

**PATTERNS OF STIGMATIZATION AND DISCRIMINATION  
AMONG HIV POSITIVE CLIENTS ATTENDING  
THE AIDS SUPPORT ORGANIZATION (TASO)  
CLINIC- MBARARA, UGANDA**

**A POST-GRADUATE THESIS**

**BY**

**AMANYIRE JORDAN MUTAMBI**

**MPH/0003/81/DU**

**SUBMITTED TO THE DEPARTMENT OF PUBLIC HEALTH,  
SCHOOL OF ALLIED HEALTH SCIENCES,  
KAMPALA INTERNATIONAL UNIVERSITY,  
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## **Dedication**

This work is dedicated to my family. My wife Amanyire Deborah, my sons, Joshua, Joash and Joab for their tolerance love and support exhibited that enabled me to continue with the academic struggle.

### Declaration

I Amanyire Jordan Mutambi (MPH/0003/81/DU) declare that this is my original work and it has never been presented to any institution of higher learning for any academic award.

Signature: .....  
**AMANYIRE JORDAN M.**

Date: 10/8/2010 .....

### Certification

This is to certify that this research work titled **PATTERN OF STIGMATIZATION AND DISCRIMINATION AMONG HIV POSITIVE CLIENTS ATTENDING TASO MBARARA CLINIC-UGANDA** Conducted by Amanyire Jordan Mutambi (MPH/0003/81/DU), was supervised by Dr. Agwu Ezera. It is being recommended to the senate of KIU as fit for the award of MPH of the University.

Signature: .....  
Dr. EZERA AGWU (PhD) SUPERVISOR.

Date: 17/8/2010

HOD, Public Health

Signature

.....

Dean, School of Allied Health Sciences

Date

18/8/2010



Signature

.....

Date

17/8/2010



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## Acronyms

ABC	Abstinence being faithful and Condom use
ACP	AIDS control programme
AIC	AIDS Information Center
AIDS	Acquired immunodeficiency syndrome
ARVs	Antiretroviral drugs
DSD	Discrimination, stigma and denial
HIV	Human immunodeficiency virus
MOH	Ministry of Health
NGO	Non governmental organization
PLWHA	People living with HIV/AIDS
SPSS	Statistical package for social scientists
TASO	The AIDS support organization
UNAIDS	United States agency for international development
UPDF	Uganda Peoples Defense Forces.
WHO	World Health organization

## **Abstract**

### **Background**

HIV/AIDS associated stigma and discrimination is now a public health challenge of global dimension. The objectives of this study were to establish and analyse different levels of HIV related stigma and discrimination.

### **Methodology**

This was a descriptive cross-sectional study of 260 HIV positive registered clients attending TASO Mbarara Clinic in the last six months selected using systematic random sampling. Both structured questionnaires and focus group discussion were used to collect data.

### **Results**

Females constituted 57.3% and males 42.7%. The majority of respondents 41.9% were married and the least 1.3% were widowers. The mean age of respondents was 36 years, maximum age 63, and minimum 15 years. Eighty nine percent of clients had disclosed HIV sero status and 10.4% had not. Nine percent of clients reported having been denied employment because of sero status and 37.7% did not feel comfortable being treated at home. Factors responsible for stigma and discrimination include; poor attitude of health workers, poverty, lack of sensitization among others. 37.7% of respondents don't feel comfortable being treated at home and 30.4% don't feel free talking about their sero status. Findings also reveal that there is no relationship between gender and HIV sero status disclosure ( $p>0.05$ ) but a strong relationship between talking about their sero status freely and marital status ( $p<0.05$ ).

### **Conclusion**

There is need for more sensitisation, awareness, HIV counselling and testing and economic empowerment in the area of HIV care and management so as to achieve the millennium development goal of HIV prevention and reduction of HIV related stigma and discrimination.

## **CHAPTER ONE**

### **1.0 Introduction**

For nearly two decades HIV and AIDS in existence, many infected people world wide still don't want to be known and because of this attitude, stigma and discrimination are the outcome and this has affected many people living with HIV/AIDS and their families. Government, civil societies and NGOs are concerned about the escalating pattern of stigma and discrimination in this century.

### **1.1 Background**

After several years of research, scientists globally have neither found a cure or a vaccine for AIDS. The epidemic therefore has continued killing millions of people worldwide.

By the beginning of 1998, WHO estimates of HIV infected people stood at nearly 36 million adults and 12 million, men, women and children died of AIDS. By the year 2001, the number of adults aged 15 to 49 years and children with 15 years living with HIV rose globally from about 29 million to over 33 million in 2007, a 14% increase (UNADS 2007). Most of the people infected with HIV AIDS come from sub-Saharan Africa (SSA) and it estimated that the total number of people living with HIV/AIDS in the region increased from 20.9 million in 2001 to 22.5 million in 2007(UNAIDS 2007)

UNAIDS / WHO estimates that Globally 33.2 million people were living with HIV/AIDS by Dec 2007 and 2.5 million people are newly infected alone.

Almost three quarters (75%) of all adults and children deaths due to AIDS in 2007 occurred in sub Saharan Africa. (UNAIDS 2007).In Uganda, by 1988, an estimated 1 million Ugandans had been infected and Uganda had one of the highest rate 30% of HIV infection in Africa. In 2005, a cumulative number of 2 million Ugandans had contracted HIV and over 1 million had already died (UNAIDS 2007).

The current National prevalence rate at 7% i.e. about 870,000 people is infected with HIV and about 150,000 already have full blown AIDS.

HIV/AIDS is one of the conditions which are characterized by high levels of stigma and discrimination because of its effects and consequences (Population council Report 2002). It is however not certain as to why after along time with the pandemic, stigma and discrimination still exists.

In Uganda, the Uganda AIDS control programme (ACP) which was established in 1986 with the mandate of controlling the spread of HIV and assisting those individual infected and families affected by HIV/AIDS respectively has done a lot of work together with many Non governmental organization but still there is a lot to be desired (ACP, MOH 2005).

HIV/AIDS positive persons experience discrimination and stigma from different people in various places such as their places of work before their fellow workers, in their homes, in public institutions such as Health facilities, schools just to mention but a few.

Discrimination is usually accompanied with exclusion from access to particular services, which in essence affects the welfare of PLWHAs yet stigmatization has got a far reaching psychological consequence which also affect their Health.

## **1.2 Rationale / Justification of the study**

No where perhaps the effects of HIV/AIDS less are under stood or more in need of under standing than in Sub-Saharan African countries and particularly in Uganda where HIV/AIDS has continued to seriously affect the community (UNAIDS 2006)

The impact of HIV/AIDS on the economy has been amply documented else where, similarly, the people at risk of HIV/AIDS infection have been widely discussed (Ankrah 1993, Asingwire, 1992).

Despite this, there seems a paucity of data on stigma and discrimination in relation to HIV/AIDS in many countries in general and Uganda in particular.

The study is coming at a time when the government is putting in much effort to reduce the rate of HIV infection in relation to millennium development goals. The

HIV prevalence rate at 7% is worrying and needs to be reduced further and this can't be realized when discrimination and stigma are still in existence.

### **1.3 Problem statement**

HIV/AIDS pandemic has been in existence World wide for nearly two decades and has affected many people, especially those from Sub Saharan Africa.

Many countries have put in much effort to avert the problem but still there is a lot to be desired. HIV/AIDS is characterized by stigma and discrimination and HIV stigma and the resulting actual or feared discrimination has proven to be perhaps the most difficult obstacle to effective HIV prevention (UNAIDS, 2006). Not enough research has been done on stigma and discrimination. Many times TASO clients have reported how they are denied property, discriminated at place of work, fear of talking about sero status publicly, a situation that needs to be addressed.

There is need to address the problem comprehensively so as to be successful in HIV/ AIDS care, management and prevention.

### **1.4 Hypothesis(es)**

- ❖ There is no difference in level of stigma among people who have disclosed their HIV status and those who have not.
- ❖ There is no relationship between gender and HIV sero status disclosure
- ❖ There is no relationship between marital status and HIV/AIDS discrimination
- ❖ There is no relationship between marital status and HIV sero status disclosure.

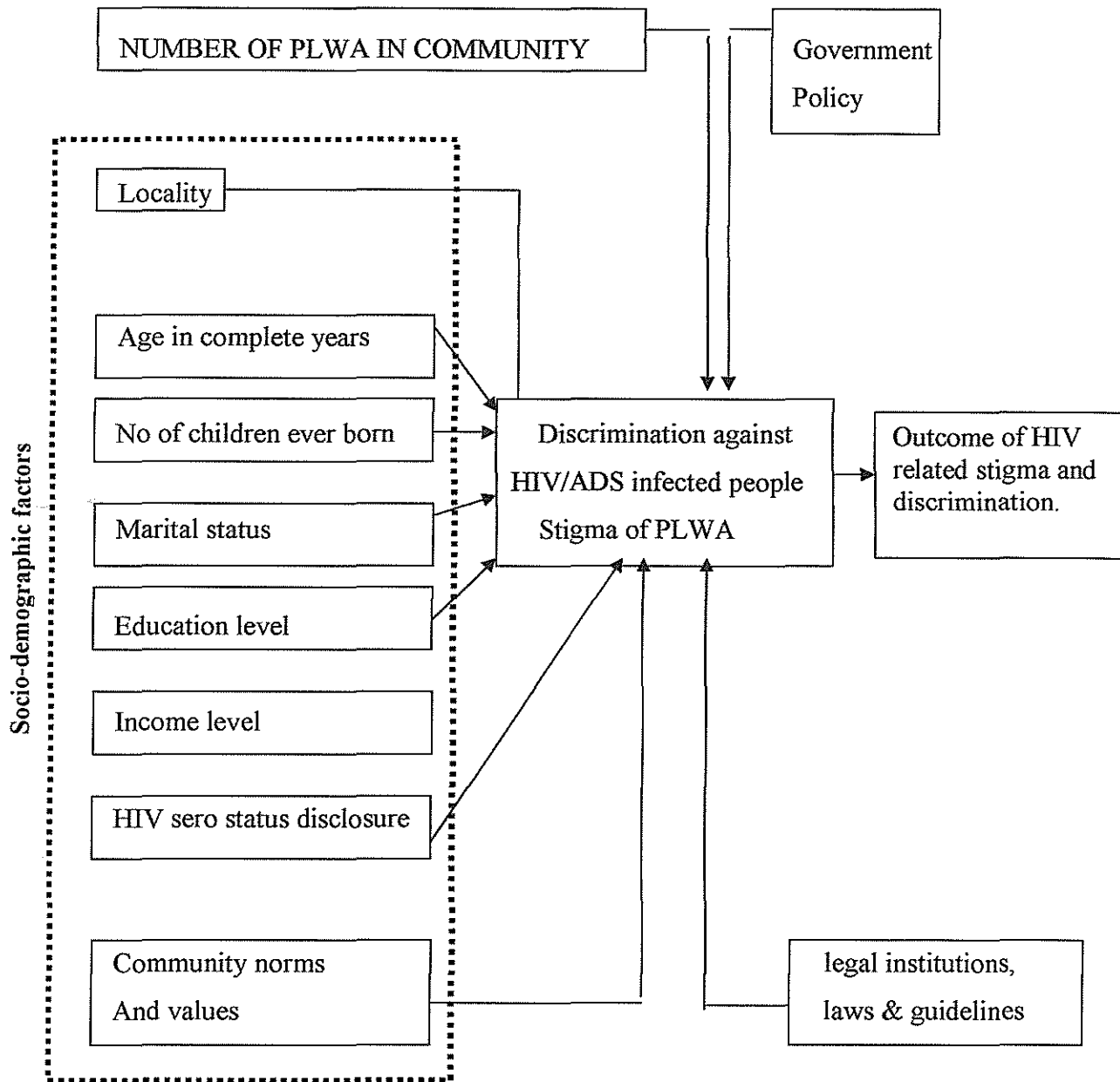
### **1.5 General objective of the study**

The over all aim or purpose of the study is to analyze the patterns of stigma and discrimination of HIV positive people with particular emphasis to those attending TASO services.

## **1.6 Specific Objectives**

1. To analyze the different forms of HIV/AIDS related stigma and discrimination experienced by TASO clients.
2. Establish factors that influence different forms of HIV/AIDS related stigma and discrimination experienced by TASO clients.
3. To determine the level of stigma and discrimination among HIV positive clients attending TASO clinic.
4. To generate data useful in the field of HIV care and management in Uganda.

## 1.7 Conceptual framework



The conceptual frame work above describes different independent variables like age, marital status, income, educational level, HIV sero status disclosure and others the way they influence stigma and discrimination, the dependent variables. It also gives the possible outcome of stigma and discrimination in a community.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

Though a lot of research has been done on HIV/AIDS, less has been specific on stigma and discrimination and its implications.

The literature review addresses the following areas:

- Government policy on HIV/AIDS
- Form of HIV/AIDS related stigma and discrimination
- Factors responsible for stigma and discrimination

#### **2.2 Government Policies**

The country's law, rules or policies regarding HIV/AIDS can have significant effects on the lives of people living with HIV/AIDS.

Discriminatory practices can alleviate and ostracize PLWHA, reinforcing the stigma surrounding the disease.

In 2008, UNAIDS reported that 67% of countries have some form of legislation in place to protect PLWHA from discrimination.

However, Ban Kii Moon, Secretary General of the United Nations believes that almost all countries permit at least some forms of discrimination.(UNAIDS 2008)

The USA, Armenia, Brunei, China, Iraq, South Korea, Moldova, the Russian federation and Saudi Arabia restrict people with HIV/AIDS from entering their country

- President Museveni of Uganda supports the national policy of dismissing or not promoting members of the armed forces who test HIV positive.
- The Chinese government advocates compulsory HIV testing for any Chinese citizen who has been living outside the country for more than 1 year.
- The UK legal system can prosecute individuals who pass the virus to somebody else, even if they did so without intent
- The United Arab Emirates (UAE) immediately deports any expatriates with HIV/AIDS (UNAIDS, 2008).



However, current studies on HIV/AIDS in Uganda (Asingwire, 1992, ACP, MOH, 1993) indicate that HIV and AIDS have continued to present the bigger challenge to the national economy and the government of Uganda enacted a national multi sectoral policy on AIDS which stipulates that. "All Ugandans have individual and collective responsibility to be actively involved in AIDS control activities in a co-coordinated way at the various administrative and political levels down to the grass root. The fight against AIDS is not only directed to the prevention of the spread of HIV but also addresses the active response to and management of all perceived consequences of the epidemic (Asingwire, 1992).

A study of seven large Mumbai – based businesses revealed that none had a policy on AIDS and that the mid level management had adapted "a wait and see" attitude – waiting to see how many workers become infected and whether this had an impact on productivity (UNAIDS 2001). At the same time, anecdotal evidence of employment related discrimination and stigmatization had begun to emerge. Individual cases of job loss, emotional isolation and denial of employment on the basis of HIV status had been reported in the media (Bhabhav, 1993) to NGO workers and social counselors and to medical practitioners.

It ought to be emphasized that the principles of no discrimination of PLWHA in various health institutions, places of work and recreational centers could not have been appropriately adhered to if the government position on persons with HIV/AIDS had not been clear. Since the first reporting of AIDS in Uganda in 1981 (ACP, 1993), the government has followed an open and positive policy towards AIDS. It has encouraged provision of love and care to PLWHA by family member and Health workers. This seems to constitute a major ray of hope to PLWHA who as a result do not feel officially discriminated against or feel they have redress in case of discrimination.

### **2.3 Forms of HIV/AIDS related Stigma and Discrimination**

AIDS related stigma can lead to discrimination towards people living with HIV/AIDS. AIDS related discrimination means that people are treated negatively and denied opportunities on the basis of HIV status, the discrimination can occur



at all levels of a persons daily life, for example when they wish to travel, use Health facilities or get a new job.

### **2.3.1 Discrimination and Stigma in Health Care**

The with holding of treatment, hospital staff refusing to treat patients, HIV testing with out consent, lack of confidentiality and denial of hospital facilities and medicines are all ways that PLWHA can experience stigma and discrimination in health care setting. Such responses are often fueled by ignorance of HIV transmission routes among doctors, midwives nurses and hospital staff (UNAIDS, 2001)

A study conducted in 2002 in four Nigerian states among 1000 physicians, nurses and midwives, one in ten doctors admitted having refused to care for HIV/AIDS patients or had denied HIV/AIDS patients admission in hospital (Population Council, 2002). In Mbarara Hospital Uganda, it has been reported by patients that nurses and doctors are reluctant to admit or care for patient after realizing that he/she is AIDS victim (TASO, 2003). According to UNAIDS (2001) study on HIV related discrimination, stigma and denial, the Health care is perhaps the most conspicuous context for HIV / AIDS related stigma, discrimination and denial.

Negative attitude from Health care staff generate anxiety and fear among PLHA. Consequently, many keep their sero status secret, fearing still worse treatment from others (Bhabhav 1993). It is not surprising that among the majority of HIV positive, AIDS related fear and anxiety and at times denial of their HIV status can be traced to traumatic experience in Health care setting (Bhabhav, 1993) - Global discrimination in these settings can be exposed in a variety of ways.

The following were reported responses from health workers; Refused to admit or treat HIV positive patients (Ankrah, 1993), the tendency to neglect patients (Omangi, 1997), the habit of testing of HIV with out consent, and breaching of confidentiality (New South Wales anti Discrimination board 1992; Peter, 2002).

In the same study carried out in India, doctors in government Health units blamed their fellow counter parts in private setting and vice-versa of discrimination and breach of confidentiality. "In private hospitals, the news of an HIV positive patient once detected is closely guarded and the patient is conveniently transferred to a government hospital - Surgeon in government Hospital. "Government hospitals are not doing their duty. The quality of care is so poor that the positive patients come to us. We give them all the necessary care without complaining"- Gynecologist in private Hospital.

Breaching of confidentiality is very common with doctors and nurses.

*"My wife is very curious about my sickness, and I had told her. She showed my case papers to the company's medical doctor and the doctor told her every thing about my problem without my knowledge. She was very angry with me and within 2 days she desert me"* - HIV positive man aged 38 years.

### **2.3.2 Stigma and Discrimination in Family Context**

According to UNAIDS (2001) study in India on stigma, discrimination and denial majority of respondents had disclosed their sero positive status only in close familial relationships, parental, spousal or siblings. Within each of these, gender was a significant factor determining the likely response. Daughters, Wives and daughters in law experienced greater level of stigma, discrimination and denial than sons, husbands and sons in law.

The relationship most strained by HIV status was that between parents in law and daughter in law, followed by the spousal relationship.

Discrimination against daughters in law was blatant even when sons received good familial care. Women were stigmatized as being "loose character" and potential source of infection to their husbands, at the same time; they were expected to provide care.

*"My in laws do not have good opinion about me. They say that my husband got this disease from me. I sometimes felt "why should I live with this insult? It is better to die!! But I am living for the sake of my children. - HIV positive woman aged 40 (UNAIDS,2001).*

*“My mother in law tells every body,” because of her, my son got this disease. My son is a simple boy as good as gold – but she brought him this disease. -*

HIV positive woman aged 26 (UNAIDS, 2001)

A study by Sophia Mukasa in Uganda (1998) also had similar findings.

There were some few pockets of deviant families that blamed their daughters in law for the death of their sons. The common belief held by these families mainly in rural areas in Mbarara was that women are the cause of AIDS in homes. In one extreme case, it was found that, “A daughter in law was excommunicated from her matrimonial home because the father in law believed that she was the cause of her husband (his sons) death.

In another instance, land lords chase away HIV positive tenants once it is ascertained that they have AIDS.

In the majority of developing countries, families are the primary care givers when some body falls ill. There is clear evidence that families play an important role in providing support & care for PLWHA (Population Council, 2002). However, not all-family response is positive. HIV infected members of the family can find themselves stigmatized and discriminated against with in the home. “When I was in hospital, my father came once. Then he shouted that I had AIDS. Every one could hear. He said, this is AIDS, she is a victim with my brother and his wife it was not allowed to eat from the same plates, I got a plastic cup and plates and I had to sleep in the kitchen. I was not even allowed to play with my kids- HIV positive woman, Zimbabwe” (UNAIDS 2001)

### **2.3.3 Stigma and Discrimination at the Work place**

In the UNAIDS (2001) employment did not emerge a major setting for discrimination and stigmatization probably because most respondents had not disclosed their HIV/AIDS status at work. Many had strong fear of social isolation and stigmatization and they worried about losing their job if they were to reveal their sero status. Those who had shared their HIV/AIDS diagnoses with work colleagues and management.

Respondents were worried about what would happen if their status were revealed to work colleagues. One widely expressed fear was that they would become “untouchable” in a society that is very concerned with social image, the prospect of damaging ones reputation and family name was extremely wrong.

*“People may not behave badly towards me but my reputation would certainly go down. Who will take the risk of telling other? People out there had dirty minds, they will only think of one thing that I went “out” and this will spoil my family name”* - HIV positive man, aged 30.

*“No body will come near me, eat with me in the canteen, no body will want to work with me, I will be an out cast”* - HIV positive man aged 27.

#### **2.3.4 Stigma and Discrimination in Schools**

A UNAIDS study in India 2001 revealed how NGOs are beginning to acknowledge school as a setting for HIV/AIDS related DSD. Problems - both for the HIV positive parents of HIV negative children and for HIV positive children were beginning to be observed at the beginning of the study.

In Mumbai (one of study sites) one HIV positive couple and one widow of a man who had had AIDS were forced to withdraw their HIV negative children from schools. No specific reasons were offered by school management, and the affected parents were too afraid to pursue the matter – in one case, reluctant to have their identity become known to others. As the grand mother of one child said, *“I was afraid the people would talk more if I argued with the school principal”*. So we moved the child to a municipal school”.

Another school displayed complete ignorance about HIV transmission routes when refusing to accept an HIV negative child of positive parents. The management of the school insisted that the child’s presence would adversely affect the other students even though they were aware that he was negative. In yet another case an HIV positive widow had to get help from social worker to enable her six-year-old son to attend a boarding school in a suburb of Mumbai, which had initially been worried about the possible impact in other children.

Other childcare institutions in India however continue to discriminate against children with HIV. In a few institutions in Mumbai, destitute children are tested for HIV at the time of admission, if positive and despite adequate staffing levels and space in the child care centre; they are either segregated or transferred to an NGO with a designated shelter programme (UNAIDS 2001)

## **2.4 Determinants of HIV / AIDS related Stigma and Discrimination**

### **2.4.1 Knowledge Level**

A UNAIDS (2001) study in India revealed how low levels of HIV/AIDS knowledge determine the stigma and discrimination of HIV/AIDS patients. In all hospital in Mumbai and Bangalore (site where the study was done) most nurses, technical staff and medical doctors appeared well informed about HIV/AIDS. Several of them had attended training programs on AIDS. However, ward staff in most hospitals generally, lacked adequate information. Some do not know the difference between HIV/AIDS. "HIV and AIDS are the same. HIV means AIDS. HIV is in English and AIDS in Marathi (the vernacular language of Mumbai". - Ward attendants and sweeper in Mumbai private Hospital. "If a doctor says HIV, we know he means AIDS" ward attendants in the opening theatre of a Mumbai private Hospital. In the related study done in Uganda, a cross section of people seem to apportion blame on the persons with HIV and AIDS implying that the PLWHA are responsible for their condition.

The under lying reason here is that AIDS is acquired through promiscuous sexual relations. There is lack of recognition of other factors through which HIV is transmitted, namely; mother to child and contaminated blood instruments.

A study in India showed that some medical staff was not aware of HIV transmission. A majority of staff across the hospitals said that they were aware that every body contact and sharing meals, drinking vessels, or clothes were not sources of infection, yet in practice, staff had significant anxieties about casual contact with people with HIV.

#### **2.4.2 Resource Availability**

In a study done in Uganda by Sophia Mukasa (1998), it was found out that resource availability is very important determinant of stigma and discrimination.

“A person who is well off and is independent is neither isolated nor discriminated against like the poor and dependent ones.

#### **2.4.3 Cultural Norms and Values**

In the same study it was widely believed in the area of study that HIV and AIDS can appropriately be avoided if the people displayed less risk behavior. It therefore implies that persons living with HIV and AIDS must have contracted the disease out of deviant behaviors that is contrary to social normal and dominant behavioral values.

#### **2.4.4 Attitudes of Health Workers**

In a UNAIDS (2001) hospital staff who were most anxious about HIV were generally those who had a negative attitudes towards HIV positive people. In Bangalore (one of study sites) staff member across hospital targeted truck drivers and sex workers as the major source of HIV transmission in their city or state, labeling them “bad” men and women with “dirty” habits, who were “not satisfied with what they have at home”. The poor, the slum dwellers, and the illiterate were commonly believed to be “AIDS infected” in larger proportions than the rest of the populations. The migrant’s population from neighboring states was targeted even more frequently.

“This illness is more in lower income groups as well as in “backward class”.

Also it will be more in higher economic groups - Nursing staff in a small public hospital - bangalore. In the same study some doctors singled out people to blame for spreading HIV. “When a truck driver comes, we are sure he is HIV positive and we get him tested for HIV. “Some special groups like cooks in Chinese hotels and even cleaners, mostly they have HIV. So we should be careful when they are admitted”- Doctors in Mumbai Hospital.

#### **2.4.5 Revealing of ones Sero Status**

A study done in Uganda by Sophia Mukasa (1998) showed that revealing sero status is one of the determinants of stigma and discrimination. The study showed that more women (52%) revealed their sero status compared to men (48%). The findings also revealed that women revealed their sero status less to public compared to men, probably due to the paradigm shift where women are leaving their traditional role as housewives and increasingly getting engaged in business. Such women may feel stigmatized and may not want to lose business because the public may fear to be infected if they deal with them.



## CHAPTER THREE

### METHODOLOGY

#### 3.1 Study Design

It was a descriptive cross sectional type of study where both qualitative and quantitative methods were used to collect data.

#### 3.2 Study Area

The study was done at TASO Mbarara clinic in Mbarara municipality, where TASO active clients were the respondents. The clinic is located about 200 meters from Mbarara regional referral hospital, just near Uganda police south western regional offices. The clinic cares for HIV positive people from the areas around.

#### 3.3 Study Population

The study population comprised of TASO Mbarara active registered clients who get services from the centre clinic. Active clients are those who have been getting services from the organisation for the last six (6) months.

#### 3.4 Determination of Sample Size

TASO Mbarara centre clinic has a number of 550 active registered clients.

Using Krejcie and Morgan (1970) formula.

$$S = \frac{X^2 NP (1-P)}{d^2 (N-1) + X^2 P (1-P)}$$

Where;

S is the required sample size

$X^2$  is the chi-square for 1 degree of freedom (3.841)

N is the population size

P is the population proportion of clients who have been discriminated according to previous study

d is the degree of accuracy.

By substitution,  $N=550$ ,  $P=0.5$ ,  $d=0.05$ .

(S) is therefore 226.

By adding 15% of total population to the selected sample,  $226 + 33 = 259$ , approximately 260. Therefore a sample size of 260 clients was selected.

### **3.5 Sampling Technique**

TASO Mbarara clinics are held on Wednesdays and Fridays. On every clinic day, a list of clients who attend was obtained from the counseling coordinator.

Averagely, 100 clients attend per clinic,

Using systematic random sampling, at least 20 clients were interviewed on each day. Out of the total sample of 260 clients, 30 clients were selected for Focus group discussion using random sampling. They were further divided into 4 segments of Young men, Young women, Old men and young women. Reasons for segmentation were to allow them share information freely with age groups especially pertinent issues related to sex and stigma.

### **3.6 Data Collection Instruments**

The instruments to collect data included;

- Questionnaires
- Focus group discussion

#### **3.6.1 Questionnaires**

This was used to collect data from clients. It had structured questions. The questionnaires were written in English and translated into the local languages spoken in the areas surveyed.

The information captured from structured questions included the bio data of respondents, information about disclosure, attitudes towards HIV positive patients and other information regarding stigma and discrimination.

### **3.6.2 Focus Group Discussion**

Four groups of Young men, Young women, Old men and Old women were selected. Reasons for segmentation were to allow them share information freely with peers. In each group they selected a group leader and rapporteur. All the proceeding discussion and findings were recorded.

### **3.6.3 Research Assistants**

Two research assistants who participated in this study were trained in data collection, coding and some analysis especially of qualitative data.

### **3.7 Reliability and Validity**

The research instruments possessed the validity and reliability characteristics. Validity refers to the extent to which the instrument measures what it is intended to measure. Reliability on the other hand is the extent to which a measuring device is consistent in measuring what ever it measures. In this regard therefore, Care had to be ensured in developing the data collecting instruments. Pre testing the instruments was done as part of reliability and validity in a nearby community to find out if they could collect the required data.

### **3.8 Data Management**

#### **3.8.1 Quantitative Data**

Data generated were edited and coded before being entered to SPSS for analysis. Statistical measures and analytical techniques were used at 2 levels, namely.

- Descriptive using tables, graphs, charts
- Inferential using cross tabulations and logistic regression

#### **3.8.2 Qualitative Data**

Substantial information collected from focus group discussions were analyzed thematically and there was coding of all responses from respondents.

Data reduction - selection, focusing simplifying, abstracting and transforming were done to increase accuracy of information generated. During this period, great care was taken to guard against bias. The responses were used to strengthen findings already indicated by quantitative analysis.

### **3.9 Ethical considerations**

This study was cleared by Kampala International University Research and Ethics committee, TASO authorities and patients informed consent.

### **3.10 Limitations to the study**

**Lack of enough funds:** Funds were needed to train the research assistants, data collection, and stationary, allowances, printing and typing work. This was solved acquiring a loan from the bank.

**Too much work for the researcher:** This was partially solved by hiring research assistants who assisted in data collection.

**Short period of time for data collection:** This was solved by considering a relatively small sample size.

Considering only clients who attend centre clinics and leaving out those who attend out reach clinics was a limiting factor.

## CHAPTER FOUR

### RESULTS

#### 4.1 Quantitative Data Findings

The results of the data analysis are presented below in form of tables, graphs, pie charts and other illustrative notes.

**Table 1: Bio-data of Respondents by Sex, Marital Status and Age Distribution (N=260)**

#### Socio Demographic Data

Variable	Number	Percentage
<b>Sex</b>		
Male	111	42.7
Female	149	57.3
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Age</b>		
15 – 20	18	7
21 – 30	103	39.6
31 – 40	92	35.3
41 – 50	26	10
51 – 60	18	6.9
61 and above	3	1.2
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Marital status</b>		
Married	109	41.9
Single	30	11.5
Divorced/separated	50	19.2
Widow	65	25.0
Widower	6	1.3
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Ethnicity</b>		
Nyankole	211	81.2
Ganda	8	3.1
Kiga	28	10.8
Nyarwanda	8	3.1
Others	5	1.9
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Occupation</b>		
Peasant farmer	142	54.6
Employed full/part time	85	32.6
Retired /pension	1	0.5
Unemployed	32	12.3
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Education level</b>		
None	46	17.7
Primary	151	58.1
Secondary	54	20.8
Tertiary	9	3.5
<b>Total</b>	<b>260</b>	<b>100</b>

From the Table 1 above there were 42.7% males and 57.3% females. From the table above, 6.9% were of years 15-20 while 39.6% were 21-30 years and 69.6% were the 31-65 years of the respondents. The Nyankole were 81.2%, the Ganda were 3.1%, Nyarwanda were 3.1%, Kiga were 10.8%, and the others were 1.9%. The Table 1 above shows 54.6% peasant farmers, 14.5% employed full/part time, 18.1% in business, 0.4% retired/pensioner, 3.1% students and 9.2% were unemployed. From the Table above, 117.7% among the respondents had no formal education, 58.1% had primary level, 20.8% had secondary level and 3.5% had the tertiary institution.

**Table 2: Other Variables of Respondents (N=260)**

<b>Variable</b>	<b>Number</b>	<b>Percentage</b>
<b>Distance</b>		
Less than 5km	31	11.9
5-20km	85	32.7
21-75km	131	50.4
Above 75km	13	5
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Number of family members</b>	<b>Number</b>	<b>Percentage (%)</b>
0-3	58	22.3
4-7	143	55.5
8-12	59	22.7
<b>Total</b>	<b>260</b>	<b>100</b>
<b>HIV Stage</b>	<b>Number</b>	<b>Percentage (%)</b>
I	77	29.6
II	166	63.8
III	16	6.2
IV	1	0.4
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Period when joined TASO</b>	<b>Number</b>	<b>Percentage (%)</b>
Less than 6 month	48	18.5
6 months – 2 years	61	23.5
2 years – 6 years	92	35.4
More than 6 years	59	22.7
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Period when had HIV test</b>	<b>Number</b>	<b>Percentage (%)</b>
Less than 2 months	23	8.8
Less than 6 months	57	21.9
More than 6 months	107	41.2
More than 6 years	73	28.1
<b>Total</b>	<b>260</b>	<b>100</b>

From the Table 2, 11.9% had a distance less than 5km from home to office, 32.7% had 5km to 20km, 50.4% had between 20-75km and only 5% had above 75km. From the Table 2 above 22.3% of the respondents had family members between zero and three, 55.5% had between four to seven members and 22.7% had between eight and twelve family members.

From the Table 2 above, 29.6% of the respondents were in HIV stage I, 63.8% in HIV stage II, 6.2% were in HIV stage III and 0.4% in HIV stage IV. Respondents

were asked whether they were on ARVs or not about 61.2% of the them were on ARVs and 38.8% were not on ARVs.

From the Table 2 above 18.5% of the respondents joined TASO less than 6 months ago, 23.5% joined 6 months to 2 years ago, 35.4% joined 2 to 6 years ago and 22.7% joined more than six years ago.

From the Table 2 above 8.8% of the respondents had an HIV test less than 2 months ago, 21.9% had it less than 6 months ago, 41.2% had it more than 6 months ago and 28.1% had the test more than 6 years ago.

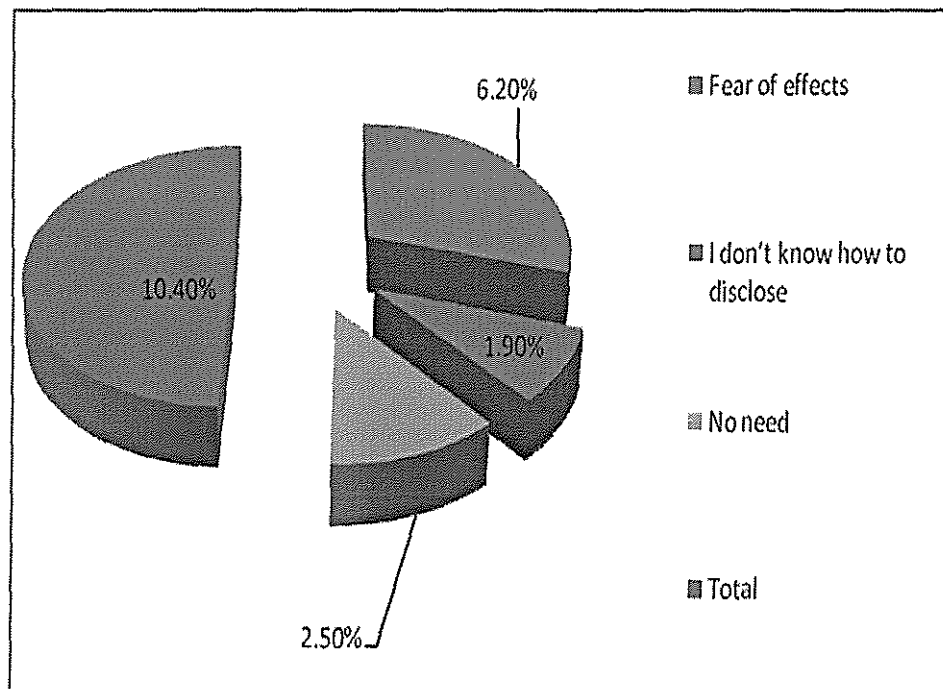
**Table 3: Reasons why Respondents Tested for HIV (N=260)**

Reasons	Number	Percentage (%)
Illness	166	63.8
Voluntary test without illness	35	13.5
Requirement for marriage	10	3.8
Exposed to unsafe sex	13	5.0
Had an STD	4	1.5
Loss of spouse	30	11.5
Others	2	0.8
<b>Total</b>	<b>260</b>	<b>100</b>

From the Table above 63.8% had an HIV tests because of illness, 13.5% it was voluntary, 3.8% Requirement for marriage, 5% Exposed to unsafe sex, 1.5% had an STD, 11.5% loss of spouse, 0.8% had other reasons.

Respondents were asked whether they had disclosed the sero status or not, 89.6% had disclosed their sero status, and only 10.4% had not disclosed their sero status.





**Figure 1: Reasons for Non Disclosure (N=27)**

6.2% of the people feared effects of disclosure, 1.9% didn't know how to disclose, and 2.5% had no need to disclose.

**Table 4: HIV Sero Status Disclosure (N=233)**

<b>To whom</b>	<b>Number of respondents</b>	<b>Percentage (%)</b>
Spouse only	39	15.0
Parents only	17	6.5
Spouse and family members	107	41.2
Only close friends	46	17.7
All community	21	8.1
Others	3	1.2
<b>Total</b>	<b>233</b>	<b>89.6</b>
<b>Reasons</b>	<b>Number of respondents</b>	<b>Percentage (%)</b>
To be supported	74	28.5
Felt free	58	22.3
Encouraged by people to test	48	18.5
Not to infect others	44	16.9
Others	9	3.5
<b>Total</b>	<b>233</b>	<b>89.6</b>
<b>Period</b>	<b>Number of respondents</b>	<b>Percentage (%)</b>
Immediately after testing	102	39.2
2 weeks after testing	63	24.2
Less than 6 months after testing	46	17.7
6 months after testing	22	8.5
<b>Total</b>	<b>233</b>	<b>89.6</b>

From the Table 4 above, 15% disclosed to their spouses, 6.5% disclosed to parents, 41.2% disclosed to spouses and parents, 17.7% disclosed to only close friends, 8.1% From table 4 above disclosed to all the community, only 1.2% disclosed to others.

From Table 4 above, 28.5% disclosed because they wanted to be supported, 22.3% to feel free, 18.5% were encouraged by people to test, 16.9% did not want to infect others, only 3.5% had other reasons for disclosure.

From Table 4 above 39.2% disclosed immediately after the HIV test, 24.2% disclosed two weeks after testing, 17.7% disclosed less than six months after testing, while 8.5% disclosed six months after testing.

**Table 5: The Reactions after Disclosing HIV Sero Status (N=233)**

<b>Effect</b>	<b>Number</b>	<b>Percentage (%)</b>
<b>Family</b>		
Separation	9	4.5
Anger	47	18.0
Nothing	45	17.3
Supported	65	25
Denied sex by spouse	10	3.8
Postponed marriage	5	1.9
Used condom	35	13.5
Rejected	16	6.2
Others	1	0.4
<b>Total</b>	<b>233</b>	<b>89.6</b>
<b>Work Place</b>		
<b>Effect</b>	<b>Number</b>	<b>Percentage (%)</b>
Rejected	1	0.4
Supported	11	4.2
Pin pointed	45	17.3
Nothing happened	165	63.5
Others	11	4.2
<b>Totals</b>	<b>233</b>	<b>89.6</b>
<b>Schooling of Children</b>		
<b>Effect</b>	<b>Number</b>	<b>Percentage (%)</b>
Children rejected	1	0.4
Supported	15	5.8
Pin pointed	16	6.2
Nothing happened	182	70.0
Children nicknamed	11	4.2
Others	8	3.1
<b>Total</b>	<b>233</b>	<b>89.6</b>
<b>The Community</b>		
<b>Effect</b>	<b>Number</b>	<b>Percentage (%)</b>
Supported	5	1.9
Pin pointed	17	6.5
Spread rumors	82	31.5
Nothing happened	128	49.0
Others	1	0.4
<b>Total</b>	<b>233</b>	<b>89.6</b>
<b>Mode of disclosure</b>		
<b>Effect</b>	<b>Number</b>	<b>Percentage (%)</b>
Got courage myself and disclosed at convenient time	70	26.9
Disclosed in the presence of a counselor	15	5.8
My counselor gave me skills to disclose	145	55.8
Others	3	1.2
<b>Total</b>	<b>233</b>	<b>89.6</b>

From the Table 5 above, 4.5% of the respondents were separated from the family after disclosing, 18% the respondents had anger from the family after disclosing, 17.3% had no reaction from the family, 25% were supported, 3.8% were denied sex by spouses, 1.9% postponed marriage, 13.5% started using condoms, 6.2% were rejected, 0.4% had other reactions from their families after disclosing their HIV sero status.

The respondents 0.4% were rejected from the work place after disclosing, 4.2% were supported, 17.3% were finger pointed at, 63.5% nothing happened to them, while 4.2% had other effects from the work place after disclosing sero status.

The schooling of children were affected in that, 0.4% respondents' children were rejected, 5.8% were supported, 6.2% were finger pointed, 70% nothing happened, 4.2% were nicknamed and 3.1% had other effects.

From the community, 1.9% of the respondents were supported as from the Table. From the Table above, 29.9% got courage themselves and disclosed at convenient time, 5.8% disclosed in the presence of a counselor 55.8% counselors provided skills to disclose, while 1.2% of the respondents had other ways of disclosing.

Respondents were asked whether HIV sero status disclosure affected them sexually, 81.9% said yes and 7.7% said no.

**Table 6: How Disclosure affected them Sexually (N=213)**

<b>Effect</b>	<b>Number</b>	<b>Percentage (%)</b>
Spouse denied sex	17	6.5
Started using condom	102	39.2
Reduced on frequency of sex	50	19.2
Stopped sex with other people	40	15.4
Others	4	1.5
<b>Total</b>	<b>213</b>	<b>81.9</b>

From the Table above, 6.5% of the respondents were denied sex by spouses, 39.2% started using condoms, 19.2% reduced on the frequency of sex, 15.4% stopped sex with other people, and only 1.5% was affected differently.

**Table 7: How Respondents Relate with Others (N=260)**

<b>Relate with Family</b>	<b>Number</b>	<b>Percentage (%)</b>
Supportive	214	82.3
No sharing cups	3	1.2
Denied property	19	7.3
Finger pointing	24	9.2
Others	2	1.0
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Relate with people at work</b>	<b>Number</b>	<b>Percentage (%)</b>
Supportive	60	23.1
Finger pointing	18	6.9
Spreading rumors	18	6.9
No problem	155	56.6
Others	9	3.5
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Relate with neighbors.</b>	<b>Number</b>	<b>Percentage (%)</b>
Supportive	87	33.5
Finger pointing	28	10.8
No problem	81	31.2
Spreading rumors	62	23.8
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Relate with community</b>	<b>Number</b>	<b>Percentage (%)</b>
Supportive	75	28.8
Finger pointing	37	14.2
No problem	117	45.0
Seeking guidance from me	9	3.5
Nick naming me	16	6.2
Not allowing me to stand in elections	5	1.9
Others	1	0.4
<b>Total</b>	<b>260</b>	<b>100</b>

From the Table 7 above, 82.3% of the respondents were supported by family, 1.2% shared no cups, 7.3% were denied property, 9.2% were finger pointed at, and only 1% had other relations

The above Table 7 shows, 23.1% were supported at work place, 6.9% were finger pointed at, 6.9% spread rumors on them, 56.6% had no problem, and 3.5% had other relations.

The Table 7 above shows that 33.5% of the respondents were supported by their neighbors, 10.8% were finger pointed at, 31.2% had no problem, and 23.8% received rumors.

Table 7 also shows that 28.8% were supported by the community, 14.2% were pin pointed at, 45% had no problem, 3.5% of the respondents were contacted for guidance, 6.2% were nick named, 1.9% were not allowed to stand in elections, and 0.4% had others relations.

It was also found out that, 58.1% of the respondents feel free talking about their sero status, 30.4% do not feel free talking about their sero, and only 11.6% didn't give any response

Respondents were asked whether they get treatment freely when sick, 82.3% of the respondents said yes, 16.9% said no and 0.8% had no response.

**Table 8: Attitude towards HIV related Work (N=260)**

<b>Do you mind a TASO labeled vehicle coming to your home</b>	<b>Number</b>	<b>Percentage (%)</b>
Yes	52	20
No	207	79.6
No response	1	0.4
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Have you been denied any employment</b>	<b>Number</b>	<b>Percentage (%)</b>
Yes	23	8.8
No	235	90
Don't know	2	0.8
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Do you feel comfortable being treated at home</b>	<b>Number</b>	<b>Percentage (%)</b>
Yes	145	55.8
No	98	37.7
Don't know	7	2.7
No response	10	3.8
<b>Total</b>	<b>260</b>	<b>100</b>
<b>Feel free talking about your sero status</b>	<b>Number</b>	<b>Percentage (%)</b>
Yes	151	58.1
No	79	30.4
Don't know	30	11.6
<b>Total</b>	<b>260</b>	<b>100</b>

From the Table above, 55.8% feel comfortable being treated at home, 37.7% do not feel comfortable being treated at home, 2.7% didn't know and 3.8% had no response

Table 8 also shows that 8.8% were denied employment, 90% were not denied any employment, and only 0.8% didn't know.

Respondents were asked whether they felt free talking about their HIV sero status in public, 58.5% said yes, 41.2% said no and 0.4% had no response.

Respondents were asked whether they felt comfortable living with community members. 240 (92.3%) said yes, 17 (6.5%) said no and 3 (1.2%) had no response.



Respondents were asked whether they felt comfortable when some one said that they were HIV positive, 16.5% said yes, 83.1% said no and 0.4% had no response.

The Table 8 above also shows 20% of the respondents mind a TASO labeled vehicle going to their homes, 79.6% wouldn't mind a TASO labeled vehicle going to their homes and 0.4% no response.

**Table 9: Relationship between Gender and Disclosure of Sero Status**

		Gender No (%)		Total
		Male	female	
Have you disclosed	Yes	95 (40.8%)	138 (59.2%)	233
	No	16 (59.3)	11 (40.7%)	27
Total	260	111 (42.7%)	149 (57.3%)	260

P-value = 0.066,  $P > 0.05$

From the Table 9 above, 40.8% disclosed and are males while 59.2% were the females who had disclosed. Among the respondents 59.3% were the males who didn't disclose while 40.7% were the females who had not disclosed. The p value is 0.066. Since the P value is greater than 0.05, it means that it is statistically insignificant thus no relationship between gender and HIV sero status disclosure implying that we accept the null hypothesis as it was hypothesized.

**Table 10: Relationship between Marital Status and Disclosure of HIV Sero Status**

Have you disclosed	Marital status No (%)						total
		Married	single	Divorced/separated	Widow	widower	
Yes		94 (40.3%)	23 (9.9%)	47 (20.2%)	63 (27.0%)	6 (2.6%)	233 (100%)
No		15 (55.6%)	7 (25.9%)	3 (11.1%)	2 (7.4%)	0	27 (100%)
Total		109	30	50	65	6	260

P. Value = 0.016,  $P < 0.05$

From the Table above, 40.3% were the married who had disclosed and 2.6% widower had disclosed, while 55.6% of the married had not disclosed 7.4% were the widow who had not disclosed. Marital status was a significant factor (P.value  $< 0.05$ ) in determining whether a client will disclose his/her HIV sero status or not implying that we reject the null hypothesis which says that there is no relationship between marital status and HIV sero status disclosure.

**Table 11: Relationship between do you feel free talking about your Sero Status and have you Disclosed Sero Status**

Have you disclosed	Do you feel free talking about your sero status				
	Yes	No	Don't know	No response	
Yes	140 (60.1%)	66 (28.3%)	24 (10.3%)	3 (1.3%)	233
no	11 (40.7%)	13 (48.1%)	3 (11.1%)	0	27
Total	151	79	27	3	260

P-value=0.168,  $P>0.05$

From the table11, 60.1% said felt free talking about their sero status, and had disclosed sero status, 10.3% didn't know whether they felt free talking about their sero status, and had disclosed. 48.1% said they did not feel free talking about their sero status and had not disclosed while 11.1% didn't know whether they felt free talking about their sero status and had not disclosed. Talking about sero status freely and sero status disclosure were not statistically significant ( $P>0.05$ ) thus accepting the null hypothesis.

**Table 12: Relationship between do you feel comfortable being treated at home and have you disclosed sero status**

Have you disclosed	Do you feel comfortable being treated at home				Total Number of Responses
	Yes	No	Don't know	No response	
Yes	139 (59.7%)	78 (33.5%)	6 (2.6%)	10 (4.3%)	233
No	6 (22.2%)	20 (74.1%)	1 (3.7%)	0	27
Total	145	98	7	10	260

P- Value=0,  $P < 0.05$

From table 12 above 59.7% had disclosed and felt comfortable being treated at home but 2.6% didn't know whether they felt comfortable being treated at home. Among the respondents 22.2% had not disclosed and felt comfortable being treated at home while 3.7% had not disclosed and didn't know whether felt comfortable being treated at home. The P. value is less than 0.05 implying that disclosure is a significant factor for a client to be treated at home thus rejecting the null hypothesis.

**Table 13: Relationship between do you mind a TASO labeled vehicle coming at your home and have you disclosed Sero Status**

Have you disclosed	Do you mind a TASO labeled vehicle at your home				
	Yes	No	Don't know	No response	
Yes	36 (15.5%)	197 (84.5%)	0	0	233
no	16 (59.3%)	10 (37.0%)	1 (3.7%)	0	27
Total	52	207	1	0	260

P-value = 0,  $P < 0.05$

From the table 84.5% disclosed and wouldn't mind a TASO labeled vehicle going at their home while 59.3% had not disclosed but would mind a TASO labeled vehicle going at their home and the p value is 0.000. Disclosure is a significant factor for a client to allow a TASO vehicle at his home thus rejecting the null hypothesis.

**Table 14: Relationship between do you freely talk about your Sero Status in Public and Disclosure**

Have you disclosed	Do you feel free talking about sero status in public				Total Number of Responses
	Yes	No	Don't know	No response	
Yes	143 (61.4%)	90 (38.6%)	0	0	233
no	9 (33.3%)	17 (63%)	1 (3.7%)	0	27
Total	152	107	1	0	260

P-value = 0,  $P < 0.05$

From the table above, 61.4% felt free to talk about their sero status in public, and had disclosed their sero status, while 63.0% didn't feel free talking about their sero status in public and had not disclosed their sero status, the p value is 0.000. This implies that disclosure is significant for a client to talk about sero status in public thus rejecting the null hypothesis.

**Table 15: Relationship between do you freely talk about your Sero Status and Marital Status**

Marital status	Do you feel free talking about sero status				Total Number of Responses
	Yes	No	Don't know	No response	
Married	64 (58.7%)	35 (32.1%)	8 (7.3%)	2 (1.8%)	109
Single	8 26.7(%)	13 (43.3%)	8 (26.7%)	1 (3.3%)	30
Divorced/separated	30 (60%)	16 (32%)	4 (8%)	0	50
Widow	44 (67.7%)	14 (21.5%)	7 (10.8%)	0	65
widower	5 (83.3%)	1 (16.7%)	0	0	6
Total	151	79	27	3	260

P-value = 0.025,  $P < 0.05$

From the table, 58.7% married respondents felt free talking about their sero status, while 7.3% single respondents didn't know whether felt free talking about their sero status, and the rest as from the table. The p value is 0.025 implying that marital status is significant for somebody to talk about his sero status thus rejecting the null hypothesis.

**Table 16: Relationship between do you feel comfortable being treated at Home and Marital Status**

Marital status	Do you feel free comfortable being treated at home.				
	Yes	No	Don't know	No response	
Married	58 (53.2%)	45 (41.3%)	4 (3.7%)	2 (1.8%)	109
Single	12 (40%)	13 (43.3%)	2 (6.7%)	3 (10%)	30
Divorced/separated	28 (56%)	20 (40%)	0	2 (4%)	50
Widow	42 (64.6%)	19 (29.2%)	1 (1.5%)	3 (4.6%)	65
Widower	5 (83.3%)	1 (16.7%)	0	0	6
Total	145	98	7	10	260

P-value = 0.286,  $P > 0.05$

From the table 53.2% said yes felt comfortable being treated at home and were married, 41.3% did feel comfortable of the married, 3.7% didn't know of the married 1.8% had no response of the married while 40% singles said yes felt comfortable being treated at home, 10% had no response of the singles and the rest as from the table and the p value is 0.286. Marital status is insignificant for somebody to be treated at home thus accepting the null hypothesis.



**Table 17: Relationship between do you mind a TASO labeled vehicle coming at your Home and Marital Status.**

Marital status	Do you mind a TASO labeled vehicle coming to your home.				Total Number of Respondents
	Yes	No	Don't know	No response	
Married	24 (22%)	85 (78%)	0	0	109
Single	8 (26.7%)	21 (70%)	1 (3.3%)	0	30
Divorced/separated	12 (24%)	38 (76%)	0	0	50
Widow	7 (10.8%)	58 (89.2%)	0	0	65
widower	1 (16.7%)	5 (83.3%)	0	0	6
Total	52	207	1	0	260

P-value = 0.112,  $P > 0.05$

From the table, 22% married did mind a TASO labeled vehicle going to their home, while 70% of the singles didn't mind, 76% of the divorced/separated didn't mind, 89.2% of the widow didn't mind a TASO labeled vehicle going to their homes, lastly 83.3% of the widower didn't mind TASO labeled vehicle going to their homes. Marital status is insignificant for a client to allow a TASO vehicle at his/her home thus accepting the null hypothesis.

**Table 18: Relationship between do you freely talk about your Sero Status in Public and Marital Status**

Marital status	Do you freely talk about your sero status in public.				Total of Responses
	Yes	No	Don't know	No response	
Married	61 (56%)	48 (44%)	0	0	109
Single	15 (50%)	14 (46.7%)	1 (3.3%)	0	30
Divorced/separated	28 (56%)	22 (44%)	0	0	50
Widow	45 (69.2%)	20 (30.8%)	0	0	65
widower	3 (50%)	3 (50%)	0	0	6
Total	152	107	1	0	260

P-value = 0.155,  $P > 0.05$

From the table above, 56% married respondents said felt free talking about their sero status in public 44% didn't, while 50% single said yes, 3.3% didn't know feeling free talking their sero status in public. Among the respondents 59.2% widow said yes, 30.8% said no feeling free talking their sero status in public and the rest as from the table and the p value is 0.155 and since it is greater than 0.05, marital status is insignificant for somebody to talk about his sero status in public places thus accepting the null hypothesis.

## **4.2 Qualitative data findings**

### **(a) Forms of HIV/AIDS related stigma and discrimination**

- Refusal to be attended to in Health care settings
- Not eating and sharing utensils with infected people
- Labeling and nicknaming them
- Spreading rumors about them
- Neglecting their children at school
- Reluctant to give them Leadership roles in Community Groups.

### **(b) Relation with Family/ Community Members**

- Giving them food
- Reminding them about taking medications
- Separation of families

### **(c) Advantages of talking about HIV/AIDS publicly**

- Getting support from friends
- Formation of peer groups
- Get relieved psychologically

### **(d) Challenges related to HIV sero status disclosure**

- People reject you
- Harassed by community
- Chased away from job
- Not selected for political positions
- Spreading HIV virus to other people

**(e) Benefits of sero status disclosure**

- Allaying anxiety and fears
- Getting closer to people
- Encouraging people to come for HIV test
- Strengthening relationship with family members

**(f) Factors influencing HIV related stigma and discrimination**

- Poor attitude of health workers
- Poor attitude of community members
- Lack of sensitization
- Education level of clients
- Cultural factors like widow inheritance
- Poverty
- Jealous where people who don't disclose their sero status spread HIV to others.

**(g) Policy and by laws supporting people living with HIV/AIDS**

- None was mentioned

**(h) Possible solutions to address the challenge of stigma and discrimination among HIV/AIDS patients**

- Having HIV infected people represented in parliament
- Strengthening community sensitization and education
- TV and radio talk shows
- Strengthening research
- HIV counseling and testing
- Formation of support groups for people living with HIV/AIDS
- Home visiting
- Economic empowerment

Detailed findings from focus group discussion are in appendix 5

## CHAPTER FIVE

### DISCUSSION OF FINDINGS

This is a general discussion of the findings, both qualitative and quantitative data, relating the findings with the objectives, hypothesis and the literature review.

The majority of the respondents, 57.3% were females, males only accounting for 42.7% (Table I). This is in line with the national standards of gender in HIV/AIDS where the majorities are females (ACP, 2002). It is a concern of everybody to involve men in National programs including voluntary HIV counseling and testing (VCT) and family planning as they are decision makers in their families. There is need for new strategies to be put in place to attract more males to come for the services.

It is not surprising that the majority of people who were interviewed were of age group 31-65 years. According to Ministry of Health, Uganda (2006) document, HIV prevalence is high among the married people compared to other categories. This can also explain what is in the same table (Table 1) where married people constitute the highest percentage of 41.9% of all the respondents. This is also because HIV is greatly found among hetero-sexual relationships.

According to the report from the Ministry of Health Uganda (2006) Surveillance Report, HIV infection is increasing more in married people than other categories. In this case the ABC strategy in HIV prevention should be encouraged.

Table 1 still shows various occupations of respondents and the majority 54.6% are peasants. This is in line with table 7 which is about the level of education of respondents where the majority 58.1% is of primary level.

The organization (TASO) is facing a big challenge of attracting people who are educated (TASO 2008). This is in line with what was discussed in focus group discussion about factors influencing stigma and discrimination.

The observation in this study is similar to the report of Sophia Mukasa (1998) who reported that people who are well off are not discriminated.

Table (2) shows the number of family members of the respondents. Most of the clients (patients) (55.5%) had families of more than 4 family members. This is explained by the fact that here in Uganda, most people live in extended families and besides, the high fertility rate of women in Uganda, now at 7.1% should be checked. HIV/AIDS has impacted on our families and has left 13.2 millions of orphans worldwide (UNAIDS 2000). Most of the respondent, (63.8%) were in HIV stage II (table2) and 61.2% were on ARVs. According to MOH Uganda (2005), ARVs are supposed to be given to one who is in advanced HIV stage III and IV and with CD4 count of 250 cells and below. This implies that much as our clients were in HIV stage II appearing health clinically, their Health status is deteriorating, the reason as to why all HIV positive clients need to be tested for CD4 cell count to monitor their immunological progress. For nearly 6 years, the organization has been giving ARVs to her clients.

Table 2 shows the time of enrolment with TASO Mbarara. The organization is widely known for caring for HIV/AIDS patients it has been existence for more than 22 years. There are even those clients that registered in 1990s who are still alive. Before the provision of ARVs started, the organization was providing counseling services and management of opportunistic infections.

Table 3 still shows various reasons why respondents had HIV test, where the majority 63.8% tested because of illness. Many people have been educated above signs and symptoms of HIV/AIDS and the moment one sees any of those, thinks about HIV testing. It was however encouraging that a good number of clients (13.5%) had tested voluntarily. In the related development, information from AIC is almost similar where the majority of people who test for HIV are sickly. In this case one should not wait to be sick and then think of HIV testing.

It is now the call from the Ministry of Health that people are sensitized for routine counseling and testing.

It is not surprising that the majority of respondents 89.6% had disclosed their sero status as shown in (Table 4). This is encouraging and the situation is different from the one done in Iran (UNAIDS: 2008) where HIV sero status disclosure was a big challenge. The organization (TASO) is encouraging clients to reveal their sero status. However, the reasons for not disclosing given by 10.4% shouldn't be underrated. There is need for counselors to put in more effort such that they support the client to disclose. The majority of clients reveal sero status first to close family members before the rest. This is in line with what was found out in India UNAIDS (2001). Recognition goes to counselors as majority of clients (39.2%) revealed sero status after testing). Revealing sero status is a gradual process, the reason why some people take long time to do so. Reasons why people take long to disclose sero status include range from fear of effects, don't know how to disclose, no need, as shown in Figure (1).

According to information gathered from focus group discussion, members gave different reasons as to why some people don't disclose and the benefits of disclosure. Some of the responses to why clients do not disclose include; harassment by the community, being rejected by the community and not having the skills to a bout how to disclose. Much as people are sensitized about stigma and discrimination; they still exist amongst our community. As it was hypothesized, there was no relationship between gender and HIV sero status disclosure.

So, when designing messages of sero, status disclosure, there shouldn't be any difference between messages for males and for females. There is need for more study to find out why men don't come for HIV/AIDS services compared to women, and also consider sexual related issues in disclosure as shown in Table 6. Tables (7 and 8) show that stigma and discrimination still exist in our communities. The big percentage of 82.3% of respondents getting support from family members and 79.6% not minding TASO labeled vehicles at their homes indicate that the majority of respondents are not discriminated. This is in line with what was said in Focus group discussion that stigma in communities has reduced.

However, (Table 10) shows that marital status is related to HIV sero status disclosure. This implies that when designing programmes relating to sero status disclosure, they should be mainly targeting the married and the singles as their percentage were with (55.6% and 25.9% respectively). Revealing sero-status in time should be encouraged as family conflicts may arise as seen during the focus group discussion. Both (Tables 12 and 14) show a positive relationship between disclosure and being treated at home and also in coming in TASO labeled vehicle, the behaviors that need to be strengthened

Tables (16-18) show no positive relationship between different identified variables, and this should be a guide to policy makers in designing appropriate messages to target groups.

Clients (patients) react differently after being told that they are HIV positive as shown in (Table 5). Loss reactions that clients pass through after being told bad news are normal processes of grief as people think that life has come to an end. It is encouraging to note that of 25% clients got support from family members after disclosing their sero status. The situation is different from the study done in India (UNAIDS 2001) where some HIV positive clients were chased away after disclosing their sero status. From this observation stigma has significantly reduced as said by the focus group discussion members.

Stigmatization at work places and schooling of children still exists but at a low level as shown in Table (5). It is good to know that a small percentage of children, 0.4% were rejected from school because of being HIV positive. The situation is different from the study done in India (UNAIDS: 2001) where schools authorities were reluctant to admit a child who was HIV positive.

HIV sero status disclosure is not easy and it is a challenge to many clients as counselors find it hard to convince clients to disclose. Disclosing sero status is a gradual process and clients need always to be supported to do so. In Many instances, clients behave responsibly after disclosing their status as shown in table (5). the reason as to why it is always encouraged as one of the ways of reducing the spread of HIV/ AIDS. Most clients reported support from the family, work



places, neighbors and community and big percentage, 90% reported having never been denied employments because of their sero status, a situation that is encouraging.

The situation is different from the UNAIDS study done in India where stigma and discrimination was reported in the employment sector.

Stigma and discriminating can manifest itself in difficult different ways that include revealing sero status, allowing to be treated at home, minding TASO labeled vehicle coming to their homes, talking about yourself in public freely that you are having HIV among others. These findings are not different from the study done in India. My opinion is that, stigma and discrimination is a global challenge affecting HIV/AIDS care and management

Table (11) shows that, there is no relationship between talking about one's sero status and sero status disclosure. This implies that even those that have not disclosed to many, can talk about their sero status.

Some clients don't want a TASO labeled vehicle coming to their home at homes much as they want to be cared for at home because of because of stigma.

Table (13) shows that there is a relationship between minding about TASO labeled vehicle at home and sero status disclosure, implying that people that have not disclosed their sero status, don't want TASO labeled vehicle at their homes. It was also found out that people who disclose feel free talking about their sero status in public places (Table 14). This implies that clients always have to be empowered to disclosure sero status (UNAIDS 2007) because it reduces stigma and discrimination, Table 15-18 have it right.

It was hypothesized that marital status had no relationship with HIV/AIDS discrimination, Tables (15-18), married people are more vulnerable to HIV infection because there are more chances of cheating on each other. Thus, increasing on the spread of HIV/AIDS. It was also mentioned in Focus Group Discussion that some men with two wives can disclose to one leaving out the other, a situation that is risky in controlling HIV/AIDS spread. Discordance in

HIV/AIDS is increasing and this has also led to high prevalence rate of Sexually Transmitted Diseases in rural areas.

Table (15) which also show a relationship between marital status and revealing sero status means that some categories of people who don't like revealing their sero status have to be supported accordingly. Basic health care messages should be targeting the categories of people who don't talk about their sero status.

However, as it is shown in Table (15) that there is no relationship between marital status and being treated at home; coming in TASO labeled vehicle and talking about one's sero status in public place Tables (16-18). This implies that in designing health messages, such issues have to be considered.

HIV/AIDS related stigma and discrimination manifest itself in difficult forms as expressed during focus group discussions. These findings are not different from what was found out in a study done in India (UNAIDS 2001). As discussed, the majority of difficult forms are experienced in our social settings like hospitals and communities. It was important to note from the respondents that such forms of stigma and discrimination are decreasing. However HIV related stigma and discrimination is being reported in many places of work including the army where people to join UPDF are first screened for HIV. Tackling the challenges of stigma and discrimination therefore needs multidisciplinary approach where health workers, counselors, local leaders, religious leaders and others have to be involved. Many factors influencing HIV related stigma and discrimination identified are not different from those given by Sophia Mukasa (1998) and in the India study of 2007 and the International center for research on women report (2002).and they include lack of sensitization, poverty, poor attitude of health workers, education level of the client and poor attitude of community members. It's not clear why in the 21<sup>st</sup> century, the health workers still have poor attitude towards HIV infected people. However it is on record that Uganda is one of the countries in sub-Saharan Africa that have taken a step further in reducing the effects of HIV/AIDS pandemic (UNAIDS, 2008).

Most of the respondents expressed ignorance about policies in place to support people living with HIV/AIDS. In 1993, the government of Uganda enacted a national multisectoral policy on AIDS those talks about collective responsibility in all AIDS related activities. A political bill is being tabled in parliament to prosecute those who intentionally spread HIV to other people. The open and positive policy towards HIV/AIDS was enacted in 1993 by Uganda AIDS control programme, however, by laws at local levels have not been put in place. There is need for more sensitization of HIV Positive clients about their rights.

Many possible solutions to avert HIV/AIDS related stigma and discrimination were mentioned. Approach to HIV/AIDs care and management needs a multi disciplinary approach. The millennium development goal of combating HIV/AIDS won't be realized when stigma and discrimination are still in existence.



## **CHAPTER SIX**

### **CONCLUSIONS AND RECOMMENDATIONS**

#### **6.1 Conclusion**

The different forms of HIV/AIDS related stigma and discrimination result into; failure to disclose HIV sero status, not talking about sero status in public places, not being comfortable to be treated at home, spreading the disease further and isolation from public places.

The factors that influence HIV related stigma and discrimination include; poor attitude of health workers and community members, lack of sensitization and education of clients, cultural factors like inheritance, jealous redundancy and poverty. The level of stigma and discrimination was determined by how respondents relate with others (Table 7) and the attitude towards HIV related work (Table 8). The findings revealed that the level of stigma and discrimination was relatively high (57.4% and 29.4% respectively).

Many factors fueling the problem can be addressed comprehensively. No policy alone can combat HIV/AIDS related discrimination. The fears and prejudice that lie at the core of the HIV/AIDS discrimination needs multi-disciplinary approach. Much as the nation has put in more effort to combat HIV/AIDS related stigma and discrimination, there is still a lot to be desired in reduction of the spread of HIV/AIDS.

#### **6.2 Recommendations**

People living with HIV/AIDS need to be better educated about their rights as patients and about how to get help to challenge the discrimination and stigmatization they face in health care setting.

There is an urgent need to extend awareness among health care staff concerning their legal duties and responsibilities towards patients in general and patients with HIV/AIDS in particular.

Continuous Medical Education (CME) for Health workers should be strengthened and refresher courses should be promoted. This can help workers to get more knowledge and skills in handling HIV/AIDS patients.

Voluntary counseling and testing services should be promoted in all areas where community members can get access. This can help many people to know their HIV sero status and in a way reduce on HIV related stigma and disclosure.

Assisted HIV sero status disclosure for clients who have challenges in disclosing should be strengthened. This should be done by counselors who have the skills in doing it.

Workshops and seminars on HIV/AIDS for AIDS Caregivers should be encouraged. These can help them to get more knowledge on HIV/AIDS especially how it is spread and prevented.

More HIV/AIDS support groups should be formed in the communities especially in rural areas because when people come together, they share a lot in common and cannot shy away from talking about HIV/AIDS openly in public places.

HIV/AIDS counseling services must be made available to all health facilities to provide for the psychosocial needs of HIV positive patients.

Special programmes should be put in place to attract male clients for HIV/AIDS care services. This should be done in conjunction with other stakeholders who are involved in HIV/AIDS care and management.

The government should strengthen the policies supporting HIV/AIDS patients to reduce discrimination and stigmatization of people living with HIV/AIDS in all areas especially in health care setting.

HIV/AIDS positive people especially the poor need to be economically empowered to start income generating activities as it was found out that poverty was one of the factors fueling stigma and discrimination.

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## APPENDICES

### Appendix 1: Time schedule for the activities

ACTIVITY	PERIOD	REQUIREMENTS	AMOUNT
Proposal writing	Sept- October 2009	Stationery allowances Type setting	340,000
Developing and pre testing instruments	Nov – Dec 2009	Stationery allowances Type setting	202,000
Training research Assistants	Nov – Dec 2009	Allowances stationery	128,000
Data collection	Jan – Feb 2010	Allowances	2,800,000
Data analysis	April 2010	Stationery allowances	766,000
Reporting	June 2010	Stationery allowances	532,000
Report submission	July 2010	Contingence (5% of total)	476,800
<b>Total</b>			<b>5,244,800</b>

## Appendix 2: Budget Explanation Notes

<b>1. Proposal writing</b>	
Lunch allowance for 14 days @ 10,000	140,000
10 reams of paper @ 8000	80,000
Typing photocopying	80,000
Type setting	40,000
<b>2. Developing and protesting instruments</b>	
4 reams of paper@ 8000	32,000
Photocopying	40,000
Lunch for 3 people for 3 days @ 10,000	90,000
Type setting and printing	40,000
<b>3. Training 2 research Assistants</b>	
@ 20,000 for 3 days	120,000
1 ream of paper	8000
<b>4. Data collection</b>	
Allowances for 2 research assistants for 14 days @ 50,000	1,400,000
Allowance for researcher 100,000= for 14 days	1,400,000
<b>5. Data analysis</b>	
Hiring a Statistician for 5 days @ 150,000	750,000
<b>6. Report writing</b>	
4 reams of paper @ 8000	32,000
allowance for 10 days @ 50,000	500,000
<b>7. Contingence (5% of total)</b>	476,800
<b>Grand total</b>	<b>5,244,800</b>

## Appendix 3: Questionnaire

### Questionnaire no.....

This questionnaire is intended to collect data from TASO Mbarara clients about discrimination and stigma of HIV positive clients. You are requested to answer questions as free as you can. The information that you can provide will be used for study purposes. Your participation in the study will not affect the quality of care you are receiving from the organization.

### BIO DATA

#### 1. Gender of respondents (tick appropriately)

Male 1 ☐

Female 2 ☐

#### 2. How old are you?.....

#### 3. Distance from your home to office

Less than 5KM 1 ☐

5KM-20Km 2 ☐

20km-75Km 3 ☐

Above 75Km 4 ☐

#### 4. Marital status

Married 1 ☐

Single 2 ☐

Divorced/Separated 3 ☐

Widow 4 ☐

Widower 5 ☐

Others(specify).....6 ☐

#### 5. Occupation of the respondents

Peasant farmer 1 ☐

Employed full/Part-time	2	<input type="checkbox"/>
Business	3	<input type="checkbox"/>
Retired/Pensioner	3	<input type="checkbox"/>
Student	5	<input type="checkbox"/>
Unemployed	6	<input type="checkbox"/>

**6. Tribe of the respondent**

Nyankole	1	<input type="checkbox"/>
Ganda	2	<input type="checkbox"/>
Kiga	3	<input type="checkbox"/>
Nyarwanda	4	<input type="checkbox"/>
Others(specify).....5		<input type="checkbox"/>

**7. Number of family members.....**

**8. Level of education**

None	1	<input type="checkbox"/>
Primary	2	<input type="checkbox"/>
Secondary	3	<input type="checkbox"/>
Tertiary institution	4	<input type="checkbox"/>

**9. When did you join TASO?**

Less than 6 months ago	1	<input type="checkbox"/>
6 months-2 years ago	2	<input type="checkbox"/>
2 years-6years ago	3	<input type="checkbox"/>
More than 6 years ago	4	<input type="checkbox"/>

**10. HIV stage of the client**

HIV stage I	<input type="checkbox"/>
HIV stage II	<input type="checkbox"/>
HIV stage III	<input type="checkbox"/>
HIV stage IV	<input type="checkbox"/>

**11. Are you on ARV's?**

- |     |   |                          |
|-----|---|--------------------------|
| Yes | 1 | <input type="checkbox"/> |
| No  | 2 | <input type="checkbox"/> |

**INFORMATION ABOUT STIGMA AND DISCRIMINATION**

**12. When did you have an HIV test?**

- |                        |   |                          |
|------------------------|---|--------------------------|
| Less than 2 months ago | 1 | <input type="checkbox"/> |
| More than 6 months ago | 2 | <input type="checkbox"/> |
| More than 6 months     | 3 | <input type="checkbox"/> |
| More than 6 years ago  | 4 | <input type="checkbox"/> |

**13. Why did you have an HIV test?**

- |                          |   |                          |
|--------------------------|---|--------------------------|
| Illness                  | 1 | <input type="checkbox"/> |
| Voluntary                | 2 | <input type="checkbox"/> |
| Requirement for marriage | 3 | <input type="checkbox"/> |
| Exposed to Unsafe sex    | 4 | <input type="checkbox"/> |
| Had an STD               | 5 | <input type="checkbox"/> |
| Requirement for school   | 6 | <input type="checkbox"/> |
| Requirement for work     | 7 | <input type="checkbox"/> |
| Loss of spouse           | 8 | <input type="checkbox"/> |
| Other (specify).....     | 9 | <input type="checkbox"/> |

**14(a) Have you disclosed your HIV sero status?**

- |     |   |                          |
|-----|---|--------------------------|
| Yes | 1 | <input type="checkbox"/> |
| No  | 2 | <input type="checkbox"/> |

**b). If no, what are the reasons**

- |                              |   |                          |
|------------------------------|---|--------------------------|
| Fear                         | 1 | <input type="checkbox"/> |
| I don't know how to disclose | 2 | <input type="checkbox"/> |
| No need                      | 3 | <input type="checkbox"/> |
| Others (specify).....        | 4 | <input type="checkbox"/> |

**(If not disclosed, go to No.22)**

**15. If yes, when did you disclose your HIV sero status?**

- |                           |   |                          |
|---------------------------|---|--------------------------|
| Immediately after testing | 1 | <input type="checkbox"/> |
| 2 weeks after testing     | 2 | <input type="checkbox"/> |
| Less than 6 months        | 3 | <input type="checkbox"/> |
| 6 months after testing    | 4 | <input type="checkbox"/> |

**16. To whom was HIV sero status disclosed?**

- |                           |   |                          |
|---------------------------|---|--------------------------|
| Spouse only               | 1 | <input type="checkbox"/> |
| Parents only              | 2 | <input type="checkbox"/> |
| Spouse and family members | 3 | <input type="checkbox"/> |
| Only close friends        | 4 | <input type="checkbox"/> |
| All community             | 5 | <input type="checkbox"/> |
| Others (specify).....     | 6 | <input type="checkbox"/> |

**17. Why did you disclose your sero status?**

- |                          |   |                          |
|--------------------------|---|--------------------------|
| To be supported          | 1 | <input type="checkbox"/> |
| Feel free                | 2 | <input type="checkbox"/> |
| Encourage people to test | 3 | <input type="checkbox"/> |
| Not to infect others     | 4 | <input type="checkbox"/> |
| Others (specify).....    | 5 | <input type="checkbox"/> |

**18. When you disclosed, what effect did it have on;**

**(a) Your family.**

- |                       |   |                          |
|-----------------------|---|--------------------------|
| Separation            | 1 | <input type="checkbox"/> |
| Anger                 | 2 | <input type="checkbox"/> |
| Nothing               | 3 | <input type="checkbox"/> |
| Supported             | 4 | <input type="checkbox"/> |
| Denied sex by spouse  | 5 | <input type="checkbox"/> |
| Postponed marriage    | 6 | <input type="checkbox"/> |
| Used condom           | 7 | <input type="checkbox"/> |
| Rejected              | 8 | <input type="checkbox"/> |
| Others (specify)..... | 9 | <input type="checkbox"/> |

**(b) Work place**

- |                       |   |                          |
|-----------------------|---|--------------------------|
| Rejected              | 1 | <input type="checkbox"/> |
| Supported             | 2 | <input type="checkbox"/> |
| Pin pointed           | 3 | <input type="checkbox"/> |
| Nothing happened      | 4 | <input type="checkbox"/> |
| Others (specify)..... | 5 | <input type="checkbox"/> |

**(c) Schooling of children**

- |                       |   |                          |
|-----------------------|---|--------------------------|
| Children rejected     | 1 | <input type="checkbox"/> |
| Supported             | 2 | <input type="checkbox"/> |
| Pin pointed           | 3 | <input type="checkbox"/> |
| Nothing happened      | 4 | <input type="checkbox"/> |
| Children nicknamed    | 5 | <input type="checkbox"/> |
| Others (specify)..... | 6 | <input type="checkbox"/> |

**(d) Community**

- |                       |   |                          |
|-----------------------|---|--------------------------|
| Supported             | 1 | <input type="checkbox"/> |
| Pin pointed           | 2 | <input type="checkbox"/> |
| Spread rumors         | 3 | <input type="checkbox"/> |
| Nothing happened      | 4 | <input type="checkbox"/> |
| Others (specify)..... | 5 | <input type="checkbox"/> |

**19. How did you disclose your HIV sero status?**

- |   |   |                          |
|---|---|--------------------------|
| Got courage myself and disclosed at convenient time | 1 | <input type="checkbox"/> |
| My counselor disclosed on my behalf                 | 2 | <input type="checkbox"/> |
| My counselor gave me skills to disclose             | 3 | <input type="checkbox"/> |
| Others (specify).....                               | 4 | <input type="checkbox"/> |

**20. When you disclosed your sero status, did it affect your sexuality?**

- |     |   |                          |
|-----|---|--------------------------|
| Yes | 1 | <input type="checkbox"/> |
| No  | 2 | <input type="checkbox"/> |



**21. If yes, how?**

- |                               |   |                          |
|-------------------------------|---|--------------------------|
| Spouse denied sex             | 1 | <input type="checkbox"/> |
| Started using condom          | 2 | <input type="checkbox"/> |
| Reduced on frequency of sex   | 3 | <input type="checkbox"/> |
| Stopped sex with other people | 4 | <input type="checkbox"/> |
| Others (specify).....         | 5 | <input type="checkbox"/> |

**22. How do you relate with family members?**

- |                       |   |                          |
|-----------------------|---|--------------------------|
| Supportive            | 1 | <input type="checkbox"/> |
| No sharing cups       | 2 | <input type="checkbox"/> |
| No eating together    | 3 | <input type="checkbox"/> |
| Denied property       | 4 | <input type="checkbox"/> |
| Pinpointing           | 5 | <input type="checkbox"/> |
| Denied treatment      | 6 | <input type="checkbox"/> |
| No problem            | 7 | <input type="checkbox"/> |
| Others (specify)..... | 8 | <input type="checkbox"/> |

**23. How do you relate with people at the work place?**

- |                       |   |                          |
|-----------------------|---|--------------------------|
| Supportive            | 1 | <input type="checkbox"/> |
| Pin pointing          | 2 | <input type="checkbox"/> |
| Spreading rumors      | 3 | <input type="checkbox"/> |
| No problem            | 4 | <input type="checkbox"/> |
| Others (specify)..... | 5 | <input type="checkbox"/> |

**24. How do you relate with neighbors?**

- |                       |   |                          |
|-----------------------|---|--------------------------|
| Supportive            | 1 | <input type="checkbox"/> |
| Pinpointing           | 2 | <input type="checkbox"/> |
| No problem            | 3 | <input type="checkbox"/> |
| Spreading rumors      | 4 | <input type="checkbox"/> |
| Others (specify)..... | 5 | <input type="checkbox"/> |

**25. How do you relate with community members?**

- Supportive 1 ☐
- Pi pointing 2 ☐
- No problem 3 ☐
- Seeking guidance from me 4 ☐
- Nick naming me 5 ☐
- Not allowing me to stand in elections 6 ☐
- Others (specify)..... 7 ☐

**From questions 26-33 choose the appropriate response to the question.**

NO.	QUESTION	1 YES	2 NO	3 DON'T KNOW	4 NO RESPONSE
26	Do you feel free talking about your HIV sero status?				
27	Do you get treatment free when sick?				
28	Do you feel comfortable being treated at home?				
29	Do you mind a TASO labeled vehicle coming to your home?				
30	Do you feel comfortable talking about your sero status in public places?				
31	Have you been denied any employment because of your sero status?				
32	Do you feel comfortable living with community members				
33	Do you feel comfortable when some one said that you are HIV positive?				

***Thank you for your co-operation***

#### **Appendix 4: Focus Group Discussion Guide**

1. Forms of HIV /AIDS related stigma and discrimination
2. Relationship with family and community members
3. Talking about HIV publicly and its implications
4. Challenges of HIV related status disclosure
5. Factors Influencing HIV related stigma and discrimination
6. Possible solutions to solve stigma and discrimination
7. Policy /bye laws supporting PLHAS

***Thank you for your cooperation***

## Appendix 5: Qualitative Data Explanations

### Introduction

This present the results and analysis of data obtained form focus group discussion. 4 groups of 7-10 participants of young men and women, old men and women were selected. Each group had a Group Leader and a Raportour. The members of each group sat in a semi-circle at TASO clinic. The purpose of the meeting, objectives of the study and ethical issues were explained to them. In each group, there was a research assistant who assisted in recording down findings and other proceedings of the discussion.

The findings are as indicated below:

### Forms of HIV/AIDS related stigma and discrimination

Participants were asked the different forms of HIV/ AIDS related stigma and the following were mentioned;

- Finger pointing them
- Spreading rumors about them
- Neglecting their children at school
- Reluctant to give them positions in community groups
- Refusal to be attended to in hospital
- Not using the same utensils with others
- Not eating with others
- Labeling and calling them different names

A young Lady said;

*"Bakampa ekitanda omwirwariro kwonka Nurse kuyamanyire ngu nyine akakooko ka silimu, yansibura ahonaaho".*

In translation meaning;

*"I was admitted in the hospital but when the Nurse knew that I was HIV positive, she discharged me very quickly."*

Another young lady said;

*“Omwaana wangye akaruga omwishomero ahabwokuguma nibamutunga akakuumu ngu arweire akakooko ka silimu.”*

In translation meaning;

*“My child left school because of persistent pin point by fellow pupils that he had HIV infection.”*

Most of the respondents however shared that most forms of stigma and discrimination are no longer in existence.

*“Hati abantu bingi bakashoma titwakibonabonesibwa ahabwa kakooko ka silimu.”*

In translation meaning;

*“Now days, many people are educated and the stigma and discrimination has reduced.”*

Most of the respondents who were interviewed tested for HIV in 2000 and above.

*“Itwe abakyebyize kare ebintu bikaba birikubi, turikweshereka abantu, kwonka hati nihakiri ahakuba buriomwe akwasirweho.”*

In translation meaning;

*“For us who tested far back in 1990s, the situation was hostile and we used to hide but now days, most of the homes are affected and there is no one laughing at another.”*

### **Relationship with family/community members**

Most of the members interviewed shared that their relationship with family members at first was not good but improved gradually. Most families have increasingly understood issues surrounding HIV/AIDS and are becoming closer to them.

*“Kunakyebyize n'omukazi omumwaka gwa 2001, omukazi wangye akagyenda ahabwokuba we bakashanga ateine kakooko ka silimu. Akansigira abaana 4, okubareberera kikaba kitanguhi.”*

In translation meaning;

*“When we tested together with my wife in 2001, we were discordant, I was positive and she was negative and she decided to leave me with my 4 children. Up bringing of those children was not easy for me.”*

Members revealed how family /community members are supportive to them.

*“Kunatandikire emibazi ya ARVs, nkaba nteine omuntu weena omunju orikuguma nanyuyisya okumira ebibazi, nkayambwa muriranwa, hati niwe arikunyamba nanaba nteine maani okunyihiraye emibazi.”*

In translation meaning;

*“When I started taking ARVs, I did not have any person at home and it was my neighbour who volunteered to be my drug companion.”*

I was interesting to hear that some clients have formed support groups in their communities. These support groups assist other family and community members to come up and support people living with HIV/AIDS.

All members shared that gone are the days when we could not see a family affected and infected with HIV/AIDS.

Most families are equally affected and no body laughs at another.

### **Talking about HIV/AIDS publicly**

A cross section of members interviewed shared how talking about HIV/AIDS publicly assisted them to reveal HIV sero status to most community members.

Some members however were reluctant to talk about HIV/AIDS in public. Those talking about HIV/AIDS shared how it was not easy at the beginning when they had tested but gained confidence later.

*“Kunakye bize nkagambiraho abantu bamwe abanyabuzare, abamwe tibarakikirize banyirira hare kwonka kuhahwireho obwire kandi beija batandika kunyamba.”*

In translation meaning;

*“When I tested my relatives almost abandoned me at the beginning but later came back and they are very supportive.”*

Some of the group members shared that they formed support groups which move from place to another especially in churches talking about the need for HIV testing.

### **Challenges related to HIV sero status disclosure**

Most of the respondents shared how they first disclosed their sero status to their closure family members, relatives and their community members.

Members brain stormed as to why some HIV positive clients do not reveal their sero status and gave the following responses:

- When you disclose, people start pin pointing you
- You can be harassed by community members
- You may be chased away from your job
- Some people may fail to select you on any political position
- Some people just want to spread the virus to other members, the reason they do not disclose.

*“Owaitu omushaija akaba nayenda kwetsimba aha bwa kansara, kwonka abantu abamwe baguma nibamugambira ngu tokutunga bururu. Ekyo kikamumara amaani ebyokwetsimba yabireka.”*

In translation meaning:

*“An HIV positive man wanted to stand on a political position in this area but some people commented that he would not get the votes because of his HIV sero status. This discouraged him and pulled out of the race.”*

Some people even fear to disclose their HIV sero status because they fear their spouses' behaviour and reactions.

*“Kunagambire omukazi wangye ngu nyine akakooko ka silimu, akakoma ebye yataaha, yansigira abaana.”*

In translation meaning:

*“When I told my wife that I tested HIV positive, she packed her luggage and went home, left me with the children.”*

Another member shared how her husband nearly killed her when she told him that she had tested for HIV. The man wondered as to why the woman had to do it alone when they were married.

Members on the other side mentioned the positive aspects of HIV sero status disclosure that include the following:

- Disclosure can assist you to be self-confident and allays fear about the infection
- When you disclose, some people can be closer to you and in the process they become helpful to you.
- Disclosure can help other people to come up and test for HIV
- Disclosure can strengthen your relationship with family members
- Disclosure can provide a steaming off of one's internal depression and creates a liberated mind.

Members shared how counselors have assisted them to disclose their HIV sero status because in most cases, they don't disclose because of lack of skills and fear of the possible outcome.

Some fear the related family response;

*“Omukazi wangye akaba atakwenda ngu ngambire abantu ngu nyine akakooko ka silimu kunagambireho abantu, kikamukwatsa ekiniga.”*



In translation meaning;

*“My wife did not want me to disclose my HIV sero status to other people, when I did, she became angry with me.”*

On the point of not disclosing HIV sero status to infect others, one member shared;

*“Hariho omuntu oundikumanya, kuyamanyire ngu aine akakooko, akafuruka yaza omumwanya ogundi ahu abantu babiire batakumanya, yatandika kujanzaza akakooko.”*

In translation meaning;

*“I know some body, when she tested HIV positive, she migrated to another place where they did not know her and started spreading the virus.”*

### **Factors influencing HIV related stigma and discrimination**

Members mentioned the following factors:

- Poor attitude of health workers
- Poor attitudes of community members
- Lack of sensitization
- Education level of client
- Cultural factors like polygamy
- Poverty

*“Omuringo ogurikututwazamu aha nimurungi, timuri nka abandi bashaho nka abe irwariro.”*

In translation meaning:

*“The way you regard and care for us is different from how other health workers treat us.”*

Health workers have been accused of stigmatizing HIV positive clients, and some shun going to the hospital.

About ignorance and lack of sensitization, participants shared that the people in communities are not informed the reason the stigmatise them. If people were informed, they would not be stigmatizing us.

*“Omuntu noshanga arikukugamba ngu oine akakooko ka silimu, kandi obwe we atakumanya okwari, obwe arikubasa kukatunga eshaaha yona.”*

In translation meaning;

*“Somebody may be stigmatizing you that you are HIV positive when he does not know that he may also be having the HIV virus.”*

The participants generally shared that the level of stigma reduced especially as many organizations have now come up to educate people about HIV/AIDS.

On the point of poverty is one of the factors influencing HIV related stigma and discrimination, participants shared that when you are poor, you live a miserable life and when you are sick, you cannot get treatment, food and people will start pin pointing you that you are already gone. But contrary to the rich ones, they have access to good food, treatment, can afford expensive drugs and therefore would not be discriminated.

*“Nimanya abantu bakuru omu gavumenti abeine akakooko kwonka tokakimanya ahabwokuba sente nibabasa burikimwe ekibarikwenda.”*

In translation meaning;

*“I know rich people in government who are infected with HIV but because they have money and can afford every thing, they cannot be discriminated.”*

About the point of polygamy, members said that in most cases, co-wives do not like each other and in case one is sick, the other one start spreading rumours about her sickness.

## **Policy and bye laws supporting people living with HIV/AIDS**

All the members shared that they are not aware of any policy and bye law supporting HIV/AIDS patients.

*“Tukabaire nitwenda ebiragiro birikutuhwera aha mirimo, omwishomero okugira ngu otakakora emirimo mingi kwonka tibiriho.”*

Literally meaning;

*“We would wish to have policy at work place like schools to enable us not be over worked but the policy is not there.”*

Members expressed ignorance of Uganda HIV/AIDS policy, even were not aware of the HIV/AIDS bill concerning intentional spreading of HIV/AIDS being tabled in parliament.

## **Possible solutions to address the challenge of stigma and discrimination among HIV/AIDS patients**

Participants brain stormed about the possible solutions and the following were mentioned:

- Having HIV infected people represented in government including parliament
- Strengthening community sensitization and community education
- TV and Radio talk shows
- Strengthening drama shows
- Strengthening research
- Formation of support groups for people living with HIV/AIDS
- HIV testing for all
- Home visiting
- Economic empowerment like income generating activities

Participants were happy with what the government has done but expressed the need for more support.

## Appendix 6: Consent Form

I.....invite you to participate in the study on pattern of stigmatization and discrimination among HIV positive clients attending TASO Mbarara clinic.

The purpose of the study is to analyze the pattern of stigma and discrimination and the factors associated to this. By participating in this study you will help to increase our understanding about the problem generally in the whole country.

The information collected from you will be kept confidential, only the researcher and the assistants will have access to it. Your participation in the study is voluntary and you will have the right to refuse to participate or answer any question you feel comfortable with. The findings will help the organization to improve on service delivery. In case you change your mind any time, the decision to withdraw will not affect any future medical care you should require.

If there is any thing unclear and you need further information, we shall be delighted.

### DECLARATION OF THE RESPONDENT

I have understood the purpose of the study as it has been read to me.

I have the opportunity to ask question about it and questions asked have been answered to my satisfaction. I consent voluntarily as a respondent and I understand that I have the right to withdraw from the study any time and this will not affect my future relationship with the organization.

.....  
Name/signature of respondent

.....  
Name/ signature of researcher/  
Research assistant

