

**DISCLOSURE OF HIV STATUS TO SEXUAL PARTNERS  
AMONGST PEOPLE WHO RECEIVE ANTIRETROVIRAL  
TREATMENT IN KAMPALA, UGANDA.**

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## **KEY WORDS**

Disclosure

HIV status

Sero-status

HIV prevention

Discordance

Sexual partners



## **ABBREVIATIONS AND ACRONYMS**

- AIDS** - Acquired Immune Deficiency Syndrome
- ART** - Antiretroviral therapy
- CDC** -Centres for Disease control and Prevention
- FGD** - Focus Group Discussion
- HBAC**- Home based AIDS Care
- HBHCT** - Home based HIV counselling and testing
- HCT**- HIV counselling and testing
- HIV** - Human Immunodeficiency Virus
- IEC**- Information, Education and Communication
- MTCT**- Mother-to-child Transmission
- MIS**- Management Information System
- PLHIV**- People living with HIV
- PMTCT**-Prevention of Mother to Child Transmission
- STIs** -Sexually transmitted infections
- TASO** - The AIDS Support Organisation (Uganda)
- VCT** - Voluntary Counselling and Testing

## Abstract

The increased number of new infections in Uganda necessitates HIV prevention programmes that address risky behaviours especially among heterosexual populations. The AIDS Support Organisation (TASO) is the largest indigenous HIV/AIDS agency serving Uganda and the Great Lakes Region. TASO endeavours to empower sexually active clients to disclose their sero-status to their sexual partners and promotes partner testing for HIV. In spite of these efforts, only 12% of 2,071 sexually active clients in Mulago centre had disclosed by the end of 2006.

This study aimed to explore the factors that influence clients' decisions to disclose their HIV status to their partners in TASO Mulago, Kampala, Uganda.

The study used a qualitative approach. Fourteen (14) in-depth interviews were conducted with English and Luganda speaking adult male and female clients on antiretroviral treatment (ART), in TASO Mulago. A focus group discussion (FGD) was conducted with 8 purposively selected ART clients who were considered to be 'expert' clients in TASO Mulago. These participants were expert clients/ peer educators, who were open about their HIV status and have been involved in HIV/AIDS education and advocacy. The individual interviews and the focus group discussion were transcribed verbatim, and subjected to thematic and content analysis.

Male and female participants who were married (primary relationship) disclosed their sero-status to their sexual partners, while few of those cohabiting or in steady relationship (only one) disclosed to their partners. Enabling factors to disclose to current sexual partners included: desire for partner to get treatment, need for the partner's support, having prior knowledge of partner's HIV status, out of anger, and having anxiety about the future. Some of the barriers to disclosure included: fear of blame and disappointing the partner, fear of abandonment, fear of stigma and discrimination.

Participants suggested that couple counselling and testing, economic independence, peer support and involvement of the TASO staff in disclosure should be considered to facilitate or promote disclosure to sexual partners.

While strategies like HBHCT and couple counselling have enhanced disclosure among sexual partners on ART living together in stable married relationships (primary), the partners in secondary relationships (cohabiting and steady) especially women, continue to face challenges in disclosure yet their sexual partners are at risk of HIV infectio

The study has re-affirmed the fact that while some people living with HIV/AIDS wish to disclose their HIV status to their partners, there are compound factors that make it difficult to disclose. This calls for effective strategies by government, TASO and other agencies to ensure that sexual partners especially in cohabiting and steady relationships are disclosed to in order to reduce their vulnerability to HIV infection.



## DECLARATION

I declare that **DISCLOSURE OF HIV STATUS TO SEXUAL PARTNERS AMONGST PEOPLE WHO RECEIVE ANTIRETROVIRAL TREATMENT IN KAMPALA, UGANDA** is my own work, that it has not been submitted for any degree or examination in any university and that all sources I have used or quoted have been indicated and acknowledged by complete references.

Signed by: \_\_\_\_\_

Tina Achilla

This \_\_\_\_\_ date of \_\_\_\_\_ 2010

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# CHAPTER ONE: INTRODUCTION

## 1.1 Global HIV/AIDS Pandemic

HIV/AIDS is an unprecedented pandemic and a public health emergency. Nearly 25 million people world-wide have died of HIV/AIDS since 1981 when the first case was recorded and the epidemic is still growing to be the biggest challenge to public health (United Nations Program on HIV/AIDS [UNAIDS], 2005). In 2008, 33.4 million people were living with HIV/AIDS worldwide (UNAIDS, 2009). 2.7 million people were found to be newly infected with HIV in 2008 alone,; 85% of whom were in the reproductive age and a total of 2.0 million died due to HIV related illnesses (UNAIDS, 2009). Sub-Saharan Africa remains the region most heavily affected by HIV, accounting for 67% of all people living with HIV and for 75% of AIDS deaths in 2007. (UNAIDS, 2008).

## 1.2 HIV/AIDS Epidemic in Uganda

In Uganda, HIV/AIDS is the leading cause of death among adults and the fourth highest cause of death among children under five years (Uganda AIDS Commission [UAC], 2006; UNAIDS, 2006). UNAIDS (2008) estimates that 940,000 people were living with HIV in Uganda as of December 2007. The 2004-05 Uganda HIV Sero-behavioural Survey [UHSBS] (Ministry of Health [MoH] & Opinion research Corporation [ORC] Macro, 2006) report an overall national HIV sero-prevalence rate of 6.4% among men and women aged 15-49 years. HIV incidence (new infections) reportedly increased from 70,000 in 2002 to 132,500 in 2005. The survey reveals that 42% of these new infections occurred within heterosexual stable relationships which accounts for 75-80% of all new infections while mother to child HIV transmission accounts for 15-25% (UAC, 2006). Although the decline in prevalence in the country has been attributed to behaviour change, evidence of such change has been uneven with researchers observing no significant increase in abstinence and fidelity (Opio, Mishra & Hong, 2008). Multiple partners, low condom use, high rates of discordance, lack of HIV sero-status disclosure to

partners, behavioural dis-inhibition due to ART and inadequate HIV information were associated with higher risk for new infections (Wabwire-Mangen, 2008).

### 1.3 Prevention of HIV Transmission

Disclosure of one's HIV status to sexual partners is essential in stopping the spread of HIV infection (Kalichman & Nachimson, 1999). Over 20 states have enacted laws making it a criminal offence for an HIV-infected individual to fail to reveal to a sex partner that he or she is HIV-infected (Lisko, 1998). Still, many HIV-infected individuals do not disclose to all their sex partners. Previous research on disclosure to past or current sex partners demonstrates that between one-fourth and one-half of those with HIV have not told their sex partners (Stein, 1998; Kalichman & Nachimson, 1999). HIV transmissions occur in the context of mutual unawareness of partner's HIV status. Anonymous surveys conducted in Cape Town, S Africa found that 42% of the participants reported a number of sex partners they had in the previous 3 months to whom they did not disclose their HIV status (Simbayi, Kalichman, Strebel, Cloete, Henda & Nqeketo, 2006). Furthermore, studies in developed and developing countries have revealed that sexual partners of HIV infected persons continue to be at a high risk of HIV transmission as a result of non-disclosure to partners (Masiye & Ssekubugu, 2008).

In sub-Saharan Africa, 59% of HIV infected adults in 2006 were women who had contracted HIV through sexual transmission from a regular partner (Tabi & Frimpong, 2003). Sexual relations with regular partners are rarely protected because they are perceived as risk-free (UNAIDS & WHO, 2006; Bauni & Obonyo, 2003). The only way to avoid the risk of HIV transmission to regular sexual partners in such populations with a high HIV prevalence is for each partner to take an HIV test and exchange/share information on each other's serostatus (Brou, Djohan, Becquet, Allou, Ekouevi, VihoLeroy & Desgreess-du-Lou, 2007). Notably, the issue of disclosure of HIV results to sexual partners remains a big challenge.

According to the Uganda National Strategic Framework for HIV/AIDS (2000), the rationale for the voluntary counselling and testing (VCT) strategy is to reduce the rate of

infection and to encourage safer sex practices. The exchange of information about one's HIV status with a partner (disclosure) is associated with safer sexual practices (Larkins, Shoptaw & Veniegas, 2005). The prevention of sexual transmission of HIV within couples involves HIV testing for each member and consistent use of condoms. This is the intervention if one of the members is HIV positive or until both members have been tested HIV negative and have adopted safe sex practices. Research exploring how the risk of sexual transmission is managed within couples in Uganda shows that these simple principles are rarely implemented. The 2004-2005 Uganda sero-behavioural survey (MOH & ORC Macro, 2006) shows high risk behaviour among couples, low uptake of HIV testing, low levels of disclosure, increased casual sex high levels of discordance and low condom use. The survey found that 88% of men and 56% of women have concurrent multiple sexual partners; it found an increase in sex with casual partners and decreased use of condoms by men with these partners. Prevention of HIV transmission to sex partners requires consistent condom use. For proper and consistent condom use particularly among discordant sexual partners, disclosure of sero-status to sexual partners is paramount.

Notably, men play a major role in decision making regarding women's reproductive health, health education, HIV counselling and testing and women's access to treatment. Programmes for women alone cannot reduce the rate of HIV infection because of their inability to make critical decisions like using condoms, HIV testing, drug taking and access to other prevention services (UNAIDS, 1999). Emphasis should be laid on involving men in HIV prevention because they influence women's access to health services through control of finances and decisions (Greene, 2002). Moreover, the survey found that in 8.1 % of co-habiting couples in Uganda one or both are HIV positive and 57% of HIV positive individuals in a partnership have an HIV negative spouse (MoH & ORC Macro, 2006).

Positive prevention efforts should focus on ensuring that HIV infected individuals and couples mutually disclose their status (King, Lifshay, Nakayiwa, Kantuntu, Lindkvist & Bunnell, 2008). Disclosing HIV results to one's sexual partner allows the couple to

engage in preventive behaviours as well as access the necessary support for coping with their HIV status.

In response to the Uganda sero-behavioral survey findings, the UAC undertook a review of the drivers of the HIV epidemic in Uganda and subsequently guided the process of outlining the Roadmap to accelerated HIV prevention in August 2006

#### 1.4 Antiretroviral Therapy and Risky sexual behaviour

Antiretroviral therapy (ART) (sometimes called highly active antiretroviral therapy or HAART) is treatment with drugs that inhibit multiplication of HIV in the body and gradually improves the quality of life of the patients (Webster, 2000). HAART typically combines three or more antiretroviral drugs that work together to keep HIV from multiplying (Mocroft & Lundgren, 2004). The goal of the treatment is to reduce HIV related morbidity, improve quality of life, restore and preserve immunologic function of life and maximally suppress viral load. ART roll-out was initiated in Uganda in 2004. The impact of ART has often elicited biblical analogies of Lazarus story as clients thought to be nearly dying have “picked up” and made remarkable health recoveries (Russell, Seeley, Ezati, Wamai, Were & Bunnell, 2007). Many HIV infected persons are now living longer as a result of ART in decreasing morbidity and mortality from the disease. However reduction in protective and preventive behaviour among HIV positive people once their physical conditions improve in response to ART raises concern (UAC, 2007, Crepaz & Marks, 2002). Successful therapy demands strict adherence to the prescribed ART regimens which entails disclosure of serostatus in order to enlist adherence support. Poor adherence to HIV treatment on the other hand can result in the development of drug resistant strains of HIV. It is possible that people living with HIV who do not adhere to treatment may transmit drug resistant virus to their sexual partners. A study conducted among positive men and women in Atlanta, Georgia that examined association between HIV treatment adherence and sexual risk behaviour, revealed that people who had not been adhering to treatment reported more sex partners and other high risk behaviours than those who adhered (Kalichan & Rompa, 2003). Strategies that target adherence to treatment and sexual risk behaviour change among people living with HIV

on ART therefore need to be prioritized. A study in South Africa (Eisele, Mathews, Chopra, Lurie, Brown, Dewing & Kendall, 2008) found that not disclosing one's HIV status to a sexual partner increased the risk of having unprotected sex among both men and women after their first year of ART. Currently in Uganda, the fear is that the availability of ART for patients with advanced HIV disease may lead to a false sense of security, laxity and complacency among individuals and communities, which could result in new HIV infections thus high costs in HIV prevention (UAC, 2007). Furthermore, Gray, Gange, Serwadda and Sewankambo (2003) assert that the current gains in prevention could be threatened by increased risk behaviour associated with widespread of ART.

The government policy of openness and political commitment to HIV/AIDS control has created high levels of awareness in the population about the dangers of the epidemic and possible means of prevention (UAC, 2006). Government policies promote HIV testing, access to treatment for people living with HIV and safer sex practices. Disclosure of HIV status in this context is important because it enables the sexual partners to be included in the decision making process as far as safe sex behaviour is concerned as well as receiving appropriate support towards ART adherence.

### 1.5 Study Setting

This study was conducted amongst clients of The AIDS Support Organisation (TASO) who are on ART. TASO is a non-governmental organization founded in 1987 by a group of 16 volunteers who were either HIV positive or had their family members or friends living with HIV. TASO is the largest HIV/AIDS agency serving Uganda and the Great Lakes Region. TASO's mission is to contribute to the process of HIV prevention, restoring hope and improve the quality of life of individuals and families affected by HIV/AIDS. TASO fills a counselling, care and support gap that has been largely neglected in the health service delivery and has become critical with the HIV/AIDS epidemic and the increase in psychosocial needs in the health sector. People diagnosed with HIV by various HIV counselling and testing (HCT) providers are referred to TASO to get registered as TASO clients. TASO provides free HIV counselling, treatment of

opportunistic infections and ART, in addition to food support to over 80,000 people living with HIV/AIDS (TASO clients) and education support to the clients' children in 11 TASO service centres across the country. TASO Uganda provides ART to 20,000 of the 90,000 patients, nation-wide (TASO, 2008). TASO ART programme is a subcomponent of the national ART scale-up.

TASO's counselling service is provided to individuals, couples and groups; home-based counselling for clients' families is also offered. TASO's counselling empowers individuals and couples to make informed decisions and to; accept diagnosis, seek medical care and adhere to treatment, access counselling, take responsibility to prevent HIV transmission to others by disclosing serostatus to partners, using of condoms, family planning and PMTCT which are some of the aspects of positive living. TASO provides sexuality counselling to clients including discordant couples, and its emphasis on sexuality issues faced by HIV-positive people (clients) shows its understanding of the importance of and need to address sexuality in the context of HIV prevention. TASO's couple counselling aims at strengthening couples' relationships and promote mutual understanding as well as promote behaviour change strategies amongst sexual partners. Clients' reports in TASO reveal that couple counselling is vital in terms of drug adherence, risk reduction, facilitating disclosure, countering stigma and is key to positive living.

TASO Mulago in Kampala has been in operation since the beginning of the organization. By the end of 2007 the centre had provided services to over 34450 cumulative (20254 female & 10043 male). HIV positive clients from seven surrounding districts. Kampala District hosts 57% of the clients; Wakiso has 19%, Mukono 11% and the rest of the other districts only 13%. (TASO, 2008). Of the registered clients at TASO Mulago 2,104 were receiving ART by end of 2007 (TASO, 2008). The numbers of clients on ART increase each year (Table 1). When TASO clients were enrolled on ART, their health improved and many became sexually active and had increased desire to give birth to children. Table 2 shows changes in sexual behaviour among 992 TASO clients in Tororo six months after commencing ART, with significant increase in sexual desire among male and

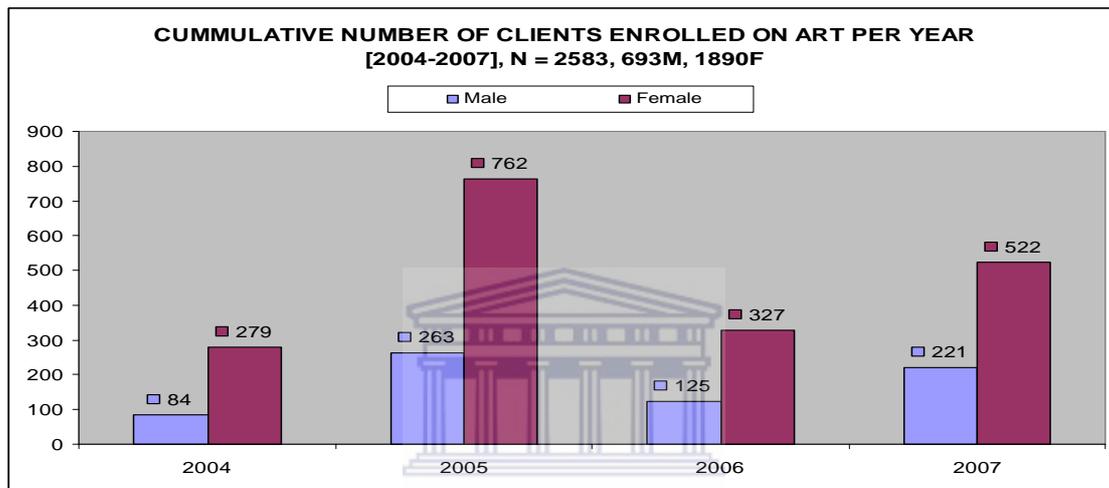
female clients due to ART. Despite the apparent changes, many clients are not yet open about their resumption of sexual activity and intention to conceive. Prevention of infection and re-infection is one of the most aspects addressed during counselling in TASO. Emphasis is placed on safe sex through condom use, avoiding multiple partners, discordance, disclosure, treatment of STIs, and family planning.

Counselling of TASO clients on ART includes providing information on the advantages and disadvantages of having sex with HIV positive or HIV negative partners and the most likely outcomes of their choices that include possibility of contracting other strains of HIV and STIs and development of resistance by a partner who is not taking ARVs. TASO therefore emphasizes the importance of clients disclosing their sero-status to their primary and secondary sexual partners. Disclosure in TASO entails clients being counselled on benefits of disclosure and making plans on who to disclose to, how and when. Counsellors may support clients who find difficulties, to disclose their sero-status to sexual partners as an essential component of behavioural risk reduction plans. Table 3 shows the number of sessions conducted during the 4<sup>th</sup> quarter, 2008 and areas focused on during the counselling such as adherence to ART, disclosure, discordance, family planning and other aspects. Furthermore, the organization introduced home-based counselling and testing (HBHCT) for family members of clients as an effort to increase awareness of HIV status among clients' partners and to improve disclosure of HIV sero-status (TASO, 2006).

As a strategy to promote adherence, partner disclosure is a prerequisite to enrolment on ART. If individuals require support to disclose, counsellors are usually available to help them. In spite of these efforts made by the organization, only 12% of 2,071 sexually active clients in Mulago centre had disclosed by the end of 2006. Moreover, in 2006, 222 out of the 2071 sexually active clients reported a pregnancy (TASO, 2007). Non disclosure before conception may increase the chances of mother-to-child HIV transmission if the mother does not get advice on how to reduce the risk. In addition, the 2006 report showed evidence of high discordance rate to be 60% among TASO sexually active clients whose partners were tested during HBHCT visits. By October 2006,

Mulago centre had registered 270 discordant couples. While there is no guarantee that disclosure will result in safer sex or that a failure to disclose will result in unprotected sex (Crepaz & Marks, 2002) disclosure of serostatus in this context is important so that partners can make informed decisions about their sexual activities.

**Table 1.TASO Mulago: Cumulative Number of Clients enrolled on ART from 2004 to 2007**



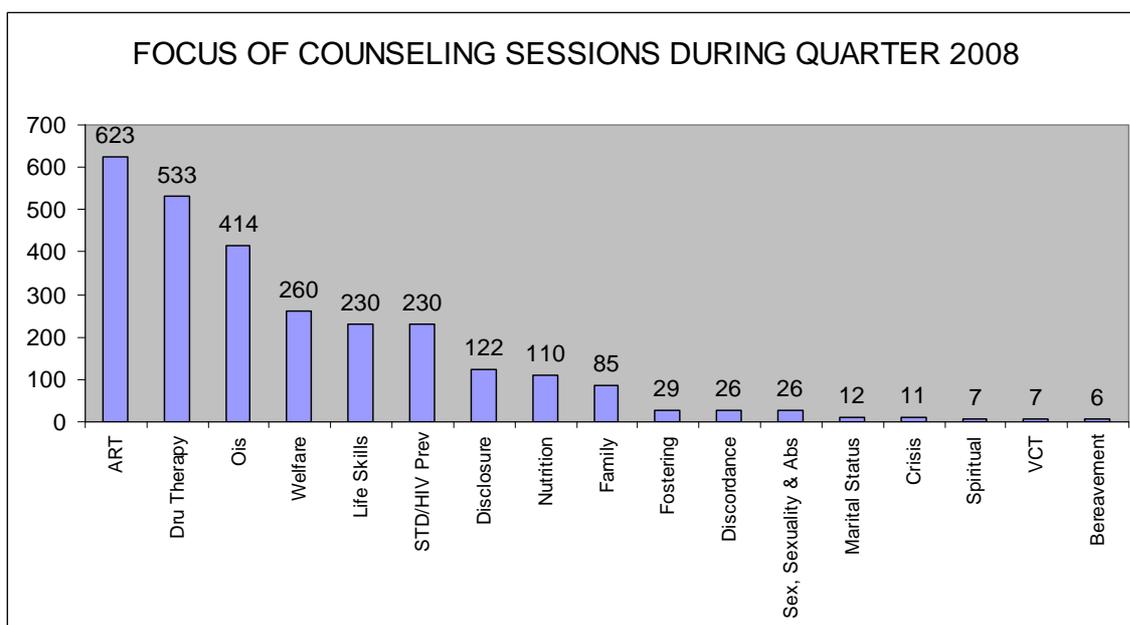
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**Table 2. Sexual Behaviour among clients on ART in TASO Tororo**  
**(Bunnell, Ekwaru, Solberg, Wamai, Bikaako-Kajura & Were, 2006).**

|                        | Baseline | 6 Months | P- value |
|------------------------|----------|----------|----------|
| <b>Men:</b>            |          |          |          |
| <b>Sexually Active</b> | 47%      | 53%      | 0.2      |
| <b>Unprotected sex</b> | 21%      | 11%      | 0.004    |
| <b>Sexual desire</b>   | 2%       | 38%      | <0.0001  |
| <b>Women:</b>          |          |          |          |
| <b>Sexually Active</b> | 21%      | 24%      | 0.18     |
| <b>Unprotected Sex</b> | 9%       | 6%       | 0.01     |
| <b>Sexual desire</b>   | 1%       | 14%      | <0.0001  |

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**Table 3: Focus of Counselling Sessions in TASO Mulago, 4<sup>th</sup> Quarter 2008**



## 1.6 Problem Statement

With the evidence of increased sexual activity and low disclosure among clients on ART, there is growing concern about likely increase in HIV (UAC, 2006). TASO management, staff and clients' representatives on the TASO governance structure have acknowledged the need for interventions to improve disclosure of sero-status to sexual partners. However, it is not clear what individual, social- cultural, service/environmental or socio-economically related factors drive inhibition to disclosure of sero-status among ART clients at TASO. There is need for an in-depth exploration of the processes people living with HIV use to make disclosure decisions to sexual partners and the factors that promote or hinder disclosure of sero status to the sexual partners. It is therefore important to explore the context that influences decisions regarding HIV disclosure to the sexual partners among TASO Mulago clients on ART. This might avail more information that might provide a deep understanding of the situation within TASO and inform management in policy development as well as guide the counsellors and other health service providers in the development of interventions addressing sexual health among TASO clients on ART in relation to HIV disclosure to sexual partners.

## 1.7 Study Aim and Objectives

The aim of the study was to explore and describe disclosure of HIV status to sexual partners among HIV positive persons receiving ART at TASO Mulago, in Kampala, Uganda.

### **Specific objectives of the study were:**

- 1) To describe disclosure behaviour among clients on ART in TASO Mulago.
- 2) To explore enabling factors for disclosure among ART clients.
- 3) To explore barriers to disclosure among ART clients.
- 4) To make recommendations for interventions to improve disclosure behaviour to sexual partners among TASO Mulago ART client

## CHAPTER TWO: LITERATURE REVIEW

### 2.0 Introduction

This chapter reviewed related literature of previous research on self-disclosure and disclosure to sexual partners. It contains sections on; definition and contextualisation of disclosure, benefits of HIV status disclosure, content of disclosure, process of disclosure, facilitators of disclosure and barriers to disclosure

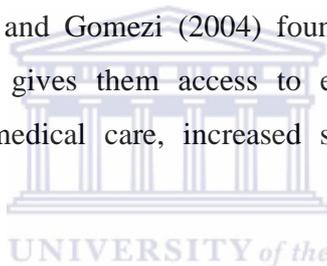
### 2.1 Definition and conceptualization of disclosure

Self-disclosure is defined as the willingness to reveal information about oneself to another person as the “target person” (Hinson, & Swanson, 1993). Self disclosure is also the act of informing another person or persons of the HIV positive status of an individual (Hoe, McKeown, Stoltz & Trow, 2003). It occurs in a context whereby HIV testing and counseling remains confidential and infected individuals are given the responsibility of disclosing the test results to their sexual and needle sharing partners (Perry, 1998). Thus disclosure of HIV positive sero status means that an HIV positive person reveals his or her status to another person, usually of significance to him/her such as a sexual partner, relative and friend (Maman, Mbwambo, Hogan, Weiss, Kilonzo & Sweat, 2003). Learning that one is HIV infected creates an internal struggle about whether or not to disclose one’s HIV positive sero-status (Marks, Richardson, Ruiz & Maldonado, 1992). Health workers and counselors encourage their clients to disclose their HIV test results to their sexual partners on their own accord (Masiye, & Ssekubugu, 2008). The decision to disclose one’s status is a difficult one. Kimberly, Serovich and Greene (1995) found that people with HIV are left open to stigma and discrimination and are put at risk of loss of employment and other social support benefits if they disclose. Disclosure of serostatus is one of the major aspects focused on in TASO’s counselling to enhance drug adherence and promote HIV prevention among sexual partners, this study aims at exploring disclosure to sexual partners among clients on ART in TASO Mulago.

## 2.2 Benefits of HIV Status Disclosure

Self-disclosure of sensitive information is generally thought to have positive effects on an individual's health by reducing stress that is associated with having HIV and the fear of others learning about it; thus leads to improved psychological health (Collins & Miller, 1994; Pennebaker, Colder, & Sharp, 1990). There has to be a certain level of disclosure for one to access AIDS-related health care and support. Pennebaker *et al.* (1990) further affirm that HIV-infected individuals who disclose their sero-status have better immune functions and make fewer visits to the clinician. This is because disclosure facilitates increased self-worth and provides emotional release through revealing information that requires substantial effort to conceal; all of which contribute to improved health.

Parsons, Van Ora, Mescaline and Gomezi (2004) found that disclosure among HIV-positive injection drug users gives them access to emotional, physical and social resources such as housing, medical care, increased social support, acceptance and intimacy with sexual partners.



Disclosure may also lead to improved access to prevention and treatment programs. This increases opportunities to improve HIV management, plan for awareness of HIV risk to untested partners and can lead to greater uptake of voluntary counselling and testing (Kilewo, Massawe, Lyamuya, Semali, Kalokola & Urassa, 2001). Similar findings by USAID (2003), reported that pregnant women attending Prevention of Mother to Child Transmission (PMTCT) services often disclose to access treatment to prevent transmission of HIV to their infants.

Furthermore, disclosure enables sexual partners to make informed productive health choices that may ultimately lower the number of unintended pregnancies among HIV positive and discordant couples and even decrease the risk of vertical transmission of HIV to the unborn child (Maman *et al.*, 2003). Thus disclosure of HIV status to sexual partners is an important prevention intervention and may lead to increased opportunities for risk reduction, care and planning for the future (Maman & Medley, 2004). Studies

show that disclosure was often associated with less anxiety, fewer symptoms of depression and increased social support among women. In a community health advisory information network (CHAIN) survey among a sample of PLHIV in New York city , individuals who disclosed their results have better adherence to ART outcomes than those who did not disclose ( Wadell & Messeri, 2006).

### 2.3 Content of Disclosure

Describing the content of the disclosure is important. There is evidence of varied understanding of what is disclosed, as indicated in a cross-sectional study conducted in India (Chandra, Deepthivarma & Manjula, 2003). It was reported that even though 52% of the subjects chose to reveal the true nature of the illness, for 34% of the subjects disclosure was partial or disguised as a less stigmatising disease.

A qualitative study in Nairobi (Miller & Rubin, 2007) found that one participant had simply told his wife that the doctor had prescribed for him some type of medicine that required them to use a condom while another, simply told the wife that he was dying. On the other hand, a descriptive study in Southern USA found that 12.5% of the 265 women categorised under full disclosure were able to meet someone and at introduction disclose to the person that they are HIV positive or simply mention their names and say how they have AIDS and how they are not ashamed of the disease (Sowell, Seals, Phillips & Julious, 2003). Notably, a study amongst HIV positive gay men found that the sense of responsibility motivates people living with HIV to disclose while feeling shame for having HIV hinders disclosure (Serovich & Mosack, 2003).

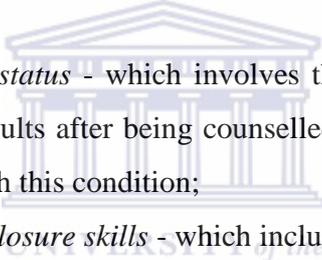
### 2.4 Process of Disclosure

The process of disclosure seems to vary depending on the context and gender. In a study conducted in a VCT clinic in Tanzania, it was found that for most men the process of disclosing their results to their sexual partners was not difficult and to some it was like having a normal conversation (Maman, Mbwambo, Hogan, Kilonzo & Sweat, 2001). Another study in Nairobi, Kenya however, found that some men spent time considering how to reveal the devastating news to their wives and used a variety of indirect

approaches including suggesting that they should both go for VCT, without revealing that they already knew their own sero-status while others still hesitated knowing that such news would be devastating to the partner (Miller & Rubin, 2007).

Disclosure should be viewed as a process and not a one-time event. This process involves a series of decisions that include when the individual may disclose, to whom, how to disclose and under what circumstances to disclose. Maman *et al.* (2001) suggest to counsellors that providing a one-time counselling may not suffice for some women that might need to weigh the consequences and rewards of disclosure as well as develop a disclosure plan.

Kimberly (1995) suggests a six-step process in decision making for disclosure that includes:

- 
- (i) *Acceptance of sero-status* - which involves the individual who has received the HIV positive results after being counselled adjusting to the diagnosis and accepting to live with this condition;
  - (ii) *Assessing one's disclosure skills* - which includes what one wants to tell based on how much one has learnt about HIV and their HIV status and how one will communicate this to the people they choose;
  - (iii) *Deciding whom to tell* - which involves assessing and making a decision whom one should disclose to at a particular time;
  - (iv) *Evaluating the recipient's circumstances*- this may include considering when to tell this person , where to tell them from and whether the persons are capable of handling disclosed information ;
  - (v) *Anticipating likely reactions* -which involves what the best is that one can hope for or the worst one would have to deal with; and
  - (vi) *Considering one's motivation for disclosure*- which enables one to reflect on why one wants to tell the people they are telling basing on what one expects from them.

The decision to disclose therefore is selective, and telling one's family is especially difficult (Kimberly *et al.*, 1995; Serovich *et al.*, 1998). In deciding whom to disclose to, the women applied criteria such as the relation to the person, whether the person is accommodating (quality of relationship) and whether the person is capable of maintaining confidentiality ( Sowell, Seals, Phillips & Julious, 2003).

There are three approaches to disclosure of HIV status to partners suggested in the "Prevention with Positives" program in San Francisco (Prevention with Positives Committee, 2005). These include:

- (i) *Self-disclosure* with service providers supporting through coaching. The client receives counselling after receiving HIV status results then the service provider /counsellor supports the client to draw a disclosure plan that includes who to tell, what and when to tell and how to tell. The client is given opportunity to rehearse this with the counsellor.
- (ii) *Dual disclosure*- where the person receives coaching and discloses to partner in presence of service provider as a mediator. After the client has received counselling and the disclosure plan made, the client will still prefer to disclose to the partner in the presence of the counsellor so that the latter can provide support by clarifying some issues or by easing tension and diffusing blame amongst the partners during disclosure.
- (iii) *Anonymous third party disclosure* -where the client can request the service provider to offer him and partner(s) counselling and testing. In this approach the client plans with the counsellor such that the client will come with partner/s and both receive counselling and testing such that the counsellor will provide the results to them irrespective of the client's knowledge.

According to Omarzu (2000), disclosure could be inherently rewarding and creates an obligation in the listener to return the favour. He further suggests that disclosures may be encouraged or influenced by the actions of others. Consistent with earlier findings, King *et al.* (2007) reported that several men and women who had not disclosed envisioned an assisted or supported disclosure process using TASO counsellors. Research further shows

that people selectively disclose in situations that offer an opportunity for rewards and little risk of harm or negative consequences (Parson *et al.*, 2004).

The findings above about the process and approaches to disclosure of serostatus amongst people who are HIV positive present a great opportunity to the counsellors generally and specifically in TASO to understand issues and the processes the clients go through as they contemplate disclosure and what they should work on as they receive support to develop their disclosure plans.

## 2.5 Facilitators of HIV Disclosure

The consequences theory of HIV disclosure suggests that persons with HIV are likely to disclose to significant others and sexual partners once the benefits for disclosing outweigh the costs involved (Serovich, 2001). Motivations regarding HIV disclosure have been divided into three categories (Derlega, Lovejoy & Winstead, 1998; Derlega, Winstead & Folk-Barron, 2000). These include:

- i) *Self focused* - this involves catharsis and seeking emotional support
- ii) *Others focused*- which involves educating others; the duty to inform others as well as combat stigma
- iii) *Relationship focused*- which involves having an emotionally close and supportive relationship with the person disclosed to.

Numerous factors have been associated with sero-status disclosure. Some of these factors include: knowledge of partner's status, duration of relationship, type of relationship, clinical stage of the disease, social support, ethical responsibility, gender, and prior discussion about HIV testing as described below:

### *Knowledge of partner's HIV status*

A cross sectional study conducted in Ethiopia found that the respondents who did not know the partner's HIV status were 98% less likely to disclose to the partner (Deribe, Woldermichael, Wondafrash, Haile & Amberbir, 2008). Furthermore, other studies have demonstrated (Marks, Richardson & Maldonado, 1991; Niccolai, King, D'entremont & Pritchett, 2006) that HIV infected individuals were more likely to disclose to a partner

whom they knew is HIV positive than to an HIV negative or partner with unknown sero-status. Simoni & Pantalone (2004) further suggest that HIV infected individuals are more likely to disclose and even have unsafe sex with a partner who they know is HIV positive because they feel less risk of rejection and less threat to the partner's health.

#### *Duration of relationship and type of partner*

A prospective study conducted among pregnant women in Tanzania revealed that women who had been in a relationship longer (approximately 2 years) were more likely to disclose than those in a relationship of shorter duration (Antelman, Smith, Kaaya, Mbwambo, Msamanga, Hunter & Fawzi, 2001). Furthermore, other studies found that younger women (below 24 years), women of lower social economic status, women who had been in relationships for a longer period of time were more likely to disclose to their sexual partners (Galliard, Meilis, Mwanyumba, Claeys, Mwigai, Mandalay & Simoni, 2002).

Disclosure also varies with type of partner; whether primary or casual sexual partners. Studies have observed that primary partners are more likely to disclose to their partners compared to casual partners (Green, 1994; Niccolai, Dorst, Myers & Kissinger, 1999). Consistent with earlier findings, a cross-sectional study measuring disclosure to sex partners found that disclosure occurred more frequently in primary heterosexual relationships than the casual partnerships (Niccolai, King, D'entremont & Pritchett, 2005). Notably, an inverse relationship between the number of partners one has and the likelihood of disclosure has been observed (Marks, Richardson & Maldonado, 1991). Moreover a qualitative study among methamphetamine dependent gay men revealed that HIV positive individuals reported that they felt a greater sense of responsibility to disclose to primary partners than casual (Larkins, Shoptaw & Veniegas, 2005).

The above studies suggest that disclosure varies with type of partner and duration of relationship.

### *Length of time after testing*

Women who knew their results for more than one year were more likely to disclose than those who had known for less than one year (Kassaye, Lingerh & Dejens, 2005). A study in Tanzania found that disclosure to sexual partners increased from 22% within two months of diagnosis to 41% after nearly four years (Antelman *et al.*, 2001). The study in Ethiopia (Deribe *et al.*, 2008) also found that although about 73% of the women disclosed their HIV status to their partners on the day they received their results, others took as long as two years before they disclosed. In another study, Mansergh, Marks and Simoni (1995) observed that there is a positive correlation between the length of time since diagnosis and the likelihood of disclosure. These studies show that the number of people who disclose increases with time.

### *Clinical stage of the disease*

Individuals in an early WHO clinical stage were less likely to disclose to a partner compared to those in advanced state of the disease (Deribe, *et al.*, 2008). Parsons, *et al.*, (2004) also found that individuals who had been living with HIV for longer periods of time and those with increased symptoms were more likely to disclose their HIV status. Deribe *et al.* (2008), Hays *et al.* (1993) and Marks *et al.* (1992) argued that delaying disclosure might be because individuals find that they require emotional or social support from family as the disease progresses or it might be that concealing their illness at a late stage becomes difficult. This implies that disclosure of one's HIV status as a result of deteriorating health especially to sexual partners could be detrimental to HIV prevention.

### *Level of Education*

Findings from a cross-sectional study among women living with HIV in South West Ethiopia (Kassaye, Lingerh & Dejens, 2005) showed that illiterate women were more likely to disclose their test results to sexual partners than educated women. However, this factor seems to vary depending on the context. A study in Burkina Faso found that women with higher education are more likely to disclose their HIV test result to their sexual partner than women who are illiterate (Issiaka, Cartoux, Ky-Zerbo, Tiendrebeogo, Meda, Dabis & Van de Perre, 2001).

### *Prior communication before HIV Testing*

In a study conducted in Ethiopia prior discussion with partners about HIV testing had a strong association with HIV sero-status disclosure (Kassaye, Lingerh & Dejens, 2005). Another study in Ethiopia (Deribe *et al.*, 2008) affirms this factor. In the last-mentioned study, about four times as many participants who reported having discussed with their partners before HIV testing, disclosed to their partners compared to those who reported having no prior discussion. A study in Tanzania (Maman *et al.*, 2003) revealed that the extent to which the partner was aware and involved in the testing experience strongly influenced the decision to disclose. In the same study more men than women were able to inform their partner before testing.

### *Social Support*

Individuals with social support tend to disclose their results more often than those without such support. Skogmar *et al.* (2006) observed that it is possible that patients' beliefs about their social network and treatment play an important role for disclosure. Perceived availability and accessibility of social support services for people living with HIV and AIDS, leads to self- disclosure. A study conducted by Simoni, Mason, Marks, Ruiz, Reed and Richardson (1995) found that seeking social support was the primary reason for disclosure to friends and family. Another study conducted in Uganda by King *et al.* (2007) found that the most frequently mentioned reason for disclosing among both men and women was access to medical or home care (social support). Research has established that sharing and discussing ideas with peers who are also HIV positive in an emotionally safe forum is critical to participants' own growth and development (Hyde, Appleby, Bailey & Morgan, 2005). In another study, (Petrak *et al.*, 2001) established significant relationships between overall rates of HIV disclosure with quality of life, mental health and satisfaction with social support. This satisfaction with social support showed a significant correlation with rate of HIV disclosure to friends but did not correlate with overall rate of HIV disclosure to family. TASO's experience indicates that

clients who are on antiretroviral therapy disclose to their family members in order to enlist their support as they receive the treatment as well as to extend the opportunity to any family member that needs to access HIV/AIDS services.

### *Ethical responsibility*

A study that focused on reasons for HIV disclosure or non-disclosure to casual sexual partners amongst gay men (Serovich & Mosack, 2003) found that men who disclosed to all their casual partners was because of the responsibility they felt to tell the partner and the person's right to know more than sense of educating others about the disease. Whereas this study focused on casual partners and amongst gay men, similar findings were found in other studies. For example in a study to determine the rates, reasons and reactions of women's self disclosure of HIV, Simoni, Mason, Marks, Ruiz, Reed and Richardson (1995) found out that ethical responsibility and concern for partner's health was a major reason cited for disclosing to sexual partners. On the other hand, the same study found that seeking social support was the primary reason for disclosure to friends and family. Moreover, a study in Nairobi, Miller and Rubin (2007) found that the men who disclosed to their wives did so primarily to enable their spouses to protect themselves from HIV infection. Another study conducted amongst people living with HIV in Uganda (King *et al.*, 2008) found reasons for disclosing to sexual partners such as; they could infect other people, may be detrimental to their relationships, should live to look after their children or should not go through the pain the infected individuals went through.

### *Gender*

Self disclosing of personal problems is perceived as appropriate to women than it is to men. Shaffer and Pegalis (2001) conducted a study dealing with personal problems and self-disclosure differences between females and males and found that females in western cultures were more likely to disclose personal problems than males. Women are expected by society to be more open about personal problems, while men are expected to be more closed and unconcerned about their personal problems. On the contrary, a prospective non-randomized study in South Africa found that males were likely to disclose their

results more often than females (Skogmar, Shakely, Ians, danell, Anderson, Tshandu, Roberts & Franciois, 2006). However, another South African study (Olley, Seedat & Stein, 2004) revealed that male sex is associated with non- disclosure of HIV status.

The above findings show that facilitators to disclosure are affected by the clients' understanding of the disease especially with regard to the risks involved personally as well as for the partners. Furthermore, the idea of trust and security in the relationship seemingly has a positive impact in facilitating disclosure. Ultimately, the knowledge that a positive serostatus is not the end of life; the need to protect one's partner from infection as well as consideration of other personal benefits of disclosure facilitate disclosure.

## 2.6 Barriers to disclosure

While it may be necessary for PLHIV to disclose their HIV status because of the benefits mentioned above and to obtain needed resources and support, negative consequences may be associated with such disclosure (Kimberly *et al.*, 1995). PLHIV's decisions related to HIV serostatus disclosure therefore are likely to be influenced by their assessment of positive or negative consequences of disclosure (Kimberly *et al.*, 1995; Serovich *et al.*, 1998). Research conducted focusing on disclosure to past or current sexual partners, demonstrates that between  $\frac{1}{4}$  and  $\frac{1}{2}$  of those with HIV have not told their sex partners (Stein, 1998; Kalichman & Nachimson, 1999). Furthermore, Petrak, Doyle, Smith, Skinner and Hedge (2001) established that persons infected with HIV may not be able to disclose their HIV serostatus due to a number of reasons like stigma, causing distress to others, discrimination and concerns about confidentiality. Studies show the barriers HIV positive people face that are related to HIV disclosure which include; stigma and discrimination, fear of abandonment, fear of violence, fear of upsetting family members and fear of accusations of infidelity (Kalichman & Nachimson, 1999; Koenig & Moore, 2000; WHO, 2004).

### *Stigma and discrimination*

The stigma related to HIV/AIDS and the behaviours associated with HIV risk have resulted in significant barriers to disclosing one's HIV status (Kalicham & Nachimson, 1999). Furthermore, Menon, Glazebrook, Campion and Ngoma (2007) argued that stigma and secrecy that frequently surround the diagnosis of HIV infection in developing countries are potential barriers to self disclosure. In communities where there are negative attitudes towards HIV positive people besides the entrenched underlying negative gender norms towards HIV/AIDS, PLHIV are unlikely to disclose their status (Koenig & Moore, 2000). HIV related stigma and discrimination are associated with not disclosing HIV status to partners in other settings. A study in S.Africa (Norman, Chopra & Kadiyala, 2007) identified stigma as a main barrier to disclosure among other things and the stress an individual goes through in the process of disclosing because of the perceived stigma of friends, family and community. Surveys conducted among 1054 HIV positive men and women in Cape Town, S Africa, found that 42% of those currently sexually active had not disclosed their serostatus to their sexual partners. Lack of disclosure among these HIV positive people was associated with previous HIV/AIDS related experiences of stigma and discrimination ( Simbayi *et al.*, 2006).

### *Fear of gender based violence and other negative outcomes*

Disclosure of HIV infection by women may present unique risks. Studies conducted among women, show that fear is the most common barrier to disclosure. Women fear disclosing their sero-status out of fear of partners' reaction, stigmatization by friends, family and community, victimization, confidants spreading the news of their sero-status, accusation of infidelity, abandonment, accusation of being the source of infection in the home and separation (Maman *et al.*, 2001; Akani & Erhabor, 2006; Simbayi *et al.*, 2006). In their studies, Heyward *et al.* (1993) and Antelman *et al.* (2001) found many women that did not disclose their serostatus to partners because they feared negative consequences. Among the different studies, fear of abandonment mentioned by the women was associated with fear of losing the economic support from their partners (Kilewo, 2001; Antelman, 2001; Rakwar, 1999; Ladner, 1996; Heyward, 1993). Women in Burkina Faso did not disclose to their partners because of fear of rejection and negative

financial consequences (Issiaka *et al.*, 2001). In a qualitative study conducted by Sigxaxhe and Mathews (2000) among 28 pregnant women in South Africa, the barriers women cited were fear of rejection, fear of discrimination, fear of verbal abuse and concerns about public ignorance of the disease. Notably, a study in Tanzania on women's barriers to HIV testing and disclosure found that HIV positive results, fear for partner's reaction and whether there had been discussion prior to the test influenced the decision to disclose to the partner (Maman *et al.*, 2001).

A woman's disclosure of her HIV infection to a sexual partner may trigger violent results. Fear of violence can have strong impact on the decision to disclose particularly amongst HIV positive women in relation to their male sexual or drug injecting partners (Gien, Campo, Faden & Eke, 1997). The same study found that one fourth of women in the study had experienced negative consequences of disclosure that included rejection, abandonment and verbal and physical abuse. Studies by Temmerman, Ndinya-Achola, Ambani and Piot (1995) and Gien *et al.* (1997) found that a significant proportion of women had negative experiences of disclosure that included physical violence. Research in Tanzania found that one woman in five who disclosed her HIV status to her partner was abandoned (Simoni *et al.* (1995). In contrast, men in Tanzania reported being little concerned with anticipating their wives' responses to news of their HIV status (Maman *et al.*, 2001).

### *Gender and power Relations*

The women's gender positioning and economic status in society, particularly in the home, limits their negotiating power in decisions related to having safe sex, condom use and accessing healthcare ( Hausermann & Danziger, 1991). Women's dependence on men, their inability to make certain decisions and the effects of social and cultural factors on them, increase their risk and vulnerability to HIV exposure and at the same time limiting their chances for seeking health services. The social-cultural and economic determinants of women's HIV infections greatly differ from those of men because of the central positions and roles of men in relationships and families (WHO, 2003). While disclosure for the men was not troublesome, the women in the study in Tanzania (Maman *et al.*,

2001) had fear of the partners' reaction, particularly fear of abandonment. Moreover in the same study 53% of the men interviewed informed their partners prior to going for HIV testing as compared to 33% of the women. Poor communication amongst the partners inhibits disclosure. Female HIV peer educators in a focus group in Zimbabwe (Kesby, 2004) reported that poor communication between couples on sexual issues made discussion of HIV with partners very difficult. In some societies, women are mistakenly perceived as the main transmitters of sexually transmitted diseases (STDs) including HIV/AIDS. Hausermann and Danziger (1991) argue that women's low status and lack of knowledge of their rights increases their vulnerability to the risk of infection and to the personal, social and economic consequences of the epidemic. Fredriksson and Kanabus (2001) concur with them in that HIV positive women are treated very differently from men in many developing countries. Men are likely to be "excused" for their behaviour that resulted in their infection, whereas women are not. In some African communities, women whose husbands have died from AIDS-related infections, have been blamed for their death. A study focusing on women, violence and HIV (Koenig & Moore, 2000) found that women with or at risk of HIV come from a population also at risk of violence. Violence may be associated with disclosure of a positive serostatus or in response to condom negotiation. With the stigma and threat of violence, women are most likely not to disclose their status to their sexual partners. Women's barriers to HIV testing and serostatus disclosure reflect the unequal and limited power that many women have to control their risk of infection. This is evidenced in the challenges experienced in PMTCT uptake in Uganda. Studies conducted (Mugenyi, Kabasinguzi & Ali, 2004; Bajunirwe & Muzoora, 2005; Onyango & Magoni, 2001) reported that most women needed to consult their spouses first before taking an HIV test and if found positive, the decision to participate in PMTCT services had to be made by their husbands. In Zimbabwe, an exploratory cross-sectional survey conducted in six hospitals (PMTCT sites) found that majority of women declined routine HIV testing mainly because they required partner's consent (Perez, Zvandaziva, Engelsmann & Dabis, 2006).

### *Duration of relationship and type of partner*

Hays (1993) expressed that telling sexual partners about HIV infection is relatively more difficult among patients who feel vulnerable to rejection, especially by partners with whom HIV-positive patients have not established a relatively permanent relationship. A study in Tanzania found that being in a cohabiting relationship, shorter duration of relationship, not knowing someone with HIV, and lower income were negatively associated with disclosure (Antelman *et al.*, 2001).

In Uganda, Human Rights Watch (2003) reported about HIV-positive women in cohabiting relationships who had hidden their sero-status for fear of being accused of adultery and blamed for the illness. Most of the studies cited focused on women. However, a qualitative study among HIV infected men who have sex with men (MSM) in USA that aimed at understanding better the factors that impact decision making process regarding HIV disclosure identified rejection, issues of confidentiality, possible missed partner's HIV status and type of sexual partner as barriers to disclosure (Driskell, Salomon, Mayer, Capistrant & Safren, 2008).

Whereas the findings in the studies above raise pertinent issues related to disclosure, they cannot be generalised to people of different gender and age and other social settings; and most of these studies do not indicate how these fears affect disclosure after an intervention to reduce fear. Women may have the above fears due to already existing socio-cultural and gender biases including gender based violence. However, a major strength is that they were carried out in different sites and countries and represent variations of cultural norms. Studies on the factors that influence decisions to disclose HIV status that are conducted among sexual partners that receive ART care are needed.

### **2.7 Summary**

The above literature review reveals that disclosure of HIV status to sexual partners is a process. The facilitators of disclosure discussed include: knowledge of partner's status, duration of relationship, type of relationship, clinical stage of the disease, social support, ethical responsibility, gender, and prior discussion about HIV testing. Whereas barriers to disclosure include: stigma and discrimination, gender and power relations and fear of

gender based violence as well as duration of the relationship. The above findings show that the idea of trust and security in the relationship; the knowledge that a positive serostatus is not the end of life ; the need to protect one's partner from infection as well as consideration of other personal benefits of disclosure facilitate disclosure. While risks of adverse outcomes of disclosure such as abandonment and violence hinder disclosure. Strategies to support disclosure and decisions to disclose to sexual partners should critically weigh these issues in the context of HIV risk reduction .



## CHAPTER THREE: METHODOLOGY

### 3.1 Study Design

A descriptive exploratory qualitative study was conducted to explore differences in perceptions, opinions and experiences about HIV disclosure to sexual partners among clients who have and have not disclosed. Qualitative methods were chosen because of their usefulness in exploration of people's views and experiences (Kitzinger, 1994). A qualitative study was useful to gain new perspective on things about which much is already known and gain more in depth information (Hoepful, 1997). The research employed in-depth interviews and focus group discussion. According to Brink (1999), the personal contact with respondents produces descriptive data and presents it in the respondents' own words, views and attitudes towards the research topic. The important thing is that the information gathered reflects what the respondents believe to be important rather than what the researcher believed should be included.

Sensitive issues like HIV/ AIDS are easily discussed in qualitative methods which use focus group discussion since people feel more relaxed about talking when they see that others have similar experiences (Kitzinger, 1994). The focus group discussion is valuable when participants are to explore certain issues in their own words and in ways that will enable them to come up with their own questions and priorities, thus group processes can help explore and clarify participant's views. Since the organization had employed various strategies to support clients to disclose to their partners and in TASO Mulago only 12% of sexually active clients had disclosed, the use of a focus group and in depth interviews was to help to explore and clarify their views and experiences in disclosure and what influences this.

Although in-depth interviews require more time, understanding and experience are developed from interview to interview and they provide more detail about an individual. This is because they provide opportunity to the researcher to probe deeply (Liamputtong

& Ezzy, 2005). This was relevant for participants who have and have not disclosed their status to partners who preferred to be interviewed individually.

### 3.2 Study population

The study population from which participants for the in-depth interviews were recruited was; the English and Luganda speaking male and female TASO Mulago registered clients who are 18 years and above, enrolled on the ART Program that was rolled out in 2004 and have a current sexual partner.

The study population from which participants for the focus group discussion were recruited was drawn from; the clients' representatives (34) who are peer educators. These are open about their sero-status, have been trained to pass over information to their peers and the public and only those with a current sexual partner and were willing to be interviewed were considered.

### 3.3 Sampling and Sample Size

The study employed purposive sampling in order to 'get information-rich' male and female participants from TASO Mulago centre. This is a type of non-probability sampling approach in which subjects are selected because they are identified as knowledgeable regarding the subject under investigation (Frankel & Devers, 2000). In the study the participants were selected because of their knowledge regarding the issue of disclosure/non disclosure to partners. The researcher establishes certain criteria thought to be representative of the target population and deliberately selects subjects according to such criteria (Burns & Groove, 1993). The participants purposefully selected were either in a discordant or polygamous relationship, or took a test during antenatal clinic, were married or cohabiting or not living together with partner.

TASO Mulago was selected because the centre is in the urban setting where prevalence of HIV is high (8.5%) according to the Uganda 2004-2005 sero-behavioural survey (MoH & ORC Macro, 2006) and the centre was the first TASO centre to roll out ART.

The criteria for selection of participants for the individual interviews:

- TASO clients on ART , 18 years of age (In Uganda this is an adult) and older with a current sexual partner
- Have or have not disclosed to the sexual partner
- Have received counselling for more than 1 year
- Were on appointment to come for services during the scheduled time for interviews
- Willingness to participate in the interview

The criteria for selection of participants for the FGD :

- Clients' representatives who are peer educators (expert clients) and are open about their serostatus
- Are on ART
- Have a current sexual partner
- Willing to participate in the group discussion

The clients are usually given appointments ahead of time by the Counselling coordinator to come on ART clinic days either at the facility or at the outreaches in the community. The Counselling coordinator with the help of the counselling team identified those who have/have not disclosed their HIV status to the sexual partners for the in-depth interviews following the criteria provided.

Effort to identify those who speak English only was made, but this category seemed to be limited, thus some interviews were conducted in Luganda, the local dialect.

In-depth interviews were conducted on 24<sup>th</sup> February, 10<sup>th</sup>, 11<sup>th</sup>, 16<sup>th</sup>, 17<sup>th</sup> March and 7<sup>th</sup> April. 2009.

The study involved 22 purposively selected participants who are clients of TASO Mulago on ART, 11 male and 11 female participants. 14 in-depth interviews were conducted while 8 purposively selected expert clients (peer educators) and are open about their serostatus were in a focus group discussion.

The in-depth interviews were conducted to gain understanding about participants' personal experiences about disclosure/non-disclosure while the FGD not only brought out

the personal experiences but also general perspective on disclosure to sexual partners in order to complement the information from the in-depth interviews.

In this study the sample size was limited because of time and money and the participants selected were because of their knowledge regarding the issue of disclosure to partners as 'information-rich' more than looking at the numbers to be interviewed.

The selection of the participants in the FGD was as per the criteria mentioned above. The mixed group was not focusing on gender related issues but on the disclosure of serostatus to sexual partners. The participants in the group were all expert clients/peer educators that are open about their serostatus and move together to educate individuals and the communities about HIV/AIDS prevention and care.

The counselling coordinator also with the chairman of the clients' council representatives mobilised participants in the FGD to come to TASO centre. They mobilised those married or cohabiting, either discordant or polygamous relationship and were willing to come for the interviews. There were four male and four female participants. The focus group discussion was conducted on 13<sup>th</sup> March 2009. Participants in the individual in-depth interviews and FGD, represented age groups in their twenties, thirties, forties and fifties.

### 3.4 Data Collection

#### *3.4.1 Individual interviews*

Information was collected through semi-structured interviews. Face-to-face interviews were conducted with each participant as described above. All participants interviewed were given an appointment date on ART clinic days in order to cut down on extra costs of transport fare. The participants were given transport refund and some refreshments.

The interview started with the researcher welcoming the participant and a brief introduction, followed by explanation of the purpose of the study, participant's voluntary involvement and withdrawal, issues of confidentiality, benefits and costs as articulated in the Participant's information sheet (Appendix 1) and the participants signed the Consent form (Appendix 2) after committing themselves to be interviewed. Using the interview guides for clients who have disclosed/have not disclosed (Appendix 3 & 4) the researcher

went ahead to conduct in-depth interviews using the relevant tool for categories disclosed and not disclosed. At the end of each the interview debriefing was carried out and some questions asked to ensure completeness. Each interview lasted for about 1 hour; was tape recorded and notes were also taken.

### ***3.4.2 Focus group discussion***

The participants were mobilised by the clients' leader and informed about the study and were requested to come to the service centre to participate in it. These clients too were given transport refund fare in addition to being provided with refreshments. The FGD was conducted with four female and four male participants. A facilitator's guide was used for the focus group discussion. Topics discussed were related to the ones for the individual interviews that were guided by relevant probing questions. The group session began with a welcome, by brief introduction followed by explanation of the aim of the study and session rules were established. These included confidentiality bearing in mind that the session was being tape recorded and not discussing information shared in the session with others outside the session, that there were no right or wrong answers and individual opinions/answers had to be respected. After sharing with participants the information on the Participants' Information sheet (Appendix 1) their willingness to participate was sought and the participants signed the Consent form(Appendix 2).

After completion of the introduction, the questions were posed to the group and discussion proceeded. Each participant was given opportunity to share their experiences on HIV testing, disclosure, what motivated decisions to disclose and inhibitors of disclosure, until no new ideas were emerging. During the FGD, the discussion was tape recorded and the researcher had an assistant who took notes. The recorded discussion was transcribed and translated then analysed by the researcher.

The participants preferred to have the discussion in Luganda the local language to facilitate common understanding and expression among participants thus increasing effectiveness of the whole process. A summary of the main views /suggestions by the

participants was raised to the group as a way of checking completeness at the end of the discussion.

### 3.5 Data Analysis

This refers to a process through which qualitative findings are built from original raw data (Patton, 1990).

The study used thematic analysis where the process of data analysis started during the process of data collection. The data from the individual interviews and the focus group discussions were re-examined using the transcribed audiotapes. This helped in refining questions and identifying new avenues of inquiry.

The transcripts were read repeatedly and coded in order to capture the range and diversity of the participants' perceptions followed by a comparison amongst them at the end of the session. The researcher analysed content elicited recurring themes related to the reasons for disclosure and non-disclosure to sexual partners through listening to -tapes, reading the transcriptions and studying field notes. Audio- taped and written notes were reviewed and transcribed to develop a comprehensive list of factors related to decision making process for disclosure to sexual partners.

Themes, categories and sub-categories were grouped and categories generated under which data was labelled,sorted and compared. Re examinations of categories identified were then done to determine how they are linked in order to get more explanations and recurring themes using a process recommended by Strauss and Cobin (1990). Themes were based on those aspects identified in the review of literature before data collection (Bailey, 1997) and those of particular interest included: process of disclosure, reasons for disclosure and barriers to disclosure. The data were presented in the form of general concepts, descriptive summaries and quotes were used to bring out the originality of the findings but also linking back to literature available. All data collection tools were then locked.

### 3.6 Strategies to ensure Rigour

In order to ensure rigour of the data, soundness of data was maintained through measures addressing the following aspects: credibility, transferability and conformability (Lincoln & Guba, 1985). The truth value of a qualitative research resides in the discovery of experiences as they are lived and perceived by the subjects rather than in the verification of a priori conceptions of those experiences (Sandelowski, 1986).

*Credibility* (truth value) in qualitative study then is when the study presents faithful descriptions or interpretations of human experience that others with such an experience would immediately recognize from those descriptions or interpretations as their own. According to Patton (1990), credibility in qualitative research depends less on sample size than on the richness of the information gathered and on the analytical abilities of the researcher. Hence in order to improve credibility, there was taking of notes during the interviews and FGD as well as using a tape recorder. In addition, triangulation of methods, which were in-depth interviews and focus group discussion, enabled the researcher to validate the emerging issues thus increasing the rigour (Mays & Pope, 2000). Triangulation of data sources through meeting clients and clients' representatives (expert clients/peer educators) increased validity by corroborating descriptions.

*Transferability or generalisabilty* relates to the extent to when the findings can 'fit' into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences (Lincoln & Guba, 1985).

In this study as Lincoln and Guba (1985) suggest, there was sufficient information that could be used by readers to determine whether the findings obtained were applicable to situations among other TASO Mulago clients. There is application of dense description or thick contextual descriptions for transferability to other clients in the same context and if possible in other TASO service centres.

*Dependability* in qualitative research refers to the degree to which the reader can be convinced that the findings did indeed occur as the researcher states they did. In this study this was achieved through the intense description of the process and research

methods besides the data recorded, showing how certain actions and opinions were rooted in and developed out of contextual interactions.

In qualitative research *confirmability* refers to the extent to which the data confirms the general findings and not simply the products of the researcher's bias. This was achieved by comparing the findings and the interpretations to the wider literature and was also done by giving feedback of the findings at the end of the interview to the participants and checking whether they agree with them, as well as the support and checking provided by the supervisor.

### 3.7 Ethical Considerations.

Permission to proceed with the study was obtained from the Director: Planning and Strategic Information in TASO, Uganda, the Deputy Director in Charge of Research and the Centre Manager, TASO Mulago. Approval to carry out the study was obtained from UWC Research and Ethics committee.

Permission was also sought from the participants before the start of the individual interviews and focus group discussion. The purpose of the research was explained at the outset of the interview, participants were assured of confidentiality. Each participant was told that the interview would be tape-recorded. It was emphasized that participation was voluntary and that individuals had the right to terminate their participation at any time.

A written informed consent explaining the objectives, the benefits and potential risks of the study (Appendix 2) was obtained from each participant. Participants were requested to sign a consent form and they were reminded that they had a right to withdraw from the study if they wished to. They were informed that this would not in any way interfere with their accessing services in TASO. Participants' confidentiality was also assured throughout the study period. The information provided was treated confidentially and would only be used for study purposes. Participants were encouraged to ask questions and assured that their names would not appear anywhere in this study report.

### 3.8 Study Limitations

The study was conducted in one centre among TASO clients on ART; the findings may not be generalisable (transferable) to all TASO clients in particular and may not be representative of HIV infected individuals not enrolled in any HIV/AIDS care organisation or all people living with HIV in general. However, they present a documentation of the range of the experiences of disclosure /non-disclosure to sexual partners of some TASO Mulago clients on ART living in both rural and urban sites during disclosure of sero-status within TASO Mulago catchment area. The sample size was limited due to time and money considerations thus could not pursue data collection until data saturation. Nevertheless, the aim was to capture the range of views and experiences, rather than produce an exhaustive account, which is used in theory development.

The study also focused on people living with HIV on ART who had already been counselled for more than one year. Clients who had just known their HIV status did not participate in the study. However, the findings provide an indication of the challenges faced when HIV positive people try to disclose their status to sexual partners.

While the researcher had expected to conduct the study in English only as per the protocol, there were some participants who were not very comfortable being interviewed in English due to their literacy levels. Most of the clients at this centre do not have a high level of education.

## CHAPTER 4: RESULTS

### 4.1 Description of Study Participants

The study involved 22 purposively selected participants, 11 male and 11 female, who are clients of TASO Mulago on ART. 14 of the participants were interviewed individually while 8 took part in a focus group discussion.

In the study, over half (15 or 68%) of the study participants were between 30 and 49 years of age.

Most participants (16 or 73%) had at least primary and some part of secondary level education. The majority of participants who stopped at primary level were female (6 out of 11) and only two male participants had attained tertiary education (Table 1).

Fourteen participants were married, of which two were in polygamous relationships and three in discordant relationships; six (27%) were co-habiting and two (9%) had a steady partner (Table 1). All the married participants disclosed their HIV status to their partners; while only one participant who was cohabiting disclosed to her partner. None of the participants who had steady a partner disclosed.

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**Table 1: Demographic characteristics of study participants**

| Characteristic     |                     | Male                | Female                 | Total |
|--------------------|---------------------|---------------------|------------------------|-------|
| Age (Years)        | 20-29               | 3                   | 2                      | 5     |
|                    | 30-39               | 2                   | 6                      | 8     |
|                    | 40-49               | 4                   | 3                      | 7     |
|                    | 50-59               | 2                   | -                      | 2     |
| Total participants |                     |                     |                        | 22    |
| Education          | Primary             | 4                   | 6                      | 10    |
|                    | Partly Secondary    | 3                   | 3                      | 6     |
|                    | Completed Secondary | 2                   | 2                      | 4     |
|                    | University          | 2                   | -                      | 2     |
| Total participants |                     |                     |                        | 22    |
| Marital status     | Married             | 8<br>(1-Polygamous) | 6-<br>(1Polygamous)    | 14    |
|                    | Cohabiting          | 2 (Not disclosed)   | 4<br>(3 Not disclosed) | 6     |
|                    | Steady Relationship | 1 (Not disclosed)   | 1 (Not disclosed)      | 2     |
| Total Participants |                     |                     |                        | 22    |

## 4.2 Self- Disclosure

Among the fourteen participants interviewed individually, only seven had disclosed their serostatus to the current partner. Of the seven, three disclosed within the same year they found out about their serostatus (1998 and 2007 respectively) while four took about one to three years before they disclosed to the current partner (*Table 2*).

The results show that disclosure to sexual partners was not necessarily related to the time frame within which the participant found out his/ her serostatus. In fact, the participants who were among the first in the group to find out about their serostatus in 1990 and 1996 respectively had not yet disclosed to their current partners.

**Table 2. Self-disclosure to Current Sexual partner**

| <b>Year tested</b> | <b>Disclosed (Year)</b> | <b>Not Disclosed</b> |
|--------------------|-------------------------|----------------------|
| 1990               |                         | 1                    |
| 1996               |                         | 1                    |
| 1998               | 2 (1998, 1998)          |                      |
| 1999               | 1 (2002)                |                      |
| 2001               |                         | 1                    |
| 2002               | 2 (2003,2004)           |                      |
| 2003               |                         | 1                    |
| 2007               | 2 (2007, 2008)          | 1                    |
| 2008               |                         | 2                    |
| <b>Total</b>       | <b>7</b>                | <b>7</b>             |

### 4. 2.1 Reasons for taking an HIV test

Most people decide to test for HIV in reaction to triggers such as long illness or persistent illness episodes.

*I had been sick and bedridden for two years and my wife who was very committed to me, was looking after me. In 1999, a friend came to see me and encouraged me to go and take an HIV test. [Male, 41 years, married]*

*I first took an HIV test in 2002. During that time I had frequent fever and really wanted to know what was happening in my body. [Male, 50 years, married]*

The other common reason for taking an HIV test among women was attending antenatal clinic, where routine counselling and testing for pregnant women under the PMTCT programme takes place.

*I tested HIV positive in 1998 when I was 18 years old while attending an antenatal clinic in Mulago Hospital. [Female, 29 years, married]*

One participant mentioned that she had not considered the probability of any personal risk to HIV infection since she had been faithful and her husband seemed healthy.

*I learnt of my status at the Antenatal clinic in Mulago when I was pregnant and we were tested. But I did not believe it because I had never had any other man apart from my husband who also looked healthy. [Female, 32 years, married]*

Other reasons for testing included death of a spouse or a child, having symptoms like herpes zoster and being urged to take an HIV test by friends or family members.

One client who lost two children explained.

*I had lost my first child earlier but did not consider that the cause of death was HIV related. It was only when I lost my second child that I was advised to go to AIC for HIV testing [Female, 40 years, married]*

Another client after losing his wife and children and attributing it to witchcraft was convinced to test by a friend.

*A friend of mine got concerned whenever he found me drunk. He asked me what the problem was and I told him about my aunt bewitching me. He would not buy my story because he was born-again Christian and insisted that I go for an HIV test [Male, 35 years, married].*

A participant who found out about her serostatus when she went for treatment said.

*In 2002 I got kisipi ( herpes zoster) and had to go for treatment. The doctor then advised me to take an HIV test and that is when I discovered I was HIV positive. [Female, 36 years, cohabiting]*

#### 4.2.2 Reactions after receiving HIV Test Results

Participants had various reactions when they received HIV positive results; for most of them, the news was emotionally devastating. Among both categories of participants who had disclosed to the partners and those who had not, were those who said they felt very sad, frightened, traumatised, angry and bitter. Two participants actually admitted that they wanted to commit suicide. The participants related feeling distraught and shattered at the prospect of dying soon or young, without having accomplished their life goals or expectations.

*It felt very sad to imagine dying soon because I was young with many responsibilities and wanted to have children, raise them and realise many of my dreams.* [Male, 27years, co-habiting]

Another participant recounted her ordeal after receiving her results, as well as her father's consequent withdrawal of support.

*When I got the results I was very much traumatised. My distress was made worse when my father told me immediately after I got the results that there was no more support for me and he now preferred to focus his attention on my siblings. My family members mistreated me, isolated me and nobody wanted to have anything to do with me. I therefore started contemplating suicide.*

[Female, 35 years, married]

Infidelity was reported to contribute to conflicts in marriage. Some of the participants were angry and reported that it was a reaction against the fact that their partners had not disclosed to them and yet they kept hearing rumours about their involvement with HIV infected partners.

*I felt bitter and was angry with my late husband. He had got involved with a woman who was infected and this annoyed me. I even wanted to commit suicide because I didn't know how I was going to live with the infection.*

[Female, 42 years, co-habiting]

Although most of the participants were shocked and devastated to find out that they were HIV positive, a few showed an evident lack of surprise at the news. Two participants among those who have disclosed to their partners said that they were not very surprised because they had led a promiscuous lifestyle with partners who had passed away, or because a number of their family members had died.

*I had lost many family members to AIDS so it didn't surprise me that much. I had to be firm. A young cousin of mine who I lived with had spread the rumour that I was infected (HIV positive) before I even took the HIV test, so there was nothing to hide.*

[Female 34 years, cohabiting]

A person's past sexual history that may indicate a probable exposure to HIV infection can make a person to seek HIV testing. One participant who had had multiple partners some of whom had passed away said;

*I was not very surprised when I was told that I was HIV positive . I had slept around with many women and some of them had passed away; thus I didn't expect good news (HIV negative results) .*

[Male , 47 years old, married]

### 4.3 Process of disclosure

The process in decision making for disclosure varies according to the context and to the person to be disclosed to. The process often entails clients in their targets of disclosure, preferring to disclose to other family members immediately after taking the HIV antibody test even before disclosing to sexual partners.

#### 4.3.1 Targets of disclosure

In deciding who to disclose to, the participants considered their relationship with the person in whom they were confiding, his [her] understanding and support and the person's level of confidentiality. The participants disclosed to family members (immediate and extended) and friends

**Table 3. Person disclosed to and reason for disclosure**

| <b>Number of Participants</b> | <b>Person disclosed to</b> | <b>Reason for disclosure</b>   |
|-------------------------------|----------------------------|--|
| 4                             | Sister                     | Support , understanding and confidentiality                                |
| 1                             | Mother                     | Social support and understanding   |
| 1                             | Father                     | Financial support  |
| 1                             | Brother                    | Social support and confidentiality   |
| 9                             | Partners                   | Support and their need to take HIV test                                    |
| 3                             | Extended family members    | Social support   |
| 2                             | Children                   | Need for children's support<br>Need to protect children from acquiring HIV |

Among the participants who disclosed, were some who disclosed to more than one person resulting in cases of multiple disclosure (*Table 3*). Two participants among those who have not disclosed to current partner had disclosed to their deceased partners.

*I disclosed to my late husband the same day I was given my HIV test results.*

*I was very devastated.* [Female, 36 years, has a steady partner]

Those who spoke to their extended family members attributed their disclosure to the support they had received.

*I talked to my aunt who was very helpful and who encouraged me not to worry but to adopt positive living and promised to help me to access appropriate treatment* [Male,42 years old, married]

Only one participant, a university student, refused to disclose to either his partner or any of his family members.

*I don't want to disclose to any of my family members. Mummy pays my fees; I know it would devastate her. I cannot disclose now, may be in future*

[Male, 22 years, has a steady partner]

### 4.3.2 Timing of disclosure

Disclosure to sexual partners was either planned or unplanned, and in some circumstances not required.

#### 4.3.2.1 Planned disclosure

Of the participants who planned disclosure to their partners, three disclosed immediately after taking the HIV test. In such cases, disclosure was done either at the testing site or at the spouse's place of work.

*My wife had accompanied me to take the HIV test. After I had received my results and the session was over with the counsellor, I came out and told my wife who was waiting for me that; “Even me I am dead (infected), they found the virus in me” [Male client, 47 years, married]*

Some female participants acknowledged disclosing to partners soon after their visit to the antenatal clinic where they found out their serostatus.

*As soon as I left the antenatal clinic, I went straight to where my spouse was working. I told him that I took an HIV test and was told that I was HIV positive. [Female, 29 years, married]*

One of the participants explained that disclosure can also be prompted by either the anticipation of understanding and support or done out of desperation since receiving HIV positive results is very challenging

*After receiving my results , I came and told my wife that I had suffered enough and then added, “ The doctors advised me to go to TASO but rumour has it that TASO gives people drugs that kill. I want to go and get those drugs so that I may die.” My wife's response was: “I have not told you that I am tired of looking after you. Why don't you accept to live as long as God allows you to?” [Male, 41 years, married]*

A participant recounted that although he intended to disclose, he found it difficult to do so immediately. He said this was because he did not know how best to present the issue.

*I decided to tell my wife three months after my second HIV test that it was important that we begin to use condoms since I had been found to be HIV positive. I was not able to tell her earlier because it was a very difficult subject to bring up and I did not know how she would react. I told her that she too needed to go and find out her status.*

[Male, 42 years, married]

#### 4.3.2.2 Unplanned disclosure

Some clients are unaware that their partners receive HIV/AIDS services at the same sites as they do: often times, this results into accidental meetings and thus unplanned disclosure. One of such cases involved a situation, where the participant inadvertently met her partner at a clinic where both had been receiving HIV/AIDS services:

*There was no time to plan disclosure, we simply met at the clinic that day and knew that both of us were infected. No one was mad at the other.*

[Female, 34 years, cohabiting]

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In other instances, disclosure was not required given that the clients met and acquired partners while accessing HIV/AIDS services. In such situations, the participants were automatically aware of their partners' serostatus.

*Since both of us knew our serostatus and we met when we were receiving TASO services, it did not require disclosure or explanation.*

[Male, 41 years, married]

#### 4.3.3 Partners' reactions

Among the participants that disclosed their HIV status to their partners, five anticipated negative reactions. Some of the anticipated reactions included blame, abandonment, being hurt, quarrelled with or even killed.

*I thought he would probably blame me or hurt me or even kill me but I still knew that I had to tell him. Instead, my husband kept quiet when he learnt about my sero status. [Female, 35 years, married]*

Some clients who access PMTCT services when they go for antenatal visits often find it a challenge to disclose to their partners. One such participant narrated her fear about what she thought would be her partner's reaction

*I expected my husband to quarrel after I had disclosed. However, he just expressed his concern about the unborn baby. I told him about the PMTCT education I had received at the clinic and the possibility of having an HIV free baby. He offered to support me.*

[Female, 29 years, married]

A few of the participants had prior discussion about testing with their spouses. Although most of them were encouraged to go for the test, one partner warned the husband not to disclose to her if he tested positive.

*Before I tested, my first wife had warned me never to disclose my status to her if I happened to have positive results. When I disclosed,, she did not listen to me but rather packed her things and left me. I therefore chose not to tell my second wife after the first one's reaction.*

[Male, 40 years, polygamous relationship]

Another participant who had been suffering from tuberculosis for a while decided to take an HIV test. When he found out that he was HIV positive, he expected his wife to abandon him.

*I thought my wife had had enough trouble looking after me and would now leave me. I did not want to burden her any longer. However she was very supportive, I received counselling and treatment and my health started improving*

[Male, 41 years, married]

Disclosure amongst discordant couples is a key issue since there is a possibility of separation. Some participants whose partners tested HIV negative had such challenges.

*When he tested HIV negative, the situation at home changed. He stopped caring for me and as far as he is concerned I no longer matter or exist to him. Although we live together, he has more or less abandoned me.*

[Female, 30 years, married]

Sex and maintenance of relations among discordant couples are also very problematic issues. In most cases among such couples, the sexual act is surrounded with fear and there is mistrust between the partners.

A participant, whose wife tested HIV negative, had to stop having sexual relations with her although he has kept looking after her at his home in the village. Eventually he decided to marry an HIV positive woman.

*Although my wife had been supportive and looked after me while I was sick for along time, we were psychologically affected when she tested HIV negative. She feared to have sexual relations with me so we agreed to stop having sex. Although she has remained in our village home and I provide for her, we have not had any sexual relations for the last ten years. I got married to another woman who is also HIV positive. We live together here in town.*

[Male, 41 years, married]

#### 4.4. Reasons for disclosure

Disclosure of sero-status to a sexual partner though challenging is associated with a number of benefits. The participants who disclosed their serostatus to partners had various reasons they said that enabled them to disclose which include; desire for partner to get treatment, need for partner's support, prior knowledge of partner's HIV status, anger and anxiety about the future.

#### 4.4.1. *Desire for partner to get treatment*

The desire for the partners to take an HIV test and also begin to access care and treatment services especially ARVs were highlighted as one motivator for disclosure. A number of clients have faith in the HIV treatment and would even go out of their way so as to access medication for themselves and their partners. Three of the participants explained that they disclosed because their partners also needed to go and get treatment.

*I realised that it would be wrong for me not to tell my wife about my serostatus because she would discover it in the long run and she too needed to get treatment*  
[Male, 42 years, married]

TASO's disclosure counselling emphasizes the importance of prevention of HIV transmission to partners and their need to access testing, care and support services. One participant who wanted her partner to access health services but was hesitant to disclose, enlisted the support of her counsellor.

*The counsellor had told me that I needed to disclose to my partner and explain the need for us to begin using condoms and his need to access TASO services. I tried to do it alone at first but failed, and then I invited the counsellor home who helped me to tell him*  
[Female, 42 years, married]

#### 4.4.2 *Need for Partner's support*

ART being a life-long treatment, there is usually need for a drug companion who in most cases is either a spouse or a household member to remind the client to take the medication on time. The fact that the ARVs are free and sometimes delivered to clients' homes by TASO staff using TASO labelled vehicles, also motivates clients to disclose to partners and other family members.

One participant in the FGD said;

*If I hadn't revealed my status, I would not have benefitted from the treatment since it required a lot of support and understanding from my spouse. It would have been difficult to hide because the medicine is taken every day and TASO staff had promised to bring it home every two months*

[Male, 40 years, married]

The pregnant women under the PMTCT program are educated to take extra precaution in childcare and this often necessitates the need for their partners' help. As a result, these women disclose to get this assistance. One female participant in the FGD commented;

*When I visited the antenatal clinic the doctor ( PMTCT Program) told us about the option of replacement feeds for the baby after breastfeeding for three months. I realised that I had to disclose to my husband to gain his support financially and otherwise.*

[Female, 30 years, married]

#### 4.4.3 *Prior Knowledge of the Partner's HIV status*

Some clients have partners who tested and then disclosed their serostatus to them before they were aware of their own. When these clients finally chose to go for the HIV test, it proved to be a lot easier to disclose to their partners who had already taken the initiative to reveal their status. One participant said;

*My wife had found out her serostatus earlier and was already receiving services at TASO. She encouraged me and I came with her for an HIV test. There was no problem disclosing to her since she too was HIV positive and had lost her first husband* [Male, 47 years, married]

#### 4.4.4 *Anger*

Some of the participants both in the individual interviews and FGD found out about their HIV serostatus while visiting antenatal clinics. The disclosure that was made to the partners was due to a reaction to the HIV positive results after an HIV test. One female participant during an individual interview said:

*On leaving the antenatal clinic I went and disclosed to my husband. I had heard rumours that he had earlier lost a spouse and a child and so I wanted to go and tell him how angry I was with him for infecting me. I said, 'How dare you marry me to kill me after knowing that you lost your spouse?!'*

[Female, 29 years, married]

In the FGD a female participant who also found out about her status while attending the antenatal clinic said,

*I was still young when I found out that I was HIV positive. I had gone to the clinic expecting our second child. There the health workers conduct routine HIV tests for pregnant women. When I went back home, I blamed my husband for bringing the infection into the family*

[Female, 32 years, married]

In these two cases above, it is interesting to note that when the spouses went to take the HIV test, they were found HIV negative.

#### 4.4.5 Anxiety about the future

Some clients foresee some of the crises they might encounter in the future and this forces them to disclose. In the study, among individual participants interviewed, one participant who had been mistreated by her family members after disclosure decided to disclose to her partner because she was depressed and was planning to commit suicide; yet the partner was understanding and supportive.

*I disclosed to my spouse about my HIV status as soon as we left my parents' home because I now felt I was useless having seen helpless people with AIDS. I had planned to commit suicide and wanted my partner to know why since at the time he was the only one willing to support me unlike my parents who had rejected me.*

[Female, 35 years, married]

#### 4.5 Barriers to disclosure

While TASO clients appreciate the importance of disclosure, there are difficulties that are rooted in the fear of the implications associated with disclosure. The participants who did not disclose to their partners mentioned such reasons as; fear of blame, fear of abandonment, fear of negative reactions, stigma and discrimination.

#### 4.5.1. *Fear of blame or disappointing the partner*

Some participants acknowledged that they were afraid to bear the blame for bringing the infection into the family. The participants were also afraid of being accused of cheating. During the interviews, the female participants especially indicated this fear. One participant whose partner had another wife and children said:

*Although someone told me that my husband had lost a spouse and child, I tried to ask him about this and he denied. I was therefore not sure that I should disclose to him because I was afraid that he would blame me for infecting him and his other wife with HIV* [Female 32 years, polygamous relationship]

Another female participant who feared to disclose to the partner re-echoed that fear.

*I suggested that both of us go for HIV testing and he said that he had already tested and was found HIV negative. The fact that he was reluctant to go with me and was living with another woman made me hesitant to disclose to him*

[Female, 46 years, cohabiting]

The fear of blame or disappointing the partner was not only mentioned by female participants, some men also acknowledged this fear. One of the participants who had lost a spouse after going through a stressful time of partner rejection and neglect said:

*..I feared she would blame me and probably neglect me like my late wife did*

[Male, 50 years, cohabiting]

Two of the male participants were also concerned about their partners' reactions.

*She is expecting a baby; I should not upset her now when she is heavy.*

[Male, 27 years, cohabiting]

Another said:

*I did not feel comfortable raising such an issue to her. It would be easier to suggest that we take an HIV test than disclose to her that I already knew my serostatus. Since she is still young too, this would make her feel bitter, shatter her life and she would blame me and probably break up with me*

[Male, 22 years, has a steady partner]

Some men particularly are afraid to disclose because of their spouses' tempers which can lead to negative social outcomes. One male participant in the FGD commented:

*The women are easily angered and can just shout at you at the top of their voices which can make the whole neighbourhood aware of your HIV status*

[Male, 35 years, married]

#### 4.5.2 Fear of abandonment

Fear of abandonment and rejection by the sexual partner was a common reason expressed by both male and female participants that hindered disclosure to sexual partners

*I did not want him to leave me. I got him before testing and I feared that if I disclosed to him this might separate us. Although I do not have any children with him, I love him.*

[Female 46 years, cohabiting]

Disclosure to one's partner is even more challenging when a client is not sure how they got infected.

*I was afraid to tell her that I was HIV positive. I did not want her to leave me or even blame me for infecting her. I'm afraid to tell her I am HIV positive because I don't know how I got infected. I could have got the infection as a baby, my parents died of AIDS in 1996. I really don't know.*

[Male, 27 years, cohabiting]

For some female participants, the fear of being abandoned or of separation from their partners was closely linked to the loss of economic support that would happen as a result.

*I could not disclose my HIV status to my partner because I was afraid that he would leave me. I have six children from my late husband and two with my new partner. Without him, I will not be able to take care of my children. I can't imagine what would happen if he left me or stopped caring for me...*

[Female, 46 years, cohabiting]

Some female participants were also hesitant to disclose because they feared their partners' reactions. They did not want to risk the possibility of a family break up or even having their partners throw away their drugs. One participant narrated:

*Many women I meet at the TASO clinic are afraid to disclose to their husbands because they fear their partners' negative reactions. A friend of mine gave birth to five children without disclosing her status to her husband ..... When I probed, she said she was afraid of being abandoned or stopped from taking her drugs.*

[Female, 36 years, has a steady partner]

#### 4.5.3 Fear of stigma and discrimination

Stigma continues to be a major factor that hinders disclosure, access to HIV services and therefore contributes to HIV transmission. Some of the participants interviewed were reluctant to disclose their sero status. They gave a few reasons for this such as fear of being talked about in their neighbourhood, fear of being discriminated against, male ego as well as being identified by those who know them. One male participant who did not disclose to the partner said:

*She would blame me and probably neglect me like the late wife did or begin to talk about me in the neighbourhood. In any case, I didn't think it is right to disclose if someone's going to tell the whole neighbourhood about my status.*

[Male, 50 years, cohabiting]

Although Uganda has been known to be in the lead in fighting against HIV/AIDS stigma some participants reported that the community still treated people living with HIV/AIDS unfairly which hinders disclosure.

*We are afraid to disclose the truth about our HIV status to people in the community because they discriminate us and isolate us and since some of us are still young, they wonder how we got infected. Some people are not aware that this disease is got in many different ways*

[Male, 27 years, married]

Some male participants commented that it seemed much easier for women to disclose HIV status than men and therefore benefit from accessing ARVs and other support.

*It is not easy for men to disclose. Male ego demands that they remain firm and guarded in times of crisis. Women open up easily to share issues that hurt them and seek advice; they are therefore always given more help.*

*Some men therefore test for HIV secretly and do not disclose to their partners. When they discover that they are positive, they even take drugs secretly without the spouses, families and community knowing*

[Male, 35 years, married]

Some clients seek services in distant places because of fear of being identified by people that know them. The youngest participant in the study travelled more than 50 km to access the TASO services. Although he could have accessed services in another TASO branch nearby, he did not do so due to stigma.

*....I come from Entebbe and it wouldn't be easy for me to seek services from the branch there. I fear to be seen around that place since I have grown up from there. That's why I came all the way here (to TASO Mulago)...*

[Male, 22 years, has a steady partner]

There were also contextual challenges to disclosure including lack of confidentiality. Participants in the FGD expressed concerns about the absence in some cases of professional confidentiality as well as client sensitivity and care among health workers which were cited as barriers to disclosure. One participant narrated a bad experience he had with a nurse when he went for treatment.

*He (the doctor) referred me to go to the laboratory for medical tests .I found a nurse who shouted at me in the crowd of other patients and said '...You who is suffering from AIDS go to the other side where the AIDS clinic is.' I was so angry that I just got transport to take me home without any treatment. I decided that I should die since that had brought me too much shame for me to bear*

[Male, 27 years, married]

Some female clients who had been educated about PMTCT during antenatal clinics experienced discrimination when it came to delivery. One participant narrated her experience.

*When I pleaded with the nurse telling her that I preferred to deliver by caesarean section and she refused, I explained to her that I was HIV positive and was opting for surgery in order to protect my baby from HIV infection. To my surprise the nurse who had been examining me added another pair of gloves to the ones she already had on in order to handle me. Can you imagine such discrimination? That is why some of us decide not to disclose*

[Female, 32 years, married – polygamous relationship]

All the participants in the FGD have disclosed their status to their current partners and are also publicly open about their status in their communities where they spend time conducting HIV/AIDS education. Nevertheless, they sometimes experience stigma when members of the public confront them and wonder how they can say that they are HIV positive when they have no signs or symptoms. One participant narrated what community members tell them.

*How do you tell people that you are sick when you don't have any signs? If we were in your position, we simply would not utter a word about our sero status unless we showed signs. Once you disclose, no one will marry you and you will generally be deprived of many things.*

The participant then commented:

*That is why disclosure for the clients on ARVS and who are looking well is a problem since people hardly believe that they are HIV positive.*

[Female, 35 years, married]

TASO promotes couple counselling to ensure that partners to registered clients, who need HIV services, can access them. However, stigma interferes with disclosure to the partners thus limits their access to services. A male participant in the FGD narrated the experience of a client who after registering with TASO was asked by the counsellor to bring his wife

so that she too could come and they could access services as a couple. This client did not come back; he decided to join a private facility instead where he receives services today. Other barriers to disclosure that participants mentioned were linked to how to disclose and what to say when disclosing. Some participants expressed their concerns in relation to the difficulty in disclosing.

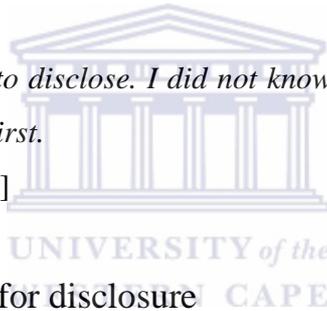
*I didn't really know where to begin from to tell him but that is why I insist on using condoms...*

[Female, 36 years, has a steady partner]

These concerns were not just an issue amongst those who did not disclose but also among the seven participants who disclosed their sero status to sexual partners. When asked whether he had any concerns about telling the partner about his sero status, one participant said:

*It was not easy for me to disclose. I did not know how to present the issue to my wife so I was afraid at first.*

[Male, 42 years, married]



#### 4.6 Conducive Conditions for disclosure

The participants who had not disclosed to their sexual partners were asked about the conditions they considered ideal for disclosure to their partners. Participants had various suggestions which include; couple counselling and testing, economic independence, peer support and involvement of the TASO staff in disclosure.

##### 4.6.1 Couple counselling and testing

Couple counselling and testing was a condition the participants raised that would favour disclosure. Among the participants that currently have a partner they have not disclosed to, is one male participant who had previously taken an HIV test with his late wife and they had received their results together.

*I went to take the HIV test with my late wife because we used to fall sick one after the other. My parents stayed nearby and they were the first people to ask us to go for HIV testing. We went and found that we were infected with HIV*

[Male, 50 years, cohabiting]

This same participant when asked about the ideal condition that would enable him to disclose to the current partner said;

*Maybe if the counsellors met us as a couple, counselled us and warned her not to talk to anybody and to accept treatment if she tests HIV positive.*

[Male, 50 years, cohabiting]

Some other participants also seemed to prefer taking the HIV test together with the partners because of the advantage of discussing with a counsellor. One participant said:

*Probably if we took a test together it would be possible for me to disclose. I think after discussing and planning with the counsellor I would be in position to inform her...* [Male, 27 years, cohabiting]

#### 4.6.2 *Economic independence*

Women's economic situation greatly influences their decisions to disclose. This was a key issue identified by the participants during discussions. Most of the female participants' fear about being abandoned or separating with their partners is based on the fact that they depend on their male partners for their livelihood. One participant when asked what she thought would be an ideal condition for disclosure responded;

*When I am confident that I can take care of myself and the children if he left me, then can I go ahead and disclose to him*

[Female, 46 years, cohabiting]

Other female participants expressed the dilemma regarding disclosure, the need for economic support and the type of relationships they engage in as a result. A female participant who has not disclosed to the partner remarked;

*Some women have sex with their partners not because they want it but because they want financial support from these partners they have sex with. It becomes impossible to tell such a partner that you are infected if you hope to remain financially supported.*

[Female, 36 years, has a steady partner]

During the discussion, the male participants also acknowledged that many women are willing to disclose as long as they have their own income so that in case their partners abandon them, they will not be stranded.

*Most women are economically dependant and as a result can only disclose when they have their own income*

[Male 40 years old, married polygamous]

Another male participant added;

*When a woman has economic support she can easily disclose; therefore there is need for women economic empowerment*

[Male 35 years, married]

#### 4.6.3 Peer Support

Support from peers is very critical in disclosure; it even favours adherence to treatment. Participants in the FGD reported how they were supported by peers and how they have often persuaded their peers to disclose by sharing their own experiences. Participants who are involved in peer counselling and community sensitisation have made a significant contribution in supporting their peers to disclose as they share their own experiences and other HIV prevention information with them.

*We personally go to the homes of other clients and support them during disclosure or share our experiences during the peer support group meetings about how we also managed to do the same. I think increased male involvement in our peer support groups will make a lot of difference in reducing HIV transmission because in the groups, we as peers share important information like condom use, Family planning and positive prevention*

[Male 35 years, Married]

*Since I disclosed my status in my village, I have supported many of my peers to open up too. I am referred to as the “TASO person” and I have become a*

*'counsellor' in the village. Disclosure helps one avoid many problems. Even my children now know about my status*

[Male, 40 years, married].

#### 4.6.4 *Involvement of the TASO staff in disclosure*

Disclosure counselling is one of the key aspects that are handled during the counselling sessions with HIV positive clients who register at TASO Mulago. The issues discussed by the counsellors during the counselling session on disclosure mainly focus on the advantages and disadvantages of disclosure, who to disclose to, and planning for disclosure. The counsellors' role is important therefore in facilitating disclosure as expressed by some participants. Most participants proposed that the counsellors should visit the clients' homes and help women disclose to their spouses as well as move from house to house conducting counselling and testing.

*I would suggest that counsellors plan to visit families and help the women tell their partners or they can ask the women for their spouses' phone numbers so that they (counsellors) contact them*

[Female 36 years old, has a steady partner]

Another female participant who has not disclosed because she is afraid of her partner's possible reaction said;

*I think that if counsellors and doctors moved from house to house conducting home based HIV counselling and testing, maybe some people like my partner would accept to be tested and treated. I realise many of my friends keep quiet in order to avoid conflict at home*

[Female 46 years old, cohabiting]]

One client who at first was shocked by her HIV positive results but was later counselled and encouraged to disclose said:

*My counsellor has helped me a lot because she even supported me as I told my husband my results. This happened after I had tried on my own and failed. Today we are all happy because he also tested positive and he is being treated.*

[Female, 42 years, married]

Even the male participants also acknowledged that talking to counsellors can prepare them to disclose to their partners. One participant in the FGD remarked:

*It is safer when the counsellor is there and you plan what to say with him or her so that when you get stuck, they will convince your partner and also counsel him or her.*

[Male 35 years, married]

Some participants however, still found it difficult to disclose in spite of the possibility of support the counsellors could provide. Participants raised varying issues that include a sense of hopelessness because the participant felt there was nothing the counsellors could do, the fear of separation due to discordance and the need for more time to gauge when disclosure would be appropriate.

One such participant said:

*I am not sure about disclosure at present because there were some clients who were encouraged to go and test then found out they were discordant and separated. Some people fear that their spouses may abandon them so it is wise to assess the situation before disclosure*

[Female 32 years, cohabiting]

#### 4.7 Conclusion

This chapter covered the results and findings of the study. The next chapter will now present discussion of the research findings comparing them to the already known findings. It will also cover the conclusion and recommendations drawn from the main issues of this study.

## CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

### 5.1 Characteristics of Study Participants

The majority of the study participants (68%) in TASO Mulago were between 30 to 49 years of age. This correlates well with the trend of registrations of new clients at TASO Uganda (TASO, 2008) where in 2007, 81% were between 25 to 50 years. In this study over 70% of participants had primary or partly secondary education, which compares well to registrations in 2007 (TASO Mulago, 2008) where 56% of the new clients had primary education and 22.7% secondary education. Level of education is often associated with knowledge about HIV/AIDS; which in turn, means that people will be able to make correct decisions regarding reproductive health. The Ministry of Health [MOH] (2009) HIV/AIDS surveillance report showed that comprehensive knowledge about HIV/AIDS increased from 27% in 2001 to 31% in 2006 for females and from 39% to 42% for males. During the individual interviews, some participants indicated that they were not confident about their knowledge about HIV/AIDS that would enable them to discuss disclosure with the partner. A study in Burkina Faso (Issiaka *et al.*, 2001) found that women with higher education were more likely to disclose. Thus interventions need to be designed to improve client's level of knowledge about HIV/AIDS and equipping clients (especially female) with negotiation skills to enable them to disclose to their partners.

### 5.2 Self Disclosure

The results of this study show that disclosure to partners did not always follow after the participants finding out they were HIV positive (i.e. testing). For example, two female participants, who tested positive in 1990 and 1996, have not yet disclosed to their current partners. This confirms that there are critical issues underlying serostatus disclosure among women that need to be addressed.

However, the results of this study show that when participants were prompted by various life circumstances (e.g. illness or pregnancy) to take an HIV test, disclosure often followed immediately. This agrees with another study on positive and negative

consequences of disclosure among sero-positive injection drug users (Parsons *et al.*, 2004) that revealed that individuals who had been living with HIV for longer periods of time and those with increased symptoms were more likely to disclose their HIV status. This indicated that disclosure of one's status as a result of ill health as opposed to personal initiative after testing is detrimental to HIV prevention among sexual partners. This calls for interventions that will enable most people to know their serostatus on a routine basis without waiting for triggers. Increasing access to testing services therefore, particularly at household level through HBHCT will enable more people to test which will contribute to scale up HIV prevention. It also requires a lot of sensitisation to the individuals who know their serostatus to understand their obligations and to take responsibility and practice positive prevention

### 5.3 Process of Disclosure

Disclosure should be viewed as a process and not a one time event. This involves various decisions including when to disclose, to whom, how to disclose and under what conditions. On-going counselling is required to provide clients with the required support as they come to terms with the reality of their sero-status and their obligation to prevent further transmission; as they make plans to share their results with their partners and adopt risk reduction strategies like condom use. The study however did not assess condom use among cohabiting relationships where disclosure did not occur making it impossible to know the possibility of condom use in these relationships mitigating some of the potential risk associated with non-disclosure.

#### 5.3.1 Targets of Disclosure

The results of the study show that immediate and extended family members were disclosed to. The choice of person to disclose to by the participant largely depended on the perceived support the person would offer to the client, the level of confidentiality, perceived implications of disclosure to that person, and client's readiness to disclose. Skogmar *et al.* (2006) affirmed that it is possible that patient's beliefs about their social network and treatment play an important role for disclosure. Derlega, Metts, Petronio and Margulis (1993) showed that the level of closeness in the relationship affected the

meaning and impact of disclosure. This implies that if interpersonal relations are poor, self disclosure will be limited.

The results show that some of the participants found out about their serostatus during PMTCT sessions. Positive outcomes of the PMTCT programme is increased involvement of male partners to the pregnant women which enables them to access more information in the prevention and care people living with HIV need. The study findings reveal that among the individual interviews and FGD, some women who tested when they were pregnant disclosed their serostatus to their partners before delivery. The disclosure could be due to the counselling they received during antenatal care that encouraged them to plan ahead regarding infant feeding options. In Abidjan (Brou *et al.*, 2007) it was also observed that women who tested during antenatal care were able to disclose their HIV status to their partners before delivery.

### 5.3.2 Partner's Reactions

The participants in the study made predictions about what they believed would be their partners' responses to the news of their HIV positive results. Most of the anticipated reactions by partners were negative: for instance, a number of participants believed that they would be blamed, abandoned, hurt, quarrelled with or even killed. However, the findings show that there was little agreement observed between anticipated and actual reactions from partners after disclosure. Most participants received understanding and support including some whose partners tested HIV negative.

Only two participants in discordant relationships faced a negative outcome which resulted in the end of their relationships. Discordance is a key factor in HIV transmission among partners if no effort is made towards HIV prevention. In Uganda for example, a study conducted by Gray *et al.* (2003) revealed that 12% of HIV positive discordant couples sero-converted annually.

Several issues are implied by the findings .First, this suggests that people who test HIV positive tend to fear negative outcomes if they disclosed. Other studies have had similar

results (Maman *et al.*, 2003; Kassaye *et al.*, 2005). TASO therefore should promote sharing of experiences by individuals who feared to disclose to partners due to anticipated negative reactions but managed to overcome this and were able to disclose. Secondly, the findings suggest that the decision to either remain in or break up a relationship after HIV status disclosure by a partner is not necessarily dictated by the disclosure of positive results but rather other factors like the attitude and commitment of the partners. Similar findings were observed in another study in USA by Ateka (2006).

Service providers should explore the client's level of comfort with disclosure of HIV status to significant persons in life such as partners, family members or friends. The client should be encouraged to disclose only when the client feels it is safe to disclose. The counsellors also need to be equipped with skills in facilitating disclosure. It is not enough to tell clients about benefits and disadvantages of disclosure. Where supported disclosure is required, counsellors should be skilled enough to provide the service or appropriately counsel the client on which approach to use. In discordant relationships therefore, the counsellor should make an effort to provide information that is convincing to the negative partner. Community sensitisation, couple counselling and HBHCT are among some of the strategies that could strengthen social support and self disclosure for PLHIV.

#### 5.4 Motivations for Disclosure

The participants who disclosed their sero status to their partners were motivated by the desire for partner to get treatment, need for partner's support, prior knowledge of partner's HIV status, anger and anxiety about the future.

Knowing the partner's positive HIV status eased disclosure of one's own status to the partner. This implies that discussing with one's partner about testing prior to seeking the service might help clients to anticipate partner's reaction and give them opportunity to plan how to disclose as observed in studies in Tanzania and USA (Maman *et al.*, 2003; Niccolai *et al.*, 2006; Simbayi *et al.*, 2007).

The findings also reveal that the patterns of disclosure varied by type of relationship. The clients who were married and were living together with their partners found it easier to

disclose their serostatus to them than clients who were cohabiting or in steady relationships. This seems to agree with another study (Niccolai, King, D'entremont & Pritchett, 2006) in which there was significant disclosure occurring most frequently in primary heterosexual partnerships than in non-primary heterosexual partnerships. TASO Mulago MIS 4<sup>th</sup> Quarter report (2008) revealed that disclosure is one of the subjects focused on during the counselling sessions. As a strategy to promote adherence in TASO, partner disclosure is a pre-requisite to enrolment on ARVs. The conditioning of disclosure to ART enrolment in TASO might explain the disclosure rate revealed in this study amongst primary partners whom the service providers possibly meet at home during HBHCT. This reflects on how the programme design might influence disclosure in the type of relationship and provides opportunity to service providers to design more positive prevention strategies and messages that would be adopted by clients in cohabiting or in steady relationships to ensure prevention.

The need for social support motivated disclosure among some participants in this study. A study on Self-disclosure of HIV status among women in Nairobi (Miller & Rubin, 2007), revealed one participant who disclosed as soon as possible because she wanted the husband and children to know while she was still healthy and thereby prepare to support her once she becomes ill.

This suggests that for effective HIV intervention, promotion of self disclosure and accessibility of social support services could result into significant reduction in HIV transmission. HIV/AIDS intervention programs promoting serostatus disclosure among PLHIV could demonstrate strategic benefits for individuals who have not disclosed their serostatus to their partners. Critical issues like HIV re-infection and the importance of protecting the HIV negative partner as well as the availability of a social support system for the HIV infected could come out explicitly as major benefits of disclosure.

### 5.5 Barriers to disclosure

The issues participants, who did not disclose their sero-status to their partners, mentioned fear of blame, fear of disappointing their partner, fear of abandonment, and

fear of stigma and discrimination. Having HIV is often associated with having multiple partners which creates a lot of stigma amongst those who are HIV positive. The men in the study particularly experienced this as a main barrier. A study in South Africa (Norman, Chopra & Kadiyala, 2005) also identified stigma as a main barrier to disclosure. The stress an individual goes through because of the perceived stigma of friends, family and community prevents disclosure and puts the partners at the risk of HIV infection.

There is need to mobilise Peer support groups especially male groups to provide support to their peers. These groups would not only encourage disclosure to partners but also prompt other men who have not taken an HIV test to do so.

The current study also shows that fear of abandonment is a barrier to HIV disclosure. For the women this was closely linked with the fear of losing economic support. This is related to other studies conducted (Kilewo, 2001; Antelman 2001; Issiaka, 2001). The participants interviewed in these studies agreed that fear was a common hindrance to disclosure. In another study in Tanzania (Maman, 2001), the women attending a VCT clinic cited the fear of their partners' reaction as the barrier to disclosure. The reaction they feared most was abandonment which would lead to a subsequent loss of economic support. It is clear from the results that lack of economic support is a key factor in increasing women's vulnerability to HIV/AIDS and fear of loss of economic support greatly inhibits disclosure to their sexual partners. For the women therefore, decisions to disclose HIV status should be made after support systems and safety nets have been put in place and careful considerations of risks such as abandonment and violence involved in such a disclosure. Since economic support has a major role in determining female clients' disclosure to their partners, TASO in an effort to scale-up HIV prevention should prioritise strategies that enhance women's economic empowerment and also seek out opportunities of linking female clients to agencies that provide the sustainable livelihood services.

In the study, another barrier participants raised was that they could not find a manageable way to disclose or did not know how to confront the situation. This barrier requires that counsellors, clinicians and peers supporting these clients be equipped with techniques

they can use to prepare their clients for disclosure. For instance Simoni and Pentalone (2004) suggest that role playing the likely scenarios on disclosure may be useful to help develop the confidence and communication skills clients need to share their results. This can facilitate successful disclosure in reality.

## 5. 6 Conducive Conditions for Disclosure

Some of the participants had various suggestions to improve disclosure such as couple counselling and testing, empowering women for economic independence, peer support and involvement of the TASO staff in disclosure. These findings affirm the current strategy of some HIV related campaigns of encouraging spouses of sexual partners to test together for HIV (Marum, Odoyo, Furnivall, Kamau & Ng'ang'a, 2004). Several participants interviewed wanted to use this approach even when they already knew their own HIV status and in that way they would avoid face to face disclosure. Counsellors should therefore assist clients to improve their interpersonal communication skills and encourage couple counselling and testing as a way to facilitate increased communication and disclosure amongst couples. As the couple gets services together this improves access to prevention messages and methods. Studies from other Sub-Saharan African countries suggest that behaviour change such as increased condom use may be greatest among couples who are counselled together (Allen *et al.*, 1992; Heyward, Batter & Malulu, 1993; Kamenga *et al.*, 1991). The results confirm that couple counselling should be promoted and open communication and dialogue amongst couples should be encouraged to enable them to discuss sexuality issues.

Increasing opportunities for couples to know their serostatus through HBHCT and supporting those who already know their serostatus to disclose, should be implemented. Counsellors should effectively handle sexuality counselling among cohabiting couples as well as those who have steady partners. They should seek to provide supported disclosure to individuals who access ART services and have not disclosed their serostatus.

People living with HIV also need Peer role models to support them in disclosure. If these role models share their own personal experiences, those who have not disclosed will learn from

them and emulate the good examples. This can be possible through encouraging the clients to join the established peer support groups of PLHIV in their communities.

## 5.7 Conclusion

While strategies like HBHCT and couple counselling have enhanced disclosure among sexual partners on ART living together in stable married relationships (primary), the partners in secondary relationships (cohabiting and steady) especially women, continue to face challenges in disclosure yet their sexual partners are at risk of HIV infection.

The study has re-affirmed the fact that while some people living with HIV/AIDS wish to disclose their HIV status to their partners, there are compound factors that make it difficult to disclose. This calls for effective strategies by government, TASO and other care agencies to ensure disclosure that will protect the individuals from negative consequences as well as ensure that sexual partners are disclosed to in order to reduce their vulnerability to HIV infection. In TASO where 60% of positive couples are in discordant relationships, disclosure is very important for curbing new infections. HIV prevention strategies in Uganda should therefore strengthen couple counselling and testing, and design strategies that ensure HIV status disclosure to sexual partners particularly those cohabiting and in steady relationships, and promote positive behaviour changes.

## 5.8 Recommendations

The following recommendations can be made based on the findings drawn from the study:

- *For Policy makers and managers* Most participants were in agreement with more sensitisation and undertaking of wider community education so that more couples are persuaded to go for couple counselling and testing which would enhance disclosure to sexual partner.
- Strengthen community outreach programmes for counselling and testing. This includes door to door HIV testing with emphasis on couples counselling and testing and community education

- Train more health workers to serve couples, conduct couples' counselling and testing and provide supported disclosure to clients who need support. Where supported disclosure is required, counsellors should be skilled enough to provide the service or appropriately counsel the client on which approach to use. TASO should give priority to issues of women economic empowerment and equipping clients with life skills during programming to ensure that they are supported to disclose without fear of negative outcomes

Traditional and cultural leaders need to be involved and educated about issues of gender inequality, HIV/AIDS and PMTCT.

*For Health workers*

Given the consequences posed by sexually transmitted strains of HIV to partners, prevention information giving to enhance adherence as well as building behavioural interventions skills interventions will be required by the clients

- Regular health talks and use of IEC materials about HIV disclosure should be made more available to support clients.
- To further de-stigmatise the community, encourage supportive structures at facility and community levels. Discordant couples' clubs, Positive men's union (POMU), Mama's club and other Peer support groups that are instrumental in serostatus disclosure and other prevention strategies like PMTCT, FP and increased male involvement in prevention and care services.

*For Clients*

- PLHIV in the Peer support groups can be encouraged to share information and experiences with their peers who have not disclosed and support them to do so.
- The music dance and drama sensitisations conducted by TASO clients who are open about their serostatus and have gone public should be targeted as another avenue to share information and demonstrate how disclosure to sexual partners could be conducted.

- Couples should be encouraged to talk about sexual matters like condom use, FP, HIV testing and disclosure.

*For researchers*

Issues of gender relations and gender based violence in the context of HIV serostatus disclosure to sexual partners need to be explored in order to come up with appropriate strategies for response.



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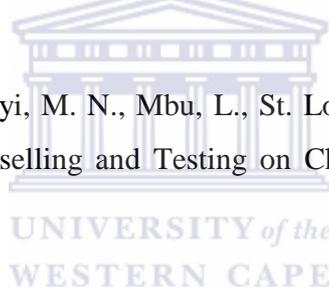
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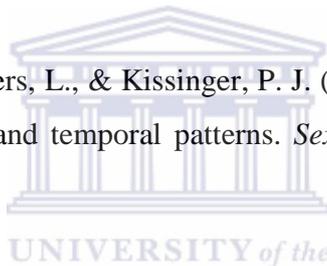
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Appendix 1



UNIVERSITY OF THE WESTERN CAPE

**School of Public Health**

Private Bag X17 • BELLVILLE • 7535 • South Africa

Tel: 021- 959 2809, Fax: 021- 959 2872

**PARTICIPANT INFORMATION SHEET**

Dear Participant

Thank you for your willingness to hear about this research. What follows will explain the purpose and process of this research and your possible involvement.

The research is being conducted for a mini-thesis. This is a requirement for the Masters in Public Health which I am completing at the School of Public Health, University of Western Cape.

Please ask me if there is anything you do not understand or are unclear about.

My contact details and those of my supervisor to whom I am accountable are recorded at the end of this Information sheet.

**TITLE OF RESEARCH**

Disclosure of HIV status to sexual partners amongst people who receive antiretroviral therapy in Kampala, Uganda.

**PURPOSE OF THE STUDY**

The counsellors at the different TASO sites have noticed that some of the clients who attend their centres choose to disclose their HIV status to their partners while others

choose not to. The research is trying to explore disclosure of HIV status to sexual partners among TASO clients on ART, what motivates and what inhibits some from disclosing their HIV status to their partners. It is hoped that with your participation a better understanding of what influences clients' decisions to disclose or not to disclose their HIV status to their sexual partners will be gained and suggestions can be presented on how to improve the disclosure. This research will inform the development of guidelines that will aim to support a more effective way of assisting clients to disclose their serostatus to sexual partners, within TASO Mulago in Kampala.

### **DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT**

The study will include individual interviews and a focus group discussion with clients on ART in TASO Mulago who have partners. Questions about your experiences/challenges in serostatus disclosure to your partner(s) will guide the interview/or discussion with you.

### **CONFIDENTIALITY**

*Your name will be kept confidential at all times. I shall keep away any other records of your participation including a consent form you will sign should you agree to participate in this research study, and destroy them after the research has been completed.*

### **VOLUNTARY PARTICIPATION AND WITHDRAWAL**

Your participation in this research is entirely voluntary in other words you do not have to participate. You will be free to stop at anytime if you choose to participate. The decision about whether or not to participate or to answer any specific questions asked in this study will not have any impact on your access to TASO services. If there is anything that you would prefer not to discuss, please feel free to say so. You will be free to get counselling support from your counsellor in case there are uncomfortable issues that arise that you feel need to be addressed.

### **BENEFITS AND COSTS**

You will not receive any direct benefit from participating in this study, though some individuals will have opportunity to interact with other clients facing similar experiences.

Nevertheless, the information obtained from the participants in the study may help the TASO counsellors and management to improve the support provided towards clients' serostatus disclosure to partners.

There are no costs for participating in the study other than the time you will spend in the interview/or group discussion

### **INFORMED CONSENT**

Before I proceed to interview you, your signed consent to participate in this research study is required. The consent form is included with this information sheet so that you review it and then decide whether you would like to participate in the study or

### **QUESTIONS**

In case you have further questions or wish to know more, I can be contacted as follows:

Tina Achilla

Student Number: 2520928

Cell phone: 256-772 541729

Email: [achillat@tasouganda.org](mailto:achillat@tasouganda.org), [achillatina@yahoo.com](mailto:achillatina@yahoo.com)

Telephone at work: 256-414-532580/1

Fax: 256-414 541 288



Below are contact details for my supervisor at UWC, whom I am accounted to.

Dr Brian van Wyk

Tel 021 959 3520 or by email [bvanwyk@uwc.ac.za](mailto:bvanwyk@uwc.ac.za)



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**INFORMED CONSENT**

**TITLE OF RESEARCH**

**Disclosure of HIV status to sexual partners amongst people who receive antiretroviral therapy in Kampala, Uganda**

As was earlier mentioned in the *Participant Information Sheet*, your participation in this research is entirely voluntary, in other words you do not have to participate if you do not want to. The decision about whether to participate in this study or to answer any specific question or withdrawal from the study will not have any impact on your access to TASO services to which you are entitled.

If you choose to participate, you are free to stop at any time .You may also choose not to answer particular questions that are asked in the study .If there is anything that you would prefer not to discuss, please feel free to say so.

The information collected in this interview will be kept strictly confidential.

If you agree to participate in this research study, your signed consent is required before I proceed with the interview with you.

I have read the information about this research study on the *Participant information sheet*.

I have been given an opportunity to ask any questions I may have, and all such questions or inquiries have been answered to my satisfaction.

I hereby consent to participate in this research study.

-----  
Participant Name (Printed)

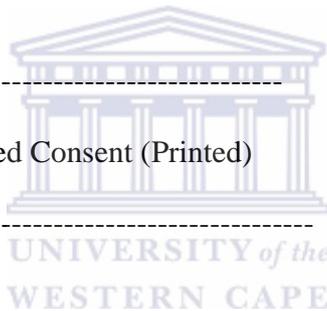
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Participant Signature

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Consent Date

-----  
Researcher Conducting Informed Consent (Printed)

-----  
**Signature of Researcher**

-----  
**Date**



### *Appendix 3*

**Question guide for TASO clients who disclosed status to partner(s)**

**Study Title: Disclosure of HIV status sexual partners amongst people who receive antiretroviral treatment to AIDS in Kampala, Uganda.**

#### **Section A: General information**

A1. Site Name: \_\_\_\_\_

A2. Interviewee Identification Number: \_\_\_\_\_

A3. Date of interview: \_\_\_\_\_

**Section B: Demographics of Interviewee:**

| Number | Questions  | Responses   |
|--------|--|---|
| B1     | Sex of Interviewee   | <input type="checkbox"/> Male <sup>(1)</sup> <input type="checkbox"/> Female <sup>(2)</sup>   |
| B2     | Age of Interviewee   | <input type="checkbox"/> 20-30 <sup>(1)</sup> <input type="checkbox"/> 30-40 <sup>(2)</sup><br><br><input type="checkbox"/> 40-50 <sup>(3)</sup>  |
| B3     | Education of interviewee                                       | <input type="checkbox"/> Completed Primary school <sup>(1)</sup><br><input type="checkbox"/> Partly Secondary school <sup>(2)</sup><br><input type="checkbox"/> Completed Secondary school <sup>(3)</sup><br><input type="checkbox"/> Post graduate degree <sup>(4)</sup><br><input type="checkbox"/> Nursing <sup>(5)</sup><br><input type="checkbox"/> Other <sup>(6)</sup> |
| B4     | How long have you been attending TASO centre?                  | <input type="checkbox"/> 1-5 yrs <sup>(1)</sup> <input type="checkbox"/> 5-10 <sup>(2)</sup><br><br><input type="checkbox"/> 10-15 <sup>(3)</sup>   |
| B5     | What type of relationship exists between you and your partner? | <input type="checkbox"/> Married/Spouse<br><input type="checkbox"/> Cohabiting/steady<br><input type="checkbox"/> Casual  |

C1. When did you first find out about your serostatus?

C2. What was your reaction when you first learned your serostatus?

C3. Who did you talk to about your test result after you found out?

The counsellors at the different TASO sites have noticed that some of the clients who attend their centres choose to disclose their HIV status to their partners while others choose not to. In order to better support and assist the clients, we are trying to understand the reasons for which they choose to disclose or not to disclose.

C4. Can you please tell me the reasons that made you decide to tell to your partner(s) your serostatus?

C4a. What made you think (feel) so?

C5. Did you have any concerns about telling your partner(s) about your status? (*Probe for which concerns and ask “what makes you think so?” for each concern given*)

C6. What reactions did you expect that your partner(s) was/were going to have?

C7. Can you please describe how you disclosed to your partner (s) (when, where, what words used)?

C8. If you could change something about how you disclosed, what would you change?

C9. If you had a friend who needed to disclose to her partner, how would you advise her to do it?

We are at the end of our interview and I would like to know if there is anything you would like to add on the subject before we leave.

Thank you for your time

#### ***Appendix 4***

#### **Question guide for TASO clients who did NOT disclosed status to partner(s)**

**Study Title: Disclosure of HIV status sexual partners amongst people who receive antiretroviral treatment to AIDS in Kampala, Uganda.**

#### **Section A: General information**

A1. Site Name: \_\_\_\_\_

A2. Interviewee Identification Number: \_\_\_\_\_

A3. Date of interview: \_\_\_\_\_

**Section B: Demographics of Interviewee:**

| Number | Questions  | Responses   |
|--------|--|---|
| B1     | Sex of Interviewee   | <input type="checkbox"/> Male <sup>(1)</sup> <input type="checkbox"/> Female <sup>(2)</sup>   |
| B2     | Age of Interviewee   | <input type="checkbox"/> 20-30 <sup>(1)</sup> <input type="checkbox"/> 30-40 <sup>(2)</sup><br><input type="checkbox"/> 40-50 <sup>(3)</sup>  |
| B3     | Education of interviewee                                       | <input type="checkbox"/> Completed Primary school <sup>(1)</sup><br><input type="checkbox"/> Partly Secondary school <sup>(2)</sup><br><input type="checkbox"/> Completed Secondary school <sup>(3)</sup><br><input type="checkbox"/> Post graduate degree <sup>(4)</sup><br><input type="checkbox"/> Nursing <sup>(5)</sup><br><input type="checkbox"/> Other <sup>(6)</sup> |
| B4     | How long have you been attending TASO centre?                  | <input type="checkbox"/> 1-5 yrs <sup>(1)</sup><br><input type="checkbox"/> 5-10 <sup>(2)</sup><br><input type="checkbox"/> 10-15 <sup>(3)</sup>  |
| B5     | What type of relationship exists between you and your partner? | <input type="checkbox"/> Married/Spouse<br><input type="checkbox"/> Cohabiting/steady<br><input type="checkbox"/> Casual  |

C1. When did you first find out your serostatus?

C2. What was your reaction when you first learned your serostatus?

C3. Who did you talk to about your test result after you found out?

The counsellors at the different TASO sites have noticed that some of the clients who attend their centres choose to disclose their HIV status to their partners while others choose not to. In order to better support and assist the clients, we are trying to understand the reasons for which they choose to disclose or not to disclose.

C5. Can you please tell me the reasons that made you decide NOT to tell to your partner your serostatus?

C4. What made you think (feel) so?

C5. Did you have any concerns about telling your partner about your status? (*Probe for which concerns and ask "what makes you think so?" for each concern given*)

C6. What reactions did you expect your partner(s) were going to have?

C7. Do you feel confident about your knowledge about HIV/AIDS to discuss the issue with your partner(s)?

C8. What do you think would be the ideal conditions for you to tell your partner(s) (examples: TASO staff disclose to partners themselves; after partner(s) are educated about HIV/AIDS first; after a number of months/years...)

C9. Is there anything that TASO staff can do to help/support you in your decision to disclose or not disclose to your partner (Example, discuss: more education about the disease; what words to use to disclose; tell partner on your behalf...)

We are arriving at the end of the interview, is there anything you would like to add before we leave?

Thank you for your time

## ***Appendix 5***

### **Guide to Conducting Focus Group Discussion**

The researcher would provide a general introduction to the group that:

The counsellors at the different TASO sites have noticed that some of the clients who attend their centres choose to disclose their HIV status to their partners while others choose not to. In order to better support and assist the clients, there is need to understand the reasons for which they choose to disclose or not to disclose.

The researcher will invite the participants to share:

- How and what enabled them to go and take an HIV test
- Whether they were able to share the results with anyone soon after.
- About their experiences in the disclosure of serostatus to their partner
- What they considered as factors that inhibit disclosure to sexual partners
- From their experiences and experiences of other clients what factors they consider to enable disclosure to sexual partners
- What suggestions they have that would improve disclosure to sexual partners among TASO Mulago clients on ART.

