



UGANDA MANAGEMENT INSTITUTE

**FACTORS AFFECTING HIV STATUS DISCLOSURE AMONG PEOPLE
LIVING WITH HIV/AIDS IN UGANDA: A CASE STUDY OF TASO
MASINDI.**

BY

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DECLARATION

I, Namanya Yusuf, hereby declare that the work presented in this report is my original piece, and confirm to the best of my knowledge that it has never been submitted either in part or in full for publication or award of a degree in any other institution

I therefore present it for the award of the degree of Masters of Management Studies (Project Planning and Management) of Uganda Management Institute.

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APPROVAL

This dissertation has been submitted for examination with our approval as supervisors.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Anti- Retroviral Therapy
FP	Family Planning
HBHCT	Home-Based HIV Counseling and Testing
HIV	Human Immunodeficiency Virus
HCT	HIV Counseling and Testing
PMTCT	Prevention of Mother- to -Child Transmission of HIV
MCH	Maternal Child Health
PHAs	People Having HIV /AIDS
PLWHAS	People Living with HIV/AIDS
VCT	Voluntary Counseling and Testing
KI	Key Informants
UNAIDS	Joint United Nations Programme on HIV/AIDS
NGO	Non-Governmental Organization
WHO	World Health Organization
SPSS	Statistical Package for Social Scientists
MOH	Ministry of Health

ABSTRACT

This study aimed at establishing the factors affecting HIV sero-status disclosure among people living with HIV /AIDS in Uganda through a case study of TASO Masindi. The study adopted a cross-sectional descriptive research design in which both qualitative and quantitative approaches were used.

The study objectives were: to establish the level of HIV-positive sero-status disclosure among TASO Masindi clients, identify social-cultural and economic factors that positively or negatively influence HIV-positive sero-status disclosure among PLWHAs in TASO Masindi, and to generate strategies that minimize the impact of the factors that hinder HIV-positive sero-status disclosure.

Data was collected using structured and non-structured questionnaires, an interview guide and documentary review. Quantitative data was entered into the Statistical Package for Social Scientists version 12.0, and analysis was done using Pearson product correlation coefficient to establish relationships between variables while regression analysis determined the strength of the relationship among the study variables.

The findings indicated that economic and gender-related factors, stigma and discrimination, and domestic violence hindered disclosure of positive sero-status among

PHAs while adequate knowledge and positive attitudes, and availability of supportive social systems promoted disclosure. It can therefore be concluded that a combination of social-cultural and economic factors affect disclosure of positive sero-status among PHAs either positively or negatively.

The study recommends that TASO Masindi Center should consider identifying avenues of strengthening available social support systems for PHAs, economic empowerment through Sustainable Livelihood Projects (SLPs) and activation of male involvement in HIV/AIDS programming so as to reduce gender-based violence related to disclosure of positive sero-status.

CHAPTER ONE

INTRODUCTION

1.1 Introduction

This study was about factors affecting HIV/AIDS status disclosure among People Living with HIV/AIDS (PLWHAs) in Uganda, through a case study of TASO Masindi. This chapter presents the background to the study, the statement of the problem, the purpose of the study, the research questions and hypotheses, the scope, the significance and the justification of the study, and operational definitions of the terms and concepts used in the study.

1.2 Background

1.2.1 Global context

The Human Immunodeficiency Virus (HIV) is unlike any other biological threat our specie has faced. HIV subversively undermines our immune system, crippling the physiological defenses designed to protect us from infections (HIV Counseling Manual, MOH, 2007).The terrible effects of HIV take time to manifest into Acquired Immune Deficiency Syndrome (AIDS), allowing an unwary host to further spread infection. HIV has, up to now, neither vaccine nor cure and is associated with a number of conditions, including intense fatigue, frequent malaria, severe pains, sand diarrhea, weight-loss and skin rashes among others. All these bring psychosocial distress, feelings of self-blame and withdrawal among PLWHAs.

According to a report of The Joint United Nations Programme on HIV/AIDS (UNAIDS 2007), there were 33 million people living with HIV/AIDS and over 2 million died of the disease in the same year globally. More than 25 million people worldwide have died of AIDS since 1981. At the end of 2007, women accounted for more than half of the people living with HIV/AIDS world-wide; and an estimated 370,000 people younger than 15 years of age became infected with HIV.

Globally, the number of children under 15 years of age, living with HIV, increased from 1.6 million in 2001 to 2 million in 2007.

In addition, it is important to note that HIV/AIDS has not only affected the human race economically; it has also had profound psychosocial challenges, including stigma and discrimination, gender-based violence and reluctance and failure to disclose HIV among others.

In view of the above, therefore, reluctance and failure to disclose HIV positive sero-status is one of the psychosocial challenges facing people living with HIV/AIDS globally, and this largely explains why this study was undertaken.

According to the HIV Counseling and Testing Manual (2009), HIV status disclosure is a situation where information about one's HIV sero-status is shared or revealed. This can be self-initiated or a counselor can help an individual to develop a plan as to when, how and to whom the HIV sero-status will be revealed or disclosed.

This definition concurs with that of Medley et al (2004) who have described HIV/ AIDS disclosure as a process that involves decisions about timing, to whom, how, and under what conditions to reveal one's HIV/AIDS sero-status.

Due to psychosocial challenges associated with HIV/AIDS, disclosure of a positive status seems to be difficult among PLWHA. For example, a study done in the French Antilles and French Guiana found out that 69.7% of the respondents had disclosed at least to one person, and 30.3 % had not told anyone (Bouillon et al, 2007). Similarly, a study conducted in South India on sero-positive disclosure revealed that, of the 68 participants, voluntary disclosure was noted in 44 participants (65%) while the other 24 participants (35%), had disclosed their status without their consent (Chandra et al, 2003). However, this study did not explain why or under what circumstances the 24 (35%) participants had revealed their positive sero-status without their consent.

Studies conducted in the United States reveal that HIV positive sero-status disclosure is still a challenge. For example, a study on the rational context of non-disclosure of HIV positive sero-status to main sexual partners among women living with HIV/AIDS, found out that, of the 366 participants, 11 % had not disclosed their sero-status to their main partner (Peterson et al, 2006). On the other hand, a qualitative study that correlated stigma to depression among older adults, found that there were higher levels of stigma among African American respondents

than among White respondents, and 60% of the same sample reported protective silence (non-disclosure) as a method of avoiding stigma.

Studies done in France by Levy et al (1999), that assessed the length of time from HIV diagnosis to disclosure, found that among the patients from an outpatients clinic, 42.5% had disclosed immediately after diagnosis, 24% within a half a month, and 24% had waited more than a year before disclosing. Across all studies, there were some individuals who never shared their sero-status with anyone.

This study, however, did not spell out the factors that facilitated the 42.5 % of the out-patients who disclosed immediately after diagnosis or that hindered or delayed the 24% that disclosed after a year and above. These factors were central to the present study. The findings of this study further suggest that the HIV disclosure rate among PLWHAs could have resulted from available HIV/AIDS services, a condition that was not explored in the study, and that the present study sought to examine.

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HIV/AIDS status disclosure to significant others has been associated with race and the types of relationship among other variables. For example, a UK-based study found that White gay men were more likely to disclose to a parent than heterosexual Black and African individuals were, and all groups addressed were more likely to have disclosed to their mothers than to their fathers (Emlet 2008).

This study, however, did not explain why individuals preferred to reveal their sero-status to their mothers rather than to their fathers, a situation that would have paved avenues for devising strategies that would promote disclosure to even significant others.

In view of the above, one can rightly conclude that HIV /AIDS status disclosure is a global challenge affecting People Living with HIV/AIDS, and that the levels and modes of HIV/AIDS status disclosure differ from situation to situation, and are influenced by factors such as race and prevailing cultural norms and other circumstances.

1.2.2. African context

The HIV/AIDS epidemic has had its most profound impact to date in sub-Saharan Africa. The majority of the people living with HIV/AIDS (68%), of new HIV infections (68%), and of AIDS-related deaths (76%) are in this region, which only accounts for 11% of the world's population. HIV is also the leading cause of death in the region, and studies have found declines in life expectancy due to HIV in many of the hardest-hit countries in sub-Saharan Africa, including Botswana, South Africa, Swaziland, Zambia, and Zimbabwe.

The epidemic has already posed serious development challenges for the region, where most countries are already low-income and heavily or moderately indebted, thereby adversely affecting communities, families, livelihoods, and numerous sectors of society. Some of these countries also face other challenges that have been exacerbated by HIV/AIDS, which include food insecurity, internal migration and conflicts.

The latest estimates from the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) indicate that new HIV infections in sub-Saharan Africa declined between 2001 and 2007, and that HIV/AIDS prevalence has stabilized, although levels of infection in sub-Saharan Africa are still the highest in the world, at 1.7 million in 2007, or more than 4,500 new infections per day (UNAIDS Report 2007).

The challenges of HIV positive sero-status disclosure in Africa do not differ significantly from those elsewhere in the world. For example, a study carried out in the Niger Delta established that 23% of the PLWHA respondents had not disclosed their sero-status, while of the 77% who had disclosed their status, 22.3% had disclosed to parents, 9.7% to siblings, 27.8% to pastors, 6.3 to friends, 10.4 to family members, and 23.6 to sexual partners. Fear of stigmatization, victimization, confidants spreading the word, accusation of infidelity and fears of abandonment were all noted to be barriers of disclosure (Ngozi et al, 2009). Just like in the case of the studies done in the French Antilles and French Guiana, where 30.3 % had not disclosed to anyone, no efforts were made to establish the factors that hindered HIV/AIDS disclosure among the Niger Delta respondents. The present study sought to establish these factors in the case of TASO Masindi clients.

HIV/AIDS disclosure has also been related to gender. For example, in a study conducted in Burkina Faso on gender-related factors influencing HIV sero-status disclosure in patients receiving Highly Active Antiretroviral Therapy (HAART), it was observed that disclosure rates to partners were 72.1% and 79.9% in males and females respectively (Ndaiye et al, 2009).

Related to the above, in a study conducted in South West Ethiopia, Kebede et al, (2008) observed that 9.2% of the respondents had not disclosed their sero-status, and 54% of those who had not disclosed their HIV sero-status stated that fear of negative reactions from their partners impeded disclosure.

Further, some studies in Africa have associated disclosure of HIV sero-status with characteristics of psychosocial support-seeking. For example, a study conducted in Western Kenya observed that across all 397 participants, HIV/AIDS disclosure was rarely reported to sexual partners, family members or friends (Shacham et al 2008). But this study, did not explain what forms of support services were given to those individuals who disclosed, a situation that would have paved an entry point into supporting PLHWAs to disclose their status.

Other studies in Africa have assessed the length of time from diagnosis to disclosure. For example, a prospective study conducted in Tanzania among pregnant women revealed that prevalence of disclosure to a partner ranged from 22% within 2 months to 40% after nearly 4 years (Antelman et al, 2001). However, no efforts were made to establish why the majority (40%) took so long to share their sero-status with anyone; yet, the higher the rate of HIV status disclosure, and the sooner disclosure occurs, the higher the chances of reducing the spread of HIV/AIDS.

On the other hand, studies done in Africa have shown diverse experiences and rates of disclosure in various communities. For example, a study conducted in two South African

communities found out that many of the experiences surrounding disclosure of HIV infection in the two communities were not entirely dissimilar: individuals in both Mbekweni and Umzimkhulu found it difficult to disclose their HIV status, went through periods of negotiation and management, and did not encounter dissimilar rates of stigma or rejection from loved ones (Norman et al, 2007).

1.2.3 Ugandan context

AIDS was first observed in Uganda in the early 1980s. As in other countries throughout the world, many people responded by denying the reality of AIDS and by stigmatizing those believed to have the disease. The first case of an HIV/AIDS victim was identified in Kasensero fishing village on the western shores of Lake Victoria. Later, the disease spread rapidly to all parts of Uganda and other parts of East, Central and Western Africa. The sufferers of HIV, commonly known as SLIM in Uganda, were not only fishermen but also traders that were involved in smuggling goods to and from Tanzania (Kaleeba et al, 2000).

According to a national sero-behavioral survey (2004-2005) conducted by the Ministry of Health, (2006) 6% of Ugandan adults aged 15-49 were infected with HIV. The same survey established that the prevalence rate among women was 8% higher than that among men, that 1.2 million people were living with HIV/AIDS; and that HIV accounted for 12% of deaths annually.

However, due to political will, Uganda managed to outperform other countries in sub-Saharan Africa in scaling down the scourge. This has been through HIV/AIDS campaigns that foster

Abstinence, Being faithful to your partner, Condom use and Disclosure of sero-status (ABCD) plus Information Education and Communication (IEC) strategies in addition to Voluntary Counseling and Testing (VCT), and HIV counseling that empowers PLWHAs to seek medical care and to practice positive living.

Like in other African countries, HIV positive sero-status disclosure still poses formidable challenges to People Living with HIV/AIDS in Uganda. For example, King et al (2008), in their study of processes and outcomes of sero-status disclosure to sexual partners among PLWHAs, found that of 1,092 participants of TASO Jinja, 31 % had not disclosed their sero-status to their most recent partners. For those who had disclosed their sero-status, disclosure was associated with being married, having attended TASO sessions for more than 2 years and knowledge of the partner's sero-status. However, this study did not establish the factors that hindered disclosure among those that had not shared their sero-status.

Further, Kadowa and Nuwaha (2009), in their control study of the factors affecting HIV disclosure in Mityana District, where they compared 139 People Having AIDS that had disclosed with 139 that had not disclosed, noted that those who had not disclosed cited the reasons for non-disclosure as fear of divorce and violence 58/139 (42%) for those in sexual relationships, fear of discrimination and stigma 40/139 (29%), fear of rumor-mongering 29/139 (21%), fear of accusation of promiscuity or infidelity 32/139 (23%) %, and having no good reason to disclose were 11/139 (8%). Asked whether they needed any kind of support to disclose, the majority 72/139 (52%) said that they did not need any support, while 38/139 (27%) said that they needed skills of disclosing their status. All the same, this study did not

provide us with information about the factors that facilitated disclosure among those that had revealed their sero-status, though there were indications that knowledge, skills, and approaches have some influence on disclosure.

1.2.3.1 *The AIDS Support Organization (TASO).*

The AIDS Support Organization (TASO) was founded in 1987 by Dr Noerine Kaleba and 15 other members, some of whom have since passed away due to AIDS. TASO is one of the largest HIV /AIDS service organizations in Uganda and Africa at large, and it is involved in the provision of preventive care and social support services to people infected with, and affected by, HIV/AIDS.

The organization has four regional offices (Central, Western, Northern and Eastern), eleven centers (Masindi, Soroti, Mbarara, Jinja, Rukungiri, Masaka, Mbale Soroti, Tororo Gulu and Mulago), and one training centre at Kanyanya, a Kampala suburb. TASO also supports 11 Mini TASO Centers throughout the country. TASO is governed by a Board of Directors elected by the general assembly. The Executive Director is the Chief Accounting Officer and below him are two Deputy Executive Directors, one for programs and strategic information and the other for support services. The organization has five directorates: Human Resource and Administration, Finance, Advocacy and Networking, Programs and Strategic Information, and Capacity-Building and Development. These are headed by directors who are assisted by deputy directors. There is also a level of regional and centre managers that head various units below whom are the Heads of Department, and finally the support staff at the bottom.

TASO Masindi opened in 2005, and is found in Masindi District in mid-western Uganda. TASO Masindi Centre is headed by the Center Manager and below him are the Heads of Department. Below the Heads of Department are the Assistants, support staff and volunteers respectively.

TASO Masindi serves people from nearby and distant areas, including those from Hoima, Nakasongora, Apac, Bulisa and Luwero districts. The people that receive HIV/AIDS services are both urban and rural, and are characterized by poverty and diverse social cultural backgrounds in addition to a multiplicity of tribes and languages. The dominant ethnic group is that of the native Banyoro who speak Runyoro. At the close of 2008, TASO Masindi had 4,000 cumulative registered clients that accessed HIV/AIDS services, including preventive care and social support.

TASO Masindi offers a number of core services, including HIV/AIDS counseling which is offered to both old and new clients at the TASO Centre, Outreach Clinics, Community Drug Distribution Points (CDDPs), clients' homes, in hospital wards, and in institutions, including schools and colleges. Within the HIV-testing and counseling (HCT) or VCT program, emphasis is placed on the importance of HIV sero-status disclosure among the HIV-infected clients, particularly to their sexual partners, bearing in mind that disclosure is an important public health goal for a number of reasons.

Counseling motivates sexual partners to seek HIV-testing services, and it promotes positive behavior change, enhances clients' coping processes at the personal level and within the systemic family, and thereby decreases transmission of HIV infection (TASO Annual Report, 2008). According to the same report, clients who attained the capacity to reveal their sero-status to significant others stood at 90% out of the 4573 cumulative registered clients of TASO Masindi (TASO Annual Report 2008).

The report further indicates that, there are more observable behaviors exhibited by some clients that reflect non-disclosure, and these include clients deliberately giving wrong home directions, clients rejecting home visits or in being identified with TASO.

This study is, therefore, meant to establish the factors affecting HIV/AIDS status disclosure among PLWHAs in TASO Masindi, Masindi District. Table 1.1 below shows crude estimates of the rates of HIV/AIDS disclosure among TASO clients by center in the year 2008.

Table 1.1: Rate of disclosure among TASO clients by centre, 2008

Center	Total active registered clients	Clients that revealed HIV/AIDS sero- status	Percentage disclosure by center
Mbarara	6500	6000	95%
Rukungiri	4700	4200	89%
Masaka	5600	5000	89%
Gulu	5600	5050	90%
Mbale	7300	6300	90%
Tororo	7400	6400	90%
Soroti	7000	6300	93%
Entebbe	5500	5000	95%
Mulago	5700	5330	93%
Jinja	6200	5600	90%
Masindi	4573	4808	90%

Adopted from TASO Annual Report 2008

1.3: Problem Statement

Uganda's national response to the HIV/AIDS pandemic has been recognized and applauded worldwide, and its success in reducing HIV prevalence is considered unique in Africa. The country practices Voluntary Counseling and Testing (VCT) services and VCT has remained the main model through which individuals learn their sero-status. Clients and patients of HIV Counseling and Testing (HCT) have access to HIV prevention messages ranging from ABC to HIV status disclosure (Uganda National Policy on HIV Counseling and testing 2005).

However, Ncama (2007) noted that the major challenge in HIV/AIDS care in all developing countries is the acceptance and disclosure of a positive HIV status by people living with HIV/AIDS. And, yet UNAIDS (1997) reveals that disclosure of one's HIV status to one's sexual partner and relatives is an important prevention goal emphasized by the World Health Organization (WHO) and the Center for Disease Control (CDC) in their respective protocols for HIV counseling and testing. Similarly, the TASO Annual Report (2008) reveals that HIV positive sero-status disclosure to significant others facilitates access to support, care and prevention efforts as well as clients' coping processes at the personal level, and within a systemic family.

Despite the continuous sensitization about the benefits of HIV positive status disclosure, the rate of disclosure among TASO clients dropped by 1%, from 90% in 2008 to 89% in 2009 (TASO Annual Report (2009)). This trend is worrisome because, already, the HIV/AIDS disclosure rate in Uganda is relatively low (78% - 89%), and any case of disclosure, however low, increases the potential for the spread of the scourge.

In addition, more observable behaviors that reflect non-disclosure have been exhibited by some clients, and these behaviors include deliberately giving wrong home directions, rejecting home visits or being identified with TASO. This does not only compromise clients' wellbeing but also TASO's ability to prevent HIV-infection.

Therefore, it is imperative to establish the factors that affect HIV/AIDS status disclosure among people living with HIV/AIDS in Uganda, through a case study of TASO Masindi Centre, Masindi District.

1.4: Purpose of the Study

The purpose of this study was to establish the factors affecting HIV status disclosure among People Living with HIV/AIDS in Uganda, through a case study of TASO Masindi Center, Masindi District. This was done with the aim of making general recommendations on how to help people living with HIV/AIDS to disclose their sero-status.

1.5 Specific Objectives

1. To establish the level of HIV positive sero-status disclosure among TASO Masindi clients from 2005 to 2010.

2. To identify socio-cultural and economic factors that influence HIV sero-status disclosure among PLWHAs in TASO Masindi.
3. To generate strategies that can minimize the impact of the factors that hinder HIV sero-status disclosure among PLWHAs in TASO Masindi

1.6 Research questions

1. What was the level of HIV sero-status disclosure among TASO Masindi Center clients from 2005 to 2010?
2. Which socio-cultural and economic factors influence HIV status disclosure among PLWHAs in TASO Masindi?
3. Which strategies can be adopted to minimize the impact of the factors that hinder HIV/AIDS status disclosure among PLWHAs in TASO Masindi?

1.7: Research Hypothesis

This study was based on one general and basic hypothesis from which the researcher derived six (6) working hypotheses as will become apparent in Chapter Four. The basic hypothesis was the following:

There are no socio-cultural or economic factors that influence HIV positive sero-status disclosure among PLWHA in TASO Masindi.

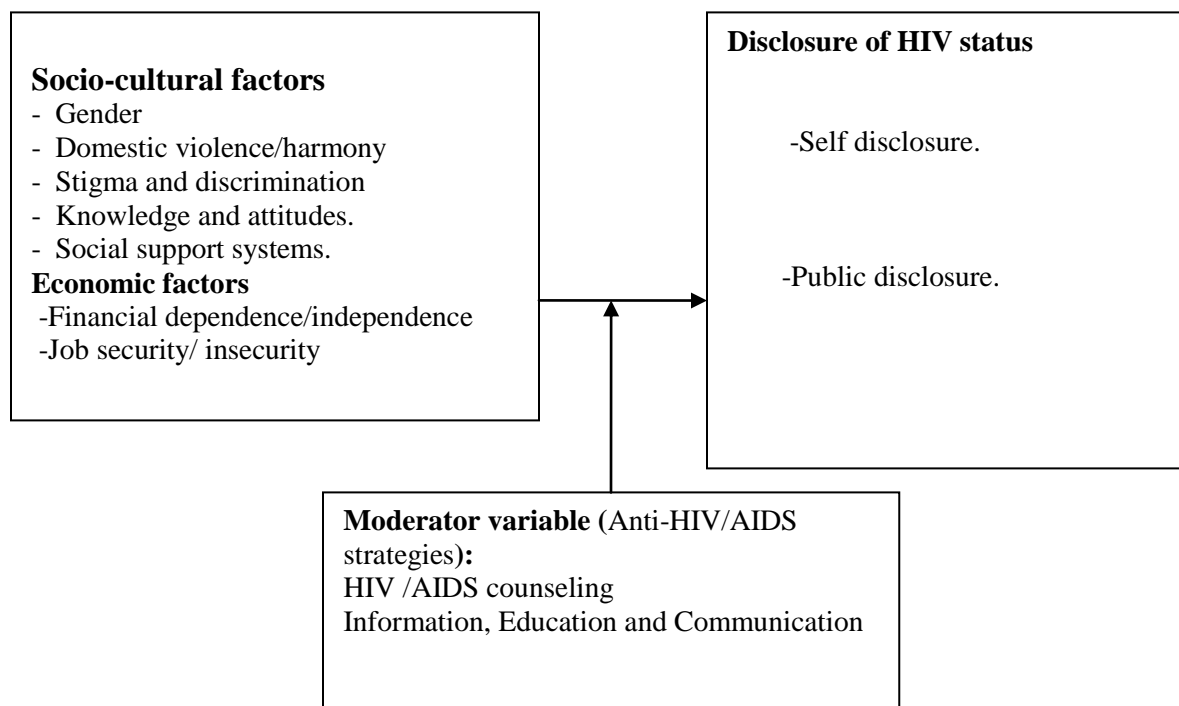
1.8: Conceptual Framework

This study was based on the concept that socio-cultural and economic factors are the independent variables that account for public and self-disclosure as the dependent variables. Moderating the impact of the independent variables on the dependent variables are anti-HIV/AIDS strategies, principally HIV/AIDS counseling, information, education and communication.

Figure 1.1: Factors affecting HIV positive sero -status disclosure among PLWHAs

Independent Variables

Dependent variable



Source: Adopted from Kimberly & Serovich (1995) and modified by Namanya Yusuf.

As Figure 1 above illustrates, the independent variables are the factors that influence HIV positive status disclosure, and they include socio-cultural and economic factors.

The dependent variable was operationalised in two forms: self disclosure and public disclosure.

1.9 Significance of the Study.

The findings of this study are likely to be of major significance to a number of categories of stakeholders, including Government of Uganda functionaries, especially the Ministry of Health, civil society organizations, particularly those engaged in efforts to combat HIV/AIDS and its effects, and students and researchers of HIV/AIDS.

Government of Uganda functionaries are likely to benefit from the findings of the study in that the study will expose the factors that promote and hinder HIV status disclosure, and suggest strategies for minimizing the impact of the hindering factors. This knowledge will help the functionaries in devising better strategies for promoting HIV disclosure and reducing the incidence of the disease and its negative consequences.

For their part, TASO and other HIV/AIDS service organizations in Uganda and elsewhere are likely to use the findings of this study to improve their management and support strategies for people living with HIV/AIDS, especially in the area of HIV status disclosure.

Finally, students and researchers of HIV/AIDS and related issues are likely to use this study as a source of reference, and to be motivated by the same study to undertake further research on the HIV/AIDS scourge.

1.10 Justification of the study.

Despite the provision of various types of HIV/AIDS counseling: individual counseling, group counseling, and continuous health education on the benefits of HIV /AIDS status disclosure, there are more observable behaviors exhibited by TASO Masindi clients that depict non

disclosure. Some clients deliberately give wrong home directions, some reject home visits while others do not want to be identified with TASO. Moreover, the 2008 and 2009 reports indicate that, though there was an increase in the total number of TASO clients, and in the absolute number of clients who disclosed their positive HIV sero-status, the rate of disclosure declined by 1% from 2008 to 2009. This suggests that infections may be on the increase, and HIV prevalence could also be increasing. Yet, combating HIV/AIDS, malaria and other diseases is one of the millennium development goals that aims at reducing the HIV/AIDS pandemic in all developing countries by 2015. It is imperative, therefore, to establish the factors affecting HIV/AIDS disclosure among people living with HIV/AIDS in Uganda through a case study of TASO Masindi Centre- Masindi District in Uganda.

1.11: Scope of the Study

1.11.1 Content scope

This study investigated the factors affecting HIV sero-status disclosure among PLWHAs in Uganda, through a case study of TASO Masindi. The study focused on establishing the level of HIV positive sero-status disclosure among TASO Masindi clients, identifying the factors that promote or hinder HIV/AIDS sero-status disclosure, and generating the strategies that would minimize the impact of the factors that hinder HIV/AIDS disclosure, thereby reducing the spread of HIV infection.

1.11.2: Geographical scope

The study was conducted at TASO Masindi Center, located in Masindi Hospital in Masindi District, Uganda. Masindi District is about 240 km on Kampala –Gulu road and borders with Hoima, Nakasongola, Apac, Bulisa and Gulu districts respectively. Masindi was chosen because it has a high incidence of HIV/AIDS and no similar study had ever been conducted in the district.

1.11.3: Time scope

The period under study was 2005 to 2010 because during this period TASO experienced stability in its core activities in the area, creating ideal conditions for data collection. The study took a period of five months, from August to December 2010.

1.12: Operational Definition of Terms and Concepts

For purposes of this study, the following terms and concepts were used to signify the meanings indicated below:

Acceptance: Conveying a sense of friendship to a person even when she or he is involved in disagreeable behavior or in a disagreeable situation (.HCT Training Manual for HIV counselors 2009)

Client: a person who is HIV-positive, registered and receives services from TASO (TASO Annual Report 2007)

Counseling: a helping relationship meant to assist a person to cope with some aspect of his or her life (.HCT Training Manual for HIV Counselors 2009)

Disclosure: a situation where, or an act by which, a client reveals his or her HIV sero-status information with another person or other persons (HCT Training Manual for HIV counselors 2009)

Positive Sero-status: a state of being HIV-positive. (TASO Annual Report 2007)

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter presents the theoretical review, the actual review and a summary of the literature review. The review was intended to establish data related to the factors affecting HIV /AIDS status disclosure among people living with HIV/AIDS and was based on both primary and secondary sources. The literature review is presented according to the objectives of the study.

2.2: Theoretical Review.

This study was guided by two theories and these are the Health Belief Model and the Consequence Theory.

2.2.1 The health belief model/theory

The Health Belief Model (HBM) is a psychological model that attempts to explain and predict health behaviors by focusing on the attitudes and beliefs of individuals. This model was developed in the 1950s to explain the lack of public participation in health screening and prevention programmes. The model was later adapted to explore a variety of long- and short-term health behaviors, including sexual risk behaviors and the transmission of HIV/AIDS (Rosen stock, Strecher and Becker 1994)

The model consists of four key variables: perceived threat, perceived benefits, perceived barriers, and cues of action.

Perceived threat is itself composed of two dimensions: perceived susceptibility and perceived severity of a health condition. Perceived susceptibility refers to one's subjective perception of the risk of contracting a health condition while perceived severity is conceived as feelings concerning the seriousness of contracting an illness and leaving it untreated, including evaluations of both medical and clinical consequences and possible social consequences. Relating this to HIV status disclosure, individuals may not disclose their sero-status due to social fears or fears of understanding the associated outcomes of the disease condition.

Perceived benefits are the sum-total of believed effectiveness of the strategies designed to reduce the threat of illness.

Perceived barriers are the perceived potential negative consequences that may result from taking particular health actions, including physical, psychological and financial demands. In the view of the above, HIV status disclosure is hindered by the fears that individuals may lose their financial support or may suffer from physical and domestic violence once they disclose or reveal their sero-status.

“Cues of action” refers to events, such media publicity, or conditions, such as physical symptoms of a health condition or environment, which motivate people to take action. Therefore, the health belief model/ theory constitutes a useful framework within which the researcher was able to identify and explain the factors that motivate or de-motivate PLWHAs to reveal their sero-status.

2.2.2: The consequence theory

Serovich (2001) introduced the consequence theory which states that persons with HIV are likely to inform significant others and sexual partners once the rewards for disclosing outweigh the associated costs. Derlega et al. (1998) contended that individuals who are HIV-positive contemplate the need for both privacy and disclosure in determining whether to disclose an HIV-positive diagnosis. This is in line with some of the literature reviewed, showing that HIV status disclosure is sometimes conceived or perceived as a threat to some of the HIV/AIDS patients because of the risks involved. Similarly, as seen above, the consequence theory can help us to identify and explain the factors that motivate PLWHAs to reveal their sero-status or that discourage them from doing so.

2.3: Actual Review of Literature

The actual review of literature was based on the main concepts as they were conceived earlier in the conceptual framework in Chapter One.

2.3.1 Disclosure

In relation to HIV and AIDS, disclosure is a process of revealing one's sero-status to partners, household members and significant others (Positive Prevention Participants' Manual, 2009). HIV status disclosure takes one or more of three forms: self-disclosure, supported disclosure, and public disclosure.

2.3.2 Level of disclosure

According to this study, the level of disclosure is operationalised by three major concepts: self-disclosure, supported disclosure and public disclosure.

Self-disclosure is where a peer discloses his or her sero-status to the sexual partner, a household member or significant others by himself or herself.

Supported disclosure is where a peer discloses his or her sero-status with the help of a counselor, a friend, a trusted and respected family member or a religious person.

Public disclosure is a situation where PLWHAs voluntarily inform the public about their sero-status at different gatherings (Positive Prevention Participants Manual, 2009).

In relation to the above, existing literature indicates that the rates of disclosure in developing countries are notably lower than those in the developed world, that is 69.3% considerably less than the average rates from the studies conducted in developed countries (79%).

In addition, a large proportion of studies from developing countries have reported that women did not disclose their test results to anyone. For example, 10% -78% of women in developing countries did not disclose their HIV sero-status as compared to 3%- 10% of women in developed country studies. A similar trend is observable among PLWHA in Uganda where, in

many cases, women fear disclosing their sero-status due to anticipated undesirable consequence.

According to available literature, disclosure is influenced by both social-cultural and economic factors. The social-cultural factors include gender, domestic violence, stigma and discrimination, knowledge and attitude, and social support systems. The economic factors include financial dependence or independence and job security or insecurity. However, these two categories of variables are moderated by two main factors: HIV counseling and Information, Education and Communication (IEC) strategies. It is these independent and moderating variables that influence HIV status disclosure either negatively or positively.

2.3.3: Factors that influence HIV positive sero-status disclosure.

2.3.3.1 Social support systems and HIV/AIDS disclosure

It has been noted that the support of close relatives is fundamental in coping with HIV/AIDS and in accessing the emotional and material support necessary for sustained adherence to treatment. This is because disclosure to family members is imperative to ensure their support, identify tools or resources that can minimize the possible risks and maximize the potential benefits of disclosure. A quantitative study conducted by Nachega et al (2004) on adherence and treatment among people living in Soweto, South Africa, found out that “fear of being stigmatized by sexual partners and the disclosure outcomes affected adherence”. Further, the study revealed that disclosure, specifically to sexual partner, is a strong factor in the overall adherence rate. Ultimately, the extra pressure of hiding their HIV status from those closest to

them, combined with the already strenuous task of maintaining ART, negatively impacted patients' ability to effectively manage their disease and adhere to their medication regimen Nachega et al. (2004). Related to the above, Wouters (2009), in his study conducted in South Africa on the impact of community support initiatives among community health workers and treatment support groups, found that there was a strong and stable positive association between community support and disclosure to family members. The immediate and long-term impact of community support on the disclosure by sero-positive patients to family members indicated that initiatives, such as community health workers and HIV support groups, run by people living with HIV/AIDS, should be strengthened, especially for those patients who cannot disclose their status to immediate family and close friends.

2.3.3.2 Knowledge, attitude and HIV/AIDS disclosure

It is commonly known that knowledge is virtue. Women and men who are economically disadvantaged are less likely to have information about HIV/AIDS than those from higher income levels, and are therefore likely to be more vulnerable to infection. An analysis conducted by Gwatkin and Deveshwar-Bahl (2001) shows that knowledge of HIV/AIDS prevention is distinctly higher among the better-off than among the disadvantaged in almost every country with available data. Moreover, regional comparisons revealed that in the lowest socio-economic groups, knowledge was higher in sub-Saharan Africa (62%) than in Latin America and the Caribbean (52 %) (Gwatkin and Deveshwar-Bahl, 2001).

As established above, lack of knowledge about sex and HIV/AIDS greatly constrains the ability of young people to protect themselves from infection. The gender gap in access to such information underscores the need to ensure that girls, in particular, have access to accurate information in a frank and open way. Although it is true that knowledge about prevention is not enough to bring about behavior change, it is also true that there are many individuals, particularly young women, who are seriously disadvantaged in this epidemic because of a lack of knowledge. In a June 2001 United Nations General Assembly Special Session on HIV/AIDS, member states committed to “ensure that by 2005, at least 90 percent of young men and women aged 15-24 have access to the information and education necessary to develop the life skills required to reduce their vulnerability to HIV” (United Nations, 2001). MacDonald et al (2004), in their study of knowledge, attitudes and beliefs of Maternal Child Health (MCH) and non-MCH adolescents (aged 10-18 years) regarding HIV disclosure, found that disclosure of HIV-positive status revealed key underlying themes, and these included a relationship of trust, maturity and stress related to the disclosure experience. Potential societal discrimination, lowered self-esteem, and concerns about confidentiality featured prominently among their concerns. Ghabili and MKamran (2008), in a study conducted among female high school students in India, found that of 300 students, 91% agreed that being an HIV carrier should not be an obstacle to obtaining education and employment; 72.5% of the students declared that the community should be informed of HIV-positive people, and 10% declared that they would feel uncomfortable towards their HIV- infected classmates.

Related to the above, one’s level of education and the degree of knowledge one possesses have been thought to positively influence disclosure of one’s HIV sero-status. However, according

to Nzioka (1996), in a study conducted in Kenya, that examined patient-doctor interaction, high literacy rates and unfavourable doctor-patient ratios were found to be the major barriers to HIV disclosure among people living with HIV at four treatment clinics. Though Nzioka's study highlights high literacy rates and unfavourable doctor-patient ratios as barriers to disclosure, this does not seem to be true of Uganda. Different researchers note that a wide range of socio-economic factors play a big role in HIV/AIDS sero-status disclosure, and these factors include fear of losing financial support and fear of a break-down of family relationships, Kadowa and Nuwaha (2009).

2.3.3.3 Stigma and discrimination, and HIV/AIDS disclosure

Nyabblade et al (2003), as cited by Byansi (2004), argue that HIV/AIDS stigma and discrimination, directed at the infected and affected, are responsible for further spread of HIV in Sub-Saharan Africa. They emphasize that stigma impedes HIV-testing, disclosure, and seeking early treatment, care and support for PLWHA and affected families. Goffman (1968), as cited by Byansi (2004), also reveals that stigma portends a gap between an individual's virtual and social identity, which, in the eyes of the individual and the public, translates into a 'handicap'. This handicap relegates the stigmatized person among those whose moral fibre and body are regarded as having been contaminated. Lehetensteins (2003), as cited by Byansi (2004), further observes that, as a consequence, non-disclosure ('passing as normal') of the stigmatizing disease becomes a coping strategy for the infected, which negatively impacts on the course of illness and propensity to seek testing and treatment, thus increasing the possibility of spreading infection to other sexual contacts.

This study sought, among other things, to establish whether or not stigma and discrimination were among the factors hindering disclosure among PLWHA in TASO Masindi, and if they were the extent to which they did so.

2.3.3.4: Gender and HIV/AIDS disclosure

Gender has been conceived as one of the factors that affect disclosure of a HIV-positive sero-status. Gender roles influence women's ability to protect themselves. For example, women are traditionally expected to bear children, cook for the family and submit to the sexual desires of their husbands. Many cultures consider ignorance of sexual matters as a sign of purity, making women reluctant to seek reproductive health information and services (Okoror et al, 2007)

Moreover, society is more intolerant of females living with HIV/AIDS than of their male counterparts (Strebel et al 2006). A study carried out in Kenya shows that 56% of women are commonly viewed to be targets of stigma compared with only 12% of men. Much of the social control over women's movements, voice and opportunities is based on the belief that they will become promiscuous if granted "too much freedom", and this could lead to contamination of the patriarchal lineage. As Amayunzu et al (2006) observe, PLWHA have become scapegoats generally, but females experience an added intensity of this phenomenon, a double stigma with a bigger social disadvantage. Women are frequently blamed as vectors of HIV transmission, although this is not always the case. In addition, most African societies expect their women to be monogamous, but expect men to have extramarital affairs or to be polygamous. Yet a woman's monogamy does not protect her from infection if her spouse has other sexual partners. This gender inequity is even stronger in Sub-Saharan Africa because most women are

dependent on their husbands for food, shelter and clothing. In general, many women refrain from testing, and if they test positive, they would rather conceal their status. According to Duffy et al (2005), a study carried out in Ghana showed that secrecy affected women's access to treatment and financial and emotional support from families. The main reasons for not disclosing HIV status were found to be fear of stigma and divorce, fear of losing confidentiality, women's low decision-making power, defective communication patterns between partners, and male partners' negative attitude to voluntary counseling and testing (VCT).

In line with the female's traditional sex role, she may not insist on condom use when a partner refuses, thus reducing her ability to prevent HIV infection and spread. Studies have shown that women who reveal their positive HIV-test results to their partners may experience a variety of reactions, ranging from support and understanding on one hand, to accusations, discrimination, physical violence and abandonment on the other (Manan et al 2001). This relates to the fourth process which is distancing, disempowerment or control.

Therefore, a woman exhibiting the independence needed to protect her health, risks condemnation from her family and the community. Although the majority of the studies show that females are more stigmatized than males, a study carried out in South Africa showed that men were more likely than women never to have discussed AIDS with friends, more likely to have been treated differently since testing, more likely to report experiencing internalized stigma, and more likely to have suffered loss of a place to stay or a job, owing to AIDS

(Simbayi et al, 2007). Part of the explanation for this could be the fact that men are more likely to have been working before the sickness, and are primarily responsible for providing shelter. (Strebel 2006 as cited by Ngonzi et al, 2009),

The present researcher sought to assess the role of gender-related factors in the disclosure of a positive HIV status among PLWHA in Uganda, through a case study of TASO Masindi.

2.3.3.5 Domestic violence and HIV/AIDS disclosure

Another disturbing outcome of the emphasis of sexual and physical domination of women as central to masculinity is violence against women. According to Heise et al (1999), in population-based studies conducted worldwide, anywhere from 10 to 50 percent of women report physical assault by an intimate partner, and one-third to one-half of physically abused women also report sexual abuse. For example, in Monterrey, Mexico, 52 percent of physically abused women had also been sexually abused; and in Leon, Nicaragua, among 188 women who were physically abused, 183 (97.3%) were also abused sexually or psychologically or both (Ellsberg et al., 1999; Granados, 1996). According to another study, most women who reported experiencing physical violence had also been sexually abused more than once (Heise et al., 1999).

The pervasiveness of violence has significant implications for HIV prevention. Research conducted in countries as diverse as Jamaica, India, Guatemala, Papua New Guinea and Haiti

found that fear of violence acted as a significant barrier to women negotiating condom use or fidelity with their partners (Le Franc et al., 1996; George and Jaswal, 1995; Bezmalinovic et al., 1994; Jenkins et al., 1995; Malow et al., 2000). That is why the threat of violence constrains women's ability to leave relationships that they perceive to be risky (Gupta and Weiss, 1993). Fear of violence can also limit women's use of HIV/AIDS counseling and testing services (Temmerman et al., 1995) and inhibit women's disclosure of their sero-status.

In a study conducted in Tanzania among women who sought HIV testing and counseling services, more than half of the women who did not disclose their status to their partners reported fear of a violent reaction as the reason why they did not do so (Maman et al., 2000).

Studies in Africa also show that the stigma associated with HIV/AIDS and the fear of violence that results, have also been found to be barriers to the success of efforts that seek to reduce the perinatal transmission of HIV. Fear of stigma and domestic violence are important reasons that pregnant women refuse HIV-testing or do not return for test results (Maman et al., 2001).

Similar concerns have been voiced by HIV-positive women who have been advised to bottle-feed their babies to avoid the risk of HIV transmission (Brown, 1998). Because breast-feeding is the norm in many African societies, women feared that using a bottle would imply that they are HIV-infected and expose them to the stigma and violence that often results. A study in Botswana also showed that fear of violence and stigma were the foremost reasons women

declined to participate in voluntary counseling and testing or programs to prevent mother-to-child transmission (Nyblade and Lyn Field, 2000).

Here in Uganda, the Ugandan branch of the International HIV/AIDS Alliance (15th September 2009) revealed that one Glorious was among five women murdered under similar circumstances in 2008. In a survey of just one district by Action Aid Uganda (2009), 100 out of 465 women said that they had experienced domestic violence as a result of disclosing their status.

In view of the above revelations, the researcher was keen to establish the role of domestic violence in the disclosure of a positive HIV/AIDS status among PLWHA in Uganda, through a case study of TASO Masindi.

2.3.3.6: Economic factors and HIV/AIDS disclosure

The economic factors that influence disclosure of HIV sero-status include economic dependence and independence as well as job insecurity and security. Below is an explanation of the dichotomous influence of each of these factors on HIV positive sero-status disclosure among PLWHAs.

- Financial dependence/ independence and disclosure

Regarding financial dependence /independence, HIV/AIDS disclosure has been associated with the ability of one's economic muscle to shoulder the economic burdens of meeting day-to-day

personal needs. For example, in a study conducted in Tanzania, Antelman et al (2006) found that women's economic dependence greatly influenced disclosure of HIV sero-status. They observed that women who were economically dependent, and had female friends, to whom they could confide their HIV status, were associated with a lower probability of disclosing to their partners. By implication, therefore, economic dependence among women can hinder disclosure.

- Job insecurity/security and disclosure

In the case of job insecurity/security and disclosure, fear of loss of employment was cited in many studies as a major barrier to HIV/AIDS disclosure. For example, studies conducted in Tanzania, Ethiopia and Zambia reported that one of the most profound consequences of stigma was its impact on ability to earn a living. Formally employed people found themselves dismissed upon disclosure of their HIV sero-status, and market vendors found their client base declining. Participants in the Ethiopian study reported that domestic workers with HIV/AIDS were usually dismissed (<http://icrw.org/doc2006stigmasyntheisis.pdf> retrieved on. 26 October 2009).

Further, Simbayi et al (2007) found that 42% of the participants in their study, who had not disclosed their sero-status, cited the reason for non-disclosure as fear of losing a job or a place to stay because of being known to be HIV-positive. Stigma and discrimination of employees with HIV/AIDS have indirectly led to early death of HIV-infected people. A study of the formal and informal private sector in Uganda by the International Labor Organization (ILO, 2009) revealed

that several firms had policies that entitled HIV-positive workers to a few months, not exceeding 6 months, of sick leave before they lost salaries and wages. Since AIDS causes sickness for a long time, often several years before death, it means that these workers are expelled from duty after which they receive a reduced salary before death.

Therefore, the researcher deemed it appropriate to explore the extent to which economic factors influence disclosure of HIV positive sero-status among TASO Masindi clients.

2.3.4: Strategies to minimize the impact of the factors that negatively influence HIV positive sero-status disclosure.

Available literature reveals two main strategies that are used to minimize the impact of the factors that hinder HIV-positive status disclosure. These strategies are: provision of HIV education and information and basic HIV/AIDS counseling and care.

2.3.4.1: Provision of HIV/AIDS education and information

It is a widely held belief that information is power. Armed with information, people are able to make choices given the alternatives available to them. This is in conformity with Anabela et al (2003) who noted that information asymmetry breeds uncertainty.

In their analysis of the problems facing Latin American countries in dealing with the HIV/AIDS problem, Anabela et al (2003) concluded that lack of accurate information about the epidemic on the part of high-risk and marginalized populations posed a big challenge in managing the HIV/AIDS epidemic.

They recommended that more innovative ways, as opposed to the traditional approaches, should be adopted to reach these hard-to-reach populations. They also suggested that community volunteers should be recruited from amongst these relatively inaccessible populations and that such volunteers should be trained and supported to repackage the information in the dialect best understood by the target population.

Use of Community Health Workers (CHWs) and volunteers is common. For instance, in their recent evaluation of the Area Development Program (ADP) in Lwamata, Uganda, World Vision International established that the impact of CHWs, including counselors, was not highly felt among the people (World Vision, 2006). They noted that this could be a result of weak structures that are non-functional at the grassroots. The evaluation team established that over sixty percent (63.3%) of randomly selected households in the ADP had not been reached by a community-based health worker. This suggests that this potentially effective means of promoting disclosure, and thus stemming the tide of the HIV/AIDS scourge, may not be optimally implemented in Uganda.

2.3.4.2: Basic HIV/AIDS counseling and care

HIV/AIDS is a terminal disease just like cancer. Patients always endure long periods of suffering punctuated by episodes of pain (CDC, 2004; Barnett, 2005). Opportunistic infections that result from the depressed immunity also present serious coping challenges. Hence there is need for both patients and primary caregivers to learn the techniques and receive encouragement to cope with all these challenges (Ibid).

Offering counseling and care is one of the recognized ways of managing these challenges (TASO, 2002; MOH 2005). Parker and Aggleton (2003) argue that counseling can successfully solve the problems associated with stigma at social and community levels, thus enhancing HIV-positive sero-status disclosure. They advocate the implementation of community-based approaches or interventions aimed at broad societal change.

A study by UNAIDS (2000) found that preventive interventions have relied on giving correct information about HIV transmission and prevention, and imparting practical skills to enable individuals to reduce the risk of HIV infection. The same study observed that many programs had found prevention to be a viable option.

In view of the above, the researcher deemed it useful to examine the role of HIV/AIDS counseling and care in encouraging HIV-positive status disclosure among PLWHA in Uganda, through a case study of TASO Masindi.

2.4 Summary of Literature Review

As the foregoing review reveals, disclosure in the HIV/AIDS context is a situation where, or an act by which, a client shares his or her HIV sero-status information with another person or other persons (HCT Training Manual for HIV Counselors 2009). There are factors that promote or hinder HIV status disclosure among People Living with HIV /AIDS .These factors are either social-cultural or economic. Some social-cultural and economic factors influence HIV-positive sero-status either positively or negatively, and these include domestic

harmony/violence, acceptance/denial of one's condition, a positive/negative attitude towards PLWHAs, availability/non-availability of social support systems, and job security/insecurity. Others also include the level of knowledge on HIV /AIDS, stigma and discrimination, culturally based gender biases, fear of loss of employment and positive/negative individual attitudes to seeking treatment among PLWHAs.

Further, the literature review indicates that HIV sero-status disclosure has both positive and negative consequences. The most frequently cited positive consequences of HIV-positive status disclosure were adherence to medication and access to social support. On the other hand, blame, disruption of family relationships, accusation of infidelity, and abandonment and rejection were the most cited negative consequences of HIV-positive status disclosure, and major barriers to HIV sero-status disclosure among People Having AIDS.

However, the literature is devoid of studies on what influences HIV sero-status disclosure specifically among adolescents, and on the challenges they face as a result of disclosing their sero-status. Yet, such studies could provide us with an opportunity to devise strategies that would accelerate prevention efforts among adolescents and young children.

Similarly, According to Nachega et al (2004), adherence to medication was solely as a result of partner notification, and yet there are other factors that promote drug adherence such as food availability, drug accessibility and a light pill burden among others. According to a survey conducted by Action Aid International (2008), 100 out 465 respondents experienced domestic

violence as a result HIV status disclosure. However, no attempts were made to identify the forms of gender-based violence these women were exposed to or the magnitude of risk.

Evidently, therefore, many studies have identified different rates of HIV sero-status disclosure among different population categories such as gender, age groups and racial groups. Other studies, particularly those conducted in Sub Saharan Africa, have identified the factors that hinder HIV sero-status disclosure. However, few studies have delved into the factors that promote or facilitate HIV positive sero-status disclosure. And yet comprehensive strategies to reduce the spread of HIV infection and AIDS must address both the factors that promote and those that hinder HIV positive sero-status disclosure. Hence the rationale of this study that sought to establish both the factors that hinder and those that promote HIV sero-status disclosure as a basis of generating the strategies to minimize the impact of those factors that hinder disclosure, through the case study of TASO Masindi.

Further the present study aspired to bridge some of the gaps identified in existing literature, and to generate more knowledge to constitute a basis for appropriate actions to support individuals living with HIV/AIDS to disclose their sero–status.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter presents the methods that were used in this study. It includes the research design, study area, study population, sample size and selection, and sampling techniques and procedures. It also includes data collection methods, instruments and procedures, pre-testing the questionnaires, data analysis and measurement of variables.

3.2 Research Design

This study adopted a case study research design that employed descriptive cross-sectional techniques in which both qualitative and quantitative approaches were used.

A case study design was preferred because it provides a detailed examination of one setting and enables the researcher to explore in-depth information of the underlying causes of the problem being investigated (Amin, 2005).

A descriptive cross-sectional survey was adopted because, as Neuman (2000) aptly states, it is simple, less time-consuming and usually affordable. Moreover, as Ezean (1998) adds, the purpose of descriptive surveys is to collect detailed and factual information that describes an existing phenomenon. Sekaran (2003) also observes that cross-sectional surveys are used to gather information just once. For example, data may be collected in either a month or a week to

solve the research problem or answer the research question. Therefore, a cross-sectional survey was deemed appropriate to this study.

This study combined both qualitative and quantitative approaches. Qualitative techniques were used to generate and analyze non-quantifiable data, such as opinions from the key informants. On the other hand, quantitative techniques were used to generate and analyze quantifiable, numeric data, mainly obtained through questionnaires.

3.3 Study Area

The study was conducted in Masindi District, one of the old districts of Uganda. Masindi District is located in mid-western Uganda, and it borders with Hoima, Nakasongola, Apac, Bulisa and Gulu districts. The study specifically covered all the service outlets of TASO Masindi Center, including the center headquarters, outreach areas and Community Drug Distribution Points (CDDP). TASO Masindi is located in Masindi Hospital premises in Masindi Town, about 240 km off Kampala –Gulu road. Masindi was chosen because, in spite of the prevalence of HIV/AIDS there, no similar study had ever been conducted in the area. In addition, the researcher lives in Masindi Town and is an employee of TASO Masindi. It was, therefore, convenient for him to work within the area, especially given that the research assignment was work-based.

3.4 Study Population

By the time the study commenced, TASO Masindi had about 7000 registered clients, 64 staff, and 250 community volunteers (TASO Masindi Center Report March 2010). The study

population comprised of three categories of respondents: TASO registered clients, including those attending the Centre and outreach clinics, TASO staff, i.e. counselors, field officers, and medical personnel who directly provide HIV counseling and care services, and finally the TASO community volunteers. The above categories of respondents were preferred because they had more information relevant to the research topic than any other population category.

3.4.1 Sample size and selection

The sample size was determined using the formula of Kish and Leslie (1965) for calculating sample size for cross-sectional survey

$$n = \frac{Z^2 pq}{d^2}$$

Where n = sample size

Z= is the standard normal deviate at the required confidence level of 95%

(1.96)

p= is the proportion in the target population of those who have not disclosed

HIV status being measured (10%=0.1)

q= 1-p

d= is the level of statistical significant set ($\alpha=0.05$)

$$n = (1.96)^2 \cdot 0.1 \cdot 0.9$$

$$\frac{\quad}{(0.05)^2} = 138$$

$$(0.05)^2$$

$$= 138$$

Using the above approach, a sample of 138 clients was selected. All the six (6) Taso staff and the five (5) (11) TASO AIDS Community Volunteers were purposively selected because they were the only ones in possession of the required information with respect to the study objectives. In addition, out of the 170 TASO clients, a sample of 138 was selected by stratified random sampling. In all, a sample of 149 respondents was constituted.

Table 3.1 below shows the distribution of the study population and the sample by category and gender.

Table 3.1: Distribution of the study population and sample by category and gender

Population category	Total population			Sample		Total	Method
			Total				
	Male	Female		Male	Female		
TASO Staff	2	4	6	2	4	6	Purposive
TASO Community Volunteers	3	2	5	3	2	5	Purposive
TASO clients	60	110	170	52	86	138	Stratified random sampling
Total	65	116	181	57	92	149	

However, as will become apparent in Chapter Four, due to unavoidable circumstances the total male respondents from the clients category was increased from 52 to 56 and that of their female counterparts accordingly reduced from 86 to 82.

3.4.2 Sampling techniques and procedures

A blend of both purposive and stratified random sampling techniques was used to select a representative sample of the study population. Purposive sampling was applied to the 6 TASO staff and 5 TASO community volunteers, all of whom were selected because they were the only ones who possessed the information necessary for the study.

Stratified random sampling was applied to TASO clients between the ages of 15 and 79 years. First of all, the researcher obtained an updated population list of the clients from the Information Management Officer, TASO Masindi. The clients were then categorized by gender, age group, longevity and service points to establish the number and proportion of clients in each category. Thereafter, the proportion of each category out of the 170 clients was converted into a corresponding numeric proportion out of 138, which represented the number of people to be selected from each group. Having achieved this stratification, the predetermined number of clients was randomly selected from each group to produce a sample whose gender and age characteristics were representative of the entire population of TASO clients.

As Moser and Kalton (1979), cited by Kayise (2003:59), states, stratified random sampling is another way of increasing precision in simple random sampling by ensuring that each study population category is fairly represented in the sample. Table 3 above shows the particulars of the sample and the corresponding sampling methods in the last four columns.

3.5 Data Collection Methods

Primary data was collected mainly from TASO registered clients, TASO Masindi staff and TASO community volunteers involved in providing care and support to PLWHAs. This was done by means of administering questionnaires and conducting interviews.

On the other hand, secondary data was gathered by means of intensive reviews of existing literature such as TASO annual reports and other documents, HIV/AIDS- related journals, magazines, textbooks, newsletters, dissertations, and Google search engines.

3.5.1: Questionnaire Administration

Questionnaire administration is one of the primary sources of data collection. The method is designed to collect information or data using either open-ended or closed-ended questions or both in a questionnaire. Amin (2005) describes a questionnaire as a self-report instrument used for gathering information about the variables of interest under investigation. For each of the two questionnaires, one for TASO clients and the other for TASO staff, the researcher prepared a set of interrelated questions about the subject based on the objectives and hypothesis of the

study. Both open- and closed-ended questions were used. Open-ended questions provided the respondents with an opportunity to express themselves freely and deeply about the issues in question while closed-ended questions were used to elicit more straightforward data, such as biographical data. According to Mugenda and Mugenda (1999), the questionnaire method is valuable in collecting data from a large number of respondents. In this study, a five-headed response rating using the Likert scale (5. Strongly agree, 4. Agree, 3. Don't know 2. Disagree and 1. Strongly disagree) was used to ease the filling of the questionnaires.

3.5.2 Interview

An interview, according to Mugenda and Mugenda, is face –to- face encounter through which a researcher can obtain accurate information about the subject under study. An interview, therefore, allows the respondents to seek clarity, and this also improves the relationship between research assistants and the respondents. Structured interview guides were designed for the key informants, mainly the TASO staff and community volunteers. This enabled the researcher to interact with the respondents and observe their body language, and to probe and collect more comprehensive and accurate data from the respondents.

3.5.3 Documentary review.

This is the method through which information is collected by reviewing documents. According to Baver (2000), documentary analysis is one way of interpreting textual data, and texts contain records of events, values, rules and norms, and traces of conflict and argument. Documentary review, therefore, provided the researcher with an insight into the factors that either promote or

hinder disclosure of HIV sero-status among clients in TASO Masindi. Using this method, the researcher reviewed reports, client's files, journals and other related documents.

3.6 Data collection instruments

The data collection instruments included a documentary check list, questionnaires, and an interview guide.

3.6.1: Questionnaires.

The researcher designed and used two questionnaires, one for TASO clients and the other for TASO staff and community volunteers. The questionnaires contained interrelated questions about the subject being investigated, and were based on the objectives and hypotheses of the study. The questionnaire for TASO clients was administered by the researcher while the other, for TASO staff and community volunteers, was self-administered. In each questionnaire, two broad categories of questions were formulated: structured or closed-ended questions to collect quantitative data, and unstructured or open-ended questions for qualitative data.

Closed-ended questions were used to elicit mainly quantifiable data, while open-ended questions were used to collect qualitative data because they allow the respondents to express themselves freely and in their own words, thereby providing in-depth information about the subject being investigated. (See appendices I and II)

3.6.2: Interview guide

One interview guide was administered to the selected groups of respondents, that is, TASO registered clients, TASO staff and TASO community volunteers. An interview guide was preferred to an interview schedule because the former minimizes response errors and places the

researcher in a better position to obtain accurate and detailed information from the respondents. Moreover, it is much more flexible than an interview schedule, thereby allowing for the collection of more and deeper information than a schedule does. The guiding interview questions were based on the specific objectives of the study and the research hypotheses (See Appendix 111).

3.6.3: Documentary review check lists.

The researcher reviewed TASO Annual Reports, journals, clients' files and HIV/AIDS workplace policy to complement data findings generated through the interviews and administered questionnaires. Baver (2000) reveals that documentary analysis is a one way interpreting textual data that generates the expressions which reflect people's culture. He also observes that texts contain records of events, values, rules and norms among others.

3.7: Pre –Testing (Validity and Reliability)

3.7.1: Reliability

Reliability being the consistency with which a research instrument collects or measures variables over the research space and time, the researcher sought to ascertain the reliability of the questionnaires by using the test–retest method. The two questionnaires were administered twice to the same groups of subjects at different periods. This was to generate the correlation coefficient that determined the relationship between the variables and the reliability of the instruments.

The two questionnaires were tested and retested on two sets of 10 respondents each, one in Gulu and the other in Mbarara. The respondents were made up of 4 TASO staff and 6 TASO clients in each of the two areas.

The researcher was able to determine the level of consistency basing on coefficient alpha and to erase the error that would come up from incorrect coding, ambiguous instruments, and random errors among others. Generally, the higher the reliability of an item the smaller the margin of error, and vice versa. The results that were found with scores above 5 meant that the items in question were highly reliable. Those with scores below five 5 indicated that the items in question were unreliable, and the researcher had to redesign and code such items.

3.7.2 Validity

Validity being the extent to which a data collection instrument collects or measures the data it is meant to collect or measure, and given that this was a case study, the researcher was keen to ensure that the main data collection instruments were valid both internally and externally.

In other words, the researcher sought to ensure that the questionnaires could collect the data that they were meant to collect and that the data would be applicable or generalisable to the rest of Uganda. After testing the instruments for reliability, the researcher sought to test them for internal validity by applying them to two similar sets of 10 respondents each in Masindi. That done, he established that the responses obtained from the two sets of respondents revealed almost identical understanding of the statements and questions in the questionnaires, and that

their understanding corresponded to that envisaged by the researcher. This proved that the instruments were internally valid.

To test for external validity, the researcher administered 10 questionnaires to 10 respondents in Gulu Municipality and in Mbarara Municipality, and compared the results obtained from the two areas. Again it was established that the Gulu respondents interpreted the questions and statements in the questionnaires in the same way as had done those of Mbarara and as was expected by the researcher. This confirmed that the instruments were capable of collecting the same data from different parts of Uganda, and that the findings based on such data would be generalisable to the entire country.

3.8 Data Collection Procedure

Upon the approval of the research proposal by the Uganda Management Institute(Appendix 4), and having received an introductory letter(Appendix 5), the researcher went on to seek permission from The AIDS Support Organization Research and Development Committee before conducting the research. In addition, the researcher explained clearly the purpose of this study to the respondents so as to avoid misinterpretation and win their consent to participate in the study. All the information gathered was handled with utmost confidentiality.

3.9 Data Analysis.

The quantitative data was cleaned, edited, coded, entered into the computer and analyzed using the Statistical Package for Social Scientists (SPSS version 12) that generates descriptive statistics, such as frequencies and percentages in form of tables and charts. The purpose of this was to enable the researcher to describe and summarize the data. In addition to descriptive statistics, the researcher used Pearson's product moment correlation coefficient to establish the relationship between study variables, and regression analysis determined the strength of the relationships among the variables of the study.

On the other hand, qualitative data was checked for missing and incorrect information and cleaned, after which transcripts were made in a logbook (master plan analysis). All this was done manually. Data was analyzed by systematically organizing and interpreting information, using categories, themes and motifs that identify patterns and relationships.

3.10 Measurement of Variables.

The Likert scale was used as a measurement scale. A five Likert scale used on the questionnaire took this form:

1. Strongly Disagree .2.Disagree 3. Don't Know 4.Agree 5. Strongly Agree

The nominal scale was used where numbers were assigned to various variables so as to identify those variables more easily and create sameness or difference.

3.11: Limitations of the study.

The level of education of the primary respondents was low, with few PLWHAs having completed primary school. This made the interpretation of the questionnaire more challenging. However, the research assistants ably interpreted the questionnaires to the respondents and translated all terminologies in local languages best understood whenever a need arose.

3.12: Ethical considerations

In keeping with standard research ethical requirements, immediately after the research proposal was approved, the researcher obtained a letter of introduction from UMI. Using this letter, he introduced himself to the local government and civic leaders in the study area to seek permission to conduct the study in their areas of jurisdiction. These leaders subsequently introduced the researcher to the potential participants in the study.

The researcher then explained the nature and purpose of the study, and informed the potential respondents that they were free to participate in the study or not to. He also assured them that whatever information they would provide, would be treated with utmost confidentiality and that it would be used exclusively for purposes of the study. In addition, the researcher assured the potential respondents that their identities would remain anonymous, and that if they so wished, they would have access to the final study report, copies of which would be made available to TASO Masindi. All this was done partly to win the confidence and trust of the respondents and partly to ensure that their rights were observed.

CHAPTER FOUR

DATA PRESENTATION, ANALYSIS AND INTERPRETATION

4.1: Introduction

This chapter presents, analyzes, and interprets the research data in the context of the research objectives, variables and hypotheses as they were indicated in Chapter One. The purpose of the study was to establish the factors affecting HIV sero-status disclosure among People Living with HIV/AIDS in Uganda, through a case study of TASO Masindi.

For this study, it was hypothesized that:

1. There are no social-cultural or economic factors that influence HIV sero-status disclosure among PLWHAs in TASO Masindi.

4.2 Respondents Categories

The study respondents were subdivided into three categories: TASO clients, TASO staff, and TASO community volunteers.

Table 4.1 below shows the distribution of the respondents by category.

Table 4.1: Distribution of respondents by category

Category	Total number respondents
TASO Clients	138
TASO Staff	6
TASO Community Volunteers	5
Grand total	149

As Table 4.1 above indicates, 149 respondents participated in the study, and data collected was analyzed by category of respondents. TASO clients were the majority, constituting 138(92.6%), followed by TASO staff who were 6(4.02%) and lastly TASO community volunteers who were 5(3.35%). In this study, there was 100% response rate, the reasons being that the researcher administered the questionnaires himself together with his Research Assistants, and the participants who decided to withdraw from the study were replaced. Although this replacement distorted the gender balance in the sample, the distortion was not scientifically significant.

4.3 Socio –Demographic Characteristics of the Respondents

The socio-demographic characteristics of the respondents considered relevant to this study were gender, age, marital status, and highest level of formal education. These characteristics were deemed important because they affect the degree of vulnerability to HIV/AIDS, the ability of people to access and internalize HIV/AIDS-related information, and therefore the behavior of an HIV/AIDS-infected or -affected person, especially with regard to testing for HIV/AIDS, disclosure, and adherence to prescribed treatment.

4.3.1 Gender of the respondents

Available data indicates that women are more infected than men, and thus it was deemed important to establish the gender of the respondents so as to enrich the findings of the study. Table 4.2 below summarizes the data on of the distribution of respondents by gender.

Table 4.2 Distribution of respondents by gender

Sex	No.	Percent
Female	88	59.1
Male	61	40.9
Total	149	100.0

As Table 4.2 above indicates, the majority were females, consisting of 88 (59.1%) respondents, while 61(40.9%) respondents were males. This gender distribution can be attributed to two facts: generally, there are more females than males in Uganda’s population, and it is possible that more females than males are infected with HIV/AIDS, especially given the fact that TASO clients constituted the majority of the respondents as seen in Table 4.1 above.

4.3.2: Distribution of respondents by age

It was noted during the literature survey that people who are in their youth and reproductive age groups were the most vulnerable to contracting HIV/AIDS. The researcher therefore sought to identify the most at-risk age groups in order to enrich his findings. Table 4.3 below illustrates the distribution of respondents by age group.

Table 4.3 Distribution of respondents by age group

Age group(years)	No.	Percent
15-24	5	3.4
25-34	56	37.5
35-44	61	40.9
45-54	22	14.8
Above 55	5	3.4
Total	149	100.0

Table 4.3 above indicates that the majority of the respondents 117(78.4%), were in the age groups of 35-44 and 25-34, with TASO clients constituting the majority of the respondents. This distribution could imply that HIV prevalence is higher among those in the prime of life and in the reproductive age bracket, for example those in the 25-34 and 35-44 age groups, than it is among other age groups.

4.3.3 Distribution of respondents by marital status.

Available statistics indicate that HIV/AIDS is more prevalent among married people than it is among those who are single. It was therefore important to identify the marital status of the respondents as this was likely to enrich the findings of the study. Table 4.4 below summarizes the data on the marital status of the respondents.

Table 4.4 Distribution of respondents by marital status

Marital status	No.	Percent
Married	72	48.3
Single	30	20.1
Separated /divorced	14	9.4
Cohabiting	4	2.7
Widowed	29	19.5
Total	149	100.0

Table 4.4 indicates that 72(48.3%) of the respondents were married, 30 (20.1%) were single, 14(9.4%) were separated or divorced, and 29 (19.5 were widowed. The above data could imply that HIV is higher among the married couples as compared to those who are single.

4.3.4: Highest level of education of the respondents.

Given that formal education influences one’s level of general awareness, the researcher found it necessary to analyze the highest levels of education of the respondents. The results of this analysis are summarized in Table 4.5 below.

Table 4.5 Distribution of respondents by highest level of education

Level of education	Frequency	Percent
None	8	5.4
Primary	64	42.9
O Level	52	34.8
A Level	10	6.8
Diploma and above	15	10.1
Total	149	100

As Table 4.5 reveals, the majority of the respondents had attained primary and ordinary secondary levels of formal education. Sixty-four (42.9 %) of the respondents had attained only primary education while fifty-two (34.8%) had attained O-level secondary education. Further, the findings indicate that ten (6.8%) of the respondents had reached the advanced level of education while, only fifteen (10.1%) respondents had a diploma and above. Since the majority of the respondents were TASO clients, this data implies that TASO Masindi serves PHAs whose levels of formal education render them less competitive in the current job market, whose income levels are low, and who are therefore most likely poor. This renders them vulnerable to opportunistic infections that result in rapid progression of HIV into AIDS, a condition that could explain the many cases of widowed people shown in the Table 4.2 above.

4.4 Level of Disclosure among TASO Masindi Clients.

The first objective of this study was “to establish the level of disclosure of HIV/AIDS positive sero-status among TASO Masindi clients. It was found that one hundred and twenty eight (92.75%) had disclosed their status while ten (7.246%) had not done so. The findings indicated a slightly higher level of disclosure as compared to disclosure rates in the 2008 and 2009 reports that were accessed and reviewed during document reviews. However, this high level of disclosure must be seen against the very low level of testing for HIV in the country: only 25% of Ugandans had been tested for HIV by the time of this study.

4.4.1 Timing of disclosure.

Whereas data generated from the survey indicates good performance in terms of HIV disclosure among TASO clients, the same data also reveals that disclosure is not rapid, and a big proportion of clients disclosed after more than a year. During the interviews, the respondents (TASO clients) were asked to indicate the period they spent from the time they were diagnosed with HIV up to the time they disclosed their sero-status, and the findings are summarized in Table 4.6 below.

Table 4.6 Length of time from diagnosis of HIV to disclosure by TASO clients

Period/Timing	No.	Percentage
Immediately	47	34
More than six months	52	38
More than a year	39	28
Total	138	100

As Table 4.6 above indicates, forty-seven (34 %) of the respondents disclosed immediately after knowing their test results, fifty-two (38%) disclosed their positive HIV sero-status within a year, while thirty-nine (28%) disclosed their status after more than one year. These findings indicate that ninety-one (66 %) of the clients did not reveal their sero-status immediately to their spouses, friends, or family members, thereby allowing for continued infection.

4.5 Socio-cultural and Economic Factors that Influence Disclosure of HIV-positive Sero-status among PLWHAs.

The second objective of this study was “*to identify socio-cultural and economic factors that influence HIV positive sero-status disclosure among TASO Masindi clients*”. In order to achieve this objective, we assessed the influence of social support systems, knowledge and attitude, domestic violence, stigma and discrimination, gender and economic factors on disclosure among PLWHAs. However, in order to provide focus and direction, each of the factors was assessed separately, and a null hypothesis was formulated to assess the extent to which each factor influenced disclosure of HIV-positive sero-status, beginning with social support systems.

4.5.1 Social support systems and disclosure

Table 4.7 below shows the extent to which respondents agreed or disagreed with the statements describing social support dimensions, including help from family members, support from spouse or partner as well as the community among PHAs at TASO

Table 4.7 Respondents' views on social support systems and disclosure

TASO clients	SA (%)	A (%)	Don't know %	D (%)	SD (%)
The desire to receive help from family members influences you to disclosure	45(32.6%)	64(46.4%)	7(5.1%)	4(2.9%)	18(13%)
The need to get support from your spouse influences you to disclosure	39(28.3%)	53(38.4%)	9(6.5%)	15(10.9%)	22(15.9%)
The desire to get support from your ,relative and community influences you to reveal your sero-status	36(26.08%)	73(52.9%)	7(5.07%)	7(5.1%)	15(10.9%)

Table 4.7 above shows that a total of one hundred and nine (79%) of the respondents agreed that the desire to receive help from family members influenced them to reveal their HIV-positive sero-status while twenty-two (15.9%) disagreed to the statement. This implies that help from family members is crucial in enabling PHAs to reveal their sero- status. The findings also indicate that, to a small extent, TASO Masindi clients do not expect or wish to be supported by their family members, immediate relatives or the community as highlighted in the last two columns of Table 4.7 above.

Further, the findings indicate that ninety-two (66.7%) of the respondents agreed that the need to get help from spouses has a lot of bearing on their decision to disclose while thirty-seven (26.8%) disagreed to the statement. Finally, the table above indicates that one hundred and nine (80.4%) of the respondents agreed to the statement that the desire to get support from friends, relatives, and the community influences their decision to disclose their sero-positive status while twenty-two (15.4%) were in disagreement to the statement. Over all, these findings suggest that the desire to get help from friends, spouses, and community members influences one's ability to disclose his or her sero-status.

4.5.1.1 The relationship between social support systems and disclosure.

To establish the relationship between social support systems and disclosure of positive HIV sero-status, the researcher was guided by the following null hypothesis which was derived from the basic hypothesis of the study, the first one being "*Social support systems do not promote HIV sero-status disclosure among people living with HIV/AIDS in Uganda.*"

Pearson's correlation coefficient was used to determine the degree and direction of the relationship as illustrated in Table 4.8 below.

Table 4.8: Correlation matrix between social support systems and disclosure of HIV positive sero-status

		Disclosure	Social support systems
Disclosure	Pearson Correlation	1	.136
	Sig. (2-tailed)	.	.112
	N	138	138
Social support systems	Pearson Correlation	.136	1
	Sig. (2-tailed)	.112	.
	N	138	138

As Table 4.8 above indicates, the correlation coefficient of 0.136 that was established is not significant. This means that there is a very weak relationship between social support systems and disclosure of a positive HIV sero-status among PLWHAs. However, contrary to this finding, qualitative data from key informant interviews reveal that social support systems promote disclosure of HIV positive- sero-status. In an interview with one key informant, he said: *“availability of supportive social systems such as a well informed community about HIV /AIDS help us to stay free from stigmatization and discrimination”*. In this regard, the key informants identified various social support systems or institutions through which individuals can be supported during or after disclosure of their sero-status, and these are summarized in Table 4.9 below.

Table 4.9: Social support systems/institutions identified by TASO volunteers?

Institution	Frequencies	Percentages
Police	1	9.0%
Family	3	27.3%
Schools	1	9.0%
Peer support groups	3	27.3%
Friends	1	9.0%
Churches	2	18.2
Total	11	100%

Table 4.9 above indicates that there are different social support systems available in the TASO Masindi area, and by implication elsewhere. The above data also indicated that family and peer support groups were the leading supportive social support systems, with equal frequencies and percentages of 3(27.3%). The implication of this is that families and peer support groups could be major units for social support; therefore, strengthening such systems would have a significant positive impact on disclosure of positive HIV sero-status among PLWHAs. This is so because of the strength of the genetic and social bonds implicit in the family and the peer group, which endows the two units with immense potential for material and moral support for a member in need. Next to the family and the peer group were churches, with a frequency of 2 or 18.18%. Again, this is not surprising because churches have as their stated mission to love and care for people, especially those in need. Indeed, churches also happen to have most of the more accessible and affordable health care facilities in Uganda; and for those without families or strong family ties, church organizations constitute the *de facto* family. During an interview with one of the respondents, she said: “social support systems such as churches which offer

couple counseling and guidance greatly minimize marital challenges, be they social or economic”.

4.5.2 Knowledge, attitude and disclosure

Similarly, in order to establish whether knowledge and attitude had any influence on disclosure of HIV positive sero-status among PLWHAs, the following dimensions of knowledge and attitude were assessed, and the findings are shown in Table 4.10 below.

Table 4.10 Responses on knowledge and attitude in relation to disclosure

Dimensions of knowledge and attitude	SA (%)	A (%)	Don't know %	D(%)	SD(%)
Ones' knowledge about various modes of transmission influences his or her decisions to disclose his or her sero-status family or significant others.	30(21.7%)	47(34.1%)	8(5.8%)	18(13%)	35(25.4%)
The attitude that disclosure may not result into loss or misappropriation of one's property or discrimination influences your ability to reveal your sero-status.	30(21.7%)	40(29.1%)	15(10.9%)	29(20.1)	24(17.4%)

Table 4.10 above indicates that seventy-seven (55.8%) of the respondents agreed that one's knowledge about various modes of HIV transmission influences one's decisions to disclose one's sero status to her family members or significant others. The fact that only slightly over half of the respondents agreed to the statement implies that there are still information gaps on

modes of HIV transmission and myths about HIV/AIDS among TASO clients and the community generally. Further, the findings suggest that if individuals have the attitude or perception that disclosure may not result into loss or misappropriation of their property or into discrimination, such an attitude or perception positively influences their ability to reveal their sero-status. However, the fact that a total of sixty-eight (48.8%) of the respondents did not agree to the statement about attitude and disclosure suggests that a significant number and proportion of TASO clients, and implicitly the public, are still unaware of the importance of attitude, especially regarding property ownership, in the decision to disclose. This is particularly detrimental to the disclosure campaign given that there is still a widespread perception that HIV-positive individuals have a short life span, and therefore no longer need their property or wealth for further investment.

4.5.2.1 The relationship between knowledge, attitude and disclosure

This study was based on the basic hypothesis that “*There are no socio-cultural or economic factors that influence HIV sero-status disclosure among PLWHA*”. However, our literature review revealed that some socio-economic factors, including the knowledge possessed by an HIV/AIDS patient and the attitude that patient has towards the disease, may influence his or her propensity to disclose his or her condition. Therefore, arising from the basic hypothesis of the study, we deduced a number of working hypotheses, the second one being that “*Knowledge and attitude do not promote HIV sero-status disclosure among people living with HIV/AIDS in Uganda*”. To test this hypothesis, the researcher sought to establish the relationship between knowledge and attitude on the one hand and disclosure of positive sero-status on the other, among TASO clients.

Pearson's correlation coefficient was used to determine the degree and direction of the relationship as illustrated in Table 4.11 below.

Table 4.11 Correlation matrix of knowledge, attitude and disclosure

		Disclosure	Knowledge and attitude
Disclosure	Pearson Correlation	1	.297(**)
	Sig. (2-tailed)	.	.000
	N	138	138
Knowledge and attitude	Pearson Correlation	.297(**)	1
	Sig. (2-tailed)	.000	.
	N	138	138

** Correlation is significant at the 0.01 level (2-tailed).

The results in the table above indicate a correlation coefficient of 0.297 that is significant at a level of 0.01. This means that there is a significant positive relationship between knowledge and attitude on one hand and disclosure of positive sero-status on the other. This implies that the more PHAs are equipped with knowledge and the more they change their attitude towards positive living, the more likely they are to reveal their HIV positive sero-status.

Regression analysis was then undertaken to establish the coefficient of determination relating to knowledge and attitude, and the results are shown in Table 4.12 below.

Table 4.12 Regression outputs on knowledge, attitude and disclosure

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.297(a)	.088	.081	.57714

a Predictors: (Constant), knowledge and attitude.

The regression analysis above shows a coefficient of determination (adjusted R square) of 0.081. This means that knowledge and attitude explain 8.1 % of variation in HIV-positive sero-status disclosure. This shows that knowledge and attitude predict disclosure of HIV positive sero-status among people living with HIV/AIDS in TASO Masindi Center.

The null hypothesis was therefore rejected and the alternative hypothesis substantiated. In other words, *knowledge and attitude do promote HIV sero-status disclosure among people living with HIV/AIDS in Uganda*”.

Similarly, qualitative analysis of data from interviews with key informants revealed that knowledge and attitude influence disclosure of HIV positive sero-status. In an interview with one of the key informants, he said, *“most of the factors affecting disclosure are not only knowledge-related but also social and economic-oriented ... knowledge is paramount”*. Another key informant said that *knowledge provides individual PHAs with an understanding of the approaches to use while disclosing to their partners or significant other family members. Knowledge also empowers us to make right decisions. On the other hand, attitude change translates negative behaviors into positive behaviors among PHAs*”.

These assertions are also supported by the level of coefficient of determination (8.1) shown Table 4.12 above.

In general, eleven factors that promote disclosure among TASO clients in Masindi were identified, and they are summarized in Table 4.13 below.

Table 4.13: General factors that positively influence HIV–positive sero-status disclosure among TASO Masindi clients

Reasons/factors for disclosure	Frequency	Percentage
The need for care and support	76	52.05%
Desire to stop spreading infection to my partner	18	12.32%
State of health (very sick)	13	8.84%
Knowledge of partner’s sero status	2	1.36%
Presence of a confidant / trusted person	3	2.55%
Availability of medication and care services	14	9.58%
Need to demystify rumours	5	3.42%
Need for further counseling from friends and family members	5	3.42%
Need for financial assistance	9	6.16%
Employment Status(Unemployment/joblessness)	1	2.17%
TOTAL	146	100%

Table 4.12 above indicates that, among the respondents, the leading factor in prompting HIV/AIDS patients to disclose their positive sero-status was the need for care and support,

which was cited seventy-six times and constituted 52.05% of the total citations of factors. This was followed by the desire to stop the spread of infection to partners, which was cited eighteen times (12.32%), availability of medication and care services, which featured fourteen times (9.58%) and state of health (very sick), which was cited thirteen times (8.84%). Other reasons included knowledge of a partner's sero-status, with a frequency of two (1.36%), availability of a confidant or trusted person, with a frequency of three (2.55%), the need to avoid rumors , which was cited five times (3.42%), the need to seek for further counseling, which featured five times (3.42%), need for financial assistance, which was cited nine times (6.16%), and unemployment, which featured only once (2.17%).

4.5.3: Stigma, discrimination and disclosure

To assess the extent to which stigma and discrimination influences disclosure of a positive sero-status, respondents were asked to react to three statements, and Table 4.14 below summarizes their reactions.

Table 4.14 Stigma and discrimination

Statements		A (%)	Don't know %	D(%)	SD(%)
Fear that disclosure of you sero-status may result into failure to get school fees among school going children determines your decision to disclose	30(21.7 %)	31(22.5%)	2(1.4 %)	9(6.5 %)	66(48%)
Fear to be seen as an embarrassment to your family may deter your ability to disclose your sero-status.	40(29%)	48(34.8 %)	3(2.2%)	17(12.3%)	30(21.7%)
Fear that the community may isolate you once you disclose influences your decision to reveal your sero-status.	40(29%)	55(39.9 %)	6(4.3%)	23(16.7%)	14(10.1%)

As Table 4.14 above indicates, fifty-six (40.6%) of the respondents agreed that, among school going children, the fear to be denied school fees determines their decisions to disclose their sero-status while seventy (57.9%) disagreed to the statement. Only three (2.2 %) respondents did not have any opinion about the statement. The above figures imply that discrimination still exists among TASO Masindi clients, and that, due to this attitudinal problem, HIV-positive people, especially children, may not be getting the necessary support from their family members.

Regarding the statement that the fear of embarrassment before the family may deter an HIV victim from disclosing his or her HIV positive sero-status, eighty-eight (64.1%) of the respondents agreed whereas thirty-seven (26.8%) disagreed. These results suggest two possible interpretations: some clients who revealed their positive sero-status may have been profoundly embarrassed before their families, and possibly denied the attention and support they deserve from their families, and the majority of PHAs in TASO Masindi encounter psycho-social challenges such as blame or accusation upon disclosure.

Regarding the statement that the fear to be isolated by the community members influences PHA's decisions to disclose or not to, ninety-five (68.9%) of the respondents agreed to the statement while thirty-seven (30.8%) disagreed, and six (4.3%) did not have any opinion about the statement. These findings indicate a high degree of intolerance and stigmatization of individuals living with HIV/AIDS on the part of the community. Logically, such intolerance and stigmatization translates into limited support for PLWHAs and limited involvement of PHAs in social activities. All in all, stigma and discrimination constitute a social cultural factor that hinders HIV positive sero-status disclosure among people living with HIV/AIDS in the study population.

4.5.3.1 The relationship between stigma and discrimination, and disclosure

Among the working hypotheses that we derived from the basic hypothesis of this study, the third one was that “*Stigma and discrimination do not hinder disclosure of a positive HIV sero-status among PLWHA in TASO Masindi*”. To test the hypothesis the researcher sought to

establish the relationship between stigma and discrimination on the one hand, and disclosure of positive sero-status among PWHAs in TASO Masindi on the other.

Pearson’s correlation coefficient was used to determine the degree and direction of the relationship, and the results are presented in Table 4.15 below.

Table 4.15: Correlation matrix between stigma and discrimination and disclosure

		Disclosure	Stigma and discrimination
Disclosure	Pearson Correlation	1	.245(**)
	Sig. (2-tailed)	.	.004
	N	138	138
Stigma and discrimination	Pearson Correlation	.245(**)	1
	Sig. (2-tailed)	.004	.
	N	138	138

** Correlation is significant at the 0.01 level (2-tailed).

The results in Table 4.15 above indicate a correlation coefficient of 0.245 at a level of significance of 0.01. This means that there is a positive significant relationship between stigma and discrimination on one hand and disclosure of a positive sero-status on the other among PLWHAs. This further implies that the more TASO fights stigma and discrimination, the higher will be the levels of disclosure among PLWHAs in TASO Masindi.

Further analysis was done using regression to establish the strength or degree of relationship and how much of the variance in the dependent variable would be caused by stigma and discrimination. The findings of the test are summarized in Table 4.16 below.

Table 4.16 Regression outputs on stigma and discrimination, and disclosure of positive sero-status

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.245(a)	.060	.053	.58603

a Predictors: (Constant), stigma and discrimination

The regression analysis reveals a coefficient of determination (the adjusted R square) of 0.053, which means that stigma and discrimination explain 5.3 % of variation in disclosure of HIV positive sero-status. This shows that together, stigma and discrimination predict disclosure of HIV-positive sero-status among people living with HIV /AIDS in TASO Masindi Center. The null hypothesis was therefore rejected and the alternative substantiated. In other words, *stigma and discrimination do hinder disclosure of a positive HIV sero-status among PLWHA in TASO Masindi*”.

The above findings were in consonance with qualitative data generated from both the interviews with key informants and the questionnaire. It was, therefore, confirmed that stigma

and discrimination hinder disclosure of a positive sero-status among PLWHAs. During the study, participants were asked to list various forms of discrimination they were exposed to after disclosing their sero-status and the findings indicate that isolation at work and leisure places, separation of bedrooms and denial of sex among couples, and neglect by spouse were the most frequently cited forms of discrimination. Others included rejection by family members, neglect of children, denial of access to loans, failure to be considered for jobs, and early retrenchment.

4.5.4: Gender factors and disclosure of a positive sero-status.

To assess the extent to which gender factors influence disclosure of a positive sero-status, respondents were asked to react to three statements expressing three different dimensions of gender-based fears among PLWHAs. Table 17 below summarizes the reactions of the respondents.

Table 4.17 Respondents’ views on gender-related factors influencing disclosure HIV positive sero-status disclosure.

Gender factors	SA (%)	A (%)	Don't know %	D (%)	SD (%)
Fear to lose your partner influences your ability to reveal their sero-status.	61(44.2%)	63(45.7%)	4(2.9%)	3(2.2%)	7(.5.1%)
Fear to be denied participation in various community activities influence your decisions to disclosure	47(34.1%)	47(34.1%)	4(2.9%)	20(14.5%)	20(14.5%)
Fear to be identified as a source of infection may influence decisions to reveal your sero status	58(42%)	46(33.3%)	14(10.1%)	6(4.3%)	14(10.1%)

Table 4.17 above indicates that a majority of the respondents, 124(89.9%) agreed that fear to lose partners influences their ability to reveal their sero-status. Only seven (5.1%) respondents disagreed to the statement while three (2.2%) did not have any opinion about the statement. This could imply that society attaches considerable value to being married or to a partner as a sign of the social integrity of a man or woman. Therefore, every man and woman has to work towards satisfying societal demands, thus compromising disclosure of HIV-positive sero-status.

Further, the above table indicates that 94(62.2%) of the respondents agreed that the fear of being denied participation in various community activities influences their decisions to disclose while forty (29%) of respondents disagreed to the statement. Only four (2.9%) of the respondents did not have any opinion about the statement. This data could imply that the majority of the PHAs in TASO Masindi are stigmatized and isolated in various aspects of social life, a situation that inhibits HIV positive sero-status disclosure or is a cause for the delay to disclose a positive sero-status as highlighted above.

Finally, Table 4.17 further shows that one hundred and four (75.3%) of the respondents agreed that the fear of being identified as, or accused of being, a source of infection may influence their decisions to reveal their sero to their spouses while twenty (14.4%) disagreed, and only fourteen (10.1%) did not have any opinion about the statement. This could imply that this fear has prevented many PHAs in the TASO Masindi area from disclosing their status, and delayed disclosure by many people, thus increasing the risk of spreading infections, and frustrating the anti-HIV/AIDS efforts of TASO and similar organizations.

4.5.4.1 The relationship between gender-related factors and disclosure

The fourth working hypothesis that we derived from the basic hypothesis of this study was that “*There are no gender-related factors that hinder disclosure of positive HIV sero-status among PLWHA in TASO Masindi*”. To test the hypothesis the researcher tried to establish the relationship between gender-related factors and disclosure of positive sero-status among PLWHAs in TASO Masindi.

Pearson’s correlation coefficient was used to determine the degree and direction of the relationship and the results are presented in Table 4.18 below.

Table 4.18: Correlation of gender-related factors and HIV positive sero-status disclosure

		Disclosure	Gender related factors
Disclosure	Pearson Correlation	1	.318(**)
	Sig. (2-tailed)	.	.000
	N	138	138
Gender -related factors	Pearson Correlation	.318(**)	1
	Sig. (2-tailed)	.000	.
	N	138	138

** Correlation is significant at the 0.01 level (2-tailed).

The results in Table 4.18 above indicate that a correlation coefficient of 0.318 was obtained, and it is significant at a level of 0.01. The same table also shows that there is a significant positive relationship between gender-related factors and disclosure of positive sero-status. This implies that the more gender-related factors are neglected and the longer they persist, the more and longer the PHAs will conceal their HIV-positive sero-status.

A regression analysis was further done to determine the strength of the relationship between gender-related factors and disclosure of positive sero-status among PLWHAs, and how much of the variance in HIV-positive status disclosure would be caused by gender-related factors. A summary of the results of this analysis is contained in Table 4.19 below.

Table 4.19 Regression outputs on gender-related factors and disclosure of HIV- positive sero-status

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.318(a)	.101	.095	.57297

a Predictors: (Constant), gender related factors

The regression analysis produced a coefficient of determination (adjusted R square) of 0.095, meaning that gender-related factors explain 9.5 % of variation in disclosing HIV-positive sero-status. This shows that gender-related factors predict disclosure of HIV-positive sero-status among people living with HIV /AIDS in TASO Masindi Center.

The null hypothesis was therefore rejected and the alternative hypothesis substantiated. In other words, *there are gender-related factors that hinder disclosure of positive HIV sero-status among PLWHA in TASO Masindi.*

4.5.4.2 Gender and disclosure according to key informants

During the study, the eleven (11) key informants were also interviewed on the relationship between gender and disclosure, and most of them agreed that there are gender-related factors that hinder disclosure of a positive sero-status among PHAs. These findings were in line with the findings from the quantitative analysis that established that gender-related factors inhibit disclosure of a positive sero-status. Some of the factors cited by the key informants are tabulated in Table 4.20 below.

Table 4.20 General gender factors influencing disclosure of positive sero-status

Factors	Frequency	Percentages
Fear of separation /divorce	7	28%
Fear of childlessness	2	8%
Gender stereotyping	2	8%
Fear of neglect	3	12%
Fear of sexual starvation	3	12%
Fear of torture /domestic violence	3	12%
Myths that men are not obliged to share information with their wives	1	4%
Fear of being blamed	1	4%

Fear of loss of financial support	3	12%
TOTAL	25	100%

As Table 4.20 above indicates, the most frequently cited gender-related factors were fear of divorce or separation, with a frequency of 7 (28%), fear of neglect, fear of sexual starvation, fear of loss of financial support, and fear of torture or domestic violence, each with a frequency of 3 (12). Other gender-related factors included fear of childlessness, gender stereotyping, fear of blame, and the belief that men are not obliged to share information with their wives. All these factors manifest themselves in a variety of ways. For example, a married person who values his or her marriage may refrain from disclosing his or her positive sero-status to his or her spouse because he or she fears that disclosure of the status may precipitate divorce or separation, which, in the case of most women, would also mark the end of financial support from the husband. In other cases, disclosure may signal the end of any sexual relationship between a couple; and, particularly for women, disclosure may translate into the husband beating up and torturing the wife. Therefore, all such potential eventualities create fear of disclosure among spouses.

4.5.5 Domestic violence and disclosure

To assess the extent to which domestic violence hinders disclosure of a positive sero-status, respondents were requested to react to a set of four statements about domestic violence and disclosure. The results of their reactions are summarized in Table 4.21.

Table 4.21 Respondents' views on domestic violence and disclosure of HIV- positive sero-status

Statements on domestic violence and disclosure	SA (%)	A (%)	Don't know %	D (%)	SD (%)
Anticipation of violent reactions from your spouse may determine whether to reveal or conceal your sero-status	50(36.2%)	50(36.2%)	8(5.8%)	12(8.7%)	18(13%)
Fear of being disrespected may limit your ability to reveal your sero-status.	35(25.4%)	60(43.5%)	6(4.3%)	13(9.4%)	24(17.4%)
Fear of being neglected can influence your decision either to disclose or conceal your positive sero-status	46(33.3%)	55(39.9%)	7(5.0%)	15(10.9%)	15(10.9%)
Anticipation of personal loss of property to your family members may influence your decisions whether to conceal or reveal your sero-status.	46(33.3%)	47(34.1%)	6(4.3%)	15(10.9%)	24(17.4%)

Table 4.21 above indicates that one hundred (72.4. %) of the respondents agreed to the statement that anticipation of violent reactions from their spouses may determine whether to reveal or conceal their sero-status while thirty (21.7 %) of the respondents disagreed to the statement. Eight (5.8%) had no opinion about the statement.

Regarding domestic violence, when the same respondents were required to react to the statement that the fear of being neglected can influence their decisions to reveal or conceal their sero-status, one hundred and one (73.2%) agreed to the statement while 21.8 % disagreed.

In addition, ninety-five (68.9%) of the respondents agreed that the fear of being disrespected either by a wife or a husband can influence their decision to disclose or conceal their positive sero-status while thirty-seven (26.6 %) disagreed. These findings imply that domestic violence may still be prevalent among TASO Masindi clients, which may explain the delayed disclosure among clients as seen in the Table 4.21 above.

4.5.3.1 The relationship between domestic violence and disclosure

The fifth working hypothesis that we deduced from the basic hypothesis of this study was that “Domestic violence does not significantly hinder disclosure of HIV-positive sero-status among PLWHA in TASO Masindi”. To test the hypothesis, the researcher tried to establish the relationship between domestic violence and disclosure of positive sero-status among PLWHAs in TASO Masindi.

Pearson’s correlation coefficient was used to determine the degree and direction of the relationship, and the results appear in Table 4.22 below.

Table 4.22 Correlation matrix between domestic violence and disclosure

		Domestic violence	Disclosure
Domestic violence	Pearson Correlation	1	.164
	Sig. (2-tailed)	.	.055
	N	138	138
Disclosure	Pearson Correlation	.164	1
	Sig. (2-tailed)	.055	.
	N	138	138

The results in Table 4.22 above show a correlation coefficient of 0.164 which is not significant.

This means that there is a very weak relationship between domestic violence and disclosure of

positive sero-status. A regression was further done to determine the strength of the relationship between domestic violence and disclosure of positive sero-status among PLWHAs, and the results are presented in Table 4.23 below.

Table 4.23 Regression outputs on domestic violence and disclosure of HIV- positive sero-status

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.164(a)	.027	.020	.59620

a Predictors: (Constant), domestic violence

From the regression analysis depicted above, the coefficient of determination (adjusted R square) of 0.02 means that domestic violence explains 2 % of variation in disclosing HIV-positive sero-status. This shows that domestic violence predicts disclosure of HIV-positive sero-status among people living with HIV /AIDS in TASO Masindi Center.

However, data generated from qualitative analysis of the views of the key informants indicates that domestic violence hinders disclosure of a positive sero-status. It is against this background that one of the respondents said: *my husband chased me away having noticed that we were in a discordant relationship, up-to now, he turns his back to me*". File reviews by the researcher also revealed that domestic violence is a major determinant of the decision to reveal or conceal one's HIV positive sero-status among TASO Masindi clients.

4.5.6 Economic factors and disclosure

To assess whether, and to what extent, economic factors influence disclosure of HIV-positive sero-status, questionnaire respondents were asked to react to a set of relevant statements, and their reactions are summarized in Table 4.24 below.

Table 4.24: Respondents' views on economic factors and disclosure

Financial position and disclosure of a positive sero-status	SA (%)	A (%)	Don't know %	D (%)	SD (%)
Your ability to support yourself influences your decision on disclosure of your sero-status.	44(31.9%)	50(36.2%)	9(6.5%)	17(12.3%)	18(13.1%)
Your position in the household influences your decisions on disclosure of your status.	31(22.5%)	44(31.8%)	11(8%)	29(21%)	23(16.7%)
Fear that disclosure may result into loss of financial assistance influences your decision to reveal your sero-status.	33(23.9%)	58(42%)	6(4.3%)	22(15.9%)	19(13.8%)

Fear of loss of employment and disclosure	SA (%)	A (%)	Don't know %	D (%)	SD (%)
The view that employers find it difficult to recruit or retain PHAs in their positions of work influences your decision on disclosure.	51(36.9%)	59(42.8%)	1(.7%)	11(8%)	16 (11.6%)
Fear that disclosure may lead to loss of your employment influences your decision on disclosure your sero status.	37(26.8%)	54(39.1%)	6(4.3%)	21(15.2%)	20(14.4%)
Fear that disclosure of your positive status may lead to decline in the customer base of your business influences your decision on disclosure.	49(35.5%)	55(39.9%)	8(5.8%)	13(9.4%)	13(9.4%)

As the results in Table 4.24 above indicate, ninety-four (68.1%) of the respondents agreed that one's ability to support oneself influences one's decision on disclosure one's sero-status while thirty-five (25.5%) of the respondents disagreed. Only eight (5.8%) of the respondents did not have any opinion about the statement. This would tend to suggest that financial dependence/dependence and access to means of sustenance are important factors in the decisions that PHAs make to disclose or conceal their status.

Regarding the statement that the fear that disclosure may lead to loss of employment influences one's decision to disclose or conceal one's HIV-positive sero-status, ninety-one (65.9%) of respondents agreed to the statement as compared to forty-one (29.7%) of the respondents that disagreed. This implies that economic factors still constrain PHAs from disclosing their sero-status.

In reaction to the statement that one's financial position in the household influences one's decisions to disclose or conceal one's positive HIV sero-status, seventy-five (54.4 %) of the respondents agreed while fifty-two (37.7%) disagreed. These figures suggest, among other possibilities, that among TASO Masindi clients, financial considerations, especially the ability of an HIV victim to support himself or herself and his or her family, constitute a major factor in the decision to reveal or conceal one's status.

Data in the above table further indicates that one hundred and ten (79.8%) of the respondents agreed that the view that employers find it difficult to recruit or retain PHAs in their positions of work influences the decisions of PHAs to reveal or conceal their status. One obvious

implication of this is that because they fear to miss out on employment opportunities or to lose their jobs, PHAs do not disclose their status. At the opposite extreme, twenty-seven (19.6%) of the respondents disagreed to the statement. Further, the findings indicate that one hundred and four (75.4%) of the respondents agreed that disclosing a positive sero-status can lead to a decline in the customer base of an HIV-positive businessperson, thereby causing underemployment, unemployment, and a decline in the income of the patient. Only twenty-six (18.8%) of the respondents disagreed to the same statement. The fact that almost 80% of the respondents agreed to the statement implies that employers in TASO Masindi, and by extension in Uganda, are generally believed to discriminate against PHAs. All in all, the data indicates that economic factors deter PHAs from revealing their sero-status in TASO Masindi Center.

4.5.6.1 The relationship between economic factors and disclosure

The sixth and the last working hypothesis that was derived from the basic hypothesis of this study was that “*There are no economic factors that hinder disclosure of positive HIV sero-status among PLWHAs in TASO Masindi*”. To test the hypothesis, the researcher sought to establish the relationship between economic factors and disclosure of positive sero-status among PWHAs in Uganda.

To achieve this, Pearson’s correlation coefficient was used to determine the degree and direction of the relationship, and the results are presented in Table 4.25 below.

Table 4.25: Correlation matrix between economic factors and disclosure of positive sero-status

		Disclosure	Economic factors
Disclosure	Pearson Correlation	1	.257(**)
	Sig. (2-tailed)	.	.002
	N	138	138
economic factors	Pearson Correlation	.257(**)	1
	Sig. (2-tailed)	.002	.
	N	138	138

** Correlation is significant at the 0.01 level (2-tailed).

The results in Table 4.25 above show that a correlation coefficient of 0.257 was obtained, and it is significant at a level of 0.01. This signifies that there is a significant positive relationship between economic factors and disclosure of a positive sero-status. This implies that the more TASO Masindi underrates economic-related factors, the more the PHAs conceal their positive sero-status and vice versa.

A regression was further done to determine the strength of the relationship between economic factors and disclosure of positive sero-status among PLWHAs and the results are presented in the Table 4.26 below.

Table 4.26 Regression output summary on economic factors and disclosure

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.257(a)	.066	.059	.58415

a Predictors: (Constant), economic factors

The above regression analysis reveals a coefficient of determination (adjusted R square) of 0.059, which means that economic factors explain 5.9 % of variation in disclosing of HIV positive sero-status. This shows that economic factors predict disclosure of HIV positive sero-status among people living with HIV /AIDS in TASO Masindi Center. The null hypothesis was therefore rejected and the alternative hypothesis was substantiated. In other words, *there are economic factors that hinder disclosure of positive HIV sero-status among PLWHAs in TASO Masindi.*

Significantly, the above findings, obtained from the quantitative analysis, were in line with those generated from qualitative data obtained from interviews with key informants and from file reviews. In connection to the above, one of the key informants had this to say:

“I started working with one of the bakeries in town, but when, on the date of my appointment, I disclosed to my boss that I was positive and needed to pick my drugs from the health centre, he allowed me; but on coming back, he told me that the bakery does not employ HIV-positive people because they can contaminate the bread”.

On the same note, another key informant who had once served as a housemaid said,

‘I got a job as a maid, but after some days, my boss asked me whether I had ever tested for HIV or not; and when I disclosed my HIV-positive to her, she kept quiet. But after a week, she gave me my money and told me that she no longer wanted to use maids’.

To assess the extent to which perceived risks, that is, fear of abandonment, accusation of moral impurity and disruption of family relationships hinder disclosure of a positive sero-status,

questionnaire respondents were asked to react to a set of statements, and their views are summarized in Table 4.27 below.

Table 4.27: Perceived risks of HIV-positive sero-status disclosure

TASO Clients	SA (%)	A(%)	Don't know %	D(%)	SD(%)
Fear of being abandoned hinders disclosure to sexual partners	55(39.9%)	68(49.3%)	3(2.2%)	7(5.1%)	5(3.6%)
Disclosing positive sero-status can result into accusation of moral impurity	46(33.3%)	71(51.4%)	6(4.3%)	11(8%)	4(2.9%)
Disclosing positive sero-status can lead to disruption of family relationships	50(36.2%)	69(50.7%)	2(1.4%)	11(8%)	6(4.3%)

As Table 4.27 above indicates, one hundred and twenty-three (89.2%) of the respondents agreed that the fear of abandonment by sexual partners hinders disclosure, while twelve others (8.7%) disagreed. Only three (2.2%) did not have any opinion about the statement. This implies that attachment to spouses is still very strong among the study population, and that the risk of rupture of family and love relationships as a result of disclosure is still very high.

Further, the analysis indicates that one hundred and nineteen (86.2%) of the clients agreed that disclosing sero-status can lead to disruption of family relationships, as opposed to seventeen (12.3. %) who disagreed. On the same note, two respondents (1.4%) did not have any opinion about the statement.

During the study, it was noticed that out of the 138 respondents (TASO clients), only ten (7.2%) had not disclosed their sero-status. This category of respondents revealed that social

cultural and economic factors hindered disclosure of their sero-status as shown in Table 4.28 below.

Table 4.28: Reasons for non –disclosure of HIV-positive sero-status

Reason for non-disclosure	Frequency	Percentage
Fear of upsetting family members/parents	4	23.52%
Inadequate positive sero-status disclosure skills	2	11.76%
Fear of domestic violence	1	0.588%
Fear of disrupting of family relationship	1	0.588%
Fear of being neglected /abandonment	1	0.588%
Fear of being blamed /accused of being the source of infection	2	11.76%
Fear of losing financial assistance	1	0.588%
Fear of failing to get a man	1	0.588%
Need for more time	1	0.588%
Fear of being denied tuition /school fees	1	0.588%
Fear of stigma and discrimination	2	11.76%
TOTAL	17	100%

Table 4.27 above indicates that the majority of the respondents (23.52%) stated that fear of upsetting family members hindered disclosure of their sero-status, followed by fear of being blamed or accused of being the source of infection, inadequate positive sero- status disclosure skills (11.76%) and fear of stigma and discrimination, all tied at 11.76%. Other fears that were cited as having hindered disclosure were: fear of being neglected, of domestic violence, of loss of financial assistance, of failing to get a man for marriage, and fear of denial of tuition/school

fees. One of the respondents said that he had got his results, and needed more time to consider what to do and how to go about it.

A review of the relevant files revealed that similar reasons were cited by clients who had delayed to reveal their sero-status; and the results of this review are summarized in Table 4.29 below.

Table 4.29: Reasons for the delay in disclosing HIV- positive sero-status

Reasons for delay	Frequency	Percentages
Fear of being ashamed	8	7.84%
Lack of a trusted person	2	1.96%
Fear of a volatile spouse	2	1.96%
Fear to worry family members and children	23	22.54%
Fear to be stigmatized or discriminated	23	22.54%
Fear of being blamed	9	8.82%
Fear of being neglected	5	4.9%
Fear of being abandoned and left with the children	6	5.88%
Fear of segregation /avoidance	4	3.92%
Fear of marital disagreement	4	3.92%
Fear of family wrangles	4	3.92%
Fear of losing friends	4	3.92%
Fear of rumour-mongering	4	3.92%
Having no reason for disclosure	2	1.96%
Lack of positive sero-status disclosure skills	2	1.96%

TOTAL	102	100%
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The table above indicates that fear of being stigmatized and fear of worrying family members and children dominated, with twenty-three (22.54%) citations, followed by fear of being blamed, with nine citations (8.82%) and fear of being ashamed, with eight citations (7.4%). Other factors or reasons included fear of losing friends, fear of marital disagreements and abandonment in addition to lack of skills, the volatility of the partner's personality, fear of family wrangles, and having no confidants. Other file citations indicated that clients had no reasons as to why they should disclose their positive sero-status. The data in Table 4.29 above implies that the majority of TASO Masindi clients have self-stigma, and this could translate into further spread of infection to either their family members or their dear ones.

Owing to the above factors that hinder disclosure of HIV-positive sero-status, it was observed that HIV counseling helps in handling HIV/AIDS disclosure. For example, out the 138 respondents (TASO clients), one hundred and thirty-six (98.6%) agreed that HIV counseling helps in handling HIV/AIDS disclosure, and that continuous counseling is key to disclosure of HIV-positive sero-status. Some revealed that HIV counseling provides avenues of shading off fears, building hope, and reducing one's worries. Others added that continuous counseling and information-sharing build confidence and inculcate in PHAs new approaches and skills that ultimately help those with disclosure problems to reveal their sero-status. They also indicated that coping with the disease becomes easier, thus providing a fertile ground for drug adherence, acceptance of the disease and recognizing one's full potential. However, only 2 respondents had no opinion on whether HIV counseling can help in reducing HIV disclosure problems,

implying that they could have been new entrants to TASO care and had no knowledge on HIV counseling or had come for the first time, seeking care for and support.

In reaction to the proposition that peer supports groups help individuals who have challenges of disclosure to reveal their sero-status, out of the 138 respondents (TASO clients), seventy-nine (57.24%) agreed. They indicated that peer support groups play a big role in the provision of knowledge and skills to those living with the disease. Further, sharing experiences, educating PHAs through drama, sensitization, counseling, advice and giving testimonies were identified as the key means of addressing non-disclosure issues by peer support groups. Examples of peer support groups cited were MAMAs club and Positive Men's Union.

On the other hand, fifty-seven (41.3%) of the respondents had no opinion on the roles of peer support groups and their intervention in reducing HIV spread.

Only one (2) respondent stated that peer support groups would hardly influence individuals living with HIV to disclose their sero-status unless provision of information, counseling and giving testimonies which are the modes of encouraging PHAs to reveal their sero-status are their core business. The table 4.30 below shows clients views about the role/importance of peer support groups in supporting PHAs to disclose their sero-status.

Table 4.30: Clients views about the role of peer support groups in supporting disclosure among PHAs.

TASO Clients	Agree (%)	Don't know (%)	Disagree (%)
Peer support groups play a big role in supporting clients to reveal their sero-status through sharing experiences, sensitization and educative drama shows	79(57.24%)	57(41.3%)	2(1.4%)

4.6 Strategies that Can Minimize the Impact of the Factors that Hinder HIV-Positive Sero-status Disclosure among PLWHAs

The third and last objective of this study was: *To generate strategies that can minimize the impact of the factors that hinder HIV-positive sero-status disclosure among PLWHAs.* To achieve this objective, the researcher assessed the extent to which anti-HIV strategies (counseling and IEC) moderate the relationship between social support systems, knowledge and attitude, gender, stigma and discrimination, domestic violence and economic factors (independent variables) and disclosure of HIV (dependent variable). Questionnaire respondents

Were asked to react to a set of pertinent statements, and their views are summarized in Table 4.30 below.

Table 4.31 Respondents' views on anti-HIV strategies (Counseling and IEC)

Views	SA (%)	A(%)	Don't know %	D(%)	SD(%)
No relationship exists between counseling and disclosure of a positive sero-status	30(21.7%)	52(37.7%)	5(3.6%)	15(10.9%)	36(26.1%)
Those who receive counseling disclose more than those who do not receive counseling	64(46.4%)	57(41.3%)	4(4.3%)	6(4.3%)	7(5.1%)
The IEC strategy facilitates disclosure of positive sero-status	59(42.8%)	66(47.8%)	3(2.2%)	7(5.1%)	3(2.2%)
Provision of information materials on disclosure empowers PHAs to disclose	62(44.9%)	68(49.3%)	4(2.9%)	2(1.4%)	1(0.7%)
Educating PHAs on dangers of non-disclosure helps them to disclose their sero-status	52(37.7%)	73(52.9%)	9(6.5%)	1(0.7%)	3(2.2%)

As Table 4.30 above indicates, one hundred and twenty-one (87.7%) of the respondents agreed that PHAs who receive HIV counseling disclose more than those who do not, while thirteen (9.4%) disagreed, and only four (4.3%) had no opinion about the statement. Those who had no opinion at all could have been new entrants into TASO care, and had therefore had little exposure to their counselors.

In addition, the findings indicate that one hundred and thirty (94.2 %) of the respondents agreed that provision of information materials empowers PHAs to reveal their sero-status, as opposed to three (2.1%) who disagreed. Four (2.9%) of the respondents had no opinion on the statement. These results suggest that the dissemination of necessary information is important, and that other media of dissemination, such as radio and television, are appropriate in educating the masses about the dangers of non-disclosure, because even illiterates can access information delivered through such media.

In order to understand and relate the findings about clients' views on HIV counseling and IEC as anti-HIV strategies, the researcher generated a combined correlation matrix to understand whether these anti-HIV strategies had any influence on any of the factors that influence disclosure. The results of the correlation matrix are shown in Table 4.31 below.

Table 4.32: Combined Correlations Matrix for anti-HIV strategies, independent variables and dependent variable (disclosure)

		Disclosure	Economic factors	Knowledge and attitude	HIV counseling and IEC strategies	Gender related factors	Stigma and discrimination	Domestic violence	Social support systems
Disclosure	Pearson Correlation	1	.257(**)	.297(**)	.293(**)	.318(**)	.245(**)	.164	.136
	Sig. (2-tailed)	.	.002	.000	.000	.000	.004	.055	.112
	N	138	138	138	138	138	138	138	138
Economic factors	Pearson Correlation	.257(**)	1	.276(**)	.116	.101	.615(**)	.108	.128
	Sig. (2-tailed)	.002	.	.001	.175	.239	.000	.207	.135
	N	138	138	138	138	138	138	138	138
Knowledge and attitude	Pearson Correlation	.297(**)	.276(**)	1	.107	.307(**)	.497(**)	.304(**)	.044
	Sig. (2-tailed)	.000	.001	.	.210	.000	.000	.000	.606
	N	138	138	138	138	138	138	138	138
HIV counseling and IEC strategies	Pearson Correlation	.293(**)	.116	.107	1	.126	.064	.012	.122
	Sig. (2-tailed)	.000	.175	.210	.	.141	.455	.893	.156
	N	138	138	138	138	138	138	138	138
Gender related factors	Pearson Correlation	.318(**)	.101	.307(**)	.126	1	.226(**)	.330(**)	.107
	Sig. (2-tailed)	.000	.239	.000	.141	.	.008	.000	.212
	N	138	138	138	138	138	138	138	138
Stigma and discrimination	Pearson Correlation	.245(**)	.615(**)	.497(**)	.064	.226(**)	1	.212(*)	.036
	Sig. (2-tailed)	.004	.000	.000	.455	.008	.	.013	.679
	N	138	138	138	138	138	138	138	138
Domestic violence	Pearson Correlation	.164	.108	.304(**)	.012	.330(**)	.212(*)	1	-.014
	Sig. (2-tailed)	.055	.207	.000	.893	.000	.013	.	.868
	N	138	138	138	138	138	138	138	138
Social support systems	Pearson Correlation	.136	.128	.044	.122	.107	.036	-.014	1
	Sig. (2-tailed)	.112	.135	.606	.156	.212	.679	.868	.
	N	138	138	138	138	138	138	138	138

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

From the table above, the Pearson coefficient of correlation of 318(**) for gender-related factors implies that gender-related factors have the most significant relationship with disclosure of HIV-positive sero-status, followed by knowledge and attitude, 297(**), then HIV counseling and IEC, 293(**), economic factors, 257(**) and stigma and discrimination at 245(**).

This implies that in the TASO Masindi setting, gender-related factors should be given a high level of attention because identifying and addressing gender-related factors increases the level of disclosure among TASO clients.

Further, the table shows that the anti-HIV strategies (Counseling and IEC) had no moderating effect on gender, stigma and discrimination, domestic violence, social support systems knowledge and attitude, or on economic factors.

During interviews with the key informants, they were asked what strategies could be devised to minimize the impact of those factors that hinder HIV-positive sero-status, and the findings are presented in Table 4.32 below.

Table 4.33 Proposed strategies for overcoming factors that hinder HIV-positive sero-status disclosure

Proposed strategies for each of the factors hindering disclosure of HIV positive sero-status	Frequency						Total freq.	% of average frequency
	TASO Clients (138)		TASO Staff (6)		TASO Community Volunteers (5)			
	No	%	N	%	N	%		
Stigma and discrimination								
Use of peer support groups for psycho-social therapy	79	57.24%	2	33.3%	1	20%	82	36.8
Sharing testimonies by expert clients	128	92.75%	6	100%	4	80%	138	90.9
Sensitization of families and communities.	120	87%.	5	83.3%	5	100%	130	90.1
Gender-related factors								
Couple-counseling before and after marriage	114	82.6%	6	100%	5	100%	125	94.2
Awareness-creation using educational materials or through media.	132	95.6	6	100%	4	80%	142	91.8
Domestic violence								
Supported disclosure	73	52.8%	6	100%	2	40%	81	64.2

Provision of information on law, ethics and referral systems to PHAs	20	14.49%	3	50%	0	00	23	21.5
Economic factors								
Sensitization of PHAs on their rights – right to employment and litigation in case of dismissal.	17	12.3%	6	100%	1	20%	24	44.1
Enforcement of HIV/AIDS workplace policy through agency sensitization	5	3.7%	5	83.3%	1	20%	11	35.6
Empowering PHAs with SLPs	67	48%	5	83.3	2	40%	74	57.1

Table 4.32 above indicates that sharing testimonies was the most frequently mentioned strategy for overcoming stigma and discrimination, with a total frequency of 138 and an average percentage of 90.9. The next strategy was sensitization of families and the communities, with a total frequency of 130 and an average percentage of 90.1%.

On the issue of gender and disclosure, of the two strategies in the questionnaire, that is, couple-counseling before and after marriage, and awareness creation using educational materials and through public media, the latter was cited 142 times and by an average 91.8 % of the respondents, thus emerging as the preferred strategy. The former was cited 125 times by 94.2 % of the respondents on average.

Regarding the economic factors that hinder disclosure, empowering PHAs with sustainable livelihood projects was ranked highest, with a total frequency of 74 and an average percentage of 57.1%

CHAPTER FIVE

SUMMARY, DISCUSSION AND RECOMMENDATIONS

5.1 Introduction

This chapter presents the summary of the study, discusses the results, and presents the conclusion and recommendations based on the study findings.

5.2 Summary of the Findings

The study aimed at establishing the factors affecting HIV sero-status disclosure among people living with HIV /AIDS in Uganda, through a case study of TASO Masindi. This was done with the aim of making general recommendations on how to help People Living with HIV/AIDS disclose their sero-status.

The study objectives were:

1. To establish the level of HIV positive sero-status disclosure among TASO Masindi clients from 2005 to 2010.
2. To identify socio-cultural and economic factors that influence HIV positive sero-status disclosure among PLWHAs in TASO Masindi.
4. To generate strategies that can minimize the impact of the factors that hinder HIV sero-status disclosure among PLWHAs in TASO Masindi.

The study adopted a descriptive case study research design, using both qualitative and quantitative methods and instruments. Data was collected from the primary respondents: TASO registered clients and TASO staff and community volunteers, using partly structured

and partly non-structured questionnaires and an interview guide. Quantitative data was cleaned, edited, coded and entered into the Statistical Package for Social Scientists version 12.0. Analysis was done using Pearson product correlation coefficient to establish relationships between the variables, and regression analysis determined the strength of the relationships among the study variables.

The findings indicated that the level of disclosure of HIV positive sero-status among TASO Masindi clients was very high, averaging 89.5% for the two years under study. However, although, there had been an increase in disclosure in absolute number, the rate of disclosure had declined by 1% from 2008 to 2009, signaling a worrisome trend. Moreover, we noted that this very high level of disclosure had to be seen in the context of almost equally low levels of testing for HIV/AIDS in Uganda: only 20% of all Ugandans had been tested for HIV/AIDS by the time of the study.

The study identified a number of factors that positively influence HIV positive sero-status disclosure among the TASO Masindi clients. The main ones were the need for care and support on the part of patients, the desire to stop the spread of HIV infection, availability of medication and care services for the infected, and the serious state of health of a patient among others. Considering the first and the last of these factors, one could conclude that the fear of death is a major motivation for disclosure.

The study also established a number of factors that hinder disclosure of HIV positive sero-status among TASO Masindi clients. The four leading ones were the fear of upsetting family

members, followed by the fear of being stigmatized and discriminated against, lack of disclosure skills, and the fear of being accused of, and blamed for, infecting others, especially spouses.

Finally, the study findings indicated that the best means of minimizing the impact of the factors that hinder disclosure would be sensitization through counseling, the IEC strategy and sharing testimonies, intensification of the dissemination of HIV/AIDS-related information, and the diversification of the dissemination media to prioritize radio and television as these can reach even the illiterate and semi-illiterate. In all, 90.9% and 90.1% of the questionnaire respondents suggested sharing testimonies and sensitization of families and communities respectively as the best strategies for overcoming non-disclosure. On the issue of economic factors, empowering PHAs with sustainable livelihood projects was ranked highest, with a total frequency of 74 and an average percentage of 57.1.

The study further established that there was a statistically significant relationship between gender factors and disclosure with, a correlation coefficient of 0,318 at a 0.000 level of significance. A correlation coefficient of determination (adjusted R square) of 0.095 explained 9.5% the variation in disclosing HIV-positive sero-status. Further, the information generated from the key informants was in conformity with the above findings and the major factors identified included, among others, the following: fear of separation, fear of childlessness, fear of abandonment and gender stereotyping.

It was also established that there was a statistically significant relationship between knowledge and attitude on one hand and disclosure of positive sero-status on the other, with a correlation coefficient of 0.297 at a 0.000 level of significance. A correlation coefficient of determination (adjusted R square) of 0.081 explained 8.1% the variations in disclosing HIV positive sero-status among PLWHAs in TASO Masindi. It was further established that the majority of TASO Masindi clients acquire knowledge through counseling which in turn enables them to attain positive behavioral change.

In addition, it was established that there was a statistically significant relationship between economic factors and disclosure of positive sero-status, with a correlation coefficient of 0.257 at a 0.002 level of significance. A correlation coefficient of determination (adjusted R square) of 0.059 explained 5.9% the variations in disclosing HIV positive sero- status among PLWHAs in TASO Masindi. Specifically, it was established that financial dependence, the fear of losing actual and potential employment or clients in the case of businessmen and businesswomen, and the fear of losing financial support for sustenance or school fees in the case of pupils and students, were the major economic factors hindering HIV/AIDS disclosure among TASO Masindi clients. Correspondingly, the need for financial assistance to sustain life encouraged many PHAs to disclose their sero-status.

In addition the study established that there was a statistically significant relationship between stigma and discrimination on one hand and disclosure of positive sero-status on the other, with a correlation coefficient of 0.245 at a 0.004 level of significance. A correlation coefficient of determination (adjusted R square) of 0.053 explained 5.3% the variations in disclosing HIV positive sero-status among PLWHAs in TASO Masindi. The fear of being stigmatized and

discriminated against was revealed as a major hindrance to disclosure of a positive HIV sero-status.

Finally, it was established that there was no statistically significant relationship between social support systems and disclosure of a positive HIV sero-status. A Pearson's product moment correlation coefficient of 0.136 at a 0.112 level of significance was established.

Therefore, on the basis of all the findings in respect of the six working hypotheses, we can conclude that the basic hypothesis that there are no socio-cultural or economic factors that influence HIV-positive sero-status disclosure among PLWHA in TASO Masindi must be rejected and the null hypothesis substantiated. In other words, there are socio-cultural factors that influence HIV-positive sero-status disclosure among PLWHA in TASO Masindi.

5.3 Discussion

The following discussion of the study findings is based on the study objectives and is done objective by objective.

5.3.1 Level of HIV-positive sero-status disclosure among TASO Masindi clients

The first objective of the study was to establish the level of HIV positive sero-status disclosure among TASO Masindi clients from 2005 to 2010. In pursuit of this objective, the researcher set out to establish the level of disclosure among TASO Masindi clients from 2005 to 2010.

The results showed that the level of disclosure among TASO Masindi clients from 2005 to 2010 was high, averaging 89.5% for the period. However, it was also established that there had been a decline in the disclosure rates from 90% in 2008 to 89% in 2009. All the same, the average non-disclosure rate of 10.5%, as compared to the French Antilles and French Guiana where 30.3% of the respondents had not disclosed (Bouillon et al, 2007), is encouraging and laudable. However, it was noted that the very high level of disclosure among the TASO clients had to be viewed in the context of a very low level of testing for HIV/AIDS in Uganda which stood at 20% by the time of the study.

Significantly, while the level of disclosure among TASO Masindi clients was very high, the study findings show that the disclosure was not rapid, and a big proportion of clients disclosed after more than a year. For example, the study findings show that less than half (47 or 34%) of the respondents had disclosed immediately after knowing their test results, 52(38%) had disclosed within a year w and 39(28 %) had disclosed a year and over after knowing that they were positive.

These findings indicate that 91(66 %) of the clients do not reveal their sero-status immediately to their spouses, friends, or their family members. Additionally, it was noted that 10(7.2%) of the respondents had not disclosed to anyone at all. This finding was almost similar to that of Peterson et al (2006) in United States where 11% of 366 participants had not disclosed their sero-status. It can, therefore, be concluded that HIV sero-status disclosure, especially on-the-

spot disclosure, still remains a challenge among TASO Masindi clients and this can aggravate the rate of infections among partners and the general public.

5.3.2 Factors that influence HIV-positive sero-status disclosure among People Living with HIV/AIDS in TASO Masindi

The second objective of the study was to identify socio-cultural and economic factors that influence HIV-positive sero-status disclosure among PLWHAs in TASO Masindi. Under this objective, some of the socio-cultural and economic factors were identified and assessed during the literature review, and these included the following: social support systems, knowledge and attitude, gender, domestic violence and economic factors.

5.3.2.1: Social support systems and disclosure of sero-status

The study findings show that there was a relationship between social support systems and disclosure of a positive sero-status among the PLWHAs in TASO Masindi. A greater proportion of the respondents indicated that supportive social systems are a cornerstone in enabling PHAs to reveal their sero-status. For example, 79% of the respondents agreed to the statement that family member support enabled them to reveal their sero-status. Similarly, 80.8% said that the support of relatives and the community enables PHAs to disclose their positive sero-status.

These findings were in conformity with those of Nachega et al (2004) who indicated that the support of close relatives is fundamental in coping with HIV/AIDS, and in accessing the emotional and material support necessary for sustained adherence to treatment. Wouters (2009)

also found that there was a strong and stable positive association between community and family support on one hand and disclosure on the other. This suggests that for HIV/AIDS patients, especially those who fear to disclose their status, to realize the immediate and long-term impact of community and family support on disclosure of positive sero-status, strong community workers' and HIV support groups, run by PLWHAs, are necessary. Similarly, the results indicate that disclosure to family members is imperative to ensuring their support, identifying tools or resources that can minimize the possible risks, and maximize the potential benefits of disclosure, and thus enable PHAs to exploit the advantages of positive living.

5.3.2.2: Knowledge and attitude, and disclosure of sero-status

The study findings show that there was a significant positive relationship between knowledge and attitude on one hand and disclosure of a positive sero-status on the other, among PLWHAs in TASO Masindi. A big number of the respondents indicated that adequate knowledge and a positive attitude enable PHAs to reveal their sero-status. However, our findings revealed a worrisome level of ignorance about HIV/AIDS among the TASO Masindi clients. For example, 55.8% of the respondents agreed to the statement that HIV infection can occur through sharing bed sheets, washing clothes of an infected person, and/or shaking hands with them. In addition, 48.8% of respondents said that school-going children who are positive should not be given school fees. These findings point to a regrettably high level of ignorance about HIV/AIDS among TASO Masindi clients.

The same findings confirm those of Gwatkin and Deveshwar-Bahl (2001) who established that lack of knowledge about sex and HIV/AIDS greatly constrains people's ability to protect themselves from infection. Although it is true that knowledge about prevention is not enough to bring about behavior change, it is also true that there are many individuals, particularly young women, who are seriously disadvantaged in this epidemic because of lack of knowledge. No wonder, therefore, that at the United Nations General Assembly Special Session on HIV/AIDS member states committed to "ensure that by 2015 at least 90 percent of young men and women aged 15-24 have access to the information and education necessary to develop the life skills required to reduce their vulnerability to HIV" (United Nations, 2001).

Our findings were also in conformity with MacDonald et al (2004) in their study of knowledge, attitudes and beliefs of Maternal Child Health (MCH) and non-MCH adolescents (aged 10-18 years) regarding HIV sero-status disclosure. That study found that disclosure of an HIV-positive status revealed key underlying themes, and these included a relationship of trust, maturity and stress to the disclosure experience. Potential societal discrimination, lowered self-esteem, and concerns about confidentiality featured prominently among their concerns. Additionally, our findings show that 48.8 % of the respondents agreed to the statement that school-going children should not be given school fees. This finding reinforces that of Ghabili et al (2008) who discovered that of 300 students, 10% declared that they would feel uncomfortable towards their HIV- infected classmates.

This implies that possession of knowledge is vital to HIV/AIDS interventions, and, therefore, availing access to the information and education necessary to develop the necessary attitudes and life skills reduces vulnerability of people to HIV-infection. On the same note, attitude change, through behavioral change communication, is paramount in aligning negative perceptions of individuals towards accepting and embracing PHAs as people who have a right to life and other human rights.

5.3.2.3: Stigma and discrimination

The findings of the study show that there was a strong positive relationship between stigma and discrimination on one hand and disclosure of a positive sero-status on the other, among PLWHAs in TASO Masindi. A big proportion of the respondents said that stigma and discrimination hinder people from revealing their sero-status. For example, 68.9% of the respondents agreed to the statement that communities isolate PHAs once the latter reveal their sero-status. Similarly, 63.8% agreed to the statement that PHAs are seen as an embarrassment to their families or communities once they reveal their sero-positive status. These findings confirm the assertion by Nyablade et al (2003), as cited by Byansi (2004), who argued that HIV and AIDS stigma and discrimination, directed at the infected and affected, are responsible for further spread of HIV in Sub-Saharan Africa. They emphasized that stigma impedes HIV-testing, disclosure, seeking early treatment, and care and support for PLWHAs and affected families. Further, the findings also conform to those of Goffiman (1968), as cited by Byansi (2004), who revealed that stigma portends a gap between an individual's virtual and social identity which, in the eyes of the individual and the public, translates into a 'handicap'. This handicap relegates the stigmatized person among those whose moral fibre and body are

regarded as having been contaminated. Lehetensteins (2003), as cited by Byansi (2004), also observes that, as a consequence, non-disclosure (‘passing as normal’) of the stigmatizing disease becomes a coping strategy for the infected, which impacts on the course of illness and the propensity to seek testing and treatment, thus increasing the possibility of spreading infection to other sexual contacts.

This implies that fighting non-disclosure among PLWHAs should target family and community members. Therefore, there is need to emphasize continuous community sensitization and provision of health education at household and community levels to accelerate the involvement of individuals in HIV-testing, seeking appropriate diagnosis, treatment and disclosure of their sero-status.

5.3.2.4: Gender and disclosure of HIV positive sero-status

The study findings show that there was a strong positive relationship between gender-related factors and disclosure of a positive sero-status among PLWHAs in TASO Masindi. A big number of the respondents indicated that gender-related factors hinder people from revealing their sero-status. For example, 89.9% of the respondents agreed to the statement that women in the reproductive age group fear losing their partners as such a loss could render them childless. Further, it was also established, as indicated by 104(72.7% of the respondents, that men and women fear to disclose their positive sero-status because they do not want their spouses or families to see them as sources of infection. On the other hand, 68.2 % of the respondents indicated that the fear of being denied participation in various community activities hinders men from disclosing their positive sero-status results. These findings are in line with those of

Ngonzi c et al, (2009) who discovered that 56% of women in Kenya were commonly targets of stigma compared with 12% of men, a condition that generally made many women to refrain from testing, and if they tested positive, to conceal their status. The only difference here is that whereas in the Kenyan study it is women, much more than men, who experience the sense of stigmatization, in TASO Masindi the majority of men exhibit the same feelings.

Other researchers have also indicated that although PLWHAs have generally become scapegoats, females experience an added intensity of this phenomenon, a double stigma with a bigger social disadvantage (Amayunzu et al 2006). Women are frequently blamed as vectors of HIV transmission, although in reality both men and women do transmit the disease (Duffy et al. 2006). Most societies in Africa expect their women to be monogamous, but expect men to have extramarital affairs or to be polygamous. Yet a woman's monogamy does not protect her from infection if her spouse has other sexual partners. This gender bias is even stronger in Sub-Saharan Africa because most women there are dependent on their husbands for food, shelter, and clothing.

Our findings were also in consonance with those of Ndebwa et al (2009) in their study carried out in Ghana. That study showed that secrecy affected women's access to treatment and financial and emotional support from families. The main reasons for not disclosing HIV status were fear of stigma and divorce, fear of losing a partner and confidentiality, women's low decision-making power, defective communication patterns between partners, and the negative attitudes of male partners to voluntary counseling and testing. This implies that male involvement in the fight against HIV/AIDS should be given due attention, that more efforts should aim at discouraging inherently bad cultural and social practices, such polygamy and

other sexual networks, and that, through affirmative action, women should be empowered in both social and economic decision-making matters.

5.3.2.5: Domestic violence and disclosure

The findings of this study have shown that there is a relationship between domestic violence and disclosure of a positive sero-status among PLWHAs in TASO Masindi. A big proportion of the respondents indicated that fear of domestic violence hinders PLWHAs from revealing their sero-status. For example, 67.7% of the respondents agreed to the statement that there is no mutual respect between husbands and wives after disclosure of positive sero-status. Similarly, 68.9% agreed to the statement that fear of neglect by the spouse and family members, makes individual PHAs to conceal their positive sero-status.

These findings conform to those of Maman et al., (2000) who found out that, of the women who sought HIV-testing and counseling services in their Tanzanian study, more than half of those who did not disclose their status to their partner reported fear of a violent reaction as the reason why they did not disclose. Similarly Maman et al., (2001) showed that the stigma associated with HIV/AIDS and the fear of violence that results from disclosure, are also barriers to the success of efforts that seek to reduce the prenatal transmission of HIV in Africa. Fear of stigma and domestic violence are important reasons that pregnant women refuse HIV-testing or do not return for test results. Further concerns have been voiced by HIV-positive women who have been advised to bottle-feed their babies to avoid the risk of HIV transmission (Brown, 1998). Because breast-feeding is the norm in many African societies, women fear that using a bottle would lead to them being branded as HIV-infected, and expose them to the

stigma and violence that often results. A study in Botswana also showed that fear of violence and stigma were the foremost reasons women declined to participate in voluntary counseling and testing or in programs to prevent mother-to-child transmission (Nyblade and Field, 2000).

According to the Ugandan branch of the International HIV/AIDS Alliance, one Glorious was among the five women murdered in 2008 under similar circumstances. Elsewhere, Action Aid Uganda surveyed just one district and established that 100 out of 465 women had experienced domestic violence as a result of disclosing their status. These findings suggest that community sensitization, psychosocial support, health education of household members, and provision of information on legal rights should, in addition to care, be part of a comprehensive anti-HIV/AIDS package.

5.3.2.6 Economic factors

The findings of this study have also shown that there is a strong and significant positive relationship between economic factors and disclosure of a positive sero-status among PLWHAs in TASO Masindi. It was noted that weak economic muscle to shoulder personal financial challenges greatly inhibited PHAs from revealing their sero-status. For example, 94(68.1%) of the respondents indicated that they would not disclose their HIV-positive sero-status to their business customers due to fear of a decline in sales.

Further, a big percentage of the respondents also agreed that they would not disclose their sero-status to their employer due to fear of loss of employment. These findings are in conformity with those of Simbayi et al (2007) who observed that 42% of their participants, who did not disclose their sero-status, cited the reason for non-disclosure as fear of losing a job or a place to stay because of being known to be HIV-positive. The same findings confirm those of a study of the formal and informal private sectors in Uganda by the International Labor Organization (ILO), which revealed that several firms had policies that entitled workers to a few months, not exceeding 6, of sick leave before they lost salaries and wages. This implies that, since AIDS causes prolonged sickness, often several years before death, AIDS-infected workers are first expelled from duty and then given minimal pay before death.

Therefore, TASO and other HIV/AIDS service organizations plus other partners, particularly those charged with human rights, should undertake massive sensitization of individuals, families, communities and employers' organizations to ensure that HIV/AIDS workplace policies are rejuvenated and implemented, and that anti-HIV/AIDS programmes and projects are monitored and evaluated.

5.3.3: Strategies to minimize the impact of the factors that negatively influence disclosure of HIV-positive sero-status

In order to provide focus and direction, strategies for each of the factors that negatively influence disclosure were proposed, and they are outlined below.

5.3.3.1: Stigma and discrimination

The fear of being stigmatised and discriminated against has been shown to be a major barrier to HIV/AIDS disclosure among PHAs. To minimize this negative impact of stigma and discrimination, the study generated two main strategies:

- use of peer support groups for psycho-social therapy; and
- continuous sensitization of community members about HIV/AIDS.

Use of peer support groups for psycho-social therapy may take various forms, principally group therapy and family therapy. Peer support groups can provide an ideal environment for members to feel free to share their feeling and to assess the challenges they face in relation to stigma and discrimination. In the process, such groups can work out possible solutions to their common problems.

For its part, continuous sensitization of community members about HIV/AIDS can increase HIV/AIDS awareness among the beneficiaries, especially with regard to the causes and challenges of stigmatization and discrimination. As a result, those infected and affected by HIV/AIDS can be empowered to demystify the myths surrounding the scourge and to live more positively than would be the case in the absence of such sensitization.

5.3.3.2: Gender factors

Economic disparity between males and females has been shown to be one of the main causes of non-disclosure. To minimize this negative impact of economic factors on disclosure, the study generated four strategies:

- gender mainstreaming in all the socio-economic interventions led by the government and civil society organizations;
- prioritization of continuous sensitization of PHAs and communities about the importance of shared responsibility among partners;
- intensification of gender awareness activities in relation to HIV/AIDS; and
- sensitisation of PHAs about their rights.

Gender mainstreaming in all government- and civil society-led socio-economic interventions would have the effect of empowering women and reducing their economic dependence on men.

Prioritization of continuous sensitization of PHAs and communities about the importance of shared responsibility among partners should emphasise couple-counseling so that both husband and wife jointly identify and understand the challenges of PHAs, and thereby develop better informed and more positive attitudes and approaches to those challenges.

Intensification of gender awareness activities in relation to HIV/AIDS should use various media, such as radio, television and educational materials to reduce the levels of ignorance about the scourge and to demystify the disease. This would in turn lead to better informed communities capable of responding positively to the HIV/AIDS challenge.

Finally, sensitization of PHAs about their rights would enable PHAs to realize that HIV infection does not necessarily spell doom for the infected, that there can, and should, be life after infection,

and that society has a moral and legal responsibility to support PHAS so that they can live in dignity in spite of their condition. Such sensitization should encourage supported disclosure among couples while at the same time providing psychosocial support, health education and marital counseling to the families and communities infected and affected by HIV /AIDS.

5.3.3.3: Domestic violence

The fear of being shunned, beaten or even killed by a volatile husband has been shown to inhibit HIV/AIDS disclosure among women. To minimize the negative impact of this fear, the study generated two strategies:

- sensitization and education of family members; and
- encouraging of PHAs to join peer support groups.

Sensitization and education of family members can be achieved through home visits during which couples would be encouraged to seek medical and counseling services together. Such home visits would also be used to empower PHAs with skills and knowledge on law and ethics, and on their rights as individuals living with HIV /AIDS.

Encouraging PHAs to join peer support groups, such as Positive Men's Unions and discordant and concordant groups can help to minimize the incidence of domestic violence because the groups can be ideal avenues for the provision of psychosocial therapy for those individuals in need of help regarding positive HIV sero-status disclosure.

5.3.3.4: Economic factors

In order to minimize the negative impact of economic factors on HIV/AIDS disclosure, the study generated three strategies:

- Sensitizing PHAs on their rights;
- empowering PHAs through training and provision of IGA inputs; and
- encouraging agency sensitization of employers and employees about human rights.

Sensitizing PHAs on their rights would involve enlightening PHAs about their right to employment and to litigation in case of dismissal from employment, and it would highlight the need to improve and enforce existing HIV/AIDS workplace policies. Human rights organizations would be the best placed to undertake this sensitization.

Empowering PHAs through training and provision of IGA inputs would involve the initiation of sustainable livelihood projects purposely to build the economic muscle and promote the economic independence of PHAs.

Finally, encouraging agency sensitization of employers and employees about human rights, especially those of PHAs, would focus on ensuring that HIV workplace policies are put in place, improved and implemented across all organizations.

5.4 Conclusions

This study set out to establish the factors affecting HIV sero-status disclosure among people living with HIV/AIDS, through a case study of TASO Masindi. This was intended to facilitate the generation of strategies that can minimize the impact of the factors that hinder disclosure. All this was in relation to the fact that although Uganda has made commendable progress in the fight against HIV/AIDS, the disease continues to cause high levels of morbidity and mortality, partly because many PHAs fail to disclose their HIV-positive sero-status. The study specifically sought to establish the level of HIV positive sero-status disclosure among TASO Masindi clients; identify the socio-cultural and economic factors that positively or negatively influence disclosure; and to generate strategies to minimize the impact of the factors that hinder disclosure. A basic research hypothesis was formulated to cater for the purpose of the study, and six working hypotheses were derived from that single hypothesis in line with the objectives of the study. The study established the following:

5.4.1 Level of disclosure of TASO Masindi clients

As indicated earlier, the first objective of this study was to establish the level of HIV positive sero-status disclosure among TASO Masindi clients. The study established that the levels of disclosure of HIV positive sero-status among TASO Masindi clients was very high, averaging 89.5% for the two years, and translating into a 10.5% non-disclosure rate. Lest these figures excite undue enthusiasm, it was noted that they have to be interpreted against the fact that only 20% of all Ugandans had been tested for HIV/AIDS by the time of the study. In addition, although the absolute number of clients and disclosures increased from 2008 to 2009, the rate

of disclosure dropped by 1%, from 90% in 2008 to 89% in 2009. All the same, the findings indicate a better performance in HIV disclosure among TASO Masindi clients than among the populations studied in the French Antilles and French Guiana where 30.3% of the respondents had not disclosed (Bouillon et al, 2007).

However, the study findings also show that disclosure among TASO clients is not rapid, and a big proportion of clients disclosed after more than a year. For example, the study findings show that 37 (28.9%) of the respondents disclosed immediately after knowing their test results, 52(40.06%) of the respondents disclosed their HIV-positive sero-status within a year while 39(30.46%) disclosed after more than one year. These findings indicate that 91(70.5%) of the clients do not reveal their sero- status immediately to their spouses, friends, or their family members. It can, therefore, be concluded that HIV-positive sero-status disclosure, especially on-the-spot disclosure, still remains a challenge among TASO Masindi clients, and poses the danger of aggravating the rates of infection.

5.4.2 Factors that influence HIV-positive sero-status disclosure among PLWHAs in TASO Masindi

The second objective of the study was to identify socio-cultural and economic factors that positively or negatively influence HIV-positive sero-status disclosure among PLWHAs in TASO Masindi. Under this objective, social support systems, and knowledge and attitude, gender, domestic violence, and economic factors were assessed.

5.4.2.1 Social support systems and disclosure

Even though there was no statistically significant relationship between social support systems and disclosure of a positive HIV sero-status, other research data indicated that social support systems of families, relatives and community members have an influence on disclosure of positive sero-status. It can, therefore, be concluded that the availability and effectiveness of supportive social systems promotes disclosure of HIV-positive sero-status among TASO Masindi clients.

5.4.2.2 Knowledge and attitude

Regarding knowledge and attitude, the statistical results confirmed that there was a positive and significant relationship between knowledge and attitude on one hand and disclosure of HIV on the other, among PLWHAs. The relationship was attributed to provision of counseling, and community sensitization on HIV/AIDS-related challenges. We can, therefore, conclude that the more knowledgeable PHAs become about HIV, through counseling, education and health talks, the more likely they are to reveal their sero-status and vice-versa. Similarly, the more PHAs and communities improve their attitudes through behavioral change communication, the more likely they are to disclose their positive sero-status.

5.4.2.3 Stigma, discrimination and disclosure

The descriptive statistics and information generated from the key informants revealed that stigma and discrimination hinder disclosure of a positive HIV sero-status. In addition, it was statistically proven that there was a positive and significant relationship between stigma and discrimination on one hand and disclosure of a positive sero-status on the other. The relationship was due the facts that, generally, the community isolates PHAs once they disclose their status, and

the majority of PHAs are seen as an embarrassment within their families and in the community as a whole.

We can, therefore, conclude that the more stigma and discrimination are reduced at the personal, family and community levels, the higher will be the rate of disclosure among PLWHA and vice-versa.

5.4.2.4: Gender-related factor and disclosure

Gender-related factors were also found to greatly hinder disclosure of HIV among PLWHAs. This was confirmed by both statistical and descriptive analysis. We can, therefore, conclude that the more TASO focuses on gender factors in relation to HIV-positive sero-status disclosure the more the PHAs are likely to disclose their sero-status and vice-versa.

5.4.2.5 Domestic violence and disclosure

Both the descriptive statistics and the information generated from the key informants confirmed that domestic violence hinders disclosure of positive HIV sero-status among TASO Masindi clients. It can, therefore, be concluded that the more TASO fights domestic violence the higher the likelihood of many clients revealing their sero-status and vice-versa.

5.4.2.6 Economic factors

The statistical and descriptive analyses conducted on data about economic factors and disclosure revealed that economic factors greatly hinder disclosure of HIV-positive sero-status among PLWHAs in TASO Masindi. We can, therefore, conclude that the more government, TASO and

other anti-HIV/AIDS crusaders focus on general and PHA-specific economic empowerment, the more the PHAs will reveal their positive sero-status.

5.4.3 Strategies to Minimize the Impact of the Factors that Hinder Disclosure of HIV-Positive Sero-status among PLWHAs

During the interviews, the participants were asked to propose strategies that can minimize the effect of the factors that negatively influence HIV-positive sero-status disclosure among PLWHAs in Uganda. Following are summarized versions of the strategies that were proposed in respect of each hindering factor or set of factors.

5.4.3.1: Stigma and discrimination

With respect to stigma and discrimination, two strategies were proposed:

- Use of peer support groups for psycho-social therapy achieved through group therapy or family therapy.
- Continuous sensitization of community members about the causes and challenges associated with stigmatizing those infected with, and affected by, HIV/AIDS.

5.4.3.2: Gender factors

Regarding the gender-related factors that hinder disclosure, the following four remedial strategies were proposed:

- gender mainstreaming in all the socio-economic interventions led by the government and civil society organizations;

- prioritization of continuous sensitization of PHAs and communities about the importance of shared responsibility among partners;
- intensification of gender awareness activities in relation to HIV/AIDS; and
- sensitisation of PHAs about their rights.

5.4.3.3: Domestic violence.

With regard to domestic violence as a barrier to disclosure, the respondents suggested the following two remedial strategies:

- sensitization and education of family members; and
- encouraging of PHAs to join peer support groups.

5.4.3.4: Economic factors

Concerning the economic factors that hinder disclosure, three remedial strategies were proposed, and they are:

- Sensitizing PHAs on their rights;
- empowering PHAs through training and provision of IGA inputs; and
- encouraging agency sensitization of employers and employees about human rights, especially those of PHAs

5.5: Recommendations.

In view of the above findings and conclusions, the study makes the following recommendations.

5.5.1: Level of HIV-positive sero-status disclosure among TASO Masindi clients

It is true that the level of disclosure among TASO Masindi clients was found to be very high. However, given that the level of disclosure had declined by 1% from 2008 to 2009 and that the vast majority of Ugandans have not yet been tested for HIV, we feel compelled to recommend that:

- (i) TASO Masindi, TASO Uganda and other anti-HIV/AIDS organizations in the country should continuously encourage the general public to be tested for HIV/AIDS, and their clients to reveal their sero-status to significant others so as to facilitate care, support, and prevention efforts.
- (ii) TASO Masindi Center should continue to focus its attention on supporting HIV sero-status disclosure among partners through provision of continuous counseling services.
- (iii) During counseling sessions, HIV/AIDS counselors should provide clients with the necessary skills to disclose their sero-status as this is likely to minimize the negative consequences of inadequate skills and approaches in disclosing HIV-positive test results and thereby increase the level of disclosure among clients.

5.5.2: Factors that influence HIV-positive sero-status disclosure among PLWHAs in TASO Masindi

5.5.2.1: Social support systems

In view of the finding that social support systems promote disclosure of HIV-positive sero-status among PLWHA, the study recommends that:

- (i) TASO management and front-line staff should work towards strengthening social support systems through continuous sensitization, mentoring of community members to organize appropriate responses to the problems generated by HIV/AIDS, provision of timely referral feed-back to and from the partner organizations, and educating family members on the purpose of supporting their PHAs.
- (ii) Concurrently, TASO should acknowledge the roles played by social support systems, and bridge the knowledge gaps among existing and future service organization/partners.

5.5.2.2 Knowledge and attitude

Having established that inadequate or incorrect knowledge and negative attitudes to HIV/AIDS hinder disclosure, this study recommends that:

- (i) TASO Masindi should consider continuous community sensitization,

psychosocial support , health education of household members, provision of information on legal rights, and attitude change counseling should be part of a comprehensive HIV/AIDS package in addition to care .

5.5.2.3 Stigma and discrimination

Since it was established that stigma and discrimination constitute a major barrier to disclosure, we recommend that:

- (i) TASO Masindi should continuously mobilize and sensitize the communities on HIV through provision of health education at the household and community levels, aimed at increasing individual involvement in HIV-testing, seeking appropriate counseling services, diagnosis, and treatment.
- (ii) One-to-one counseling which empowers an individual to make informed decisions should be emphasized and key messages that focus on HIV-prevention, improving quality of life, and facilitating the balance between rights and responsibilities should also be encouraged.

5.5.2.4: Gender-related factors and disclosure

In view of the finding that gender-related factors are a major hindrance to disclosure, this study recommends that:

- (i) TASO Masindi Center should consider continuous sensitizations of PHAs on their rights, together with families and communities infected and affected by HIV/AIDS.

- (ii) TASO Masindi should consider energizing the HIV service providers to carry out home visits, and activating male involvement in HIV/AIDS care programming, implementation and evaluation.

5.5.2.5: Domestic violence and disclosure

This study has established that the fear of domestic violence is a major hindrance to disclosure among TASO Masindi clients, and most likely throughout the country, especially among women.

We therefore recommend that:

- (i) TASO and other organizations with similar objectives should intensify sensitization and education of family members against domestic violence, through home visits and couple-counseling.
- (ii) TASO and other organizations with similar objectives should empower PHAs with skills and knowledge on the law, ethics and their rights as individuals living with HIV/AIDS.
- (iii) Supported disclosure as a technique of HIV sero-status disclosure should be encouraged in cases where clients cannot reveal their status on their own.
- (iv) PHAs should be encouraged to join or form peer support groups, such as Positive Men's Unions and discordant and concordant clubs for psychosocial therapy.

5.5.2.6: Economic factors and disclosure

In view of the negative impact of economic factors on disclosure that this study has established, we recommend that:

- (i) TASO Masindi and her partners, particularly those charged with human rights and advocacy, should undertake massive sensitization to ensure that HIV/AIDS workplace policies are adhered to and practical action taken on implementation, monitoring and evaluation of these policies.
- (ii) TASO Masindi and similar-minded organizations should encourage agency sensitization and awareness-creation among PHAs about their legal rights, such as the right to employment.
- (iii) Government, civil society, and trade unions should sensitize employers' associations and workers, especially PHAs, about HIV/AIDS workplace policies, and provide legal support in an effort to enforce those policies.
- (iv) TASO Masindi and TASO centers elsewhere in Uganda should prioritise the empowerment of PHAs through the initiation of sustainable livelihood projects in their HIV/AIDS programmes.
- (v) Finally, strategies to minimize the factors that negatively influence HIV-positive sero-status disclosure should be multifaceted, targeting individuals, families and communities, and addressing the socio-cultural and economic dimensions of life.

5.5.3: Other recommendations

We further recommend that:

- (i) Further, information about the formation of post-test clubs should be made available to TASO Masindi clients in an effort to promote disclosure of HIV sero-status among

themselves and significant others. This is because such clubs have proved effective in providing preventive and supportive counseling to members mainly by facilitating information exchange and sharing experiences, providing peer counseling and education, encouraging participation in social and recreational activities and enhancing positive living concept among others.

- (ii) Information about the formation of PHA support groups should be continuously shared with the clients during counseling sessions given that some PHA support groups have chosen to be open about their sero-status. In such groups, individual PHAs can learn and apply life skills and other techniques for revealing their sero-status without any difficulty.

5.5.4 Areas for further research

1. Although Home-Based HIV Counseling and Testing (HBHCT) is considered as a main model of VCT that targets provision of HIV/AIDS services to the family members of the people living with HIV/AIDS, enrolled on treatment and care programs, such as anti-retroviral therapy for TASO clients, its effectiveness is yet to be scientifically established. Therefore we recommend that future research efforts should focus on establishing the impact of Home-Based HIV Counseling and Testing (HBHCT) on disclosure of positive sero-status among PHAs in Uganda, more particularly in TASO Masindi.

2. Given that many HIV-positive mothers breast-feed their babies in order to avoid being known to be HIV-positive, further research should be conducted to establish the impact of non-disclosure on the utilization of PMTCT services in Uganda.

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Appendix 1 A QUESTIONNAIRE FOR TASO CLIENTS

Re: Introduction

Dear respondent,

I am Namanya Yusuf a participant at Uganda Management Institute pursuing a Masters Degree in Management Studies (Project Planning and Management). I am carrying out a research on factors affecting HIV status disclosure among people living with HIV/AIDS in Uganda through a case study of TASO Masindi. This study will begin from June 2010 and end in Dec 2010. Therefore I am requesting you to fill this questionnaire as honestly as possible so that I am able to produce tangible and quality work, that can be used in supporting those individual PHAs with challenges of HIV sero-status disclosure. This study is purely academic and the information given herein will remain confidential, and will not serve any other purpose. Further, no financial incentives shall be advanced to any of the participants in form of pay or allowance for participating in this study, and you are free to accept or withdraw from participating in the study.

Thank you in advance,

Yours truly,

Namanya Yusuf 0782160217/0716160217

Please circle the most appropriate answer as indicated below

SECTION 1 BIO DATA

1. Sex: 1. Female 2. Male

2. Age in complete years:

3. Date of birth:...../...../.....

3. Marital status: 1) married 2) single 3) separated /divorced

4) Cohabiting 5) widowed

4. What is your highest level of education?

1) None 2) Primary 3) O Level 4) A level 5) Diploma 6) degree.

SECTION 11. Please indicate the extent to which you agree or disagree with the following statements. (Select the most appropriate)

1) Strongly disagree 2) disagree 3) don't know 4) agree 5) strongly agree

SECTION 11. SOCIAL- CULTURAL AND ECONOMIC FACTORS.					
A	Gender and disclosure				
5	Fear to lose your partners influences your ability to reveal their sero-status.	5	4	3	3 1
6	Fear to be denied participation in various community activities influence your decisions to disclosure	5	4	3	3 1

7	Fear to be identified as a source of infection may influence decisions to reveal your sero status	5	4	3	3	1
	DOMESTIC VIOLENCE AND DISCLOSURE					
8	Anticipation of violent reactions from your spouse may determine whether to reveal or conceal your sero-status	5	4	3	2	1
9	Fear of being disrespected may limit one's ability to reveal his or her sero-status.	5	4	3	2	1
10	Fear to be neglected influences ones decision either to disclose or conceal his or her positive sero-status	5	4	3	2	1
11	Fear of anticipating personal loss of property to your family members may influence your decisions whether to conceal or reveal your sero-status.	5	4	3	2	1
		5	4	3	2	1
	KNOELEDGE AND ATTITUDE					
12	Ones' knowledge about various modes of transmission influences his or her decisions to disclose his or her sero status family or significant others.	5	4	3	2	1
13	The attitude that disclosure may not result into loss or misappropriation of one's property or discrimination influences your ability to reveal your sero status.	5	4	3	2	1
	STIGMA AND DISCRIMINATION					
14	Fear that disclosure of you sero-status may result into failure to get school fees determines your decisions to disclose	5	4	3	2	1
15	Fear to be seen as an embarrassment to their families may deter your ability to disclose your sero status.	5	4	3	2	1
16	Fear that community may isolate you once you disclose influences your decisions to reveal your sero-status	5	4	3	2	1
	SECTION 111. ECONOMIC FACTORS					
	ECONOMIC DEPENDENCE.					
17	Your ability to support yourself influences your decisions to disclose your sero-status.	5	4	3	2	1
18	Your position in the house hold influences your decisions to disclose	5	4	3	2	1
19	Fear disclosure may result into loss of financial assistance influences your decisions to reveal your sero-status.	5	4	3	2	1
	FEAR FOR LOSS OF EMPLOYMENT					
20	The view that employers find it difficult to recruit or retain PHAs in their positions of work determines your position to disclose.	5	4	3	2	1

21	Fear that disclosure may lead to loss of your employment influences your decisions to reveal your sero status.	5	4	3	2	1
22	Fear that disclosure of your positive status may lead to decline in customer base for your business influences your decisions to disclose.	5	4	3	2	1
	Moderating variables.					
	HIV counseling					
23	There is a relationship exists between counseling and disclosure of a positive sero-status	5	4	3	2	1
24	Those who receive counseling disclose more than those who don't get	5	4	3	2	1
	IEC					
25	IEC strategy facilitate disclosure of positive sero-status	5	4	3	2	1
26	Provision of Information materials on disclosure empowers PHAs to disclose	5	4	3	2	1
27	Educating PHAs on dangers of non- disclosure helps them to share their sero-status	5	4	3	2	1
	SOCIAL SUPPORT SYSTEMS					
28	The desire to receive help from family members influences you to disclosure	5	4	3	2	1
29	The need to get support from your spouse influences you to disclosure	5	4	3	2	1
30	The desire to get support from your ,relative and community influences you to reveal your sero-status	5	4	3	2	1
	PERCEIVED RISKS OF HIV/AIDS DISCLOSURE					
31	Fear of being abandoned hinders your ability to reveal your status	5	4	3	2	1
32	Sharing positive sero-status can result into accusation of moral impurity	5	4	3	2	1
33	Sharing sero status can lead to disruption of family relationships	5	4	3	2	1

34. Please tick, if you have ever disclosed your HIV positive sero-status to any of the following persons indicated below.

1) Yes

2) No

If No, please skip to question 58

Sibling [1] parent [2] spouse [3] friend [4] relative [5] workmate [6] Schoolmate
[7]

35. If you revealed your HIV positive sero-status, how long did it take you to reveal your status to any of the persons indicated above?

1). Immediately 2) Less than one year 3) More than a year

36 State the reasons for sharing your HIV positive sero-status sero status to any of the above persons.

37 If you did not share your HIV positive sero-status, state the reasons why

38) If you delayed to reveal share your HIV positive sero status to any of the persons shown below, state the reasons for the delay to

Sibling, parents, spouse, friends, relatives or workmates

39) Do you think that, HIV counseling can support you in handling HIV/AIDS related disclosure issues?

1) Yes

2) No

3) not sure

11 Give your reasons for the any of the above answers except (no3)

.....
40) How can people living with HIV/AIDS be helped to disclose their HIV status?

41) Do you think that, belonging to a PHA peer support group can help you to reveal your HIV positive sero-status to your family members and significant others?

1) Yes 2) no 3 not sure

11 .If yes, how can such groups motivate People living with HIV/AIDS to disclosure their status to the family members and significant others?

.42) If no, why do you think that belonging to such groups doesn't help members to reveal their HIV positive sero-status?

Thank you for your precious time.

If yes, how many cases are you aware of that have been reported in TASO Masindi?.....

Of those that were reported, how many are men..... and how many are women?

Suggest ways of preventing domestic violence among people who learn and share their sero positive status to their partners or significant others?

.....

If none, what strategies have been in place to counteract the emergence of domestic violence in relation to HIV positive sero-status disclosure?

SECTION D: STIGMA AND DISCRIMINATION

Are you personally aware that stigma and discrimination exist among PLWHAs in TASO Masindi?

- 1) Yes 2) No

If yes, what are the common forms of discrimination that you know?

Are there possible ways of reducing stigma and discrimination among people who learn and share their HIV positive sero-status your clients and those who stigmatize them?

SECTION E: KNOWLEDGE AND ATTITUDE

Do you agree that having knowledge on the importance of HIV positive sero-status disclosure influences PHAs to disclose their sero status?

1. Yes 2.No

Comment/Give reasons for your answer

.....

SECTION F: SOCIAL SUPPORT SYSTEMS

Are you personally are that, presence of social support systems can promote HIV status disclosure among your clients among PHAs?

1. Yes 2.No

State different types of social support systems which can promote HIV positive sero-status disclosure among PLWHAs?.

.....

Are there ways of strengthening the above mentioned support systems if any so that PLWHAs are enabled to reveal their sero-status more easily?

ECONOMIC FACTORS SECTION 11

Do you agree that fear of loss of employment hinder PLWHAs from sharing of sero positive status?

1. Yes 2.No

If yes, how does it hinder individuals from sharing their sero status?

How many cases are you aware of that lost their jobs as a result of HIV positive status disclosure?

Suggest strategies that can be put in place to support PHAs who lose their jobs as a result of sharing HIV positive their sero status to their employees

ECONOMIC DEPENDENCE: SECTION 6

Do you think that individuals who are economically independent don't experience any difficulty in sharing their HIV positive sero-status disclosure?

1. Yes 2.No

Give reasons for any of the answers mentioned above

.....

Give/suggest ways of empowering clients who are economically dependent to share their sero-status.....

Do you agree that HIV/AIDS counseling promotes disclosure of positive sero status?

1) Yes 2) No

How many clients under your care that you know who have not disclosed their HIV positive sero-status to any one yet have been receiving HIV counseling services.....

What are the appropriate measures that can be put in place to encourage clients who don't disclose their sero-status?

In your own view, how has Information, Education and Communication strategy helped in overcoming the challenges associated with HIV disclosure among PHAs

APPENDIX 111: INTERVIEW GUIDE

What are the gender-related factors that hinder or promote HIV/AIDS status disclosure among PLWHAs?

How can gender-related problems be addressed to minimize the risks/ negative outcomes of HIV/AIDS disclosure among people in your communities?

What comments do you have about gender and HIV/AIDS disclosure in relation to clients in your community?

SECTION C: DOMESTIC VIOLENCE

What forms of domestic violence are experienced by PHAs/your clients after sharing their sero status?

What could be major ways/strategies of minimizing domestic violence among PHAs? Who reveal their sero-status?

SECTION D: STIGMA AND DISCRIMINATION

How does stigma and discrimination hinder your clients/PHAs from sharing their sero-positive status to their partners and significant others?

How can stigma and discrimination be solved among people who learn and share their sero positive status to their partners?

What could be major ways of solving stigma and discrimination in relation to HIV/AIDS disclosure among your clients?

SECTION E: KNOWLEDGE AND ATTITUDE

What are the major challenges faced by PHAs who share their sero-status to their family and other community members?

What perception does your community have towards individuals living with HIV/AIDS and you that serve them?

SECTION F: SOCIAL SUPPORT SYSTEMS

Does presence of social support systems influence HIV positive status disclosure among your clients?

1) yes

2)no

If yes, what social support systems that you know that can enable PHAs to share their sero status in their communities?

ECONOMIC FACTORS SECTION 11

Does fear of loss of employment hinder PHAs from sharing their sero status?

1) Yes

2) No

If yes how can it be minimized?

List the strategies that can be adopted to minimize the impact of barriers to disclosure?

Thank you

