

UNIVERSITY OF CAPE COAST

STIGMATISATION AND DISCRIMINATION AGAINST HIV AND AIDS: A  
CASE STUDY OF PATIENTS AT ST. FRANCIS XAVIER HOSPITAL AT  
ASSIN FOSU

BY

DZIFA ABLA DUWOR

Thesis submitted to the institute for development studies of the faculty of social sciences, university of cape coast, in partial fulfillment of the requirements for the award of master of philosophy in development studies

November, 2016

## **DECLARATION**

### **Candidate's Declaration**

I hereby declare that this dissertation is the result of my own original work and that no part of it has been presented for another degree in this university or elsewhere.

Candidate's Name: Dzifa Abla Duwor

Signature:..... Date:.....

### **Supervisor's Declaration**

We hereby declare that the preparation and presentation of the dissertation were supervised in accordance with the guidelines on supervision of dissertation laid down by the University of Cape Coast.

Principal supervisor's Name: Prof. Akwasi Kumi Kyereme

Signature:..... Date:.....

Co-supervisor's Name: Prof. Akua O. Britwum

Signature:..... Date:.....

## **ABSTRACT**

The study explores the nature of HIV and AIDS stigma felt by PLWHAs and the effect this has on them in the Assin Fosu Municipality. This was pursued through examining the effect of stigma on the PLWHAs and assessing the coping strategies of the PLWHAs.

Descriptive and cross-sectional research designs were adopted to study the 256 HIV carriers from the Saint Francis Xavier Hospital at Assin Fosu. Interview schedules were used to collect data from the respondents. Statistical tools used to analyse the data collected included descriptive tools such as means, medians, frequencies, and percentages. Mann-Whitney U test was also used to test for significant differences where applicable and chi-square was used to test for significance in associations where applicable.

The study found that the forms of stigma could be describes as internalised stigma, workplace stigma, family-related stigma and stigma/discrimination at health posts. Moreover, the effects of stigma on PLWHAs were internalised, personal, family, community and health related. The coping strategies were mostly adaptive in nature. For example, in order to deal with stigma, most of the respondents chose adopted learning from educational campaigns, participating in HIV programmes, accepting the status quo, and avoiding confrontation. The study recommended further education campaigns, a focus on internal stigma and adopting self-help approaches for HIV carriers.

## **ACKNOWLEDGEMENTS**

I wish to acknowledge the support of my supervisors, Prof. Akwasi Kumi Kyereme and Prof. Akua O. Britwum, who had the patience to guide this work to a successful completion. I am also thankful the Saint Xavier Hospital administration and staff for the data they provided me with. I also wish to express my sincerest gratitude to all the respondents who participated in the study and to the staff of Assin Fosu Municipal Hospital who led me through the field survey. I also want to thank all my 2010 class mates of I.D.S, who were always on standby to lend a helping hand.

## **DEDICATION**

To my dear husband, Rev. Raymond Amarkyne and my three lovely children,  
Edmund, Kelvin, and Samuel.

## TABLE OF CONTENTS

<b>Content</b>	<b>Page</b>
DECLARATION	ii
ABSTRACT	iii
ACKNOWLEDGEMENTS	iv
DEDICATION	v
TABLE OF CONTENTS	vi
LIST OF TABLES	ix
LIST OF FIGURES	xi
LIST OF ABBREVIATIONS	xii
CHAPTER ONE: INTRODUCTION	1
Background to the Study	1
Statement of the Problem	7
Objectives of the Study	9
Hypothesis of the study	9
Significance of the Study	11
Organisation of the Thesis	12
CHAPTER TWO: REVIEW OF RELATED LITERATURE REVIEW	14
Introduction	14
Theories of Discrimination and Stigmatisation	14
Conceptualising Stigma and Discrimination	21
Types of HIV and AIDS Stigma	25
Manifestations of Stigma and Discrimination	31
Effects of HIV and AIDS Stigmatisation and Discrimination	36
Coping Strategies	40

Interventions to control HIV and AIDS Discrimination	43
Empirical Studies	46
Lessons learnt from Empirical Studies	54
Conceptual Framework for examining HIV-Related Stigma and Coping strategies	55
<b>CHAPTER THREE: METHODOLOGY</b>	<b>59</b>
Introduction	59
Study Area	59
Study Design	62
Study Population	63
Sample Size for the Study	63
Sampling Procedure	64
Data and Sources	64
Research Instrument	65
Pre-testing of Instruments	65
Ethical Issues	66
Data Processing and Analysis	66
<b>CHAPTER FOUR: RESULTS AND DISCUSSION</b>	<b>68</b>
Introduction	68
Demographic Characteristics of Respondents	68
The Nature of HIV and AIDS Stigmatisation	78
Workplace Discrimination and Stigmatisation	79
Family-related Discrimination and Stigmatisation	83
Discrimination in a Community Context	89
Healthcare Context	93





## LIST OF TABLES

Table		Page
1	Sex and age description of respondents	69
2	Length of living with HIV	78
3	Nature of workplace discrimination and stigmatisation	81
4	Discrimination in visitation	83
5	Discrimination in physical contact with family	85
6	Discrimination with sharing meals	86
7	Verbal abuse by family	87
8	Physical abuse by family	88
9	Family attempt to hide HIV carriers	89
10	Exclusion from community events	90
11	Secondary discrimination of relatives of HIV carriers	91
12	Verbal abuse by community members	92
13	Ostracism from community	93
14	Discrimination in health services	94
15	Internalised stigma among HIV carriers	96
16	Effects of HIV Stigma on healthcare services	100
17	Effects of HIV stigma on family and friends relations	101
18	Effects of HIV stigma on the upkeep of HIV carriers by sex	103
19	Effects of HIV stigma on the upkeep of HIV carriers by age	104
20	Coping strategies for internalised stigma	106
21	Coping strategies for stigma from family and friends	109

## LIST OF FIGURES

Figure		Page
1	Conceptual framework for HIV stigmatization	58
2	Educational characteristics of respondents	72
3	Marital status of respondents	73
4	Religious affiliation of respondents	74
5	Occupational characteristics of respondents	75
6	Modes of contracting HIV	76
7	Mode of diagnosis of HIV status	77
8	Discrimination at work place	80

## **LIST OF ABBREVIATIONS**

Abbreviation	Meaning
AIDS	Acquired Immunodeficiency Syndrome
HIV	Human Immunodeficiency Virus
NGO	Non-governmental Organisation
PLWHA	People living with HIV and AIDS
UNAIDS	United Nations Programme on HIV and AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

# **CHAPTER ONE**

## **INTRODUCTION**

### **Background to the study**

HIV and AIDS is one of the most devastating worldwide public health problems in recent history (UNAIDS, 2007; World Health Organisation (WHO), 2015). It is estimated that 41.4 million people around the world are living with HIV and AIDS as at the end of the year, 2014. Despite, the unrelenting efforts by various governments to curtail the spread of the pandemic, the rate of infection is high. According to UNAIDS (2015), approximately 2 million people worldwide were infected with HIV as the close of 2014. Since 2000, around 38.1 million people have become infected with HIV and 25.3 million people have died of AIDS related illnesses. (UNAIDS, 2015)

The primary modes of HIV transmission are unprotected sex with an infected person and intravenous drug use (WHO, 2010). More than 70 percent of HIV infections however are transmitted through sexual contact. Traditionally, in the United States the majority of cases were found in homosexual or bisexual men (Kusmer, 1990).

In 2007, about half of new HIV cases were acquired by men having sex with other men. Fewer than 20 percent of HIV-positive Americans were women. However, this is not the case worldwide, where transmission by heterosexual individuals is common. As of early 2009, there was no vaccine available to prevent HIV infection. Until such a vaccine was developed, all forms of HIV and AIDS therapy were focused on improving the quality and length of life for people

who are infected by slowing or halting the replication of the virus and treating or preventing infections and cancers that often develop in people with AIDS.

AIDS is a global pandemic, but the highest number of HIV and AIDS cases is found in sub-Saharan Africa and Southeast Asia. WHO (2009) reports that sub-Saharan Africa continues to be the most affected region in the whole world with more than three quarters of women living with HIV and two thirds of total number of people living with HIV in sub Saharan Africa.

Persons Living With HIV (PLHIV) are stigmatised throughout the world to varying degrees. PLHIV and people suspected of having HIV and AIDS have been the targets of stigma ever since the disease was first detected in the United States in 1981 (Herek, 1990). Whereas the characteristics of AIDS as an illness probably make some degree of stigma inevitable, AIDS has also been used as a symbol for expressing negative attitudes toward groups disproportionately affected by the epidemic (Herek et al., 2003). Stigmatisation is what is currently crippling the efforts made to reduce the HIV and AIDS pandemic (UNAIDS, 2004). Crocker, Major and Steele (1998) defined stigma as any characteristic, real or perceived, that conveys a negative social identity.

Stigma is a severe social disapproval of or personal discontent with a person on the grounds of their unique characteristics distinguishing them from others in society. Almost all stigmas are based on a person differing from social or cultural norms. Goffman (1963) sees stigma as the process by which the reaction or perception of others spoils another individual's normal identity. According to Falk (2004), there are basically three forms of stigma recognised by

social scientists; that is the experience of a mental illness, a physical form of deformity or an undesired differentness, and an association with a particular race, religion, belief and so forth.

Numerous factors have been identified to influence the development of HIV related stigmas. When conditions improve or worsen with the passage of time, symptoms appear gradually or suddenly, meaning; the patient may be rendered unattractive by the disease and this will cause other people to react towards him/her in various ways (Herek, 1997).

AIDS is a condition that displays a number of characteristics that are especially vulnerable to stigmatization: first, stigma is more often attached to a disease whose cause is perceived to be the bearer's responsibility (Akrutu, 2002). To the extent that an illness is perceived as having been contracted through voluntary and avoidable behaviours, especially if such behaviours evoke social disapproval, it is likely to be stigmatized and to evoke anger and moralism rather than pity or empathy (Herek et al., 2003). Thus, because the primary transmission routes for HIV are behaviours that are widely considered voluntary and immoral, (homosexuality, promiscuity, sex with sex workers, injecting drug use and so forth), PLHIV are regarded by a significant part of the public as being responsible for their condition and consequently are stigmatized (Falk, 2004).

Second, greater stigma is associated with illnesses and conditions that are unalterable or degenerative (Falk, 2002). Since the earliest days of the epidemic, AIDS has been widely perceived as a fatal condition. Being diagnosed with such a disease is often regarded as equivalent to dying, and those who are diagnosed may

represent a reminder, or even a personification, of death and mortality (Falk, 2004).

Third, greater stigma is associated with diseases or conditions that are perceived to be contagious (UNAIDS, 2002). Perceptions of dangers and fear of contagion have surrounded AIDS since the beginning of the epidemic. Fourth, a condition tends to be more stigmatized when it is readily apparent to others, and disrupts a social interaction or is perceived by others as repulsive, ugly or upsetting (Falk, 2002). In this regard, the advanced stages of AIDS dramatically affect an individual's physical appearance and stamina, evoking distress and stigma from observers (Herek et al., 2003).

AIDS related stigma may be defined as all unfavourable attitudes, beliefs, behaviours, and policies directed at persons perceived to be infected with HIV (Falk, 2002). This means that a vast number of people have experienced some form of discrimination based on their HIV status, and that many more have the potential of becoming vulnerable to stigmatization, rejection and discrimination once their status becomes known to others. AIDS-related stigma and discrimination refer to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS (Falk, 2002). AIDS stigma has been manifested in discrimination, violence, and personal rejection of people living with HIV and AIDS-PLHIV (UNAIDS 2002). AIDS stigma around the world is expressed through social ostracism and personal rejection of PLHIVs, discrimination against them, and laws that deprive them of basic human rights (Mann et al. 1992). According to Herek (1990), AIDS stigma includes being

evicted from their homes, fired from their jobs, and shunned by family and friends.

The consequences of stigma are wide-ranging and include being shunned by family, peers and the wider community; poor treatment in healthcare and education settings, an erosion of rights, psychological damage, and a negative effect on the success of HIV testing and treatment (Herek et al. 1997). Discrimination could be understood as unfairly disadvantaging a person on the basis of some capacity or quality attributed to that person. Discrimination is a highly subjective phenomenon as it is mostly determined by perceptions and preconceived notions of the person who is discriminating. It does not have to be based on verifiable facts (Herek et al. 1997). For example, a person who is merely suspected to have HIV and AIDS can be a target of discrimination just as much as someone who has tested positive and has disclosed his/her status to others (Herek, 1997).

Although HIV stigma is effectively universal, it takes different forms from one country to another and its specific targets vary considerably (Rogers et al., 1993). This variation is shaped in each society by multiple factors, including the local epidemiology of HIV and pre-existing prejudices within the culture. A consistent pattern is that stigma is often expressed against unpopular groups disproportionately affected by the local epidemic (Mann et al., 1992). The public has consistently expressed negative attitudes toward PLHIVs since the epidemic began and has supported authoritarian and punitive measures against them, including quarantine, universal mandatory testing, and even tattooing of infected



individuals (Herek & Glunt, 1988). Such attitudes have fluctuated in their prevalence, with support for punitive policies highest in the late 1980s (Blendon, et al., 1992; Herek et al. 2003; Rogers et al.1993; Herek, 1997). In a 1997 national telephone survey, more than one fourth of the U.S. public expressed discomfort about associating with a PLHIV in a variety of circumstances (Herek et al. 1997). In 1996, federal legislation was enacted that singled out HIV-positive military personnel for discharge while ignoring other active-duty personnel with comparable serious medical conditions (Shenon, 1996). As part of the stigmatisation in South Africa, an HIV-infected volunteer was beaten to death by neighbours who accused her of bringing shame on their community by revealing her HIV infection (McNeil, 1998). In rural Tanzania, having AIDS is often attributed to witchcraft and PLHIV are frequently blamed for their disease (Nnko, 1998).

AIDS stigma affects the well-being of PLHIVs and influences their personal choices about disclosing their serostatus to others (Ghana Human Development Report, 2004). It also affects PLHIVs' loved ones and their caregivers, both volunteers and professionals. Stigma has hindered society's response to the epidemic, and may continue to have an impact as policies providing special protection to people with HIV face renewed scrutiny (UNAIDS, 2002). Herek (1990) opines that the issue of HIV and AIDS stigma still remains increasingly resilient in many societies due to widespread fear of the disease, lack of accurate information about its transmission, and willingness to support

draconian public policies that would restrict civil liberties in the name of fighting AIDS.

### **Statement of the problem**

As stated by The UN Secretary-General Ban Ki Moon in 2008, stigma is a chief reason the AIDS epidemic continues to devastate societies around the world. The reason according to him is that, people fear the social disgrace of speaking about HIV, or taking easily available precautions. In Ghana, HIV stigma and discrimination is a significant factor and is a hindrance to accessing HIV prevention services resulting in exposure to HIV infection (Amoa, 2005). It has been reported by the Ghana Behavioural Surveillance Survey (2006) that HIV and AIDS stigma may well be the greatest obstacle to action against the epidemic, for individuals and communities, as well as political businesses and religious leaders. This is mainly due to the fact that the nature of HIV and AIDS stigma and its complexities remain poorly understood and under-explored.

According to Galvao et al. (2013), after nearly two decades of extensive public education about HIV and AIDS and its related stigma, one would have expected that AIDS-related prejudice and discrimination would have been relics of the past. Despite the important scientific advances that have been made, stigma and discrimination still create major challenges that must be overcome if we are to have a meaningful and lasting response to HIV. These challenges carry a high cost in human suffering and in the violation of the human rights of PLHIV across the world. They are obstacles that stand in the way of making the necessary

transformations to reduce new HIV infection rates and associated diseases and deaths. (Galvao et al. (2013).

Stigma reduction can only be successful when there is a deeper understanding of the nature of stigma and the complexities surrounding its continual existence. In fact, the need for a systematic inquiry into the nature of HIV and AIDS stigma and its concomitant implications is long overdue. . Even though HIV and AIDS research is not new to scientific enquiry in Ghana, majority of the empirical studies have been centred on its causes, effects, prevention and clinical treatments of the pandemic Comparatively, little academic research is available on HIV and AIDS related stigma and discrimination and its implications on persons living with HIV and AIDS (Piot & Seck, 2001).

This study therefore attempts to fill a gap in the Ghanaian HIV and AIDS research on stigmatization and discrimination by providing some quantitative evidence regarding the nature and complexities of HIV and AIDS stigma and its implications for HIV and AIDS prevention, care and treatment.

In relation to the problem identified above, the following research questions have been formulated to help bridge the gap: What is the nature of stigma against PLHIV? Does stigma has any effect on PLHIV? What mechanisms (coping strategies) do HIV patients employ to overcome stigma? What measures can be put in place to address the phenomenon of HIV and AIDS stigma?

## **Objectives of the study**

The main objective of the study was to explore the nature of HIV and AIDS stigma felt by PLHIV and the effect this has on them in the Assin Fosu Municipality. Specifically, the study strove to:

1. Analyze the nature of stigma against PLHIV;
2. Examine the effect of stigma on PLHIV;
3. Assess some of the mechanisms employed by PLHIV to overcome being stigmatized; and
4. Discuss some of the ways by which stigma against PLHIV can be reduced.

## **The study will test the following Hypothesis**

### **1. Hypothesis tested for the psychological effects of stigma on PLHIV**

The effects of stigma on the individual were related to gender to assess whether or not being male or female influences the effects of stigma on an individual. This was done to confirm or otherwise the assertion made by Galvao et al. (2013).

The following hypotheses are tested for the significance using the data;

A.

$H_0$ : Being male or female does not influence Self blame

$H_1$ : Being male or female influences self blame.

B.

$H_0$ : Being male or female does not influence Lost of hope

$H_1$ : Being male or female influences Lost of hope.

C.  $H_0$ : Being male or female does not influence depression and loneliness

$H_1$ : Being male or female influences depression and loneliness

**2. Hypothesis tested for the effects of stigma on upkeep of PLHIV by sex and age.**

The effects of HIV stigma on the upkeep of PLHIV by sex is tested for significance in age differences of respondents given adequate food and those who were not.

A.

$H_0$ : There is no significant relationship between the sex of respondents and their feeding at home.

$H_1$ : There is no significant relationship between the sex of respondents and their feeding at home.

B.

$H_0$ : There is no significant difference in the ages of respondents and their feeding at home.

$H_1$ : There is a significant difference in the ages of respondents and their feeding at home.

C.

$H_0$ : There is no significant difference in the ages of respondents who were asked to leave home and those who continued to stay with their families after the HIV diagnosis.

$H_1$ : There is a significant difference in the ages of respondents who were asked to leave home and those who continued to stay with their families after the HIV diagnosis.

D.

$H_0$ : There is no significant difference in the ages of the respondents who had adequate health support at home and those who did not.

$H_1$ : There is a significant difference in the ages of the respondents who had adequate health support at home and those who did not.

### **Significance of the study**

The literature on HIV and AIDS shows that much academic inquiry has been done on topical issues like the modes of transmission, treatments available, preventive mechanisms and so forth but much less has been carried out on stigmatisation patients of this disease suffer from their friends, relatives and of course co-workers. This study therefore seeks to make an inroad into the nature and complexities surrounding HIV and AIDS related stigma and discrimination and the implications on persons living with the disease. This would help provide information for national and international agencies and policy makers such as the World Health Organization, NGOs and the Ghana AIDS Commission to evolve high priority programmes to mitigate the stigma surrounding the pandemic. That is, findings from this investigation would pave the way for reducing the idea of fear and misconception surrounding PLWAs.

This is necessary because the increasing rate of HIV and AIDS transmission and the non-effectiveness of intervention programmes have been blamed on widespread stigmatisation associated with the epidemic (UNAIDS, 2007; WHO, 2009). This study would further contribute to the existing stock of knowledge on HIV and AIDS related stigmatisation and discrimination and also

serves as a basis for further researches by academics, students and other scholars on the stigma surrounding the disease.

### **Organisation of the thesis**

The study is structured into five chapters. Chapter One which presents the background to the study comprises the research problem, objectives, rationale for the study, hypotheses and organization of the thesis. Chapter Two addresses the conceptual and theoretical approaches relevant to the study. Some of the theories reviewed included the Goffman's theory of social stigma, social identity theory, instrumental and symbolic stigma model, PEN-3 model and the human needs theory/Maslow's pyramid of needs. The Goffman (1963) theory of social stigma framework was considered suitable and adapted for the study.

Chapter Three describes the specific research methods used in the study and addresses issues such as the epistemological and philosophical underpinnings of the study. These include the study design, the target population, data and sources, sample size and sampling procedures. Others are data collection instruments, data processing and analysis, ethical issues involved and limitations. Results and discussion constituted Chapter Four. The chapter presents the main findings of the study and situates them in the context of the conceptual and theoretical framework. It also discusses the nature of stigma against PLHIV, the effect of HIV and AIDS stigma on PLHIV, the mechanisms employed by PLHIV to overcome stigma and some of the ways by which HIV and AIDS stigma can be reduced in the Municipality.

Chapter Five, which is the final chapter, presents the summary, conclusions and recommendations. The chapter synthesizes the key issues which emerged out of the discussion, summarises the main findings, and draws conclusions and recommendations.



## CHAPTER TWO

### REVIEW OF RELATED LITERATURE REVIEW

#### **Introduction**

This chapter deals with theoretical, empirical issues as regards HIV and AIDS stigmatisation. Theories, concepts, and empirical studies are synthesised in a conceptual framework which is presented diagrammatically.

#### **Theories of discrimination and stigmatisation**

From a social context, stigmatisation has been described as placing negative labels on certain behaviours, objects and personalities. One of the pioneering theories is the labelling theory, which is supported by writers such as Becker (1963) and Goffman (1963).

Durkheim (1952) first referred to stigmatisation as a form of deviant labelling, which satisfies societies need to control acts that outrage society. Stigmatisation results from a socially constructed and reconstructed conception of the self through the interactions that each person has with the community. The labelling theory therefore suggests that people obtain labels from how others view their tendencies or behaviours. The theory is also based on the assumption that each individual in society is aware of how they are judged by others. It is therefore the assumption that the stigmatised minorities are aware of society's reaction towards them because they have engaged in many different social interactions and can predict the reactions of those present.

The labelling theory maintains that society stigmatises actions believed to be deviant and thus, any individual who engages in such an action automatically assumes that stigma. For example, HIV is often labelled as a deadly infection and society often labels it with deviant behaviours. The general assumption is therefore that any HIV carrier must have engaged in some sort of deviant sexual act to have contracted the virus (Link et al., 1989). As such, HIV and AIDS stigma is perceived as an individual's deviance from socially accepted standards of normality and can include such deviances as immorality, promiscuity and perversion. The publicly known HIV carrier is readily stigmatised as some kind of a deviant in society based on the fact that he/she carries an infection, which is generally associated with deviant behaviours (Zhou, 2007).

This leads to a situation where society generally shuns the stigmatised in order to avoid being labelled with the negative assumptions, which are attached to the minorities. Smart (2004) gives a similar explanation underlying some reasons people living with HIV and AIDS are estranged by families and friends. In some societies, Vito stigmatisation is used as a form of punishment and to caution other members of the society about the labelled ones. This leads to general discrimination towards the stigmatised and in some cases society accepts and expects mass discrimination against those stigmatised.

Although the labelling theory offers a useful insight into the social construction of deviance, it has been criticised on the grounds that it describes the person being labelled as passive victims, who play little or no role in the labelling process. The deviants may continue their behaviour because they find it

rewarding, thus encouraging further negative labelling of their deeds and their personalities.

The labelling theory is also criticised for being weak in explaining the motivation behind deviant acts that attract labelling. According to Cullen (1984), the proponents of the theory offer a sound analysis of the process of becoming deviant, but no explanation of why some are in that position to be labelled in the first place.

He also argued that critics of the labelling theory fail to recognise the real nature of its task. He clarifies that the purpose of the theory was to examine the social processes governing the nature, emergence, application and consequences of labels. In this sense, the labelling theory sees society as constructed through an exchange of gestures, such as body postures, closeness and touch, as well as symbolic communication, such as clothes and talk, and negotiated meanings between people. Therefore, in the sense of HIV and AIDS stigmatisation, the labelling theory applies when gestures and symbolic communication between HIV carriers and other people express meanings that show stigma and discrimination (Smart, 2004).

Deng et al (2007) emphasise that a major consequence of stigmatisation is discrimination, which occurs when an individual is treated unfairly and unjustly due to the perception that the individual is deviant from others. In theory, Becker's (1957) taste-based theory originally indicates that people, such as employers, customers, and employees sometimes refuse to work with particular kinds of people because they have preference against the those groups. Parker and

Aggleton (2003) explains that this may result from preconceived ideas about the avoided class and the social stigma that is perceived to result from associating oneself with the avoided class. For example, in Smart's (2004) description of enacted stigma against people living with AIDS/HIV (PLHIV), it is indicated that society or individuals within may physically and socially isolate PLHIV in order to avoid being stereotyped along with PLHIV.

Becker (1957) also theorises that discrimination can be underlain by incomplete information about the group being avoided. For example, Gilmore and Somerville (1994) indicate that individuals harbouring inaccurate information and belief about the transmission and causes of HIV and AIDS may discriminate against HIV carriers; one can however argue that, describing discrimination based on incomplete or inaccurate information is not satisfying because it implies that individuals are making systematic errors about other groups within society. Mill (2003) emphasises that individuals may discriminate against particular groups because the groups may express and demonstrate behaviours, which reinforce negative prior beliefs about members therein. Thus, these negative perceptions become self-fulfilling exemplifying that, fears of associating oneself with an HIV and AIDS carrier may be reinforced if someone who openly associates him/herself with HIV and AIDS carriers contracts the disease, even if that individual did not contract the disease from any of those HIV and AIDS carriers with which he or she allies with.

Becker (1957) proposes a general theory of discrimination, but at its core, the theory only describes discrimination based on results of actions that resembles

discriminatory behaviour. He asserts that the theory only provides a circular definition of discrimination. In Heyer and Jayal's (2009) opinion, Becker (1957) readily assumed the fact that discrimination is always against the minority group, but Heyer and Jayal (2009) states the case of positive discrimination, where members of a minority group are given preferential treatment over a majority group, often by gender, race, age or sex orientation.

Discrimination may also result from an individual's sense of him/herself based on his/her group membership (Smart, 2004). Tajfel (1986) theorised this form of discrimination as the social identity theory. The social identity theory originally explained the psychology behind prejudice and discrimination against particular groups in society. The theory proposes three cognitive processes which lead to prejudice and discrimination, which are social categorisation, social identification and social comparison. Social categorisation refers to the process of deciding which group one belongs to. Goffman (1968) emphasises that society establishes the means of categorising persons and the complement of attributes felt to be ordinary and natural for its members.

According to Parker and Aggleton (2003), social categorisation forms the basis for individuals to derive their sense of identity according to the social categories which they perceive themselves as belonging. Social identification therefore refers to identifying oneself with the in-group overtly and adopting the norms and attitudes of other group members within the group (Anderson, 2004). In the final stage, the individual becomes wrapped-up with the in-group and holds the perception that the in-group is better than the out-group. Thus, stereotypes are

formed about the out-group and overtly manifested in other forms of discrimination and preferential treatment.

Every person identifies with some institution or attribute in society, for example on the basis of gender, family affiliation, physical attributes, or health status. In further elaboration a taller person may harbour or enact some stereotypes about shorter people, because the taller person may be of the conception that it is physically more esteemed to be taller. Other superiority complexes may be formed from being male against being female and in the same way, society may hold lesser esteem for HIV carriers and thus discriminate against them as the out-group.

The theory therefore suggests that an individual may identify with several groups and assume mixed attitudes and self-esteem from the different groups. It is therefore possible for a person to have several stereotypical conceptions about other people who are outside the groups with which he/she associates.

Foster and Potgieter (1995) maintain that stereotypes are formed through the process of social comparison, in which one's own group is compared to specific out groups using some dimension of comparison. The outcome of the process is a graduation differences, termed a status hierarchy (Turner 1986). If an out-group is perceived to be superior to the in-group in some relative dimension, it is accorded a higher status. On the other hand, if it is perceived as inferior, it assumes a lower status and negative stereotypes, which may also be described as stigma; this may be described as the self-esteem hypothesis, in which the perception of oneself leads encourages discrediting others based on their

perceived moral flaws. Therefore, an HIV-negative person may assume some level of self-esteem over HIV-positive persons based on some form of discrediting perception against PLHIV. Deacon et al.(2005)also indicates that, in the categorisation process, the perception of people in terms of categories has relevance to the classifier's predisposition about the moral conceptions within society. For example, people who use ways of transmission as a classifying criterion may argue that those who lead a promiscuous life deserve to be HIV-positive, but may feel pity for those who are infected through blood transfusion (Mankoe et al, 2008).

There are some controversies with the social identity theory. Some writers however, argue that the self-esteem hypothesis misunderstands the distinction between a social identity and a personal identity. For example, the self-esteem hypothesis, which is central to the social identity theory is criticised for being more related to self-identification than to group identification. Thus, self-esteem hypothesis would be more appropriate in the description of in-group comparison than to inter-group comparison.

Some researchers assert that social identity theory draws a direct link between identification with a social group and in-group favouritism and that a main premise of social identity theory is that in-group members will favour their own group over other groups. (Operario & Fiske, 2001) Other researchers argue that though popular versions of social identity theory argue that social identification leads automatically to discrimination and bias, in fact, discrimination and conflict are anticipated only in a limited set of circumstances

(Turner, 1986). He explains further that the likening of social identity theory with in-group favouritism is attributable to the fact that Tajfel (1986) included empirical examples of in-group favouritism in the theory.

Social identity theory has also been criticised for having far greater explanatory power than predictive power (Miller and Rubin (2007). The criticism establishes that while the relationship between self-esteem and the resulting intergroup behaviour may be consistent with the theory in retrospect, the particular behavioural outcome is often not that which was predicted at the outset. Tuner and Reynolds (2001) argue, on the other hand, that the theory was never proposed as the definitive answer to understanding intergroup relationships. Instead, it is stated that social identity theory must go hand in hand with sufficient understanding of the specific social context under consideration.

### **Conceptualising stigma and discrimination**

Gilmore and Somerville (1994) indicate that stigma has two major meanings; one which refers to physical bodily marks, and the other which denotes marks of disgrace, discredit, or infamy. According to Parker and Aggleton (2003), literature on HIV and AIDS stigma does not explicitly define stigma, but cursorily refers to stigma as a mark of disgrace. This conception, in Deacon et al.(2005)'s (2005) opinion, is underlain by Goffman's (1963) definition of stigma as an attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted and discounted one.

Generally, stigma is seen as that part of identity that has to do with prejudice. It is the setting apart of individuals or groups through the attachment of



heightened negative perceptions and values (Mawar et al. (2005). UNAID (2005), for example, describes stigma as a dynamic process of devaluation that significantly discredits an individual in the eyes of others. Marta et al. (2008) also define stigma as the social expression of negative attitudes and beliefs that contribute to processes of rejection, isolation, marginalisation and harm of others. Similarly, one can also deduce that stigma refers to the identity that a group creates about a person or a group, based on some physical, behavioural or social traits that do not conform to the normal or acceptable traits in society.

Link and Phelan (2001) argue that stigmatisation is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination. They therefore disaggregate stigma into components, including labelling, stereotyping, separation, status loss, and discrimination, and further indicate that for stigmatisation to occur, these components must co-occur in a power situation that allows them to unfold. In Shisana and Simbayi's (2002) opinion, the interaction of these components, leads to attaching a label of shame to someone or a group, which leaves the stigmatised with a feeling of being responsible for the assigned undesirable status. Similarly, Parker and Aggleton (2003) also define stigma as social processes that is linked to societal power structures.

According to Maluwa et al. (2006), stigmatisation is often antecedent to discrimination, because society tends to treat the stigmatised differently and often

with less favour than other upheld members of society. Discrimination can therefore be conceptualised as one of the many results of stigmatisation (Thomas, 2006). Zhou (2007) captures this notion in the definition that discrimination is an action based on a pre-existing stigma, and it is a display of hostile behaviour towards members of a group, on account of their membership to that group. UNAIDS (2008) also agrees that discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatised. The acts of discrimination may include any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group .(Galvao et al. (2013).

Discrimination, as a concept, is therefore the prejudicial and/or distinguishing treatment of an individual based on their actual or perceived membership in a certain group or category, in a way that is worse than the way people are usually treated. It involves the group's initial reaction or interaction, influencing the individual's actual behaviour towards the group or the group leader, restricting members of one group from opportunities or privileges that are available to another group, leading to the exclusion of the individual or entities based on logical or irrational decision making.

Deacon et al. (2005), however, argues that defining stigma as something that result in discrimination reduces the analytical clarity about the relationship between stigma and its effects. Deacon et al.(2005)draws this conclusion from Joffe's (1999) explanation that anyone can stigmatise, no matter what their social

position. Poorer and more marginal groups can stigmatise wealthier and more powerful groups, both within and between societies. The process of stigmatisation can therefore continue to happen because there is a psychological pay-off for the stigmatiser, whether or not it can be acted as discrimination in the current social context.

Secondly, even in the absence of any active discrimination, stigma may have a negative impact on the self-concept and actions of stigmatised people. Expecting to be stigmatised or discriminated against may change people's behaviour, causing social withdrawal and consequent disadvantage. Mills (2003) shows how fear of HIV and AIDS-related stigma affects people's ability to accept and access services from clinics and home-based carers in South Africa.

From the above discussions, it can be concluded that internalisation of stigma alone can lead to self-doubt, lower self-esteem, depression, immune-suppression and even premature death.

With reference to HIV and AIDS infections, stigmatising discourse allows people to distance themselves and their self-defined in-groups from the risk of infection by blaming contraction of the illness on characteristics normally associated with out-groups, who are classified as deviants. Mawar et al. (2005) also observe that stigmatisation is used to set the affected persons or groups apart from the normalised social order and this separation implies devaluation. Mawar et al. (2005) further elaborate that in different contexts, for example, various different groups have been defined as particularly at risk for, and somehow responsible for contracting HIV and AIDS, including those labelled as

promiscuous people, gay men, commercial sex workers and women, in general. Deacon et al.(2005)therefore describe HIV and AIDS stigmatisation as a social process in which the illness is constructed a preventable, but some people's choice to discontinue behaviours, which are classified by society as immoral, cause them to get infected, and as such status loss is projected onto them, which may or may not result in their disadvantage.

According to Taylor (2001), stigmatising views exist as social discourse and draw on existing forms of social prejudice and power, but they are enacted by individuals to reduce perceptions of personal risk. Therefore, Deacon et al's definition of HIV and AIDS stigma helps in the understanding of both the individual and the social dimension of stigma. In Bond et al.'s (2002) opinion, Deacon et al. (2005) links stigma to its necessary consequences, such as status loss in the view of the stigmatiser, without defining it specifically in terms of discrimination.

### **Types of HIV and AIDS stigmaand discrimination**

The nature of stigma can be best described within the context of the different types of stigma. Simbayi et al. (2007) maintain that distinguishing between the various types of stigma helps to establish the socio-cultural and historic context within which HIV and AIDS stigma and discrimination occurs. Several authors, such as Smart,(2004) and Miller and Rubin (2007), agree that stigmatisation can be categorised into felt stigma, instrumental and symbolic stigma.

Smart (2004) characterises felt stigma as value-laden behaviours, such as denial and fear, that compromises human rights of those affected. In this context, people living with HIV or those suspected to be carriers of the virus, are often seen as self-blaming and convinced that they deserve it because the transmission of the virus is linked to stigmatised behaviour (Thomas, 2006). In Smart's (year) opinion, felt stigma comprises pointing out or labelling differences, leading to avoidance, shunning, isolation and stereotyping. Nyblade (2006) adds that felt stigma may also cover overt or subtle attribution of differences to negative behaviour, leading to loss of status. Other authors, such as Jacoby (1994), (2002) and Mbwambo et al. (2004) maintain that felt stigma is the feelings that individuals harbour about their condition, and also about the likely reactions of others.

Falk (2002) asserts that felt stigmatisation refers to the expectations that stigmatised people have as to how others will react to their conditions, which can be characterised as self-stigmatisation or the fear of stigmatisation. Bond et al. (2002) explain that self-stigmatisation is the shame, self-blame and self-depreciation that people living with HIV and AIDS experience when they internalise the negative responses and reactions of others. Falk (2002) emphasises that felt stigma is an internal, psychological process for the stigmatised person, and it often leads people to hide their stigmatising condition so that they can avoid being subjected to discrimination.

Brown et al.,(2003) indicate that, felt stigma can also be manifested in the fears that people have around being stigmatised if they are HIV-positive and

choose to disclose their status to others. Therefore, Mawar et al. (2005) emphasise that, felt stigma can be said to be the real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, or disease such as HIV or association with a particular group, such homosexuals.

Felt stigma often precedes instrumental stigma and may limit the extent to which the latter is experienced (Jacoby et al. 2004). For example, some people living with HIV, aware that many people with HIV and AIDS have been treated badly by others, may conceal their HIV status. To the extent that they are successful in “passing” as non-infected, such individuals may limit the amount of enacted stigma prevalent in a society or community, at least in the short term.

This presupposes that instrumental stigma is underscored by people’s fears and the reasons underlying their reluctance to associate with PLHIV. Jacoby et al (2004) further elaborates that people may fear the casual transmission of the virus, the loss of productivity of PLHIV, and that resources may be wasted on them. Nyblade and MacQuirrie (2006) also emphasise that, the fear of casual transmission, expressed in instrumental stigma, underlies both the direct cause of stigma (fear of HIV transmission) and the resulting stigmatising action (refusal of contact with people living with HIV and AIDS. In some cases, the fear of causal transmission exists among those who are of the knowledge that AIDS cannot be transmitted through casual contact (Smart, 2004).

Various attempts to measure instrumental stigma involve asking hypothetical questions about a respondent’s willingness to interact with a person with HIV and AIDS, for example sharing a meal, buying food, or caring for a

person living with the virus. This method has been used to validated a wide range of indicator-related items for actual fears of both community and health providers in Tanzania by Tanzania stigma-indicators field testing group (2005).

Instrumental AIDS stigma shares many characteristics with other diseases that are typically associated with high levels of stigma (Herek et al., 1997). AIDS has been widely perceived to be an unalterable, degenerative, and fatal condition. Thomas (2006) therefore maintains that how people think of AIDS as a disease and of a PLHIV may not be based on the biomedical facts, but typically a social cognitive construct of a disease, often termed an illness schema. In this context, stigma can consist of all kinds of myths or cultural beliefs.

Symbolic stigma emphasises associations between HIV and AIDS and social objects (Herek, 1988;). As he explains, symbolic stigma represents the use of the disease as a basis for expressing attitudes towards the groups perceived to be at risk for AIDS and the behaviours that transmit HIV. In other words, the symbolic view stresses the connection people make between AIDS and the associated stigma, symbolic stigma therefore likens HIV and AIDS to moral decadence and other behaviours that society discourages, such as homosexuality and promiscuity(Falk, 2002).. In this context, when people react negatively to someone with AIDS or HIV, they may be expressing their feelings about the symbol, not necessarily the disease. With symbolic stigma, the HIV carrier is connected with ideas and emotions that come to mind when others think about HIV and AIDS (Mawar et al., 2005). HIV and AIDS may be associated with drug users, homosexuals, hedonism, minorities, promiscuity, prostitution and death,

which are charged with emotions in connection with PLHIV. (Galvao et al. (2013).If someone thinks of HIV and AIDS as a disease involving homosexuality for example, and despises homosexuals, then AIDS will symbolise homosexuality and hate, which will come to mind when PLHIV are discussed (Pryor and Reeder, 1999).

With such emotions in place, people are likely to enact their stigma and resentment for HIV or the HIV carriers through acts of discrimination and unfair treatment of HIV carriers (Petros et al., 2006). All three forms of stigma therefore refer to the actual experience of discrimination, when individuals are actively discriminated against because of their HIV status, whether actual or perceived (Thomas, 2006)

Thomas, (2006) draws a distinction among three types of discrimination; namely realistic competition, social competition, and consensual competition. Realistic competition explains discrimination or prejudice towards the out-group, for real or perceived scarcity of resources, such as money, political power, or military protection. This type of discrimination is therefore driven by self-interest and is aimed at obtaining material resources, such as food, territory, and customers, for the in-group by favouring an in-group in order to obtain more resources for its members, including the self. Those stigmatised in society or the out-group is perceived not to deserve any or as much as share of the resources as the in-group, because of the deviance or particular stigma. In this context, one may be of the conception that feeding an HIV or AIDS patient may be a waste of scarce food, given the stigma that the HIV carrier is timed to die at anytime.



Social competition is predicted to occur where group boundaries are considered impermeable, and where status relations are considered to be reasonably unstable. Social competition is driven by the need for self-esteem and is aimed at achieving a positive social status for the in-group relative to comparable out-groups by favouring an in-group in order to make it better than an out-group. In this context, Petros et al. (2006) indicate that HIV and AIDS carriers are often stigmatised with shame and disgrace, which seeks to erode their self-esteem and barring them from social functions. Consequently, disallowing or seeking to exclude HIV carriers from social events amount to discrimination.

Discrimination can also be consensual. In this form, discrimination reflects stable and legitimate intergroup status hierarchies, and may typically include favouring a high-status in-group. It is consensual because those being discriminated against recognise their own low status and by that accept that the person of the higher status should be given preferential treatment. This may emanate from self-devaluation and the perception of oneself as unequal and undeserving of proper treatment.

Falk (2004) establishes that an individual needs not be actually harmed in order to be discriminated against, but he/she only needs to be treated worse than others for some arbitrary reason. If an institution, such as a church, school or affirm, disallows admission to an HIV carrier, based only on the fact that he/she is an HIV carrier, then the action can be considered as discriminatory. On the other hand, if the applicant is disallowed admission based on his/her failure to meet the

general minimum requirements for acceptance or employment into the particular institution, and then the action cannot be termed as discriminatory.

From the various discussions, one can deduce that HIV related stigma and discrimination are linked to gender. The impact of HIV and AIDS related stigma and discrimination on women reinforces pre-existing economic, educational, cultural and social disadvantage and unequal access to information and services. Similarly, discriminating acts against female HIV carriers is linked to long-standing gender inequalities underpinned by ideas about masculinity and femininity that have historically resulted in women being blamed for the transmission of sexually transmitted infections of all kinds, and have guilt imputed to them out of assumed 'promiscuity'. For example Bond et al.(2002) observes that in areas where heterosexual transmission is significant, the spread of HIV and AIDS infection has been associated with female sexual behaviours that are not consistent with gender norms. In many cases female sex workers are often perceived as transmitters of the virus who put their clients and their clients' sexual partners at risk.

### **Manifestations of stigma and discrimination**

HIV and AIDS-related stigma and discrimination take different forms and are manifested at different levels-societal, community and individual-and in different contexts (UNAIDS 2000; Malcolm et al., 1998). The following highlights where HIV and AIDS related stigma and discrimination have been most frequently documented and where there is the greatest potential for interventions to reduce or mitigate stigma and discrimination.

## **Policy and legal contexts**

Societal laws, rules, policies and procedures may result in the stigmatisation of people living with HIV and AIDS but they are often justified as necessary to protect the general population (Mawar et al., 2005). These laws may include legislation for the compulsory screening and testing of groups and individuals; the prohibition of PLHIV from certain occupations and types of employment as well as the medical examination, isolation, detention and compulsory treatment of infected persons. Similarly, some laws allow the deportation of foreigners, in case the authorities realise that they are HIV-positive (Malcolm et al., 1998). Mawar et al. (2005) observe that discriminatory policies serve only to increase and reinforce the stigmatisation of people living with HIV and AIDS. For example, they note that, discriminatory policies encourage a misplaced sense of security among those who are not infected.

Some governments have introduced legislation to protect the rights of PLHIV to education, employment, confidentiality, information, and treatment (Mann et al. 1992). However, even when supportive legislation exists, it is not always enforced. Furthermore, there are many ways the government can actively discriminate against people or communities with (or suspected of having) HIV and AIDS. For instance, Marta et al. (2008) observe that the government of Uganda allows the dismissal of the armed forces that test HIV positive. Also, the Chinese government advocates compulsory HIV testing for any Chinese citizen who has been living outside the country for more than a year. Similarly, the United Kingdom's legal system can prosecute individuals who pass the virus to somebody else, even if they did so without intent.

## **Education and schools**

Children with HIV and AIDS or associated with HIV through infected family members have been stigmatised and discriminated against in educational settings through teasing by classmates of HIV-positive school children or children associated with HIV (Gilborn et al., 2001). Discrimination against HIV-positive children in the USA and Brazil, including exclusion from collective activities or expulsion from school, has led to non discrimination legislation (Galvao, 2000). However, less concern has been shown for young people who are perceived to be responsible for their HIV infection and who are already stigmatized and discriminated against because they are sexually active, homosexual, or drug users .(Galvao et al. (2013).

## **Employment and the workplace**

In the work place, PLHIV suffer stigma such as social isolation and ridicule or experience discriminatory practices from their co-workers and termination of appointment or refusal of employment from their employers, .(Galvao et al. (2013). Galvao et al. indicate that discriminatory practices at the workplace may also include pre-employment screening, denial of employment to individuals who test positive, and termination of employment of PLHIV.

Schemes providing medical assistance and pensions to employees have come under increasing pressure in countries seriously affected by HIV and AIDS, and some companies have used this as a reason to deny employment to PLHIV(Mawar et al., 2005). Few companies have developed strategies to combat S&D or defined their responsibilities toward employees with HIV.

## **Healthcare systems**

There have been many reports from health care settings of HIV testing without consent, breaches of confidentiality, and denial of treatment and care. This was an issue the researcher experienced as respondents were interrogated at the HIV and AIDS clinic at the ST. Francis Xavier Hospital. Failure to respect confidentiality by revealing serostatus to relatives without prior consent, or releasing information to the media or police appear to be problems in some health services. For example, WHO (2008) found out that in India, Indonesia, Philippine, and Thailand 34 percent of respondents reported breaches of confidentiality by health workers that health care professionals, particularly those who infrequently encounter HIV-positive people, can be insensitive to their patients' concerns. The fear of contagion and death often has negative effects on health care providers' attitude and treatment of HIV-positive patients. Factors contributing to these stigmatising and discriminatory responses may include lack of knowledge, moral attitudes, and perceptions that caring for PLHIV is pointless because HIV and AIDS is incurable (Masini & Mwampeta 1993; Herek et al. 2003; Herek & Glunt, 1998).

## **Community contexts**

In societies with cultural systems that place greater emphasis on individualism, HIV and AIDS may be perceived as the result of personal irresponsibility, and thus individuals are blamed for contracting the infection (Galvao et al. (2013). In contrast, in societies where cultural systems place

greater emphasis on collectivism, HIV and AIDS may be perceived as bringing shame on the family and community.

Community-level stigma and discrimination can manifest as ostracism, rejection and verbal, physical abuse and murder (UNAIDS, 2008). For example, there have been reports from many countries of attacks on men who are assumed to be gay, of violence toward sex workers and street children in Brazil (Peterson 1990; Byrne 1992), and of HIV and AIDS-related murders in Colombia, India, Ethiopia, South Africa, and Thailand (AFAO 1997). Similarly, in December 1998, Gugu Dhlamini was stoned and beaten to death by neighbours in her township near Durban, South Africa after speaking openly on World Day about her HIV status. (Galvao et al. (2013).

### **Family contexts**

The family is the main source of care and support for PLHIV in most developing countries. However, negative family responses are common. Infected individuals often experience stigma and discrimination in the home, and women are often more likely to be badly treated than men or children. Negative community and family responses to women with HIV and AIDS include blame, rejection, and loss of children and home

Since HIV and AIDS-related stigma and discrimination reinforce and interact with pre-existing stigma and discrimination, families may reject PLHIV not only because of their HIV status but also because HIV and AIDS is associated with promiscuity, homosexuality, and drug use. In many cases, HIV and AIDS-related stigma and discrimination has been extended to families, neighbours and

friends of PLHIV. This ‘secondary’ stigmatisation and discrimination has played an important role in creating and reinforcing social isolation of those affected by the epidemic, such as the children and partners of PLHIV.

### **Individual contexts**

The way in which individuals react to HIV and AIDS carriers depends on family and social support and the degree to which people are able to be open about such issues as their sexuality as well as their serostatus. In contexts where HIV and AIDS is highly stigmatised, HIV carriers may isolate themselves to the extent that they no longer feel part of civil society and are unable to gain access the services and support they need. This has been called internalised or felt stigma. In extreme cases, this has led to premature death through suicide (Gilmore & Somerville, 1994; Hasan, Farag & Elkerdawi, 1994). Even when laws exist to protect PLHIVs’ rights and confidentiality, few individuals are willing to litigate for fear that this will result in disclosure of their identity and HIV status.

### **Effects of HIV and AIDS stigmatisation and discrimination**

HIV-related stigma is multi-layered, tending to build upon and reinforce negative connotations through the association of HIV and AIDS with already marginalised behaviours, such as sex, work, drug use, and homosexual and transgender sexual practices. The effects of stigmatisation and discriminatory practices against HIV and AIDS carriers are diverse and can be internal to the carrier or be expressed in more overt ways that others can acknowledge (Bond et al., 2002).

Despite the important scientific advances that have been made, stigma and discrimination still create major challenges that must be overcome if we are to have a meaningful and lasting response to HIV. These challenges carry a high cost in human suffering and in the violation of the human rights of PLHIV across the world. They are obstacles that stand in the way of making the necessary transformations to reduce new HIV infection rates and associated diseases and deaths. ( Galvao et al. (2013).

Galvao et al indicate that stigma against HIV carriers can make them depressed, withdrawn and feel of worthless. Internalising stigmatisation and blaming oneself for contracting HIV and AIDS can silence and sap the strength of already-weakened individuals and communities. According to Galvao et al (2013), internal stigma can be a coping mechanism against external stigma and can often result in thoughts or behaviour such as the refusal or reluctance to disclose a positive HIV status, denial of HIV and AIDS and unwillingness to accept help. This collective public denial in societies is reflected by avoidance of mentioning any terminal illness including HIV AND AIDS and unwillingness to confront matters related to sexuality (Wood & Lambert, 2008). It can be deduced that felt stigma may prevent someone who is at risk of HIV from getting tested because they want to avoid the discrimination they may face if the test comes back positive.

Smart (2004) is of the view that stigma can affect HIV carriers in more subtle ways, and they may include feeling of shame, dejection, self-doubt and inferiority. The individual therefore loses his/her self-esteem and confidence and



withdraws socially, which may result in isolation and inability to express physical affection towards partners and family members. Mankoe et al. (2008) add that when HIV and AIDS carriers confine themselves to solitude, they also exclude themselves from services, including medical services and other opportunities, such as help from others, which might help to prolong their lives, thus leading in many cases to pre-mature deaths.

According to Smart (2004), felt stigma is worse when an individual is first diagnosed, and discrimination at this point can lead to thoughts and acts of suicide. When instrumental stigma is shown through discrimination, Ngozi et al. (2009) assert that the effects are wide-ranging and may include actions taken by the stigmatised person in response to stigma, and actions taken against the person being stigmatised.

Stigma and discrimination impede both willingness and ability to adopt HIV preventive behaviour, to access treatment and to provide care and support for people living with HIV (Parker & Aggleton, 2003). Valdiserri (2002) also maintains that fear of stigma impedes prevention efforts, including discussions of safer sex and preventing mother-to-child transmission, utilisation of voluntary counselling and HIV testing (CT) services, as well as the disclosure of HIV status. In Nyblade's (2006) explanation, resources like medicine, transport to health services, food and other amenities may be withheld because of a perception that people living with HIV are hopeless cases and will die anyway, and therefore PLHIV often avoid medical care and support in order to avert any suspicions about their status.

Given widespread negative community and family responses, many people choose not to know or reveal their serostatus. Individuals who are already marginalised may be fearful of negative or hostile reactions from others, regardless of their serostatus reflecting the interaction between HIV and AIDS-related and pre-existing sources of stigma and discrimination. This may contribute to further spread of the disease onto uninfected persons.

Mawar et al. (2005) add that HIV and AIDS stigma and discrimination can affect prevention and spread of the disease, because, fear of negative social consequences of a positive HIV test result can deter some persons from getting tested. Anderson (2004) confirms that stigma is associated with a decreased likelihood of being tested for HIV. Anderson (2004) explains the danger in this situation that people who are HIV positive, but do not know their HIV status are less likely to try to prevent transmitting HIV to others. Simbayi et al. (2007) also indicate that some HIV persons may fear that disclosing their HIV status or using condoms may bring partner rejection, limit sexual opportunities or increase risk for physical and sexual violence.

Stigma surrounding HIV, homosexuality, commercial sex work and drug use can also make it difficult for HIV prevention services to be offered in a variety of settings (Nyamathi et al., 2007). While it is widely accepted that HIV prevention should be integrated into a broader health and community context, many community venues such as churches, businesses, jails, prisons and schools have resisted incorporating frank discussions of HIV (Mbaraka, 2011). Moutsiakis (2007) also maintains that HIV-positive persons may not seek

treatment or delay going to doctors due to real or perceived discrimination against them. For example, Valdiserri (2002) found that, in some parts of the United States, 36 percent of adult HIV-positive patients reported experiencing discrimination by a health care provider, including eight percent who had been refused medical service.

Fortenberry, McFarlane and Bleakley (2002) note that some HIV carriers do not have adequate support networks, because they fear that friends or family will abandon them or will be stigmatised. Rapkin and Remien (2005) found high levels of internalised stigma among Asian and Pacific Islanders (API) living with HIV. They found that APIs avoided seeking support because they were afraid of disclosure and saw themselves as unworthy of getting support. In some studies it has also been noted that stigmatisation from disclosure of one's HIV status has led to employment losses, which worsen the predicaments of HIV positive people (Kayungilizi, 2007; Mbaraka, 2011). From the ongoing discussion, it is noted that stigmatisation leads to loss of self-confidence, which leads to self-withdrawal, self-blame, and loss of self-worth. These may also sever family and career relations with HIV carriers, leading to inadequate support for HIV positive people.

### **Coping strategies**

People living with HIV (PLHIV) and their families are often subjected to prejudice, discrimination and hostility related to the stigmatisation of AIDS (Makoae et al., 2008). The effects of such stigma can be devastating to the carriers and their families, and in some cases, nothing can be done about the

stigma and discrimination because they are deeply rooted in societal culture and behaviours (Makoae et al., 2008). Some HIV-positive people find ways of coping with the stigma in order to enjoy a relatively normal life as compared to those who get overwhelmed with the discriminatory behaviour of others and self-guilt (Weiten & Lloyd, 2008). Coping strategy refers to a conscious effort to solve personal and interpersonal problems, and seeking to master, minimise, or tolerate stress or conflict.

Damodharan and Priya (2007) are also of the view that coping styles can be adaptive or maladaptive in nature and it differs in each individual, depending on the stress experienced by the individual. Adaptive coping strategies refer to the strategies that help to reduce stress levels. In one study, Petros et al. (2002) found that adaptive coping strategies adopted by HIV carriers included listening to music, thinking about good things, making your own decisions, being close to a loved one, sleeping, trying on your own to deal with problems, eating, watching television, daydreaming and praying. Generally, adaptive coping strategies include positive reinterpretation and growth, which may include learning from experience and searching for positive alternatives to dealing with stigma (Bond et al. 2002). For example, some HIV carriers learn that they should not readily state their HIV status to people or groups until they can assess their predisposition about HIV and AIDS (Duffy, 2005).

Adaptive strategies also include seeking social support from others who have had similar experiences or talking to someone who can do something to help (Zeidner & Endler, 1996). For example, HIV carriers may form support groups,

share experiences and advice each other about what to do in certain situations (Zeidner & Endler, 1996). Madiba and Canti-Sigaqa (2012) observe that support groups encourage in-group members that they are not alone; and also provide a place where they can share their psychological and social trauma without being stigmatised. Madiba and Canti-Sigaqa (2012) however assert that there are barriers to participating in supports groups, which are related to issues unavailability of support groups in local communities including; the timing of meetings and lack of transport money; as well as fear of unintended disclosure of HIV status due to breach of confidentiality with resulting stigma and social rejection.

On the other hand, some HIV carriers despair from stigma and adopt maladaptive coping mechanisms (Zeidner & Endler, 1996). According to Stoeber and Janssen et al. (2001), maladaptive coping is not often desirable because they can reduce symptoms in the short-term but will generally maintain and strengthen the disorder. Janssen et al. (2001) further emphasises that maladaptive coping mechanisms may typically include denial of the situation, mental avoidance, venting emotions and substance abuse, such as alcohol abuse and the use of methamphetamines.

Ngozi (2009) maintains that how an HIV carrier deals with stigma or the disease itself is partly controlled by personality, such as habitual traits, but also partly by the social context, particularly the nature of the stressful environment. Issues such as culture, religion, law and general morale judgment of society may influence the carrier to adopt adaptive coping or maladaptive coping.

## **Interventions to control HIV and AIDS discrimination**

Mawar et al. (2005) mention that while it may be unrealistic to think that stigma to HIV can be eliminated altogether, it can be reduced through a variety of intervention strategies including information, counselling, coping skills acquisition, and contact. Mawar et al. (2005) emphasise that information-based approaches often present factual description of the disease, transmission mode, and methods of risk reduction and can be delivered by advertisement, or through leaflets, information packs, or presentation in a class or lecture. Information-based approaches have been tested in Israel (Soskolne et al., 1993), United States (Ashworth et al., 1994), Jamaica (Hue & Kauffman, 1998), and Tanzania (Mwambu, 1998). Overall these studies found that the information-approach alone increased tolerance towards PLHIV.

Some studies (Kaleeba et al. 1997; Kerry & Margie 1996; Kikonyogo et al., 1996; Nansubuga, et al., 1996; Simpson et al., 1998) tested the counselling approach whereby individuals received personal support for resolving issues or situations with spouses, families, and communities in a safe environment. The interventions in both of these studies reduced anxiety and distress in the experimental groups as compared to controls, but there were no differential treatment effects across experimental groups. The interventions tested in Uganda (Kaleeba et al. 1997) and in Zimbabwe (Kikonyogo et al., 1996) revealed that counselling increased disclosure among PLHIV and improved community attitudes compared with a baseline measure, although there were no control groups.

Contact with infected or affected groups was used alone or in combination with other approaches in some studies (Batson et al., 1997; Bean 1989; Herek et al. 2003; Mwandha & Were 1998; Venkataraman et al. 1996; Wyness, Goldstone, & Trussler 1996). According to Mawar et al. (2005) contact creates an environment in which the general population can interact with the stigmatized group, either directly or vicariously. The theory is that a more personal relationship with a PLHIV, either through face-to-face conversations or hearing a testimonial from infected or affected individuals, will demystify and dispel misinformation and generate empathy, which in turn reduces stigma and prejudice.

UNAIDS (2005) asserts that within these interventions, certain strategies are necessary to reduce stigmatisation to HIV and PLHIV. The first strategy is to use or promote approaches that address the root causes of stigma and the key concerns of affected populations. An overarching principle for tackling stigma and discrimination is to address their immediate underlying causes, which are remarkably similar across different countries and continents. In their opinion, a course of action and a target audience can be identified for each cause of discrimination and stigma.

UNAIDS (2007) identifies lack of awareness and knowledge of stigma and their harmful effects as one actionable cause of discrimination against PLHIV. In order to control this, UNAIDS suggests that government officials, civil society, NGOs, and PLHIV should create awareness of what stigma and discrimination are, the harm they cause, and the benefits of reducing them. This

may be pursued through participatory education, which involves activities that encourage dialogue, interaction and critical thinking, through mediums such as mass media campaigns.

Contact strategies may also be used to overcome fear of acquiring HIV through everyday contact and caring for infected people (Huurne, 2006). Contact strategies may involve direct or indirect interaction between people living with HIV. The PLHIV can share their experience with the audience in order to provide more detailed first hand information to dispel myths about people affected with HIV.

UNAIDS (2005) also proposes that the most promising approaches to stigma and discrimination reduction feature a combination of empowerment of people living with HIV and AIDS, updated education about HIV, and activities that foster direct or indirect interaction between PLHIV and key audience. This type of interaction, whether through mass media, community panels, or working together toward common goals, is considered particularly useful in dispelling harmful myths and changing attitudes (DFID, 2007).

UNAIDS, (2007) notes that one promising mechanism for scaling-up stigma reduction activities quickly and effectively is to conduct a cascade of training of trainers workshops. It should further include addressing the attitudes and practices of health care workers and also meeting their needs for HIV information, training in health care for people living with HIV, and supplies for universal precautions to prevent occupational exposure to HIV. People living with HIV need to be actively involved in developing and implementing stigma and



discrimination-reduction effort (Huurne, 2006; UNAIDS, 2005). The strategy should also challenge stigma and discrimination in institutional settings and also focus on building human rights and legal capacity at community levels.

### **Empirical studies**

This section reviews specific empirical research conducted on HIV and AIDS stigmatisation in different countries. It takes into consideration the methods of research adopted and the results derived from these studies. The purpose is to inform this study, and to derive a basis for comparison of the results found in this study.

Vanable et al. (2006) studied the impact of HIV-related stigma on health behaviours and psychological adjustment among HIV-positive men and women. The study examined the role of stigma in relation to the current health status, mental health, medication adherence, and sexual risk behaviours among HIV-positive men and women receiving care at a clinic.

Consecutive outpatients from a university-based Infectious Disease Clinic in central New York State were recruited on designated study days during a 16 month period beginning in July, 2001. The study adopted a quantitative approach and used a descriptive design in answering the research questions. A patient was eligible for the study if he or she was 18 years of age or older, HIV-positive, English speaking, and capable of providing informed consent based on medical and research staff observations. A total of 314 patients met eligibility criteria and were invited to participate, but 221 consented to participate. A census of all the

patients was therefore conducted. Primary data sources were the patients and interview schedules were used to collect data from them.

The mean age of study participants was 40.4 (SD = 7.9), with 77% percent of participants falling between the ages of 30–49 years old. Most participants were unemployed (67%) and impoverished (68% reporting incomes of less than \$1,000 per month). Thirty-eight percent had less than a high school diploma, 37% completed high school, and 20% had completed some college. Stigma-related experiences were reported by a significant minority of participants in this diverse sample of HIV-positive men and women. For example, 41% agreed that people often behaved negatively around them once they learned of their HIV status and 29% reported that people often avoid contact with them because they are HIV-positive. Stigma-related experiences were positively associated with time elapsed since HIV diagnosis ( $r = 0.25$ ,  $p\text{-value} < 0.01$ ) and occurred more frequently among participants who were currently unemployed,  $t(219) = 3.06$ ,  $p\text{-value} < 0.01$  and those reporting lower personal income ( $r = -0.14$ ,  $p\text{-value} < 0.05$ ). The occurrence of stigma-related experiences did not vary as a function of age, sexual orientation, gender, ethnicity, or education (all  $p\text{-value} > 0.15$ ).

The study concluded that stigma contributes to psychological adjustment difficulties among HIV-positive men and women. The study recommended that interventions to reduce the negative impact of stigma on the lives of persons living with HIV should be pursued on several fronts. First, risk reduction, adherence, and coping interventions should address HIV-positive patients' concerns about stigmatisation. At a minimum, interventions should provide a

supportive environment for discussing the ways in which stigma interferes with mood management, medication adherence, and sexual partner communication.

In another study, Kayungilzi (2007) analysed the socio-economic effects of HIV and AIDS-related stigma and discrimination of Wayawavi group in Dar es Salaam. The study was driven by the hypothesis that HIV and AIDS stigmatisation leads to unemployment, increased illiteracy, child labour, and street children. It aimed to investigate the effects of HIV and AIDS stigma on the socio-economic status of PLHIV and to investigate the relationship between stigma and disclosure, as well as to investigate the impacts of stigma on the use of counselling and testing (CT) services.

Quantitative and qualitative research approaches were adopted, in which cross-sectional research design was used in association with content analysis and case study. The community population was 350, but 50 were sampled using stratified sampling technique. The sample therefore comprised of 25 widows, 5 orphans, and 20 community members. A survey of all 147 members of the Wayawavi group was conducted. Primary data were collected using questionnaires and observation, while secondary data, including documentaries, were collected from the Wayawavi group. The study used frequencies and percentages in describing the quantitative data and summarised the case studies and documentary reviews according to their contents.

The study found that 83 percent of the community had a relative living with HIV and 89 percent were unwilling to go for HIV tests, out of which 78 percent expressed that this was due to the fear of isolation by community

members. Moreover, 61 percent of the community members agreed that PLHIV can still be socially and economically productive, but 89 percent were unwilling to get services from a person who is HIV positive. The study also found that 90 percent of the respondents admitted that woman face high level of stigmatisation. About 80 percent of the PLHIV had income generating activities, but 60 percent lost their economic activities and 75 percent reported that the community members avoided their services. The study concluded that stigmatisation hinders HIV status disclosure and also leads to minimise choices of economic activities. The study recommended community sensitisation programmes, implementing programmes on income generation for PLHIV, and establishing trust fund for HIV and AIDS orphans.

Mankoe et al. (2008) studied how HIV patients cope with stigma in five African countries, including Lesotho, Malawi, South Africa, Swaziland, and Tanzania. The study adopted a qualitative approach, in which a descriptive design was used to explore the experience of HIV-related stigma of PLWH, nurses working with HIV-infected clients, and volunteers working with HIV-infected persons. A total of 43 focus group discussions were derived from a sample of 251 participants, including 114 nurses, 111 PLHIV, and 26 volunteers.

Coping strategies used to deal with HIV-related stigma were coded. Seventeen strategies were identified; 6 were labelled emotional and 11 were labelled problem-focused. Emotional coping strategies (44.9%) were activities the person could do alone, involving emotional self-management. Problem-solving coping strategies (55.1%) involved addressing the problem more directly and

engaging with others. Emotional strategies included rationalisation, seeing self as normal, avoiding confrontation and passively accepting stigmatising behaviour. Others chose to turn to God, hoping, and humour. Problem coping strategies included being open and truthful about being infected with HIV, going for counselling, talking to others, helping others, and educating others about HIV. Others also decided to keep busy and acquire more knowledge about the disease.

Some data suggest that HIV-infected persons may seek to restructure their situations in ways that might be negative or destructive for themselves or for others. The study indicated that, within the African context, coping appears to be self-taught and only modestly helpful in managing perceived stigma. The study recommended further education of the general population in order to control stigmatisation of HIV carriers.

Armah-Attoh (2009) reviewed HIV counselling and testing related stigma in Ghana. The study was inspired by the problem that although the government of Ghana had made VCT for HIV free and accessible, the up-take of service was as low as 5 percent in 2007 and some studies, such as Amenya (2008), had related this to HIV stigmatisation. The study aimed to describe the root causes of HIV related stigma and to explore the effect of HIV related stigma on the uptake of VCT services.

The study used a quantitative approach, by adopting content analysis of 42 research studies after screening 138 articles on HIV related issues on Ghana. The sample of the articles followed a four-step screening process, in which duplicates, articles without full texts, and those that were not relevant to the study were

eliminated. The main inclusion criteria was that the article must be in English language and should address whether implicitly and explicitly HIV counselling and testing related stigma and should also be well referenced.

The analysis of the contents was based on Holzemer et al.'s (2007) model for HIV/AIDS stigma, which identified contextual factors influencing stigma process in a four part iterative process, including triggers, stigmatising behaviours, stigma types and outcomes. The stigma also established the relationships between HIV and AIDS stigma and environmental factors, such as culture and tradition, religion, laws, gender and socio-economic variables.

The study found that gender inequality, shame, lack of anti-discrimination policies, criminalisation of female sex workers, homosexual men and drug use were the root causes of HIV stigma in Ghana. Moreover, the study noted that due to stigma attached to HIV infection, people are generally not willing to go for VCT services. It was found that coverage for VCT among 15-59 year olds, for 2007 in Ghana was 4.1 percent, which was lower than the 30 percent target set for the year. In further analysis, the study indicated that less than 10 percent of the PLHIV in Ghana were aware of their positive sero-status, due to low patronage of VCT services. The study recommended further sensitisation programmes that can help to reduce the stigma associated with HIV AND AIDS.

Ulası et al. (2009) assessed HIV AND AIDS-related stigma and discrimination of people living with HIV AND AIDS (PLHIV) in Kumasi, Ghana. The study was driven problem that Ghanaians are very attached to morale and cultural values and that stigmatisation of HIV carriers could stem from such

beliefs. It was therefore hypothesised that at least 50 percent of the adult population of Kumasi would express some form of stigmatisation attitude against PLHIV and that at best this figure would be 40 percent.

The study adopted across-sectional design, in which 104 respondents were randomly sampled from the four sub-districts or sub-metros of the Kumasi Metropolitan Assembly, including Subin, Asokwa, Bantama and Manhyia. Primary data sources comprised the participants, who were asked to respond to questionnaires. The study analysed the data using descriptive statistics, such as frequencies and percentages and tested for associations using Chi-square statistics. Structural equation modelling and ordinary least squares (OLS) regression were also conducted to evaluate the factors influencing the stigma constructs.

The sample characteristics showed that majority of the participants were less than 30 years of age (61%), had less than a senior secondary school education (59%), and were Christians (80%). Only 13% of these participants had been tested for HIV and AIDS. About 59 percent of the respondents did not know why HIV makes people sick, and 67% could not correctly name or write two symptoms or opportunistic infections associated with HIV and AIDS. About 36 percent indicated that they would not let their child(ren) play with a child with HIV and 59 percent of participants agreed that PLHIV should inform other people of their HIV and AIDS status, while 28 percent also agreed that PLHIV should be isolated in certain villages or towns. Twelve percent of participants indicated that they

would request a job change if one of their co-workers, with whom they work closely, became HIV positive.

Four stigma constructs, employment-based discrimination, screening and identification of HIV positive people, revelation of HIV status and social contact stigma were determined based on reliability measures from responses to the questionnaire. Regression analysis showed that participants with higher educational attainment were more likely to favour policies denying employment to PLHIV ( $p < 0.05$ ), but disapproved of revealing HIV sero-status ( $p < 0.05$ ). Muslims were more likely than Christians to agree with identifying PLHIV ( $p < 0.05$ ) and more likely to advocate revealing HIV sero-status ( $p < 0.05$ ). Males were more likely to favor revealing HIV status ( $p < 0.05$ ). Employed persons were more likely to have social contact with PLHIV ( $p < 0.05$ ).

This study concluded that work place discrimination exists. Also, people with lower education also exhibited some other forms of stigma, and they were also more likely to favour mandatory screening and identification of HIV status, revelation of HIV status, and social distancing of people with HIV and AIDS. Non-Christians, predominately Muslims, were more likely to be in favour of mandatory screening, identification and revelation of HIV status. In many cases, PLHIV perceive and/or experience further discrimination when their HIV sero-status is revealed.

The study recommended training for HIV-carriers to help them improve their self-esteem and self-efficacy and positive coping skills. Public educational programmes were also recommended to remove the belief among members of the



community that they can be physically, socially and morally tainted by interacting with PLHIV.

### **Lessons learnt from empirical studies**

The study drew lessons from the empirical review with respect to the types and effects of HIV stigmatisation, as well as the coping strategies used by HIV carriers. It was noted that the studies on HIV stigma mostly followed a quantitative approach (Ulasi et al., 2009; Armah-Attoh, 2009), but Mankoe et al.'s (2008) study followed a qualitative approach, while other studies used a mix of quantitative and qualitative approaches (Kayungilzi, 2007). This was confirmed by the study designs that were adopted by the reviewed empirical literature. Vanable et al. (2006) used a descriptive design, Kayungilzi (2007) employed a cross-sectional design and content analysis, Mankoe et al. (2008) used exploratory design, and Armah-Attoh (2009) adopted content analysis.

The sampling procedures used by the studies were also founded in quantitative and qualitative research designs. The empirical review showed the use of purposive sampling (Vanable et al., 2006), stratified sampling (Kayungilzi, 2007), and simple random sampling (Ulasi et al., 2009). Armah-Attoh (2009) conducted the study with only secondary data from articles. Interview schedules (Vanable et al., 2006) and questionnaires (Kayungilzi, 2007) were used to collect primary data from respondents.

Vanable et al. (2006) employed both descriptive and inferential analytical tools, including frequencies and percentages and multiple regressions to show the effects of stigma on HIV carriers using demographic data as covariates.

Kayungilzi (2007) and Mankoe et al. (2008) used only descriptive statistical analysis. Armah-Attoh (2009) used content analysis based on Holzemer et al.'s (2007) model for HIV/AIDS stigma.

The empirical review supports the labelling theory and the social identity theory. All the studies showed that stigmatisation of HIV carriers was a common practice, however the effects varied. Vanable et al. (2006) found that stigma contributes to psychological adjustment difficulties among HIV-positive men and women. Kayungilzi (2007) found that stigmatisation led to loss of employment and reduced economic activities for HIV carriers. Mankoe et al. (2008) found that HIV positive people used different strategies, which were broadly to cope with their emotions or with the problem of stigma. In most cases, the studies recommended public education as the solution to reducing HIV related stigma.

### **Conceptual framework for examining HIV-related stigma and coping strategies**

The conceptual framework (Figure 1) of the study portrays an interaction between the socio-cultural, traditional, economic, political and legal environment within society, on the one hand, and labelling and discrimination against HIV carriers on the other hand. At the core of the framework is the HIV carrier who is settled in a particular society with some general culture, moral behaviour, law and policies towards HIV and AIDS infections.

The framework shows that these societal factors can interact and produce two distinct approaches to dealing with HIV infections and those infected with HIV. On one hand, socio-cultural attitudes and the laws may encourage labelling

of HIV positive people as out-group of deviants against community members that are not infected or suspected of HIV infection. By this means, those who are labelled are stigmatised as dangerous or associated with negative descriptions, including deviance, promiscuity, homosexuality, and death. They are further isolated and treated differently from other community members, and often with disfavour. This reinforces discrimination against the HIV positive members of the community.

Stigmatisation and discrimination interacts to have certain effects on the HIV carrier, in terms of his/her psychology, social interaction and economic status. This may include self-blame, social isolation, refusal of support, workplace discrimination and loss of jobs, as well as loss of self-confidence and self-worth. The framework further accentuates the coping strategies that HIV carriers may adopt to deal with the effects of stigma and discrimination.

This may take the dichotomous forms of adaptive or maladaptive techniques. The conceptual framework links maladaptive techniques, such as drug and alcohol abuse, anger and resentment towards others and refusal of support, to further labelling and discrimination of the victim. On the other hand, those who engage in adaptive coping techniques, such as seeking group support, seeking information and clarity about dealing with the disease, accepting the situation, and adjusting behaviours due lessons learnt from experiences are able to some extent cohabitate with other members of the society, engage in economic activity and distress their psyche from stigma and discrimination.

Society can also help in the commingling of the HIV carriers back into society by educating the public on the facts of the disease, as well as establishing counselling and training programmes for HIV carriers, for their psychological and economic well-being. These can encourage adaptive behaviours among HIV carriers.

The framework was able to relate the theories reviewed to the practical lives of PLHIV. It was also able to draw a clear distinction between adaptive and maladaptive coping strategies and the ability to re-absorb PLHIV into the society.

The limitations of the conceptual framework is that it fails to explain the underlying reasons behind the stigmatization of PLHIV and the result of PLHIV who resort to maladaptive coping strategies. A third weakness of the framework is the fact that it does not also capture what influences one's choice to either adopt adaptive or maladaptive coping strategies.

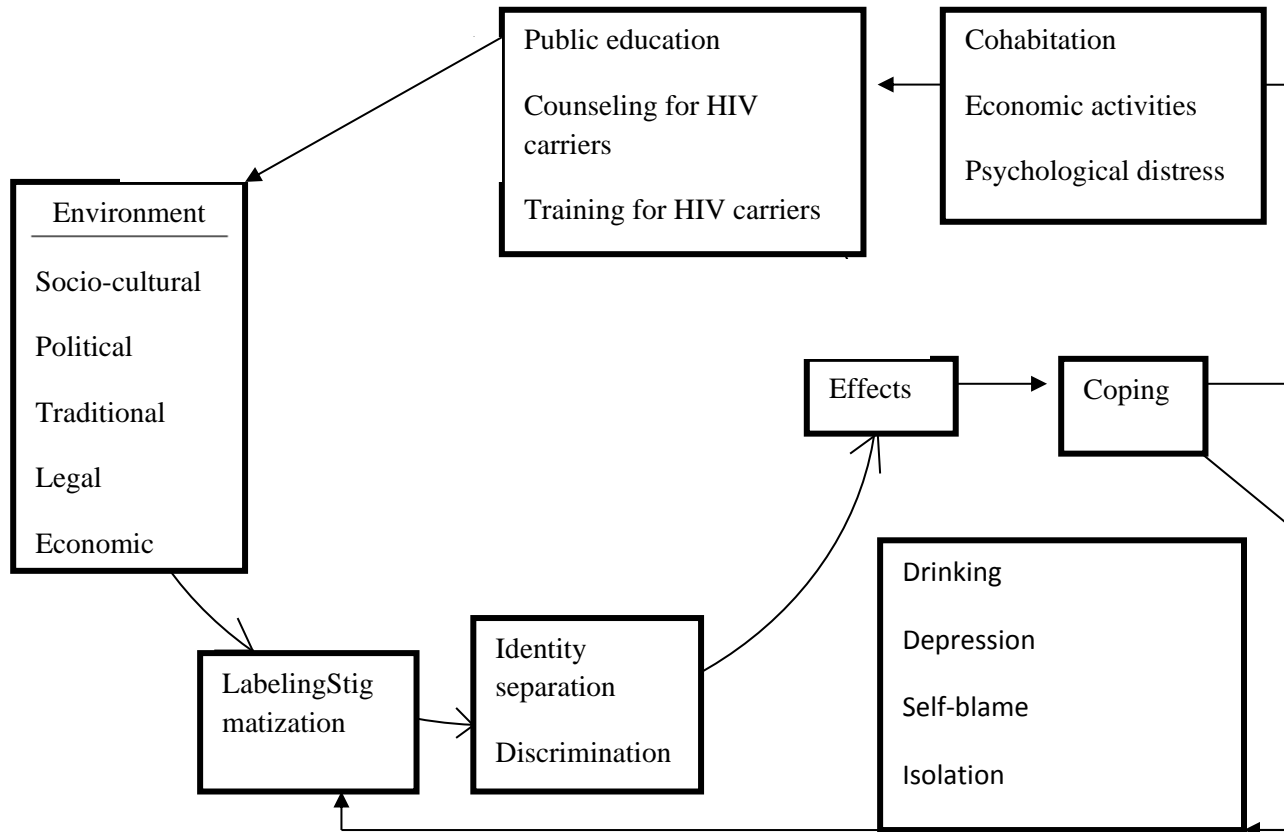


Figure 1: Conceptual framework for HIV stigmatization

Source: Author's construct, 2013

## **CHAPTER THREE**

### **METHODOLOGY**

#### **Introduction**

This chapter discusses how data was collected for this study. It deals with the description of procedures adopted in carrying out the study. It delineates the study area, study design, the research philosophy, types and sources of data collected. The instruments used for data collection, sample and sampling techniques of data analyses, pretesting of instruments and challenges during the fieldwork are also presented in this chapter.

#### **Study area**

The profile of the study area comprised location and physical characteristics, socio-demographic characteristics, infrastructural facilities, and economic activities. The Assin North Municipality (with Assin Fosu as the Municipal capital) is among the seventeen districts of the Central Region of Ghana. It lies within Longitudes 1° 05' East and 1° 25' West and Latitudes 6 ° 05' North and 6° 40 South. The Assin North Municipality shares common boundaries with Twifo Hemang Lower Denkyira on the West, Assin South District on the South, Asikuma Odoben-Brakwa and Ajumako Enyan-Esiam on the East, Upper Denkyira East Municipal on the North-West and Ashanti Region on the North. The Municipality covers an area of about 1,500 sq. km. and comprises about 1000 settlements.

According to the 2010 Population and Housing Census report, the population of Assin North Municipality stood at 161,341 (GSS, 2012). This figure showed an increase of 38.7 percent over the 2000 population of 116,349 and gave

an inter-censal growth rate of 2.9 percent. The rate is one of the lowest in the Central Region. It is however higher than the national average of 2.7 percent (GSS, 2014). The Municipality has 7.3 percent share in the total regional population of 2,201,863 with a population density of 140 persons per square kilometre.

The high population growth rate of the Municipality can be attributed to high in-migration as a result of the relatively fertile farming lands, which supports the cultivation of diverse food and cash crops (Ministry of Lands and Rural Development, 2010). In addition, the vibrant economic activities at Assin Fosu serve as an attraction contributing to the high in-migration. This consequently has implications for the provision of social and economic infrastructure as well as the utilization of available resources. The frequent in-flows of people into the Municipality further has serious health implications, in particular, the spread and control of HIV and AIDS and other related sexually transmitted diseases.

A socio-economic survey conducted by the Ghana Statistical Service (2014) revealed that as much as 49.1 per cent of the Municipality's population are migrants as against 51.9 per cent being natives. The Municipality can therefore be described as a heterogeneous one. The high number of immigrant population recorded in the Municipality might have explained the high incidents of HIV and AIDS currently observed by the Ghana AIDS Commission in 2012.

Most of the major settlements are located along the main Cape Coast - Kumasi Highway in the Municipality. The Municipal capital, Assin Fosu was the only urban settlement in 1960 and 1970 with population of 5284 and 7239

respectively. By 1984, Assin Fosu was the only community that had population over 5,000. As at the year 2000 two settlements could be described as urban. These are Assin Fosu (22,837) and Assin Bereku (5,985). The rest of the settlements may be described as rural with only nine (9) of them having population between 3,762 and 1809. The rest have populations below 1000.

The Municipality has only one Municipal Hospital, St. Francis Xavier Catholic Hospital at Assin Fosu. The Fosu hospital caters for all referral cases in the Municipality. The health needs of the people are provided by various health institutions. It is evident that the Municipality is not well served with health facilities considering its population size and the fact that HIV and AIDS prevalence is high in the area (Ghana AIDS Commission, 2012). The proximity of the Municipality to Cape Coast however affords the population access to health services provided in the hospitals and polyclinics within the city. In spite of these facilities, the people still have a problem with access to health facilities. This is due to the poor physical conditions of the roads in most parts of the municipality.

The major source of income in the Municipality is crop farming which accounts for 52 per cent of all incomes. This is followed by wages and salaries 21.6 per cent, business and trading 16.4 per cent and industry 10 per cent. Business and trading, and crop farming followed closely with monthly incomes of 049,494 and 049,527 respectively. The fact that the annual per capita income of the general population of the area falls below the national average confirms the Ghana Statistical Service Report of poverty rankings in Ghana where the Central region ranked fourth among the ten regions in Ghana. The low level of incomes



among the population has a lot of health implication in terms of HIV and AIDS spread.

### **Study design**

The study utilised a quantitative approach. The study designs adopted by the study were descriptive and cross-sectional research designs. Grimes and Schulz (2002) explain that a descriptive study is concerned with and designed only to describe the existing distribution of variables, without regard to causal or other hypotheses.

According to Biemer and Lyberg (2003), cross-sectional survey design is the type in which the information about the variables of interest represents what is going on at only one point in time. Levin (2006) confirms that cross-sectional studies are carried out at one time point or over a short period. They are usually conducted to estimate the prevalence of the outcome of interest for a given population. A cross-sectional design is therefore useful for obtaining an overall picture as it stands at the time of the study. Furthermore, in a cross-sectional study, both outcomes and exposures are assessed on the individual level without either forward or backward timing.

In this way cross-sectional studies provide a snapshot of the outcome and the characteristics associated with it, at a specific point in time. They are limited, however, by the fact that they are carried out at one time point and give no indication of the sequence of events (Grimes & Schulz, 2002). These study designs were appropriate, because the study sought to ultimately describe nature of stigma against PLHIV, the effect of stigma on PLHIV, the mechanisms

employed by PLHIV to overcome stigmatisation in Assin Fosu Municipality, as they pertained at the time of the study.

### **Study population**

The study population included all HIV carriers, who were receiving treatment at the municipal hospital, and were aged 18 years or older. The rationale for confining the study to the hospital was to make it easier to target and access participants. The total number of HIV and AIDS patients that reported for treatment at the Saint Francis Xavier Hospital, as at the time of the study was 789. This was based on a list obtained from the Assin Fosu Municipal Health Directorate and Ghana AIDS Commission.

### **Sample size for the study**

The sample size was determined based on the Krejcie and Morgan (1970) sample estimation matrix. The underlying formula for the matrix adopts a margin of error ( $d$ ) of 0.05. The chosen ( $d$ ) corresponds to a z-value ( $z$ ) 1.96. It also adopts population proportions ( $p$ ) of 0.05 and ( $q$ ) of 0.05. These population proportions yield the largest sample size within 95 percent confidence bounds. Given that there may be possible non-responses, yielding the largest sample size for any particular population helps in attaining a substantial sample, even in the case of non-responses and non-cooperation from the targeted respondents. For a population of 789, the matrix yielded a sample size of 256. Thus, the study sample comprised 256 HIV patients from the municipal hospital. The finite estimation technique was adopted due size of the population (less than 50,000).

### **Sampling procedure**

The study adopted simple random sampling to select the respondents from the target population. The empirical review showed that Ulası et al. (2009) adopted simple random sampling in their study on the effects of HIV stigmatisation. A list of all HIV and AIDS patients who were on ART was sought from the Assin Fosu Municipal Health Directorate with their contact details. The numbered list of the patients formed the sampling frame for the study.

### **Data and sources**

Data for the study were derived from primary. Primary sources of data comprised the HIV patients at the municipal hospital. The aim of collecting data through this means was to obtain firsthand information about their lived experiences. The data collected from primary sources covered socio-demographic profile of the respondents, sources and determinants of HIV and AIDS stigma, the various forms of stigma HIV and AIDS patients experience, the effect of stigma on their wellbeing, the mechanisms employed to overcome stigma and suggested policy programmes that can be employed to address stigma and discrimination in the municipality.

The primary data were supplemented with secondary information and these were obtained from the Assin Fosu Municipal Assembly Records, Ghana Statistical Service reports, Ghana AIDS Commission, the Assin Fosu Municipal hospital records, both published and unpublished dissertations and thesis, journals, and other surveys done by researchers and organizations that treat different aspects of the topic under study.

## **Research instrument**

Interview schedules were used to collect data from primary sources. This was based on the fact that the study could not assume that all the respondents could read and understand the English language which was used to design the instruments.

The interview schedule was structured into six main modules (A, B, C and D). Module A elicited responses on issues regarding the socio-demographic profile of the respondents (age, sex, marital status, education etc). Module B dealt with issues regarding the nature of HIV and AIDS stigmatization and discrimination of PLHIV. Module C assessed the effects of stigma on the HIV and AIDS patients. It looked at the implications of stigma on clinical care and treatment, as well as the psychosocial and economic impact stigma brings on PLHIV. Module D explored the mechanisms employed by HIV and AIDS patients to overcome stigma in their daily activities. It covered issues regarding how they relate with others within the larger family, community, workplace and hospital environment without being stigmatised or discriminated. Some of the policy interventions that patients think can be devised to address the phenomenon of HIV and AIDS stigma and discrimination in the Municipality were also covered in Module D

## **Pre-testing of instruments**

The instrument was pre-tested at Cape Coast Central Regional Hospital to check the internal reliability of the instruments. Cape Coast was selected for the pre-test because the area has similar socio-economic and demographic characteristics just like the Assin Fosu Municipality such as language, ethnicity,

and the nature of their economic activities. In all, 10HIV and AIDS patients were interviewed during the pre-test. The results helped to restructure some of the questions in the interview schedule. It also enabled the researcher to appreciate some of the problems that were most likely to be encountered during the actual data collection.

### **Ethical issues**

Throughout the course of the research, standard ethical concerns in social sciences research were given prominent attention. This was done by explaining the main purpose of the research to all the respondents. Furthermore, all respondents were given informed consent forms to be completed and signed. The researcher also adhered to issues of confidentiality, privacy and anonymity. Given the highly sensitive nature of the study, the services of a counsellor from the Assin Foso Municipal Hospital were sought in cases where respondents required some form of counselling.

### **Fieldwork**

The field work was conducted from 6th February to 24th December, 2013. Prior to the field work, five research assistants were recruited and trained in a three-session meeting on the ethical and practical administration of the interview schedules. The interviewers were dispatched to interview the respondents under the supervision of the researcher and professional counsellor of the facility. The respondents were seen early in the morning and mid day when they came to take or request for the anti retroviral drugs. A total of 256 interview schedules were administered to PLHIV, comprising 123 males and 133 females.

### **Field challenges**

A major challenge was getting sufficient number of interview schedules completed within the time schedule for the data collection. Some of the respondents only reported to the centre on a monthly basis thus, about 24 visits spanning six months had to be made to identify and interview several of these respondents.

### **Data processing and analysis**

The completed interview schedules were screened for errors and edited accordingly. A coding manual was created for open ended questions, after which the responses to open-ended questions were coded. The data were then inputted into the Statistical Product and Service Solutions (SPSS) version 16.0, which was used to clean the data by running and examining frequencies, to ensure that their maximum and minimum values correspond with the codes in the variable view. The data were then analysed to reflect the specific objectives.

Demographic characteristics were analysed using frequencies, percentages and appropriate descriptive statistical tools. The interrelationships between or among demographic characteristics and specific nature of HIV stigmatisation and discrimination were analysed with cross-tabulations. The decision to adopt parametric or non-parametric analytical tools was based on the skewness of the distributions ( Pallant, 2005). Prevalence rates of the study variables in relation to the sample sub-groups were examined by using statistical tools for comparison, such as ANOVA and independent sample t-test. All tests for statistical significance were based on an alpha of 0.05.

## **CHAPTER FOUR**

### **RESULTS AND DISCUSSION**

#### **Introduction**

This chapter presents the results and discussion of the study in relation to the specific objectives. Results of statistical significance and practical importance are explained with respect to the issues of HIV and AIDS stigma felt by PLHIVs and the effect this has on them in the Assin Fosu Municipality. A total of 256 interview schedules were completed for people living with HIV and AIDS at the Saint Francis Xavier Hospital in Assin Fosu Municipality. Implications of practical and educational significance of the findings are reported in this chapter. The first section of the results focuses on demographic issues, while subsequent sections discuss the findings based on the specific objectives.

#### **Demographic characteristics of respondents**

The demographic characteristics of the respondents studied were sex, age, as well as educational, occupational, marital and religious characteristics. These were studied in order to provide a background profile of respondents. The disaggregation of the results was important because the omnibus presentation would exclude intimate relationships that may exist between HIV and AIDS stigma and the respondents' characteristics.

The sex and age characteristics of the respondents are presented in Table 1 below. The results show that the females (52%) covered by the study were slightly more than the males (48%). Thus, it was found that the number of female patients of the Saint Francis Xavier Hospital, who were living with HIV AND

AIDS, was a bit more than their male counterparts. The youngest PLHIV was 18 years and the oldest was 65 years. This conformed to the approach used by Vanable et al. (2006) in New York, where a patient was eligible for the study if he or she was 18 years of age or older. Overall, the average age of the respondents, represented by the median age, was 29 years. The median age was reported because the distribution of ages was associated with a skewness statistic of 1.113 (std. error = 0.152), which was higher than the normal distribution skewness of  $\pm 0.5$ . Thus, based on Pallant's (2005) recommendation to report medians for skewed data, the median ages were reported.

The respondents of this study were generally, younger than the mean age of PLHIV found in Vanable et al.'s (2006) study in New York where the average age of a PLHIV was 40 years. However, the results also tallied with Uiasi et. al.'s (2009) study of PLHIV in Kumasi where the average age fell below 30 years. Thus, the study confirmed that, PLHIV in Ghana are generally a younger population.

**Table 1: Sex and age description of respondents**

Sex	N(%)	Age (years)					Skewness	
		Min	Max	Mean	Median	Mode	Stat	Error
Male	123(48.0)	18	55	30.81	26.00	24.00	0.840	0.218
Female	133(52.0)	20	65	33.71	30.00	24.00	1.143	0.210
Total	256(100.0)	18	65	32.32	29.00	24.00	1.113	0.152

Mann-Whitney U = 7136.5 ; Z = -1.765; p-value = 0.078

Source: Field survey, 2014



The ages of the respondents were examined for males and females. The males were aged from 18 to 55 years, while the females were aged from 20 to 65 years. The statistical age range, calculated by deducting the minimum age from the maximum age, was therefore smaller for the males (37 years), than the females (45 years). The ages of the females PLHIV were therefore spread across a wider age range than the males.

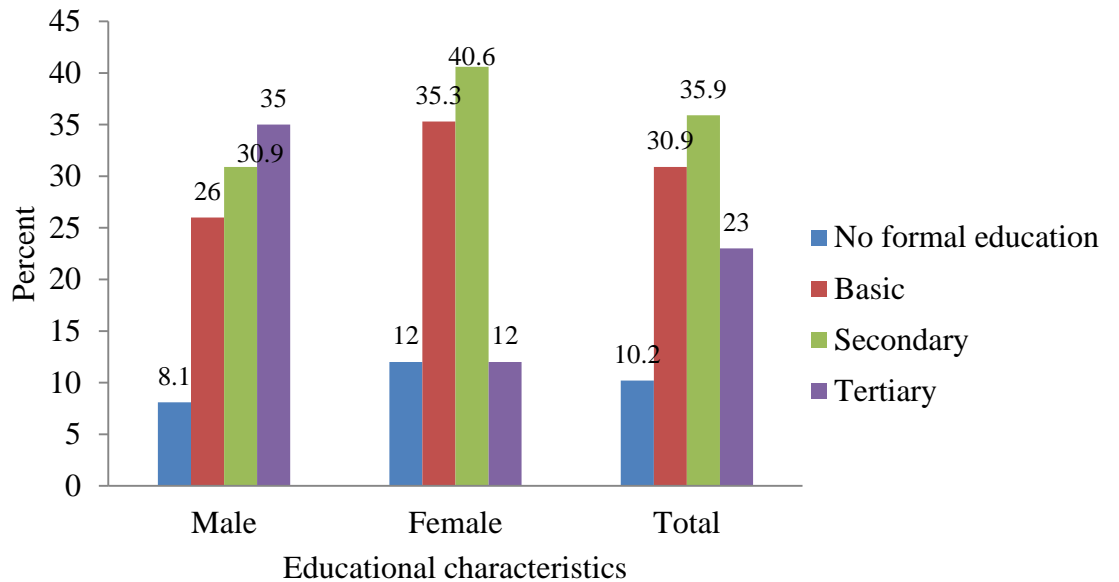
The average age of the males PLHIV was 26 years, whereas the average for the females was 30 years. The average male PLHIV was therefore younger than the average female PLHIV. Based on the z-score of -1.765 and a p-value of 0.078, the study found that the differences in the average ages of the male and female respondents were not statistically significant. Therefore, the males and females were of similar ages with no significant difference.

The study also explored the educational characteristics of the respondents. The researcher wanted to have enough background information on the respondents. The researcher assumed that there was some form of relationship between HIV and AIDS stigma and educational disadvantage even though Vanable et al. (2006) found that HIV-related stigma was not a function of the patient's educational background. Besides the fact that the study sought to establish the contextual settings of the respondents, it also aimed to provide some evidence in support of, or to contradict such assertions by Vanable et al. (2006).

Figure 2 presents the results on the educational characteristics of the male and female respondents. Overall, it was found that 40.6% of the respondents had secondary education. Those with lesser than secondary education were 41.1

percent, which was lower than Ulasi et al.'s (2009) study in Kumasi which established that PLHIVs with lesser than secondary education were 59 percent of the population. The disaggregated results showed that a greater section of the males (35%) had tertiary education as against the females (40.6%) who mostly had secondary education. A lesser fraction of the males (34.1%) also had educational qualification lesser than secondary education, as against the females (47.3%).

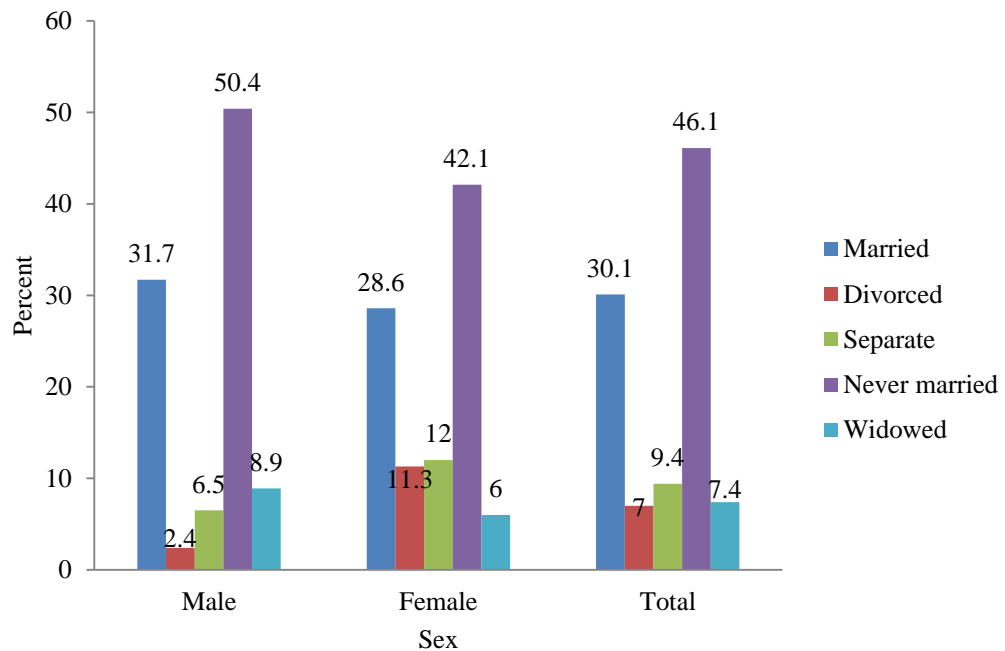
Thus, the results point to the fact that the males were slightly more educated than the females. If HIV and AIDS contraction is related to education background of patients as suggested by Bond et al. (2002) such that those who are less educated have higher prevalence rates, then that might explain why the sample captured more females. However, it was found that male and female respondents with secondary or higher education were more than those with lesser than secondary education and that would contradict Bond et al.'s(2002) assertion. Thus, the results remain inconclusive.



**Figure 2: Educational characteristics of respondents**

Source: Field survey, 2014

The marital status of the respondents was also explored on the basis of establishing a link between the marital status and the serostatus of the respondents. Some studies in Tanzania, Lesotho and Zimbabwe established that HIV patients are very likely to be widowed or divorced, in comparison to those who are never married (Mankoe et al., 2008; Mwambu, 1998). In this study, the respondents who had never married (46.1%) were more than the respondents in any of the marital categories (Figure 3). Thus, the likelihood that PLHIV in the Saint Francis Xavier hospital had never married was higher than the likelihood that they were married, divorced, separated, or widowed. This might be explained by the higher number of younger people in the study population.

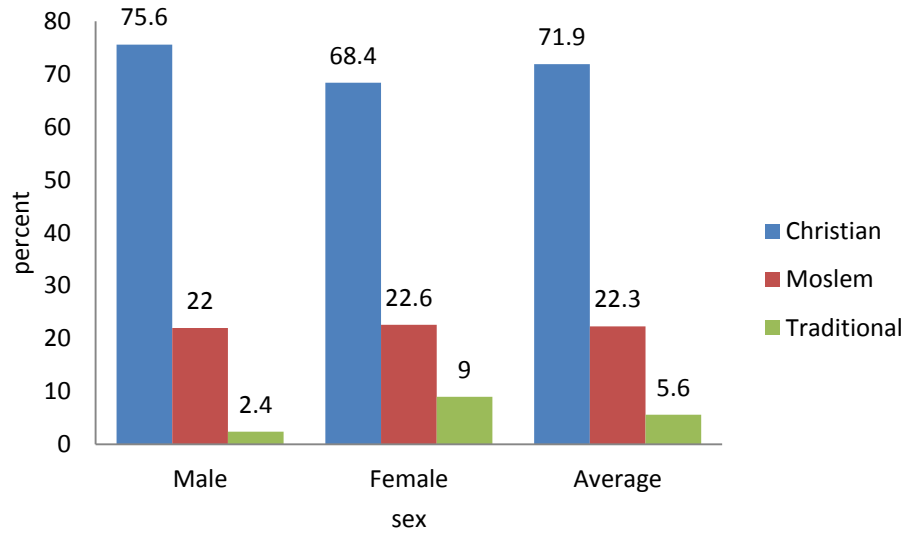


**Figure 3: Marital status of respondents**

Source: Field survey, 2014

The situation was the same for the male and female respondents. The greater portion of the males (50.4%) and the females (42.1%) had never married. Thus, for the males and females, Mankoe et al.'s (2008) assertion on the link between the marital status and the serostatus of PLHIV was disconfirmed..

The religious affiliation of the respondents was also examined. Figure 3 presents the religious affiliation of the PLHIV as sampled by the study. The analysis covered the total number of 256 respondents and it was found that an overwhelming majority (71.9%) of the respondents were Christians. Some studies have linked HIV infection to religion and found that in Moslem communities HIV infection is very low, but Christian community or countries record high HIV and AIDS prevalence.



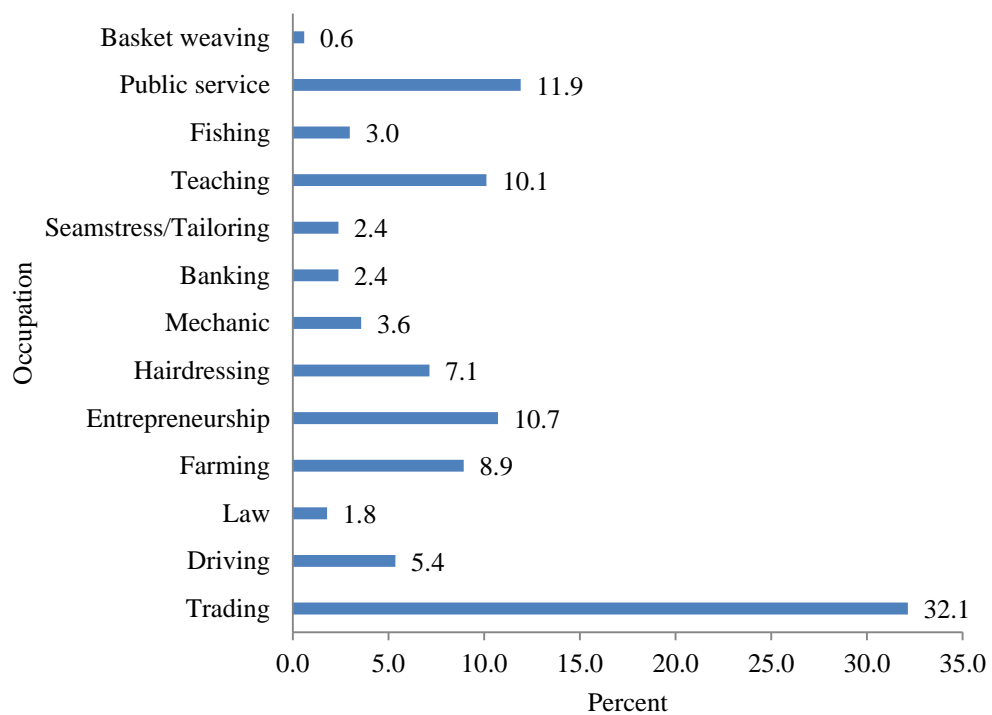
**Figure 4: Religious affiliation of respondents**

Source: Field survey, 2014

Thus, these studies suggest that people of the Christian faith are more likely to have HIV infection than those who adhere to the Moslem doctrine. Their assertions were founded in the moral and behavioural inclinations of people belonging to different religions. The results of this study provide some support in respect of studies that link high moral adherence in Islamic religion to low HIV prevalence in Islamic states (Hasnaian, 2005).

The study also confirmed Ulasi et al.'s (2009) study in Kumasi in which 80 percent of the PLHIVs were Christians. This was true for both males (75.6%) and females (68.4%), because most of them were also Christians. Therefore, generally, the likelihood that a PLHIV was also a Christian was higher than being a Moslem and also an HIV carrier. However, due recognition must be given to the fact that Assin Fosu is largely a Christian community, and that might explain why a greater section of the PLHIVs were Christians.

The employment status of the respondents was explored. From the results, the majority (65.6%) of the respondents were employed, as against those who were unemployed (34.4%). The types or categories of jobs that the respondents pursued were further explored, as shown in Figure 5. The occupational background of the respondents cut across several lines of employment. The findings covered 168 respondents who indicated that they were employed. Mostly, trading (32.1%) was the popular occupation among the employed respondents. Next to trading, was public service (11.9%), occupations that could be categories into a form of entrepreneurship (10.7%) and teaching (10.1%).



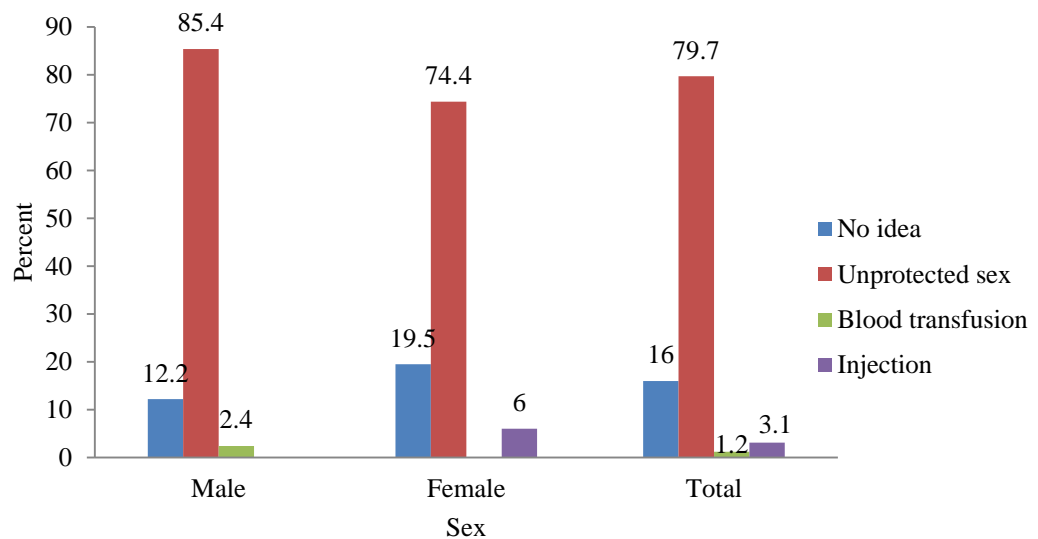
**Figure 5: Occupational characteristics of respondents**

Source: Field survey, 2014

The categories of employment identified among the responses reflect the vibrant primary production and economic sector, as indicated by the Ministry of Land and Rural Development (2010). The results also indicated that HIV and

AIDS prevalence is not confined to any particular occupation as Mawar et al. (2005), in India, found that some groups often associate HIV and AIDS prevalence with sex workers.

The respondents' knowledge of their serostatus was also explored. Their awareness of the mode by which they contracted the disease, how they realised they were infected and the length of time they have lived with HIV and AIDS were explored. Figure 6 presents the responses regarding the mode of HIV and AIDS contraction among the respondents. The results showed that 16 percent of the respondents had no idea how they contracted HIV and AIDS, whereas 179.7 percent were certain that they contracted the virus through unprotected sex.



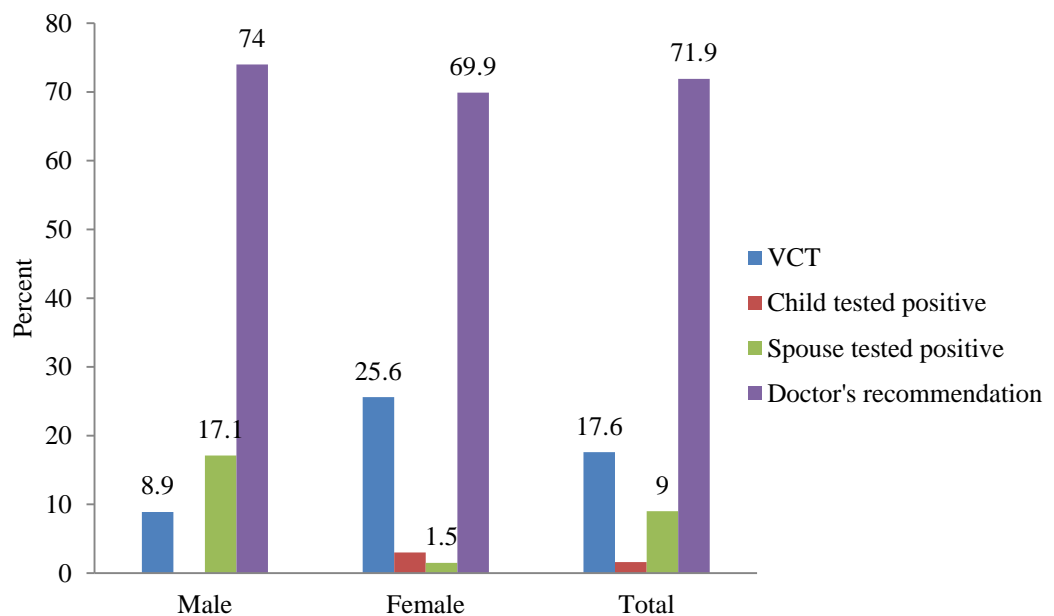
**Figure 6: Modes of contracting HIV**

Source: Field survey, 2014

Unprotected sex was the primary mode of transmission for both males (85.4%) and females (74.4%), but a few males (2.4%) and females (6%) also indicated that they believed they contracted the HIV virus through blood transfusion and by injection. The results confirmed that unprotected sex remains

the main mode of HIV transmission, as estimated by the WHO (2010) that about 70 percent of HIV transmission is through sexual contact.

The means by which the respondents became aware of their serostatus were explored, as shown in Figure 7. Overall, 71.9 percent of the respondents indicated that they were diagnosed after following through with their doctor’s recommendation to conduct the HIV test. This was the situation for most of the males (74%) and the females (69.9%). Diagnosis based on counselling and testing(CT) was 17.6 percent. For others, their spouses (9%) or child (1.6%) tested positive and that encouraged them to test as well. The results indicated that VCT was very low among the respondents, which confirmed low patronage of VCT, as found by Armah-Attoh (2009) and Ulasi et al. (2009) in their studies of HIV-related stigma. However, VCT was very low among the males (8.9%) as compared to the females (25.6%).



**Figure 7: Mode of diagnosis of HIV status**

Source: Field survey, 2014



Table 2 shows the summary statistics for the number of months that the respondents had been living with HIV and AIDS. The results showed that a greater (34.8%) section of the respondents had lived with HIV for a period of two to five years. In total, 30.1 percent had lived with the virus for less than a year and only a few over 10 years. By using the raw data collected in number of months that the respondents had lived with HIV, it was found that the respondents had lived with HIV from two months to 252 months (21 years). Given that the distribution had a skewness statistic of 3.384 ( $> \pm 0.5$ ), the average, represented by the median, was 24 months, equivalent to two years. Thus, on the average, the respondents had lived with the virus for approximately two years.

**Table 2: Length of living with HIV**

Period in yrs	Frequency	Percent
Up to 1 yr	77	30.1
Between 1 – 2 yrs	70	27.3
Between 2 – 5 yrs	89	34.8
Between 5 – 10 yrs	17	6.6
Over 10 yrs	3	1.2

Summary statistics in months:

Min: 2; Max: 252; Mean: 30.72; Median: 24.00; Mode: 24; Skewness: 3.384; Std Error of Skewness: 0.152.

Source: Field survey, 2014

### **The nature of HIV and AIDS stigmatisation**

The nature of HIV and AIDS discrimination can take many forms. These have been extensively discussed in literature (Mahlalela, 2006; Parker &

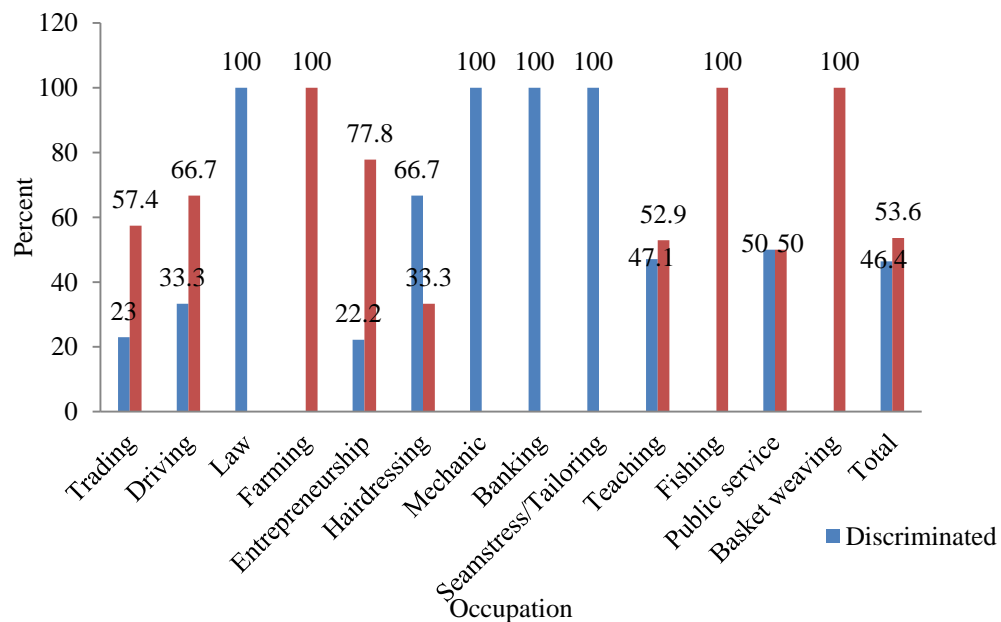
Aggleton, 2003; Simbayi et al., 2007). The exact nature of HIV and AIDS related discrimination experienced by the respondents of this study was explored to add to the literature on HIV discrimination and stigmatisation, and also to inform strategic approaches to overcome HIV and AIDS related discrimination. The respondents were asked to indicate by 'Yes' or 'No' their experience in terms of certain discriminatory and stigmatisation acts that result from their serostatus as HIV carriers. The thematic areas of investigation were grouped under job place discrimination, discrimination by family, community-based discrimination and health-care discrimination.

### **Workplace discrimination and stigmatisation**

According to Marta et al. (2008) PLHIV suffer various stigma from their co-workers and employers. This study explored the discrimination related with the jobs of the respondents. Overall, 75.9 percent of the respondents indicated that they had not been fired because they were HIV-positive, whereas 23.7 percent had lost their jobs, specifically because they were HIV-positive. The rest of the analysis under the workplace discrimination covered those who were currently employed.

The respondents were asked if they had experienced some form of workplace discrimination in their line of job. The responses were obtained from the 168 respondents who were employed at the time of the study. Overall, 53.6 percent of the respondents noted that they had not been discriminated against in any way at their workplace. In the disaggregated results, it was found that none of the farmers and weavers had been exposed to any form of discrimination because

of their serostatus. On the other hand, all the lawyers, mechanics, bankers, tailors/seamstresses and the majority of the traders (57.4%), hairdressers (66.7%), as well as some of the teachers (52.9%), and other entrepreneurs (77.8%) had been discriminated against because of their serostatus. The results therefore showed that mostly the respondents in primary occupation had no work-related stigmatisation whereas those engaged in service provision, such as teaching, banking, law and tailoring were exposed to some form of workplace discrimination: this disparity may probably be due to the fact those engaged in service provision are sometimes obliged to declare their health status to their employers who take administrative decisions based on health unlike those in the primary sector who do face such workplace requirement. The results confirmed the fact that HIV-related discrimination exists in various fields of occupation as indicated by several earlier studies (Marta et al., 2008)



**Figure 8: Discrimination at work place**

Source: Field survey, 2014

According to Mawar et al. (2005) workplace discrimination can include pre-employment screening and forced disclosure of an employees' HIV status. The study explored this statement based on the specific context of the PLHIVs in Assin Fosu. It was found that 70.8 of the respondents had never been forced to disclose their HIV status as a requirement to either gain employment or keep their jobs, as against 29.2 percent of who had been subjected to such treatment. This confirmed Mawar et al.'s findings that workplace discrimination can involve forced disclosure of one's serostatus, and by extension, the individual may lose his/her job if found positive with HIV.

**Table 3: Nature of workplace discrimination and stigmatisation**

Preamble	Frequency	Percent
Forced disclosure		
Yes	49	29.2
No	119	70.8
TOTAL	168	100
Discriminated by colleagues		
Yes	78	46.4
No	90	53.6
TOTAL	168	100
Changed duties		
Yes	35	20.8
No	133	79.2
TOTAL	168	100
Offered early retirement		
Yes	38	22.6
No	130	77.4
TOTAL	168	100

Source: Field survey, 2014

Moreover, 53.6 percent of the respondents declined the statement that the attitudes of their colleagues were discriminatory or stigmatising because of their serostatus as HIV carriers. The findings confirm the notion that factors contributing to these stigmatisation and discrimination of PLHIV may include moral attitudes towards PLHIVs (Masini & Mwampeta 1993). However, in this study, such discriminatory practices were low among the populace.

Discrimination may also include change of job responsibilities in the guise that the HIV carrier is more suited for certain jobs or to avoid contact with the HIV carrier (Ulas et al., 2009). In this study, 79.2 percent of the employed respondents noted that their job responsibilities had not been changed because they were HIV positive, whereas 20.8 percent were of the view that their employers had changed their duties because of their HIV status. The results therefore showed that HIV carriers were mostly allowed to carry on with their regular duties.

Workplace discrimination may also take the form of subtle attempts to get rid of HIV carriers in the form of early retirement. The subtlety exists in the form of a dismissal but in this case, the HIV carrier is allowed to leave with the compensation of a pensioner. This study revealed that 77.4 percent of the respondents indicated that they had not been offered early retirement as a form of discrimination because of their HIV status. The rest (22.6%) of the respondents however noted that they had been approached with an early retirement offer. Most of the respondents had therefore not been exposed to subtle forms of dismissal such as involuntary early retirement packages.

### Family-related discrimination and stigmatisation

According to Galvao et al. (2013), PLHIV often experience stigma and discrimination in the home, and women are often more likely to be badly treated than men or children. This study explored the discriminatory practices exhibited by the families of the PLHIV as one of the thematic areas of discrimination against PLHIV.

According to the study, 67.2 percent of the respondents noted that their family members visit them irrespective of their serostatus, whereas 32.8 percent responded that their family members had stopped visiting them because of their serostatus.

**Table 4: Discrimination in visitation**

	Sex		Total N(%)
	Male	Female	
	N(%)	N(%)	
Family visits	87(70.7)	85(63.5)	172(67.2)
Family does not visit	36(29.3)	48(36.1)	84(32.8)
Total	123(100.0)	133(100.0)	256(100.0)

Chi-square = 1.349; df = 1; phi = 0.073; p-value = 0.245

Source: Field survey, 2014

The negative family response, manifested in deserting the HIV carrier, was minimal among the respondents. The notion that, in the family context, female carriers of HIV are more likely to be treated badly was also explored. A greater section of both the males (70.7%) and females (63.9%) noted that their families still visited them after their HIV status was made known to the family.

The relationship between the respondents' sex and their responses was examined using Chi-square, phi, and their associated p-values. The statistics showed that the distribution of the responses was associated with a phi-statistic of 0.073 which represents a very weak association. The chi-square of 1.349 (df = 1) and p-value of 0.245 also showed that the association was not statistically significant at an alpha of 0.05. The implication was that male and female HIV carriers in this study received similar treatment, in respect of visits from their families. Thus, the results contradict Aggleton et al.'s (2003) idea that women HIV carriers are more likely to be treated badly than men.

Further statistical analysis showed that the distribution of the responses was associated with a phi of 0.212, which indicated a weak association between the sex of the respondents and the willingness of their family to touch them physically. This association was also backed by a Chi-square of 11.457 (df = 1) and p-value of 0.001, which established that the association, although weak, was statistically significant at an alpha of 0.05. Therefore, the study maintained that a significantly greater proportion of male HIV carriers were given physical contact, as opposed to the section of the females who were treated the same way by their family members.

The labelling theory sees society as constructed through an exchange of gestures, such as closeness and touch. Smart (2004) therefore deduced that the labelling theory applies when gestures and symbolic communication, such as avoiding to touch an HIV carrier, convey a stigmatising notion. In this study, 72.3 percent of the respondents indicated that their families still kept physical contact

with them, whereas 27.7 percent responded that their family members had refused to touch them (Table 5). In the disaggregated responses, the majority of both the males (82.1%) and females (63.2%) confirmed that their family members still touched them willingly.

**Table 5: Discrimination in physical contact with family**

	Sex		Total
	Male	Female	
Preamble	f(%)	f(%)	f(%)
Family physical contact	101(82.1)	84(63.2)	185(72.3)
Family does not touch me	22(17.9)	49(36.8)	71(27.7)
Total	123(100.0)	133(100.0)	256(100.0)

phi = 0.212; p-value = 0.001

Source: Field survey, 2014

The familial relationship with HIV carriers was also analysed in terms of the willingness of family members to eat with the HIV carriers. This was an attempt to explore the existence of instrumental stigma within the family context. In this study 53.1 percent of the respondents indicated that their family members still ate with and shared food with them. This was the case for 63.4 percent of the males and 43.6 percent of the females. Thus, it was revealed that a greater section of the females were not allowed to eat with other family members. According to Galvao et al (2013), instrumental stigma resulting from fear of contact with the HIV carrier may include the fear to touch or eat with the HIV carrier. In this study, such manifestations of instrumental stigma within the family context were



minimal. This could probably be related the cultural setting where members of the extended family are more supportive of one another in spite of one's health condition.

**Table 6: Discrimination with sharing meals**

	Sex		Total
	Male	Female	
Preamble	f(%)	f(%)	f(%)
Family shares meal with me	78(63.4)	58(43.6)	136(53.1)
Family does not share meal with me	45(36.6)	75(56.4)	120(46.9)
Total	123(100.0)	133(100.0)	256(100.0)

Source: Field survey, 2014

UNAIDS (2008) maintains that verbal abuse remains one of the major manifestations of discrimination and stigmatisation of HIV carriers. The respondents were asked to indicate whether they were verbally abused by their family members. According to the study, 76.2 percent of the respondents indicated that their family members did not verbally abuse them. This was the case for majority of the male (81.3%) and female (71.4%) respondents (Table 7). The study therefore showed that, generally, the HIV carriers were not subjected to verbal abuse by their families. The differences in the responses of the males and females were also found not to be statistically significant, given the chi-square of 3.432 and a p-value of 0.064. The results therefore revealed that a similar percentage of the males and females were exposed to verbal abuse by their families.

**Table 7: Verbal abuse by family**

	Sex		Total
	Male	Female	
Preamble	f(%)	f(%)	f(%)
Family verbally abuses me	23(18.7)	38(28.6)	61(23.8)
Family does not abuse me verbally	100(81.3)	95(71.4)	195(76.2)
Total	123(100.0)	133(100.0)	256(100.0)

Chi-square = 3.431; df = 1; p-value = 0.064

Source: Field survey, 2014

The respondents' exposure to physical abuse was also examined by the study. The results indicated that most of the respondents did not suffer physical abuse from their family members as found in other studies (Nyblade, 2006). On the other hand, most (78.1%) of the respondents in this study had not been exposed to any form of physical abuse. A greater percentage of both the males (78.9%) and females (77.4%) disagreed to the statement that they had been exposed to some form of physical abuse (Table 8). It was showed that enacted stigma in the form of verbal and physical abuse was not common among the families of the HIV carriers.

**Table 8: Physical abuse by family**

	Sex		Total
	Male	Female	
Preamble	f(%)	f(%)	f(%)
Family abuses me physically	26(21.1)	30(22.6)	56(21.9)
Family does not physically abuse me	97(78.9)	103(77.4)	200(78.1)
Total	123(100.0)	133(100.0)	256(100.0)

Chi-square = 0.075; phi = 0.017; df = 1; p-value = 0.784

Source: Field survey, 2014

The symbolic stigma within the family was analysed based on the respondents' indication on whether their family members hide them to prevent people from knowing the HIV status of the respondents. The results showed that overall, 73 percent of the respondents disagreed to the statement that their family members hid them from the public. This was expressed by the majority of the males and the females alike, but the association between the sex of the carriers and their responses was weak (phi = 0.144; p-value = 0.022s). In comparison with the males, a greater percentage of the females indicated that their family members hid them from the public.

**Table 9: Family attempt to hide HIV carriers**

	Sex		
	Male	Female	Total
Preamble	N(%)	N(%)	N(%)
Family hides me	25(20.3)	44(33.1)	69(27.0)
Family does not hide me	98(79.7)	89(66.9)	187(73.0)
Total	123(100.0)	133(100.0)	256(100.0)

Chi-square = 5.282; phi = 0.144; df = 1; p-value = 0.022

Source: Field survey, 2014

### **Discrimination in a community context**

Community-level stigma and discrimination can manifest as ostracism, rejection and verbal, physical abuse and murder (UNAIDS, 2008). Evidence of such acts has been found in Brazil (Peterson 1990; Byrne 1992), Colombia, India, Ethiopia, South Africa, and Thailand (AFAO 1997). The conceptual framework emphasises that community level discrimination also describes the social context of discrimination, to some extent and in that respect, the results were disaggregated by the sex and religion of the respondent. This was to further investigate the relationship stigmatisation has with gender and religion.

Table 10 shows the relationship of the community level discrimination and the sex and religions of HIV carriers. According to the study, 82.8 percent of the respondents declined the statement that their families were excluded from social events because they had an HIV positive relative. For most males (81.3%) and females (84.2%), their families were not excluded from social events, based on

the reason that those families had relations with an HIV positive person. Furthermore, 87.7 percent of the Moslems, 82.1 percent of the Christians and 73.3 percent of the Traditionalists indicated that neither they nor their families were denied participation in community events.

**Table 10: Exclusion from community events**

Community events	Sex		Religion			Total
	Male f(%)	Female f(%)	Moslem f(%)	Christian f(%)	Traditional f(%)	
Excluded	23(18.7)	21(15.8)	7(12.3)	33(17.9)	4(26.7)	44(17.2)
Not excluded	100(81.3)	112(84.2)	50(87.7)	151(82.1)	11(73.3)	212(82.8)
Total	123(100.0)	133(100.0)	57(100.0)	184(100.0)	15(100.0)	256(100.0)

Source: Field survey, 2014

In that respect, the study found that community discrimination against HIV carriers and their families in terms of social exclusion from events was minimal among the respondents. Thus, the UNAIDS (2008) findings that ostracism of HIV carriers at the community level, which was very pronounced in Colombia, India, Ethiopia, South Africa and Thailand (AFAO 1997) was not the case in Assin Fosu.

In countries like USA and Brazil (Galvao et al. (2013), stigmatisation of children associated with HIV through infected family members has been one of the major forms of secondary stigma. In this study, the nature of secondary stigma was explored based on the respondents' assertion regarding the refusal or acceptance of other families to allow their children to play with others.

The study showed that 152 respondents had children and 77.6 percent of them denied the assertion that other people in the community refused to play with their children (Table 11). Thus, the indication was that secondary stigmatisation was not pronounced in PLHIV. Most of the males (75%) and females (80.3%), as well the majority of the Moslems (82.5%), Christians (77.9%), and half of the Traditionalists (50%) who had children also asserted that other families allowed their children to play with the children of the HIV carriers.

**Table 11: Secondary discrimination of relatives of HIV carriers**

Children play with others	Sex		Religion			Total
	Male f(%)	Female f(%)	Moslem f(%)	Christian f(%)	Traditional f(%)	
Yes	19(25.0)	15(19.7)	7(17.5)	23(22.1)	4(50.0)	34(22.4)
No	57(75.0)	61(80.3)	23(82.5)	81(77.9)	4(50.0)	118(77.6)
Total	76(100.0)	76(100.0)	40(100.0)	104(100.0)	8(100.0)	152(100.0)

Source: Field survey, 2014

The findings of the study indicated that, as opposed to the forms of HIV-related secondary stigma found by Gilborn et al. (2001) and Galvao et al. (2013), secondary stigma in Assin Fosu was relatively low.

The study further explored the community discrimination in the form of verbal abuse and attempts at ostracising the HIV carriers. UNAIDS (2008) showed that verbal abuse and ostracism lay the foundation for some of the HIV-related murders, especially when the HIV carriers ignore the abuse and refuse to leave the community. In this study, 77.3 percent of the respondents denied that the community members had verbally abused them because they are HIV positive

(Table 12). For most of the males (72.4%) and females (69.2%), the community members were not verbally abusive because of their HIV status. Similarly, the majority of the Moslems (78.9%) and Christians (70.1%) also maintained that community members were not verbally abusive because of their HIV status. On the other hand, 53.3 percent of the Traditionalist noted that they had been verbally abused because of their HIV status.

**Table 12: Verbal abuse by community members**

Verbal abuse by community	Sex		Religion			Total f(%)
	Male f(%)	Female f(%)	Moslem f(%)	Christian f(%)	Traditional f(%)	
Yes	34(27.6)	41(30.8)	12(21.1)	55(29.9)	8(53.3)	75(29.3)
No	89(72.4)	92(69.2)	45(78.9)	129(70.1)	7(46.7)	181(70.7)
Total	123(100.0)	133(100.0)	57(100.0)	184(100.0)	15(100.0)	256(100.0)

Source: Field survey, 2014

Support for UNAIDS' (2008) assertion of verbal abuse was found mostly among the Traditionalists in this study. For the other groups of respondents, that is, males and females in general, as well as the Moslem and Christians, verbal abuse was minimal.

In further analyses, the study revealed that most of the respondents had not been asked to leave the community because of their HIV status. This was expressed by most of the males and females, as well as the majority of the Moslems and Christians. However, a greater fraction of the Traditionalists (53.3%) asserted that some community members asked them to leave the community because they were HIV positive. The results therefore showed that

generally, attempts to ostracise HIV carriers from the Assin Fosu community was not a major issue of concern as found in other studies in Lesotho, Malawi, South Africa, Swaziland, and Tanzania (Mankoe et al., 2008).

**Table 13: Ostracism from community**

Ostracism attempts	Sex		Religion			Total f(%)
	Male f(%)	Female f(%)	Moslem f(%)	Christian f(%)	Traditional f(%)	
Yes	17(13.8)	41(30.8)	8(14.0)	39(21.2)	8(53.3)	55(21.5)
No	106(86.2)	95(71.4)	49(86.0)	145(78.8)	7(46.7)	201(78.5)
Total	123(100.0)	133(100.0)	57(100.0)	184(100.0)	15(100.0)	256(100.0)

Source: Field survey, 2014

### **Healthcare context**

According to Nyblade's (2006), PLHIV often avoid medical care and support in order to avert any suspicions about their status. This may also result because of stigmatisation and discrimination in the healthcare system. The nature of discrimination and stigmatisation of HIV carriers seeking healthcare were examined in this section.

In that respect, the study explored the experience of the HIV carriers with regard to the treatment and advice which they are given, and which may be termed as stigmatising or discriminatory due to the HIV status of the respondents. According to the study, 71.1 percent of the respondents noted that health workers do not refuse to treat them because of their HIV status. Most of the males and females indicated that health workers do not refuse them treatment because of their HIV status. Thus, the results indicated that, first, refusal of health workers to treat HIV carriers, due to speculated fear of contagion and death was not the case



for most of the respondents. Secondly, the findings discounted the assertion that women HIV carriers are often treated badly as against the males. In this case, the discriminatory act of treatment refusal was minimal among the respondents.

Further analyses revealed that 83.6 percent of the respondents declined the statement that they had been forced to pay additional medical bills for treatment because they were HIV positive. On the other hand, 16.4 percent had paid unofficial medical bills in order to get treatment for ailments, because they were HIV positive. Most of the males and females had not experienced forced payment of unofficial medical bills and thus the findings suggested that this form of discrimination was minimal among either sex and across the population.

**Table 14: Discrimination in health services**

Preamble	Male N(%)	Female N(%)	Total N(%)
<b>Health workers refuse me treatment</b>			
Yes	34(27.6%)	40(30.1)	74(28.9)
No	89(72.4%)	93(69.9)	182(71.1)
<b>Forced to pay additional bills</b>			
Yes	27(22.0)	15(11.3)	42(16.4)
No	96(78.0)	118(88.7)	214(83.6)
<b>Advised not to have children</b>			
Yes	34(27.6)	36(27.1)	70(27.3)
No	89(72.4)	97(72.9)	186(72.7)
<b>Forced to agree to an abortion</b>			
Yes	6(4.9)	16(12.0)	22(8.6)
No	117(95.1)	117(88.0)	234(91.4)

Source: Field survey, 2014

This study further explored the medical advice given to HIV carriers in an attempt to detect some major discriminatory practices in the health systems. The

respondents were asked to indicate whether they had been advised by medical practitioners not to have children because of their HIV status. In respect of this, the majority (72.7%) of the respondents noted that they had never been advised against bearing children because of their HIV status and most (91.4%) of them also noted that no medical practitioner had advised them to agree to an abortion because they were HIV positive. In Brazil, Barbosa et al. (2012) found that HIV infection is a common reason to interrupt pregnancies, but this study found that the decision to interrupt pregnancy because of HIV infection was minimal among the respondents.

### **Effects of HIV stigma and discrimination**

According to UNAIDS Global Report, 2013, HIV continues to be driven by gender inequalities and harmful gender norms that promote unsafe sex and reduce access to HIV and sexual and reproductive health services for men, women and transgender persons. The epidemic imposes a particular burden on women and girls.

The effects of stigmatisation and discriminatory practices against HIV and AIDS carriers are diverse and can be internal to the carrier or be expressed in more overt ways that others can acknowledge (Vanable et al., 2006). The study explored the effects of HIV stigma on the psyche, health, family relations and up keep of the HIV carriers. Hypotheses were constructed for each effect of stigma as revealed by the study.

The research found out that HIV stigmatization had a major effect on the psychological makeup of the PLHIV. The following hypotheses were formulated to bring out the various shades of psychological effects of stigma on the PLHIV,

According to the study, 50.4 percent of the respondents indicated that they did not harbour any internal feelings that they weren't as good a person as others who did not have HIV. On the other hand, 49.6 percent felt people without HIV were better off than those with HIV carriers. This indicated that close to half of the respondents suffered felt stigma in terms of looking down on themselves because of their HIV status. This confirms the findings of Falk (2002) and Mawar et al. (2005) that felt stigma is common among HIV carriers and this may lead to hiding one's HIV status and also lead to self-blame.

**Table 15: psychological effects of stigma on PLHIV**

Preamble	Male N(%)	Female N(%)	Total N(%)
Feeling of inferiority			
Yes	60(48.8)	67(50.4)	127(49.6)
No	63(51.2)	66(49.6)	129(50.4)
Self-blame			
Yes	82(66.7)	60(45.1)	142(55.5)
No	41(33.3)	73(54.9)	114(44.5)
Loss of self-confidence			
Yes	71(57.7)	58(43.6)	129(50.4)
No	52(72.4)	75(56.4)	127(49.6)
Lost hopes			
Yes	55(44.7)	54(40.6)	109(42.6)
No	68(55.3)	79(59.4)	147(57.4)
Depression and loneliness			
Yes	51(41.5)	53(39.8)	104(40.6)
No	72(58.5)	80(60.2)	152(59.4)

Source: Field survey, 2014

In respect of self-blame, which is another measure of felt stigma (Jacoby et al., 2004), most of the respondents noted that they blamed themselves for their HIV status. This confirmed Galvao et al's (2013) indication that HIV and AIDS carriers are often stigmatised with shame and disgrace. This also emanates from self-devaluation and the perception of oneself as unequal to non-carriers of HIV.

In the disaggregated responses, it was found that most of the males (66.7%) blamed themselves for their HIV status, but the majority of the females (54.9%) felt otherwise. The distinction between the responses was tested for statistical significance and it was found that, with a chi-square of 12.019 and a p-value of 0.001, the association between the sex of the respondents and their self-blame was statistically significant at an alpha of 0.05. Therefore, it was asserted that the male HIV carriers were more likely to harbour self-blame than their female counterparts. This therefore fails to accept the null hypothesis that being male or female does not influence self blame.

In further analyses, 50.4 percent of the respondents noted that they had lost considerable self-confidence due to stigma attached to HIV disease. Most of the males agreed that they had lost considerable self-confidence, but most of the females noted otherwise. The results, generally, confirmed Smart's (2004) findings that stigma can affect HIV carriers in more subtle ways, such that they may harbour feeling of shame, dejection, self-doubt and inferiority, which are manifestations of lost self-confidence. Kayungilizi (2007) also found that HIV-related stigma affects the self-confidence of the stigmatised person, which leads to self-withdrawal, self-blame, and loss of self-worth.

Table 15 also showed that 57.4 percent of the respondents noted that they still had hopes of achieving their life goals, whereas 42.6 percent noted that they had lost all hopes of achieving their life goals. This is a clear example of maladaptive coping strategies; a feeling of helplessness which is associated with depression and loss of self-worth, as consequences of internalised stigma.

Most of the males and females noted that they had not lost all hopes of achieving their life goals. This was associated with a chi-square of 0.442, phi of 0.042 and a p-value of 0.508, which indicated that the association between sex and the loss of hope negligible and not statistically significant at an alpha level of 0.05. The results therefore indicated that the feeling of lost hope was not related to whether the carrier was male or female, but common phenomena to both sexes. This therefore accepts the null hypothesis that being male or female does not influence lost of hope.

In this study, 59.4 percent of the respondents mentioned that they were neither lonely nor depressed about their HIV status. This was true for 58.5 percent of the males and 60.2 percent of the females. The association between the respondents' depression about their HIV status and their sex was also negligible and not statistically significant at an alpha of 0.05 (chi-square 0.069; phi = 0.016; p-value = 0.793). Therefore, in contrast with studies reviewed earlier, self-depression was not expressed by most of the HIV carriers on Assin Fosu. This therefore accepts the null hypothesis that being male or female does not influence depression and loneliness.

The health effects of HIV-related stigma were also explored in the context of the respondents from the Saint Xavier Hospital at Assin Fosu. The health effects, are such that HIV carriers may not want to access healthcare because of the possible stigma associated with disclosure of one's HIV status. In this study, the possible effects of HIV stigma on such avoidance of health services were explored.

It was found that 87.1 percent of the respondents did not avoid health services because of possible stigmatisation associated with exposure of their serostatus (Table 16). This assertion was confirmed by 87 percent of the males and 87.2 percent of the females. This indicated that generally the majority of the respondents, irrespective of their sex did not avoid health services in order to avoid stigmatisation associated with disclosing their HIV status. The assertions made by, Aggleton (2003) and Mill (2003) that often HIV carriers avoid medical care in order to avoid stigmatisation with disclosed serostatus was not the case for the HIV carriers in Assin Fosu.

It was also found that 90.2 percent of the respondents declined the assertion that they preferred to buy medicine to treat myself because they would be stigmatised at the hospital. This was confirmed by 87 percent of the males and 93.2 percent of the females. Thus, it could be asserted that self-medication and its complication were not a main issue among the respondents and that the respondents were not particularly discouraged to seek medical care because of possible stigmatisation, as indicated by Aggleton (2003), Mill (2003) and Nyblade (2006).

The knowledge offered through health campaigns are beneficial to HIV carriers, since they often publicise the appropriate lifestyles, such as eating habits, exercising and other important health practices that might help to keep the HIV carriers healthy (UNAIDS, 2007). However, exposure of one's serostatus might cause HIV carriers to avoid such health campaigns in the fear of avoiding stigmatisation related with exposure of ones serostatus. In this study, 67.2 percent of the respondents declined the assertion that they avoided health campaigns in order to avoid disclosure of their serostatus.

**Table 16: Effects HIV stigma on access to health services**

Preamble	Male N(%)	Female N(%)	Total N(%)
<b>Avoid treatment/medication</b>			
Yes	16(13.0)	17(12.8)	33(12.9)
No	107(87.0)	116(87.2)	223(87.1)
<b>Self-medication</b>			
Yes	16(13.0)	9(6.8)	25(9.8)
No	107(87.0)	124(93.2)	231(90.2)
<b>Avoid health care campaigns</b>			
Yes	42(34.1)	42(31.6)	84(32.8)
No	81(65.9)	91(68.4)	172(67.2)

Source: Field survey, 2014

The effects of the HIV related stigma on the family relations of the respondents was also examined. The results indicated that most (86.7%) of the respondents indicated that they had not been isolated from their families. Smart (2004) indicates that familial dejection is commonly related to HIV related

stigmatisation. However, in the case of this study, familial dejection was not much related to HIV related stigma for most of the respondents. Similarly, most of the respondents indicated that they still had their friends and family close to them and 73 percent of the respondents also noted that they could still make new friends, irrespective of their HIV positive status. Most of the respondents also disagreed that people avoided conversation with them because of their HIV status.

**Table 17: Effects of HIV stigma on family and friends relations**

Preamble	Male N(%)	Female N(%)	Total N(%)
Isolated from family			
Yes	7(5.7)	27(20.3)	34(13.3)
No	116(94.3)	106(79.7)	222(86.7)
Lost friends			
Yes	24(19.5)	38(28.6)	62(24.2)
No	99(80.5)	95(71.4)	194(75.8)
Cannot make new friends			
Yes	27(22.0)	42(31.6)	69(27.0)
No	96(78.0)	91(68.4)	187(73.0)
People avoid talking to me			
Yes	16(13.0)	38(28.6)	54(21.1)
No	107(87.0)	95(71.4)	202(78.9)

Source: Field survey, 2014

The effects of HIV related stigma on the living conditions of the respondents were also examined. Table 18 presents the detailed results of the living conditions of the respondents, in respect of their feeding, sheltering,



clothing and health. In this study, the results showed that most of the males (93.5%) and females (87.2%) alike declined the statement that they were not given enough food to eat at home. The association between the sex of the respondents and their feeding at home was not statistically significant at an alpha of 0.05, given a chi-square of 2.858 and a p-value of 0.091. Nyblade (2006) as well as Whitley and Kite (2010) found that food is sometimes withheld from HIV carriers, under the perception that people living with HIV are hopeless cases and will die anyway. This was not the case in this study, as, according to most of the respondents, they were given enough food although they were HIV carriers.

Most (94.1%) of the respondents also declined the statement that they had been asked to live outside their family homes, given their HIV status or for fear of contagion. This was expressed by most of the males and females, which indicated that the majority of the males and females alike were not cast out from their homes. Moreover, 82 percent of the respondents indicated that, in their homes, adequate attention was given to their health, which was in contrast to Nyblade's (2006) findings that HIV carriers are left hopelessly to die in their homes, because of the perception that they are doomed to die. In this study, the results also suggested that such perceptions leading to the maltreatment of HIV carriers were not traits of the community members.

Most (94.1%) of the respondents also declined the statement that they had been asked to live outside their family homes, given their HIV status or for fear of contagion. This was expressed by most of the males and females, which indicated that the majority of the males and females alike were not cast out from their

homes. Moreover, 82 percent of the respondents indicated that, in their homes, adequate attention was given to their health, which was in contrast to Nyblade's (2006) findings that HIV carriers are left hopelessly to die in their homes, because of the perception that they are doomed to die. In this study, the results also suggested that such perceptions leading to the maltreatment of HIV carriers were not traits of the community members.

**Table 18: Effects of HIV stigma on the upkeep of HIV carriers by sex**

Preamble	Male N(%)	Female N(%)	Total N(%)
Not given enough food			
Yes	8(6.5)	17(12.8)	25(9.8)
No	115(93.5)	116(87.2)	231(90.2)
Asked to live outside home			
Yes	3(2.4)	12(9.0)	15(5.9)
No	120(97.6)	121(91.0)	241(94.1)
Adequate attention to health			
Yes	18(14.6)	28(21.1)	46(18.0)
No	105(85.4)	105(78.9)	210(82.0)

Source: Field survey, 2014

The living conditions of the respondents were also disaggregated with the ages of the respondents.

This was to know the differences in the treatment of the respondents with regards to the age of the respondents. The Mann-Whitney U test (z-stat = -0.802; p-value = 0.423) showed not statistically significant differences in the ages of respondents

given adequate food and those who were not. The Mann-Whitney U test was used, given that the data was not normally distributed and the medians, instead of the means were used as the averages, based on Pallant's (2005) recommendation. This indicated that age differences did not account for difference in the feeding of HIV carriers.

With reference to Table 19, the effects of HIV stigma on the upkeep of HIV carriers by age was also tested with the Mann-Whitney U test whether there was a significant difference in the ages of respondents were asked to live outside home and those continued to stay with family. Therefore the null hypothesis for this study was;

**Table 19: Effects of HIV stigma on the upkeep of HIV carriers by age**

Sex	N(%)	Age (years)					Skewness	
		Min	Max	Mean	Median	Mode	Stat	Error
Not given enough food								
Yes	25(9.8)	20	42	30.0	29.0		0.190	0.464
No	231(90.2)	18	65	32.5	29.0		1.122	0.160
Asked to live outside home								
Yes	15(5.9)	20	37	27.4	29.0		0.248	0.580
No	241(94.1)	18	47	32.6	29.0		1.101	0.157
Adequate attention to health								
Yes	46(18.0)	20	50	32.9	33.0		0.105	0.350
No	210(82.0)	18	65	32.1	28.0		1.226	0.168

Source: Field survey, 2014

The study also showed that the mean age of respondents, who were driven from their homes and those who still stayed in their family homes were also 29 years on the average. It was also discovered that the average age of respondents, who were not given enough food was 29 years, and those given adequate food was also 29 years, The Mann-Whitney U test ( $z\text{-stat} = -1.914$ ;  $p\text{-value} = 0.056$ ) showed a-not-too wide statistically significant differences in the ages of respondents who were asked to leave home and those who continued to stay with their families after the HIV diagnosis.

In respect of healthcare of the respondents, the average age of the respondents who did not receive adequate health attention was 33 years, but those who gained the needed health attention at home were 28 years on the average. The Mann-Whitney U test ( $z\text{-stat} = -0.885$ ;  $p\text{-value} = 0.376$ ) showed no statistically significant differences in the ages of the respondents who had adequate health support at home and those who did not. Thus, in general, age difference did not account for differences in the treatment of HIV carriers in terms of their feeding, health and living conditions.

### **Coping strategies**

PLWH and their families are often subjected to prejudice, discrimination and hostility related to the stigmatisation of AIDS (Makoae et al., 2008). Some HIV-positive people find ways of coping with the stigma in order to enjoy a relatively normal life as compared to those who get overwhelmed with the discriminatory behaviour of others and self-guilt (Weiten & Lloyd, 2008). In this study the coping mechanisms adopted by PLHIV were explored in the context of

the overcoming their internalised stigma, social stigma, as well as stigma from family and at the workplace.

Table 20 presents the results on the coping strategies of the respondents with regards to maintaining their self-worth, morale, self-respect, and self-confidence, which are essentially the indicators of internalised stigma. According to the study, 77 percent of the respondents noted that they coped with internal stigma by learning from educational programmes on living with HIV.

**Table 20: Coping strategies for Internalized stigma**

Preamble	Male N(%)	Female N(%)	Total N(%)
<b>Learning from educational campaigns</b>			
Yes	98(79.7)	85(63.9)	183(71.5)
No	25(20.3)	48(36.1)	73(28.5)
<b>Participating in HIV campaigns</b>			
Yes	84(68.3)	73(54.9)	157(61.3)
No	39(31.7)	60(45.1)	99(38.7)
<b>Accepting the situation</b>			
Yes	92(74.8)	105(78.9)	197(77.0)
No	31(25.2)	28(21.1)	59(23.0)
<b>Avoiding confrontation</b>			
Yes	79(64.2)	76(57.1)	155(60.5)
No	44(35.8)	57(42.9)	101(39.5)
<b>Drinking</b>			
Yes	19(15.4)	28(21.1)	47(18.4)
No	104(84.6)	105(78.9)	209(81.6)

Source: Field survey, 2014

Most of the males and females responded that they learned from educational programmes on living with HIV. Zeidner and Endler (1996) and several other studies, including Duffy (2005) and Madiba and Canti-Sigaqa (2012) describe such an approach as adaptive and helps to reduce the stress of stigma and discrimination. Thus, the study found that the majority of the respondents adopted a rather positive approach to overcoming internalised stigma.

Furthermore, 61.3 percent of the respondents indicated that they participated in HIV awareness campaigns as an adaptive approach to maintain their self-worth, morale, self-respect, and self-confidence. A greater percentage of the males (68.3%) and females (54.9%) noted that they maintained their self-worth, morale, self-respect, and self-confidence through participating in HIV awareness educational campaigns. Further analyses revealed that 77 percent of the respondents also coped by accepting their status and trying to maintain a healthy life which is also an adaptive coping strategy. Similarly, 60.5 percent of the respondents avoided unnecessary confrontation about their HIV status and 81.6 percent refrained from using maladaptive approaches like drinking.

The respondents also noted the methods by which they coped with stigma from their family and friends. According to the study, 72.7 percent of the respondents declined that they dealt with family stigma by completely isolating themselves from those who treat them badly. This was supported by 75.6 percent of the males and 69.9 percent of the females. Therefore, the coping mechanism in respect of dealing with stigma from family and friends was similar for the males and females.

Moreover, most of the respondents declined that they had moved out of their family homes in order to cope with stigma from their family and friends. Thus, according to 74.8 percent of the males and 68.4 percent of the females, they still stayed with their families even after their diagnosis and in spite of possible stigma and discrimination from their family members and friends. Moreover, the study also found that most of the males (66.7%) and females (62.4%) declined the statement that they maintained minimal contact with their family members who treated them badly.

The above statistics indicate that, majority of the respondents adopted the adaptive strategies (learning from educational campaigns, participating in HIV campaigns, accepting the situation and avoiding confrontation) whilst minority resorted to the maladaptive coping strategy (Drinking). The skewness in this analysis towards adopting adaptive strategies may be due to the progressively improving education on HIV, monitoring and support by Health workers who go on house-to-house visitations and also support family relations. This implies that, majority of PLHIV who adopt the adaptive measures will be healthier, will be absorbed back into society and will live longer as compared to their counterparts who adopt maladaptive coping strategies as depicted in the conceptual framework.

**Table 21: Coping strategies for stigma from family and friends**

Preamble	Male N(%)	Female N(%)	Total N(%)
Isolated self from family and friends			
Yes	30(24.4)	40(30.1)	70(27.3)
No	93(75.6)	93(69.9)	186(72.7)
Moved out of home			
Yes	31(25.2)	42(31.6)	73(28.5)
No	92 (74.8)	91(68.4)	183(71.5)
Minimal contact			
Yes	41(33.3)	50(37.6)	91(35.5)
No	82(66.7)	83(62.4)	165(64.5)

Source: Field survey, 2014

The research proved that isolation and self-denial are maladaptive coping strategies, that is, the fact that the respondents were generally willing to still maintain personal contacts with their relatives and friends indicated that most of the males and females were more inclined towards positive coping strategies. As shown above, majority of the respondents failed to adopt the maladaptive strategies (isolated from family and friends, moved out of home and maintained minimal contact). The skewness in this analysis is against maladaptive strategies; this may also be due to the progressively improving education on HIV, monitoring and support by Health workers who go on house-to-house visitations and also support family relations. This implies that, majority of PLHIV who adopt the adaptive measures will be healthier, will be absorbed back into society and



will live longer as compared to their counterparts who adopt maladaptive coping strategies as depicted in the conceptual framework.

## **CHAPTER FIVE**

### **SUMMARY, CONCLUSIONS AND RECOMMENDATIONS**

#### **Introduction**

This chapter presents the summary of major findings of the study. It also presents the conclusions drawn from the study as well as recommendations derived from the conclusions of the study. The first section of the chapter summarises the entire study and also presents the key findings. This is followed by the conclusions and recommendations drawn from the findings. Suggestions for further studies are added in the end.

#### **Summary**

The study set out to explore the nature of HIV and AIDS stigma felt by PLHIVs and the effect this has on them at the Saint Francis Xavier Hospital. Descriptive and cross-sectional research designs were adopted to study the 256 HIV carriers from the Saint Francis Xavier Hospital at Assin Fosu. Interview schedules were used to collect data from the respondents. Statistical tools used to analyse the data collected included descriptive tools such as means, medians, frequencies, and percentages.

The results showed that the females covered by the study were slightly more than the males. Thus, it was found that the number of female patients of the Saint Francis Xavier Hospital, who were living with HIV and AIDS, was a bit more than their male counterparts. The youngest PLHIV was 18 years and the oldest was 65 years.

The marital status of the respondents was also explored on the basis of establishing a link between the marital status and the serostatus of the respondents. The results showed that, on the average 46.1% of the entire population were never married.

The religious affiliation of the respondents was also examined. The analysis covered the total number of respondents and it was found that an overwhelming majority of the respondents were Christians. Some studies have linked HIV infection to religion and found that in Moslem communities HIV infection is very low, but Christian community or countries record high HIV and AIDS prevalence.

Thus, this study suggests that people of the Christian faith are more likely to have HIV infection than those who adhere to the Moslem doctrine. Their assertions were founded in the moral and behavioural inclinations of people belonging to different religions. The results of this study provide some support in respect of studies that link high moral adherence in Islamic religion to low HIV prevalence in Islamic states. However this cannot be enough evidence since a further test was not conducted to analyse the relationship between religion and the contraction of HIV.

The employment status of the respondents was explored. From the results, the majority of the respondents were employed, as against those who were unemployed. The types or categories of jobs that the respondents pursued were further explored. The occupational background of the respondents cut across several lines of employment. The findings covered 168 respondents who indicated

that they were employed. Mostly, trading was the popular occupation among the employed respondents. Next to trading, was public service and other occupations that could be categorised into a form of entrepreneurship and teaching.

The categories of employment identified among the responses reflect the vibrant primary production and economic sector, as indicated by the Ministry of Land and Rural Development (2010). The results also indicated that HIV and AIDS prevalence is not confined to any particular occupation as established by Mawar et al. (2005), that some groups often associate HIV and AIDS prevalence with sex workers in India.

The study probed further to enquire about the length (number of months) that the respondents had been living with HIV and AIDS. The results showed that a greater section of the respondents had lived with HIV for a period of two to five years. A small percent had lived with the virus for less than a year and only a few over 10 years. By using the raw data collected in number of months that the respondents had lived with HIV, it was found that the respondents had lived with HIV from two months to 252 months (21 years).

Unprotected sex was the primary mode of transmission for both males and females but a few males and females also indicated that they believed they contracted the HIV virus through blood transfusion and by injection since they were sure they had not engaged in unprotected sex with any body, The results confirmed that unprotected sex remains the main mode of HIV transmission.

The means by which the respondents became aware of their serostatus were explored. An overwhelming majority of the respondents indicated that they

were diagnosed after following through with their doctor's recommendation to conduct the HIV test after a long period of prolonged sickness.

The study analysed the nature of stigma against PLHIV as the first objective and the following were found:

1. There was some form of workplace stigma against PLHIV which took the forms of forced disclosure of one's HIV status, discrimination by colleagues, changing of work duties and offers of early retirement. However, in all the cases, most of the respondents had never experienced any form of workplace discrimination.
2. Only 32.8 percent of the respondents noted that their families stopped visiting them, whereas 27.7 percent were not touched by their family members and for 46.9 percent, their families did not share meals with them. Verbal abuse and physical abuse by family members was experienced by 23.8 percent and 21.9 percent of respondents respectively.
3. Only 17.2 percent of the respondents were excluded from social events. Most of the respondents of both sexes and all religious affiliations were allowed to social events. Other parents did not allow their children to play with the children of 22.4 percent of the respondents. About 29.3 percent of the respondents had experienced some verbal abuse and 21.5 percent had been ostracised from their communities.

4. In all the cases, the respondents had not experienced any form of discrimination in receiving medical care. However, health workers refused to treat 28.9 percent of the respondents. About 16.4 percent had been forced to pay unofficial bills, 27.3 percent had been advised against having children and 8.6 percent had been forced to agree to an abortion.

The above results from the study validates the assertion made by Jacoby et al (2004) and Nyblade and MacQuirrie (2006) that, since people fear the transmission of the virus, the loss of productivity of PLHIV, and that resources may be wasted on them, there is a certain level of stigma and discrimination at the workplace, family, community and healthcare centres, even though a smaller percentage of the respondents experienced minimal forms of stigma.

The second objective examined the effects of stigma on PLHIV and the major findings were that:

1. About 49.6% of the respondents had inferiority complexes, 55.5% harboured self-blame, 50.4% had lost self-confidence, 42.6% had lost all hopes to achieve their life goals, and 40.6 % were depressed. In all cases most of the males and females had not experienced any of these effects of stigma on their state of mind.
2. Few (12.9%) of the respondents avoided treatment because of stigma. Only 9.8 percent preferred self-medication over doctor's prescription, and 32.8 percent avoided health campaigns for HIV carriers.

3. Only 13.3% of the respondents had been isolated from their families, 24.2 % had lost their friends, 27 percent could not make new friends and 21.1 % were avoided by others in the community. In all cases most of the males and females had not experienced any of these effects of stigma on their community relations.
4. Only 9.8% of the respondents were not given enough food in their homes. Also, 5.9 % had been asked to live outside their family homes and 18 % did not receive the required attention on their upkeep. In all cases most of the males and females had not experienced any of these effects of stigma on their upkeep.

Earlier studies pointed that being shunned by family, colleagues and the community and healthcare centres were some of the effects of stigma. This is confirmed by the findings of the study in which a number of respondents suffered various effects of stigma.

The final objective of the study was to assess some of the mechanisms employed by PLHIVs to overcome being stigmatized and the results were that:

1. The adaptive coping strategies for internalised stigma included learning from educational campaigns (71.5%), participating in HIV programmes (61.3%), accepting the status quo (77%) and avoiding confrontation (60.5%). The maladaptive coping strategy practiced by 18.4 percent of the respondents, was drinking.
2. The maladaptive coping strategies for stigma from community, family and friends included self-isolation (27.3%), leaving home (28.5%) and

keeping minimal contact with others (35.5%). In all the cases, the minority of the males and females adopted such coping strategies.

These findings are in line with Damodharan and Priya (2007), who are of the view that coping styles can be adaptive or maladaptive in nature and it differs in each individual, depending on the stress experienced by the individual. This is depicted in the conceptual framework of the study where PLHIV who adopt adaptive coping strategies are accepted back into the normal socio-politico cultural setting through participation in educational campaigns and training workshops where they are seen as good ambassadors of PLHIV.

## **Conclusions**

Minimal forms of HIV-related stigma were found at the workplace, in the family, community, and health service. Overall, HIV-related stigma was low at the ST. Francis Xavier Hospital in Assin Fosu. The forms of stigma could be described as internalised stigma, workplace stigma, family-related stigma and stigma/discrimination at health posts. Some minimal forms of instrumental stigma, such as verbal and physical abuse were found in the community and within families.

The effects of stigma on PLHIV were internalised (personal) family, community and health related. Internalised effects included inferiority complex, self-blame, depression, and loss of hopes. In the family, a few were isolated and some were abandoned by the community members. The effects of stigma on the personal upkeep of the respondents were minimal and some negative effects on



the health practices of the PLHIV were found, such as avoiding treatment and self-medication.

The research came out with the finding that the male HIV carriers were more likely to harbour self-blames than their female counterparts.

The distinction between the responses was tested for statistical significance and it was found that, with a chi-square of 12.019 and a p-value of 0.001, the association between the sex of the respondents and their self-blame was statistically significant at an alpha of 0.05. Therefore, it was asserted that the male HIV carriers were more likely to harbour self-blame than their female counterparts. This therefore fails to accept the null hypothesis that being male or female does not influence self blame.

When it came to the issue of lost of hope, an associated with a chi-square of 0.442, phi of 0.042 and a p-value of 0.508, indicated that the association between sex and the loss of hope was negligible and not statistically significant at an alpha level of 0.05. The results therefore indicated that the feeling of lost hope was not related to whether the carrier was male or female, but common phenomena to both sexes. This therefore accepts the null hypothesis that being male or female does not influence lost of hope.

The research also sought to establish whether there was a relationship between the respondent's sex and their susceptibility to depression and loneliness. The association between the respondents' depression about their HIV status and their sex was negligible and not statistically significant. In contrast with studies reviewed earlier, self-depression was not expressed by most of the HIV carriers

on Assin Fosu. This therefore accepts the null hypothesis that being male or female does not influence depression and loneliness.

The health effects of HIV-related stigma were also explored in the context of the respondents from the Saint Xavier Hospital at Assin Fosu. The health effects are such that HIV carriers may not want to access healthcare because of the possible stigma associated with disclosure of one's HIV status. In this study, the possible effects of HIV stigma on the avoidance of health services were explored.

It was found that 87.1 percent of the respondents did not avoid health services because of possible stigmatisation associated with exposure of their serostatus. There was an indication that the majority of the respondents, irrespective of their sex did not avoid health services in order to avoid stigmatisation associated with disclosing their HIV status. The assertions made by, Aggleton (2003) and Mill (2003) that often HIV carriers avoid medical care in order to avoid stigmatisation with disclosed serostatus was not the case for the HIV carriers in Assin Fosu.

It was also found that most of the respondents declined that they preferred to buy medicine to treat themselves because they would be stigmatised at the hospital. Thus, it has been asserted that self-medication and its complication were not a main issue among the respondents and that the respondents were not particularly discouraged to seek medical care because of possible stigmatisation.

The relationship between the sex of the respondents and their feeding at home was not statistically significant at an alpha of 0.05, given a chi-square of

2.858 and a p-value of 0.091. Nyblade (2006) as well as Whitley and Kite (2010) found that food is sometimes withheld from HIV carriers, under the perception that people living with HIV are hopeless cases and will die anyway. This was not the case in this study, as, according to most of the respondents, they were given enough food although they were HIV carriers.

This work also wanted to find out if there was any difference in the treatment of the respondents with regards to the age of the respondents and their feeding. The Mann-Whitney U test showed that there was not a statistically significant difference in the ages of respondents given adequate food and those who were not. This indicated that age differences did not account for difference in the feeding of HIV carriers.

The Mann-Whitney U test showed a-not-too wide statistically significant differences in the ages of respondents who were asked to leave home and those who continued to stay with their families after the HIV diagnosis.

The coping strategies were mostly adaptive in nature. For example, in order to deal with stigma, most of the respondents adopted learning from educational campaigns, participating in HIV programmes, accepting the status quo, and avoiding confrontation. However, a few also isolated themselves, resorted to drinking, and kept minimal contact with others, which can be described as maladaptive.

As mentioned earlier, the study has established that, most of the PLHIV out of the study population have adopted adaptive strategies. This may be due to the progressively improving education on HIV, monitoring and support by Health

workers who go on house-to-house visitations and also support family relations.

This implies that, majority of PLHIV who adopt the adaptive measures will be healthier, will be absorbed back into society and will live longer as compared to their counterparts who adopt maladaptive coping strategies as depicted in the conceptual framework. The sad thing is that the small percentage of PLHIV who resort to maladaptive measures are not able to come out of the labelling stage; they linger about in the society being labelled till they drop dead. The case was experienced by the researcher when one such PLHIV who refused medication because she couldn't bring herself to accept that she had HIV lost her life.

Generally the study came out with findings that were in consonant with issues captured in the conceptual framework.

### **Recommendations**

Based on the findings and conclusions of the study, the following recommendations were drawn to reduce the forms of stigma found in the study.

1. Since the research established that male HIV carriers were more likely to harbour self-blame than their female counterparts educational campaigns should be consciously targeted at men. This could still help to reduce the rate of self blame among male HIV carriers.
2. Workshops and educational programmes for HIV carriers should focus more on helping HIV carriers with internalised stigma as this form of stigma was more pronounced among the respondents.

3. Self-help strategies and self-employment workshops should also be the focus of educational campaigns for HIV carriers since, as much as 34.4 percent of the respondents were unemployed.
4. Counselling should be extended to families and friends ( and the community as a whole) of PLHIV on supporting and lending a helping hand to PLHIV so as to encourage them to adopt positive coping mechanisms which will eventually help absorb them back into society.

### **Suggestions for further research**

A qualitative approach to the study could enhance the understanding of some of the felt stigma and the experiences of the PLHIV. Moreover, a broader coverage of the respondents to include households and those not receiving treatment at the hospital can be considered in future studies. A household perspective on the HIV-related stigma can also be considered.

## REFERENCES

- Amoa, S. A. (2005). *Facing the challenge: A serious dialogue about HIV and AIDS*. Accra: Ghana AIDS Commission.
- Blendon, R. J., Donelan, K., & Knox, R. A. (1992). 'Public opinion and AIDS: Lessons for the second decade'. *Journal of the American Medical Association*, pp. 267, 981- 6.
- Bond, V., Chase, E., & Aggleton, P. (2002). Stigma, HIV and AIDS and prevention of mother-to-child transmission in Zambia. *Evaluation and Programme Planning*, 25(4). pp. 347-356. Retrieved from <http://www.researchonline.Ishtm.ac.uk/17358/>
- Brown, L., Macintyre, K., & Trujillo, L. (2003). *Interventions to reduce HIV and AIDS stigma: What have we learned?* Washington DC: Population Council.
- Communicable Disease Surveillance Centre (1985). 'The Acquired Immune Deficiency Syndrome. In Department of Health & Social Security (Ed.), *Acquired Immune Deficiency Syndrome: General information for doctors*. Booklet 1, May, 1985.
- Deacon, H., Stephney, I., & Prosalendis, S. (2005). *Understanding HIV and AIDS stigma: A theoretical and methodological analysis*. Cape Town: HSRC Press.
- Deng, R., Li, J., Sringernyuang, L., & Zhang, K. (2007). Drug abuse, HIV and AIDS and stigmatisation in a Dai community in Yunnan, China. *Social Science & Medicine*, 64, 1560-1571.

- Duffy, L. (2005). Suffering, shame, and silence: The stigma of HIV and AIDS. *Journal of the Association of Nurses in AIDS Care*, 16(1), 13-20.  
[Http://dx.doi.org/10.1016/j.jana.2004.11.002](http://dx.doi.org/10.1016/j.jana.2004.11.002)
- Foster, D., & Potgieter, J. L. (1995). *Social Psychology in South Africa*. Johannesburg: Lexicon Publishers.
- Galvao, G., Tereshinha, M., & Gir, E., Reis, R. K., (2013): Challenges to an effective response for addressing stigma and discrimination related to HIV: from denial of rights to construction of support networks. *J Int AIDS Soc.* 2013; 16(1): 18931. Published online 2013 December 1. doi: 10.7448/IAS.16.1.18931. PMID: PMC3854119
- Ghana Statistical Service (2014). 2010 Population Housing Census Analytical Report. Assin-North Municipal. Retrieved from <http://www.statsghana.gov.gh/>
- Gilmore, N., & Somerville, M. A. (1994). Stigmatisation, scapegoating and discrimination in sexually transmitted diseases: Overcoming them and us. *Social Science and Medicine*, 39(9), 1339-1358.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Prentice-Hall.
- Goffman, E. (1968). *Stigma: Notes on the management of spoiled identity*. Harmondsworth: Pelican Books.
- Herek, G. K., & Glunt, K. G. (1988). An epidemic of stigma: Public reactions to AIDS. *American Psychologist*, 43(11), 889-891.

- Herek, G. M. (1990). Illness, stigma, and AIDS. In P. T. Costa, Jr., & G. R. VandenBos (Eds.), *Psychological aspects of serious illness: Chronic conditions, fatal diseases, and clinical care* (pp. 103-150). Washington, DC: American Psychological Association.
- Herek, G. M. (1997). The HIV epidemic and public attitudes toward lesbians and gay men. In M. P. Levine, P. Nardi, & J. Gagnon (Eds.), *Changing times: Gay men and lesbians encounter HIV and AIDS* (pp. 191-218). Chicago: University of Chicago Press.
- Herek, G. M., & Glunt, E. K. (1993). AIDS and Stigma: *Public attitudes toward AIDS-related issues in the United States*. . [Http://psychology.ucdavis.edu/./abs99\\_intro.p](http://psychology.ucdavis.edu/./abs99_intro.p)
- Herek, G. M., Capitano, J. P., & Widaman, K. F. (2003). Stigma, social risk, and health policy: Public attitudes toward HIV surveillance policies and the social construction of illness. *Health Psychology, 22*, 533-540.
- Pryor, J. B., & Reeder, G. D., (Eds.), (1999). *The social psychology of HIV infection* (pp. 229-261). New Jersey: Lawrence Erlbaum.
- Jacoby, A. (1994). Felt versus enacted stigma: A concept revisited. *Social Science and Medicine, 38*, 269-274.
- Jacoby, A., Gorry, J., Gamble, C., & Baker, G. A. (2004). Public knowledge, private grief: A study of public attitudes to epilepsy in the United Kingdom and implications for stigma. *Epilepsia, 45*(11), 1405-1415.
- Janssen, R. S., Holtgrave, D. R., Valdiserri, R. O., Shepherd, M., Gayle, H. D., & De Cock, K. M. (2001). The serostatus approach to fighting the HIV



epidemic: Prevention strategies for infected persons. *American Journal of Public Health*, 91(7), 1019-1024.

Joint United Nations Programme on HIV and AIDS [UNAIDS] (2007). AIDS epidemic update 2008. Retrieved from [http://data.unaids.org/pub/EPIslides/2007/2007\\_epiupdate\\_en.pdf](http://data.unaids.org/pub/EPIslides/2007/2007_epiupdate_en.pdf)

Link, B. G., & Phelan, J. C. (2001). Conceptualising stigma. *Annual Review of Sociology*, 27, 363-385.

Maluwa, M., Aggelton, P., & Parker, R. (2006). HIV- and AIDS-related stigma, discrimination, and human rights. *Health and Human Rights*, 6, 1-18.

Mann, J. M. (1989). AIDS: A worldwide pandemic. In M. S. Gottlieb, D. J. Jeffries, D. Mildvan, A. J. Pinching, & T. C. Quinn (Eds.), *Current topics in AIDS*, vol. 2. New York: John Wiley and Sons.

Mann, J., Tarantola, D. J. M., & Netter, T. W. (Eds.). (1992). *AIDS in the world*. Cambridge: Harvard University Press.

Mawar, N., Saha, S., Pandit, A., & Muhajan, U. (2005). The third phase of HIV pandemic: Social consequences of HIV and AIDS stigma and discrimination and future needs. *Indian Journal of Medical Research*, 122(6), 471-484.

McNeil, D. G., Jr. (1998, December 28). Neighbours kill an HIV-positive AIDS activist in South Africa. *New York Times*, p. A5.

Mill, J. E. (2003). Shrouded in secrecy: Breaking the news of HIV infection to Ghanaian women. *Journal of Transcultural Nursing*, 14(1), 6-16.

- Miller, A. N., & Rubin, D. L. (2007). Factors leading to self-disclosure of a positive HIV diagnosis in Nairobi, Kenya: People living with HIV and AIDS in the Sub-Sahara. *Qualitative Health Research, 17*(5), 586-598.
- Moskowitz, G. B. (2005). *Social cognition: Understanding self and others*. Guilford: Guilford Press.
- Nnko, S. (1998, July). AIDS stigma: A persistent social phenomenon in Mwanza, Tanzania. Conference record of the 12<sup>th</sup> World AIDS Conference, Geneva, Switzerland. American Behavioral Scientist (ABS)-Sage publications. [Http://m.abs.sagepub.com/content/42/7/1106.refs](http://m.abs.sagepub.com/content/42/7/1106.refs)
- Nyblade, L. C. (2006). Measuring HIV stigma: Existing knowledge and gaps. *Psychology, Health and Medicine, 11*, 335-345.
- Operario, D., & Fiske, S. T. (1999). Integrating social identity and social cognition: A framework for bridging diverse perspectives. In D. Abrams & M. A. Hogg (Eds.), *Social identity and social cognition* (pp. 26-54). Cambridge, MA: Blackwell.
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science and Medicine, 57*, 13-24.
- Simbayi, L., Ramlagan, S., Petros, G., Airhihenbuwa, C. O., & Brown, B. (2006). HIV and AIDS othering in South Africa: The blame goes on. *Culture, Health and Sexuality, 8*(1), 67-77.
- Piot, P., Quinn, T. C., & Taelman, H. (1984). Acquired Immunodeficiency Syndrome in a heterosexual population in Zaire. *The Lancet, 2*, 65-69.

- Rogers, T. E, Singer, E., & Imperio, J. (1993). The polls: AIDS – an update. *Public Opinion Quarterly*, 57, 92-114.
- Saint Francis Xavier Hospital (2010). Annual report 2010. Unpublished report, St. Francis Xavier Hospital, Assin Foso.
- Shenon, P. (1996, February 11). Reluctantly, Clinton signs defense bill. *The New York Times*, p. A12.
- Shisana, O., & Simbayi, L. C. (2002). *Nelson Mandela/HSRC study of HIV and AIDS: South African national HIV prevalence, behavioural risks and mass media household survey 2002*. Cape Town: Human Sciences Research Council.
- Simbayi, L. C., Kalichman, S., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Internalised stigma, discrimination and depression among men and women living with HIV and AIDS in Cape Town, South Africa. *Social Science and Medicine*, 64(9), 1823-1831.
- Tajfel, H., & Turner, J. C. (1986). The social identity theory of intergroup behaviour. In S. Worchel & W. Austin (Eds.), *The social psychology of intergroup behaviour* (pp. 7-24) Chicago: Nelson-Hall
- Taylor, B. (2001). HIV, stigma and health: Integration of theoretical concepts and the lived experiences of individuals. *Journal of Advanced Nursing*, 35(5), 792-798.
- Thomas, F. (2006). Stigma, fatigue and social breakdown: Exploring the impacts of HIV and AIDS on patient and career well-being in the Caprivi Region, Namibia. *Social Science and Medicine*, 63, 3174-3187.

- Ulasi, C. I., Preko, P. O., Baidoo, J. A., Bayard, B., Ehiri, J. E., Jolly, C. M., & Jolly, P. E. (2009). HIV and AIDS-related stigma in Kumasi, Ghana. *Health and Place, 15*(1), 255-262.
- UNAIDS (2004). *Global report on the AIDS epidemic*. Geneva: UNAIDS.
- UNAIDS(2015). *Global report on the AIDS: Fact sheet*.  
[Http://www.unaids.org/en/resources/fact-sheet](http://www.unaids.org/en/resources/fact-sheet)
- UNAIDS/WHO (2007, 31st January). Cellulose sulphate microbicide trial stopped. [Http://www.who.int/mediacentre/news/statements/2007/s01/en/](http://www.who.int/mediacentre/news/statements/2007/s01/en/)
- Wood, K., & Lambert, H. (2008). Coded talk, scripted omissions: The micro politics of AIDS talk in South Africa. *Medical Anthropology Quarterly, 22*(3), 213-233.
- Zhou, Y. R. (2007). If you get AIDS, you have to endure it alone: Understanding the social constructions of HIV and AIDS in China. *Social Science & Medicine, 65*, 284-295.

## APPENDIX 1

### INTERVIEW SCHEDULE FOR PEOPLE LIVING WITH AIDS

This is a quest for data to explore the nature of HIV AND AIDS stigma felt by PLHIV and the effect this has on them in the Assin Fosu Municipality. Please be candid in your responses. The data will be used for only academic purposes and your anonymity is assured.

#### Module A: Demographic characteristics of respondents

1. Sex                    a. Male [ ]                    b. Female [ ]
2. Age \_\_\_\_\_
3. Level of education
  - a. No formal education
  - b. Primary
  - c. Secondary
  - d. Tertiary
4. Marital status
  - a. Married
  - b. Divorced
  - c. Separated
  - d. Never married
5. Religious affiliation
  - a. Moslem
  - b. Christian
  - c. Traditional

- d. Others, please specify
  - e. No religious affiliation
6. If you are employed, what is your occupation? \_\_\_\_\_
7. How do you think you contracted the HIV virus?\_\_\_\_\_
8. How did you know you were HIV positive\_\_\_\_\_
9. For how long have you been living with HIV and AIDS\_\_\_\_\_
10. Were you married and living with your spouse when you found out you had the virus?
- a. Yes [ ]
  - b. No [ ]
11. If yes, are you still living with your spouse? a. Yes [ ] b. No [ ]
12. Do you have children?
13. If yes, are they living with you?

**Module B: HIV and AIDS Stigmatisation/discrimination**

14. For the following set of issues about disclosure of your HIV status, *Tick all that apply*
- a. Telling someone I have HIV is risky [ ]
  - b. People with HIV lose their jobs when their employers find out [ ]
  - c. I never feel ashamed of having HIV [ ]
  - d. Having HIV makes me feel unclean [ ]
  - e. Some people who know I have HIV have grown more distant [ ]

- f. Since learning I have HIV, I worry about people discriminating against me [ ]
- g. Most people are uncomfortable around someone with HIV [ ]
- h. I never feel the need to hide the fact that I have HIV [ ]
- i. As a rule, telling others that I have HIV has been a mistake [ ]
- j. I have lost friends by telling them I have HIV [ ]
- k. I regret having told some people that I have HIV [ ]

15. In what ways have you felt discriminated against (treated badly) by your family because of your HIV status? Tick all that apply:

They:

- a. Don't visit me [ ]
- b. Don't touch me [ ]
- c. Don't eat with me [ ]
- d. Don't sit with me [ ]
- e. Deserted me [ ]
- f. Verbally abuse me [ ]
- g. Physically abuse me [ ]
- h. Hide me so no one knows I have HIV [ ]

16. In general, have you felt discriminated against (treated badly) by your community because of your HIV status?

- a. Yes [ ]
- b. No [ ]

17. In what ways have you felt discriminated against (treated badly) by your community ?*Tick all that apply*

- a. Family was excluded in community events [ ]
- b. Nobody played with my children [ ]
- c. Neighbours stopped visiting the house [ ]
- d. Neighbours told/warned others about my HIV status [ ]
- e. Verbal abuse by the community [ ]
- f. Was asked to leave the community [ ]
- g. People stare at me and pass remarks [ ]
- h. Other

18. Have you ever because of your HIV status? Tick all that apply

- i. Had a health care worker refuse to treat you/denied access to medical treatment or care [ ]
- ii. Experienced a delay in the provision of health services/treatment [ ]
- iii. Been stopped from accessing health care services [ ]
- iv. Forced to pay additional charges for medical services [ ]
- v. Ever lost or been denied private insurance [ ]
- vi. Been forced to change your place of residence because you are known to be HIV-positive [ ]
- vii. Been ridiculed, insulted or harassed [ ]
- viii. Been threatened by physical violence [ ]
- ix. Been excluded from any social functions [ ]



- x. Been forcibly required to submit to any medical health procedure [ ]
- xi. Experienced discrimination in your work environment
- xii. Felt discriminated against by your colleagues [ ]
- xiii. Lost your job [ ]
- xiv. Had your job description or duties changed [ ]
- xv. Been offered early retirement [ ]
- xvi. Experienced harassment or discomfort on the job [ ]
- xvii. Had family members exclude you from usual family activities [ ]
- xviii. Had your partner desert you [ ]
- xix. Had your child (or children) involuntarily taken away from you [ ]
- xx. Been advised to not have a child [ ]
- xxi. Been coerced into an abortion or sterilization [ ]
- xxii. Been dismissed, suspended, prevented from continuing with your education or denied admission into any education institution [ ]
- xxiii. Been excluded from any associations/societies/clubs/self-help groups [ ]

### **Module C: Effects of HIV/stigma and discrimination**

19. In what ways do stigma and discrimination affect your psyche?

- a. I feel I am not as good a person as others because I have HIV [ ]
- b. I blame myself for my HIV status [ ]
- c. I have lost considerable self-confidence due to stigma attached to my HIV status
- d. I have lost all hopes of achieving my life goals
- e. I am lonely and depressed
- f. None of the above
- g. Others, please specify

20. In what ways do stigma and discrimination affect your health behaviour?

- a. I often avoid going for treatment/medication at the clinic
- b. I often go the clinic because I am given preferential treatment
- c. I often prefer to buy medicine to treat myself because I will be stigmatised at the hospital
- d. I often do not attend any educational campaigns for HIV positive people because others will know that I am a carrier
- e. None of the above
- f. Others, please specify

21. In what ways do stigmatisation and discrimination affect your relationship with family/friends/community?

- a. I have been isolated from my family
- b. I have lost most of my friends
- c. I cannot make new friends
- d. People avoid conversations with me
- e. I have been asked not to attend community gatherings
- f. None of the above
- g. Others, specify

22. In what ways do stigmatisation and discrimination affect your upkeep?

- a. I am not given enough food
- b. I have been asked to live outside the house
- c. I do not have proper clothes
- d. Adequate attention is not given to my health status
- e. I generally live in deprived conditions
- f. None of the above
- g. Others, please specify

23. In what ways do stigmatisation and discrimination affect your occupation and income earning opportunities?

- a. I was asked to leave my job
- b. People avoid doing business with me
- c. I receive lesser remittances from family and friends
- d. None of the above
- e. Others, please specify

24. Do you feel that there are certain jobs you cannot do because of stigma/discrimination related to your HIV status?

a. Yes please explain \_\_\_\_\_

b. No please explain \_\_\_\_\_

25. If yes, what types of jobs can you identify?

a. Food vending

b. Petty trading

c. Hair dressing

d. Tailoring

e. Teaching

f. Nursing

g. Others, specify

26. In what ways do stigmatisation and discrimination affect your group socialisation?

a. I am not allowed into religious services

b. I am not allowed to family gatherings

c. I am not allowed to certain public places

d. I have been asked not to attend traditional events like durbars

e. None of the above

f. Others, please specify

## **Module D: Coping strategies**

27. How do you boost your self-respect, morale, self-worth, and self-confidence?

- a. Learning from educational programmes on living with HIV
- b. Participating in HIV awareness campaigns
- c. Accepting the situation and doing my best to stay healthy
- d. Avoiding unnecessary confrontation with others about my status
- e. Drinking
- f. Sleeping a lot
- g. None of the above
- h. Others, specify

28. How do you cope with social stigma/discrimination?

- a. Avoiding social/ public events
- b. Sticking to other events meant for HIV carriers
- c. Participating in HIV awareness programmes
- d. None of the above
- e. Others, please specify

29. How do you deal with stigma from family/friends?

- a. Completely isolating myself from those who treat me badly
- b. I have moved out of the family house
- c. I keep minimal contact with family/friends who treat me badly
- d. None of the above
- e. Others, please specify

30. How do you deal with workplace stigma and discrimination?

- a. I ignore stigmatising and discriminatory attitudes
- b. I report to authorities
- c. I have stopped working to avoid being stigmatised
- d. None of the above
- e. Others, specify

31. How do you fend for yourself?

- a. I have a wage job
- b. I rely on remittances from family and friends
- c. I practice subsistence farming
- d. I rely on begging others for support
- e. None of the above
- f. Others, please specify

32. Do you think your life would be generally better without being stigmatised because of your HIV status?

33. In what ways can stigma/discrimination against HIV carriers be controlled?

- a. Public education about the facts of HIV and AIDS
- b. Public awareness of the effects of stigma on HIV carriers
- c. Acts and Laws which punish discrimination
- d. Economically empowering HIV carriers to minimise their dependence on others

- e. Targeting institutions for awareness campaigns about HIV work-related stigma
- f. Others, specify