# STIGMA AND DISCRIMINATION OF PEOPLE LIVING WITH HIV/AIDS IN BUNYARUGURU COUNTY, BUSHENYI DISTRICT, UGANDA

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# RESEARCH REPORT SUBMITTED IN TO THE INSTITUTE OF OPEN AND DISTANCE LEARNING FOR PARTIAL FULFILLMENT FOR THE AWARD IN BACHELOR OF GUIDANCE AND COUNSELING OF KAMPALA INTERNATIONAL UNIVERSITY

**JULY 2010** 

#### **DECLARATION**

I, TUMUSIIME PAUL declare that this project is my original work and has never been presented to any other university for award of any academic certificate or anything similar to such. I solemnly bear and stand to correct any inconsistency.

Signature

**TUMUSIIME PAUL** 

BCG/0026/61/DU

DATE: 16-08-2010

#### APPROVAL

This is to acknowledge that this Report has been under my supervision as a university supervisor and is now ready for submission.

**Signatures** 

Date

16/8/10

MR. LAAKI SAMSON

#### **DEDICATION**

This work is affectionately dedicated to my beloved wife and my children for their support patience and understanding during this period of study not forgetting all those who constantly wished me success.

#### **AKNOWLEDGEMENT**

I also owe a lot of appreciation to all those who assisted me in carrying out this research. I am grateful to my supervisor Mr. Lakii who tirelessly went through my work and inspired me to dig deeper into the core of the matter. His kind criticism, patience and understanding, assisted me a great deal.

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#### **ABSTRACT**

The purpose of this research study was to The overall objective of this study was to examine whether people living with HIV/AIDS in Bunyaruguru county Bushenyi District are subject to discrimination and if so, what influence does it have on their possibilities to enjoy their human right to health. The objectives of the study were determine if the HIV/AIDS-positive people in Tororo District are discriminated in their closest social context, determine the ways in which HIV/AIDS-positive people in Tororo District are subject to discrimination; to determine how discrimination affect their possibilities to maintain a good health. The methods used for data collection were questionnaires to the HIV positive people. The findings indicate that many cases of discrimination have occurred in the health sector. However, despite this, many interviewees still had faith in the public health care system. They believed that the services in the Infectious Diseases Hospital (IDH) and Ward 33 of the General Hospital were good, and that they were treated well. A few agreed that free health care provided by Government hospitals gave people who could not afford private health care access to treatment they would otherwise be denied. However, there was much consensus that awareness among health staff, in public and private hospitals, must be addressed. They brought up several instances where health staff including doctors, nurses, attendants and minor staff had discriminated against people living with HIV/AIDS and their families. The study recommended that MOH needs to deliver a strong message to all health care workers that people living with HIV/AIDS and their families are to be treated with respect and professionalism. This message should be backed up with training programmes for health care staff, new recruits and health administrators, at the national and regional levels

## **CHAPTER ONE**

#### INTRODUCTION

#### 1.1 Background of the study

Recent estimates indicate that 42 million people were living with HIV/AIDS (Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome) by the end of 2002. The total of AIDS deaths in 2002 was 3.1 million. No country or region is immune or shielded from the pandemic, though the prevalence rates vary (Joint United Nations

Programme on HIV/AIDS [UNAIDS], 2002a).

Sub Saharan Africa (SSA) is the worst affected region, where 29.4 million people are living with HIV/AIDS (UNAIDS, 2002g). 10 million out of these are young people between the ages of 15-24, while 3 million are children under the age of 15 (UNAIDS, 2002a). Overall about twice as many young women as men, aged 15-24, are infected in some SSA countries (UNAIDS, 2002b). Teenage girls are 5 times more likely to be infected than boys, as girls often become infected by older men (United Nations Development Fund for Women [UNIFEM], 2003).

Approximately 3.5 million people in SSA became infected with HIV in 2002. In some countries the prevalence amongst the adult population, aged 15-49, has risen higher than expected, exceeding 30% of the population (UNAIDS, 2002a). The number of HIV/AIDS deaths in SSA during 2002, is estimated to 2.4 million (UNAIDS, 2002g). Due to insufficient HIV prevention, treatment, care and support, death stalks the continent and the numbers of deaths are believed to continue rising (UNAIDS, 2002b). Patel et al. (2002) put it quite eloquently: "The human costs are, like the distances between stars, impossible for a human being to properly appreciate."

Perhaps one of the most complex psychological and sociological HIV/AIDS-related phenomena is that of stigmatization. In many countries there are well-

documented cases of PLWHA being stigmatized due to their HIV-status (Muyinda et al., 2003).

People can live with HIV/AIDS for many years, but stigma reduces the life-quality of PLWHA (France, 2001). Stigma can prevent people from attending testing, acknowledging and disclosing their HIV-status, suggesting safe sex, and seeking treatment, care and support (Muyinda et al., 2002c). It's upon this background that this study will investigate the status of stigmatization and discrimination of people living with HIV/AIDS in Bushenyi District.

#### 1.2 Statement of the problem

Research in the last decade has increased the understanding of many psychological and social aspects of HIV/AIDS (King, 2002). However, most of the international HIV/AIDS research resources have been put into sophisticated medical research. Such research is important but has seemingly excluded attempts to confront the many non medical impacts of HIV/AIDS (Barnett & Blaikie, 1992). Parker and Aggleton (2003) point to how social science research and campaigns mainly have focused on prevention and information, and less on care and support for PLWHA. Documented attempts of challenging HIV/AIDS-related stigma remain relatively rare. Research is urgently needed to identify and exemplify the most effective ways of dealing with this stigma across a range of contexts hence the need for this study.

#### 1.3 Purpose of the study

The overall purpose of this study is to examine whether people living with HIV/AIDS in Bunyaruguru County Bushenyi District are subject to stigma and discrimination.

1.4. Objectives of the study

- 1. Assess if the HIV/AIDS-positive people in Bushenyi District are discriminated in their closest social context
- 2. Determine the ways in which HIV/AIDS-positive people in Bushenyi District are subject to discrimination.
- 3. Find out how discrimination affect their possibilities to maintain a good health

#### 1.5 Research Questions

- Are HIV/AIDS-positive people in Bushenyi District discriminated in their closest social context?
- 2. In what way are HIV/AIDS-positive people in Bushenyi District subject to discrimination?
- 3. How does discrimination affect their possibilities to maintain a good health?

## 1.6 Scope of the study

The study investigated the status of stigma and discrimination in people living with HIV/AIDS in Bunyaruguru County Bushenyi District. Bushenyi District is a district in South Western Uganda. Like other Ugandan districts, it is named after its 'chief town', Bushenyi. The district headquarters are located in the town of Bushenyi. The study was carried out for a period of four months from May to September 2010.

#### 1.7 Significance of the study

This study will be of great importance both at the macro and micro level;

At the macro level, informed decisions in policy formulations and in the building of the institutions aimed at HIV/AIDS counseling as a management tool for the fight against stigma and discrimination.

At the micro level, the local community leaders and a number of NGOs responsible for the fight against stigma and discrimination may adopt the recommendations put forth, and use the findings to address issues in the report.

The research will help researchers and academicians to increase on the available literature for further studies

#### **CHAPTER TWO**

#### **REVIEW OF RELATED LITERATURE**

#### 2.0 Introduction

This chapter reviews literature as an account of the knowledge and ideas that have been established by accredited scholars and experts in the field of study. It is guided by the objectives of the study outlined in chapter one

#### 2.1 Stigma

The term stigma was created by the Greeks; stigma meant a bodily sign that someone's moral status was unusual or bad. They used to burn or cut a visual mark into a persons skin that they thought acted wrongly or were sick or enslaved, so that everyone could se that it was a bad person. Stigma is today defined in many ways; one thing that is common for different ways of defining stigma is that a person that is subject to stigma is someone that differs, in the eyes of others, in some way from the rest of their social group. There is no word for stigma in many African languages but there is one in Portuguese, the word discrimination is more common in many local languages. Discrimination is seen as the consequence of stigma and it is therefore important to understand the concept of stigma to be able to understand what discrimination is (Bond, 2004).

Every society has their own ways of categorizing their members into different groups. Every group has their own norms for what is right or wrong, what kind of behavior and way of looking that is normal. What is normal in one social group might very well be wrong and not normal in another social sphere. One person can be subject to stigmatization in one group and be totally normal in another. Erving Goffman has distinguished three different types of stigma. The first one is when you can see a bodily abomination of some kind. It can be everything from a handicap to a rash on someone's skin. The second type of stigma is apprehended weaknesses of individual character such as a lack of integrity, lack of honesty or a passion that is to strong or unnatural. The result of these

weaknesses of character can be a different way of behaving that is subject to stigma, examples here are promiscuity, homosexuality, unemployment, alcoholism, or other behaviors that are not seen as normal in a specific group. The third type of stigma is the tribal stigma that can be transferred between generations and that you therefore can be born with. This can be ethnicity, nationality or religion (Goffman, 2002).

#### 2.2 Discrimination

Discrimination signifies an unequal treatment of a person or group. There is positive, neutral or negative discrimination, although the term is often associated with negative treatment of someone. It is necessary to look at the norms that are accepted in a specific society, to be able to establish that someone has been discriminated. There is both individual and institutional discrimination. Institutional discrimination are when rules, practices and regulations in a social system leads to that people or groups are getting treated different; some are getting discriminated. National legislation and international law are supposed to protect everyone from unfair treatment (Bergman, Erland in Nationalencyklopedin, 2005).

One definition of discrimination is that someone is being treated different because of their belonging of a specific group. If this different treatment should be classified as discrimination the difference cannot be morally justified. The cause (for example sex, age or ethnicity) of the difference in treatment has to be known in order to state if it is discrimination. Some distinction in treatment is morally justified and lawful (such as student discounts). A different treatment is very common in social life, as an example; children are not treated in the same way as their parents by their relatives and amongst each other.

Discrimination is one possible cause of inequality; only if other possibilities have been eliminated can it be identified as the main cause. Discrimination is an individual action, but since several members of one group can be discriminated, it can also be a social phenomenon. It can be hard to identify the motive for discrimination. Some might discriminate another person without the intention of doing so, while others know very well the motives of why they are treating people different. It is important to separate discrimination as an action, and prejudices as an attitude. Prejudices can lead to discrimination but it does not always do that. In finding the cause for discrimination it is vital to study the legal system and the culture where the discrimination appears. Discrimination is rarely an isolated act but part of a larger system; a behavioral pattern that suppresses for example women, blacks or handicapped (Banton, 1994).

#### 2.3 HIV/AIDS and stigma

When HIV started to spread in a high amount around the world, several researchers conducted surveys in which they made fast conclusions. The conclusions about why Africa was worst affected often focused on the so-called *African sexuality* that were supposed to be promiscuous. The term promiscuous is very negatively value-laden and can be questioned, but this term shows how HIV/AIDS are regarded by a significant amount of people. *African sexuality* was seen as a cultural expression, and African culture was therefore blamed for the spread of the HIV/AIDS epidemic. The so-called Western culture was seen as less promiscuous and therefore the virus did not spread as fast there (Schoepf, 2004).

There are several diseases that are subject to stigma but one might question why this particular virus is badly looked up on. Leprosy, cholera and polio have in the past been subjected to stigma because of deep-rooted social fear, anxieties and prejudices (Aggleton, 2002). These feelings are familiar to how people feel about HIV/AIDS today. According to the Jackson (2004) the fact that the HIV virus is mainly transmitted sexually makes this disease especially vulnerable for stigmatization, although there are other ways to catch the virus such as through blood transfusion, mother to child, breast feeding and injections with needles with infected blood. The fact that the virus is sexually transmitted has probably led to

a way of regard an infected individual as someone with a weakness of character (Goffman, 2002):

#### 2.4 HIV/AIDS and discrimination

One definition of discrimination is that someone is being treated different because of their belonging to a specific group, in this case people living with HIV/AIDS. If this different treatment should be classified as discrimination the difference cannot be morally justified, to treat HIV-positive people different does not have any moral justification. If fear of catching the virus is the reason (and it probably is in some cases) a lack of knowledge of how HIV transmits is the problem since it only transmits through exchange of body fluids and not through body contact or by breathing the same air. The cause (ex. sex, age or ethnicity) of the difference in treatment has to be known in order to state if it is discrimination (Banton, 1994). It can be difficult to know the cause of discrimination of HIV/AIDS-positive people. It might be the assumption that the affected has had a promiscuous life, or is assumed to be a prostitute, or it might be fear of death that causes stigma and discrimination.

Discrimination is an individual action, but since several members of one group can be discriminated, it can also be a social phenomenon. This interviewee says that everyone that lives with HIV/AIDS is discriminated and it is therefore a social phenomenon. He also explains how the families that live with the HIV/AIDS-positive person can be subject to this destructive behavior. It can be difficult to see why people are discriminating others. Some can discriminate another person with no intention of causing harm, while others are very well aware of the reason to why they are treating people in a bad way. Prejudices can be the reason to discrimination but one does not automatically lead to the other (Banton, 1994).

#### **CHAPTER THREE**

#### **METHODOLOGY**

#### 3.0 Introduction

This chapter focuses on the method and procedure used in the study. This includes the research design, area of study, sample selection, instrument and procedure of data collection and analysis.

### 3.1 Research design

Since the study was largely an evaluation one seeking opinions and attitudes, the researcher will use a descriptive research design, adopting a cross sectional survey. The descriptive survey attempts to picture or document current conditions or attitudes to describe what exists at the moment Mouser & Katton (1989). A cross sectional survey design was particularly chosen because the study is concerned with gathering perceptions from a cross section of community members. Hence views across the various community members) will be obtained and levels of significance of motivation computerized per section of people.

The study employed both qualitative and quantitative methods of data analysis. Most of the findings were analyzed qualitatively.

#### 3.2 Area of study and population

The study was conducted in Bushenyi district. The population of the study included community members, community leaders and NGOs dealing with HIV/AIDS prevention in the area.

#### 3.3 Sample selection

Using a convenience sampling technique, a total of two hundred (200) which is 20% of One thousand eighty three (1083) total numbers of people in the area where the study was carried out, was selected for the study. The researcher

further adopted the probability proportional to size sampling design to arrive at the required sample.

#### 3.4 Source of data

#### 3.4.1 Primary data

The primary data used was from the community members who participated in the study.

#### 3.4.2 Secondary data

The secondary data about the stigmatization and discrimination of HIV/AIDS positive people comprised of information from the following;

Bushenyi district annual reports

Library Publications and Articles

Media Publications and reports

The Internet

#### 3.5 Data collection methods

#### 3.5.1 Instrument

A questionnaire structured to give information by way of content and purpose was the main instrument of data collection. A 3-point Likert Scale (1-disadgee, 2-agree and 3-strongly agree) will be used for the questionnaire. All questions were close ended to increase the response rate of the respondents.

After the necessary introductions and outlining the objectives of the study to the authority in the areas of the study, the researcher was granted permission to carryout this research in the places of interest for the study. Which the assistance of two (2) trained researcher assistants, questionnaires were administered to the selected respondents

#### 3.6 Data analysis and interpretation

#### 3.6.1 Data analysis tools

Data from each questionnaire was categorized and edited for accuracy and completeness of information. This is to ensure that all questions are answered. All the questions was pre coiled. After this process, the statistical packages for social science (SPSS 12.0 version) computer programme was used to produce frequencies and percentages.

#### 3.6.2 Data interpretation

Analyzed data from the questionnaires waere presented in chapter four (4) in form of tables showing frequency counts and percentages. This information was further triangulated with information from secondary sources for meaningful interpretation and discussion.

#### 3.7 Chapter summary

In this chapter, the researcher has presented the research techniques and procedures adopted in the study.

#### **CHAPTER FOUR**

#### PRESENTATION, INTERPRETATION AND DISCUSSION OF THE FINDINGS

#### 4.1 Introduction

This chapter is a presentation, interpretation and discussion of the field results.

Results are presented in tables and in form of frequency counts and percentages.

#### 4.2 Health Care

The findings indicate that many cases of discrimination have occurred in the health sector. However, despite this, many interviewees still had faith in the public health care system. They believed that the services in the Infectious Diseases Hospital (IDH) and Ward 33 of the General Hospital were good, and that they were treated well.

A few agreed that free health care provided by Government hospitals gave people who could not afford private health care access to treatment they would otherwise be denied. However, there was much consensus that awareness among health staff, in public and private hospitals, must be addressed. They brought up several instances where health staff including doctors, nurses, attendants and minor staff had discriminated against people living with HIV/AIDS and their families.

#### a) Breach of Confidentiality

According to the interviewees, there were several cases in which confidentiality regarding a patient's HIV status was not respected. A few interviewees mentioned that they had lost their jobs as a result of their status being made public. In one case, the lab technician had been shocked by the results, for it had been the first time he had seen a test come back positive for HIV. He had shared the information with his colleagues at the lab and the rest of the hospital. In the case of a patient who has since passed away due to complications resulting from

AIDS, the interviewee was diagnosed with HIV at the General Hospital. A person working in the hospital had found out his HIV status and spread this information around their village. This resulted in the stigmatization of both the patient and the family by members of the community.

Another case which implicates the confidentiality issue occurred at a private hospital. The patient had been tested there since his brother-in-law was employed by the hospital. When the test result returned positive, prior to informing the patient, the doctor had passed the result on to the patient's brother-in-law. Furthermore, the test results had been leaked by the hospital lab, and as a result, the entire hospital staff learnt about it. The patient stated that the immediate family was only notified after everyone in the hospital had already found out. People outside the hospital, such as van drivers parked near the hospital, were told of the case. One such van driver was from the same village as the patient and spread the news of the patient's HIV+ status throughout the village. This led to various acts of discrimination — people wanted them to leave the village, making derogatory comments and informing the child's school, which in turn led to complications at school.

"The doctors at the General Hospital told everyone who came to see him that he has HIV. The thing is, he was moved from the bed to the ground, so people in our family asked them why, and then the doctors told them that he has HIV, we don't generally keep AIDS patients. They had said a lot of things to my younger sister's husband. So everyone in our family knows about his status." (HIV positive patient, Bushenyi Hospital)

"Attendants bring visitors from other wards and show them the HIV+ people pointing them out as if they are exhibits; hence it is clear that they discuss these cases in other wards in order to appear important. In one instance the father of one HIV positive

patient was so upset when this happened that he said his son was admitted for TB but the attendant loudly argued with him in front of the visitors and said it was HIV." (HIV positive patient, Bushenyi Hospital)

#### b) Unprofessional/Unkind Treatment by Health Staff

Health staff should be educated on and sensitized towards HIV/AIDS, so that they will be able to take proper precautions and treat the patients in a non-discriminatory manner. It is also important that health staff are knowledgeable about the disease, so that they can educate the public and give them accurate information, thereby dispelling fear and misconceptions.

At a government hospital, a patient was operated on by hospital staff without any testing or consultation with the patient's family. After the operation, the patient's mother had informed the doctor that the patient was HIV+. Though the doctor had behaved respectfully towards the patient and family, the attendants and minor staff had treated both the patient and family badly. The mother of the HIV+ person, when interviewed, stated that the health staff were ignorant of HIV/AIDS and this resulted in discrimination. She went on the mention that the hospital staff had even refused to touch the sheets on the patient's bed.

"The doctor there told me that there is nothing we can do, death is the only thing. So I asked him when will my husband die. Then the doctor said that he couldn't say. It could be tomorrow or day after or a year or two but that he can't say. Then I asked if there was any medicine for this and he said no, there is medicine but you won't be able to afford it. You have to go abroad and get treatment. Death is the only thing." (HIV positive patient, Bushenyi Hospital)

The majority of the interviewees stated that they sought counseling after finding out that they were HIV+. This generally had a positive impact in helping people cope with their HIV/AIDS status and provided support for their families. However,

in one case, a doctor advised the spouse of an HIV+ person to leave him. In this case, the HIV+ person had hoped the doctor could explain to his spouse the nature of HIV/AIDS to raise her awareness of HIV/AIDS thereby preserving the relationship. Instead, the doctor's advice resulted in the spouse leaving him as well as having a negative impact on the relationship he had with his child.

An interviewee related her experiences in a government hospital, where staff, including doctors, had made derogatory comments and scolded her for being HIV+. On one occasion, her hand had passed over the doctor's tea cup; she had been scolded by the doctor for infecting the cup. On another occasion, her husband, who is also HIV+, was admitted to hospital for treatment. When he was discharged, his mattress was burned in his and his family's presence.

#### c) Lack of Informed Consent/Counseling

The majority of the people interviewed stated that they had consented to being tested. At the same time, nobody had informed them about HIV/AIDS. Many had very little knowledge on what HIV/AIDS is, and some had misconceptions on how it could be transmitted. The majority of interviewees claimed that the doctor present had explained what HIV/AIDS was only after the results had come back positive. The doctors had then directed the people to places where to get assistance and support. There were no cases where pre-test counseling was conducted.

#### d) Refusal of Treatment

There was one case in which a person was refused treatment at a private hospital as a result of being HIV+. The interviewee had been admitted to the Hospital and his blood was tested. He had notified the health staff of his positive status so that they could wear gloves. This had resulted in his being refused treatment, and the doctor-in-charge had stated that it was hospital policy not to treat HIV+ patients.

#### e) Lack of Basic Services

"On admission i found that the patients are left alone in the rooms without even the beds being prepared for him\her, also without any assistance to arrange their belongings in the bedside cupboards. These cupboards are very dirty and inside are discarded empty plastic bottles, bags and a conglomeration of rubbish. I set about cleaning these out, arranging the beds, then discovered that no pillows are provided as they burn these after the departure of each patient and expect the families to provide this as well as the covering sheet. Also, no plates, cups and cutlery are given and i was very helpfully advised to buy everything in plastic to avoid breakage!"

"The toilets are in a filthy condition so much so that the wife said she holds up as long as she can. She also said she was reluctant to even have a bath. The conditions were so bad."

#### f) Screening of Blood

The Nakasero national Blood Bank and its branches in the rest of Uganda screen blood before making it available to all government hospitals. Most private hospitals have their own facilities to test blood but there does not seem to be a uniform method in practice. This could lead to loopholes in the system where contaminated blood is made available. Blood should be tested by all medical facilities before being made available for transfusions as this would reduce the risk of contaminated blood being used.

The giving of contaminated blood to a patient by health staff or an institution is an act of negligence. An interviewee narrated the details of his wife's operation in May 2006, at the Hospital. The hospital gave her blood obtained from another Hospital. She later tested HIV+, and after questioning the hospital authorities, the family found out that she had contracted the virus from contaminated blood used during the transfusion. When the family raised this issue with the authorities at

the Hospital, they placed the blame on the patient and refused to take any responsibility.

#### g) Other Issues

Issues pertaining to access to health care and medication needs to be addressed. A few interviewees cited financial difficulty in receiving such access. Assistance was provided by various organizations, but this was limited and did not cover all procedures.

In the interviews conducted, there was no evidence of forced medical procedures such as sterilizations and abortions. The majority stated that the results had been conveyed to them before any family members or others.

A few interviewees who had tested positive had got their spouse or partner tested. Except for one case, the test was done with the consent and knowledge of the spouse or partner. In one particular case, the husband had got his wife's and child's blood tested without their knowledge; his rationale was that his wife would never have consented to the test.

#### 4.4 Employment

The majority of the people interviewed during the study were unemployed, and a few were self-employed. Several cases involving discrimination in the workplace were highlighted. In these cases, the people living with HIV/AIDS had to leave their employment.

#### a) Loss of Employment

One interviewee narrated several instances where he had been asked to leave his job as a result of his HIV status. He had started working in a restaurant with his cousin, when someone leaked his status to his cousin; his cousin had then requested he quit. The cousin's concern was that no one would come to the restaurant if they knew that there was a HIV+ person working there. The

interviewee's second job was at a flower shop, but after six months, the owner had heard about his status and forced him to leave. In this situation, the owner had not even allowed the interviewee to come by the shop to collect his pay cheque, but had insisted on posting it.

In another case, a husband was employed to deliver bread. He lost his job when his employers found out he was HIV+. In yet another case, the interviewee was employed by one Company and had taken some days off as a result of his deteriorating health. When questioned by his boss, he had revealed his HIV status. The boss had told him that others in the company might not feel comfortable working with a HIV+ person and might decide to leave. As a result, the interviewee felt pressured to resign from his employment.

#### b) Mandatory Testing

Several interviewees claimed that they had learned of their HIV status as a result of tests that are mandatory for those going to some companies for employment. There was no pre-test or post-test counseling available.

#### c) Breach of Confidentiality

Another issue that needs to be considered by employers is the protection of an HIV+ person's confidentiality. An interviewee stated that he had not divulged his status to anyone as he did not want to be stigmatised or discriminated against. News of his positive status was leaked to third parties by his employer which led to problems from people in his area and workplace.

#### 4.5 Family Life

Many of those interviewed felt shock at first finding out that they were HIV+. They questioned why and how they had contracted the disease, many times sking 'why me?', 'what did I do to deserve this?' and 'why am I getting it at this time when I have a good job and loving family?' They also wondered how they would be able to face their families, friends, colleagues and society in general.

"I was shocked and it affected the spirit of my existence. Why me was the question. It kicked me. I had a stable life, a caring and loving wife who had just got pregnant and at work I was steadily climbing the corporate ladder. All went into a doom because of this. I wanted to lock myself in my room because I thought even my presence in public would affect others."

#### a) Positive Aspects

The majority of interviewees have only shared knowledge of their HIV+ status with their close family: spouses, children, parents or siblings. It is only in a few cases that they have revealed it to others.

"It was not easy in the beginning. It was not something that you can tell your parents, family or your friends. But now I have built a stable environment around me which makes my existence much easier."

According to the majority of the interviewees, their close family and friends were supportive and understanding, and looked after their needs. All the interviewees admitted that family members and friends who were informed of their status had initially been shocked; people who were unaware or had little knowledge regarding HIV/AIDS were fearful. A few interviewees admitted that family and friends had treated them differently after finding out their status. However, after learning more about HIV/AIDS, they often became more accommodating and understanding. There were a few cases in which family members had been unconditionally supportive. One interviewee stated that he had even married after finding out his HIV+ status, for when he had notified his fiancée of his HIV status, she had still wanted to marry him.

The majority of interviewees stated that they received emotional and psychological support from their families and friends; some even received financial support.

#### **CHAPTER FIVE**

#### CONCLUSION AND RECOMMENDATIONS

#### 5.1 Introduction

The study looked at the to examine whether people living with HIV/AIDS in Bunyaruguru county Bushenyi District are subject to discrimination and if so, what influence does it have on their possibilities to enjoy their human right to health. In an attempt to achieve the above, three objectives were developed. This chapter presents the conclusions and recommendations of the findings

#### 5.2 Conclusions

According the findings it was discovered that the HIV/AIDS-positive people in Bunyaruguru county Bushenyi District are discriminated in their closest social context in so many ways among which are at wok, at home and in the community at large.

Also it was discovered that people in Bunyaruguru county Bushenyi district are discriminated through there employment, lack of health care, lack of counseling and the un kind medical staff to the these people in the district.

Discrimination affects their possibilities to maintain a good health by making them worried all the time. Hence they loose apatite for food and so they end up sick all the time

#### 5.3 Recommendations

The feedback received through interviews and focus group discussions has assisted in drawing a profile of the problems faced by people living with HIV/AIDS in the areas of health care, education, employment, family life, housing

and social life. Though only a limited number of interviews were conducted, they highlighted important issues that must be considered by stakeholders when attempting to reduce levels of stigma and discrimination.

Further, it is vital that future initiatives keep in mind people living with HIV/AIDS and involve them as much as possible in the process. The following recommendations have been made taking into consideration the research findings and the feedback received at the discussion. The recommendations are targeted at various actors including government institutions and officials, employers, educational and health institutions, the media, religious leaders, professional bodies, the donor community and civil society.

#### Ministry of Health (MOH):

MOH needs to deliver a strong message to all health care workers that people living with HIV/AIDS and their families are to be treated with respect and professionalism. This message should be backed up with training programmes for health care staff, new recruits and health administrators, at the national and regional levels.

MOH should formulate and implement a policy that ensures all HIV tests are performed by adhering to standards such as voluntary testing, informed consent, pre and post test counseling and confidentiality.

MOH should provide training and resources for universal precautions which will ensure that health care staffs are protected when dealing with HIV/AIDS. This

should include the provision of plastic gloves, masks, and sharps boxes for safe disposal of needles and adherence to safe laboratory practices.

MOH should formulate and implement a comprehensive and multi-sectoral HIV/AIDS policy and regulations related to HIV/AIDS.

MOH should introduce guidelines and strengthen existing structures to ensure that blood is tested by all medical facilities, which follow a uniform method, thereby reducing the risk of using contaminated blood.

## Central Government, Provincial Governments and Local Authorities:

The Central Government, Provincial Governments and Local Authorities should take a greater role in raising awareness. There should be a code of best practices that provide guidance to local and national policymaking bodies on means of actively involving people living with HIV/AIDS at various levels.

#### **Advertising Agencies:**

Advertising agencies should raise awareness among professional involved in advertising on HIV/AIDS and provide training on modalities of sensitive advertising. This would ensure sensitized advertising which respects the privacy of people living with HIV/AIDS.

#### Religious Leaders:

Religious leaders should take an active role in promoting awareness about and working to reduce stigma and discrimination related to HIV/AIDS. Programmes should be initiated at the national, regional and local levels.

#### **Professional Bodies:**

The Judiciary, Police, Bar Association, Accredited Advertising Agencies' Association and others should implement programmes to sensitize their members on HIV/AIDS issues.

#### **Civil Society and the Donor Community:**

More programmes aimed at raising awareness and educating the public on HIV/AIDS must be conducted. These should be more long term and should involve follow up work.

Providing medical, legal and other assistance to people living with HIV/AIDS and their families.

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# APPEDIX I: INSTRUMENTS Appendix (a) Questionnaire for People Living With HIV/AIDs

#### Dear respondent,

I am a student of Kampala International University carrying out an academic research on the topic "to examine whether people living with HIV/AIDS in Bushenyi District are subject to discrimination and if so, what influence does it have on their possibilities to enjoy their human right to health." You have been randomly selected to participate in the study and are therefore kindly requested to provide an appropriate answer by either ticking the best option or give explanation where applicable. The answers provided will only be used for academic purposes and will be treated with utmost confidentiality.

NB: do not write your name anywhere on this paper

#### (I) Personal Data

- 1.) Sex:
- 1. Male 2. Female
- 3.) Age:
- 1. 15 25 yrs

4.46 - 55 yrs

2.26 - 35 yrs

5.56 - 65 yrs

3.36 - 45 yrs

6. 66 yrs and above

- 4.) Marital Status
- 1. Single

2. Married

3. Divorced

4. Widowed

5. Other\_\_\_\_

#### (III) Privacy

1.) When and how did you find out your status?

.....

2.) Where was the tes	t taken?			
3.) Did you give your o	onsent for th	ne test?		
4.) If Yes, what advice			prior and after the	test?
5.) If No, how did you f				
6.) What was your read	ction?	••••••••		
7.) What steps did you	take?			
8.) Who informed you o	of the result?	•		
9.) How were you infor				
10.) Was anyone told o	f your result	s before you	u were informed? .	•
(IV) Health Care		***************************************		•
	V. GOOD	GOOD	UNHELPFUL	NO COMMENT
1.) How is the status of the Healthcare System?				
2.) Has a hospital refuse	ed to treat yo	ou as a resu	ılt of your HIV stat	us?
3.) Have there been del HIV status?	ays in treatn	nent/providi	ng medicine as a r	esult of your

4.) Have you had to pay extra for health care services as a result of your HIV status?
5.) Has your family or people associated with you ever been refused treatment by a health care worker or hospital as a result of your HIV status?
6.) Has your family or people associated with you ever experienced delays in treatment/care as a result of your HIV status?  7.) Has your family or people associated with you ever had to pay extra as a result of your HIV status?  8.) Has anyone advised you not to seek health care services? Give details.
9.) Have you ever been denied or lost insurance or benefits as a result of HIV your status or for taking a HIV test?
(V) Social Life

1.) Have you/family member ever been, as a result of	YOU		FAMILY M	EMBER
your/family	YES	NO	YES	NO
member's HIV				
status,				
Threatened				
Assaulted		***************************************		
Ridiculed				

Harassed			***************************************	
, , , , , , , , , , , , , , , , , , , ,	<u> </u>			
2.) Have you e	ver undergo	one any medical	or health YES	NO
procedures wit	hout your co	onsent?		
Abortion		TO THE STATE OF TH	***************************************	
Sterilisation				
Other (specify)				
			,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	••
4.) Have	YOU	WWW.		
4.) Have you/family member ever	YOU		FAMILY MEN	
you/family member ever been, as a	YOU			
you/family member ever	YOU	NO		
you/family member ever been, as a result of		NO	FAMILY MEN	MBER
you/family member ever been, as a result of your/family		NO	FAMILY MEN	MBER
you/family member ever been, as a result of your/family member's HIV		NO	FAMILY MEN	MBER
you/family member ever been, as a result of your/family member's HIV status,		NO	FAMILY MEN	MBER
you/family member ever been, as a result of your/family member's HIV status, Detained		NO	FAMILY MEN	MBER

5.) Have you ever been charged or brought to court on an offence or act related

to your status? .....

6.) Have you/family member ever been, as a result of	YOU		FAMILY MEI	MBER/FRIENDS
your/family	YES	NO	YES	NO
member's HIV				
status,				
excluded from		į		
joining any				
Organization			Vicinità I	
Club				
Society				
Meeting				
Gathering				

7.) has your family or people associated with you restricted you or stopped you
from joining any organisation, club, society or meeting?
8.) How helpful have religious leaders in your area been in HIV/AIDS work?
(education, awareness raising, advocacy vs. increasing stigma and
discrimination e.tc.)
9.) Have they been effective? Give details.
10.) Have actions (related to HIV/AIDS) by religious institutions and religious
leaders directly affected you, your family or anyone closely associated with you?
(VII) Employment
1.) Does anyone at your workplace know of your status?
2.) If Yes, who?

3.) How?	•••••	•••••		
4.) Has their relationship with you	changed s	ince finding	out your statu	s?
	•••••	• • • • • • • • • • • • • • • • • • • •	•••••	
5.) Have you/family member ever		YOU	FAMILY	MEMBER
experienced any discrimination at	Vide.			
work as a result of your/family				
member's HIV status?	YES	NO	YES	NO
6.) Have you/family member ever	<u> </u>	/OU	FAMILY M	MEMBER
been terminated from work as a				
result of your/family member's HIV				
status?	YES	NO	YES	NO
	160		1110	INO
8.) Have you/family member ever		OU		(EMDED
been harassed at work as a result	i i	00	FAMILY N	IEWBER
of your/family member's HIV				
status?	YES	NO	YES	NO
				1
9.) Has your work changed as a res	ult of your	· HIV status?	?	
	• • • • • • • • • • • • • • • • • • • •	••••••		
10.) Have you/family member	Y	OU	FAMILY M	EMBER
ever been offered early				
retirement as a result of				777
Your/family member's HIV status?	YES	NO	YES	NO
		f		

**THANK YOU** 

# Appendix II: Time Frame

Activity	Time in Months			
	1	2	3	4
Proposal writing				
Data collection				
Data analysis				
Submission				

# Appendix III: Proposed Budget

Item	Amount (UgShs)		
Stationery – Papers - Pens	50,000/=		
Transport Phone calls	100,000/=		
Internet Usage	70,000/=		
Typing and printing	50,000/=		
Miscellaneous	200,000/=		
Total	600,000/=		



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# Institute of Open and Distance Learning

Office of the Director

21st July, 2010

# To Whom It May Concern:

Dear Sir/Madam,

#### Introduction Letter For Research

I have the pleasure to introduce Tumusiime Paul – BGC/0026/61/DU to you. He is a student of Bachelors Degree in Guidance and Counseling at Kampala International University. He is carrying out his research on Stigma and Discrimination of People Living With HIV/AIDS in Bunyaruguru District, Uganda. He is at the data collection stage and your Institution / Organization has been identified as his area of study. It will therefore be appreciated if you can give the best assistance to him for a dependable research work.

The university will be counting on your kind cooperation.



Appendix V: Map of Bushenyi Showing Research Area

