

**A STUDY ON HIV RELATED STIGMA AND DISCRIMINATION
EXPERIENCED BY PEOPLE LIVING WITH HIV/AIDS IN KATETE DISTRICT**

BY

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Thesis
M.P.H.
2006
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**A Dissertation submitted to the University of Zambia in partial fulfillment
of the requirements of the degree of Master of Public Health [MPH]**

University of Zambia
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2006



DECLARATION

I hereby declare that to the best of my knowledge the work presented in this study, for the Master in Public Health Degree is my own and is not being currently submitted for any other degree. The various sources to which I am indebted are gratefully acknowledged in the text and in the references.

Signed

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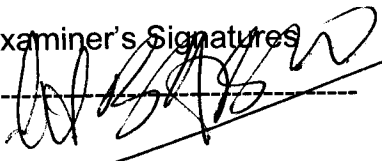
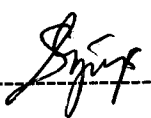
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ABSTRACT

As we enter the third decade of the AIDS pandemic the temptation is great to assume that the epidemic of stigma has ended. Most countries have introduced legislation protecting People Living With HIV/AIDS [PLWHA] against discriminations. Educational messages have been delivered and knowledge base is high among people. Despite these developments, anecdotal evidence is showing that AIDS related stigma still persists. The objective of the study was to determine dimensions associated with HIV/AIDS related stigma experienced by PLWHA.

A cross sectional study was carried out at St. Francis Hospital in Katete District. Sample selection was done randomly from the PLWHA attending the 'Sandie Logie's Clinic'. The sample size was 246. Inclusion criterion was all PLWHA aged 15 years and above. Data was collected using structured interview complimented by focus group discussions. Data was coded, open-ended questions were categorized and computer entry made. Data analysis was done by use of EPI INFO statistical package. Ethical clearance was sought from the Research Ethical Committee. Permission from relevant institutions was sought.

The findings of the study showed that 64 [26%] of the respondents had not told anyone about their status due to fear of stigma, discrimination, being talked about and witch craft. Lack of disclosure allows for the continued denial of the spread of the disease and is the breeding ground for stigma, suspicion and violence. The study results showed that the HIV status was only revealed to a carer because of the need for support. Fear of stigma and discrimination limits the possibility of disclosure even to potential important sources of support such as family and friends.

A large proportion 63.4% attributed causes of HIV/AIDS stigma to promiscuity and low morals and lack of education.

The study further showed that 63 [25.6%] of respondents reported that PLWHA experienced stigma in many forms like people not wanting to shake hands with them, not wanting to share food, always in a hurry to move on and fearing to sit next to you. 34.1% of the respondents said they had lost their self-esteem and [24%] wished that they were dead because of the pain and outcome of HIV/AIDS.

In conclusion, stigma associated with HIV/AIDS and discrimination against PLWHA is a major problem. People often avoid learning about or admitting to being infected with HIV because of the stigma attached to the disease and fear of discrimination. Such avoidance limits diffusion of knowledge about HIV/AIDS in the general population and increases the risk of transmission to loved ones and others. HIV/AIDS interventions should focus on provision of an enabling environment to increase acceptance of PLWHA as a normal part of any society through intensified advocacy, support at all levels and involvement of PLWHA and communities in programme design and implementation.

DEDICATION

This dissertation is dedicated to my mother and father, my children, Mubanga and Kafula for their unwavering support during my period of study.

ACKNOWLEDGEMENT

Sincere gratitude and deep appreciation duly go to the following without whom; this dissertation would not have been possible: My supervisor, Professor S. Siziya, who read my numerous revisions and helped make some sense of the confusion. *Special thanks to my Co-Supervisors, Dr. Ndonyo Likwa and Professor K.S Baboo, who offered guidance and support.*

I am greatly indebted to my sponsors ADB who made it possible for me to pursue my studies at the University of Zambia.

My deep and sincere gratitude go to Zambia American Partnership for their commitment in supporting programmes related to HIV/AIDS. The funds enabled me to successfully carry out this research on HIV/AIDS related stigma experienced by PLWHA in Katete.

My sincere thanks go to Professor Mafongoya and Dr. Maimbolwa for the advice and support given during the development and implementation of the project.

I wish to thank Dr. Susan Alltyne and Mr. Shibalatani for proof reading my dissertation, Dumasseh for her un-wavering support and vigilant search for literature, Mr. Kunda data analyst and Edna and friends for helping in data collection, my colleagues Dr. Katepa, Regis, Florence, Emily, Ethel and Mwaka for their invaluable support.

Many thanks go to my family, Mr. and Mrs. Chayafya and all PLWHA who participated in the research. Finally I thank the Executive Director of St. Francis Hospital for the support rendered to me through out this project. Sincere thanks go to Katete Health Management Board for permitting me to carry out the research in their district.

TABLE OF CONTENTS

	Page
Title Page-----	I
Declaration-----	ii
Copyright-----	iii
Certificate of completion of Dissertation-----	iv
Approval certificate-----	v
Abstract-----	vi
Dedication-----	Vii
Acknowledgement-----	viii
Table of Contents-----	ix
List of tables-----	xii
List of Abbreviations-----	xiii

CHAPTER ONE

1.0 INTRODUCTION-----	1
1.1 Background Information-----	1
1.2 Statement of the problem-----	5
1.3 Study Justification-----	7

CHAPTER TWO

2.0 LITERATURE REVIEW-----	8
-----------------------------------	----------

CHAPTER THREE

3.0 OBJECTIVES OF THE STUDY-----	14
3.1 General Objective-----	14
3.2 Specific Objectives-----	14

CHAPTER FOUR

4.0	METHODOLOGY-----	15
4.1	Identification of Variables-----	15
4.2	Study Type/design-----	16
4.3	Research Setting-----	16
4.4	Study Population/Sample -----	16
4.5	Sample Size -----	16
4.6	Inclusion criteria-----	17
4.7	Exclusion Criteria-----	17
4.8	Data Collection-----	17
4.9	Quality Control Checks-----	17
4.10	Data processing-----	18
4.11	Data Analysis-----	18
4.12	Ethical Considerations-----	18
4.13	Pre-testing of the questionnaire-----	18
4.14	Administration and Monitoring-----	19
4.15	Plan for utilization and dissemination of results-----	19
4.16	Study Limitation-----	19

CHAPTER FIVE

5.0	DATA ANALYSIS AND PRESENTATION -----	20
------------	---	-----------

CHAPTER SIX

6.0	DISCUSSION OF FINDINGS-----	30
------------	------------------------------------	-----------

CHAPTER SEVEN

7.0	Conclusion and Recommendations-----	36
7.1	Conclusion-----	36
7.2	Recommendations-----	36

8.0	References-----	37
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Appendix 1 Conceptual Frame work-----	41
Appendix 2 Questionnaire-----	42
Appendix 3 Focus Group Discussion Guide-----	52
Appendix 4 Information Sheet-----	54
Appendix 5 Informed Consent form-----	56
Appendix 6 Letters of request for permission-----	57
Appendix 7 Letters of permission-----	61

LIST OF TABLES

Table 1	Socio-Demographic Characteristics-----	20
Table 2	Told someone [Privacy]-----	21
Table 3	Discrimination-----	22
Table 4	Discrimination in workplace-----	23
Table 5	Attitude of family/Significant others-----	24
Table 6	Knowledge on HIV/AIDS related stigma-----	25
Table 7	Perceived opinions of people about PLWHA-----	26
Table 8	Forms of stigma experienced-----	26
Table 9	Disclosure/Self-esteem/selfblame-----	27
	Summary of focus group discussion-----	28

LIST OF ABBREVIATIONS

ARC	Aids Related Complex
AIDS	Acquired Immune deficiency Syndrome
DHS	Demographic and health survey
HIV	Human immune Virus
IEC	Information Education and Communication
MOH	Ministry of Health
PLWA	People Living with HIV/AIDS
OR	Odds Ratio
STI	Sexually Transmitted Infection
USAID	United States Agency for International Development
UNAIDS	United Nations Program on Aids
WHO	World Health Organization
ZSBS	Zambia Sexual Behavior Survey
REC	Research Ethical Committee
UNZA	University of Zambia
KDHB	Katete District Health Board
VCT	Voluntary Counseling and Testing
SANDIE LOGIE	Clinic for people living with HIV/AIDS

CHAPTER ONE

1.0 INTRODUCTION

1.1. BACK GROUND INFORMATION

The Human Immunodeficiency Virus [HIV] and the Acquired Immune Deficiency Syndrome [AIDS] have for the past two decades continued to spread across all continents causing death to millions of adults in their prime, disrupting and depriving families, turning millions of children into orphans, weakening the workforce and threatening the social and economic fabric of communities [NAC, 2002]

The HIV/AIDS epidemic has become a serious health and development crisis throughout much of sub-Saharan Africa, including Zambia. UNAIDS estimates the number of infections worldwide at about 37.8 million by end of 2003, of which about 25 million were found in sub-Saharan Africans. About 4.8 million persons became infected in 2002, 3 million of whom were sub-Saharan Africans. Worldwide, about 2.9 millions persons died from AIDS in 2002. Sub-Saharan Africans accounted for 2.24 million of the total [NAC, 2004].

Demographic impact of HIV/AIDS in the region has also been serious. Life expectancy has dropped significantly from 62 to 47 years. New HIV infections are highest among young people. Young women have consistently been found to have higher [in some cases as much as six times as high] prevalence rates of HIV than men of the same age [UNAIDS, 2002].

From the epidemiological surveillance of HIV/AIDS in the region, it is not uncommon to find HIV sero prevalence rates in excess of 20% or more in the adult population in most urban areas of the SADC region. This in essence means that a large number of productive and skilled men and women will lose their lives prematurely to HIV/AIDS, with dire consequences for the socio-economic development of the region. Yet the full impact of HIV/AIDS is yet to

come because of the prevailing high levels of HIV infection in the communities which will ultimately translate into AIDS patients requiring care and social support.

HIV/AIDS was officially reported in Zambia In 1984 and by July 1997, 45,000 cases of HIV/AIDS had been reported to Ministry of Health [MOH, 1999].

The seriousness of the HIV/AIDS epidemic has been heightened by a number of reasons e.g. the high growth rate, the drop in life expectancy, high maternal rate etc.

According to the Demographic and Health Survey in 2002, the HIV prevalence rate for the entire country was nearly 16% in urban areas, the prevalence rate among 15-49 year olds, was more than 23%. In rural areas, it was about 11% [NAC, 2004]. The high rate of HIV infection in the urban areas is especially important because Zambia is more urbanized than most sub-Saharan countries [NAC, 2004].

The Demographic and Health Survey found that women are 1:4 times more likely to be HIV-infected than men. Prevalence among women is higher in the younger age groups than it is among men and it peaks earlier. [NAC, 2004].

The trend in HIV prevalence still remains high. When prevalence remains at a high level, it means that the number of people who become newly infected is about equal to the number of those who die from AIDS each year. A very large number of Zambian adults became newly infected each year during the 1990s for prevalence to continue at a very high level [NAC, 2004].

All over the world, the shame and stigma associated with the epidemic have silenced open discussion, both of its causes and of appropriate responses. This has caused those infected with HIV and affected by the disease to feel guilty and ashamed, unable to express their views, and fearful that they will not be

taken seriously. They have led politicians and policy-makers in numerous countries to deny that there is a problem and that urgent action needs to be taken [MOH/CBOH, 1999]. The reason behind the continuing high prevalence in HIV/AIDS lies in the 'S- factor', 'stigma', 'shame' and 'silence'. This leads to discrimination, denial and blaming others there by delaying action [NAC, 2002-2005]

HIV/AIDS- related stigmatization and discrimination threaten the effectiveness of prevention and care programs. Fear, ignorance, and denial lead people to react to people living with HIV/AIDS [PLWHA] in ways that can have negative effects on individuals, families, and communities. Those at risk or already infected may not seek prevention and care services for fear of being stigmatized by service providers or their community. [Research Update January, 2002]

The stigma and discrimination associated with HIV/AIDS have many other effects. They have powerful psychological consequences for how people with HIV/AIDS come to see themselves, leading in some cases to depression, lack of self-worth and making people afraid to find out whether or not they are infected, for fear of other people's reactions to them. They cause those at risk of infection and some of those affected to continue practicing unsafe sex in the belief that behaving differently would raise suspicion about their HIV-positive status. This causes PLWHA erroneously to be seen as some kind of problem rather than part of the solution to contain and manage the epidemic.

In countries all over the world, there are well-documented cases of people with HIV/AIDS being stigmatized, discriminated against and denied access to services on the grounds of their sero status. At work, in education, in health care and in the community, people may lack the education to understand that HIV/AIDS cannot be transmitted through everyday contact. In addition they may not know that infection can be avoided by the adoption of relatively simple precautions. This lack of awareness can lead people to stigmatize and

discriminate against those infected or presumed to be infected with HIV/AIDS. Related HIV/AIDS stigma and discrimination also affects the capacity of societies to respond constructively to the devastation caused by the epidemic. Despite the catastrophe, silence prevails and actions are slowed because of stigma and denial and ultimately, because of fear associated with being open.

Concern about HIV/AIDS-related stigma and discrimination is not new. It is now widely recognized that there are three phases to the AIDS epidemic in any society. The first of these is the epidemic of HIV infection. This enters a community silently and unnoticed. Next follows the epidemic of AIDS, which appears when HIV triggers life-threatening infections. Finally, there is the epidemic of stigma and discrimination; blame and collective denial that make it so difficult to effectively tackle the first two. [Mann, 1987] HIV/AIDS related stigmatization and discrimination make prevention difficult by driving the epidemic out of focus and under ground.

"Piot [2001]" at a Plenary of the world conference against Racism, Racial Discrimination, Xenophobia and Intolerance said HIV/AIDS related stigma comes from the powerful combination of shame and fear. Shame because the sex or drug injecting that transmits HIV is surrounded by taboo and moral judgment. Fear because AIDS is relatively new, and considered deadly. Responding to AIDS with blame or abuse towards people living with AIDS, simply forces the epidemic underground creating the ideal conditions for HIV to spread. The only way of making progress against the epidemic is to replace shame with solidarity, and fear with hope. In Zambia, evidence shows that various HIV/AIDS services including VCT are undermined by the pervasive stigma related to HIV/AIDS and by resulting discrimination [Bond and Mitimangi, 2002; Boswell and Banda, 2002; Ndubani et al., 2000; Msika et al., 1997].

1.2 STATEMENT OF THE PROBLEM

As we enter the 3rd decade of AIDS the temptation is great to assume that the epidemic of stigma has ended. Most countries have enacted laws protecting PLWHA from discriminations. Educational messages have been delivered and knowledge base is high among people. Despite these developments, anecdotal evidence is showing that AIDS related stigma persists and this has serious implications on the preventive programs, care providers and utilization of voluntary counseling and testing services.

From the onset, the HIV/AIDS epidemic has been accompanied by an epidemic of fear, ignorance and denial, which has led to stigmatization of and discrimination against people with HIV/AIDS, their family members and certain groups perceived as morally deviant. As one woman in rural Zambia explained “there are no good things that an AIDS patient can be talked about. It is always bad things”. [Bond and Panos, 2001]. The nature of the stigma remains an enigma. Fundamental questions remain. What is stigma? From where does it arise? Why does it persist despite increasing knowledge about HIV/AIDS? And how can we effectively confront it? HIV/AIDS remains heavily stigmatized, limiting the number of people who seek testing and care in both the private and public sectors. [MOFNP 2002]

HIV/AIDS related stigma is a real or perceived negative response to a person or persons by individuals, communities or societies. It poses as a serious threat to the basic human rights for all people infected, affected or associated with the disease. Stigma and discrimination threaten all the basic rights of an individual. [NAC, 2004]. The negative impact on social relationships, social support provision and psychological well being of people living with HIV/AIDS is pervasive.

In Zambia even the rhetoric and metaphors that are used maintain and reinforce HIV/AIDS related stigma and reflect the underlying causes for stigma that

people living with HIV/AIDS face. Terms like "*kanayaka*" meaning "the light is on" are used. This term touches on the see through physical frailty people living with HIV/AIDS [Bond and Mitimangi, 2002]. This type of attitude can profoundly affect their self-esteem, their views and how they relate to others.

Individuals can be denied access to information, health services and company support that they need. They can also face loss of a job, subjected to compulsory testing, violence and quarantine. These experiences contribute to a climate of fear where people are afraid to disclose their HIV status.

The purpose of the study was to determine dimensions associated with HIV/AIDS related stigma experienced by PLWHA so as to develop strategies for mitigating the impact of HIV/AIDS stigma. The study will further attempt to answer questions of what stigma is, why it persists, how it can be confronted effectively and the impact it has on the PLWHA.

Assumptions

- Lack of knowledge leads to HIV related stigma
- Perception of HIV/AIDS leads to HIV/AIDS related stigma
- Blame leads to HIV/AIDS related stigma

1.3 JUSTIFICATION OF THE STUDY

The significance of the study is that not much data exists on the subject outside the urban setting. This type of study can play a key role in providing information necessary to develop effective programs to combat HIV/AIDS stigma. Data generated will assist government leaders, health providers, and the general public as they debate new policies concerning HIV treatment, prevention and monitoring.

CHAPTER TWO

2.0. LITERATURE REVIEW

Stigma undoubtedly poses several challenges, but the mechanism, which places it at the heart of the AIDS pandemic need to be explored. Stigma and discrimination are part of complex systems of beliefs about illness and disease that are often grounded in social inequalities [Valdiserri, 2002]

Although AIDS stigma is effectively universal, it takes different forms in different countries. The specific groups targeted for AIDS stigma vary considerably across cultures and national borders, as does the extent to which stigmatizing attitudes are enshrined in laws and policies. Goffman [1963] defines a stigmatized person as some one who has a spoilt identity due to some difference they possess. Discrimination is a consequence of stigma. It is a form of distinction, exclusion, or restriction affecting a person because of this difference [Ranger, 1992, Hereck and Glunt, 1988]. Enacted stigma refers to the real experience of discrimination. Discrimination constitutes acts or omissions in which the content of the stigma is applied, either at an individual or family or community level [Link and Phelan, 2002].

In Africa, AIDS is a shame for the family. In a study conducted on 731 people in the Northern district of Botswana in 1999 [UNAIDS, 2001-2003] several of the people surveyed proposed killing HIV carriers either by burning them or by "euthanizing" them in the Hospital, by identifying them with a mark on the body in the form of tattoo under the armpit or, by isolating them in homes, etc. This proves that we are still far from gaining real knowledge and acceptance about the disease. Most of the countries are at the level of fear rejection and stigmatization except for Uganda, which is one of the few rare countries that had succeeded in attaining an acceptable level of tolerance, acceptance and solidarity [UNAIDS, 2002]. Studies conducted in India, Uganda, Tanzania, Ethiopia, Burkina Faso and Zambia revealed that HIV/AIDS related stigma and resulting discrimination assume many forms [Nyblade et al., 2002; ICRW,

2002B; Aggleton, 2000, Bharat, 1999]. Goffman, [1963] describes three types of stigma; abominations of the body, stigma related to physical deformities, and, stigma related to blemishes of individual character.

According to a study done in Vietnam between January and February 2003 it was discerned that stigma is caused by factors in the social, cultural, political and economical environment. Key factors affecting the nature and degree of stigma also include the stage of the disease. It was also found that the media is having a negative impact by reinforcing, rather than challenging, the prevailing fears, misapprehensions and stereo types that fuel and exacerbate HIV-related stigma. These findings resonate strongly with findings from studies on stigma conducted elsewhere [Nyblade et al., 2003; Bond et al, 2003]. Documented evidence shows that people with HIV/AIDS are being stigmatized, discriminated against and denied access to services because of their HIV status. [UNAIDS, 2001].

A study carried out in three New Delhi hospitals by the Horizons Program and SHARAN [Society for Service to Urban Poverty], found prejudices among health workers against PLWHA and patients. The study concluded that health workers had incomplete knowledge about HIV transmission and were fearful about contact with blood-borne pathogens, including HIV and hepatitis. Grellier [1996] in a research on Midwives knowledge of the HIV virus and its implications for their Attitude and Practice revealed that there was a potential conflict between the professional rhetoric of non-judgmental care. Many midwives said that they found it difficult to avoid adopting different practices with someone whom they knew to be or suspected of being HIV positive. These feelings are not unique to midwifery; negative emotions have been expressed by other health workers in a number of studies [Bond et al., 1990; Reutter et al., 1994; Vanwissen, et al., 1994].

Research has shown that stigma and discrimination in hospital settings beyond delays in treatment and denial of care to include unwarranted referral to other

facilities, segregation on wards, labeling of patients' beds and files. In one famous case, blood donated by a man for a friend in need of a transfusion was tested for HIV. When the results showed that he was HIV positive, the hospital informed his employer and family without telling him, and he was fired from his job and ostracized by his family and community. [Vaishali et al., 2004/2]

HIV affects every one. The impact of HIV goes far beyond HIV Positive individuals. It has great implications for their sexual partners and family members including future children. People with HIV have an important role in providing support to others, as their experience of living with the virus can help them to understand people's feelings and reactions. They should not be seen just as 'clients' or passive recipients of care, but should have the same opportunities as others to train as counselors or educators.

Goffman, [1963] states that stigma adheres not only to the person or persons with the discrediting characteristic, but sometimes to their families as well. In a study in Vietnam, the families of Drug users or sex workers who become HIV infected are also criticized heavily. It was felt that the family had neglected the education of its children causing them to become degraded.

Feelings of guilt and regret are common in part because of the stigma often associated with AIDS. People may feel responsible for exposing their partner to infection or guilty because they feel they have brought shame to their families or friends. Failure to settle debts, fulfill ambitions or responsibilities to children can cause feelings of guilt, sorrow and regret. A person may want forgiveness or to discuss ways of resolving problems they feel responsible for

There are powerful psychological consequences for how people with HIV/AIDS come to see themselves, leading in some cases to depression, lack of self worth and despair. They also undermine prevention by making people afraid to

find out whether or not they are infected, for fear of the reactions of others. A central issue for people living with HIV is the stigma they face at the workplace, their home and in their community. Combating stigma is fundamental to fighting the spread of HIV, as well as ensuring that people with HIV are able to enjoy healthy and productive lives.

Results from a study on linking research and action for stigma reduction in South Africa showed that PLWHA are perceived as guilty and deserving, and judged according to a continuum of guilt and innocence. HIV-positive single women were seen as promiscuous and therefore guilty, while HIV-Positive men were usually regarded with more sympathy. Many PLWHA report verbal and physical abuse, and some are excluded from social opportunities. His/her family may not send a young PLWHA to University because she/he is considered to be dying soon. The fear of HIV/AIDS has created a culture of suspicion. As a result, employees working in HIV/AIDS programs and those that are passionate about the subject are considered to be HIV-Positive. [Ndivhuwo, 2004/2] Stigma has a lot of negative effects on the individual. It leads to silence, rejection and denial, all of which cause added stress for the individual, placing a greater burden on their already stressed immune system.

According to Clay, the KARA research showed that AIDS orphans can be subjected to double discrimination, firstly because their parents have died of AIDS, and secondly because the children are seen by the relatives now caring for them as unwanted mouths to feed when resources are scarce. This has been supported by a participatory rural appraisal done in three villages in Zambia's Southern Province. Stigma and discrimination were confirmed in discussions with orphans, who indicated that they were made accountable for the fact that their parents were HIV infected. They reported being called names like dogs, and many being treated like slaves and perceived as a burden [Kogelenberg et.al., 2004/2]. Orphans indicated that stigmatization by the community and the lack of opportunity to come to terms with the loss of their

parents was much more painful than going hungry, without decent clothing, or lack of schooling.

Discussions with widows revealed stigma and discrimination, and the lack of a support system for them in the community. Widows are often told to go back to their families because in the Zambian context when *lobola* has been paid the children belong to the husband's family [Kogelenberg et al., 2004/2]

Despite examples of successful litigation, stigma and prejudice against PLWHA remain a major problem. A research conducted by the South African Department of Health to try and understand the extent and causes of unfair discrimination against PLWHA, revealed substantial evidence of residual stigma and misunderstanding [Heywood, 2001]. Stigma and discrimination was a legacy of the early days of the disease, when the media portrayed AIDS as an affliction of gay and promiscuous people [PLUS NEWS].

Zulu, a PLWHA [PLUS NEWS] acknowledges stigma and says that there is lack of political will to tackle HIV and AIDS in Zambia. He said, "They have passed the AIDS BILL now let them pass the stigma," He further added that it has always been assumed that stigma is among the ignorant or the rural poor, but we are seeing discrimination among seemingly educated, well informed people. During a parliamentary debate on Government's new AIDS Bill one Member of Parliament argued that HIV positive people should be isolated from the rest of society. Though he later apologized for his remarks following a public outcry, the level of the debate on the AIDS BILL suggested that few parliamentarians understood the implications of the legislation, which seeks to promote a more coordinated response to HIV/AIDS in a country where more than 20 percent of adults are believed to be HIV positive [PLUS NEWS].

CONCLUSION

Evidence shows that experience of Stigma and discrimination are similar across countries. The manifestations appear in multiple ways and vary from the overt and blatant to the more covert and subtle. Prejudice, unfair discrimination and human rights violations are a very serious barrier to HIV prevention and management because they deter people from VCT as well as from seeking treatment. It is for this reason that research on HIV/AIDS related stigma is very pertinent in the mitigation of HIV/AIDS.

CHAPTER THREE

3.0 OBJECTIVES OF THE STUDY

3.1 General objective

To determine the various dimensions associated with HIV/AIDS related stigma experienced by PLWHA so as to mitigate the impact of HIV/AIDS stigma.

3.2 Specific Objectives

- To determine the proportion of PLWHA affected by HIV/AIDS related stigma in relation to the total population in the sample.
- To determine the extent to which stigma affects PLWHA
- To determine the extent of discrimination towards PLWHA
- To determine the level of knowledge of PLWHA on HIV/AIDS related stigma
- To determine the self-esteem experienced by PLWHA
- To determine the attitude of family towards PLWHA
- To make recommendations to relevant stake holders and authorities

CHAPTER FOUR

4.0 METHODOLOGY

4.1 IDENTIFICATION OF VARIABLES

Refer to Appendix 1

4.1.1 Dependent Variable

The dependent variable was HIV/AIDS related stigma

4.1.2 Independent Variables

The independent variables examined included the following:

- Knowledge of HIV/AIDS
- Religion
- Self esteem
- Perception of HIV/AIDS
- Attitude of family
- Discrimination

4.1.3 Operational Definitions

Discrimination	Unjust exemption from any social activity or employment because of one's HIV status
Stigma	Rejection, ostracism and moral Judgment because of one's HIV status.
Self-esteem	Positive or negative expression of oneself
Attitude	Negative and positive responses to PLWHA
Knowledge	Correct responses to questions asked about HIV/AIDS related stigma

4.2 STUDY DESIGN

A cross sectional study design was applied to determine factors associated with HIV/AIDS related stigma experienced by PLWHA aged 15 years and above. The information was solicited from PLWHA in the study population. This type of study was intended to provide useful information for planning interventions that are related to the perceived problems of PLWHA.

4.3 Research Setting

The study was conducted in Katete District at St. Francis Hospital. The site was chosen because of easy access to respondents'. It is a second level hospital, but also serves as a first level hospital for the district. The socio economic status of the immediate catchment's population is predominantly subsistence farming. Poverty and illiteracy levels are high. Cultural values and practices e.g. polygamy and sexual cleansing is of critical concern for people living in this area and is a major contributor to the spread of HIV/AIDS.

4.4 Study Population/Sample

Study population "is an aggregate of all objects, subjects or members that conform to a set of specifications". The study accessible population is the population of subjects available for a particular study" [Polit and Hungler, 1999]. The accessible population comprised of all adults living with HIV/AIDS "The target population is the total group of subjects about whom the results could reasonably be generalized" [Polit and Hungler, 1999]. The target population comprised all PLWHA from the age of fifteen onwards attending the 'Sandie Logie's Clinic at St. Francis" Mission Hospital.

4.5 Sample Size

A sample is "a subset of a population selected to participate in a research study" [Polit and Hungler, [1999]. The sample was collected from a total population of 195,638 [Katete District Action plan, 2003], which is the total population of Katete District. The participants were selected using a random sampling. The

total number of participants was 246. The sample size was determined using the standard formula $[n = Z^2 PQ / d^2]$, Where $Z = 1.96 @ \alpha = 0.05$ and $Q = 100 - P$

$$= [1.96]^2 * 80 * [100 - 80] / 5^2$$
$$= [1.96]^2 * 80 * 20 / 25 = 245.9$$

$n = 246$.

The formula yielded a sample size of 246.

4.6 Inclusion Criteria

According to Burns and Grove, [1997] inclusion criteria “are characteristics that must be present for the element to be included in the sample”. The inclusion criteria included all PLWHA aged 15 years and above and consented to be interviewed

4.7 Exclusion Criteria

All PLWHA less than fifteen years of age and those coming from outside Katete District and those who did not consent to participate.

4.8 Data Collection

Data was collected over a period of two-month beginning 3rd week of May 2005 using a structured interview schedule questionnaire which had both open and closed ended questions. This technique was chosen for easy facilitation of communication and eliciting correct information from the respondents both literate and illiterates. In order to facilitate full discussion of responses a focus group discussion was also used to collect data from PLWHA. It was hoped that the FGD would bring out pertinent issues that might not be obtained by a questionnaire.

4.9 Quality Control Checks

To ensure quality of data collected, the Research Team put into place the following:

- All questionnaires had serial numbers.
- Each interviewer was required to complete his/her code number on each questionnaire completed
- Field spot checks to ensure that data was properly collected and recorded

4.10 Data Processing

Data was coded before entry in the computer. Open-ended questions were categorized, coded and entered in the computer. This was followed by data cleaning before analyzing. Descriptive statistics was used for frequency tabulations.

4.11 Data Analysis

The data collected was coded and fed into a computer using EPI INFO 6.4 statistical package, with the help of a statistician data analysis was done. Data analysis consisted of mainly running frequency tables and the variables were cross tabulated.

4.12 Ethical Considerations

Ethical approval was sought from the Research Ethics Committee. Permission to access information from St. Francis Mission Hospital and the District Health Centre was requested for in writing. Participation in the study was voluntary. The respondents were assured of confidentiality and privacy was maintained. Questionnaires were assigned numbers as opposed to individual names on the interview form. A written consent [witnessed] was obtained from each participant.

4.13 Pre-testing of the Questionnaire

In preparation for the study, a research team comprising of four people was identified to carry out a pretest. Orientation to the research protocol and procedures was carried out in the course of data collection. A pretest was

carried out on fifteen people living with HIV/AIDS before the main study. This was done to ensure clarity, precision and consistency of questions. The Pre-testing was done in Chipata instead of Katete District to avoid contamination of the study population. Gaps in the tool were noted and appropriate corrections were made.

4.14. Administration and monitoring

The principal investigator supervised the human, material, financial, and logistical resources of the project. Monitoring of the project was continued throughout its implementation in order to alert the research team on problems that might have developed and changes that needed to be made.

4.15 Plan of utilization and dissemination of results

A summary of major findings and recommendations of the research findings was compiled at the end of data analysis. Printed copies were made available to the relevant authorities responsible for policymaking, planning and implementation, [Ministry of Health, University of Zambia, Katete District Management Health Board and St. Francis Health Management Board. The community where data was obtained was briefed on the results of the research through the District Health Office. The respondents were briefed through the neighbourhood committee.

4.16 Study Limitation

The following were the limitation of the study:

1. Varying patient turnover affected recruitment of respondents.
2. Erratic funding of the study greatly affected the duration of its completion.
3. Data collection was done alongside the normal work routine this meant that only a few PLWHA were interviewed per day

CHAPTER FIVE

5.0 DATA ANALYSIS AND PRESENTATION OF FINDINGS

The research results were obtained from 246 respondents from PLWHA giving a 100% response rate.

SOCIAL-DEMOGRAPHIC CHARACTERISTICS OF THE RESPONDENT

Table 1 shows the distribution of the respondents by demographic characteristics. Of the 246 respondents 97 [39.4%] were aged between 25-34 years while 84 [34.1%] were aged between 35-44 years. About twice as many females compared to males. Most 119[46%], of the respondents were married. The majority of the respondents 216 [87.8%] were Christians and most had some formal education. A large proportion was not in formal employment.

TABLE 1 Distribution of the respondents by demographic characteristics [n=246]

Characteristics	Frequency	Percentage
<u>Age group</u>		
15-24	19	7.7
25-34	97	39.4
35-44	84	34.1
45 and above	46	18.7
<u>Sex</u>		
Male	84	34.1
Female	162	65.0
<u>Marital Status</u>		
Single	26	10.6
Married	114	46.3
Divorced	35	14.2
Widowed	55	22.4
Separated	16	6.5

SOCIAL DEMOGRAPHIC CHARACTERISTICS CONTINUED

<u>Religion</u>		
Christian	216	87.8
Non Christian ¹	30	12.2
<u>Level of Education</u>		
None	37	15.0
Primary	99	40.2
Secondary	100	40.7
Technical	10	4.1
<u>Occupation</u>		
Employer	73	29.7
Unemployed	159	64.3
Self Employed	14	5.7

¹The non-Christians included the Muslims, Zionists, Atheist

TOLD SOMEONE OR DISCLOSED HIV STATUS [PRIVACY]

Table 2 shows that 26% had not told any one about their HIV status. The reasons for not telling any one about their status showed that 18 [7.3 %] out of 64 respondents eluded this to people talking a lot and 19 [7.7%] attributed this to fear of stigma while 3 [1.2%] feared witchcraft. Another 3 [1.2%] said they feared discrimination.

TABLE 2 TOLD SOMEONE or DISCLOSED HIV STATUS [n=246]

Told some-one	Frequency	Percentage
Yes	182	74
No	64	26

DISCRIMINATION

Table 3 shows that 3 [1.2%] respondents were removed or asked to leave a public establishment because of their HIV status while 9 [3.7%] had been ridiculed and 2 [0.8%] had their privileges withdrawn while 7[2.8%] were excluded from social functions. Discrimination by friends was 12 [4.9%].

TABLE 3 DISCRIMINATION [n=246]

	Frequency	Percent
<u>Refused Entry</u>		
Yes	3	1.2
No	243	98.8
<u>Ridiculed</u>		
Yes	9	3.7
No	237	96.3
<u>Privileges with drawn</u>		
Yes	2	0.8
No	244	99.2
<u>Exclude social</u>		
Yes	7	2.8
No	239	97.2
<u>Friends discriminated</u>		
Yes	12	4.9
No	234	95.1

DISCRIMINATION IN WORKPLACE

The majority 63 [25.6%] respondents who were in formal employment were not discriminated against while 4 [1.6%] were discriminated against, 2 [0.8%] lost their jobs 6 [2.4%] had their job description changed and 3 [4.47%] were offered early retirement due to their HIV status.

TABLE 4 DISCRIMINATION IN WORKPLACE [n=246]

	Frequency	Percent
<u>Unemployed</u>	179	72.8
Yes	4	1.6
No	63	25.6
<u>Lost Job</u>		
Unemployed	179	72.8
Yes	2	0.8
No	65	26.5
<u>Job-Description changed</u>		
Unemployed	179	72.8
Yes	6	2.4
No	61	24.8
<u>Offered Early Retirement</u>		
Unemployed	179	72.8
Yes	3	1.2
No	64	26.0

ATTITUDE OF FAMILY

Table 5 shows that 37[15%] were excluded from family duties while 26 [10.6%] reported partner desertion due to their HIV status

TABLE 5 FAMILY EXCLUSION AND PARTNER DESERTION [n=246]

	Frequency	Percent
Family Exclusion		
Yes	37	15
No	209	85.0
Partner Desertion		
Yes	26	10.6
No	220	89.4

KNOWLEDGE ON HIV/AIDS RELATED STIGMA

Table 6 shows that the majority, 213 [86.6%], of the respondents perceived HIV/AIDS related stigma as a problem in Zambia. In relation to its increase, the majority 156 [63.4%] attributed it to promiscuity being adopted as a strategy for survival. Others said it was because morals and cultural values were low. In relation, to causes, the majority 203 [85%] said HIV/AIDS related stigma was due to lack of knowledge, while 15 [6.1%] said it was due to fear of contagion and a similar proportion said it was a result of self-blame.

TABLE 6 KNOWLEDGE ON HIV/AIDS RELATED STIGMA [n=246]

	Frequency	Percent
<u>Stigma a Problem</u>		
Yes	213	86.6
No	31	12.6
Don't know	2	0.8
<u>HIV On Increase</u>		
Moral/cultural values low today	79	32.1
Promiscuity	156	63.4
Don't Know	5	2.0
Any Other	6	2.4
<u>Causes</u>		
Lack of knowledge	203	85.0
Fear of contagion	15	6.1
Self blame	15	6.1
Family beliefs and values	5	2.0
Religious beliefs	2	0.8

PERCEIVED OPINION OF PEOPLE ABOUT PLWHA

Table 7 shows perceived opinions of people towards PLWHA. The majority 166 [67.5%] of the respondents said people were of the opinion that PLWHA deserve to be helped like anyone else while 49 [19.9%] said they were irresponsible people and 25 [10.2%] said they deserved what they were suffering from.

TABLE 7 PERCEIVED OPINIONS OF PEOPLE ABOUT PLWHA [n=246]

	Frequency	Percent
Deserve to be helped like anyone	166	67.5
Irresponsible people	49	19.9
Deserve what they are suffering from	25	10.2
Others	6	2.4

DIMENSIONS OF HIV/AIDS RELATED STIGMA EXPERIENCED

Table 8 shows that the majority of respondent, 183 [74.4%] experienced no form of stigma while 17 [6.9%] reported refusal to share food, 10[4.1%] said people did not want to sit close and 23 [9.3%] experienced friends not visiting.

TABLE 8 DIMENSIONS OF HIV/AIDS RELATED STIGMA EXPERIENCED [n=246]

	Frequency	Percent
<u>Forms of Stigma Experience</u>		
Fear of offering handshake	27	11.0
Afraid to sit close to you	10	4.1
Always in a hurry to move on	9	3.7
Refusal to share food with you	17	6.9
None	183	74.4
<u>Friends Visiting</u>		
NA	5	2.0
Yes	218	88.6
No	23	9.3

DISCLOSURE AND SELF ESTEEM

Table 9 shows that the majority of respondents 176 [71.5%] did not openly talk about their HIV status while 51[20.7%] blamed their HIV status on previous partners or spouses and 59 [24.0%] wished that they were dead, while 84 [34%] of the respondents said they had lost their self esteem because of their HIV status

TABLE 9 DISCLOSURE SELF BLAME, WISH DEAD LOSS OF SELF-ESTEEM [n=246]

	Frequency	Percent
<u>Disclosure</u>		
Yes	70	28.5
No	176	71.5
<u>Self Blame</u>		
Yes	51	20.7
No	195	79.3
<u>Wish Dead</u>		
Yes	59	24.0
No	187	76.0
<u>Lost Self-Esteem</u>		
Yes	84	34.1
No	151	61.4

SUMMARY OF THE FOCUS GROUP DISCUSSION WITH PLWHA

Two focus group discussions were held at the clinic. The focus groups were asked as to what they thought caused AIDS to be on the increase. The reasons included that it was because people were having multiple sexual partners. This meant that people were having indiscriminate sex and there was lack of abstaining. Others said it was as a result of poverty so sex was being used as a strategy for survival. One person said its transmission can occur when you are caring for someone and you have cut/s on your hands. The majority said the increase was as a result of lack of education. It was generally agreed that without education it would be very difficult to contain the stigma being experienced. The group felt that it was not possible to contract HIV infection from free association/socializing with PLWHA.

On the opinion about PLWHA being separated from those who were not infected or had not tested positive, it was felt that such an action would not be appropriate as it would bring about a lot of problems like people refusing to test, hiding ones status. Others said such a practice would lead to emotional abuse and people will die early because of depression. On whether to make HIV results public, the respondents had two schools of thought, one group thought that it was good because the government would be able to assist them. Another group said it would not be good practice because such an act would bring many problems among those who are affected like fueling the growth and perpetuation of stigma. Others said that people would say these are finished, meaning that they are going to die and stop caring for the person affected. During the discussion it was also revealed that people only emphasized on one mode of transmission that is sexual transmission. The only group of infected people exempt from this accusation was that of children who got infected through other means.

People have many different feelings when they think about people who have HIV/AIDS. The focus group discussions revealed that most people were

stigmatized. The actions considered stigmatizing were: “not paying” attention to what “you say”. In addition they do not regard you as a human being with contributions to make, though they pretend to. One reported that people when they think you are out of hearing range say “*angakambe cinji pakuti niosila*”, meaning “what can he say because he is already finished”. Some reported that food left over by them was always thrown away and never given to anyone else to eat the left over food. Children are told not scratch e.g. an uncle who has a rash and has HIV should never share sweets or bubble gum with any one infected. Though this is in line with preventive measures the discussant thought this was a discriminating act.

People who have tested positive have refused to go public for fear of “*ukubasula mu society*”. In English it literally means being looked down upon. PLWHA kept to them- self and people accused them that they did not want to socialize and yet they were trying to avoid stigma. It was also said such remarks made it difficult to disclose because even if you told some one and you happen to have misunderstandings with them they would reveal your status by saying this one is sick. The other reason given for reluctance to disclose was because no one wanted people to feel that they were useless, dying or are already dead.

It was also discussed that it was now easy to come for testing because one did not have to pay for drugs if found infected and there are a lot of support groups in the community. The policy of free medication and education on VCT has contributed a lot to the wellbeing of PLWHA, because people are able to see the benefits. The group felt that the only way to rid the community of the HIV/AIDS stigma was through education and this should not be centered around those that are infected but on every one.

CHAPTER SIX

6.0 DISCUSSION OF FINDINGS

The study was aimed at determining the various dimensions associated with HIV/AIDS related stigma experienced by PLWHA. The study revealed that there was a significant difference in the age and sex distribution of PLWHA. The majority 162 [65%] of PLWHA were female and results showed that women in all age groups were more willing to disclose their HIV status as opposed to their male counterparts. The majority 216 [87.8%] were Christians and 100 [40.7%] had attained secondary school status. Discussion of the findings will be centered on the following: Demographic characteristics, proportion of PLWHA affected extent of discrimination experienced, knowledge attitudes and self esteem.

Demographic Characteristics of the Respondents

The study showed that there was a significant difference in the age and sex distribution. The majority 39.4% was aged between 25-34 years while 34% were aged between 35-44 years. In all the age groups the females were more than the males. This could probably be attributed to the fact that the females are more open and willing to discuss their sexual activities or because it is easier to recruit and offer VCT to women attending reproductive health services at health facilities. This study supports most literature that says that the majority of people living with HIV/AIDS are women, [UNAIDS, 2002].

The research revealed that a large proportion 88% of respondents were Christians and 40% had reached primary education while 41% had reached secondary education. This scenario makes it feasible to impart education and spirit of caring to communities. At the same time one should be wary of the fact that stigma and associated beliefs can also impact on people receiving educational inputs. At the level of providing education and getting people to listen, there are many taboos about sex from traditional culture, religion, morality, as well as the hidden nature and sensitive role sex plays in

interpersonal relationships. The addition of information on a stigmatized disease like AIDS makes intervention all the more complicated [Crewe, 1992]

FORMS OF STIGMA

Stigma is manifested in many forms. Data from the study revealed that 25.6% of the respondents reported that PLWHA experienced stigma in many forms like people not shaking hands, sharing food, fearing to sit close and always in a hurry to move on because of one's status. This was supported in the focus group discussion when respondents discussed actions that were considered stigmatizing as: people not paying attention to what you say, not regarding you as a human being with a contribution to make and throwing food left over from your plate. The research is inclined to support the view that the respondents experienced "felt" stigma because the research results revealed that a large proportion did not reveal their HIV status. Felt stigma has also been referred to as self-stigmatization and fear of stigma. HIV thrives in an atmosphere of silence and secrecy. The stigma, real or feared, of HIV/AIDS often is a barrier to HIV prevention programs. Most of the respondents did not disclose their status nor openly talk about their HIV status. Lack of disclosure allows for the continued denial of the spread of the disease and is the breeding ground for stigma, suspicion and violence. Denial is generally seen as an individual or collective inability to face an intolerable reality by saying it does not exist.

Study results highlighted that a large proportion of 174 [70.7%] did not talk openly about their HIV status. This finding is supported by Mbwambo et al., [2001], who found that those who are aware they are HIV positive in Southern Africa often do not reveal their status for fear of the very real risk of being socially ostracized, abandoned or subjected to physical harm. Stigma also introduces a desire not to know one's own status, thus delaying testing and accessing treatment [Skinner, 2001].

It was further revealed that 2 [0.8%] had their privileges withdrawn while the majority 244 [99.2%] of the respondents had no privileges withdrawn as a result

of being HIV infected. Probably the majority did not have their privileges withdrawn because others did not know their status.

The study results revealed that 6 [2.5%] were excluded from social function because of their status but the majority 239 [97.2%] reported that they had not. The percentage of friends that reported discrimination was 4.5%. The high percentage of respondents that was not discriminated can be attributed to the fact that the majority of PLWHA had not revealed their status because of similar reasons that have been postulated for refusal of testing, or partner disclosure, such as stigma and fear of violence and desertion [Buyse, 2002, Sweat, et al., 2002]. The implication of these findings is that people are not aware of their status and have no basis to act negatively or positively.

KNOWLEDGE

Data highlighted that the majority [86.6%] of respondents agreed that HIV/AIDS related stigma was a problem; that was probably due to the fact that most of the respondents had attained primary and secondary education and were able to comprehend issues well. The findings of this research are in line with a research done in South Africa by Skinner and Mfecane [2004] who found that HIV/AIDS stigma is present and it has been documented that PLWHA experience stigma and discrimination on an ongoing basis.

In order to ascertain the causes of HIV being on the increase, the majority of respondents 156 [63.4%] attributed the increase to promiscuity being adopted as a strategy for survival while 79 [32.1%] attributed the increase to morals and cultural values being lower today. Morality has also become a key factor in the development of stigma in AIDS [Das, 2002]. HIV signifies moral digression and having had sex with some one you should not have had sex with. Hence, people point fingers at someone they suspect has HIV in Zambia, pronouncing, his own promiscuous and careless behaviour has caught up with him [Bond and Panos, 2001]. The implication of such a result makes it difficult to address the issue of

HIV/AIDS related stigma. This type of attitude re-enforces the silence because no one wants to be associated with a disease that has a sexual connotation attached to it.

Causes of HIV related stigma was well addressed by the respondents. The majority [85%] answered that it was due to lack of knowledge. Ignorance is often cited as one of the causes of HIV/AIDS stigma. Evidence in Zambia, Tanzania and Ethiopia shows that even when people have correct knowledge, people still have genuine fears about HIV transmission through casual contact with people they suspect to have HIV/AIDS [ICRW, 2002b]. Fear of contagion also arises from other dimensions of HIV/AIDS stigma: the fear of death, the fear of disfigurement and severe illness, and, moral attitudes [ICRW, 2002b]. Only a small proportion of the respondent in the current study attributed the causes of HIV/AIDS stigma to fear of contagion and self blame.

People have varying opinions of PLWHA. A large proportion 166 [67.5%] perceived that people said PLWHA deserve to be helped just like anyone else while 49 [19.9%] said all PLWHA were irresponsible people. Another 25 [10.2%] said they deserved what they were suffering from. The results of this research supports other studies that found a significant number of respondents who want people living with HIV to be clearly identifiable, to be separated from the rest of the population, or excluded from contact in schools, work and social institutions [Matthew et al., 1990; Strebel and Perkel, 1991]. This study has confirmed the suggestion of previous authors that people suspected to have HIV/AIDS are called 'careless' immoral, and castigated for having brought the disease on themselves [Bond and Panos, 2001].

DISCRIMINATION

Discrimination in the workplace based on HIV/AIDS status may include such consequences as dismissal from the job, unjustified restrictions relating to promotion [NAC, 2004]. Zambia has suffered long-term economic decline and

steady employment is highly valued. Data revealed that 18 [7.3%] of the respondents were discriminated and 0.8% had lost their job and 2.4% had their job description changed because of their HIV status. This could probably explain why people do not want to learn or admit their HIV status for fear of job loss.

The study revealed that 36 [14.6%] were excluded from family duties. The respondents were mainly excluded from performing heavy duties like farming and washing clothes. Some respondents saw this differential of treatment as an act of discrimination. This was more pronounced in respondents who were not permitted to do any form of household chores. This could be as result of self perceived discrimination or as a result of families deliberately not wanting them to participate.

Only a small proportion of respondents were deserted on disclosing their status. This is probably due to the fact that the majority of respondents were already widowed or divorced before knowing their status. A significant number 17 [6.9%] had been excluded from a social group because of their HIV status. This has negative impact on people who may want to disclose their status.

Regarding whether the clients had friends and relatives visiting them, the research results revealed that the majority 218 [88.6%] were not affected but 23 [9.3%] reported that friends were not visiting them because of stigma but others said this had no relevance because they had not disclosed their status. Reasons attributed to non-disclosure were fear of publicity and people talking a lot. Others said it was their secret and did not want people to know because they did not want to be stigmatized. According to Bond and Ndubani [1999] one man in rural Zambia said, "HIV is private here. No one likes to have their status known when they are still strong and they will keep it private I have never known anyone to go public because of his or her HIV status here. But it is public

because of the signs and symptoms even a child can tell that someone has HIV when they are very sick”.

Data on self-blame revealed that 51 [20.7%] blamed themselves for having tested HIV positive. Those who did not blame themselves attributed the blame to their partner or previous relations. Transmission from Mother to child may also have implications in the future. The results showed that one respondent blamed her mother who was sero positive at the time of conception. To be able to blame others is psychologically re-assuring as it divides the society into ‘us’ and ‘them’. Others may feel guilty as a result of their behaviors. They may feel guilty of allowing themselves to be infected but also of infecting innocents. This creates the stigma load borne by those groups seen as responsible [Crewe, 1992].

SELF ESTEEM

The study results revealed that 34.1% of the respondents felt they had lost their self-esteem and 59 [24%] wished that they were dead because of the problems that they may face. These included the burden of overcoming the illness, finding guardians for their children etc. The problems are so immerse that the respondents felt that there was no way out and therefore no point of living. Loss of self-esteem may cause one to have suicidal tendencies. A study carried out in New York City found that 9% of suicide victims were HIV positive [Mazruk, et al, .1997]. The disease is highly stigmatized and there are many instances of discrimination against sufferers and families. This could lead to suicide, both in infected as well as affected individuals because depressive symptoms are common among patients with HIV infection [Judd, et al,. 1997].

CHAPTER SEVEN

7.0 CONCLUSIONS AND RECOMMENDATIONS

7.1 CONCLUSION

The data highlights that stigma towards PLWHA is manifested in many forms like different treatment, gossip, loss of identity and loss of resources/ livelihood. HIV/AIDS related stigma is prevalent in PLWHA attending the Sandie Logie

clinic at St. Francis Hospital in Katete District. The results showed that 7.3% reported being discriminated. This study suggests that HIV/AIDS related stigma experienced by PLWHA attending the Sandie Logie clinic at St. Francis Hospital is manifested in the form of “felt” stigma. This is supported by a large proportion [71.5%] of respondents that did not disclose their HIV status due to fear, stigma and being talked about. Literature has supported that one of the greatest barriers to control of the Global Aids pandemic remains stigma. An understandable fear of other people’s prejudice, of how they will be seen by other people, the desire to protect their dignity and any person from various forms of assault, undermines HIV prevention by deterring people from seeking care

7.1 Recommendations

- Provision of a more enabling environment to increase visibility, of PLWHA as a normal part of any society through the national support structures like, MOH/Faith Based Organization/Private sector etc.
- Confront the fear based messages and biased social attitudes, in order to reduce the discrimination and stigma of people who are living with HIV/AIDS
- Scale up some of the core interventions particularly those targeting the community through information, education, communication with the local communities, faith based organization, government and Ministry of Community Development
- Continued support for activities that build the capacity and capability of the government to respond with timely actions e.g. HIV programs in primary/secondary and colleges.

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CONCEPTUAL FRAME WORK OF INDEPENDENT AND DEPENDENT VARIABLES



APPENDIX 2

QUESTIONNAIRE

Structured Interview Schedule for HIV/AIDS Related Stigma.

Date-----Questionnaire number-----

Interviewers code no. -----

INSTRUCTIONS TO THE INTERVIEWER

1. Please do not attempt to administer this instrument to other respondents without first familiarizing yourself with the attached interview guide.
2. When you interview respondents remember to ensure their privacy conduct the interview in a private place, preferably alone with the respondent.
3. Begin by administering the information sheets and consent form. Please make sure you read out this section and get the respondent's oral consent to participate in this study. You must get the informed consent before the interview. If the respondent refuses consent for the interview, please thank him/her and terminate the interview. Indicate the answer to the question by ticking [] in the box provided and write the response to open ended questions in the space provided. Please ask all questions.
4. At the end of the entire interview, check each questionnaire for completeness and accuracy and note down all the questions and concerns expressed by the respondents.

DEMOGRAPHIC DATA

1. **How old are you?**
- | | | |
|----|----------------------|---------|
| 1. | 15 years to 24 | [] |
| 2. | 25 years to 34 years | [] |
| 3. | 35 years to 44 years | [] |
| 4. | 45 years and above | [] |

2. **Sex**
- | | | |
|----|--------|---------|
| 1. | Male | [] |
| 2. | Female | [] |

3. **What is your marital status?**
- | | | |
|----|-----------|---------|
| 1. | Single | [] |
| 2. | Married | [] |
| 3. | Divorced | [] |
| 4. | Widowed | [] |
| 5. | Separated | [] |

4. **What is your religion?**
- | | | |
|----|---------------|---------|
| 1. | Christian | [] |
| 2. | Non Christian | [] |

5. **What is your highest level of education?**
- | | | |
|----|------------|---------|
| 1. | None | [] |
| 2. | Primary | [] |
| 3. | Secondary | [] |
| 4. | Technical | [] |
| 5. | University | [] |

6. **What is your occupation-----**

7. **How much is your house holds income?**
- | | | |
|----|---------------------|----------|
| 1. | Below K200, 000 | [] |
| 2. | K200, 000-K400, 000 | [] |
| 3. | Above K400, 000 | [] |

8. **How many children do you have** []

HEALTH STATUS

9. **How would you describe your health status?**
- | | | |
|----|-----------------|----------|
| 1. | Very good | [] |
| 2. | moderately good | [] |
| 3. | Unwell | [] |
| 4. | Very sick | [] |

10. **Are you currently taking anti retro viral medication for HIV infection?**
- | | | |
|----|-------------------|----------|
| 1. | Yes | [] |
| 2. | No | [] |
| 3. | If not why? ----- | |

11. **Have you experienced any discrimination by any health care worker due to your HIV status?**
- | | | | |
|----|------------|-----------------------|----------|
| 1. | Yes | [please give details] | [] |
| 2. | No | | [] |
| 3. | don't know | | [] |

12. If yes, how often has this happened to you?

- | | | |
|----|-------------|---------|
| 1. | Seldom | [] |
| 2. | Quite often | [] |
| 3. | Very often | [] |
| 4. | Constantly | [] |

13. Had a health worker ever refused to treat you/denied access to medical treatment or care because of your HIV status?

- | | | |
|----|------------|---------|
| 1. | Yes | [] |
| 2. | No | [] |
| 3. | Don't know | [] |

14. If yes, has this happened within the past year?

- | | | |
|----|-----|---------|
| 1 | Yes | [] |
| 2. | No | [] |

PRIVACY

15. What year did you test? []

16 Why was the test taken?

- | | | |
|----|--------------------------------------|---------|
| 1. | Employment | [] |
| 2. | Pregnancy [if woman] | [] |
| 3. | STI | [] |
| 4. | Referred due to HIV related symptom[|] |
| 5. | Partner tested positive | [] |

Others-----

17. Did you feel you were prepared to take the test at the time it was done?

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

18. **Were you coerced into having the test?**

1. Yes []

2. No []

19. **Did you receive any counseling before the test was taken?**

1. Yes []

2. No []

20. **Was someone else with you when you got the results?**

1. Yes []

2. No []

If yes what was their reaction? -----

21. **Did you want the other person to be with you at the time?**

1. Yes []

2. No []

22. **Has a health care worker ever told other people about your HIV status without you wanting them to know?**

1. Yes []

2. No []

3. Don't know []

23. **Have you told any one about your HIV status?**

1. Yes []

2. No []

24. If yes Why? -----

If no Why? -----

DISCRIMINATION

25. **Have you ever been refused entry to, removed from or asked to leave a public establishment due to your HIV status?**

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

26. **Have you ever been ridiculed insulted or harassed because of your status**

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

27. **Have any benefits, privileges or services given to others been denied to you because of you HIV status**

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

28 **Have you been excluded from any social function due to your HIV status?**

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

29. **Have friends ever discriminated against you because of your HIV status?**

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

RIGHT TO EMPLOYMENT

30. **Were you in paid employment at the time of you HIV diagnosis?**

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

31. Have you ever experienced any AIDS related discrimination in your work environment?

- | | | |
|----|------------|---------|
| 1. | Yes | [] |
| 2. | No | [] |
| 3. | Don't know | [] |

32. Has your employer ever discriminated against you because of you HIV status?

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

33. Have you ever felt discriminated against by your colleagues because of you HIV status?

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

34. Have you ever lost you job because of your HIV Status

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

35. Has your job description or duties changed because of you HIV status?

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

36. Have you been offered early retirement due to your HIV status?

- | | | |
|----|-----|---------|
| 1. | Yes | [] |
| 2. | No | [] |

RIGHT TO MARRY, AND FORM SIGNIFICANT RELATIONSHIPS

37. Since your diagnoses, have family members excluded you from usual family activities?

- | | | |
|----|-----------------------------|---------|
| 1. | Yes | [] |
| 2. | No | [] |
| 3. | If yes what activities----- | |

38. Has your partner deserted/divorced you because of you HIV status?

1. Yes []

2. No []

39. Has a health care worker ever advised you about having a child from the time you were diagnosed as HIV positive?

1. Yes []

2. No []

RIGHT TO SELF DETERMINATION AND ASSOCIATION

40. Have you ever been excluded from an association/societies/clubs self help groups due to you HIV status?

1. Yes []

2. No []

41. Do you know of a local self-help group for people living with HIV?

1. Yes []

2. No []

42. Do you intend to join a peer self-help group in the near future?

1. Yes []

2. No []

KNOWLEDGE

43. Do you think HIV/AIDS stigma is a problem here in Zambia?

1. Yes []

2. No []

44. Why do you think HIV is on an increase?

- | | | |
|----|--|---------|
| 1. | Morals & cultural values are low today | [] |
| 2. | Promiscuity has increased for survival | [] |
| 3. | I do not know | [] |
| 4. | Any other specify----- | |

45. What causes HIV/Aids related stigma?

- | | | |
|----|---------------------------|---------|
| 1 | Lack of knowledge | [] |
| 2. | Fear of contagion | [] |
| 3. | Self blame | [] |
| 4. | Family beliefs and values | [] |
| 5. | Religious beliefs | [] |

ATTITUDES

46. What is the opinion of people concerning PLWHA?

- | | | |
|----|--------------------------------------|---------|
| 1. | They deserve help like anyone | [] |
| 2. | There are irresponsible people | [] |
| 3. | Deserve what they are suffering from | [] |
| 4. | Any other----- | |

47. In what form do people show their stigma to you?

- | | | |
|----|--|---------|
| 1. | Fear of offering a handshake during greeting | [] |
| 2. | Afraid to sit close to you | [] |
| 3. | Always in a hurry to move on | [] |
| 4. | Refusal to share food with you | [] |
| 5. | Any other----- | |

48. In your opinion what measures should be put in place to improve the attitudes of people to wards PLWHA? -----

49. From the time you tested positive have your friends and relatives been visiting you?

1. Yes []

2. No []

If no, why? -----

SELF ESTEEM

50. Do you openly talk about your HIV status to friends and relatives?

1. Yes []

2. No []

3. If yes, why? -----

4. If no, why? -----

51. Do you blame your self for having tested HIV positive?

1. Yes []

2. No []

3. If not whom do you blame-----

52. Do you wish at times that you were dead because of your status?

1. Yes []

2. No []

3. If yes why? -----

53. Do you feel that you have lost your self-esteem since you were diagnosed HIV positive?

1. Yes []

2. No []

3. I don't know []

THANK YOU VERY MUCH FOR YOUR PARTICIPATION. YOU HAVE NOW COMPLETED THE QUESTIONNAIRE.

APPENDIX 3:

FOCUS GROUP DISCUSSION GUIDE

TITLE OF STUDY:HIV/AIDS RELATED STIGMA AND DISCRIMINATION EXPERIENCED BY PLWHA

OBJECTIVE: To determine the various dimensions/factors associated with HIV/AIDS related stigma experienced by PLWHA.

INTRODUCTION

The purpose of FGD is to obtain in-depth information on concepts, perceptions and ideas of the group. It is aimed at being more than a question answer interaction.

The members of the FGD will be PLWA. Twelve PLWHA will be selected randomly using lottery method. The interviewers will do a self-introduction. This will be followed by self-introduction of the group members. An explanation of the purpose for the focus group discussion will be explained to the respondents. The introduction of the specific topics will be read out to the group.

KNOWLEDGE

1. In your opinion what are the causes of HIV/AIDS?
2. What do you understand by the word stigma?

ATTITUDES

3. What is your opinion about people with HIV/AIDS, being separated from the public?
4. Should the names of the people with HIV/AIDS be made public?
5. Do you agree with the view of most people that PLWHA are responsible for their illnesses?

FEELINGS TOWARD PEOPLE WITH HIV/AIDS

6. People have many different feelings when they think about people who have HIV/AIDS, what actions would you consider stigmatizing?

HIV TESTING AND CONCERNS ABOUT STIGMA

7. What would be your concern if one of your significant others was going to be tested, and was found to be HIV positive.

INTERACTIONS FEELINGS AND INTENTION

8. For those who are working how are you treated by your fellow workers?
10. In your opinion why do you think people PLWHA are blamed and devalued when discovered to be HIV positive?
11. Are people afraid of contracting the HIV infection if they freely associated/socialized with you?
12. What would you recommend as the best practices for the community to rid themselves of the HIV/AIDS related stigma?

THE FACILITATOR SHOULD GIVE A SUMMARY AT THE END OF THE DISCUSSION OF THE POINTS RAISED AND THANK THE PARTICIPANTS



APPENDIX 4:

INFORMATION SHEET

This information sheet briefly introduces a research study on HIV and AIDS related stigmatization and discrimination. It is being carried out by an MPH student as part of the Masters in Public Health Dissertation

The study intends to collect information on HIV/AIDS related stigmatization /discrimination. The study will contribute towards a greater understanding of the nature of the stigmatization and discrimination to people living with HIV/aids.

I would like to interview you as part of the study. All information collected is to be voluntary, anonymous, and confidential. No record will be made of your name or other identifying details if you agree to take part in the study. You have the right to withdraw at any time, and to request that any data the project has gathered from you be destroyed.

During the interview you will be asked about your experiences, as a person living with HIV, in areas such as health, employment, education, privacy, freedom from inhuman treatment, family life, via a detailed questionnaire. The final report of the project will include the overall results from PLWHA in Katete. It is hoped that this report will be used as a tool for change e.g. in challenging community attitudes.

Risks

Although we are taking all the necessary steps to identify and reduce any psychosocial risk in participating in this study, there is a low risk of breaches of your confidentiality. In certain circumstances a breach of confidentiality could lead to stigmatization, such as losing Social Status, deprivation of Services, loss of job, media exposure, losing family and community support, being targeted by the authority or pressured by authorities to disclose the status of other participants.

All the interviewers are trained counselor and have signed agreements to protect the confidentiality of the participants. All data collected during this study will be kept confident and stored in a locked filing cabinet in the office of Principal Investigator until six months after the completion of the project, when all data will be destroyed. In addition no names will appear on the questionnaire.

Discomfort

There is the possibility that you may experience some emotional distress during the interview. You may decide to pause or stop the interview at any time, if necessary. In the event that you need psychological or physical support or advice concerning education, health or social support, a list of referrals to appropriate professional support services will be available to you.

The interview process takes approximately 30 to 45mins to one hour.

Benefits to participants and others

It is hoped that the data collected in this study will contribute towards a greater understanding of the nature of AIDS- related stigma and discrimination experienced by PLWHA. Data is essential in developing appropriate legal, social, cultural, and institutional responses to combat discrimination and human rights violations faced by people living with HIV.

APPENDIX 5:

INFORMED CONSENT FORM

TITLE: HIV/AIDS RELATED STIGMATIZATION/DISCRIMINATION IN KATETE

My name is **A. M. Chipungu**; I am collecting data on HIV and Aids Related Stigmatization/Discrimination in Katete District. If you have any questions about any aspects of the study, please feel free to contact **A.M. Chipungu, Cell No. 097-700877/095330624** or The Chairperson, Research Ethical Committee, Ridgeway box 50110, Lusaka.

Before you answer any questions I would like you to know that:

1. Your participation in this study is entirely voluntary. There are no risk or harm to you by virtue of your participation.
2. Even if you did not participate in this study you will still receive care in the hospital just like any body else.
3. You are free to terminate this interview at any time
4. There is no direct benefit to you but the information will be helpful in the prevention of HIV AND AIDS.
5. During the FGD we seek your permission to record the proceeding.

The data collected in this interview will be kept strictly confidential and will be available only to members of the research team. Excerpts from individual interviews may form part of the final research report, but under no circumstances will your name or any identifying characteristics be included in the report

May I seek your consent to interview? [If the respondent declines to be interviewed please thank the respondent and discontinue the interview]

Thank you for agreeing to take part in this study. I will now declare that you have given written consent for the interview

Name of interviewer: _____

Signature/Thumb print of respondent: _____

APPENDIX 6:

**LETTERS OF REQUEST AND PERMISSION TO CONDUCT RESEARCH ON
HIV/AIDS RELATED STIGMA AND DISCRIMINATION BY PLWHA IN KATETE**

The University of Zambia
Department of Community
Medicine
Box 50110,
Lusaka.

22nd December, 2004

The chairperson,
Research Ethics Committee,
P.O. Box 50110
Lusaka.

U.F.S.: The Head of Department
Community Medicine,
Lusaka.

Re: PERMISSION TO CARRY OUT A STUDY ON HIV AND AIDS RELATED
STIGMATIZATION/DISCRIMINATION IN KATETE DISTRICT

My name is A.M. Chipungu. I am kindly seeking for permission to carry out a study on the mentioned topic. I hope to carry out the study in St. Francis Katete. The research will entail interviewing clients visiting the clinic.

Thanking you in Anticipation

A.M CHIPUNGU
MPH STUDENT

The University of Zambia
Department of community
medicine
Box 50110,
Lusaka.

22nd December 2004

The Executive Director,
St. Francis Hospital,
P/bag 11,
Katete

U.F.S.: The Head of Department
Community Medicine,
Lusaka.

**RE: PERMISSION TO CARRY OUT A STUDY ON HIV AND AIDS RELATED
STIGMATIZATION/DISCRIMINATION IN KATETE DISTRICT**

My name is A.M. Chipungu and I am kindly seeking for permission to carry out a study on the mentioned topic. I hope to carry out the study in St. Francis Katete. The research will entail interviewing clients visiting the clinic and on ARVS. A letter to the ethical committee has already been written to seek for permission.

Thanking you in Anticipation

A. MAKANTA CHIPUNGU
MPH STUDENT

The University of Zambia
Department of community
medicine
Box 50110,
Lusaka.

22nd December, 2004

The Executive Director,
Katete Heath Board,
P.O. BOX 550089,
Katete

U.F.S.: The Head of Department
Community Medicine,
Lusaka.

**RE: PERMISSION TO CARRY OUT A STUDY ON HIV AND AIDS RELATED
STIGMATIZATION/DISCRIMINATION IN KATETE DISTRICT**

My name is A.M. Chipungu and I am kindly seeking for permission to carry out a study on the mentioned topic. I hope to carry out the study in St. Francis Katete. The research will entail interviewing clients visiting the clinic and on ARVS. A letter to the ethical committee has already been written to seek for permission.

Thanking you in Anticipation

A. MAKANTA CHIPUNGU
MPH STUDENT

Telephone: 06-252104
Telefax: 06-252134



In reply please quote

No.

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH

KATETE DISTRICT HEALTH BOARD

OFFICE OF THE DIRECTOR

P.O. BOX 550089
KATETE, ZAMBIA

KDHMB/EP/101/5/28

27th April, 2005.

Ms. A.M. Chipungu
Saint Francis Hospital
Private Bag 11
Katete.

Dear Madam,

**REF: PERMISSION TO CARRY OUT STUDY ON HIV/AIDS RELATED
STIGMATIZATION/DISCRIMINATION IN KATETE DISTRICT**

On behalf of Katete DHMT I acknowledge receipt of your letter in which you are seeking permission to carry out a study on the above subject.

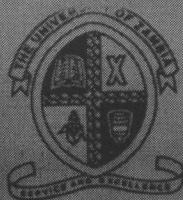
You are most welcome to conduct this study in Katete District. Your findings and recommendations will very much assist the district in putting in appropriate interventions.

Wish you the best of luck.

Yours Faithfully,

D.C. Popo

ACTING DISTRICT DIRECTOR OF HEALTH SERVICES - KATETE.



THE UNIVERSITY OF ZAMBIA

RESEARCH ETHICS COMMITTEE

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@zamtel.zm

Assurance No. FWA00000338
IRB00001131 of IOR G0000774

9 May, 2005
Ref.: 016-02-05

Mrs Makanta A. Chipungu
Department of Community Medicine
School of Medicine
University of Zambia
LUSAKA

Dear Mrs Chipungu,

RE: **SUBMITTED RESEARCH PROPOSAL**

The following research proposal was presented to the Research Ethics Committee meeting held on 30 March, 2005 where changes were recommended. We would like to acknowledge receipt of the corrected version with clarifications. The proposal has now been approved. Congratulations!

Title of proposal: **"HIV-related stigma and discrimination experienced by people living with HIV/AIDS in Katete District"**

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).

Yours sincerely,

Prof. J. T. Karashani, MB, ChB, PhD
CHAIRMAN
RESEARCH ETHICS COMMITTEE

Date of approval: 9 May, 2005

Date of expiry: 8 May, 2006



**THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE**

Telephone: 252640
Telegram: UNZA, Lusaka
Telex: UNZALU ZA 44370
Fax: + 260-1-250783
Email: kbowa@yahoo.com

Dean's Office
P.O. Box 50100
Lusaka, Zambia
Your Ref:

12th September, 2005

Mrs. Anne Chipungu
Department of Community Medicine
School of Medicine

Dear Mrs. Chipungu,

Re: MASTER OF PUBLIC HEALTH RESEARCH PROPOSAL

Your research proposal for the Master of Science in Public Health entitled: **"HIV-Related Stigma and Discrimination Experienced by People Living with HIV/AIDS in Katete District"** was presented at the Graduate Studies Committee of the School held on 13th May, 2005.

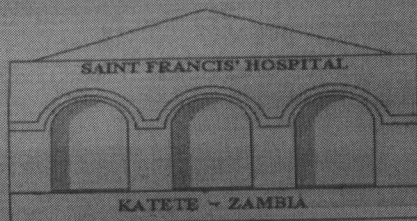
I am pleased to inform you that your proposal was approved by the Committee. You can proceed to Part II of the programme and your Supervisor is Prof. S. Siziya.

I wish you every success in your studies.

Yours sincerely,

Mr. K. Bowa
ASSISTANT DEAN, POSTGRADUATE

c.c Director, Graduate Studies
 Dean, School of Medicine
 Head, Department of Community Medicine
 Prof. S. Siziya, Department of Community Medicine



St Francis' Mission Hospital

Private Bag 11, Katete, Zambia

Tel: 062 52210/52344

Fax: 062 52278

Email: saintfrancis@zamtel.zm

27 April 2005

Ms Ann Chipungu
St. Francis' Hospital
P/Bag 11
KATETE

Dear Ann,

Re: RESEARCH ON HIV/AIDS RELATED STIGMATISATION

You are most welcome to perform this research here. I am sure the acting District Director of Health will also welcome you. We shall be looking forward to the results and any recommendations you have for the future.

Yours sincerely,

MEDICAL SUPERINTENDENT
ST. FRANCIS' HOSPITAL
P. BAG 11
KATETE, ZAMBIA

Dr S. Parkinson
EXECUTIVE DIRECTOR

cc. The District Director of Health