

**A study on how HIV and AIDS-related stigma and discrimination
contribute to the spread of HIV among internally displaced populations
in Gulu District, Uganda**

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DECLARATION

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December, 2010

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ABBREVIATIONS

AIDS	Acquired immune deficiency virus
ARV	Antiretroviral therapy
CSOs	Civil Society Organizations
EVI	Extremely Vulnerable Individuals
FGD	Focus Group Discussions
HCT	HIV and AIDS Counseling and Testing
HIV	Human Immunodeficiency Virus
ICRW	International Center for Research on Women.
IDP	Internally displaced peoples
ILO	International Labour Organization
KAP	Knowledge, Attitudes and Practices
LRA	Lord's Resistances Army
MoH	Ministry of Health
NGO	Non-Governmental Organizations
NSP	National Strategic Plan
NUSAF	Northern Uganda Social Action Fund
OPM	Office of the Prime Minister
OVC	Orphans and other vulnerable children
PLWHA	People living with HIV and AIDS
PRDP	Peace, Recovery and Development Programme
PSNs	People with Special Needs
STI	Sexually transmitted infection
UAC	Uganda AIDS Commission
UN	United Nations
UNAIDS	Joint United Nations Program on HIV/AIDS
UNGASS	United Nations General AIDS Special Session
UPDF	Uganda Peoples Defence Forces
VCT	Voluntary Counseling and Testing

ABSTRACT

Stigma and discrimination concerning HIV/AIDS has been shown to be a barrier to HIV prevention, voluntary counselling and testing, and care in many international settings. Most published stigma scales are not comprehensive, and have been primarily tested in developed countries.

The study had the following specific objectives: analyze the drivers of the HIV and AIDS epidemic; identify and analyze the contributing factors for HIV and AIDS-related stigma; find out and analyze barriers to HIV testing and disclosure; establish the different forms of HIV and AIDS related stigma and discrimination; and establish, in terms of gender, the most affected by HIV and AIDS related stigma and discrimination.

The study adopted both study, quantitative and qualitative approach. Four focus group discussions were conducted, a sample of 121 respondents were selected randomly and interviewed with the aid of an FGD guide and a questionnaire respectively.

Poverty, physical stigma, like sharing eating utensils, clothes, and bed linens, are marked and separated for PLWHA was found to be a predominant form of stigma and discrimination. Women and girls living with HIV and AIDS were more stigmatized and discriminated compared to men and boys as reported by 75% of the respondents. Lack of HIV and AIDS comprehensive knowledge was found as a key driver of HIV and AID-related stigma and discrimination.

OPSOMMING

Stigma en diskriminasie rakende MIV/Vigs staan dikwels in die pad van MIV voorkoming, vrywillige berading, toetsing en versorging.

Die studie het die volgende spesifieke doelwitte: om die dryfveer van MIV/Vigs epidemie te ontleed; om faktore te bepaal wat bydra tot MIV/Vigs-verwante stigma; om hindernisse tot MIV toetsing en bekendmaking te bepaal en om in terme van geslag, te bepaal wie die meeste geraak word deur MIV en Vigs verwante stigma en diskriminasie.

Die studie het 'n kwantitatiewe sowel as 'n kwalitatiewe benadering gevolg. Data is ingesamel deur middel van 4 fokusgroepbesprekings, onderhoude en die invul van vraelyste.

Armoede en kwessies rakende die deel van eetgerei, klere en bedlinne het getoon om die sterkste vorm van stigma en diskriminasie te wees. Stigma en diskriminasie het geblyk om hoër te wees teenoor vroue en dogter wie met MIV/Vigs leef. 'n Tekort aan voldoende kennis rondom MIV/Vigs is gevind om die sterkte dryfveer van MIV/Vigs-verwante stigma en diskriminasie te wees.

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CHAPTER 1

1.1 Introduction

The aim of this chapter is to provide an overview of the general HIV and AIDS situation in Uganda. For this purpose, an overview of the HIV and AIDS; short history and the origin of HIV; a global picture/perspective of HIV and AIDS; regional statistics; HIV and AIDS in Uganda; and legal and policy framework is provided.

1.2 Background

Stigma and discrimination on the basis of HIV status or AIDS is a trend that has existed since the early days of the HIV epidemic. Until stigma and discrimination related to HIV and AIDS is addressed, the pandemic will continue to grow (Save the children, 2001).

HIV related stigma and discrimination undermines prevention efforts by making the person afraid to engage in safe behaviour or seek testing for fear that such acts would themselves raise suspicion in the minds of others about the person's sero status.

It should also be noted that there is little information gathered on the stigma and discrimination levels in internally displaced peoples (IDP) camps. This was the basis for doing this study.

1.3 A Short History and Origin of HIV

A number of theories have been put forward in regard to the origins of HIV, the virus that causes AIDS. Key among these HIV origin theories is the so called "hunter theory" In which, the virus was transferred to humans as a result of chimpanzees being killed and eaten or their blood getting into cuts or wounds on the hunter. The jump of the virus from animal to humans probably occurred in the late 1930s or early 1940s <http://www.avert.org/origin-aids-hiv.htm>. The details of the HIV origin theories are, however, out of the scope of this Study.

1.4 A Global Perspective of HIV and AIDS

In 2008, the total number of people living with HIV was estimated to be an average of 33.4 million with 2.7 million of these being new infections and 2 million AIDS-related deaths. Since the beginning of the epidemic, almost 60 million people have been infected with HIV and 25 million people have died of HIV-related causes (UNAIDS, 2009).

Sub-Saharan Africa is the most affected region and is home to 22.4 million people living with the Virus. Table 1, below, gives a statistical overview of the regional HIV infections.

Table 1.1: Regional HIV Infections

Region	People living with HIV	New HIV infections 2008	AIDS-related deaths 2008	Adult HIV Prevalence (%)
Sub-Saharan Africa	22.4 million	1.9 million	1.4 million	0.052
South and South-East Asia	3.8 million	280 000	270 000	0.003
East Asia	850 000	75 000	59 000	<0.1%
Latin America	2.0 million	170 000	77 000	0.60%
North America	1.4 million	55 000	25 000	0.40%
Western and Central Europe	850 000	30 000	13 000	0.30%
Eastern Europe and Central Asia	1.5 million	110 000	87 000	0.70%
Caribbean	240 000	20 000	12 000	1.00%
Middle East and North Africa	310 000	35 000	20 000	0.20%
Oceania	59 000	3900	2000	0.30%
Total	33.4 million	2.7 million	2 million	0.80%

Source: *UNAIDS* (2009)

1.5 HIV and AIDS in Uganda

The HIV and AIDS epidemic in Uganda was first discovered in the 1980's on the shores of Lake Victoria in Rakai district and spread rapidly, initially in major urban areas and along major road highway network, with heterosexual contact being the major infection route. The first National AIDS Control Programme was set-up in Uganda at the Ministry of Health (MoH) to sensitize and educate the public on the prevention of HIV infection using the Abstinence, Be faithful, correct/ consistent Condom use (ABC) strategy, ensure availability of safe blood for transfusion, conduct HIV surveillance and to initiate programmes for care and treatment.

By the early 1990s a large part of the HIV and AIDS infected population had succumbed to opportunistic infections with a higher prevalence in urban areas as compared to rural areas. It

is estimated that the epidemic had its peak during this period with the average national antenatal HIV prevalence of 18 % in rural areas and 25%-30% in major urban areas (UNGASS, 2007).

It was realized that addressing the epidemic needed a collective effort from all stakeholders in their different mandates and areas of comparative advantage and capabilities. Political leadership, political commitment and openness about the epidemic were identified as key in controlling the epidemic. This marked the first phase of the epidemic (UNGASS, 2007).

The second phase (1992-2000) showed a declining HIV prevalence and incidence, particularly in urban areas. Nationally, HIV prevalence declined during the 1990s among antenatal clinic attendees and voluntary counseling and testing (VCT) clients. Similarly, there were declining HIV incidence and prevalence levels in population-based cohorts in rural areas of Masaka district and Rakai district. The decline in HIV incidence and prevalence was attributed to the increased age of sexual debut; reduction in sexual partnerships outside of marriage; and increased use of condoms.

The third phase of the Uganda HIV epidemic (since 2000) has been characterized by stabilization of the HIV prevalence at a level ranging from 6-7%. However, there are anecdotal indications, from the national surveillance system corroborated by data from longitudinal cohort studies, of an apparent increase in HIV prevalence and incidence during the last few years (UNGASS, 2007).

In Uganda, some of the factors driving the epidemic include behavioral factors, social-cultural, socio-behavioral, economic and geographic factors. These include higher risk sex (which include non-marital sex, extra-marital sex, non-consensual sex, commercial sex, transactional sex, intergenerational sex and sex for survival), mother to child transmission, HIV discordance and non-disclosure, poverty, early marriage, glorification of non-marital sex, multiple sexual partners, stigma, discrimination and sexually transmitted infection (STI) prevalence (UAC, 2007).

1.6 Legal and Policy Framework

Uganda still lacks explicit legislation regarding HIV and AIDS. However, a number of laws have a direct bearing on the human rights of people living with, affected by, and at risk of

HIV. Binding instruments to which Uganda is state party include: Universal Declaration of Human Rights; International Covenant on Economic, Social and Cultural Rights; International Covenant on Civil and Political Rights; Convention on the Elimination of all Forms of Racial

Discrimination; Convention on the Rights of the Child; Convention on all Forms of Discrimination against Women.

Under Chapter 4 Article 21, the Constitution of the Republic of Uganda (1995) provides for equality and freedom from discrimination. This could be interpreted to include HIV and AIDS. The Children's Act of 1997 contains provisions on the welfare and rights of children that should apply regardless of whether or not there is HIV and AIDS in the family. Some of the critical provisions in the context of HIV and AIDS and children's rights include: A child's right to stay with his or her parents or guardians; The duty of the parent, guardian, or other person having custody of the child to maintain the child, meeting all the child's needs and rights including education and guidance, immunization, adequate diet, clothing, shelter, and medical attention; The right to play and enjoy leisure.

Section 6 of the Employment Act of 2006 prohibits discrimination on the basis of HIV and AIDS status among other grounds. This law is stronger and more explicit than the Constitution, and it strengthens the principles of the HIV and AIDS and the Workplace Policy. The prohibition of sexual harassment under section 7 creates legal protection, particularly for female employees who are placed at risk of contracting HIV/AIDS through demands for sex by their employers.

The National Strategic Paper (NSP) highlights the importance of promoting a human rights response in the identification and targeting of vulnerable and most at risk populations. These are defined in the NSP to include commercial sex workers, fishing communities, uniformed services, internally displaced persons, persons with disability, orphaned and vulnerable children (OVCs), and discordant couples.

The National Policy on HIV and AIDS and the World of Work whose goal is to "provide a framework for prevention of further spread of HIV/AIDS and mitigation of the socio-economic impact within the world of work in Uganda" has the following guiding principles

which relate to law and human rights: Non-discrimination at the place of work on the basis of known or perceived HIV status; Confidentiality, including the right to privacy and no obligation on employees to reveal their HIV status to the employer' Prohibition of compulsory HIV testing as a condition of recruitment, promotion or career development; and provision of HIV testing (Mukasa & Gathumbi, 2008).

Uganda's draft HIV/AIDS Prevention and Control Bill mandates HIV testing of pregnant women, their partners, and other specified populations, and criminalizes the intentional transmission (or attempted transmission) of HIV. In addition, the bill grants health practitioners the power to notify sexual partners (and those "in close and continuous contact") of a person living with HIV of that person's sero-status, and criminalizes a wide range of conduct related to failure to follow medical orders or follow "safe procedures." (Human Rights Watch, 2010).

1.7 Statement of the Problem

Uganda has been heralded as a model country in the fight against HIV and AIDS because of the concerted prevention efforts since the start of the epidemic. It was able to reduce national antenatal HIV prevalence of 18 % in rural areas and 25%-30% in major urban areas in 1990s to 6.3% by 2009 (UAC, 2008). Despite its success, stigma and discrimination remain a reality for people living with HIV and AIDS as HIV transmission remains linked to lifestyle and perceived morality.

Because HIV and AIDS is a condition related to sex, blood, death, disease and behaviour which may be illegal – commercial sex, homosexuality, injecting drugs, the fear and taboos associated with these subjects lead to the denial, stigma and discrimination that surround HIV and AIDS, and breed the secrecy that hinder private and community discussion about the issues and behaviour involved (UNAIDS, 2000).

“If we do not appreciate the nature and impact of stigma, none of our interventions can begin to be successful. AIDS is probably the most stigmatized disease in history” (Cameron, 2007). HIV and AIDS related stigma and discrimination affect women, men, orphans, youth, care providers, and the most at-risk populations. A failure to understand and address this problem represents a failure of imagination across the spectrum of prevention, treatment, and care, and, ultimately, in our ability to shape an effective response (Policy Project, 2000).

HIV prevalence rates in the IDP camps in Gulu District are estimated to be over 12%, far above the national rate of 6.4% (Ministry of Health, 2007). The study sought to understand the dynamics around the high HIV infection rates and the high prevalence of HIV and AIDS related stigma and discrimination. The specific research problem the study investigated was **“Does HIV and AIDS-related stigma and discrimination contribute to the spread of the HIV epidemic among the internally displaced populations in Gulu District?”**

The sub-problems/questions addressed by the study included:

- Do HIV and AIDS- related stigma and discrimination actually exist in the IDP camps in Gulu district?
- What are the drivers of the high prevalence rates of the HIV epidemic in IDP camps in Gulu District?
- Who are the most affected by HIV and AIDS-related stigma and discrimination in terms of gender?
- What factors contribute to HIV and AIDS stigma and discrimination in the IDP camps?
- What forms of HIV and AIDS related stigma and discrimination exist at the IDP camps in Gulu District?
- What are the barriers to HIV testing and disclosure?
- How do PLWHA cope with HIV and AIDS stigma and discrimination?

1.8 Research objectives

The specific objectives of the study were defined as follows:

- Analyze the drivers of the HIV and AIDS epidemic in the IDP camps in Gulu District.
- Identify and analyze the contributing factors for HIV and AIDS-related stigma in the IDP camps in Gulu District.
- Find out and analyze barriers to HIV testing and disclosure.
- Establish the different forms of HIV and AIDS related stigma and discrimination in the IDP camps in Gulu District.
- Establish, in terms of gender, the most affected by HIV and AIDS related stigma and discrimination in the IDP camps in Gulu District.

1.9 Significance of the Research

The Study will be of significance in the following ways:

- **People Living with HIV and AIDS (PLWHA) and their Care-Givers:** PLWHA are the major victims of HIV and AIDS related stigma and discrimination. The findings of this study may go a long way in providing workable recommendations to be adopted in the fight against this problem.
- **Civil Society:** Civil society organizations, which include, networks of PLWHA, HIV and AIDS Activists, NGOs and the media among others, may find the findings of this study important in their advocacy campaigns against HIV and AIDS stigma and discrimination.
- **Office of the Prime Minister (OPM):** OPM is charged with issues of refugees, IDPs and the general reconstruction and pacification of Northern Uganda, which had been the battlefield of the LRA rebellion for the last two decades. The Ministry may find this study useful, especially, in dealing with or developing policies related HIV and AIDS because it provide a baseline on the level of the knowledge, attitude and practices (KAP), upon which interventions can be planned.
- **The general public:** The finding of this study may be used to develop interventions to reduce fear of casual transmission, stigma and discrimination in the communities.
- **Researchers/Academicians:** Little research has been done on the topic of study and therefore, information generated may be useful to researchers who will require data for further research or replication of the same study elsewhere with displaced populations or refugees.

1.10 Scope of the Study

The study focused on assessing how HIV and AIDS-related stigma and discrimination contribute to the spread of HIV among internally displaced populations in Gulu District, Uganda. The study was carried out in Gulu District. A sample of two camps was selected randomly. The time period to be covered under this study was from 1990 to the time of data collection when the LRA war gained momentum and where almost 90% of communities in the Gulu District were confined in the IDP camps.

1.11 Independent and Dependent Variables

The independent variable in this study was the “spread of HIV and AIDS at the IDP camps”, while “stigma and discrimination” were the dependent variable.

1.12 Limitation of the Study

- HIV and AIDS issues are very sensitive; some of the responses given may have been biased. This was, however countered by using two methods of data collection, what is referred to as “triangulation” in research.
- The study was conducted in only two IDP camps out of over 40 due to limited time that was available to the researcher and also because of resource constraints. Nevertheless, it is assumed that the study managed to capture a general situation of HIV and AIDS-related stigma and how it contributes to HIV spread in the camps.
- Language was a limitation in that the researcher was not well conversant with Acholi language which is the main one spoken in the study area and which was used during the FGDs. The researcher relied on a translator and it is possible that some detail or accuracy was lost during translation.
- Since the study was cross-sectional in nature it therefore means that the direction of causality could not be determined.

1.13 Organization of the Report

This research report is presented in five chapters. The first chapter focuses on the background to the study, statement to the problem, objectives of the study, research questions, scope of the study, significance of the study, research variables, and limitations of the study and organization of the research report. Chapter two presents related literature, while chapter three focuses on the methodology, and is sub-divided into research design; sampling procedure and sample size; research area; ethical considerations; research instruments; and method for data analysis. Chapter four presents the analysis of the study findings while chapter five is focused on discussion of the findings. Chapter six presents conclusions and recommendations.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

There is an ongoing debate, however, about whether stigma and discrimination actually fuel the persisting spread of HIV, or slow it down by reducing contacts between the whole population and high-risk groups. This chapter provides an evaluation of relevant literature pertaining to internal displacement in Uganda as well as HIV and AIDS related stigma and discrimination. Furthermore, the chapter examines the forms of stigma and discrimination; impacts of HIV and AIDS related stigma and discrimination; gender and HIV and AIDS stigma and discrimination; and HIV and AIDS related stigma and discrimination reduction interventions.

Many studies have shown that people living with HIV and AIDS (PLWHA) suffer from stigma and discrimination. One year after a study began, 64.2% of all PLWHAs and 83.7% of nurses reported experiencing one or more HIV stigma events over the last 3 months (Holzemer, 2009).

2.2 The Internally Displaced People (IDP) in Northern Uganda

For over two decades, Northern Uganda has been affected by an internal conflict caused by activities led by Joseph Kony's Lord's Resistance Army. As a result of the conflict and the Government of Uganda's counter insurgency response, over 1.8 million Northern Ugandans have been internally displaced and forced to live in internally displaced person's (IDPs) camps. Long term displacement has led to social deterioration and a heavy dependency on food rations and non-governmental organisation (NGO)/United Nations (UN) support resulting from a lack of access to traditional agricultural land and agrarian self sufficiency (Erb, 2008).

The conflict in northern Uganda began in 1986. A history of antagonism and dis-trust between the Acholi people of northern Uganda and southern-based tribes dominating the government contributed to the formation of the Lord's Resistance Army (LRA) in 1987, led by Joseph Kony. The LRA purportedly aimed to overthrow the government led by current president Yoweri Museveni, rebuild the Acholi nation and culture and rule Uganda in accordance with the biblical Ten Commandments (www.internal-displacement.org).

In the period up to 1996, some people in the Acholi sub-region fled their villages as a direct result of LRA attacks, but the main cause of the subsequent large-scale displacement was the government's decision in 1996 to force civilians into IDP camps which it described as "protected villages". The displacement crisis worsened in October 2002, when the army, in the course of a large-scale offensive entitled "Operation Iron Fist", ordered all civilians remaining in "abandoned villages" to move to government camps. Around the same time, the area affected by displacement expanded as the LRA moved eastwards into the Lango and Teso sub-regions. Operation Iron Fist failed to defeat the LRA, and in March 2004 the army launched "Operation Iron Fist II", causing further massive displacement. By the end of 2005, a total of about 1.8 million people were living in IDP camps (www.internal-displacement.org).

The LRA repeatedly attacked IDP camps, although the army was deployed to protect them. The army's failure to ensure security and the appalling humanitarian conditions in the camps further entrenched the Acholi people's sense of political and social marginalization (www.internal-displacement.org).

As of May 2009, 378,000 IDPs remained in camps (about 20 per cent of the peak IDP population of 1.8 million); a further 244,000 had moved from camps to "transit sites" closer to their land, while the remainder had returned to their home villages. However, there were substantial regional variations: in Gulu district only 68 per cent of the original camp population had returned to their home villages.

In May 2008 the government issued *Camp Phase-Out Guidelines*, which were followed in June 2008 by *Guidelines for the Demolition of Abandoned Structures*. By the end of March 2008, although OCHA noted at the time that "several thousand" IDPs remained in the former camps, including about 700 people with specific needs who remained there without family or community support. In the Acholi sub-region, 60 out of a total of 121 camps had been assessed for phase-out by July 2009, but none had been closed officially.

The remaining camp population largely consists of four groups: firstly, so-called "extremely vulnerable individuals" (EVIs) and other people with special needs (PSNs); secondly, people who cannot go back to their areas of origin because of land disputes; and thirdly, young people who have been left behind by their family so they can access services in the camps, primarily education but also health care.

2.3 The Causes of HIV and AIDS related Stigma and Discrimination

There are many reasons for the stigma and discrimination and secrecy that surround HIV and AIDS, and these will differ from culture to culture. In general, however, it can be pointed out that the following are the major sources of stigma and discrimination:

- **Unavailability of treatment for the epidemic.** The fact that for many there is no available treatment, cause individuals to fear getting tested for HIV and to fear disclosing it to health care workers, for care; to families and communities, for support; and to sexual and drug-injecting partners, to prevent onward transmission of HIV (UNAIDS, 2000).
- **Ignorance or misunderstanding of HIV and AIDS.** Fear of and preoccupation with transmission through everyday casual contact leads directly to stigma in the form of isolation of persons living with HIV and AIDS in all aspects of daily life. It occurs everywhere, from within the home, to social gathering places in the neighborhood, to the market place, health facilities and even sometimes in places of worship. In one of the studies in Zambia, it was found that a respondent feared eating with an HIV positive person for fear of swallowing the virus and contract HIV (ICRW, 2005).
- **Lack of education.** The silence and stigma that hold back individuals from accessing HIV preventative services and advice are exacerbated not only by the lack of education of those individuals, but by lack of education amongst the communities in which they live. (Oxfam, 2004). Recent studies in Zambia and elsewhere show that better educated people have lower rates of HIV infection. Higher levels of education are directly related to increased awareness and knowledge of HIV and AIDS, greater knowledge of testing facilities, higher rates of condom use, and better communication between partners about HIV prevention (UNAIDS 2004).
- **Morality judgment toward PLWHA.** HIV and AIDS-related stigma and discrimination are fueled by assumptions about the moral integrity and values of people with HIV or AIDS as people tend to associate AIDS with moral

impropriety. In a 2004-5 study in Tanzania, more than 65 percent agreed with the “blame and judgment” statement that HIV and AIDS is a punishment for bad behavior (ICRW, 2006). The moral judgment is reinforced by religion as getting infected with HIV and AIDS is seen as a result of promiscuity and carelessness. That they deserve to be punished by God for the disobedience of His commandments (ICRW, 2006).

2.4 Forms of HIV and AIDS Stigma and Discrimination

ICRW, 2005, identifies four broad, loosely defined expressions and forms of stigma: physical, social, verbal and institutional.

The forms of physical stigma includes: Physical isolation of people living with HIV and AIDS and which occurs in all locations, from the home to community gathering or public spaces (like tea shops, markets, sports grounds, buses, places of worship), to within workplaces, schools and hospitals. Common expressions within the home include marking and separating out typically shared objects like eating utensils, clothes, and bed linens and making those with HIV and AIDS sleep in separate quarters and eat alone. Expressions in public spaces include not sitting next to or moving away from a person with HIV in public transport, in places of worship, while waiting in a queue or on a bench, or at a tea shop or bar. In places where eating together from a shared platter, sharing a communal drinking container, or even sharing washed cups is common, people living with HIV and AIDS may be publicly excluded, or the usual customs visibly altered when an infected person is present. For example, suddenly individual plates or spoons and forks appear, where eating with hands from a common platter is the norm (ICRW, 2005).

Social stigma manifest in following: social isolation, loss of identity and role, and voyeurism. It takes the very visible form of the disappearance of invitations to significant family and community events such as weddings, or outright orders to stay away. No longer being asked to participate in the planning or hosting of events. Another form of stigma is voyeurism, where there is an increase in visits to people living with HIV, particularly once AIDS has set in where the specific intent is to see how the person is progressing in their illness and report back to the community.

In addition, social stigma is also expressed through the taking away or diminishing of the roles, responsibilities, and social standing of those living with HIV and AIDS within the

family and larger community. As a result, HIV positive people lose power, respect, and identity (ICRW 2005).

A third form of stigma is verbal as identified by ICRW (2005). This can be direct (pointing fingers, insulting, taunting, or blaming), or more indirect (gossip and rumors). Gossip and rumors focus on speculation about whether a person has HIV, usually because of visible signs, illness, behavior, or association with groups seen as “high risk. An integral and hurtful expression of the verbal stigma is the use of derogatory, demeaning and pessimistic or despairing language to talk about or label people with HIV and AIDS. For instance “walking corpse” The fourth form of stigma according to ICRW (2005) is institutional stigma, which refers to differential treatment within any broadly defined institutional setting that leads to a negative outcome for the person living with HIV. It has to do with loss of or inability to secure livelihoods, housing, health care, and education. It also includes losing access to new or future opportunities because an HIV test is required to qualify for a job, loan, scholarship, or visa for travel; differential treatment within an institution that leads to poorer outcomes (for example having to wait longer for health services); and the way those with HIV are depicted in the media.

2.5 Impacts of HIV and AIDS related Stigma and Discrimination

- **Inhibits ability of caregivers to provide.** “Stigma, discrimination and courtesy stigma directed towards adults can affect the ability of caregivers to provide” (Deacon, 2007). The quality of care by family members is improved when stigma is low (ICRW, 2009). While many families do support relatives who are living with HIV, others find the shame of HIV an insurmountable barrier to accessing HIV treatment and services. People living with HIV report that family will withhold support for fear of the shame and loss of family honor associated with HIV (Policy Project, 2000).
- **Barrier to expanding testing and treatment access.** Fear of judgment from healthcare workers and family members and fear of disclosure prevents many people from seeking voluntary counselling and testing. The desire to avoid possible negative reactions causes people to delay seeking treatment until they become symptomatic with an AIDS defining illness, limiting the efficacy of ARV treatment (Policy Project, 2000). HIV and AIDS stigma and

discrimination undermines drug adherence and delimits access to medical care (Stein, 2005). In one US study, patients with high stigma concerns were 3.3 times more likely to not adhere to their ART regimen (Dlamini, P. S., D. Wantland, L. N. Makoae, M. Chirwa, T. W. Kohi, M. Greeff, J. Naidoo, J. Mullan, L. R. Uys and W. L. Holzemer., 2009) quoted by (ICRW, 2009)

Stigma and discrimination are major obstacles to the take-up of essential services such as voluntary counselling and testing (VCT) and treatment, even when free. The fear or experience of stigma and discrimination including rejection by family and friends, loss of jobs or housing, poor treatment from healthcare workers, and, in extreme cases, violence is a powerful deterrent to seeking HIV testing and treatment (Policy project, 2000).

- **Inhibits efforts aimed at promoting HIV and AIDS prevention. HIV and AIDS** related stigma and discrimination have been identified as major barriers to achieving universal access to prevention, treatment, care and support as Stephens (2004) observe, the durability and success of HIV and AIDS prevention programs depend on the ability to understand and overcome stigma and discrimination. Discrimination and stigmatization of people living with HIV and AIDS inhibits efforts aimed at promoting HIV and AIDS prevention: if people are frightened of the possibility of discrimination, they may conceal their status, and are more likely to pass on the infection to others. Moreover, they are not likely to seek treatment and counselling.

In a study carried out in Malawi and South Africa in regard to prevention of mother-to child transmission services, fear of stigma and discrimination, along with fear of household conflict, divorce, and lack of support from husbands, was often cited as a reason for women dropping out following their initial antenatal clinic visit (ICRW, 2009).

Stigmatisation prevents VCT uptake, interferes with the adoption of safer sexual practices and legitimises social denial. It also undermines drug adherence and delimits access to medical care (Stein, 2005).

- **Causes depression, lack of self worth and despair.** Since much of the meaning of our lives is derived by way of an orientation towards the future, the terminal diagnosis accompanying an HIV-positive diagnosis in the absence of ARVs fractures one's sense of purpose. In areas of high prevalence, this leads to large-scale psychosocial trauma and a pervading sense of hopelessness (Stein, 2005). In another study, HIV and AIDS related stigma was positively associated with psychopathological symptoms (e.g., depression, loneliness)

2.6 Gender and HIV & AIDS Stigma and Discrimination

Women generally bear the strongest brunt of HIV and AIDS related stigma and discrimination. The reason underlying this is that women in Sub-Saharan Africa are expected to uphold the moral traditions of their societies. HIV is regarded as evidence that they have failed to fulfill this important social function. In a study done in Ethiopia, Tanzania and Zambia, it was found that women with HIV tended not only to be more stigmatized for having “failed as proper women,” but also blamed for “bringing” HIV into a family or marriage. On the other hand, men are generally expected to be reckless, adventuresome and more likely exposed to a whole host of sexually transmitted infections (ICRW, 2006).

Defeating HIV and AIDS means attacking a more deep-rooted and in many ways a tougher adversary, namely, the inequality between men and women. The burden of the HIV and AIDS pandemic is borne most by women and young girls. “If we can stop the spread of HIV among women and girls we have a fighting chance of turning the pandemic around,” (UNAIDS, 2004).

In Sub-Saharan Africa, for every ten men with HIV, thirteen women are infected (UNAIDS, 2004). Women are more likely to experience, more extreme manifestation of physical isolation including complete abandonment by family, divorce, or separation from children (ICRW, 2005). Women are more easily deterred by stigma from being tested for HIV or seeking care (ICRW, 2009).

2.7 HIV and AIDS Stigma and Discrimination Reduction Interventions.

There are many scholars who have documented responses to HIV and AIDS related stigma and discrimination, which the researcher attempts to evaluate in the following paragraphs.

Community-based interventions: Community-based programmes focusing on dialogue about values and beliefs is important for reducing more than fear-based stigma and tackling other drivers of HIV and AIDS stigma and discrimination. These may include: awareness-raising and sensitization and HIV knowledge awareness (ICRW, 2009). Interventions designed to provide more information about a particular illness to ‘put right’ incorrect beliefs, to increase tolerance by increasing empathy, or to reduce anxiety or fear on the part of the broader population, without confronting underlying social processes (Goudge, Ngoma, Manderson, & Schneider 2009).

There is need to invest in creating the facilities for HIV testing, as well as in backing community-based programmes which create a supportive environment and encourage people to come forward for HIV testing, counseling, care, treatment and support. Then beneficial disclosure will increase and lead to more prevention and more care and support for those already infected (UNAIDS, 2000). Similarly, it has been observed by ICRW (2009) that exposure to edutainment programs, such as serial dramas aired on TV or radio, was correlated with more accepting attitudes in Botswana and Kyrgyzstan.

Other community-based programmes like micro-credit that partners with HIV-positive and negative loan recipients have also been known to effectively reducing HIV and AIDS related stigma (ICRW, 2009).

Patient centred approaches within organisations: Effective response to HIV and AIDS stigma and discrimination are programmes working with and led by people living with HIV (ICRW, 2009). Active involvement of people living with and affected by HIV and AIDS is critical and help to change attitudes from stigma and discrimination to respect and support. It also gives a human face to the epidemic, to reaffirm the value of people with HIV and AIDS and to change attitudes of stigma (UNAIDS 2000).

Rights-based approaches: Social movements, supported by government action with a rights based approach can build communal resistance to HIV and AIDS stigma and discrimination, structurally changing the context in which both individuals and communities operate as they respond to HIV and AIDS. This is what UNAIDS (2000) reinforces, that enactment of laws and policies against HIV-related discrimination and against breaches in confidentiality and informed consent helps in reducing incidences of HIV and AIDS stigma and discrimination.

Training and sensitization of professionals who work with people affected by HIV and AIDS. Key professionals like health care workers, police, social service providers, lawyers and judges should be trained and sensitized in the management of clients living with HIV and AIDS. It is often at the hands of such professionals that people affected by HIV and AIDS suffer the worst discrimination, despite the professional and ethical responsibility to treat people who are HIV positive with dignity and compassion, and to protect their confidentiality in appropriate ways (UNAIDS, 2000).

CHAPTER 3

METHODOLOGY

3.1 Introduction

This section describes the methodology that was used in this study. It describes the research design; study area; ethical considerations; study population; sampling procedure and sample size; research instruments, and method of analysis. The chapter concludes with the operational definitions of the terms used.

3.2 Research Design

The study used both quantitative and qualitative research methods. First, a survey and more specifically face-to-face method of data collection was employed as a research technique. A survey is defined as “a method of collecting standardized information by interviewing a representative sample of some population”. Compared to others, the face-to-face method has the advantage of clearing any ambiguities with questions asked and has higher completion rates (Christensen, 2007). This is reinforced by Public Affairs Branch, Treasury Board of Canada, Secretariat (Undated) report which observes that when properly conducted, a survey offers an efficient and accurate means of ascertaining the characteristics (physical and psychological) of almost any population of interest.

Second, a correlation study was done, which consists of measuring two variables and then determining the degree of relationships that exist between them. The advantage with this method is that of enabling the goal of prediction (Christensen, 2007). This study describes the degree of relationship that exists between the two measured variables, i.e. “spread of HIV and AIDS at the IDP camps” as the independent variable and stigma and discrimination as the dependent variable.

3.3 Research Area

Gulu District in Northern Uganda is located 332 km north of the Ugandan capital of Kampala and consists of four countries: Kilak, Achwa, Omoro, and Nwoya (Kilak and Nwoya county has been integrated to form Amuru District). It has an estimated population of about 479,496 people. More than $\frac{3}{4}$ of these population were by 2005 in the internally displaced peoples (IDP) camps. This is because Gulu District has been a battlefield between the rebel Lord's Resistance Army (LRA) and the Uganda Peoples Defence Forces (UPDF), which only came to end in 2007 after twenty one years. The Uganda Government, in an attempt to protect the

local population forced them to settle in satellite camps locally known as internally displaced peoples (IDP) camps. There were over 31 IDP camps in Gulu District by 2005.

Though official figures indicate that in Gulu District alone, over 85 per cent of former internally displaced persons have returned home and several camps have been closed, there are still a number of people living in the camps. Table 3.1 Update on IDPs Movement by Dec-09

District	Original Camps (2005)	Estimated original camp population - end 2005	Current estimated IDPs in Camps	Estimated IDP % remaining in camp	Estimated IDPs in transit sites	Estimated returnees in villages of origin
Gulu	31	204,000	22,699	11%	21,000	191,000

Source: UNHCR Sub-office Gulu - Quarterly Field Updates - December 2009

The IDP camps are characterized by overcrowding, accelerated transmission of communicable diseases including epidemics, limited access to some camps by government and humanitarian agencies, limited access by camp population to essential health services and inequitable distribution of health facilities and services to the IDPs. The consequences of these are high mortality and morbidity rates due to malaria, HIV/AIDS, violence and diarrhea diseases. (OPM 2005), quoted in (Henttonen, 2006) describes a camp setting appropriately:

A typical camp is semi-urbanised traditional rural life. The urbanised environment that the camp represents has also implanted certain aspects of modernity. Nearly all bigger camps have bars and video parlours. The camps look like gigantic villages, with one important difference, there are little cattle around, and people can rarely work in the fields anymore. These bars and video parlours are sites for relaxation and intoxication, but also a venue for prostitution and women exchanging sex for favours. (P.12)

3.4 Ethical Considerations

A scientist is obliged to consider the ethics of conducting research that utilizes humans as participants because it may subject participants to humiliation, physical pain and

embarrassment (Christensen, 2007). Ethical permission to carry out the research in the IDP camps was sought at two levels: The Local Government level, i.e. Sub-country as well as from the camps leadership level. Accordingly, respect was accorded to the respondents through a thorough explanation of the purpose of the study as well as being given the right to choose to participate in it.

3.4.1 Confidentiality

At every stage of the interview process, starting with invitations to participate in the study (see Appendix 3), and potential respondents were assured of confidentiality and that the purpose of the study was for academic purposes only and not any other purpose. Again, before going to the field, the research assistants were given an orientation of the research objectives, and confidentiality and sensitivity issues involved.

3.4.2 Informed Consent

Participants were informed about all aspects of the study so as to allow them make voluntary and informed decisions and to choose to either decline to participate in the study or give his or her informed consent. A consent form (see appendix 4) was read to each respondents including FGDs before the interviews were conducted.

3.5 Sampling Procedure and Sample Size

According to the Krejcie and Morgan (1970) sample size determination criteria, a sample size of 121 was found adequate for this study. This study used random sampling. Random sampling is a control techniques that equates groups of participants by ensuring every member an equal chance of being assigned to any group (Christensen, 2007). This method of sampling was used to select respondents for both household questionnaires and for FGDs.

3.6 Study Population

Population is defined as a group of people or organisms that are of interest to the researcher or the organisms that can assist the researcher to answer the question asked (Christensen, 2007). The study population in this case was drawn from PLWHA living in the IDP camps; community leaders from the respective IDPs; as well as other community members.

3.7 Research Instruments

Key Informant interview schedule

A combination of both open and closed-ended questionnaire was developed and administered to 121 key informants identified for the study. (See Appendix 1)

Focus group discussions (FGDs) Guide

A total of four FGDs were conducted to elicit information from selected respondents. FGDs guidelines and instructions were prepared before data collection. (see Appendix 2). FGDs are facilitated group discussions in which an interviewer asks a series of questions of a group. The group provides answers to the questions, and a discussion follows. Through discussion by the participants, a range of views is elicited, and new insights can be generated. The purpose of a focus group is to understand the participants' attitudes, feelings, beliefs, experiences and reactions in a way that would not be feasible using one-to-one interviews. Attitudes and feeling are often more likely to be revealed in a group setting, where there is interaction and discussion (<http://www.intrac.org>).

3.8 Method for Analysis

Data Preparation: The raw data collected, was first, checked for accuracy. That is, whether what was collected conforms or was in line with the research problem. Errors in coding and careless entry were identified and corrected.

Data entry into the computer: Once checking for accuracy was done, the quantitative data was then entered into the computer using MS Excel spreadsheets with support from a statistician.

Summary Tables: Data analyzed was summarized into tables and graphs that show the relevant information to the study. All irrelevant data collected was sieved out.

3.9 Definitions of Key Terms

Stigma: UNAIDS (2007) defines HIV-related stigma as: "...a 'process of devaluation' of people either living with or associated with HIV and AIDS" Discrimination on the other hand follows stigma and is the "unfair and unjust treatment of an individual based on his or her real or perceived HIV status."

A dictionary meaning of stigma is a “disgrace or reproach attached to someone”. Operationally, HIV related stigma is an attribute that is deeply discrediting and reduces the HIV positive person from the usual whole person to a tainted, discounted one.

Discrimination: Discrimination on the other hand entails a person acting on a pre-existing sentiment or stigma, which result in a person being treated unfairly. It is the imposing of restrictions on people living with or those perceived to be living with HIV or AIDS. For instance, some people who are found to be HIV positive may be denied some jobs in some other companies because of the sero status.

3.10 Conclusion

In this chapter, the research methodology adopted for the study has been outlined. Specifically, the research design, description of the study area, sampling design, ethical considerations and the instruments employed in the research have been stated. The chapter concludes with method of data analysis and definitions of key terms.

CHAPTER 4

ANALYSIS AND FINDINGS

4.0 Introduction:

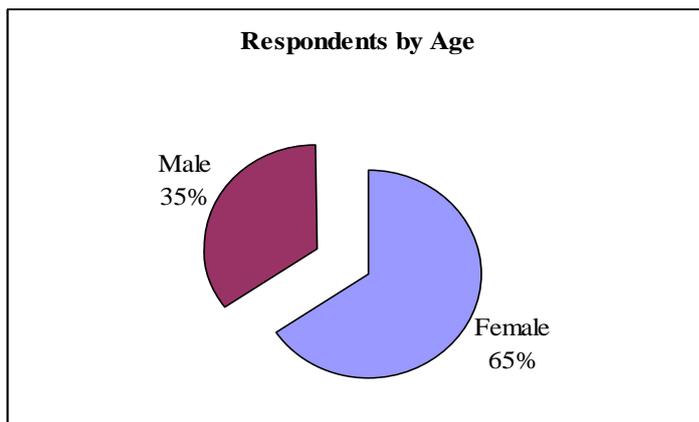
This chapter presents the findings of the study. Figures, charts and tables have been used for illustration purposes. For qualitative findings from FGDs, quotations or text boxes have been used.

4.1 Demographic Characteristics of Respondents

4.1.1 Gender of Respondents

Majority (65%) of the respondents surveyed were female and 35% were male as shown in the figure below:

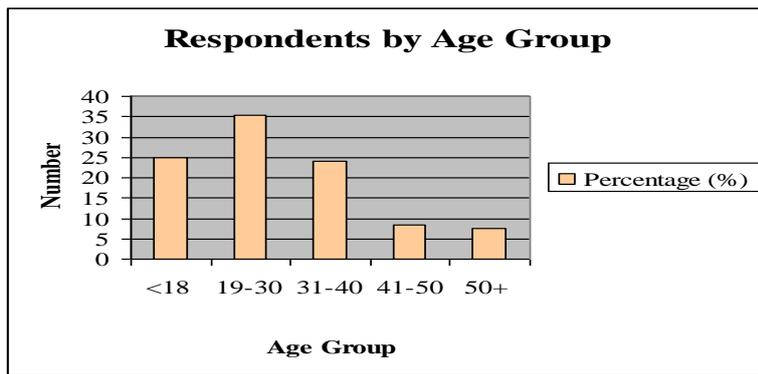
Figure 1: Respondents by Gender



4.1.2 Respondents by Age Group

Figure 2 below shows respondents by age group. Majority (35%) were in the 19-30 age groups. Respondents in the age groups <18; 31-40; 41-50 and 50+ had 25%; 24%; 8.3% and 7.4% respectively.

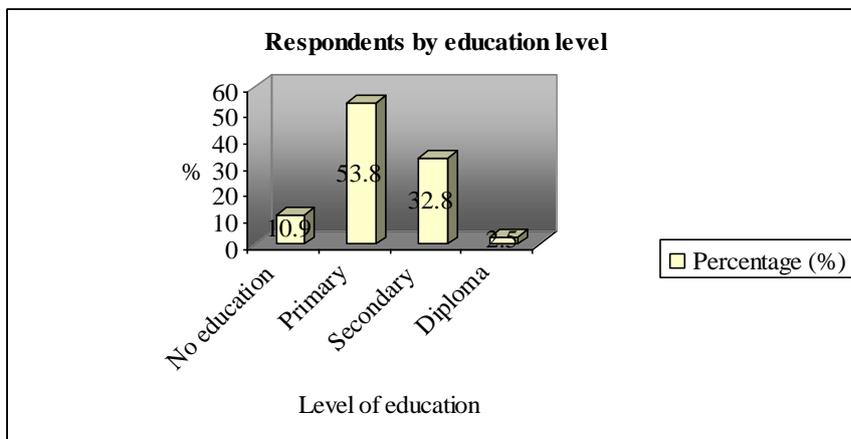
Figure 2: Respondents by Age-group



4.1.3 Respondents by Education Level

Figure 3 below shows respondents by level of education. Most of the respondents had ever attained primary school level education with 53.8%. Only 32.8% had ever attained secondary level education, while 2.5% had diploma level education and 10.9% had never had any formal education.

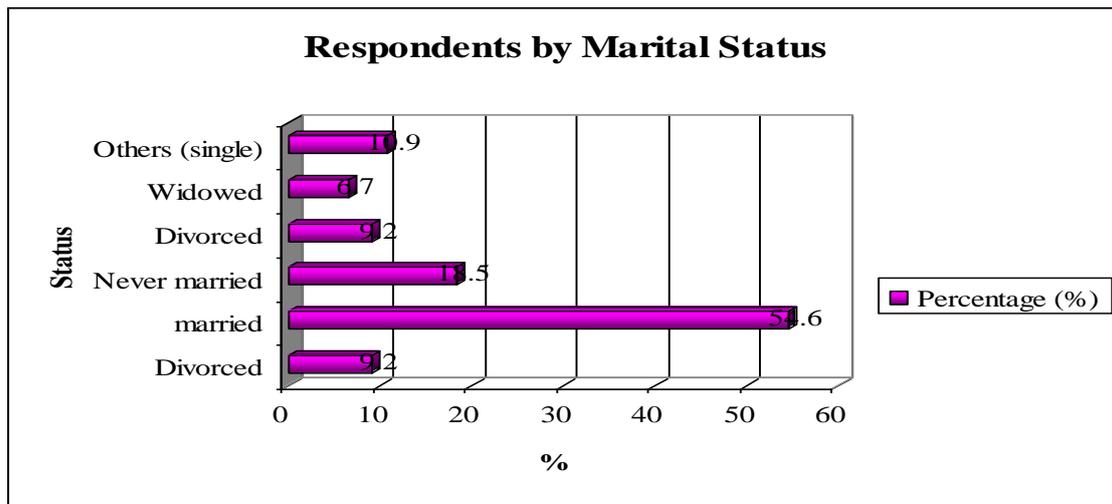
Figure 3: Respondents by Education level



4.1.4 Respondents by Marital Status.

Figure 4 shows respondents by their marital status. Majority (54.6%) were married; 18.5% had never married; 9.2% had divorced; 6.7% had widowed and 10.9% were still single or were unmarried.

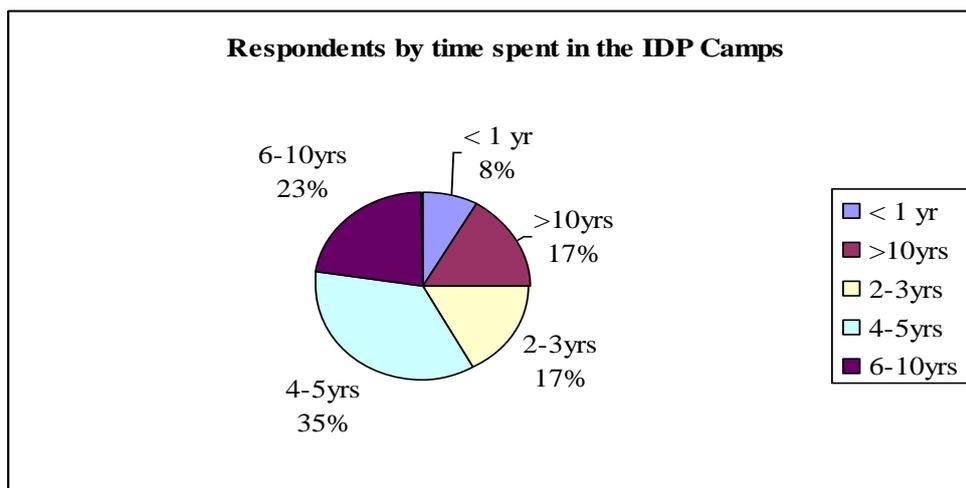
Figure 4: Respondents by Marital Status



4.1.5 Respondents by Time Spent in the IDP Camps

Among the respondents surveyed, majority (35%) had spent 4-5 years in the IDP camps. Respondents who spent over 10 years in the IDP camps were 17%, while those who had spent 6-10 years were 23%. Those who had spent between 2-3 years and less than 1 year were 17% and 8% respectively. Figure 5 below gives a summary of the time spent in the IDP camps.

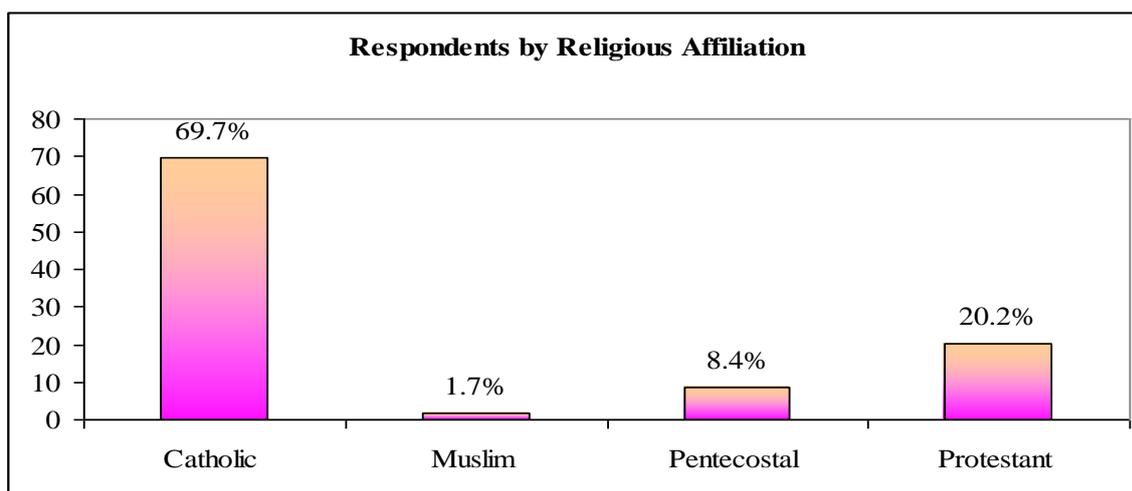
Figure 5: Respondents by Time Spent in the IDP Camps



4.1.6 Respondents by Religious Affiliations

As indicated in figure 6 below, majority (69.7% of the survey respondents were affiliated to the Catholic faith. Those who were affiliated to Protestant faith; Pentecostalism and Islam (Muslim) were 20.2%; 8.2% and 1.7% respectively.

Figure 6: Respondents by Religious Affiliations



4.1.7 Knowledge of Modes of Transmission of HIV

To gauge the HIV transmission knowledge levels, respondents were asked to mention the ways HIV is transmitted. Table 3.1 below, gives a summary of the responses. Un-protected sexual intercourse was mentioned by 97.5%. This was followed by sharing of sharp instruments (needles) mentioned by 57%. Unsafe blood transfusion; mother to child; mother to baby during breastfeeding were mentioned by 38.8%; 30.6% and 21.5% respectively.

Table 3.2 Responses on the modes of HIV Transmission

Mode of HIV transmission	Frequency(n=121)	Percentage (%)
Un protected sexual intercourse	118	97.5
Mother to child	37	30.6
Mother to baby during breast feeding	26	21.5
Sharing dirty needles	69	57
Unsafe blood transfusion	47	38.8

4.1.8 Divers of HIV and AIDS Epidemic in IDP camps

From the FGDs, a number of factors were given as the drivers of the HIV and AIDS epidemic in the camps. In this case, it can be summarized as economic, behavioral, and social–cultural factors. The findings from the FGDs have been summarized in the below text box.

Socio-Economic

- *poverty (lack of income); Sharing of rooms with children, where children learn about sex early and when experimenting, get infected; Idleness in the camps where sex is the only recreational activity; Over consumption of alcohol; prostitution, night discos/night clubs, where young girls are paid to watch a film in exchange with sex ; pornographic videos; ignorance of PMTCT; mobility of men in search of income or food; sex for food; separation of spouses due to domestic conflicts;*

Socio-Cultural

- *Polygamy, which perpetuates unfaithfulness; widow inheritance, use of TBAs for treatment of ailments, forced marriages*

Behavioural

- *Deliberate attitudes to infect others maliciously, fear of disclosure; and rape by soldiers.*

4.1.9 M4.1.9 Manifestations of HIV and AIDS Stigma and Discrimination

Respondents were asked whether they knew someone suspected to be living with HIV and AIDS who has shared objects like eating utensils, clothes, and bed linens marked and separated from others. About 24% indicated knowledge of people with shared objects marked and/or separated from others. They were again asked whether they knew someone suspected to have HIV and AIDS who had been denied involvement in social events, religious services, or community events in the last 12 months. Majority (88.3%) indicated that they did not know, while 11.7% mentioned knowledge of such stigma happening in their community.

Respondents were further asked whether they knew someone suspected to have HIV and AIDS who had been insulted, blamed or finger pointed in the last 12 months. Majority (55%) mentioned “yes”. Another question on whether they knew someone, because of visible signs like skin rashes, long illness, or association with groups seen as “high risk” e.g. soldiers who had been gossiped and speculated about whether he/she had HIV in the last 12 months. About 59.2% mentioned that they knew. Table... below gives a summary of the responses.

Table 3.3 Responses on Knowledge of PLWHA Stigmatized and Discriminated

S/N	Question	Yes		No	
		Freq.	Percentage (%)	Freq.	Percentage (%)
1	Do you know someone suspected to be living with HIV and AIDS who has had shared objects like eating utensils, clothes, and bed linens marked and separated from others?	29	24.2	91	75.8
2	Do you know someone suspected to have HIV and AIDS who has been denied involvement in social events, religious services, or community events in the last 12 months?	14	11.7	106	88.3
3	Do you know someone suspected to have HIV and AIDS who has been insulted, blamed or finger pointed in the last 12 months?	66	55	54	45
4	Do you know someone, because of visible signs like skin rushes, long illness, or association with groups seen as “high risk” e.g. soldiers who has been gossiped and speculated about whether he/she has HIV in the last 12 months?	71	59.2	49	40.8

From the FGDs, a question was posed to respondents to describe how women suspected to have or living with HIV and AIDS are regarded in their community. The same question was again posed for the case of men suspected or living with HIV and AIDS. In the below text box is a summary of responses given.

4.1.10. Stigmatizing Attitudes

To get insight into the respondent's attitudes to PLWHA, a number of questions were asked. First, they were asked whether they would buy fresh vegetables from an HIV positive vendor/shopkeeper. Majority (96.7%) were willing compared to only 3.3% who were unwilling. Second, they were asked their opinion on whether a female teacher who has HIV but not sick, should be allowed to continue teaching. Again, majority (93.3%) opined that they ought to be allowed to teach as opposed to 6.7% who said they need not be allowed. Third, the same question as the second was posed for the case of a male teacher and the response was 95.8% opined that they ought to be allowed, while only 4.2% were opposed to it. Fourth, they were asked their opinion on whether people with HIV should be ashamed of themselves. Similarly, majority (83.5%) said PLWHA need not be ashamed of themselves, while 16.5 said they ought to. The fifth and final question in regard to attitudes of respondents to PLWHA was their opinion on whether HIV and AIDS is a punishment for bad behavior and therefore, people with HIV should blame themselves. The response was that 80.2% of the respondents said it was not, while 19.8% said it was. The table below gives a summary of the responses to the five questions above.

Table 3.4 Questions regarding Attitude towards PLWHA

S/N	Question	Yes		No	
		Freq.	Percentage (%)	Freq.	Percentage (%)
1	Would you buy fresh vegetables from an HIV positive vendor/shopkeeper?	116	96.7	4	3.3
2	If a female teacher has HIV but not sick, she should be allowed to continue teaching?	112	93.3	8	6.7
	If a male teacher has HIV but not sick, he should be allowed to continue teaching?	115	95.8	5	4.2
3	People with HIV should be ashamed of themselves?	20	16.5	101	83.5
4	HIV and AIDS is a punishment for bad behavior and therefore, people	24	19.8	97	80.2

S/N	Question	Yes		No	
		Freq.	Percentage (%)	Freq.	Percentage (%)
	with HIV should blame themselves?				

4.1.11 Coping Mechanisms of PLWHA against Stigma and Discrimination.

Asked to describe how PLWHA cope with HIV and AIDS related stigma and discrimination, seeking for counseling, and forming or joining HIV positive groups had the highest responses of 24.2% each. This was followed by prayer and involvement in church activities with 8.4%. The table 3.5 below gives the details of the responses.

Table 3.5 Coping with HIV and AIDS Stigma and Discrimination

Coping with stigma and discrimination	Frequency (n=95)	Percentage (%)
Prayer and involvement in church activities	8	8.4
Associate with good people like pastors	1	1.1
Seek for counseling	23	24.2
Form or join HIV+ groups	23	24.2
Form or join Village Saving Groups	1	1.1
Form drama groups	4	4.2
Going for video shows	3	3.2
Ignore what people say	19	20
Relocating to other places	1	1.1
Report stigma cases to local authority	1	1.1
Seek medical attention	1	1.1
Engage in income generating activities	5	5.3
Staying with family members	5	4.2
Staying alone	1	1.1

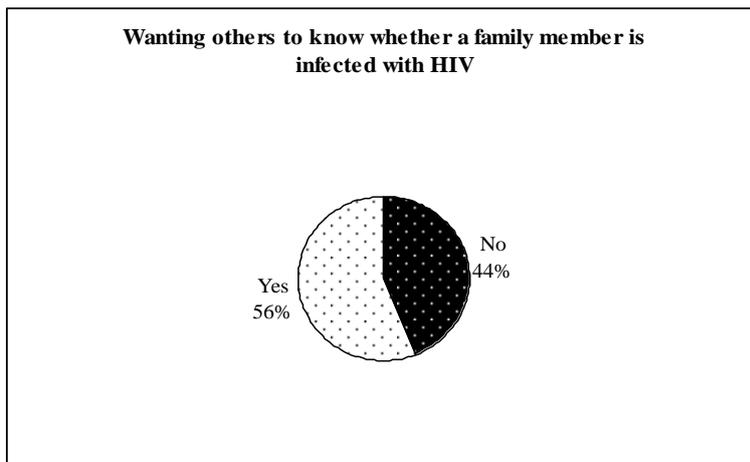
From the FGDs, other coping strategies not mentioned above include:

Making fun of it, marrying other HIV positive spouses who will mutually understand each other, opening up to those most likely to stigmatize and discriminate and challenging those who stigmatize to also test for HIV.

4.1.12 HIV and AIDS Disclosure Concerns

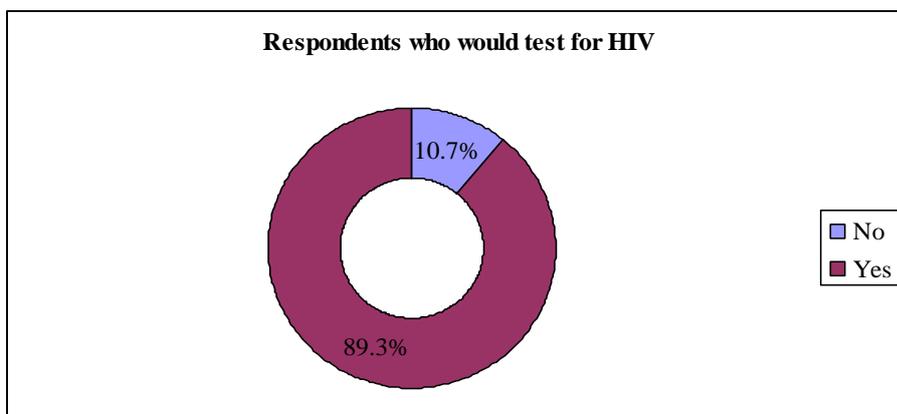
Respondents were asked whether they would want others to know if a family member became infected with HIV. A huge 44% expressed not wanting compared to 56% who did not have any reason for others knowing that their family member became infected with HIV. Figure 7 below, illustrates the responses given.

Figure 7: Respondents Expressions on whether they would want others to know if a Family Member was infected with HIV.



In addition to the above, respondents were asked whether they would test for HIV if opportunity was given. As indicated in figure 8 below, 10.7% expressed unwillingness, while the rest were willing.

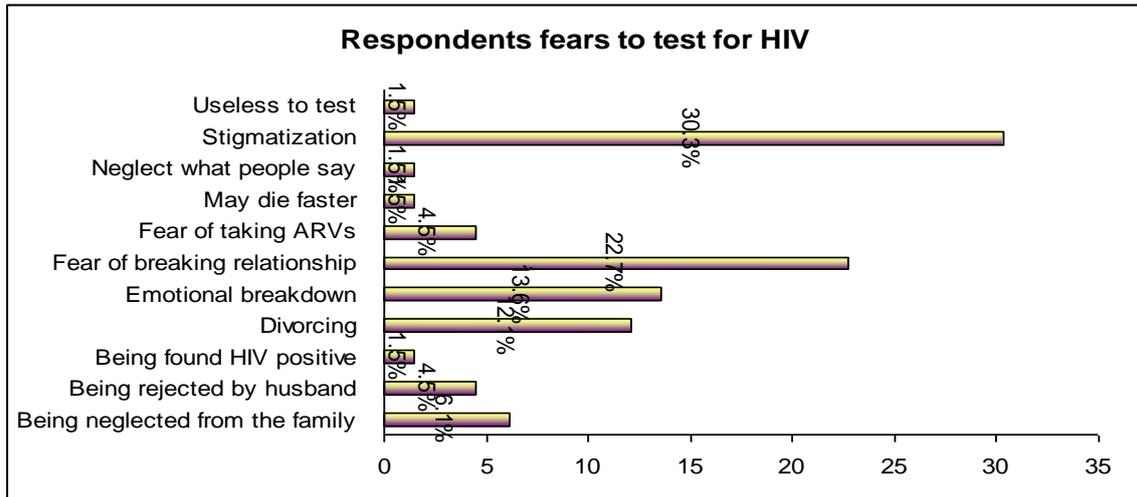
Figure 8: Respondents Expression of Willingness to take an HIV Test.



Furthermore, respondents were asked their fears for testing for HIV. Out of 66 responses given and as indicated in figure 9 below, stigma is the main fear with 33% of the responses

given. This was followed by the fear that it would break relationships with the spouses if the test results are positive. Other major fears included emotional breakdown after a positive HIV test (13.6%; divorce (12.1%) and being neglected with 6.1% responses.

Figure 9: Respondents Fears to Test for HIV



Again, respondents were asked whether they would disclose if they happened to test for HIV and the result was positive. Whereas the majority (75%) was willing, another 25% expressed unwillingness to do so. Those who observed that they would disclose their HIV positive test results were further asked to mention the first person they would disclose to. Out of 90 responses given, 18.9% reported mother. This was followed by both parents with 17.8% and husband with 16.6%. Table 3.6 below gives the details.

Table 3.6: Disclosure to others

First person respondents would disclose an HIV+ test result	Frequency(n=90)	Percentage (%)
Aunt	5	5.5
Brother	4	4.4
Children	6	6.6
Closest friend	5	5.5
Elder son	1	1.1
Family members	5	5.5
Father	2	2.2

First person respondents would disclose an HIV+ test result	Frequency(n=90)	Percentage (%)
Grand mother	1	1.1
Husband	15	16.6
Mother	17	18.9
Mother in law	2	2.2
Both parents	16	17.8
Sister	4	4.4
Uncle	1	1.1
Wife	6	6.6

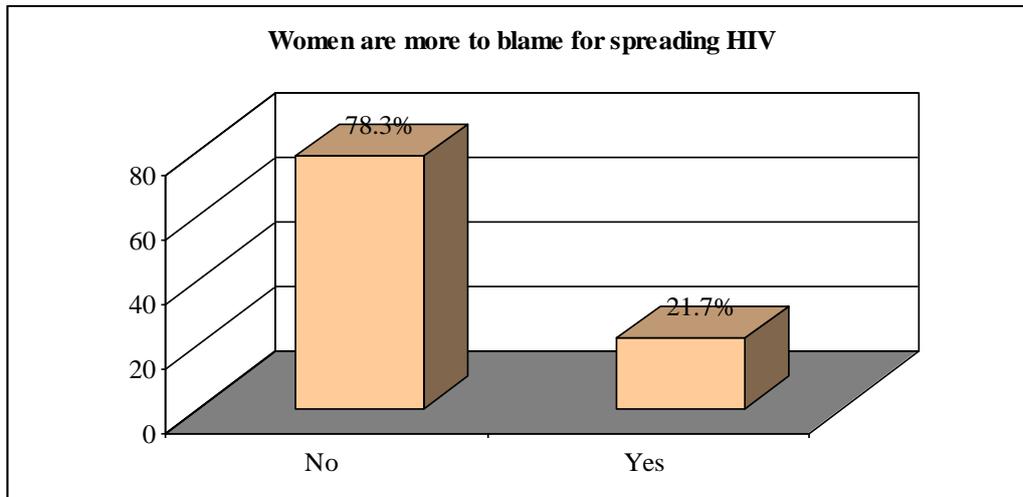
From the FGDs, respondents were asked to give their opinion on the statement that “if someone is ill or dies of AIDS, witchcraft is used as a scapegoat to abate or deflect HIV and AIDS related blame, shame, stigma and discrimination. Is this true for your community here?” The text box below gives a summary of the responses.

- *TB/Cough ;*
- *Common illness*
- *Spirits have killed due to failure to appease them*
- *As people do not go to health facilities for fear of stigma, they go to traditional healers who always advise that PLWHA have been bewitched.*
- *Malaria*
- *Liver problem*
- *Food poisoning*
- *A hump*

4.1.13 HIV & AIDS and Gender Considerations

To ascertain gender issues that relate to HIV and AIDS, respondents were asked to give their opinion on the statement whether women were more to blame in the spread of HIV in their community. As indicated in figure 10 below, majority (78.3%) did not agree with the statement while 21.7% agreed that they were indeed to blame.

Figure 10: Respondents opinions on whether women were more to blame for the spread of HIV in their community.



From the FGDs, respondents made the following observations as being the reasons for blaming women and girls for the spread of HIV in their community.

- *Not trustworthy;*
- *Not strong-hearted and thus easily deceived with petty things, which are got through sex; and*
- *Have more than one sexual partner*
- *Some women have a tendency to entice young boys into sex by, for instance buying eggs for them.*
- *Women are easily deceived because of money.*
- *Women have the responsibility of fending for children. Therefore, the need for money for the survival of their children forces them into risky sexual behaviours.*

To gain more in-depth data on gender issues as it relates to HIV and AIDS-related stigma and discrimination, respondents were further asked their opinions on whether women and girls who were HIV positive were more stigmatized and discriminated compared to HIV positive men and boys in their community. As indicated in table 3.7 below, 75% observed that it was true while the remaining 25% observed that it was not true.

Table 3.7: Women and girls who are HIV+ more stigmatized/discriminated compared to men and boys

Women and girls who are HIV+ more stigmatized/discriminated compared to men and boys	Frequency(n=120)	Percentage (%)
No	30	25
Yes	90	75

CHAPTER 5

DISCUSSION OF FINDINGS

5.1 Introduction

This chapter looks at discussions of the findings in the context of the research questions/objectives and the related literature.

5.2 Drivers of HIV and AIDS Epidemic in the IDP camps in Gulu District.

As observed in the introduction and the literature sections of this report, the key drivers of HIV and AIDS in Uganda, are behavioral, social–cultural, socio-behavioral, economic and geographic factors (UAC, 2008). The findings of this study confirm the assertion.

Poverty: HIV and AIDS are closely linked with poverty (Turmen, 2003), (World Bank, 1999). This study reveals that poverty (lack of income), is one driver of the HIV epidemic in the IDP camps. Poverty is associated with the failure of the households to meet their basic needs and therefore, women and girls, to cope with the situation use sex as a weapon to gain access to resources they need for basic survival of their families. The fact that the local population is confined in the camps and can hardly access their farmlands, where they could grow crops for livelihoods, they, therefore resort to transactional sex, which predispose to HIV infection. The quotation below from the FGDs confirms this. “Some of the mothers here send their young girls to other men to get money”. Soldiers, NGO workers and businessmen take advantage of the vulnerability of these IDP women and girls.

As pointed out from the data presented, poverty seems to be main driving factor of HIV and AIDS epidemic. It is responsible for forcing people to migrate in search of employment; the sharing of rooms with children, where children learn about sex early and when experimenting, get infected with HIV; domestic conflicts leading separation of spouses; idleness leading to watching of pornographic videos etc.

Stigma and Discrimination: HIV and AID related stigma and discrimination was reported as another driver of the HIV and AIDS epidemic in the IDP camps. This is in line with what is pointed out in the literature review section, if people are frightened of the possibility of discrimination, they may conceal their status, and are more likely to pass on the infection to others and are not likely to seek treatment and counseling.

Over consumption of alcohol: This study findings show that heavy consumption of alcohol is another silent driver of the HIV and AIDS epidemic among the internally displaced populations. This is in line with the MoH (2007) report which ascertained that alcohol drinking, for majority of men in the IDP camps was a way of passing time given that there is little for them to do in the camps. Over consumption of alcohol negates people's sense of judgments, which exposes to risky sexual activity.

Socio-Cultural Factors: Some socio-cultural factors can be havens of high risk behavior of HIV infection (World Bank 1999). Widow inheritance- "taking care of brothers' wife", polygamy, dependence on traditional healers for treatment of ailments and other related cultural factors were found by this study as vehicles for HIV in the IDP camps. Polygamy, compounded by other factors like poverty, for instance creates a conducive atmosphere of unfaithfulness, which has a bearing in the spread of HIV.

Lack of Comprehensive Knowledge: As pointed out in section 5.3.3, below, there seems to be lack of comprehensive knowledge about HIV and AIDS among the IDP populations. This is consistent with Tu'rmen (2003) who observes that, in a certain study conducted in Cameroon, 90% of young women aged 15–24 had heard about AIDS but only 16% of them had sufficient knowledge to protect themselves. This is particularly true for PMTCT. Communities here have little or inadequate knowledge on some of the known HIV preventive methods, which drives the epidemic underground.

5.3 HIV and AIDS-related Stigma and Discrimination in the IDP camps

5.3.1 Forms of Stigma and Discrimination

One of the sub-problems this study intended to investigate was whether HIV and AIDS stigma and discrimination actually existed in the IDP camps in Gulu district. From the study, it is evident three out of the four forms of stigma identified in the literature review section are manifest in the IDP camps. Physical stigma, where shared objects like eating utensils, clothes, and bed linens, are marked and separated from others are common occurrences and was mentioned by majority of the respondents. As it was revealed in the study, 24% respondents indicated knowledge of people experiencing physical stigma.

From the study, there is evidence of manifestation of social stigma, which takes the form of exclusion of persons suspected to be living with HIV and AIDS from community events such

as weddings, or outright orders to stay away from religious services. This was observed by 11.7% of the respondents. Verbal stigma where persons suspected to be living with HIV and AIDS are directly finger-pointed, insulted, blamed, or gossiped whether a person has HIV, usually because of visible signs, illness, behavior, or association with groups seen as “high risk” was also manifest in the IDP camps.

The fourth form of stigma, which is institutional stigma, which refers to differential treatment within any broadly defined institutional setting that leads to a negative outcome for the person living with HIV, was out of the scope of this study. It is, however, probable that it may be prevalent in the camps too as all the different forms seem to “move together”, i.e. where one is manifest; others are also present, except the levels may differ.

5.3.2 Gender Dimensions of HIV and AIDS Stigma and Discrimination

Compared to men and boys, women and girls are more blamed for spreading HIV and AIDS. As revealed in the study findings, 21.7% respondents agreed that women and girls were indeed to blame for the spread of HIV in the family. This was equally true from the FGDs. This findings tally well with the literature review that women in Sub-Saharan Africa are expected to uphold the moral traditions of their societies of being faithful, chaste, and morally upstanding and, therefore, contracting HIV is regarded as evidence that they have failed to fulfill this important social function and where men are generally expected to be reckless, adventuresome and more likely exposed to a whole host of sexually transmitted infections (STIs) (including HIV) (ICRW, 2006).

What ought to be noted, however, is that women in the IDP camps are culturally expected to fend for their children. The idleness in the camps coupled with poverty seems to be the reason behind some women engaging in HIV risky sexual behaviors.

Again, right from the literature review section to the findings section, it is crystal clear that women and girls generally bear the strongest brunt of HIV and AIDS-related stigma and discrimination. From the study findings, those living with HIV and AIDS were more stigmatized and discriminated compared to men and boys as reported by 75% of the respondents. This compares well with a study conducted in Tanzania in 2004-5, where nearly two-thirds of women with HIV reported experiencing stigma in the past year, as opposed to slightly less than half of men (ICRW, 2006).

5.3.3 Factors Contributing to HIV and AIDS-related Stigma and Discrimination in the IDP camps

The fact that 97.5% of the respondents mentioned sexual intercourse as a major mode of HIV transmission which is consistent with UDHS report (2006), quoted in UAC (2008), which observes that 98.7% of persons living in Internally Displaced People's (IDP) camps aged 15-49 years were reported to have heard about HIV & AIDS, it is likely that majority of these people lack HIV and AIDS comprehensive knowledge, which is at the root cause of HIV and AIDS-related stigma and discrimination. HIV and AIDS comprehensive knowledge which is described as (a) those who know that the risk of getting AIDS virus can be reduced by using condoms at every sexual contact or by having only one sexual partner who neither does not have HIV nor any other partner, (b) who know that HIV cannot be transmitted through mosquito bites or sharing food with an infected person and (c) who know that a healthy looking person could have HIV (UAC, 2008).

The lack of comprehensive knowledge is compounded by what Chiu (2008) observes as the multiplicity in message that has added to public confusion about the disease and exacerbated existing stigma.

Secondly, Morality judgment toward PLWHA as observed in the literature review section; seem to be a vehicle of stigma and discrimination among the internally displaced populations in Gulu. From this study, 19.8% responses were given by respondents on their opinion on whether HIV and AIDS is a punishment for bad behavior and therefore, people with HIV should blame themselves. This was reinforced by the findings from the FGDs that "at some points, PLWHA need to be blamed for the love for material things". It is also important to observe that morality judgment is not as widespread but there are pockets of this within the camps.

Thirdly, myths surrounding HIV and AIDS treatment seem to drive HIV and AIDS underground in the camp populations. There are local beliefs that ARVs have the potential to damage internal body organs and may lead to mental illness (madness).

5.3.4 Barriers to HIV Testing and Disclosure

HIV Testing: HIV and AIDS stigma and discrimination seem to be the greatest barrier to HIV testing and disclosure. From the study 10.7% expressed unwillingness to take an HIV test if they were given opportunity citing stigma and discrimination related reasons. This is in line with other studies done elsewhere in Sub-Saharan Africa, for instance, among antenatal clients in Nigeria, only 89% were willing to be tested while those who were unwilling cited stigma and discrimination (Adeneye et al., 2006) cited in ICRW (2009).

Other fears to HIV testing as found by the study included the fear that it would break relationships with the spouses if the test results are positive, fear of emotional breakdown after a positive HIV, divorce and being neglected by family members and friends. All these fears are hinged on stigma and discrimination.

Disclosure of a Positive HIV Test: Some people find it difficult to disclose a positive HIV test because of the stigma that might follow. They cannot stand to lose the respect of their community and family and friends and so live in silence (Policy Project, 2005). From this study, 25% respondents expressed unwillingness to disclose an HIV test. Again, 44% expressed not wanting to disclose if a family member became infected with HIV. This serves to reinforce the above statement of people not ready to stand to lose community respect and could be one reason why people would associate an AIDS related death to other causes in order to abate the stigma that goes with HIV and AIDS. As was found out from the FGDs, people at the IDP camps on many instances associate AIDS-related deaths to witchcraft, refusal to appease spirits, malaria, liver problems and food poisoning.

If disclosure was to happen, majority of the IDP populations would prefer in confiding to mothers and both parents (mother and father). This is in line with the ICRW (2002) report that women studied, first turned to their female relatives, particularly their mothers for emotional support and practical advice and help when they were tested HIV positive. This could be due to the fact that these categories of people will show love and support for PLWHA and keep confidentiality compared to others.

5.3.5 How PLWHA cope with HIV and AIDS stigma and discrimination

From both the FGDs and individual household respondents interviewed, IDPs who are suspected or living with HIV and AIDS cope with stigma and discrimination by adopting a number of mechanisms:

Joining HIV and AIDS Support Groups: HIV and AIDS support groups have been found to be effective in helping combat HIV disclosure challenges as well in dealing with HIV and AIDS stigma and discrimination. In a support group people with the same problem find ways to cope with and defeat the problem (TAC, undated). They help one another to come to terms with an HIV diagnosis and share their experiences of disclosure (ICRW, 2002). This is based on the concept that peer support is an effective model for education and social empowerment. Majority of the PLWHA in the IDP camps as revealed in the study form or join already existing HIV and AIDS support groups to help them cope with stigma and discrimination and ensuring their rights are respected.

Counseling: Counseling on how to live with HIV and explanations that having it is not the end of life is imperative in coping with stigma and discrimination. This was one of the strategies PLWHA in the IDP camps cope with stigma and discrimination the study revealed. In a study carried out in Tanzania, there seemed to be less stigma associated with HIV in communities that had good counseling services (ICRW, 2002). Seeking counseling services to cope with HIV and AIDS-related stigma and discrimination, therefore, is a good step in the right direction.

Prayer and involvement in church activities: From the FGDs and individual respondents interviewed, another stigma and discrimination coping strategy for PLWHA is engaging in prayer and/or involving in church activities. Christianity, which, close to 99% respondents practiced, seem to have taken root in the IDP camps and therefore has a lot of influence, including providing comfort to those experiencing psychological distress like HIV and AIDS-related stigma and discrimination.

Ignoring talk related to HIV and AIDS-related stigmatization and discrimination: Ignoring what people talk in regard to one's HIV status was reported as another coping strategy against stigmatization and discrimination. This may be in light of the fact that there

have been a number of sensitizations of PLWHA and most of these people have been armed with many of the strategies, of which this might be one of them.

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This chapter looks at conclusions drawn and the recommendations the researcher thinks can be adopted as far as HIV and AID-related stigma and discrimination is concerned. The conclusions and recommendations made here are not a complete list but priority ones that the researcher deems important and urgent.

6.2 Conclusions

The following conclusions can be drawn from this study:

- The study illustrates that HIV and AIDS-related stigma and discrimination in the IDPs is real. Physical stigma is the most predominant, where shared objects like eating utensils, clothes, and bed linens, are marked and separated for PLWHA and is mainly caused by lack of comprehensive HIV and AIDS knowledge.
- Poverty related issues seem to be the drivers of the high prevalence rates of the HIV epidemic in IDP camps. HIV and AIDS stigma and discrimination have a great share of their contribution too.
- In terms of gender, women and girls bear the greatest burden of HIV and AIDS-related stigma and discrimination. Apart from being blamed for spreading HIV in their families, they bear the brunt of HIV and AIDS stigma and discrimination.
- HIV and AIDS-related stigma and discrimination is, again, the major barrier to HIV testing and disclosure among the internally displaced communities in Gulu. If exposure was to be achieved parents, especially mothers are more trusted and confided on by majority of the IDP community.
- PLWHA cope with HIV and AIDS stigma and discrimination in a number of ways. Key among them is by joining HIV and AIDS support groups, seeking counselling services from professional counsellors and ignoring negative, stigmatizing and discriminating talks about them

6.3 Recommendations

As a result of what the study has revealed it is recommended that:

- Stakeholders working with IDPs like OPM, CSOs and other institutions, need to increase

HIV and AIDS comprehensive knowledge of the IDP communities. Specifically address issues of HIV and AIDS knowledge gaps, which are the underlying causes of HIV and AIDS-related stigma and discrimination.

- With the relative peace and the mass exodus to original villages by the IDPs, Government will need to take an affirmative action in targeting the vulnerable women headed households affected by HIV and AIDS to benefit from government and donor supported project interventions. The Peace, Recovery and Development Programme (PRDP), Northern Uganda Social Action Fund (NUSAF 2) projects need to be targeted to such households so as to revive their economic and livelihood bases.
- Parents, especially the mothers need to be equipped with HIV and AIDS related knowledge as they are more trusted for disclosure of HIV positive tests. Organizations involved in HIV testing and counselling (HCT) may need to consider integration of this into their programmes since they offer the first layer of absorbing shocks related to HIV tests.
- Any Government, donor or CSOs HIV and AIDS programme need to integrate gender into it, especially considering how culturally, economically and socially women and girls are disadvantaged and susceptible to HIV infection among IDPs.
- HIV and AIDS service organizations and Government may need to build the capacity of HIV and AIDS support groups as they offer greater leverage in dealing with stigma and discrimination issues.
- Anti-HIV and AIDS groups or Activists with support from government should carry out rights education of PLWHA. Popular versions and or translations of legislations related to rights of PLWHA could be developed to facilitate community education programmes. This may go a long way in structurally changing the context in which both individuals and communities operate as they respond to HIV and AIDS.

6.4 Areas for Further Study

Based on the findings of this study, the following research areas are recommended:

- The study identified parents, especially mothers being key people in relation to HIV testing and disclosure issues. There is need for an in-depth research to better understand the role of parents in providing social and psychological care and support.
- This study did not explore the knowledge levels of PLWHA in the IDP camps on their human rights as enshrined in different legislations both at local and international level. There is, therefore, need for a more comprehensive study to ascertain the knowledge level. This is

based on the fact that, rights knowledge level is directly proportional to one's ability to claim for the observance of such rights.

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Appendix 1: Questionnaire for Key Informants

Confidentiality:

Dear Respondent,

This questionnaire seeks to collect information on how HIV and AIDS related stigma and discrimination contribute to the rapid spread of HIV in internally displaced peoples (IDP) camps in Gulu District, Uganda. You have been selected to participate in this study because I believe you will provide the information I need. The information you provide will be used for purely academic purposes and will be treated with utmost confidentiality.

Thank you for your time and cooperation

SECTION I: GENERAL INFORMATION

Name of Village:

Name of Parish:

Name of Sub-County:

Please tick the appropriate response for the questions below:

Demographic Characteristics

1. **Gender:** **Male** **Female**

2. **Age:**

Code	1	2	3	4	5
Age	Below 18	19-30	31-40	41-50	50+

3.

Education:

Code	1	2	3	4	5	6
Level	No	Primary	Secondary	Diploma	Bachelors	Postgraduate

	Education				degree	
Tick						

4. Marital Status

Code	1	2	3	4	5
Status	Married	Never married	Divorced	Widowed	Other (Specify)
Tick					

5. How

long have you been in this IDP camp?

Less than 1 year (1)	2 – 3 yrs (2)	4 – 5 yrs (3)	6 – 10 yrs (4)	Above 10 yrs (5)

6. Religion

Code	1	2	3	4	5	6
Religion	Catholic	Protestant	Pentecostal	Muslim	Traditionalist	No Religion
Tick						

Please indicate by ticking in the appropriate box to the extent to which you agree with the statement below:

SECTION II: KNOWLEDGE OF MODES OF TRANSMISSION OF HIV

Please tell me the ways HIV is transmitted

S/N	Means of transmission	Tick as the respondent mentions
A	Unprotected sexual intercourse	
B	Mother to child	
C	Mother to baby during breast feeding.	
D	Sharing dirty needle	
E	Unsafe blood transfusion	
F	Do not know	

SECTION III: FORMS OF STIGMA AND DISCRIMINATION:

		Yes	No
	FORMS OF STIGMA AND DISCRIMINATION MANIFESTED		
1	Do you know someone suspected to be living with HIV and AIDS who has had shared objects like eating utensils, clothes, and bed linens marked and separated from others?		
2	Do you know someone suspected to have HIV and AIDS who has been denied involvement in social events, religious services, or community events in the last 12 months?		
3	Do you know someone suspected to have HIV and AIDS who has been insulted, blamed or finger pointed in the last 12 months?		
4	Do you know someone, because of visible signs like skin rashes, long illness, or association with groups seen as “high risk” e.g. soldiers who has been gossiped and speculated about whether he/she has HIV in the last 12 months?		

		Yes	No
	STIGMATIZING ATTITUDES		
1	Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person had HIV?		
2	If a female teacher has HIV but is not sick, she should be allowed to continue teaching in school		
3	If a male teacher has HIV but is not sick, he should be allowed to continue teaching in school		
4	People with HIV should be ashamed of themselves?		
5	HIV and AIDS is a punishment for bad behavior and, therefore, people with HIV should blame themselves?		
6	How do PLWHA cope when stigmatized and discriminated.		

		<i>Yes</i>	<i>No</i>
	<i>DISCLOSURE CONCERNS</i>		
1	Would you want others to know if a family member became infected with HIV		
2	If given opportunity, would you test for HIV now?		
3	What would be your fears to test for HIV?		
4	If you tested for HIV and the result is positive, would you disclose your status?		
5	If the response to 4 above is yes, who would be the first person for you to disclose to?		

		<i>Yes</i>	<i>No</i>
	<i>GENDER AND HIV & AIDS</i>		
1	Women are more to blame in the spread of HIV in this community?		
2	Women and girls who are HIV+ are more stigmatized and discriminated compared to HIV+ men and boys in this community?		

Appendix 2: Focus Group Discussion Guide

Possible warming up question: What is the first thing that comes to your mind when thinking about HIV and AIDS?

1. What do you think are the major drivers of the HIV epidemic in this community? What cultural or religious factors do you think are responsible for the spread of HIV in this community?
1. Describe how women suspected to have or living with HIV and AIDS are regarded in this community.
2. Describe how men suspected to have or living with HIV and AIDS are regarded in this community.
3. Women are more blamed for bringing HIV into the household. What are your opinions in regard to this statement?
4. One of the HIV prevention methods is exclusive breastfeeding for Mother-to-child-transmission (MTCT). What are some of the reasons this method is not being used by mothers who may be HIV+?
5. If someone is ill or dies of AIDS, witchcraft is used as a scapegoat to abate or deflect HIV and AIDS related blame, shame, stigma and discrimination. Is this true for your community here?
6. What is your opinion that PLWHA need blame themselves for being careless and promiscuous?
7. PLWHA should have rights to employment, run political positions and be treated like any other human being. What are your opinions about this?
8. HIV and AIDS have treatment that prolongs life. What are the main reasons people would not go for the treatment?
9. How do people suspected to have HIV and those with AIDS cope with stigma and discrimination in this community?
10. What would you recommend for improving the lives of peoples PLWHA?
11. Are there any other issues regarding the topic of HIV & AIDS related stigma and discrimination that you feel need to be discussed?

Appendix 3: Letter of Invitation

A STUDY ON HOW HIV AND AIDS RELATED STIGMA AND DISCRIMINATION CONTRIBUTE TO THE SPREAD OF HIV AMONG INTERNALLY DISPLACED POPULATIONS IN GULU DISTRICT, UGANDA

You are invited to participate in a study on how HIV and AIDS related stigma and discrimination contribute to the spread of HIV in this community. This study is being done by Sam Edison Anguria as part of his Masters Degree studies (MPhil. HIV/AIDS Management) in Africa Centre for HIV/AIDS Management at Stellenbosch University, South Africa. The study will involve a face-to-face interview that will last about 1- hour in length. The interview may be audio tape recorded and will be done in the setting most comfortable for you. The research interview includes questions about factors that are responsible for the spread of HIV; your experiences and opinions on who is blamed for bringing HIV into the household; how people suspected or living with HIV and AIDS are treated and how they cope with it; and what you recommend in improving the lives of people living with HIV and AIDS.

There will be no reimbursement for participation. However, you may enjoy the experience of talking to someone about some important issues in your life. Also, the information you provide may help in the development of appropriate interventions against HIV and AIDS, which will help all humanity.

ALL INFORMATION WILL BE KEPT CONFIDENTIAL

If you would like to participate in the study or for more information about the study, please contact the researcher Mr Anguria Edison Sam at 0782477304 or by email at anguriasam@yahoo.com

Appendix 4: Informed Consent Form

Purpose of the Study: You are invited to participate in a study on how HIV and AIDS related stigma and discrimination contribute to the spread of HIV in this community. This study is being done by Sam Edison Anguria as part of his Masters Degree studies. The research interview includes questions about factors that are responsible for the spread of HIV; your experiences and opinions on who is blamed for bringing HIV into the household; how people suspected or living with HIV and AIDS are treated and how they cope with it; and what you recommend in improving the lives of people living with HIV and AIDS. The interviewer may use an audio tape recorder during the interview.

Benefits: You will derive no personal benefit from the Study. Your participation, however, may help in the development of appropriate interventions against HIV and AIDS. You may request a copy of the study report.

Alternative Therapy: This is not a therapeutic study. You have the alternative not to participate.

Risks, Inconveniences, and Discomforts: It is possible that some of the questions may make you uncomfortable or ask you about experiences that may be unpleasant to recall. Additional risks associated with your participation in this study are: having confidential information collected, being asked personal questions, being taped using an audio device, and being inconvenienced by the time spent in the interview (a total of about one hour).

Cost of Participation: The only cost to you for participating in the research is the time that you will spend during the interview.

Research Related Injury: In the event of physical and/or mental injury resulting from your participation in this research project, the researcher will not provide compensation. If injury occurs, you may be referred to nearby Government of Uganda health facilities that provide free medical treatment.

Confidentiality of Records: The researchers will treat your identity with professional standards of confidentiality. The information obtained in this study may be published, but

your identity will not be revealed. No identifying information will be used to connect personal information about you to the audio tape recording. No identifying information will be used to identify you in the data analysis or the final report of study findings. Access to research data is limited only to the researcher.

Withdrawal: Participation in this study is voluntary. You are free to withdraw your consent and discontinue participation at any time. You may ask that the interview be stopped and that the audio recording be destroyed. You may also request after the interview that the information gathered in your interview be destroyed. If you, however, decide to withdraw from this study, you should contact Mr Anguria Edison Sam at 078247730. You will not be penalized in any way if you decided to discontinue your participation in this research.

Authorization for Participation: I understand that as a participant in this research study:

- My participation is voluntary. I am not required to participate; I can choose to quit at any time.
- The confidential research interview will be recorded using an audio recording device.
- My identity will not be revealed in any publication or document resulting from this study or to anyone other than the researcher.

I have read or had read to me the above, and I have decided that I will participate in the research interview. Its general purposes, the particulars of involvement and possible risks and benefits have been explained to my satisfaction. My signature also indicates that I have received a copy of this consent form.

Research Participant's Name (Print):

Research Participant's Signature:

Date:

Witness Name (Print):

Witness Signature:

If you have further questions about the research interview you may contact the researcher, Mr Anguria Edison Sam at 0782477304.

