are able to do things together and come to a common understanding and are now able to accept each other and things work out very well.

Data from FGD (man) said:

“Socially and in the family I have helped because I have also assisted my families, friends and neighbours to know their status and assisted those whose condition are worsening and resume their production again. For me disclosure generally after initial hitch finally led to acceptance in the family. My spouse finally accepted me and I accepted her. On my side when I disclosed my HIV status to my spouse, it gave me a lot of freedom.”

It takes time for family and community to accept one his/her status since when people learn that you are HIV positive they think it's the end of you and you don't have any life to live forgetting that one can live more than 20 years. The best moment is when the spouse accept the status Of each other and they give freedom and they lead happy life.

The above results from the respondents was supported by The health care provider who was one of the key informant supported the positive outcomes of disclosure by saying the following .The health care provider indicated as follow:

“I find it nice to be open about HIV positive status because once many people know that you have this problem, you may get some assistance. Sometimes, support is given to HIV infected people so it is easier to communicate with you when you are needed. Those who do not disclose, they deny themselves their basic rights.”

Those who are open with their status are free to live and in most informal settlement are being supported with many humanitarian organizations which their aim is to support the HIV/AIDS people to lead positive life. Due to this help and support in the area, those who have not disclosed their status are encouraged and motivated to disclose theirs. This gives the right of accepting their lives.

Further the study find out that it is very important to disclose HIV status to family members because once one fall sick they will know that they should take him/her to the hospital. Also, they will remind them to take medications whenever they forget to do so because they know they

should not miss the dose. They also remind them when clinic appointment is due. When they become sick, they can wash their clothes. It is important to disclose their status so that they can wear protective gear such as gloves to prevent them from infection when they attend to them.

Most respondents in the disclosed group reported positive outcomes following disclosure apart from one respondent who reported to have been abandoned and rejected after disclosure. Positive outcomes of disclosure reported included: increased social support, acceptance by the spouse, openness between spouses, freedom in relating and speaking about HIV, enhanced relationship and a sense of relieve as the spouse got tested too .

Another Key informant who was a community development worker was on opinion that disclosure of HIV ensures assistance from the family on ARVs adherence, following clinic appointment and being taken care of when becomes critically sick

It is important to disclose ones HIV/Aids status as it brings opportunities like receiving free counselling services, attending antenatal clinic for PMTCT, giving birth to health and an infected children, free medical services, employment, attending treatment literacy courses, travelling out of the country for exchange programs, being community educators and health workers hence supporting other affected members, advocating for better medication in terms of ART and influencing policies in the country regarding health and human rights issues .

4.8 The Role of Counselling in HIV Status Disclosure

From the findings all the respondents admitted that they went through counselling. However, the experiences differed between the undisclosed and the disclosed group: while the disclosed group appreciated good counselling support, the undisclosed participants felt it was not sufficient for disclosure.

From the findings it was found out that counselling helps a lot, it gave the respondents moral support, life, education hope in life, they have got a lot of awareness and even knowing they need to disclose what they have known through counselling. Counselling is good because even when you are anxious, people share and you feel supported and not alone. At times when I am stressed I talk to a counsellor and I leave a very relieved person.

The study found out that Counselling has really saved many peoples life, when they learnt their status. Every time had an infection, would run to a counsellor before even consulting the Doctors because with the counsellors would discuss anything and everything freely without being judged. Through counselling, were send to a post-test club where they got more moral and psychosocial support from my peers. one woman indicated as follow:

“I have attended treatment literacy courses offered by MSF-B, am now actively participating in sensitizing other members of the community to go for testing. All these I learnt through counselling and yes, my experience of counselling is that it really helps people cope with what they cannot change. It also helped me in behaviour change because I was taught about re-infections”

Those who have disclosed their status are trained on how to help others to be tested more those who doubt their status. Counselling helps them to cope with their status at hand and it gives them insight on behaviour change like for those who are aware are HIV positive and want to spread by infecting more people to be like them. Counselling helps them to minimize infections and this leads to have a safe society.

The study found out that the respondents believe actually without counselling it would have been difficult for them to disclose to their partners. Most of them indicated that counselling actually is a vital tool. Counselling to them was a pillar of support because once they testes, they really don't know how to go about it.

Data from KI (counsellor) indicated as follow:

“They gave me the skills to use in the disclosure and also how to take care of my own life so I would say without counselling disclosure would be very difficult if not next to impossible.”

After disclosing their status, the victim needs counselling time in and time out, counselling enables the victim to move from one step to another in life. Counselling provides HIV victims with immediate and relevant solutions to their life and of their spouses.

However, the undisclosed group felt there was inadequate support and need for more support from counselling. The findings show that the undisclosed group istaught little though it takes time before getting training on their status. Further it reveals that when are told the counsellor in this clinic to bring a treatment assistant, are heart broken most of them disappeared for one year

before they come back. Most are scared by the counsellor they found in hospital and this make them not come back when are told the side effects of drugs like going blind. HIV status, it addresses fears and promotes Prevention of Mother to Child Transmission.it is also a key to adherence because the spouses are open to another and there is no longer be hiding when taking drugs and in fact one will act as treatment assistant and a buddy to another. This is a tool or a kit which can go away with fear in their lives and destroy the fear and know how to overcome the fear.

Data from KI (counsellor) indicated as follow:

“With Counselling in HIV amongst spouse helps in promoting the program to prevent mother to child transmission that we can get children who are HIV free and have generation that is HIV free.”

Counselling plays a vital role in spouses living with HIV and AIDS. Most couples who are HIV positive don't even want to give birth since some are not aware that HIV/AIDS parents can give birth to a HIV negative baby.If couples are well counselled and educated on mother to childtransmission. Also counselling helps in promoting the programs to prevent mother child transmission and this has given chance to those who are victims to get the exact number of children they want to attain their life dreams without any fear that they will infect their children.

The study find out in regard to counselling it is true that the impact of HIV/AIDS in the relationships of the infected persons, family, and significant others on the responses and adaptation of the infected person to the virus, is often overlooked. Unfortunately in the area of HIV counselling, therapists have often found that people's belief are often a major block to their adjustment. A common example of the way a person's belief inhibit their adjustment is their

reactions to an HIV positive diagnosis. Data from FGD expressed the same on counselling and beliefs of people inhibit their adjustment toward HIV positive diagnosis.

Data from FGD (a man) said:

“This can’t be true it can’t be me, look unless I got it from the Bible, I am a pastor, look at my wife she is faithful and she was the first woman I had in bed, what are you telling us.”

There are many cults and sects in slums which in most cases practices funny religions with funny beliefs. Majority of people only know that HIV/AIDS are only transmitted through sex intercourse not knowing that there are other means of transmission. These people in these cults and sects it’s difficult to make them understand that they are victims. They even don’t want to go for testing and to be counselled and this leads to having multiple infections in society and high rate of HIV spread.

The study found out that prevalent view of the community is that “HIV positive” equals “AIDS” equals “imminent death”. This belief is often held by those diagnosed with HIV, and their families, and often results in an emotional paralysis and inability to make plans for the future. It is only when these beliefs are challenged and start to change that they begin living with HIV and rebuild a future self. This will only happen if the counsellor has a good relationship with the client in the counselling session. A non- blaming, respectful counselling model which seeks to empower clients to feel in control of their lives and futures may assist people living with HIV/AIDS to live more meaningful lives in general, and with their significant others.

Most of respondents especially those who had not disclosed said there was inadequate knowledge on disclosure and they feel that this had not been addressed adequately by counsellors. Counselling is a key requirement for successful disclosure process and eventually to adherence to ARTS.

CHAPTER FIVE: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This Chapter discusses the study's findings and draws conclusions and recommendations based on the research objectives. This study aimed to explore the barriers and opportunities of disclosure of HIV/AIDS amongst spouses of Korogocho settlement scheme of Nairobi County

5.2 Summary of the findings

This study found out that there are a variety of pains connected to HIV/Aids: physical problems from opportunistic infections/ illnesses. emotional pain, especially for faithful partners learning about their HIV positive status, when they least expect and emotional pain when no body seems to understand them. This was expressed by all the respondents in the study as seen in findings. They all attributed the pain to circumstances under which the test was undertaken. This was fuelled by the initial response regarding disclosure from testing spouses.

Loss, shock, and denial was expressed by respondents on diagnosis from the findings. Kubar (1987) states that one undergoes a mourning process and it is only adjustments that can help them come to terms, and one may start shifting from denial, isolation, anger, bargaining, depression, acceptance and loping. This is where the FGD respondents who had disclosed described themselves to be. Others may never recover from these losses and so they do not move through these stages. This perfectly represented the in – depth interview with respondents who had not disclosed their HIV for none of them was willing to make an effort to move. Shock and disbelief on learning of infection was the common denominator among the respondents. But to

my surprise, one of the respondents said he did not experience these he acknowledged his earlier promiscuous life style. All the respondents reported were wounded through these experiences.

In regard to barriers, Stigma and discrimination was found to be the key constraining factor to all respondents. Most treatment program including MSF-Belgium try to reduce stigma by encouraging disclosure to at least one member of the family such as treatment support but they still find it hard. Respondents from FGD said that while it's not easy to disclose their HIV status to community members they do not know well, it is very easy to do so among other PLWHAs. They generated many comments about stigma discover and disclosure. Stigma and discrimination apparently cuts across all the interactions in life. According to testimonies of respondents, stigma remains a major problem. Moreover, disclosure and stigma seem to be different sides of the same coin. On one hand, disclosure may cost the individual their job, social support and their family. On the other hand a substantial number of respondents especially those who had disclosed were receiving support from family members. Although disclosure can have both negative and positive effects it was more generally linked to better and more positive living.

Gender inequality and violence are critical barrier factors in spreading HIV/AIDS. All female respondents who had not disclosed mentioned fear of violence. Respondents mentioned that violence manifested through sexual abuse, assaults, abandonment, rejection on disclosure and even physical assault. In the context of gender equality male attitudes and behaviours appear to be the centre of HIV/AIDS problems.

Results from nineteen respondents interviewed showed that there was a strong linkage between poverty, illiteracy and HIV status disclosure. Due to fear of being abandoned together with the children by their partner, most respondents resorted or vowed never to disclose their status to the spouses as expressed in the findings. This exposed them more to re-infection and non-adherences. There was a linkage between non-disclosure and non-adherence to medication. This is because manifestation of poverty is enhanced by women's disadvantages in terms of access to resources, liabilities, and lack of upwards mobility among others.

Most of respondents especially those who had not disclosed said there was inadequate knowledge on disclosure and they felt that this had not been addressed adequately by counsellors. Counselling is a key requirement for successful disclosure process and eventually to adherence to ARTS. However, it was indicated that there was intensive counselling during testing after which there was very little counselling unless they had particular problems. Yet it is well recognized by Horne and others that disclosure and adherence rate decline with time (Horne et al 2001). If a patient has not disclosed then, the counsellor would suggest approaches to disclosing. But again to whose benefit is disclosure? Since from the findings it's true that there is more risk in disclosing the status to partners than not disclosing at all. One female respondent reported to have been abandoned, rejected or physically assaulted on disclosing. It was also evident that counsellors needed to be equipped more in disclosure issues.

The study also found out that to have successful disclosure of HIV status programme depends on certain level of knowledge and awareness among PLWHAs and ARV users. However this study

found a wide variation in the level of knowledge among respondents about HIV/AIDS and disclosure. While knowledge about HIV/AIDS is generally good, beliefs and misconceptions that people have been bewitched, had a spell cast, or been afflicted by an AIDS devil or HIV/AIDS belongs to prostitutes as indicated in findings are commonplace and inhibit disclosure among spouses. Most respondents expressed that myths and misconceptions and communication barrier from the spouse as a hindrance to disclosure. Greater efforts are needed to educate both the community and PLWHAs about HIV in an effort to dispel beliefs about witchcraft.

The Role of counselling was found to be a motivating factor for disclosure: When the FGD group that had disclosed were asked about what facilitated the disclosure, and what kind of support that the respondents who had not disclosed their status would need, all those who had disclosed echoed counselling as a support for their life up to date. On the other hand, those who had not disclosed expressed the need for counsellor-client support in disclosure. The effectiveness of the counselling process was highlighted by some respondents who stated that even though they experienced challenges in disclosure they knew the importance of it, but were overcome by fear.

The study pointed out that the Commitment to significant others was also a motivating factor. The desire to stay alive can be greatly reinforced by the recognition that your loved ones might not cope after your death. All respondents showed great concern about their children and aged parents. The desire to continue to be around them was found to be a critical motivator / opportunity for most of them to disclose their HIV status. This coupled with concern for partners health was the major reason for disclosing to family and spouses. Most respondents said to have disclosed so that they avoid infecting partners and adhering to medication. Whereas seeking

social support was a primary reason for disclosure to family, friends, and medical providers, the past personal experience of HIV in the family was a motivating factor to most respondents and they felt need to protect others from re-infection.

In regard to community involvement and education, all the FGD respondents reported that what helped them to disclose was education and awareness they got from counselling and through the Post Test Clubs (PTCs) they were involved in. This gave them an opportunity to go for outreach programmes, to create awareness among community members. This involvement was then a factor that motivated them to disclose. On the other hand, the respondents who had not disclosed cried for help in issues of disclosure. They expressed that they need to be prepared properly for disclosure either through education, trainings or counselling as much as they desired to disclose to their spouses.

The study established the Severity of the disease as a facilitating factor for disclosure. It was associated with disclosure to partners, family and friends among respondents who had not disclosed. The respondents who had not disclosed, confessed that they will wait until the spouse was sick and weakened by the disease so that they would be safe from violence. Female respondents mostly expressed this hence this relates to Gender based violence. On the same note, as the symptoms of the disease become more pronounced, HIV infected individual were more likely to share their status with others.

Most of the respondents especially those who had disclosed attributed it to the time factor. Among all the respondents, none had disclosed before 6 months of diagnosis. They all said that time was the best healer. On the other hand, respondents who had not disclosed at all said they needed more time to deal with some unfinished businesses then they would disclose. The researcher found this quite interesting, given that some respondents had lived with their partner for over ten years and had not been able to disclose.

It was also established from the study that most respondents from the undisclosed group expressed their desire to disclose to their partners; however they said they were helpless for they did not know how to go about it. They said that the only way out was to get the partner tested through some assistance of collusion with counsellor or health care workers. This is an ethical and professional suicide yet at the same time, it's in the client's interest that the counsellor needs to care about.

In regard to the outcome of disclosure, Social support was seen as a result. Social support is based on the kind of relationship and interactions that offer individuals an atmosphere of attachment. Generally most respondents who had disclosed agreed that after disclosure, there was availability of social support, which was critical. For those in stable relationships, the availability of social support from the partners depended on whether that partner had been tested and accepted his/her status. This stemmed from the fact that without disclosure it was difficult to use medication in the presence of other people in view of the complexity of the medication

schedules. It is difficult to have the privacy that would keep people from noticing regular medication use.

However some respondents also perceived that disclosure carried a number of risks such as, emotional injury, loss of intimate relationships and job loss. The husband abandoned one of the respondents after disclosure. It was generally believed that without disclosure the level of social support would not be adequate.

In regard to Strengthening of relationship, all respondents agreed that disclosure caused closeness to their spouses and family members or others in the social network. This leads to acceptance, kindness, decreased anxiety and feelings of relief from both parties especially for the disclosing partners. Out of the seven respondents who had disclosed, only one was abandoned on disclosing her HIV status to her spouse as a negative outcome. Disclosure was also reported to have led to the increased HIV preventive behaviours including condoms use. Having the partners accept to take a HIV test, and reduction of infections and re-infections among other spouses.

Concerning the experience of counselling, all the respondents reported that HIV counselling was a crucial point in tackling barriers of disclosure. Counselling was experienced as enhancing relationships among partners; they mentioned that it addresses fears and a tool for accepting and coping with HIV status. It was also concluded that counselling was a source of hope for all the respondents, as it makes disclosure and adherence to medication possible and promotes PMTCT. However, some respondents from the undisclosed group felt that there was inadequate support from Researchers when it came to issues of disclosure and hence needed more support from the Researchers.

5.3 Conclusion

Experiences of HIV status disclosure among spouses are painful and need urgent redress. Gender inequalities exist everywhere in all spheres of their life. Stigma, discrimination, disempowerment and poverty cripple and affect their coping mechanisms. Those interviewed felt the need of unconditional acceptance and support from the entire community, health care providers for them to be able to curb the barriers to disclosure and explore more into the opportunities for disclosure. It was concluded that counselling is an important point of contact that can be used to address barriers to HIV status disclosure. However, it was revealed that there is need for improvements in the level of and type of counselling offered when providing test results.

5.4 Recommendations

1. Counselling strategies need to be culturally appropriate to the target audience hence there is need for counsellor / Client initiated disclosers
2. Ongoing counselling and HIV support groups (PTCs) may present a key opportunity for discussing fears and concerns around disclosure as well as sharing disclosure strategies amongst peers.
3. Community- based programs are needed to reduce stigma associated with HIV/AIDS
4. Social support for example through support groups or ongoing counselling may help HIV-infected individuals to overcome the barriers to disclosure.
5. Promotion of couple counselling is an important step to facilitate positive outcomes and minimize negative outcomes.
6. More research is needed to identify factors associated with negative outcomes of disclosure in order to develop better screening tools for counsellors.

5.5 Future Research direction

- An investigation into the effects of lack of HIV status disclosure on ARV's adherence among couples on ART in informal settlements.

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