

**STIGMATIZATION AND DISCRIMINATION OF PEOPLE LIVING WITH  
HIV/AIDS AND ITS IMPLICATIONS FOR PREVENTION AND SPREAD:**

**A CASE STUDY OF NSAWAM/ADOAGYIRI MUNICIPALITY.**

**BY**

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**THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON  
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## DECLARATION

I hereby declare that this submission is my own work towards the Master of Arts Degree in Development Studies and that, to the best of my knowledge, it contains no material previously published by another person nor material which has been accepted for award of any other degree of any University and all the resources that I have used or cited have been indicated and acknowledged by means of complete references.

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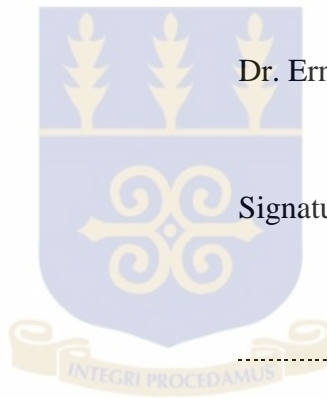
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## DEDICATION

This piece of work is dedicated to the joy of my beloved mum, Madam Veronica Peprah, who has single handedly provided all my needs up to this level.

To God Almighty who gave me life and strength to embark on this journey.

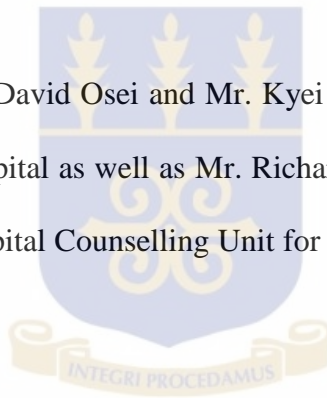


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## ABSTRACT

The purpose of this study was to examine the level and pattern of stigmatization and discrimination against PLWHAs and its implications for spread and prevention in the Nsawam/Adoagyiri municipality in the Eastern region of Ghana.

Data were gathered quantitatively with some qualitative supplementary data. The quantitative data were gathered through administration of questionnaires to 70 persons living with HIV/AIDS, with the qualitative data been gathered through in-depth interviews with one health worker and two NGOs operating in the municipality. Focus group discussion was also conducted with 20 community members to supplement the quantitative data. Two focus group discussions were conducted and each group was made up of 10 participants.

The Statistical Package for Social Sciences software was used for the quantitative data analysis. Data from the in-depth interviews and focus group discussion were tape recorded, transcribed under themes and used as supplementary information for the quantitative data. Both probability and non-probability sampling techniques were used in the selection of the total number of respondents to be interviewed. Both primary data and secondary information were used.

Majority of respondents' educational level was relatively low as most of them had either primary education, Junior High or middle school education or secondary education with a very small percentage of them who had post-secondary education. Most of them were traders, farmers, doing other jobs or unemployed. The main mode of HIV/AIDS contraction was through sexual intercourse.

Respondents who had experienced stigmatization and discrimination as a result of their status were less than those who had never experienced it. However, the proportion of females who had ever experienced stigma and discrimination was higher than that of the males.

Stigmatization and discrimination mostly took the form of verbal assault, social stigma and job loss. Those who had ever experienced stigma and discrimination believed they were being stigmatized as a result of the mentality people have about the disease that it is infectious and deadly. Stigmatization and discrimination had affected respondents' lives in numerous ways.

Respondents were shocked, sad or doubtful upon hearing their status for the first time. More males reported being shocked than the females whereas more females expressed sadness than males. Respondents who were co-habiting or single but with sexual partners had not gathered the courage to inform their partners about their status but a sizeable number of the respondents who were married had disclosed to their partners. As a coping mechanism, respondents who had disclosed their status to people decided not to do further disclosure due to their experience of stigma upon their first disclosure. Others had decided not to disclose their status at all to prevent any form of stigma.

In the assessment of community perceptions on the treatment meted out to PLWHAs, some were of the view that PLWHAs must be treated well because it may be that someone can be infected without any fault of his or hers.

The study calls for intensive education on the adverse effects of stigmatizing and discriminating against People Living with HIV/AIDS at all levels of society and intensification of voluntary counseling and testing.

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**LIST OF ACRONYMS**

|        |  |
|--------|--|
| ADRA   | Adventist Development and Relief Agency    |
| AIDS   | Acquired Immune Deficiency Syndrome        |
| CDC    | Centers for Disease Control and Prevention |
| DFID   | Department for International Development   |
| FGD    | Focus Group Discussion                     |
| GAC    | Ghana AIDS Commission                      |
| GHS    | Ghana Health Service                       |
| GSS    | Ghana Statistical Service                  |
| HIV    | Human Immunodeficiency Virus               |
| IBM    | International Business Machine Corporation |
| IDU    | Injection Drug Users                       |
| ICRW   | International Center for Research on Women |
| MOH    | Ministry of Health                         |
| MTCT   | Mother to Child Transmission               |
| NCCE   | National Commission for Civic Education    |
| NGOs   | Non-Governmental Organizations             |
| PLWHAs | People Living With HIV/AIDS                |
| UN     | United Nations                             |

|        |  |
|--------|--|
| UNAIDS | Joint United Nations Programme on HIV/AIDS         |
| UNGASS | United Nations General Assembly Special Session    |
| USAID  | United States Agency for International Development |
| WHO    | World Health Organization                          |

## CHAPTER ONE

### BACKGROUND TO THE STUDY

#### 1.0 Introduction

HIV/AIDS related stigma and discrimination is seen worldwide as an impediment to HIV testing, prevention, accessing health care and seeking treatment. Stigma, according to Ngozi C.Mbonu, Bart Van Den Borne and Nanne K. De Vries (2009), enhances secrecy and denial, which are also catalysts for HIV transmission. This study attempts to find out the extent and patterns of stigmatization and discrimination against people living with HIV/AIDS for prevention and spread of the disease in the Nsawam/Adoagyiri municipality.

HIV belongs to an unusual group of viruses called retroviruses, which include viruses that cause leukemia in humans, cats, cattle and other animals, and certain other viruses found in monkeys and apes, sheep and goats. Retroviruses also belong to a subgroup called lentiviruses, because they are slow to cause disease (World Health Organization, 2012). AIDS is caused by a virus, HIV (Human Immunodeficiency Virus) and it is transferrable from an infected person to uninfected person. Infected blood, semen or vaginal secretions, are modes or vehicles of transmission. It can also be transmitted from mothers to babies either through delivery or breastfeeding. People with an HIV infection eventually get AIDS (National AIDS/STI Control Programme, 2001).

The first HIV/AIDS case worldwide was reported in 1981 in the United States among men who have sex with men (MSM) (Centers for Disease Control and Prevention, 2001). The number of people infected with HIV exploded globally and by the end of 2012, 35.3 million

people were estimated to have been living with the virus worldwide. During that year, 2.3 million people were newly infected with HIV and 1.6 million people lost their lives to AIDS (UNAIDS, 2013). Sub-Saharan Africa is the region hardest hit by the HIV epidemic. According to UNAIDS, in 2010, about 68% of all people infected with HIV globally live in sub-Saharan Africa, and this region accounts for three-quarters of all AIDS deaths. Currently in sub-Saharan Africa, out of an estimated 22 million infected by HIV, the majority of this estimated number (59 percent) is women (UNAIDS, 2011).

In Ghana, the first case of Acquired Immune Deficiency Syndrome (AIDS) was reported in March 1986 and by the end of the year, the number of reported cases was 42. In January 1991, a more detailed report on AIDS in Ghana appeared in which 107 Human Immunodeficiency Virus (HIV) positive cases were said to have been recorded in 1987 (The MEASURE Project; Ghana AIDS Commission, 2003). The National AIDS Control Programme in 2011 as cited by the Ghana AIDS Commission's National HIV/AIDS Research Conference (2013) estimated that 225,478 adults and 30,395 children were HIV positive out of a population of 24.6 million. In 2011, 15,263 people in Ghana died of AIDS. The Ghana AIDS Commission's MEASURE Project (2003), noted that in 1999, Ghana had an estimated 119,410 children under 15 who had lost their mother or both parents to AIDS. However, the current adult national HIV prevalence in Ghana has been stabilized at 1.5% declining from 2.7% in 2005. With an estimated number of 225,478 persons living with HIV and AIDS, 100,336 were males whereas 125,141 were females. There was new HIV infections made up of 12,077 adults and 1,707 children in that same year (GAC, 2013). Eastern region where this study is conducted has been recording the highest number (5,275, 5,757 and 5,877) of HIV cases in 2008, 2009 and 2010 respectively in Ghana (National AIDS Control/STI Programme, 2010). Since the report of the first case in the country and the

world as a whole, there has been in-depth research in relation to finding drugs to cure this disease but all to no avail.

UNAIDS (2013) noted an estimated number of new HIV infections of 2.3 million people worldwide in 2012 including estimated 390,000 among children. The total estimated HIV prevalence rate in Sub-Saharan Africa in 2010 was at about 5.0% with 3.3% and 1.4% for females and males respectively.

As indicated by the Joint United Nations Programme on HIV/AIDS in collaboration with the World Bank report on new infections by mode of transmission in West Africa (2010), the proportion of new infections worldwide occur among adults through key modes of transmission, such as sex work, multiple partnerships, stable partnerships, men who have sex with men (MSM), injecting drug use (IDU), unsafe medical injections and contaminated blood transfusions. However, in some countries the largest number of new infections may be due to sex work or needle sharing among injecting drug users while in other countries most new infections may occur primarily among stable couples. The report further indicates that close to one-fifth of new infections occur among people with multiple sexual partners with another one-third occurring in stable couples who do not currently report outside partners and about 10% of new infection also occurs as a result of sex work.

In Ghana, the predominant mode of HIV/AIDS transmission is through sex (GAC, 2013).

According to the 2013 U.S. President's Emergency Plan for AIDS Relief report, almost 40% of new adult infections can be attributed to female sex workers (FSWs), their clients and the partners of their clients, and men who have sex with men (MSM). Twenty nine percent of new infections are attributed to casual heterosexual sex and the partners of those who engage

in casual heterosexual sex. Mother-to-child transmission of HIV also accounts for 9 percent of all HIV transmission

During the early days of the HIV/AIDS pandemic in the country, the disease was reported to have mostly infected commercial sex workers who travelled to Cote d'Ivoire and their clients. The early target population of the HIV/AIDS infection made people to perceive infected persons as prostitutes thereby aggravating the stigmatization and discrimination of PLWHAs (Ghana AIDS Commission, 2003).

According to the 2010/2011 Ghana AIDS Commission's Country AIDS Response Progress report, in 2011, the most severely affected age group was 30–34 years (2.9%). People 15 – 24 years old are increasingly vulnerable, with an HIV prevalence rate of 1.7%. The 20 – 24 year age group recorded the lowest prevalence rate while that in the 15 – 19 year age group rose sharply to 1.9% (GAC, 2012). Vulnerable population groups include the poor, migrants and displaced populations, women and youth especially orphans and vulnerable children (OVC) and the aged (GAC, 2013).

HIV/AIDS is a highly stigmatized disease. The stigmatization of the disease has been known to result from its main mode of transmission which is sexual contact. As indicated by Ngozi C. Mbonu, Bart van den Borne and Nanne K. De Vries (2009), HIV/AIDS-related stigma and discrimination occurs on the basis of subcultural beliefs, religion or individually conceived causal processes with certain mediating factors such as cultural constructions, stereotyping and specific beliefs, access to and the role of antiretroviral therapy and gender. Explaining cultural construction of stigmatization and discrimination of PLWHAs, Mbonu et al (2009) pointed out that it is due to the idea attached to specific sexual behaviours as socially

unacceptable and immoral act thereby branding people living with HIV/AIDS as promiscuous. As a way of stereotyping, PLWHAs are perceived to bear certain characteristics that fall outside the normal societal norms which makes PLWHAs to be described as prostitutes. An individual's past social history may also be recalled to justify why such a person has AIDS. Mbonu et al (2009) continued that there exist beliefs which are common in many societies that associate HIV/AIDS with danger, attribution of contagion, incurability, immorality and punishment for one's sinful act. Some churches link sexual transgressions and AIDS with sin and immorality. The religious approach warrants stigmatizing people as "saved" or "sinner", "pure" or "impure", "us" or "them", and it strengthens the broader social stratifications within which stigma flourishes (Mbonu, van den Borne & De Vries, 2009).

HIV related stigma and discrimination have adverse effect on the general life of people living with the virus as well as their families. Stigma makes diagnosed people to live in fear which makes them less likely to adopt preventive behaviour, to go in for testing, disclose their serostatus to others, access care and as well stick to treatment. As echoed by Edward Cameron, a South African constitutional court justice, AIDS is the most stigmatized disease in history whose impact and nature needs to be appreciated in order for its interventions to be successful (International Center for Research on Women, 2010).

### **1.1 Problem statement**

There have been several attempts in finding solution to the HIV/AIDS pandemic since its inception by many bilateral and multilateral organizations as well as individuals. With these various researches ongoing, there have been many approaches either to prevent or reduce the rate of transmission (abstinence, use of condoms, faithfulness, etc.). Many people worldwide have accepted the above mentioned preventive modes. One critical factor that constitutes a

barrier to prevention and perpetuates spread of the disease is stigmatization and discrimination. Stigmatization and discrimination, described by the UN Secretary General, Ban Ki Moon as a “silent killer”, is still pervasive across nations and within societies (Ban Ki Moon, August 6, 2008). People stigmatize and discriminate against persons infected and affected by HIV/AIDS based on factors such as perceptions about the spread and mode of transmission, personal and social fears, religious beliefs, misconceptions, myths and cultural issues, among others (Kafuko, 2009).

As the sixth of the Millennium Development Goals adopted by the United Nations in September 2010 and the declaration of commitment on HIV/AIDS by all political leaders, it was targeted to halt and reverse the spread of HIV/AIDS by 2015 (United Nations, 2011).

Though programmes have been put in place by the leaders of various nations including Ghana, in their attempt towards achieving this goal, one important issue dragging the realization of this goal is stigmatization and discrimination of HIV positive persons. Despite the existence of this disease for quite a number of years now, stigma and discrimination still persists at different levels, in communities and in various forms, and impeding the various forms of responses to halt this pandemic.

For fear of being stigmatized and discriminated against, infected persons may remain silent about their status with its consequent effects on their lives, prevention of the disease and the nation as a whole. During country and regional consultations on universal access to HIV prevention, treatment, care and support, in 2005 - 2006, stakeholders reported that stigma and discrimination against people living with HIV were major barriers to universal access and undermined the effectiveness of national responses to HIV (UNAIDS, 2006). Stigma and discrimination weaken the ability of individuals and communities to protect themselves from HIV and to stay healthy if HIV positive. Stigma and discrimination therefore act as barrier to

achieving universal access to HIV prevention, treatment, care and support and hinder progress towards achieving the related Millennium Development Goals. An international survey of people living with HIV in 2010 revealed that more than one third had experienced loss of employment, denial of health care, social or vocational exclusion and/or involuntary disclosure (UNAIDS, 2010).

As noted by the UN Secretary General, “Stigma remains the single most important barrier to public action. It is the main reason too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason the AIDS epidemic continues to devastate societies around the world”, (UN Secretary General, Ban Ki Moon, August 6, 2008). Since the most at risk population of the HIV/AIDS infection is the active labour force, turning a deaf ear to its preventive modes will adversely affect the productivity of a nation.

The 2008 Ghana Demographic and Health Survey reported of a relatively high level of stigmatizing and discriminating against people living with HIV/AIDS in Ghana as a result of the misconceptions people still have about the disease (GDHS, 2008).

Ghana is one of the countries that signed the 1998 Abuja Declaration and the declaration of commitment on HIV/AIDS adopted by the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in June 2001. Ghana being a signatory to the two declarations indicates its commitment to HIV/AIDS which includes protection of PLWHAs from discrimination under the section on HIV/AIDS and Human Rights (GAC, September 2005). Considering the level of HIV-related stigma and discrimination, the Government of Ghana with support from USAID in 2001 introduced national campaigns which began with the “stop AIDS love life” campaign which was aired on both national and local televisions as well as

radios. This was followed by “reach out and show compassion” campaign which focused on the need for people to show compassion. The basic campaign components were the advocacy component where religious leaders from different religious backgrounds came together to show support to PLWHAs who shared their stories in a video recording. It was however noted in the report that these activities led to no concrete results as HIV/AIDS-related stigma remained relatively high in most Ghanaian communities (The Global Health Technical Assistance Project, 2011).

In a baseline study by ADRA in four selected regions (Greater Accra, Ashanti, Eastern and Brong Ahafo) to gather relevant benchmark data to guide project implementation, monitoring and evaluation, Eastern region emerged as the region where PLWHAs were most stigmatized which also makes a lot of people from the region to conceal their status (ADRA 2010). The Akuapim South Medium Term report also indicates that more people in the Nsawam/Adoagyiri are believed to be infected with the disease due to the bread business that exposes them to long distance drivers who sleep in the municipality (Akuapim South Medium Term Development Plan, 2010). As one of the newly created municipalities in the country, we do not know the number of PLWHAs in the municipality who face the challenge of stigma and discrimination, the type of stigma and discrimination commonly faced by these people, the manifestations as well as the coping mechanisms adopted by these people to enable them live a normal life in the society.

It is in this context that the study seeks to find out the level and pattern of stigmatization and discrimination against PLWHAs and to assess its implications for spread and prevention of the disease in Nsawam/Adoagyiri municipality.

## 1.2 Objectives of the study

The general objective of this study is to examine the level and pattern of stigmatization and discrimination against PLWHAs and to assess its implications for spread and prevention.

The specific objectives are to:

- ❖ Assess people's perception and attitudes about PLWHAs and their views on treatment meted on them as a result of their status.
- ❖ Determine the various forms of stigmatization and discrimination against PLWHAs.
- ❖ Ascertain the causes of stigma and discrimination against PLWHAs
- ❖ Assess the mechanisms adopted by PLWHA to cope with stigma and discrimination.

## 1.3 Research Questions

In order to achieve the above mentioned objectives, the research poses the following questions:

- ❖ What are people's perceptions, attitudes and views on PLWHAs and the treatment meted to them as a result of their status?
- ❖ What are the various forms of stigmatization and discrimination against PLWHAs?
- ❖ What are the causes of stigma and discrimination against PLWHAs?
- ❖ What mechanisms are adopted by PLWHA to cope with stigma and discrimination?

## 1.4 Significance of the study

Every nation's development prospects depend on its active and healthy labour force and with the current statistics on HIV/AIDS prevalence, the Ghanaian youth is the most at risk of getting infected. As stigma and discrimination are pervasive in our society and can perpetuate

spread of the disease, there is the need for sustained research to assess the levels of entrenchment and the possible effects on PLWHAs.

The findings of this research will add to existing knowledge to strengthen the fight against the spread of the disease. Also, research of this nature will serve as a useful reference for both governmental and non – governmental organizations as well as individuals in their further studies or research work.

More importantly, for the Nsawam/Adoagyiri as a newly created municipality, the findings of this research will be useful to the HIV and counseling units of the hospital, non-governmental organizations working on HIV/AIDS programmes within the municipality and the Municipal Assembly in general in drawing new strategies for addressing problems of stigma and discrimination and also to improve on the existing programmes.

The findings and recommendations based on this study will inform policy makers in the study area and the country as a whole.

### **1.5 Limitations of the study**

In every research work, there is some sort of challenge or difficulties encountered by the researcher. In the first place the study was limited to the Nsawam-Adoagyiri Municipality only. Subsequently, inferences made pertain to that study area only and therefore cannot be generalized to other parts of Ghana. Another challenge encountered in this study was that some of the PLWHAs were reluctant during the interview to respond objectively to some issues. For example, some of them were unwilling to disclose how they contracted the disease and this might affect the truthfulness of the responses provided in that respect.

## **1.6 Definition of Concepts**

### **HIV/AIDS**

HIV refers to human immunodeficiency virus. It is the virus that can lead to acquired immunodeficiency syndrome, or AIDS. HIV affects specific cells of the immune system, called CD4 cells, or T cells. Over time, HIV can destroy so many of these cells that the body finds it difficult to fight infections and disease. When this happens, HIV infection leads to AIDS (Centers for Disease Control and Prevention, 2013).

### **HIV Stigmatization**

Stigma related to HIV is the beliefs and attitudes that deeply discredit a person or group because of their HIV status. This is caused by lack of awareness and knowledge, misconceptions around HIV transmission that lead to fear of acquiring HIV through everyday contact with infected people and values linking people with HIV to behaviour considered improper and immoral (Department for International Development, 2007). HIV - related stigmatization was defined at the 26<sup>th</sup> meeting of the UNAIDS Programme Coordinating Board in Geneva 2010, “as the negative beliefs, feelings and attitudes towards people living with HIV and or associated with HIV” and other key populations at risk of HIV transmission, such as people who use drugs, sex workers, men who have sex with men and transgender people (UNAIDS, 2010; WHO/UNAIDS Technical Guidance Note, 2011). Stigma occurs through social and cultural norms which shape the relationships among people according to these norms. It further marks the boundaries a society creates between “normals” and “outsiders”, between “us” and “them” (de Bruyn, 1998). Stigma defined by Goffman (1963) as quoted by Parker and Aggleton is “an attribute that is significantly discrediting which in the eyes of society, serves to reduce the person who possesses it. Stigmatized persons possess an undesirable difference. Stigma is conceptualized by society on the basis of what

constitutes difference or deviance and that is applied by society through rules and sanctions resulting in the description of the person involved as a spoiled identity” (Goffman quoted in Parker and Aggleton, 2003). Stigma, as noted by Parker and Aggleton, is a social process that produces and reproduces relations of power and control which gives some groups sense of superiority to others. Stigmatization takes shape in the context of culture and power (Parker and Aggleton, 2003). Considering the different definitions by different authors, this study therefore adopts the definition by Joint United Nations Programme on HIV/AIDS during the 26<sup>th</sup> meeting of the Coordinating Board in Geneva, 2010.

### **Discrimination of PLWHAs**

Discrimination of PLWHAs as defined by UNAIDS is “the unfair and unjust treatment (act or omission) of an individual based on his or her real or perceived HIV status” (UNAIDS, 2010:2). Discrimination in relation to HIV also includes unfair treatment of other key populations, such as sex workers, people who use drugs, men who have sex with men, transgender people, people in prison, and in some social contexts women, young people, migrants, refugees and internally displaced people. HIV-related discrimination is usually based on stigmatizing attitudes and beliefs about populations, behaviours, practices, sex, illness and death. Discrimination can be institutionalized through existing laws, policies and practices that negatively focus on people living with HIV and marginalized groups, including criminalized populations (WHO/UNAIDS Technical Guidance Note, 2011).

### **1.7 Organization of the study**

This study is organized in five main chapters with chapter one covering background to the study, the problem statement, objectives and significance of the study. Limitations and organization of the study are also captured in this chapter.

Chapter two is made up of the literature review relevant to general studies on HIV/AIDS, effects of stigmatizing and discriminating against PLWHAs, perceptions and knowledge about PLWHAs and the causes and forms of stigmatization and discrimination of PLWHAs. Also included in this chapter is the conceptual framework which guides the study.

Chapter three covers the profile of Nsawam/Adoagyiri Municipality covering areas such as health and educational facilities, water and sanitation, religion, the ethnic composition as well as economic activities of the people, among others. The methodology which outlines the sampling techniques, data collection methods and other sources of data and information are further discussed in this chapter.

Chapter four contains the analysis and discussion of findings from the primary data that was gathered from the field. Chapter five which is the last chapter focuses on the conclusions and recommendations that are drawn on the findings of the research.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.0 Introduction

The essence of this chapter is to review literature relevant to this research in order to know what already exists especially on issues raised in the objectives. The review of literature is divided into the following sections;

- Knowledge of stigma and discrimination and perceptions about PLWHAs
- Causes and types of stigma and discrimination
- Treatment and the forms of stigmatization and discrimination that affect PLWHAs
- Mechanisms adopted by PLWHA to cope with stigma and discrimination

#### 2.1 Knowledge of stigma and discrimination and perceptions about PLWHAs

In the broader context, as indicated by Parker and Aggleton (2002), the Western world has certain racist assumptions about “African Sexuality” as well as the Africans’ perception about the Western World’s immoral behaviour hence the disease been described by Africans as a “Whiteman’s” disease whereas the Western world also describe it as African disease.

Kafuko (2009) noted in a study conducted on the knowledge, attitudes and practices related to HIV/AIDS in Uganda that PLWHAs knew about HIV related stigma and offered varied definitions to stigma. Through focus group discussion conducted with PLWHAs, some gave the meaning of stigma as “negative thoughts or feelings about a person, or the attitude towards PLWHAs, a state that causes someone dishonour, shame, disrespect, causing those feelings to someone who is either HIV positive or suspected to be living with HIV/AIDS and an attitude, towards someone because of their HIV status through backbiting and mistreating

the infected persons”. PLWHAs are aware that stigma is a broader phenomenon that can apply to situations where individuals or groups carry labels that are considered socially inappropriate and demeaning. In a focus group discussion with religious leaders and care takers in the same study, they associated discrimination with isolation but not human rights violations.

It was noted in a study conducted in Nagasaki, Japan by Maswanya, Moji, Aoyagi, Yahata, Kusano, Nagata, Izumi and Takemoto (2000) on knowledge and attitudes towards AIDS among 383 female college students that although a lot of the students had correct knowledge on the transmission of the disease, more than half of the respondents were reluctant to take care of a person living with HIV/AIDS. The reluctance on the part of the students was due to the existence of misconception they had on the possible routes of the disease transmission.

Kafuko’s (2009) study also noted that PLWHAs classified two types of stigma which are “enacted stigma” and “self-stigma”. Enacted stigma occurs when other people behave in ways that label and discriminate an individual or group of persons due to their HIV status. Self-stigma on the other hand occurs when an infected person feels personal insecurity and inadequacies which results from feelings of the individual about their HIV status and the fear of repercussions of others towards a person living with HIV/AIDS.

In a study conducted among African and Caribbean communities in Toronto by Erica Lawson, Fauzia Gardezi, Liviana Calzavara, Winston Husbands, Ted Myers, Wangari Tharao (2006), it was revealed in a focus group discussion that people living with HIV are stigmatized within their communities based on a range of assumptions about infection. Caribbean participants in particular perceived PLWHAs as ‘gay’ and homosexuals without

taking into account how one contracted the disease as they believe HIV is a “gay disease”. Participants in the focus group discussion spoke about HIV-related stigma being viewed by the communities originating from outside the African and Caribbean communities as a Black or African disease.

A survey conducted in Ghana by Appiah, Afrane and Price (2002) showed some negative attitudes of community members towards PLWHAs. It was mentioned that these negative attitudes towards PLWHAs varied from community to community. It was indicated that some communities held stronger negative attitudes towards females than towards males and vice versa. The survey revealed that in communities that had negative attitudes towards females, they believed infected females were promiscuous. In the same communities where females face such negative attitudes, males who get infected are blamed for going in for promiscuous women. The study further revealed that community members made negative statements about PLWHAs that persons who get the disease are immoral; promiscuous and disgraceful to their families. Other statements made were that infected persons must be feared and again, PLWHAs are living but dead.

In another study conducted in Port Harcourt city in Nigeria by Mbonu, Van Den Borne and De Vries (2011) as well as one by Lawson et al (2006) among African and Caribbean communities in Toronto noted that most people believe that HIV is contracted through sexual contact, hence PLWHAs are believed to be promiscuous who go around flirting about and as such deserved to be blamed. PLWHAs are therefore perceived to be close to death as the disease is associated with death which makes people to avoid them as most people fear death. The study further noted that there are differences in perception about female persons living with HIV and male persons living with HIV. Females who are HIV positive are perceived by people as prostitutes. The reason for the differences in blame is that the cause of infection for

women is always believed to be sex whilst males are normally perceived to contract it from barbering salon.

A similar study conducted by Awusabo-Asare (1995) in Ghana on perceptions, attitudes and post-diagnosis behaviour of PLWHAs, revealed that PLWHAs themselves had certain perceptions about the disease as most of them got angry, sad or shocked upon hearing their results for the first time. This results to denial of seropositive status by some infected persons thereby refusing to inform other people. Out of 137 respondents in the study, 86 per cent reported being shocked, afraid, angry and sad. The study further indicated that more females were shocked and sad than males due to negative views such as the disease affecting immoral people and its incurable nature. A number of PLWHAs reported in the study that “once you are informed about your seropositive status then you have been given your death warrant”. A lot of the people remained silent about their HIV seropositive status as 26 per cent at the time of the survey had not informed anybody.

In another survey in Ghana by Appiah, Afrane and Price, it was revealed that diagnosed persons had mixed feelings. Out of a total number of 101 respondents, 41% were shocked, 37% were worried and disturbed and 31% became sad or unhappy with 6% having disbelief. Their main reasons for these actions were fear of death as well as isolation (Appiah, Afrane and Price, 2002).

It was observed in Kafuko’s study in Uganda that children who had HIV/AIDS were seen as a source of stigma and shame by their parents. Stigma and discrimination was linked to the relationship between HIV transmission and sexuality. This view was however very

pronounced among religious leaders as they associated HIV/AIDS to sexual immorality and sin, hence PLWHAs perceived as immoral and sinners (Kafuko, 2009).

## **2.2 Causes of stigmatization and discrimination**

As noted by the UNAIDS (2000), stigmatization and discrimination related to HIV/AIDS exist due to series of powerful metaphors on the epidemic in its earlier days. Among these metaphors stated by the UNAIDS were description of the HIV/AIDS epidemic as death through certain images and also as punishment for immoral behavior. UNAIDS continued that during the earlier days, HIV/AIDS was seen again by many as a crime especially related to both innocent and guilty victims; as war which needs to be fought against; as horror which infects demonic people thereby making them fearful and as a disease of others which infects a certain group of people or population. The report further notes that these stereotypes enable some people to deny their status.

According to de Bryun (1998), diseases such as mental illness, cancer, tuberculosis, syphilis and epilepsy are also stigmatized in society but HIV/AIDS stigma is more pronounced due to factors such as its association with already stigmatized or deviant behaviours like homosexuality and injection drug use. Other causes of HIV/AIDS-related stigma as mentioned by de Bryun as well as Mbonu, Van Den Borne & De Vries (2011) are the fact that HIV has been described as a life threatening disease; the fact that people fear to contract HIV; the thought of people with HIV/AIDS as responsible for contracting HIV and religious or moral beliefs of others which makes them to conclude that living with HIV/AIDS is the result of immorality such as promiscuity or deviant sex that deserves punishment.

Parker and Aggleton (2002) also stated that HIV/AIDS related stigma and discrimination interact with pre-existing stigmatization and discrimination which is associated with sexuality, gender, race, poverty, preexisting fears about contagion and disease. Earlier

metaphors related to AIDS as death, as horror, as punishment, as guilt, as shame and as the disease for others have made HIV/AIDS-related stigma and discrimination worse. HIV/AIDS-related stigma and discrimination associated with sexuality is as a result of the most common transmission of the virus through sexual intercourse which is a stigmatized act in society due to the fact that most reports of the disease at its initial stages was high among populations whose sexual practices or identities were opposite to the normal societal norms. The belief that homosexuals are to be blamed for the epidemic or the most at risk population as well as promiscuous sexual behaviour by women been responsible for heterosexual epidemic is still common in most societies. As indicated by Parker and Aggleton (2002), linking gender to HIV/AIDS related stigma and discrimination is where heterosexual transmission is more pronounced in the society. Parker and Aggleton (2002) continued that in such settings, the spread of HIV has been associated with female sexual behaviour, prostitution that is considered inconsistent with gender norms. In the same way, men in these settings are blamed for heterosexual transmission based on male sexual behaviour, such as men's preference for multiple sexual partners.

According to Parker and Aggleton (2002), class, race and ethnicity also interact with HIV/AIDS related stigma and discrimination. On the basis of class, HIV/AIDS epidemic has interaction with pre-existing stigma and discrimination associated with economic marginalization whiles in some contexts, the epidemic has been characterized by assumptions about the rich which associates HIV/AIDS with affluent lifestyles. Parker and Aggleton further notes that the disease has been characterized by both racist assumptions about "African sexuality" and by perceptions in the developing world of the Western world's immoral behavior thereby contributing to the marginalization of minority population groups which eventually makes these groups vulnerable to HIV/AIDS which in turn worsens stigmatization and discrimination (Parker and Aggleton, 2002).

The International Center for Research on Women in (2010) mentioned that HIV related stigma has immediate underlying causes which are consistent across different contexts. These causes include lack of awareness of stigma and its damaging effects, fear of acquiring HIV through everyday contact and values that link people with HIV to behaviour considered improper and immoral.

### **2.3 Types of HIV-related stigma and discrimination**

According to Lekganyane and du Plessis (2011), stigma can be felt (anticipated or internal) which leads to an unwillingness on the part of diagnosed persons to seek help and to access resources. It can also be enacted (external stigma), leading to discrimination on the basis of one's HIV status. Stigma can either be external or internal. External stigma refers to the actual experience of discrimination whereas internal stigma (felt or imagined stigma) refers to the shame associated with HIV/AIDS and PLWHAs' fear of being discriminated against. Internal stigma, as further indicated by Mbonu, Van Den Borne and De Vries (2009), serves as a powerful survival mechanism that helps one to protect him or herself from external stigma which often results in thoughts or behaviour such as refusal or reluctance to disclose one's HIV positive status, denial of HIV/AIDS and unwillingness to accept help (Ngozi C. Mbonu et al., 2009).

A research conducted by UNAIDS (2000) in Uganda and India on HIV and AIDS related stigmatization, discrimination and denial revealed that HIV-related stigmatization, discrimination and denial may appear in a variety of contexts. Central among those are the family and local community, employment and the workplace, and the health care system. In majority of developing countries, families are the primary care givers and play an important role in providing support and care for PLWHAs. Infected and affected family members may experience stigmatization and discrimination within the home. The family's efforts to

“manage” stigmatization within the wider community also have consequences for quality of care. Families may shield affected members from the wider community by keeping them within the house or by protecting them from questioning.

Additionally, although HIV is not readily transmitted in the majority of workplace settings, employment and workplace stigmatization and discrimination has been enacted through termination or refusal of employment by many employers. In countries where employer sponsored insurance schemes that provide medical assistance and pensions for employees have come under increasing pressure in countries that have been seriously affected by HIV/AIDS, some employers have used this pressure to deny employment to PLWHAs (UNAIDS, 2000).

It is further reported by UNAIDS (2000) on the extent to which individuals are stigmatized and discriminated against by the health care system. Many accounts also proliferate of withheld treatment, non-attendance of hospital staff to patients left lying in their beds, HIV testing without consent, breaches of confidentiality and denial of hospital facilities and medications.

#### **2.4 The forms of stigmatization and discrimination that affect PLWHAs**

Stigmatization and discrimination of people living with HIV/AIDS occur in different forms and at different levels. The UNAIDS (2000) as well as de Bryun (1998) explained the different levels where stigma and discrimination occur are at the societal, programmatic and personal levels. At the societal level, it occurs based on race, gender, sexual orientation, drug use, criminal status among others which make stigmatized people socially disadvantaged which exacerbates this group susceptible to the HIV/AIDS infection. At the programmatic level, as further noted by the UNAIDS (2000) and de Bryun (1998), it is evident in unavailability of programmes that can empower and respect the dignity of people living with

HIV/AIDS. Personal level stigma and discrimination also occurs directly in day-to-day occurrences with family, friends, service providers and the public. The UNAIDS further stated stigmatization and discrimination occurs indirectly through conditions that are created by discrimination at the societal level through imposition of limitations at the programmatic level (de Bryun, 1998; UNAIDS, 2000).

According to the UNAIDS Global Report on the Epidemic AIDS (2012), fear, ignorance and discrimination regarding HIV has its own consequences on the life of persons living with HIV/AIDS which includes the worst forms of both abusive treatment and violence. The report further notes that communities' negative attitudes and beliefs towards PLWHAs can increase internalized self-stigma such as guilt, shame as well as feelings of alienation by the affected persons. More than half representing 52% of people living with HIV in Zambia experienced verbal abuse due to their HIV status and 1 out of 5 people living with HIV/AIDS reported feeling suicidal in Nigeria and Ethiopia in data collected through People Living with HIV Stigma Index (UNAIDS, 2012).

Stigma and discriminatory attitudes has an adverse effect on the provision of essential HIV prevention and treatment services. In a survey conducted using the People Living with HIV Stigma Index reported that more than 1 in 5 people in Nigeria (representing 21 per cent) are denied health services due to their HIV seropositive status. Also, a nine-country study by International Labour Organization and Global Network of People Living with HIV as cited by the UNAIDS, the percentage of people living with HIV who reported discriminatory attitudes as a result of their HIV status among employers and co-workers ranged from 8 per cent in Estonia to 54 per cent in Malaysia (UNAIDS, 2012).

It was reported by female Persons living with HIV in a focus group discussion in Kafuko's survey in Uganda that people pretend to be supportive when a person living with the disease still looks healthy. However, people even fear to touch the same person when the health deteriorates. It was further noted that supervisors blocked the promotion of staff as a result of their seropositive status. Some PLHIV lost their jobs whereas some were reassigned to lower positions within their organization due to their HIV positive status. A male PLHIV in the survey also reported of an unfriendly and inhuman ideas of the community towards HIV positive people where the community said all HIV people should be killed to get rid of the virus. Another community member said HIV positive people should bear a unique spot for their easy identification in the society. Families also had the tendency to exclude HIV-positive members from discussions and decision making due to the belief that PLWHAs were incapable of making any important contributions (Kafuko, 2009).

Some kin members either withdraw physically or emotionally from patients in order to prevent shame brought by them to the family. Some HIV/AIDS patients in Ghana were in desperate conditions as they lived in poor and isolated conditions as a result of abandonment by relatives as well as irregular source of income. They were dependent on charity and on health facilities for treatment support in areas such as drugs, food and money for transport (Awusabo-Asare, 1995).

In 2012, a UNAIDS database on HIV-related restrictions on entry, stay and residence noted some National governments also exert negative treatment on persons living with HIV/AIDS in the form of legal laws. PLWHAs are restricted in their movements to an extent that some national governments have HIV-related restrictions on entry, stay and residence. Five countries including Brunei Darussalam, Oman, Sudan, United Arab Emirates and Yemen

maintain a total ban on entry by persons living HIV. Five other countries, Egypt, Iraq, Qatar, Singapore and Turks and Caicos Islands require individuals wishing to stay for a short period (about 10 to 90 days) to demonstrate that they are HIV-negative. Some 20 countries also have laws that deport individuals discovered to be living with HIV.

The Gulf States, an important destination for millions of migrant workers demonstrate a practical experience of HIV-related restrictions (UNAIDS, 2012). The six members of the Gulf Cooperation Council which are Bahrain, Kuwait, Oman, Qatar, Saudi Arabia and the United Arab Emirates test people for HIV before visas are renewed for either residence or working permit. Those tested HIV-positive while working in the Gulf are often quarantined, summarily deported, denied appropriate health care and ostracized upon their return to their home countries. HIV positive migrants are categorized as ‘permanently unfit’ for entry into any Gulf Cooperation Council country in the future. This is done through the sharing of migrants HIV-positive test results with all approved medical centres in the Gulf Cooperation Council.

In the International Center for Research on Women’s report on the scaling up response to HIV stigma and discrimination, it was stated that there are various forms of stigma being experienced by People living with HIV/AIDS worldwide. This includes social stigma which excludes PLWHAs from family and community events with its consequent effect on their loss of power and respect in community. In addition to this are physical stigma which takes the form of isolation (such as separate sleeping quarters in the home or a separate seating area in places of worship) and violence, verbal stigma including insults, taunts, blame, gossip and rumours and institutional stigma which also includes job loss due to one’s HIV status,

eviction from homes, loss of educational opportunities and substandard health care (ICRW, 2010).

## **2.5 Coping Mechanisms adopted by PLWHAs**

In a study involving 43 focus groups comprising 251 participants that was conducted on coping with HIV/AIDS Stigma in Five African countries, 17 coping strategies were identified. Out of this number, 6 were labeled emotional coping strategies whereas 11 were labeled problem-focused coping strategies (Lucia N. Makoae, Minrie Greeff, René D. Phetlhu, Leana R. Uys, Joanne R. Naidoo, Thecla W. Kohi, Priscilla S. Dlamini, Maureen L. Chirwa and William L. Holzemer, 2008).

The emotional coping strategies identified in the study by Makoae et al (2008) were activities that were personally done by the stigmatized individual which involves emotional self-management. Problem solving coping strategies on the other hand involved how the problem of stigma could be addressed directly whiles engaging with other people.

The emotional strategies identified were: rationalization where respondents focused on positive thinking and had alternative meanings for their illness; seeing self as being OK, that is seeing one's self as normal or as OK and courageous in the face of the illness or stigma.

Also, letting it be, a situation where stigmatized people avoid confrontation and passively accepting or ignoring stigmatizing behavior.

In addition to the above mentioned emotional strategies is turning to God which focuses on spiritual aspects and includes activities such as praying, joining religious groups, depending on and building hope in God in response to the illness.

More so, hoping, where references to hope were not linked to any specific source, rather, the hope that all would change without any intervention and humor, this involved the use of joking words about the illness or stigma in order to lessen the fear and seriousness associated with HIV.

The problem focused coping strategies that were identified also included joining a group (support group). Disclosing i.e. openly disclosing HIV status to reduce gossip and rumours. Moreover, problem focused coping strategies include going for counseling from health workers or peer counselors in order to feel better and understand the illness better. Other problem focused coping strategies are talking and chatting to others i.e. informal socializing and talking; helping others i.e. give help to other HIV positive persons; educating others; changing lifestyle; keeping busy; acquiring more knowledge and learning from others i.e. learning from others who are infected (Makoae et al, 2008).

In Kafuko's study in Uganda, as a way of coping with stigma, PLWHAs keep quiet about their status while some keep away from the public eye. HIV positive mothers go as long as breastfeeding their babies even when they know that it is not right to do so all because of fear of denial and rejection by spouses, families and community (Kafuko, 2009).

In his study conducted in Ghana, Awusabo Asare (1995) noted that, for fear of being stigmatized and isolated by family members, some PLWHAs have to keep their serostatus as

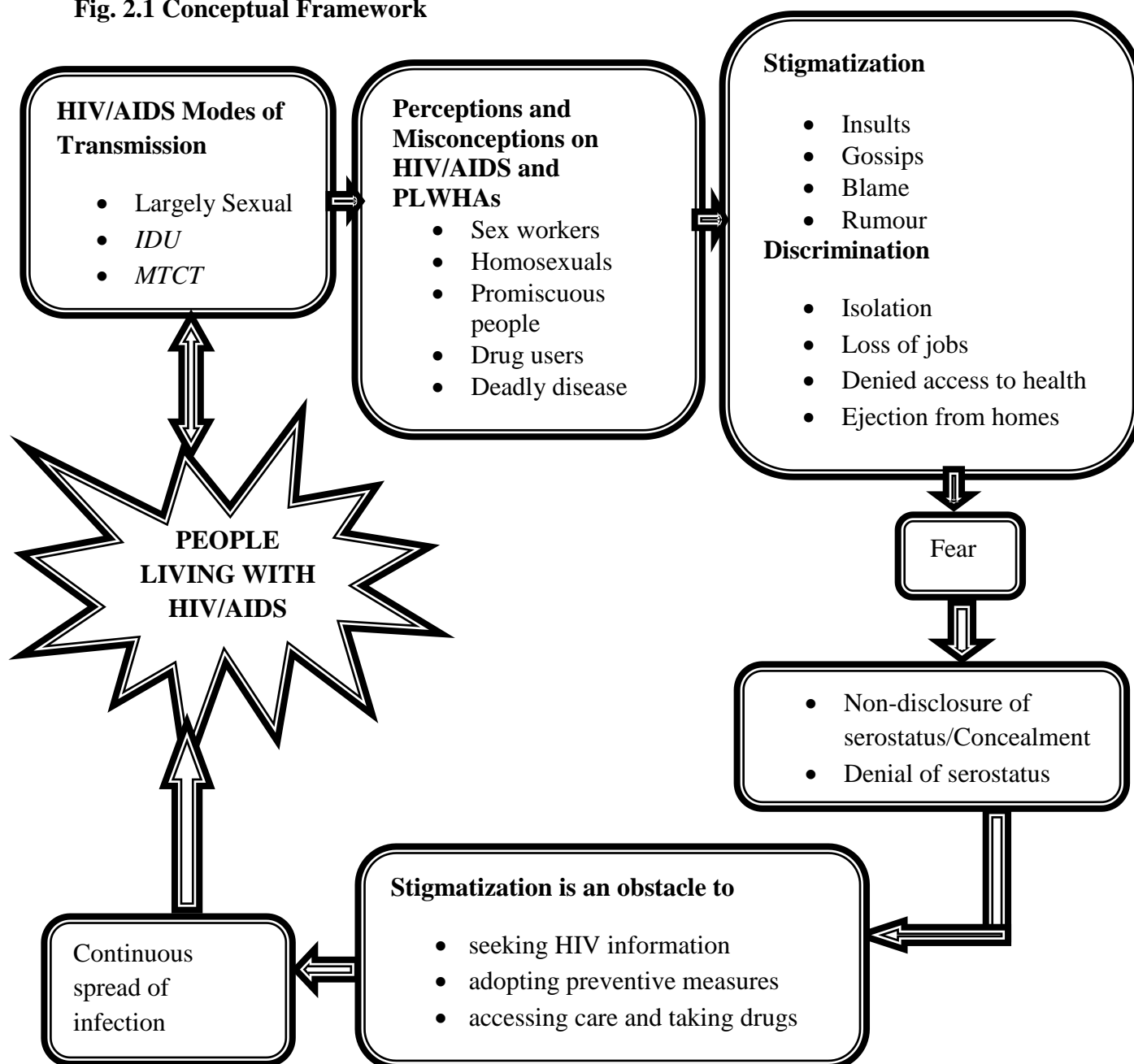
a secret from family members. This is due to the breakdown of the social 'safety net' which was once provided by the corporate clan to individual family members. This 'safety net' no longer makes provision for such support systems.

Barkey (2010) mentioned in another study conducted in Ghana that PLWHAs and their family members have different methods and strategies that enable them to cope with stigmatizing behaviour in society. The study stated that some PLWHAs cope by disclosing their status to their family members and colleagues in order to get support from them whereas others either conceal or deny their serostatus as a coping mechanism. Another coping mechanism for some PLWHAs is their association with area networks or support groups to have a sense of belongingness. Whiles some PLWHAs do not disclose their status, others also relocate as a way of coping with HIV related stigma and discrimination. The study further revealed that some PLWHAs and their families' explanation for HIV diagnosis as a result of bewitching provides them with some form of protection against societal stigma and discrimination.

## **2.6 Conceptual framework**

A Conceptual framework according to Ahaideke is an outline of possible relationships between concepts (Ahiadeke, 2008:131). The conceptual framework showing how stigmatization and discrimination of people living with HIV/AIDS affect prevention and spread is represented in the figure below.

Fig. 2.1 Conceptual Framework



**Source:** Author's Personal Construct, 2013

As shown by the conceptual framework above, earlier reports on HIV/AIDS as a deadly disease with its main mode of transmission being sex which affected populations such as sex workers, homosexuals and injection drug users has created certain misconceptions and perception of persons living with it to be in either one or more of these category of population. The existing misconception and perception have resulted to stigmatizing attitudes

such as insults, gossip, blame, rumour which eventually leads to discriminating attitudes like refusal to employment, denial of access to health care and ejection from homes, among others. These negative attitudes towards PLWHAs put some kind of fear in them which leads to non-disclosure of serostatus or concealment and at times denial of serostatus by persons diagnosed as infected. This as noted by many studies and international bodies like the United Nations serves as an obstacle to PLWHAs to seek information on HIV, adopt preventive measures as well as take drugs which eventually leads to continuous spread of the disease.

## CHAPTER THREE

### PROFILE OF THE STUDY AREA AND METHODOLOGY

#### 3.0 Introduction

This chapter provides the profile of the study area and discusses the methods adopted in undertaking the study. These include the target population, sample size and sampling, sources of data, instruments and techniques of data collection as well as tools for data analysis.

#### 3.1 Profile of the study area

The study was undertaken in the Nsawam/Adoagyiri municipality. Nsawam/Adoagyiri, a stop over town for many travellers from the north to the south of Ghana and vice versa, serves as the meeting point of several economic and social activities. Nsawam is well known for its brisk bread and fried turkey tail business. As the district capital, it serves as a market centre for other villages and small towns surrounding it. Additionally, it serves as environment for other engagements and interactions.

##### 3.1.1 Location and Size

The municipality is located 23km from the national capital, Accra, and covers a land area of 503sq.km. The municipality lies along the Accra Kumasi Highway sharing political boundaries with the Ga and Tema Municipalities to the south, Akuapem North Municipality to the north, and Suhum-Kraboia Coaltar District and the West Akim Municipality to the west. It is one of the newly created assemblies with Nsawam as the district capital. It was carved from the Akwapim South Assembly in mid- 2012. River Densu, an important water body in Ghana, passes through the municipality separating the Nsawam and Adoagyiri townships. The municipality has over 122 communities. Other notable settlements in the municipality

are Sakyikrom, Djankrom, Ntoaso, Amoakrom, Owuraku, Prisons, Dobro and Atsikope (Nsawam/Adoagyiri Composite Budget, 2013).

### **3.1.2 Demographical Data and Ethnic Composition**

The estimated total population of the area is 87,407. Out of this number 42,790 are males and 44,617 are females. The municipality has a population density of 173 persons per square kilometer with a population growth rate of 1.6 per cent. The largest ethnic group in the municipality is the Akans mainly Akuapims who constitute 67% of the total population, followed by other Akans 17% and Ewes constituting 9% with other ethnic groups constituting 7% (Field report, 2012; Nsawam Composite Budget, 2013).

### **3.1.3 Health Facilities**

With the health sector, the municipality has a district hospital, four maternity homes, two eye clinics, one orthopaedic centre and three private clinics. It also has one Level 'A' Primary Health Centre and four level 'B' Primary Health Centres. The doctor-patient ratio of the municipality is estimated at 1:16,000 ([www.ghanadistricts.com](http://www.ghanadistricts.com)).

The major health problems of the municipality are buruli ulcer, maternal mortality, under five malnutrition, food hygiene and environmental sanitation. The one hospital and other service levels have 135 beds with 8 doctors made up of 5 specialists. There are 79 nurses and 20 paramedics, 25 midwives and 24 community health nurses.

Nsawam/Adoagyiri is one of the municipalities in Ghana with highest reported cases of HIV/AIDS although the level of incidence of HIV/AIDS in the municipality is not known (Nsawam Composite Budget, 2013). In 2010, there were 146 reported cases including transfers (newly HIV reported cases from different hospitals other than Nsawam Government Hospital) with 122 people on ARV. Out of this number, 55 were males and 91 females. In

2011, the number shot up to 213 with 89 males and 124 females. However in 2012, 197 cases had been reported by the last quarter of the year. The number of reported cases of HIV/AIDS was lower due to shortage of test kits. Out of the 2012 number, 114 were females whereas 83 were males. Most of the infected people were between the ages 20 and 50 years (Field report, 2013).

HIV/AIDS awareness is believed to be above 90 percent in the Municipality, but this is not reflected in the lifestyles of the people, especially the youth who constitute the greater population and are much more prone to the disease. The bread business also puts the traders at risk with the long distance drivers who spend the night at Adoagyiri (Akuapim South Medium Term Development Plan, 2011).

The municipality has a counseling unit which takes care of HIV/AIDS cases as well as referral cases from other nearby health centres. The HIV/AIDS unit has 12 workers, made up of six health workers and six peer educators. Out of the six health workers, two are pharmacists, two are laboratory technicians and the remaining two are counselors.

### **3.1.4 Economic Activities**

The local economy is made up primarily of agriculture, both subsistence and commercial, agro-processing, and commercial activities. Agriculture is the sector that employs the greatest proportion of the labour force. It employs about 37% of the total labour force, majority of this labour force are into crop farming. The Municipality produces pineapples and pawpaw for export.

The second largest sector which employs a number of the labour force is the commercial sector which employs about 28% of the labour force, with the industrial and service sectors

employing 20% and 15%, respectively. Activities under commerce include the sale of clothing, electrical gadgets, foodstuffs, plastic wares, chemicals, beverages and toiletries. The baking and sale of bread is an industry giving the municipality a unique identity. The municipality also houses the famous Nsawam Medium Security Prison.

The Municipality has factories and industries ranging from pharmaceuticals to fruits processing where high technology and equipment are used. There are other agro-based and related industries, wood/timber related industries such as quarrying and construction industries and mechanical workshops that use light/low level technology in their production and service processes.

**Table 3.1 Some Major Industries and Their Products**

| <b>Industries</b>              | <b>Products</b>                       |
|--------------------------------|---------------------------------------|
| Adafot Sawmill Enterprise      | Timber Boards                         |
| Ghana Paper Finishing Company  | Paper Products                        |
| Nsawam Canary                  | Beverage and Food Products            |
| Astek Fruit Processing Limited | Fruit Beverages and Mineral Water     |
| Paebo Quarry Limited           | Quarry Projects                       |
| Gem Mineral Water industry     | Mineral Water                         |
| Pam Pharmaceuticals            | Drugs                                 |
| Densu Industries               | Disinfectant, Blue, Polish, etc.      |
| Still Pure Water               | Bottled Water                         |
| Blue Skies Limited             | Pineapple, Pawpaw, Water Melon juices |
| Mobile Water                   | Mineral Water                         |

**Source: Nsawam Composite Budget, 2013**

## **3.2 Methodology**

This section outlines the methods adopted in undertaking the study. This includes the selection of respondents and the various data collection approaches utilized.

### **3.2.1 Target Population**

The target population for the study was People living with HIV/AIDS for which those interviewed constituted the unit of analysis. Information was also obtained from health workers working with PLWHAs, community members and non-governmental organizations working on HIV/AIDS programmes in the municipality.

### **3.2.2 Sample Size and Sampling Techniques**

Prior to the sample size determination, an ethical clearance was given to the researcher to enable her get information from the Nsawam/Adoagyiri government hospital. For PLWHA respondents, the researcher was given a list of reported cases of HIV/AIDS which showed there were 197 persons living with HIV/AIDS. Based on the total number of reported cases in the municipality, I decided on an initial sample size of 100. The reason for setting out on 100 respondents at the initial stage was to make the results more representative of the interviewees (PLWHAs).

A multi-stage sampling procedure was adopted in selecting respondents for the study. In the first stage stratified sampling was adopted in splitting the PLWHAs into males and females. Stratified sampling guarantees representativeness within a sample (Neuman, 2011). As indicated by Kumepkor (2002), stratified sampling makes it possible for estimate of sampling units within each stratum to be more accurate and more realistic. Based on the number of males and females among the 197 PLWHAs, quotas were assigned in the second stage in

selecting the total number of male PLWHAs and female PLWHAs to be interviewed. The proportion of males to be interviewed was 42% whereas females were 58% based on the total number of HIV reported cases. Each of the sexes was sampled according to its proportion in the total population of PLWHAs in the community.

In the third stage, the convenient or accidental sampling approach was adopted in picking respondents for interview as and when they were encountered and were willing to be interviewed. This approach was considered appropriate because the target group was a rare population that was difficult to reach and to interview. Subsequently their selection did not lend itself to probability sampling as pre-selected samples might never have been found or might have refused to be interviewed. Seventy out of the 100 targeted respondents were eventually interviewed. The shortage of 30 respondents was as a result of the difficulty encountered in getting respondents as well as time constraint for the field work. Out of the total number of 70 respondents interviewed, 30 were males and 40 were females.

For health workers, purposive sampling was used to select one health worker working in the HIV counseling unit and two HIV support groups for in-depth interviews. As mentioned by Kumekpor (2002), purposive sampling is useful in studying communities with respect to cause of, or reason for, interest in, indifference or opposition to specific projects, ideas or innovations. The reason for using this method in selection of the health worker was as a result of the interest the health worker had in HIV/AIDS cases and its related stigmatization and discrimination in the Nsawam/Adoagyiri municipality. In purposive sampling, the units of the sample are intentionally picked for a study because they satisfy certain qualities which are not randomly distributed in the universe, but they are typical or exhibit most of the characteristics of interest to the study (Kumekpor, 2002).

The application of this technique to the selection of persons living with HIV/AIDS support groups was due to the educational activities of these NGOs as well as their fight against cases related to HIV/AIDS and issues of stigmatization and discrimination in the community.

Two FGDs were conducted in Nsawam/Adoagyiri, the two main towns in the municipality and the district capital. As the pivot towns for many commercial activities and other transactions, Nsawam/Adoagyiri attracts all sorts of people from all walks of life. Recruiting participants for the FGD from this town was worth it as participants had different cultural backgrounds. The objective of the study was explained to the participants at a mini durbar where those who were interested in the topic agreed to participate in the discussion. In order for the views of participants in the focus group discussion to be representative of the entire community and also all ages, the age group for the males' participants ranged from 18 to 50 years. However, for the female participants, the youngest among the participants was 16 years with 45 years as the oldest age.

#### **3.2.4 Sources of data:**

Information from both primary and secondary sources was collected in order to reflect the effect stigmatizing and discriminating against PLWHA has on the prevention and spread of the disease. The primary data was collected using questionnaire for PLWHAs, an interview guide for the health worker, and FGD guide for community members. Secondary data relevant to the study were collected from the Nsawam Government Hospital, publications of Ministry of Health, Ghana AIDS Commission and National AIDS Control Programme were used for the study.

### **3.2.5 Methods and instruments of data collection**

This study was largely quantitative; however some qualitative data was collected to supplement the data obtained. The methods for data collection were questionnaire and interview guide.

The questionnaire was used on PLWHAs and had both open ended and closed ended questions to elicit information from the PLWHAs.

In order to allow PLWHA respondents express themselves in a way that stigma and discrimination affect their lives, the open ended questions were used to elicit such information from them. Closed ended questions were framed in such a way that gave the respondents a number of responses to choose from which make such responses easy to handle and less cumbersome (Kumekpor, 2002). All the interviews were face to face where the interviewer had the opportunity to create rapport between her and the interviewees in order to get the right information.

In-depth interview with the use of interview guide was done with one health worker from the counseling unit as well as two HIV/AIDS support groups working in the municipality. The questions for the interview were structured and conducted in English and tape recorded. The interview with the health worker lasted for one and half hours whilst the one with the two support groups lasted for one hour each. Among some of the questions asked during the interview with the health worker were whether he had ever experienced stigma and discrimination as a result of his work, the implications and consequences of stigmatizing and discriminating against persons living with HIV/AIDS, available support systems provided for PLWHAs when faced with such problems in society and how stigma and discrimination can be reduced. The questions for the support groups also covered themes such as HIV/AIDS

related programmes and measures adopted by the various groups in fighting against stigma and discrimination in the municipality.

Two focus group discussions, one for male and one for female participants with each group made up of ten members were conducted in Nsawam/Adoagyiri.

As noted by Kumekpor (2002), focus group discussion provides a great deal of insight into issues under study. Anaman (2003) also indicated that focus group discussion offers an opportunity to stimulate discussion of a particular topic or issue. This method was adopted to enable me get broader knowledge on the treatment given to PLWHAs as well as better understand reasons why certain actions are taken by non-infected people against PLWHAs in the community. One of the advantages of focus group discussion is that it allows members of the group to express their views, opinions and counter opinions on attitudes, beliefs and practices, useful for explaining or understanding behavioural issues. Both English and Twi (a local language) were used since participants were made up of both literates and non – literates.

The main topics for deliberations included community members' perceptions about HIV/AIDS and persons infected with the disease, awareness of stigma and discrimination, views on the treatment meted out to persons infected and affected by HIV/AIDS and suggestions as to how the problem of HIV related stigma and discrimination can be reduced if not eliminated in the society. The discussion with the males lasted for 45 minutes whilst that of the females lasted for 41 minutes. Responses from the discussions were recorded with an MP3 recorder and transcribed into a word document under themes.

The major problem encountered during the FGD was digression of issues of some contributors in the male FGD. I addressed this problem through repetition of the question been asked and constant reminder to participants to be brief in their submissions. Among the

FGD with the female group, some particular persons tended to dominate the discussions. This problem was overcome by encouraging everybody to say anything they had in mind as there was no right or wrong answer to questions asked.

### **3.3 Data Analysis and presentation:**

Responses through the administration of open ended and closed ended questions were analyzed. The statistical package for social sciences software version 20 was used for analyzing quantitative data (International Business Machine Corporation – IBM, 2011).

Descriptive statistics was used to summarize the results into graphical and frequency tables. Bivariate analyses were used where necessary largely to assess gender differentials and the understanding of dynamics behind responses.

Responses from both the in-depth interview and the focus group discussions were transcribed into word and analyzed under themes. The responses were used to support findings from the quantitative data.

## CHAPTER FOUR

### PRESENTATION OF DATA AND DISCUSSION OF FINDINGS

#### 4.0 Introduction

This chapter focuses on the analysis of data collected from the respondents. Questionnaires were administered to people living with HIV/AIDS and in-depth interviews were conducted with counselors and leaders of support groups. Community members were engaged in focus group discussions. Univariate and bivariate analyses have been utilized in the presentation of data. This is to describe the data and to show variations in responses based on socio-demographic background of respondents. The data are presented in tables and graphs showing percentage distributions.

#### 4.1 Demographic characteristics of respondents

This section of the analysis looks at the age, sex, marital status, educational and occupational profiles of the PLWHAs respondents.

**Table 1: Percentage distribution of respondents' age by sex**

| Age group | Male  |         | Female |         | Total |         |
|-----------|-------|---------|--------|---------|-------|---------|
|           | Freq. | Percent | Freq.  | Percent | Freq. | Percent |
| 20-24 yrs | 0     | -       | 1      | 2.5     | 1     | 1.4     |
| 25-29 yrs | 2     | 6.7     | 6      | 15.0    | 8     | 11.4    |
| 30-34 yrs | 5     | 16.7    | 7      | 17.5    | 12    | 17.1    |
| 35-39 yrs | 2     | 6.7     | 10     | 25.0    | 12    | 17.1    |
| 40-44 yrs | 9     | 30.0    | 7      | 17.5    | 16    | 23.0    |
| 45-49 yrs | 4     | 13.3    | 5      | 12.5    | 9     | 12.9    |

|                  |    |       |    |       |    |       |
|------------------|----|-------|----|-------|----|-------|
| 50 yrs and above | 8  | 26.7  | 4  | 10.0  | 12 | 17.1  |
| <b>Total</b>     | 30 | 100.0 | 40 | 100.0 | 70 | 100.0 |

**Source: Field data, 2013**

From Table 1, it can be noted that the ages of the respondents spread between 25 years and 50 years. A little more than half of the respondents were aged between 40 and 50 years while the rest were aged between 25 and 40 years. The single largest proportion of the respondents (23%) was within the age group 40 – 44 years. However taking males and females separately, the proportion of males was higher than females. Thus while that age group (40 – 44 years) males constituted 30%, among the females they constituted almost 18%. While for the females 25% of them were within the 35-39 years age group, the males constituted just 6.7% within that same age group. Within the 50 years and above age group, the males were around 27% whereas the females were 10%. The 20 – 24 age groups had the least number of respondents. This group constituted about 3% of females whereas there were no male respondents in that age group.

The least affected age group in the municipality was the youth within the ages 20 – 24 years. This finding in the municipality reflects the national least affected age group (20 – 24 years) in 2011 in the Country's HIV Response Progress report by the Ghana AIDS Commission.

The table presents the marital status of the respondents by the sex groups. The intention was to find out the level of infection among the marital statuses.

**Table 2: Marital Status of respondents by sex**

| Marital Status | Male  |         | Female |         | Total |         |
|----------------|-------|---------|--------|---------|-------|---------|
|                | Freq. | Percent | Freq.  | Percent | Freq. | Percent |
| Married        | 18    | 60.0    | 25     | 62.5    | 43    | 61.4    |
| Single         | 7     | 23.3    | 6      | 15.0    | 13    | 18.6    |
| Cohabiting     | 1     | 3.3     | 1      | 2.5     | 2     | 2.9     |

|              |           |              |           |              |           |              |
|--------------|-----------|--------------|-----------|--------------|-----------|--------------|
| Divorced     | 1         | 3.3          | 5         | 12.5         | 6         | 8.6          |
| Widowed      | 3         | 10.0         | 3         | 7.5          | 6         | 8.6          |
| <b>Total</b> | <b>30</b> | <b>100.0</b> | <b>40</b> | <b>100.0</b> | <b>70</b> | <b>100.0</b> |

**Source: Field Data, 2013**

It can be observed from Table 2 that majority (61.4%) of the respondents were married with a small percentage of 2.9% cohabiting. Considering males on one side with females on another side, about 63% of the females were married compared to 60% of the males. With those who were divorced, about 13% of the females were divorced compared to 3% of the males. Ten percent (10%) and about 8% of the males and females respectively were widowed.

Table 3 is a presentation of the educational background of the respondents.

**Table 3: Respondents education by sex**

| Highest Education   | Male      |              | Female    |              | Total     |              |
|---------------------|-----------|--------------|-----------|--------------|-----------|--------------|
|                     | Freq.     | Percent      | Freq.     | Percent      | Freq.     | Percent      |
| None                | 1         | 3.3          | 5         | 12.5         | 6         | 8.6          |
| Primary             | 4         | 13.3         | 19        | 47.5         | 23        | 32.9         |
| JHS/Middle          | 15        | 50.0         | 3         | 7.5          | 18        | 25.7         |
| Secondary/Technical | 8         | 26.7         | 11        | 27.5         | 19        | 27.1         |
| Diploma             | 2         | 6.7          | 0         | -            | 2         | 2.9          |
| Degree              | 0         | -            | 2         | 5.0          | 2         | 2.9          |
| <b>Total</b>        | <b>30</b> | <b>100.0</b> | <b>40</b> | <b>100.0</b> | <b>70</b> | <b>100.0</b> |

**Source: Field Data, 2013**

The results in table 3 depict a relatively low level educational attainment by respondents. Most of the respondents (32.9%) had primary education, followed by secondary/technical school leavers (27.1%) and (25.7%) of Junior High or Middle school leavers. Only 6% of the respondents were diploma and degree holders whereas 8.6% had never been to school. Half of the females had primary education as their highest level of education as compared to half

of the males who had JHS/Middle School education. With tertiary education, while 5% of the female respondents had degree, none of the males had degree education. On the other hand, the proportion of the females without education was higher than the males. Generally, the educational level among the females was relatively lower compared to the males.

A lot of the respondents were found in the informal sector with (35.7%) involved in trading activities as shown in Table 4. Only about 3% were engaged in professional occupation such as teaching and they were all females. However, in comparison to other occupation, majority of the males were farmers or engaged in businesses such as driving, barbering, security, among others while the common occupation among the females was trading activity, that is almost 53% of them. Although majority of the respondents were working, about 13% of them were unemployed which comprised 12.5% of females and 13.3% of males.

**Table 4: Respondents occupation by sex**

| Current occupation | Male  |         | Female |         | Total |         |
|--------------------|-------|---------|--------|---------|-------|---------|
|                    | Freq. | Percent | Freq.  | Percent | Freq. | Percent |
| Teacher            | 0     | -       | 2      | 5.0     | 2     | 2.9     |
| Trader             | 4     | 13.3    | 21     | 52.5    | 25    | 35.7    |
| Unemployed         | 4     | 13.3    | 5      | 12.5    | 9     | 12.9    |
| Cook               | 0     | -       | 4      | 10.0    | 4     | 5.7     |
| Farmer             | 7     | 23.3    | 2      | 5.0     | 9     | 12.9    |
| Other              | 15    | 50.0    | 6      | 15.0    | 21    | 30.0    |
| <b>Total</b>       | 30    | 100.0   | 40     | 100.0   | 70    | 100.0   |

**Source: Field Data, 2013**

#### **4.2 Experience of HIV/AIDS**

This section discusses among others the number of years respondents had lived with the virus, the various modes through which they got infected, respondents' reaction upon hearing

their sero-positive status for the first time, the decision made and reasons for making such decisions, the number of respondents who had disclosed status to anyone and their reasons for disclosing to such persons.

#### 4.2.1 Years of living with HIV/AIDS

Table 5 is a presentation of data on the number of years respondents had lived with the virus.

**Table 5: Number of years of living with HIV/AIDS by sex**

| Years of living with HIV/AIDS | Male      |              | Female    |              | Total     |              |
|-------------------------------|-----------|--------------|-----------|--------------|-----------|--------------|
|                               | Freq.     | Percent      | Freq.     | Percent      | Freq.     | Percent      |
| Less than 1 year              | 10        | 33.3         | 14        | 35.0         | 24        | 34.3         |
| 2 – 3 years                   | 11        | 36.7         | 16        | 40.0         | 27        | 38.6         |
| 4 – 5 years                   | 3         | 10.0         | 3         | 7.5          | 6         | 8.6          |
| More than 5 years             | 6         | 20.0         | 7         | 17.5         | 13        | 18.6         |
| <b>Total</b>                  | <b>30</b> | <b>100.0</b> | <b>40</b> | <b>100.0</b> | <b>70</b> | <b>100.0</b> |

**Source: Field Data, 2013**

The data as presented in Table 5 shows that 38.6% of the respondents had lived with the disease for 2 – 3 years while 34.3% had lived with it for less than 1 year. Males who had lived with the virus for 2 – 3 years constituted about 37% as compared to 40% of the females who had lived with the virus for the same period. Whereas 10% of the males had lived with the virus for 4 – 5 years, about 8% of the females had lived with the virus for this same number of years. However, with those who had lived with the disease for more than 5 years, the males were proportionately higher (20.0%) than the females who constituted 17.5%.

#### 4.2.2 Modes of infection

Below is a presentation on the various modes through which respondents got infected by HIV/AIDS.

**Table 6: Mode of infection by sex**

| How disease was contracted | Male      |              | Female    |              | Total     |              |
|----------------------------|-----------|--------------|-----------|--------------|-----------|--------------|
|                            | Freq.     | Percent      | Freq.     | Percent      | Freq.     | Percent      |
| Blood transfusion          | 3         | 10.0         | 5         | 12.5         | 8         | 11.4         |
| Sex                        | 24        | 80.0         | 29        | 72.5         | 53        | 75.7         |
| Don't know                 | 2         | 6.7          | 6         | 15.0         | 8         | 11.4         |
| Other                      | 1         | 3.3          | 0         | -            | 1         | 1.4          |
| <b>Total</b>               | <b>30</b> | <b>100.0</b> | <b>40</b> | <b>100.0</b> | <b>70</b> | <b>100.0</b> |

**Source: Field Data, 2013**

Looking at table 6, more than half (75.7%) of the respondents contracted the disease through sexual intercourse which is the most common mode of transmission across the globe. While 11.4% mentioned they contracted the disease through blood transfusion, the same percentage (11.4%) of respondents also stated they did not know how they got infected. A small percentage (1.4%) of the respondents mentioned they contracted the disease through different means other than sex and blood transfusion.

Eighty percent (80%) of the males contracted the virus through sexual intercourse as against about 73% of the female respondents. Moreover, females who indicated they had no idea of how they contracted the disease were more (15%) than the males who were about 7%. Only 3% of the males mentioned other means of infection other than the modes of transmission mentioned in the table.

During an interaction with the community members in the focus group discussion, most of the participants mentioned sexual intercourse as the main mode of transmission, hence they think PLWHAs living with the disease are promiscuous, especially, married people. They did

not understand why faithful couples should be infected with the disease. Others noted that some people got infected through using sharp items like blade, needle, and even tooth brush.

The common process of the disease contraction through sex confirms a study conducted by Mbonu, Van Den Borne and De Vries (2011) in Port Harcourt city, Nigeria and reports of the Ministry of Health (2001) as well as Ghana AIDS Commission (2013) which indicated that the predominant mode of infection occurs through heterosexual contact. Also, the finding of Lawson, Gardezi, Calzavara, Husbands, Myers and Tharao, (2006) among African Caribbean communities in Toronto showed that most people believed HIV is contracted through sexual intercourse is consistent with what the community members mentioned as the main mode of transmission during the focus group discussions.

#### **4.2.3 Reaction on sero-positive status**

The following is a presentation of data on the expression of respondents' feelings upon hearing their sero-positive status for the first time.

Looking at the statistics in Table 7, it can be noted that 31% of the respondents constituting the highest single proportion got shocked when they were informed of their status for the first time. Thirty-one percent were sad, and almost 23% were also doubtful when they heard their sero-positive status for the first time. The proportions of males who were shocked and doubtful i.e. 46.7% and 30% respectively were higher than the females (45%) and about (18%). However, more of the females, (about 38%) were sad as compared to 23% of males who got sad upon hearing their sero-positive status for the first time.

**Table 7: Respondents' reaction upon hearing HIV/AIDS sero-positive status by sex**

| Reaction | Male  |         | Female |         | Total |         |
|----------|-------|---------|--------|---------|-------|---------|
|          | Freq. | Percent | Freq.  | Percent | Freq. | Percent |
|          |       |         |        |         |       |         |

|              |           |              |           |              |           |              |
|--------------|-----------|--------------|-----------|--------------|-----------|--------------|
| Sad          | 6         | 23.3         | 13        | 37.5         | 19        | 31.4         |
| Shocked      | 13        | 46.7         | 14        | 45.0         | 27        | 45.7         |
| Doubtful     | 4         | 30.0         | 7         | 17.5         | 11        | 22.9         |
| <b>Total</b> | <b>30</b> | <b>100.0</b> | <b>40</b> | <b>100.0</b> | <b>70</b> | <b>100.0</b> |

**Source: Field data, 2013**

A study conducted by Awusabo-Asare (1995) in Ghana revealed that most people became shocked, sad, angry and afraid upon hearing of their HIV sero-positive status. The study further noted that more females were sad and shocked than males due to such reasons as they being branded as immoral. This study also found out that more females were sad than males which is in conformity to Awusabo-Asare's study. In an in-depth interview with a counselor at the Nsawam Government hospital she revealed that due to fear, people go as far as attempting to strangle the counselor who disclosed the results to the person for the first time.

Table 8 below presents the reasons why respondents reacted in various ways after their sero-positive status was disclosed to them.

**Table 8: Respondents reaction on sero-positive status by reasons for reaction**

| Reaction     | Reason for such reaction |             |            |             |                |            |                        |             |           |              |
|--------------|--------------------------|-------------|------------|-------------|----------------|------------|------------------------|-------------|-----------|--------------|
|              | Fear denial              |             | Fear death |             | Fear isolation |            | Wasn't Flirting around |             | Total     |              |
|              | Freq.                    | Perce.      | Freq.      | Perce.      | Freq.          | Perce.     | Freq.                  | Perce.      | Freq.     | Perce.       |
| Sad          | 4                        | 5.7         | 7          | 10.0        | 1              | 1.4        | 10                     | 14.3        | 22        | 31.4         |
| Shocked      | 5                        | 7.1         | 6          | 8.6         | 3              | 4.3        | 18                     | 25.7        | 32        | 45.7         |
| Doubtful     | 2                        | 2.9         | 2          | 2.9         | 2              | 2.9        | 10                     | 14.3        | 16        | 22.9         |
| <b>Total</b> | <b>11</b>                | <b>15.7</b> | <b>15</b>  | <b>21.4</b> | <b>6</b>       | <b>8.6</b> | <b>38</b>              | <b>54.3</b> | <b>70</b> | <b>100.0</b> |

**Source: Field Data, 2013**

The data shows that the respondents were either sad, shocked or doubtful upon hearing their sero-positive result for the first time. Their main reason for this action was that they were not flirting around. Ten percent of those who got sad, about 9% of those who got shocked and almost 3% of those who were doubtful also cited they feared death. This finding implied the respondents themselves had the mentality that HIV/AIDS is deadly and also a disease for people who had indiscriminate sexual lifestyle or not stable in their relationship. Almost 6% of those who were sad, 7% of those who were shocked and 3% of those who were doubtful about their sero-positive results reacted that way because they feared they would be denied by people.

Community members hold some views about PLWHAs. From an in-depth interview with the leader of Precious Women support group, she mentioned that “once people get to know your status they think you are “ashawo” (prostitute) or “kakaē” (a weird animal).

During the focus group discussion, a man said that people with HIV/AIDS have no future because the disease is incurable thereby making people with HIV/AIDS as nonentities.

The counselor mentioned in the in-depth interview that people still hold certain perception on the disease as being disgraceful to mankind and PLWHAs as well. She revealed that one woman came in for HIV/AIDS counseling and testing and mentioned that if she should test positive, she will poison herself because she cannot live with such a disgraceful disease in her community. This is consistent with a finding in Appiah, Afrane and Price (2002) where some community members believed PLWHAs are a disgrace to their families.

One man said he sees PLWHAs as “living but dead” because HIV is incurable collaborating Mbonu, Van Den Borne and De Vries (2011) that PLWHAs are associated with death as well as a survey by Appiah, Afrane, and Price (2002) where some respondents gave derogatory statements about PLWHAs as living but dead.

#### 4.2.4 Decision on sero-positive status

Per Table 9, I present data on the decisions respondents made upon hearing the HIV/AIDS sero-positive status.

**Table 9: Decision taken by respondent by the reason for taking that decision**

| Reason for making such a decision |             |             |              |             |                    |             |                        |             |              |             |           |              |
|-----------------------------------|-------------|-------------|--------------|-------------|--------------------|-------------|------------------------|-------------|--------------|-------------|-----------|--------------|
| Decision                          | Avoid shame |             | Avoid stigma |             | Avoid maltreatment |             | Avoid dying shamefully |             | To live long |             | Total     |              |
|                                   | No.         | %           | No.          | %           | No.                | %           | No.                    | %           | No.          | %           | No.       | %            |
| Commit suicide                    | 4           | 5.7         | 4            | 5.7         | 1                  | 1.4         | 4                      | 5.7         | 0            | -           | 13        | 18.6         |
| Not disclose to anyone            | 3           | 4.3         | 11           | 15.7        | 12                 | 17.1        | 0                      | -           | 5            | 7.1         | 31        | 44.3         |
| Leave everything to God           | 0           | -           | 0            | -           | 0                  | -           | 3                      | 4.3         | 5            | 7.1         | 8         | 11.4         |
| Follow treatment                  | 1           | 1.4         | 1            | 1.4         | 2                  | 2.9         | 0                      | -           | 14           | 20.0        | 18        | 25.7         |
| <b>Total</b>                      | <b>8</b>    | <b>11.4</b> | <b>16</b>    | <b>22.9</b> | <b>15</b>          | <b>21.4</b> | <b>7</b>               | <b>10.0</b> | <b>24</b>    | <b>34.3</b> | <b>70</b> | <b>100.0</b> |

Source: Field Data, 2013

From table 9, the main decision most of the respondents took when their sero-positive status was disclosed to them was not to disclose their sero-positive status to anyone. Almost 33% of those who decided not to disclose their status to anyone gave reasons such as to avoid stigma and discrimination and also maltreatment from non-infected people. Some of the respondents after hearing their status also decided to commit suicide or leave everything to God or follow treatment. A UNAIDS (2012) report indicated that 1 out of 5 people felt suicidal in a study conducted in Nigeria and Ethiopia. Some decided to leave everything to God. Those who

wanted to commit suicide outlined that they wanted to avoid any stigma and discrimination, avoid any shame brought by them to their families as well as avoid dying shamefully. For those who left everything to God, the main reasons were to live long and to avoid dying shameful death. Almost 26% of the respondents decided to follow treatment mainly to be able to live for a longer time.

#### 4.2.5 Sexual partner's knowledge about HIV status

The table presents results of whether respondents who were in any sexual relationship had disclosed their status to their partners. This included respondents who were married, cohabiting or single but with sexual partners.

**Table 10: Sexual partner's knowledge about status by marital status**

| Whether partner knows respondent's status | Marital Status |      |                            |     |            |     |       |       |
|---|----------------|------|----------------------------|-----|------------|-----|-------|-------|
|   | Married        |      | Single with sexual partner |     | Cohabiting |     | Total |       |
|   | No.            | %    | No.                        | %   | No.        | %   | No.   | %     |
| Yes                                       | 31             | 68.9 | 0                          | -   | 0          | -   | 31    | 68.9  |
| No  | 10             | 22.2 | 2                          | 4.4 | 2          | 4.4 | 14    | 31.1  |
| <b>Total</b>                              | 41             | 91.1 | 2                          | 4.4 | 2          | 4.4 | 45    | 100.0 |

**Source: Field Data, 2013**

The data shows that close to 70% of those who were married had disclosed their sero-positive status to their partners. None of those cohabiting as well as single but with partners had disclosed their sero-positive status to their partners.

Table 11 is a presentation of data on the reasons why some respondents had not been able to tell their partners about their sero-positive status.

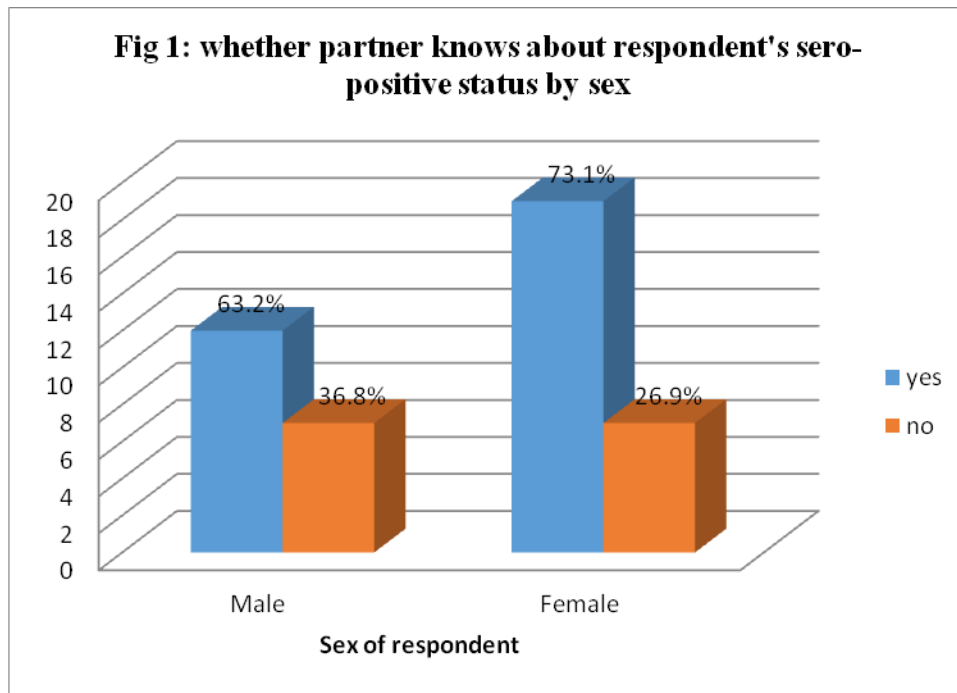
**Table 11: Reason for not telling partner by marital status**

| Reason for not disclosing status to partner | Marital Status |      |                            |      |            |      |       |       |
|---|----------------|------|----------------------------|------|------------|------|-------|-------|
|   | Married        |      | Single with sexual partner |      | Cohabiting |      | Total |       |
|   | No.            | %    | No.                        | %    | No.        | %    | No.   | %     |
| Don't have confidence to tell him/her       | 5              | 35.7 | 0                          | -    | 0          | -    | 5     | 35.7  |
| He/she will desert me                       | 1              | 7.1  | 0                          | -    | 2          | 14.3 | 3     | 21.4  |
| It is not necessary                         | 3              | 21.4 | 1                          | 7.1  | 0          | -    | 4     | 28.6  |
| Other                                       | 1              | 7.1  | 1                          | 7.1  | 0          | -    | 2     | 14.3  |
| <b>Total</b>                                | 10             | 71.4 | 2                          | 14.3 | 2          | 14.3 | 14    | 100.0 |

**Source: Field Data, 2013**

It can be observed from table 11 that lack of confidence (35.7%) was the main reason given by those who were married but had not been able to tell their partners about their sero-positive status. Other reasons the married respondents outlined for their non-disclosure of sero-positive status to partners were that it was not necessary and also that they feared to be deserted by their partners. Fourteen percent of those co-habiting stated that they were afraid to be deserted by partners if their partners should have any knowledge about their sero-positive status. The only reason that was outlined by those single but in sexual relationship was that it was not necessary to disclose their sero-positive status to their partners.

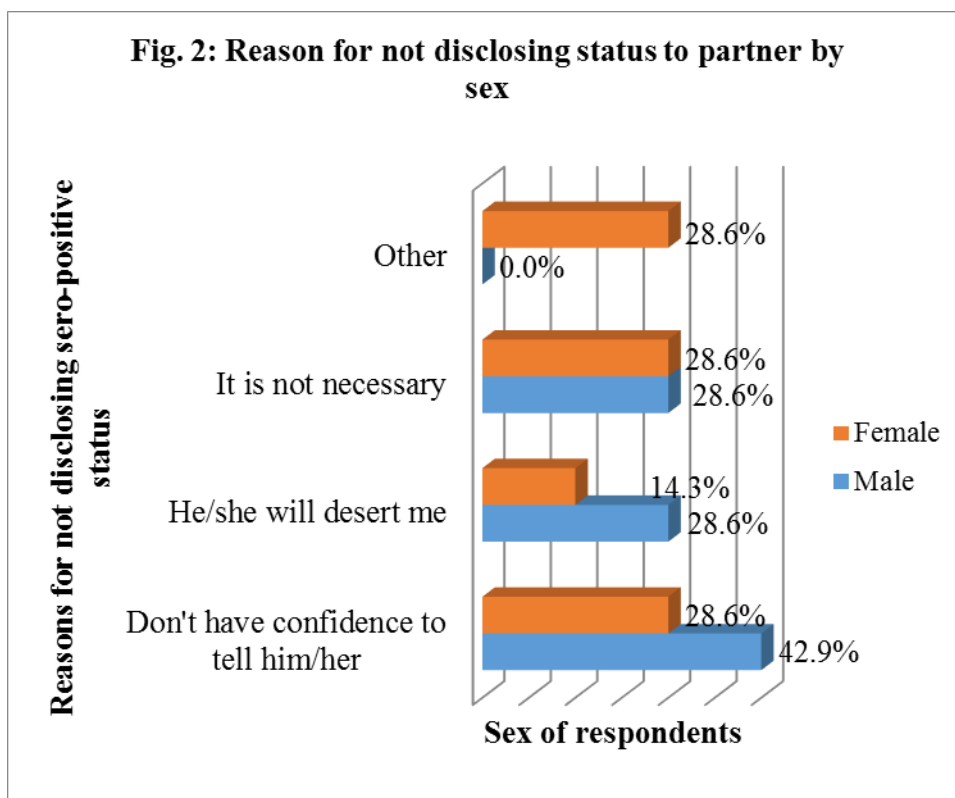
Fig. 1 is a graphical presentation of the male and female respondents in sexual relationship who had informed partners about their sero-positive status.



**Source: Field Data, 2013**

Figure 1 shows that respondents who had disclosed their sero-positive status to partners were more than those who had not done so. Whereas 73% of the females had disclosed their sero-positive status to partners, 63% of the males had also done so. While almost 27% of the females had not disclosed their status to their partners, almost 37% of the males had also not disclosed status to their partners.

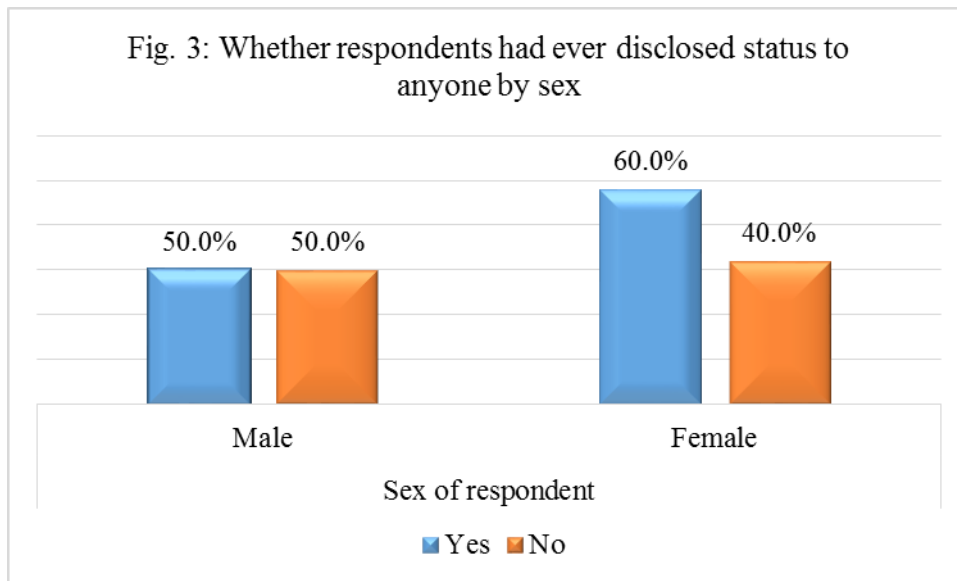
Below is a graph showing the differences between males' and females' reasons for not disclosing status to their partners.



**Source: Field Data, 2013**

From Figure 2, it can be depicted that many of the respondents who had not disclosed their status to their partners was due to lack of confidence. The proportion of males who had not had the confidence to disclose their sero-positive status to their partners was higher (42.9%) than females (28.6%). Among the major reasons given by the respondents were that it was either not necessary to disclose status to partner or their partners will desert them when they get to know they were HIV positive.

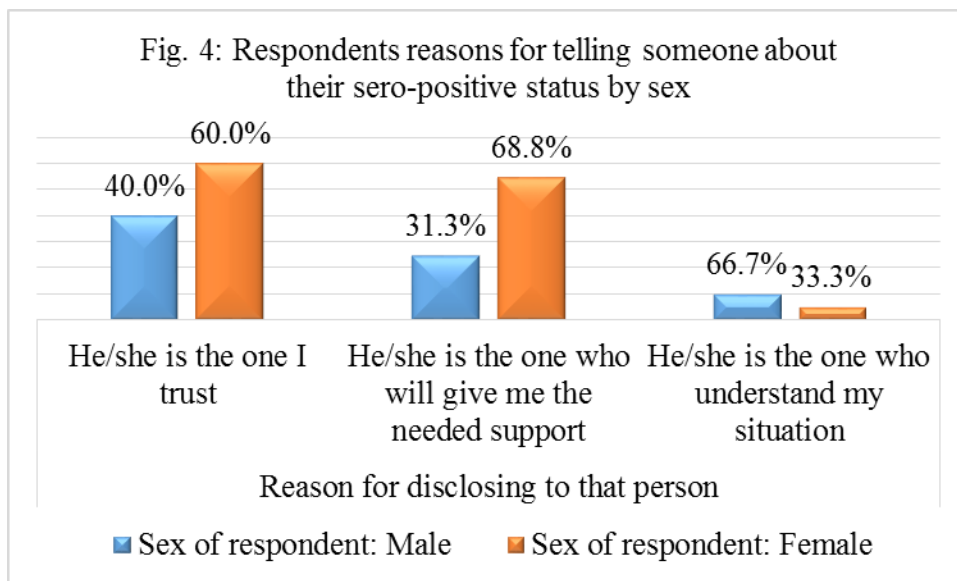
Figure 3 is a graphical presentation of whether all respondents had ever disclosed status to any other person apart from their partners.



Source: Field Data, 2013

It can be noticed from Figure 3 that more than half of the respondents had disclosed their status to other people other than their partners. From the same graph, the number of females who had disclosed their status to other people was higher than that of the males. It is worthy of note that the proportion of males who had disclosed their status to other people was the same as those who had not disclosed their status to other people.

The various reasons outlined by respondents as to why they disclosed their status to other people is represented in figure 4.



**Source: Field Data, 2013**

From the graph, it can be observed that the respondents who had disclosed their status did so to people they trusted. While 60% of females disclosed their status to people they trusted, 40% of the males also did same. However, the proportion of males who had disclosed their status to people who understood their situation was higher than that of the females. Also the need for support was a major reason that informed the choice of whom to disclose status to. The data showed that close to 69% of females compared to 31% of males had disclosed their status to someone they perceived as likely to offer them support.

#### **4.2.6 Relationship between respondents and Confidants**

Table 12 outlines the relationship between people respondents disclosed their sero-positive status to and their reasons for disclosing to those particular people.

**Table 12: Person sero-positive status was disclosed to by reason**

| Relationship between respondent and confidant | Reason for disclosing to that person |      |   |      |   |     |       |       |
|---|--------------------------------------|------|---|------|---|-----|-------|-------|
|   | He/she is the one I trust            |      | He/she is the one who will give me the needed support |      | He/she is the one who understand my situation |     | Total |       |
|   | No.                                  | %    | No.   | %    | No.   | %   | No.   | %     |
| Spouse  | 0                                    | -    | 3   | 7.7  | 0   | -   | 3     | 7.7   |
| Mother  | 7                                    | 17.9 | 5   | 12.8 | 1   | 2.6 | 13    | 33.3  |
| Brother/Sister                                | 4                                    | 10.3 | 4   | 10.3 | 2   | 5.1 | 10    | 25.6  |
| Pastor  | 0                                    | -    | 1   | 2.6  | 0   | -   | 1     | 2.6   |
| Other   | 9                                    | 23.1 | 3   | 7.7  | 0   | -   | 12    | 30.8  |
| <b>Total</b>                                  | 20                                   | 51.3 | 16  | 41.0 | 3   | 7.7 | 39    | 100.0 |

**Source: Field Data, 2013**

Data as presented in Table 12 show that quite a number of respondents who had informed people about their status disclosed largely to their nuclear family. The data show that over 30% disclosed to their mother, close to 26 percent disclosed to a sibling and about 8% to a spouse. The other (30.8%) respondents disclosed their sero-positive status to their children, fathers, uncles, aunties and friends. Almost 67% of the respondents who had disclosed their status to their nuclear family members was mainly because they trusted them or they expected to receive support from them.

A tabular presentation of the results on the reasons why some respondents have kept their sero-positive status to themselves is provided in the next section.

**Table 13: Respondents reasons for remaining silent about their status by sex of respondent**

| Reason                           | Male |       | Female |       | Total |       |
|----------------------------------|------|-------|--------|-------|-------|-------|
|                                  | No.  | %     | No.    | %     | No.   | %     |
| Fear of losing social dignity    | 0    | -     | 2      | 12.5  | 2     | 6.5   |
| Fear of losing close social ties | 3    | 20.0  | 3      | 20.0  | 6     | 19.4  |
| Fear of how people will treat me | 9    | 60.0  | 7      | 43.8  | 16    | 51.6  |
| Fear of being branded as immoral | 0    | -     | 1      | 3.2   | 1     | 3.2   |
| Other                            | 3    | 20.0  | 3      | 18.8  | 6     | 19.4  |
| <b>Total</b>                     | 15   | 100.0 | 16     | 100.0 | 31    | 100.0 |

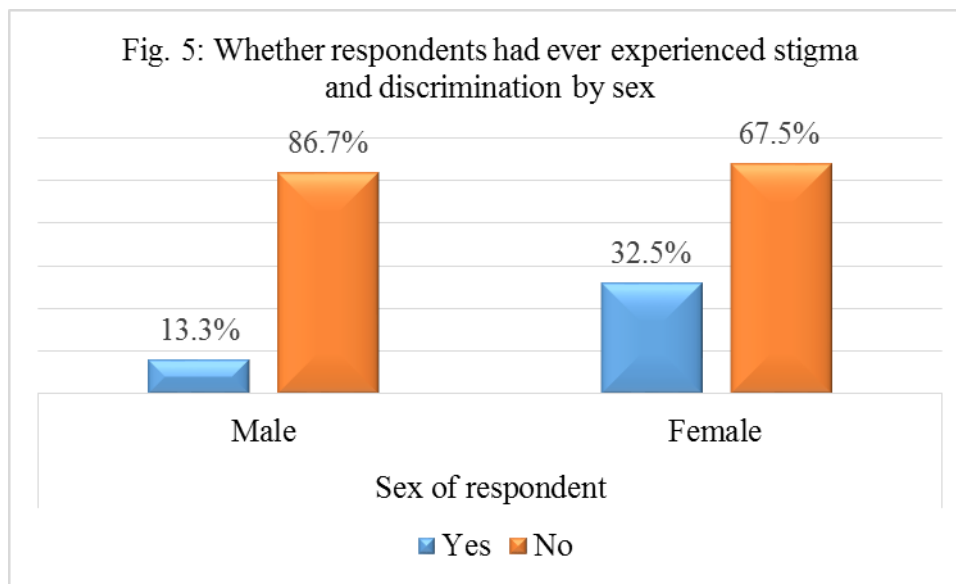
**Source: Field Data, 2013**

More than half of those who had not informed anyone about their status was due to the fear of how people will treat them. Nineteen percent of the respondents had remained silent about their sero-positive status for fear of losing close social ties. For fear of losing social dignity, almost 7% (all females) of the respondents had not disclosed their status to anyone. Three percent of the respondents (again all females) had not gathered the courage to disclose their status to anyone for fear of being branded as immoral. The proportion of males who had not disclosed their status to anyone due to the fear of how people will treat them was higher (60.0%) than the females (43.8%). Whereas about 13% of the females also feared losing their social dignity, none of the males mentioned fear of losing social dignity.

During the FGD with the female group, it was mentioned that due to how people will treat a person with sero-positive status, some would rather keep their status to themselves instead of informing other people about it.

### 4.3 Experience of stigma and discrimination

Almost 76% of the respondents had never experienced stigma and discrimination. Figure 5 shows about 33% of the females had experienced stigma and discrimination as against 13% of the males. The reason for the difference in experience of stigma and discrimination may be that once more of the females had disclosed their status, their experience of stigma and discrimination will definitely be more pronounced than the males.



Source: Field Data, 2013

#### 4.3.1 Forms of stigmatization and discrimination

Per Table 15, the experiences of various stigma and discrimination acts of respondents are presented and discussed.

**Table 14: Respondents' experience of stigmatization and discrimination by sex**

| Respondents experience of stigma and discrimination | Male     |              | Female    |              | Total     |              |
|---|----------|--------------|-----------|--------------|-----------|--------------|
|   | No.      | %            | No.       | %            | No.       | %            |
| People insult me in public                          | 1        | 25.0         | 3         | 23.1         | 4         | 23.5         |
| My business collapsed/was sacked from work          | 0        | -            | 1         | 7.7          | 1         | 5.9          |
| My family never eat or drink from my pot            | 0        | -            | 4         | 30.8         | 4         | 23.5         |
| People ridicule me                                  | 0        | -            | 1         | 7.7          | 1         | 5.9          |
| My husband/wife/family neglected me                 | 2        | 50.0         | 3         | 23.1         | 5         | 29.4         |
| Other   | 1        | 25.0         | 1         | 7.7          | 2         | 11.8         |
| <b>Total</b>  | <b>4</b> | <b>100.0</b> | <b>13</b> | <b>100.0</b> | <b>17</b> | <b>100.0</b> |

**Source: Field Data, 2013**

The data show family neglect as the major ordeal experienced by both males and females. The data indicate that about 31% of the female respondents who had ever experienced stigma and discrimination mentioned their family members never ate or drunk from their pots. The common experience of stigma and discrimination by the male respondents who had ever experienced stigma and discrimination had been neglect by family (50.0%), the same difficulty experienced by 23% of the female respondents who had ever been stigmatized and discriminated. Again, over 20% of both females and the males who had ever experienced stigmatization and discrimination lamented they were insulted in public. Furthermore about 8% of the females suffered loss of job or were ridiculed respectively as a result of stigmatization and discrimination.

Respondents who were insulted in public is a reflection of a study conducted by UNAIDS in 2012 in Zambia. The study revealed that more than 52% of people living with HIV

experienced verbal assault. In 2010, a report by The International Center for Research on Women on Scaling Up the Response to HIV Stigma and Discrimination also mentioned verbal assault as one of the ways PLWHAs experience stigma and discrimination. The International Center for Research on Women's report in 2010 categorized various acts of stigmatization and discrimination attitudes towards PLWHAs as social stigma, physical stigma, verbal stigma and institutional stigma. The report further explained that the social stigma occurred when PLWHAs were excluded from family and community events with its consequent effect on their loss of power and respect in community. In addition to this were physical stigma which took the form of isolation (such as separate sleeping quarters in the home or a separate seating area in places of worship), verbal stigma including insults, taunts, blame, gossip and rumours and institutional stigma which also included job loss due to one's HIV status, eviction from homes, loss of educational opportunities and substandard health care. Based on International Center for Research on Women's categorizations in 2010, the experiences of respondents as revealed in this study can be categorized under such forms as social stigma, institutional stigma and physical stigma.

There were different views on the treatment meted out to persons living with HIV/AIDS in the society during the focus group discussions. Some were of the view that PLWHAs must be treated well because it may be that one may be infected without any fault of his or hers. All the females stated that the time PLWHAs need people most is when they are demoralized due to the sickness and therefore people who are not infected must draw PLWHAs closer and encourage them as well to enable them live long. One of them made a contradictory statement that the name "AIDS" is very scary thereby it is very dangerous to draw such persons closer. One of the females gave a personal encounter with a young lady who tested positive in her house and was maltreated by the parents till she died. She believed the lady rather died out of

trauma and not the disease itself therefore maltreating people even kills them faster than the disease itself.

One of the males indicated in the discussion that maltreating PLWHAs is not an antidote to the cure of the disease, so it is not right for PLWHAs to be maltreated.

The leader of the Precious Women Support Group mentioned in the interview that a young lady with HIV was abandoned in an uncompleted building by the father and she was treated like an animal. The room she was abandoned in had neither doors nor windows and she was bedridden as well. The father treated her that way all because the lady did not listen to his advice and went to Togo, so if she had been infected with HIV/AIDS, she deserved to suffer. The sad aspect of it is that the lady eventually died. This finding confirms de Bryun's study in 1998 as well as Mbonu, Borne and De Vries' study in 2011 which revealed that people thought PLWHAs are responsible for contracting HIV and therefore deserve to be punished.

Most of the female respondents in the focus group discussion indicated they could eat, drink or live in the same house with an HIV positive person. See also Maswanya et al (2000). However, many of the men were not willing to eat from the same plate or drink from the same cup with an HIV infected person. Those who said they could eat together with an HIV person stressed that their ability to do so will depend on the type of food. It was further noted that if they would be eating with spoon they could, but if they should eat with the hand, then it will be difficult for them to do that because they would not know if the person may have a cut on the hand or not.

In Table 16, I present what those who have experienced stigma and discrimination think is the reason for non-infected people's attitudes towards them.

**Table 15: Causes of stigmatization and discrimination by sex**

| Cause of stigma and discrimination | Male |       | Female |       | Total |       |
|------------------------------------|------|-------|--------|-------|-------|-------|
|                                    | No.  | %     | No.    | %     | No.   | %     |
| Promiscuity label                  | 0    | -     | 2      | 15.4  | 2     | 11.8  |
| Infectious disease                 | 2    | 50.0  | 4      | 30.8  | 6     | 35.3  |
| Deadly disease                     | 1    | 25.0  | 3      | 23.1  | 4     | 23.5  |
| Source of shame to the family      | 1    | 25.0  | 2      | 15.4  | 3     | 17.6  |
| Don't know                         | 0    | -     | 2      | 15.4  | 2     | 11.8  |
| <b>Total</b>                       | 4    | 100.0 | 13     | 100.0 | 17    | 100.0 |

**Source: Field Data, 2013**

Respondents who were stigmatized and discriminated in one way or the other attributed the cause to HIV/AIDS being seen by society as infectious disease (35.3%) thereby withdrawing from infected persons to prevent being infected too. Half (50%) and almost 31% of the males and females respectively stated that the stigmatizing and discriminatory attitudes towards them was as a result of the infectious nature of the disease. Over 20 percent of both males and females attributed the cause of such behaviours towards them to the description of the disease as a deadly one. Whereas 25% of the males thought the stigmatizing and discriminating attitudes towards them resulted from the shame being brought by them to their family, 15% of the females also attributed their ordeal to the same cause. It is worthy of note that while 15% of the females attributed the cause to them been seen as promiscuous none of the males attributed the cause to promiscuity.

This seems different from the finding of a UNAIDS (2000) study which revealed that all respondents' attributed the cause of discrimination and stigmatization to immorality.

PLWHAs who attributed the cause of their predicament to the disease been seen by others as deadly and infectious is similar to de Bryun, and Mbonu, Van Den Borne & De Vries' studies in 1998 and 2011 respectively that attributed other causes of HIV/AIDS-related stigma to the

fact that HIV had been described as a life threatening disease, the fact that people fear to contract HIV.

Tables 17 and 18 below show how stigma and discrimination had affected the personal life of those who had experienced it.

**Table 16: Whether stigma and discrimination has affected respondents by sex**

| Whether respondents affected by stigma and discrimination | Sex of respondent |       |        |       |       |       |
|---|-------------------|-------|--------|-------|-------|-------|
|   | Male              |       | Female |       | Total |       |
|   | No.               | %     | No.    | %     | No.   | %     |
| Yes   | 3                 | 75.0  | 11     | 84.6  | 14    | 82.4  |
| No  | 1                 | 25.0  | 2      | 15.4  | 3     | 17.6  |
| <b>Total</b>  | 4                 | 100.0 | 13     | 100.0 | 17    | 100.0 |

**Source: Field Data, 2013**

Stigma and discrimination has had adverse effect on the personal lives of almost all the respondents who had been stigmatized in one way or the other. As shown in Table 17, stigma and discrimination had affected 82.4% of respondents' personal lives. About 85% of the females indicated stigma and discrimination had affected their personal life and 75% of the males also indicated that their personal life had been affected.

**Table 17: How stigma and discrimination has affected respondents by sex**

| How stigma and discrimination have affected personal life | Male |      | Female |      | Total |      |
|---|------|------|--------|------|-------|------|
|   | No.  | %    | No.    | %    | No.   | %    |
| Homeless  | 0    | -    | 1      | 10.0 | 1     | 7.1  |
| Jobless   | 1    | 33.3 | 1      | 10.0 | 2     | 14.3 |
| Excluded from taking part in family decisions             | 1    | 33.3 | 0      | -    | 1     | 7.1  |

|                                    |   |       |    |       |    |       |
|------------------------------------|---|-------|----|-------|----|-------|
| Have developed high blood pressure | 0 | -     | 1  | 10.0  | 1  | 7.1   |
| Have lost close relations          | 1 | 33.3  | 5  | 40.0  | 5  | 35.7  |
| Other                              | 0 | -     | 3  | 30.0  | 3  | 21.4  |
| <b>Total</b>                       | 3 | 100.0 | 10 | 100.0 | 14 | 100.0 |

**Source: Field Data, 2013**

As a result of respondents' sero-positive status, about 36% of them had lost close relations with 40% of females affected as compared to 33% of males. In addition, a third of males who have experienced discrimination and stigma had been affected by exclusion from family decisions or had experienced the effect of loss of job respectively as a result.

The finding that some respondents had been excluded by families from taking part in family decisions is similar to findings of a study by Kafuko (2009) which revealed that some families excluded HIV-positive members from discussions and decision making due to the belief that PLWHAs were incapable of making any important contributions. Those who had been rendered jobless also affirms the result of a focus group discussion conducted in Uganda by Kafuko in 2009 where some PLWHAs mentioned they had lost their jobs as a result of their seropositive status.

It was mentioned by the counsellor during the in-depth interview that a hairdresser's status was disclosed by another health worker to a PLWHA's friend who also spread the news in the community. This resulted in her losing all her customers, and for her to also prove to people that she was uninfected, she defaulted on her medication. Her CD4 as mentioned by the counsellor had reduced drastically the last time she visited the hospital. This finding collaborates Lekganyane and du Plessis report in 2011 which stated that stigma can be felt either anticipated or internal which leads to an unwillingness on the part of diagnosed persons to seek help and to access resources. This hairdresser in question although decided to quit

medication herself, it can be stated that she made that decision as a result of the betrayed attitude of this health worker towards her.

#### **4.4 Mechanisms adopted by respondents to cope with stigmatization and discrimination**

In order for respondents to have a normal lifestyle, they had adopted various strategies to enable them do so. This section looks at the coping mechanisms respondents resort to. It further discusses the causes of stigma and discrimination from the perspective of all the respondents, and how stigma and discrimination can be eliminated

##### **4.4.1 Coping mechanisms**

The main coping mechanism adopted by respondents was to remain silent or did not want to do further disclosure (81.4%). For those who had ever experienced stigma and discrimination, 35% had decided to be silent about their status and did not want to do further disclosure due to their experiences. For those who had not experienced any discrimination and stigma yet presumably because they had not disclosed their status, 96% had decided to remain silent for the rest of their life in order to live their normal life in society. Furthermore, for those who had experienced some stigmatization and discrimination, more than a quarter had decided to isolate themselves from public gathering to guard against any embarrassment in public, and close to 12% had changed their place of residence or do not care about what people may say.

**Table 18: Respondents coping strategies by whether stigma had been experienced**

| Coping Strategy   | Whether respondent has experienced stigma and discrimination |       |     |       |       |       |
|---|--|-------|-----|-------|-------|-------|
|   | Yes  |       | No  |       | Total |       |
|   | No.  | %     | No. | %     | No.   | %     |
| Remain silent and don't want to do further disclosure about my status | 6  | 35.3  | 51  | 96.2  | 57    | 81.4  |
| Isolate myself from public  | 5  | 29.4  | 0   | -     | 5     | 7.1   |
| Change place of residence   | 2  | 11.8  | 0   | -     | 2     | 2.9   |
| Close ears to what people say   | 2  | 11.8  | 2   | 3.8   | 4     | 5.7   |
| Other   | 2  | 11.8  | 0   | -     | 2     | 2.9   |
| <b>Total</b>  | 17   | 100.0 | 53  | 100.0 | 70    | 100.0 |

**Source: Field Data, 2013**

The coping mechanisms respondents adopted such as remaining silent about one's status and isolation from public gathering revealed in the study were also found by Kafuko (2009) who mentioned that some PLWHAs in Uganda kept quiet about their status while others kept away from public as a way of coping with stigma and discrimination. Respondents who changed their place of residence is similar to a finding in a study by Barkey (2010) in Ghana that in order for some PLWHAs to cope with stigma and discrimination, they relocated to new places.

As shown in Table 20, 30% of the respondents attributed the cause of stigmatization and discrimination in society to the disease being seen by many as a deadly one. The data indicate that the proportion of females was the same as that of the males. Almost 23% and 7% of the females and males respectively attributed the cause to negative media publications. Twenty percent of both males and females attributed the cause to the disease being seen as infectious and 8% attributed it to inadequate information on the disease.

**Table 19: Views on causes of stigmatization and discrimination by sex**

| Causes of stigma and discrimination     | Male      |              | Female    |              | Total     |              |
|---|-----------|--------------|-----------|--------------|-----------|--------------|
|   | No.       | %            | No.       | %            | No.       | %            |
| Negative Media Publications             | 2         | 6.7          | 9         | 22.5         | 11        | 15.7         |
| Deadly disease                          | 9         | 30.0         | 12        | 30.0         | 21        | 30.0         |
| Infectious disease                      | 7         | 23.3         | 7         | 17.5         | 14        | 20.0         |
| Immorality attached to infected persons | 2         | 6.7          | 3         | 7.5          | 5         | 7.1          |
| Physical appearance                     | 0         | -            | 1         | 2.5          | 1         | 1.4          |
| Inadequate information on the disease   | 3         | 10.0         | 3         | 7.5          | 6         | 8.6          |
| Don't know                              | 7         | 23.3         | 5         | 12.5         | 12        | 17.1         |
| <b>Total</b>                            | <b>30</b> | <b>100.0</b> | <b>40</b> | <b>100.0</b> | <b>70</b> | <b>100.0</b> |

**Source: Field Data, 2013**

According to the leader of the Ultimate Life Foundation in an in-depth interview, as a result of PLWHAs physical appearance, they stigmatize themselves which gives other people the opportunity to do same.

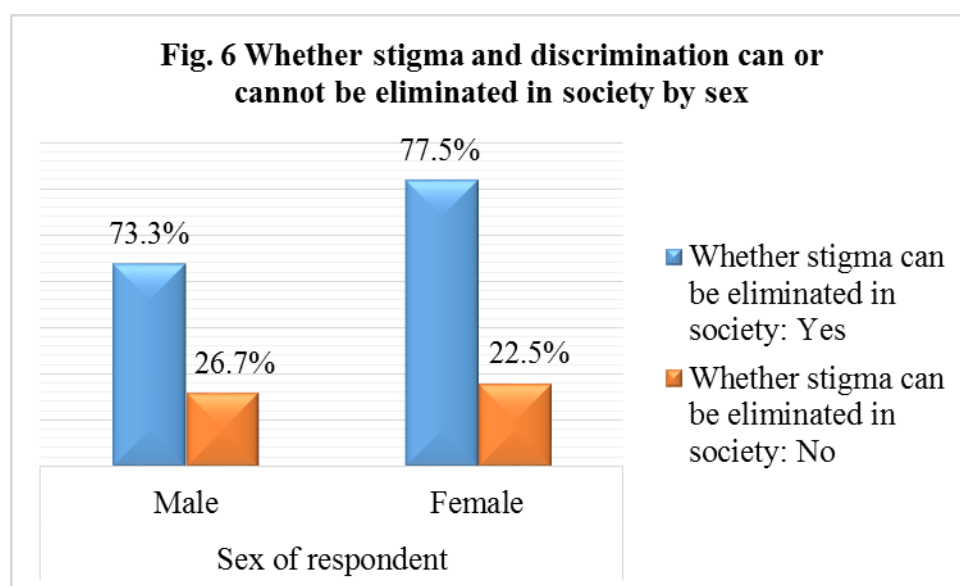
“HIV is infectious which makes me fearful to associate myself with a person living with the disease, withdrawing from them is the best option” a man’s answer to why people stigmatize and discriminate against PLWHAs during the focus group discussion. This collaborates what Appiah, Afrane and Price (2002) mentioned in their study that some community members believed PLWHAs are to be feared.

One of the male participants in the focus group discussion said due to how HIV is described as infectious and dangerous, he sees someone with HIV as a “bad” person.

#### 4.4.2 Elimination of stigmatization and discrimination

Figure 6 shows that on the average, 75% of the PLWHAs respondents believed stigma and discrimination can be eliminated in society. The proportion of females in the total female respondents who believed so were almost 78%, whereas that of the males was 73%.

During the focus group discussion, some people mentioned that stigma and discrimination can never be eliminated as a result of how HIV has been described and communicated to the public as incurable and deadly.



**Source: Field data, 2013**

Table 20 indicates that 80% of the respondents suggested education on stigma and discrimination must be effective through the media, mini durbars and various social gatherings in order to reduce if not eliminate stigma and discrimination from society. Ten percent also suggested persons living with HIV/AIDS must be encouraged to go for their drugs to enable them live long and a normal lifestyle in society. It is only when PLWHAs take their drugs that people will believe the ARTs work effectively therefore, the rate at which stigma and discrimination persist in the community will be minimized.

**Table 20: Respondents' suggestions on elimination of stigma and discrimination**

| <b>Suggestions</b>   | <b>Frequency</b> | <b>Percent</b> |
|--|------------------|----------------|
| Adverts on media must be stopped                                 | 1                | 1.4            |
| Media should reverse previous adverts                            | 3                | 4.3            |
| People who stigmatize must be punished                           | 3                | 4.3            |
| Education on stigma and discrimination must be effective         | 56               | 80.0           |
| Persons living with HIV must be encouraged to go for their drugs | 7                | 10.0           |
| <b>Total</b>   | <b>70</b>        | <b>100.0</b>   |

**Source: Field Data, 2013**

Four percent of the respondents also suggested the media must reverse previous adverts portraying HIV/AIDS as a deadly disease without drugs.

It was further suggested by 4% of the respondents that people who stigmatize PLWHAs must be punished.

## CHAPTER FIVE

### SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATION

#### 5.0 Introduction

This chapter presents the main findings of the study. The study broadly sought to examine the level and pattern of stigmatization and discrimination of people living with HIV/AIDS and its implication for prevention and spread. The Nsawam/Adoagyiri municipality was used as a case study. It specifically assessed the reaction of people with the disease upon being informed of their positive status and the reasons for reacting as such as well as the mechanisms adopted by PLWHAs in Nsawam/Adoagyiri to cope with stigma and discrimination and have a normal life in the community. The forms, causes and the effects of stigmatization and discrimination on the lives of persons living with HIV/AIDS as well as community members' perceptions of people living with HIV/AIDS were also examined.

The study interviewed 70 people living with HIV/AIDS. Three in-depth interviews, two of which were with PL support groups and a counselor were also conducted to serve as supplementary information. Two separate focus group discussions with community members comprising ten (10) males and ten (10) females were also organized.

#### 5.1 Summary of Findings

The finding from the study showed that the severely affected age group of people living with HIV/AIDS in Nsawam/Adoagyiri municipality were between the ages of 40 and 44 years but the proportion of the males was higher than the females. Besides the 40 to 44 years old, the proportion of females was higher than the males among all the age groups. The least affected age group was the 20 to 24 years, but none of the males was affected in this age group. The

proportion of respondents who were married was higher than those who were single, cohabiting, divorced or widowed. On the average, respondents' educational level was relatively low as most of them had either primary education or Junior High or Middle School education. Low income occupations such as trading and farming was the main occupation of the PLWHAs respondents. Some of the PLWHAs respondents were either unemployed or engaged in other activities. Also many of them had lived with the disease for less than a year or two to three years. A few of them too had lived with the disease for more than five years.

The main mode of HIV/AIDS contraction was through sexual intercourse, even though some also stated that they did not know how they got infected. This can be seen in the conceptual framework in Chapter 2. Upon hearing their status for the first time, they were shocked, sad or doubtful. Although the proportion of males who were shocked or doubtful was higher than the females, more of the females were sad than the males. The findings further showed that PLWHAs themselves had certain perception about the disease. Their reason for being sad was due to the fear of death and also they never flirted around. Those who were shocked or doubtful did so because they thought they were not flirting. The perception PLWHAs themselves had about HIV/AIDS stresses the misconceptions people have about HIV/AIDS as described in the conceptual framework.

Most of the respondents after hearing their status decided not to talk to anyone about it to avoid maltreatment. A sizeable number also decided to follow treatment in order to live long. Others decided to commit suicide or leave everything to God. Those who wanted to commit suicide stated that they wanted to either avoid any stigma and discrimination from people or to avoid dying shamefully. Those who left everything to God outlined that they wanted to avoid dying shamefully or wanted to live long

More than half of both males and females had been able to inform their partners about their status but the proportion of females who had informed their partners of their sero-positive status was higher than that of males. Only married people had been able to inform their partners. Those who were co-habiting or single but in a relationship had not informed their partners about their status. The major reasons given by those who had not informed their partners were that they did not have the courage to do that or that they feared they might be deserted by their partners. Also, more than half of the people living with the disease had been able to disclose their status to other people other than their partners, but the proportion of females was greater than the males. The respondents who had disclosed their status disclosed to their mothers or brothers/sisters because they trusted them and again due to the needed support they anticipated to receive from them. But for those who had not told anyone, they explained they feared people would treat them badly after getting to know their status. Others also noted that they might lose their close friends and their dignity they had in their communities and could even be branded as immoral. This result affirms various reasons for concealment of sero-positive status as mentioned in the conceptual framework.

Again, 20% reported that people have gotten to know their status in their respective communities after disclosing their status to their confidants. People's knowledge of their status came about because of their physical appearance and their frequent admission at the hospital. For one of the respondents, it was the mother who informed the people.

Only 24.3% of them had experienced stigmatization and discrimination as a result of their status. Majority of them had never been stigmatized and the proportion of females who had ever experienced stigma and discrimination was higher than males. These stigmatization and discrimination mostly took the form of verbal assault, social stigma (such as family members refusing to share food, drink or have any relation with the person, marriage break down) and job loss. The causes given by those who had been stigmatized and discriminated against were

that people believed the disease is infectious and deadly. Others were also discriminated because they had brought shame to the family as people perceive the disease as resulting from promiscuous lifestyle.

The respondents who had experienced stigma and discrimination noted that the stigma and discriminating attitudes of people had affected their lives as it has rendered some jobless, homeless and even banned them from taking part in family decision making.

The study also showed that those who had ever disclosed their status to other people wanted to be henceforth silent about it and not disclose it any further. This is because, after disclosing their status, they have been stigmatized in various ways and this had affected their lives. Others did not mind what people said about them, isolated themselves from public gathering or changed place of residence to help them cope with the situation. On the other hand, majority of those who had not disclosed their status wanted to remain silent about it forever due to the experiences of other PLWHAs who had disclosed their sero-positive status.

Generally, the respondents listed some of the possible causes of stigmatization and discrimination as it being perceived as a deadly and infectious disease and negative media reporting on the disease. The inadequate information on the disease was also cited as one of the causes of stigmatization likewise the immorality attached to people who get the disease. The physical appearance of people was also seen as fostering stigmatization and discrimination.

People Living with HIV/AIDS respondents noted that stigmatization can be eliminated while a few believed it cannot be eliminated. Those who believed stigmatization can be avoided suggested the need to intensify education on the disease and the implications of stigmatizing and discriminating against people living with HIV/AIDS.

Those who believed it cannot be eliminated, explained that the level of education among the general Ghanaian population is low and the fact that the disease is incurable makes it difficult to stop the stigmatization associated with it. Also, a few noted that some earlier public awareness campaigns in the media which described the disease as dangerous and deadly without a cure hence, people have to be careful not to contract it will make it difficult for stigma and discrimination to be eliminated.

As a way of solving the problem with stigmatization, majority of them suggested that there should be intensive public education on stigmatization and discrimination. Others also believed that people living with the disease should be encouraged to take their drugs for people to know that although there is no cure for it, there is a treatment for it. Others also believed that those who stigmatize others must be punished and for the media, they were also advised to change their adverts and advertise on how to stop stigmatization and discrimination.

Community members were against treatment meted out to PLWHAs and emphasized the need for society to get closer to them. An interesting revelation during the discussion was that although most of them were not in support of the treatment meted on them, some were not willing to eat or drink from the same plate or cup with an HIV infected person.

PLWHAs were perceived as prostitutes, people who were waiting to die and also people with no future. Among some of the causes of discrimination and stigmatization mentioned were the disease being seen as infectious, incurable, dangerous and deadly and therefore they needed to withdraw from infected persons to prevent infection.

## **5.2 Conclusion**

This study recognized that after all the efforts and resources invested by the government, NGOs and various stakeholders in educating and sensitizing the general public about HIV/AIDS and the need to support PLWHAs, they continue to face various forms of stigmatization and discrimination. The stigmatization and discrimination affected their lives and even affected their social status in society. Stigmatization and discrimination mostly took the forms of verbal assault, social stigma (such as family members refusing to share food, drink or have any relation with the person, marriage break down) and job loss. People perception about the disease as being infectious and deadly were considered the main causes of the stigmatization and discrimination in the Nsawam/Adoagyiri municipality. Although some of the respondents had disclosed their status to someone, for fear of anticipated maltreatment from both close relatives and people in the community in general, some people as well as even married people had decided to remain silent about their status. This silence, to some extent, perpetuates spread of the disease since infected persons will behave as if everything is alright with them. The fear of dying, coupled with the fear of denial and being branded as immoral drove people to take all forms of decision among which were to isolate themselves and commit suicide. The study therefore concluded that initiatives directed at addressing these causes will impact positively on reducing the level of stigmatization and discrimination against people living with HIV/AIDS.

## **5.3 Recommendations**

Based on the findings of the study, the following recommendations are put forward.

The findings from the study have proved that stigmatization and discrimination of people living with HIV/AIDS stem from the perceptions people have about the disease. From this premise, the study recommends an increase in the level of public education and sensitization

on the need for society to embrace PLWHAs instead of ignoring them. It is therefore necessary for the National Commission for Civic Education, media and stakeholders in the Nsawam/Adoagyiri municipality and the nation as a whole to offer periodic and regular education to the general public on the adverse effect of stigmatizing and discriminating against PLWHAs. As presented in the conceptual framework, if nothing is done about HIV-related stigma and discrimination, HIV/AIDS will continue to spread in the society.

It was also noted from the study that many of the married or cohabiting PLWHAs had not been able to disclose their status to their spouse. This tends to intensify the spread of the disease. Based on this, the study recommends to counsellors and health practitioners to encourage their clients to inform their spouses about their status. They mentioned that their spouse might abandon them. Organizing special workshops for people with partners to explain the need to embrace their partners will go a long way to help reduce the spread of the disease.

Knowing that HIV/AIDS is infectious and incurable, people are afraid to know their status. The study therefore recommends for the collaboration of the government, NGOs, stakeholders, religious and traditional leaders, opinion leaders, media and the general public to increase the awareness creation on the need for people to know their status.

The study also recommends to the Ministry of Health to increase the screening of people for the disease. A campaign must be launched aiming at screening at least three quarters of the general public within a stipulated period of time. This also means the collaboration of the government to raise funds to support the MOH to take this action.

Although stigma and discrimination occurs at societal level, it begins from the family level which is the first contact of socialization for every member. As revealed in the study, most of the respondents experienced stigma and discrimination in their own families. It will be

beneficial to the entire society if special education and programmes on the need for persons with HIV to be accepted and treated as any other member of the family. If properly done, it will go a long way to help reduce stigma and discrimination which will eventually help in curbing the spread of the disease. In solving any menace, tackling it from the root is the best option therefore tackling stigma and discrimination at the family level will eventually lead to its reduction at the societal level and eventually national level.

Both print and electronic media must educate the general public on the existence of anti-stigma and discrimination laws which most people are not aware of.

Also, HIV must not be communicated as a deadly disease due the availability of ART drugs which enable PLWHAs to live normal lives as non-infected persons do. The media must stress the implications of stigma and discrimination in the society.

It is further recommended that education on the mode of transmission be intensified. It was revealed in the study that those who were shocked, doubtful or sad upon hearing of their sero-positive status did so because they thought they were not flirting. Intensifying education on other modes of transmission will let people know that it does not take flirting alone to get infected. The disease must be communicated to the general public as a normal sickness which can infect anyone and not only promiscuous persons.

Non-governmental organizations and PL support groups working in the municipality should organize programmes that will empower PLWHAs to be able to accept their status. These programmes can be in the form of drama for PLWHAs themselves to see the need to accept their status. The success of such programmes will reduce self-stigma.

Finally, there must be effective laws that will punish people who stigmatize and discriminate PLWHAs at both local and national levels. In this case, stigmatization and discrimination

must be treated as criminal offence in the society. By way of doing so, people will feel protected to disclose their status when there is the need for it because they will know they are protected under statutory laws therefore no one can stigmatize or discriminate against them.

When this is done, continuous spread of the disease will reduce.

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- a. Blood transfusion [ ]      b. Sex [ ]      c. don't know [ ]      d. Other (Specify) .....
8. How did you react upon hearing your status for the first time?  
 b. Sad [ ]      b. Angry [ ]      c. Shocked [ ]      d. Doubtful [ ]      e. Other (Specify) .....
- B. Why did you react in such a way or manner?  
 a. Fear of denial [ ]      b. fear of dying [ ]      c. fear to be blamed [ ]  
 d. fear of isolation [ ]      e. Other (Specify) .....
9. What was the decision you made upon hearing your status for the first time?  
 a. Commit suicide [ ]      b. Not disclose to anyone [ ]      c. infect other people [ ]  
 d. Other (Specify) .....
- B. Why did you make such decision?  
 a. To avoid shame brought to my family [ ]  
 b. To avoid stigma and discrimination [ ]  
 c. To avoid maltreatment from people [ ]  
 d. Other (Specify) .....
10. Are you in any sexual relationship?      a. Yes [ ]      b. No [ ]  
 B. If yes, does your partner know of your status?      a. Yes [ ]      b. No [ ]  
 C. If no, why have you not disclosed to him/her?  
 a. I don't have the confidence to tell him/her [ ]  
 b. He/she will desert me [ ]  
 c. He/she will maltreat me [ ]  
 d. He/she will disrespect me [ ]  
 e. Other (Specify) .....
11. If you are not in a relationship, do you intend entering into one?      a. Yes [ ]  
 b. No [ ]  
 A. If yes, do you intend disclosing your status to your partner?      a. Yes [ ]  
 b. No [ ]  
 B. If no, why?  
 a. I want to plan when and how to disclose to him/her [ ]  
 b. He/she will not accept my proposal [ ]  
 c. He/she will tell other people [ ]  
 d. He/she will verbally abuse me [ ]  
 e. Other (Specify) .....
12. Have you disclosed your status to anyone?      a. Yes [ ]      b. No [ ]  
 B. If yes, what is the relationship between you and that person?

- a. Spouse [ ]      b. Mother [ ]      c. Brother/Sister [ ]      d.  
 Pastor [ ]  
 e. Other (Specify) .....
- C. Why did you disclose to that person?  
 a. He/she is the one I trust [ ]  
 b. He/she is the one who will give me the needed support [ ]  
 c. He/she is the one who will sympathize me [ ]  
 d. He/she is the one who will understand my situation [ ]  
 e. Other (Specify) .....
- D. If no, why? Please give reasons  
 a. Fear of losing social dignity [ ]  
 b. Fear of losing close social ties [ ]  
 c. Fear of how people will treat me [ ]  
 d. Fear of being branded as immoral [ ]  
 e. Other (Specify) .....
13. Do you think people are aware of your status?    a. Yes [ ]      b. No [ ]
14. If yes, how do you think people got to know about your status?  
 a. My mother informed them [ ]  
 b. From my physical appearance [ ]  
 c. Through my frequent admission at hospital [ ]  
 d. Through the treatment given to me by my family [ ]  
 e. Other (Specify) .....

## SECTION C

### EXPERIENCE OF STIGMA AND DISCRIMINATION AND ITS FORMS (FOR THOSE WHOSE STATUS IS KNOWN TO OTHERS)

15. Have you in any way been stigmatized and/or discriminated against by virtue of your HIV/AIDS status?    a. Yes [ ]      b. No [ ]  
 i. If yes, kindly share with me some of your experiences  
 1. ....  
 2. ....  
 3. ....  
 4. ....  
 5. ....
16. What do you think is the cause for this behavior towards you?  
 .....

17. Have you in anyway been affected by stigma and discrimination due to your HIV/AIDS status? a. Yes [ ] b. No [ ]

B. If yes, how has this affected your Personal life?

- a. Am homeless [ ]
- b. Am out of school [ ]
- c. Am jobless [ ]
- d. Am banned from taking part in family meetings [ ]
- e. Have stopped going to church [ ]
- f. Other (Specify) .....

18. Have any of your family members experienced stigma and discrimination as a result of your status? a. Yes [ ] b. No [ ]

A. If yes, in what specific ways?

- a. They are humiliated in public [ ]
- b. They are verbally assaulted [ ]
- c. They are physically assaulted [ ]
- d. They are labeled as promiscuous [ ]
- e. Other (Specify) .....

B. In what ways have these affected you and your family members?

- a. They are ridiculed in public [ ]
- b. They are blamed for immoral behavior [ ]
- c. They are banned from taking part in community discussions [ ]
- d. Have been sacked from church [ ]
- e. Other (Specify) .....

## SECTION D

### MECHANISMS ADOPTED BY PLWHAs TO COPE WITH STIGMATIZATION AND DISCRIMINATION (FOR THOSE WHOSE STATUS IS KNOWN TO OTHERS)

19. As a person living with HIV/AIDS, how do you cope with problems of stigma and discrimination?

- a. Remain silent about my status [ ]
- b. Isolate myself from public gathering [ ]
- c. Change place of residence [ ]
- d. Other (Specify) .....

**FOR THOSE WHOSE STATUS IS NOT KNOWN TO OTHERS**

- 18a. Do you intend to let anyone know of your status at some point? A. Yes [ ]  
 b. No [ ]

18b. At what point will that be?  
 .....

20. Whom would you like to disclose your status to? a. My Mother [ ] b.  
 Pastor [ ]  
 c. A friend [ ] d. My partner [ ] e. Other (Specify)  
 .....

19a. Why those persons? Please give reasons

- a. He/she is the one I can easily confide in [ ]  
 b. He/she is the one who will support me both emotionally and physically [ ]  
 c. He/she is the one who will sympathize me [ ]  
 d. He/she is the one who will understand my situation [ ]  
 e. Other (Specify) .....

**SECTION E****VIEWS ON THE EFFECTS OF STIGMATIZATION AND DISCRIMINATION OF PLWHAs FOR SPREAD AND PREVENTION**

20. Do you agree with the statement that stigma and discrimination of PLWHAs can be an obstacle to prevention and spread of the disease? 1. Yes [ ] 2. No [ ]

B. Can you tell me some of the causes of stigmatization and discrimination of PLWHAs in the society?  
 .....

C. Please if you agree to this statement, can you kindly tell me some of the ways and processes through which this can perpetuate spread of the disease?  
 .....

C. Do you think HIV related stigma and discrimination can be eliminated in society?

- a. Yes [ ]                      No [ ]

Please give reasons

.....  
.....  
.....  
.....

D. What suggestions do you have on how stigma and discrimination can be reduced or eliminated in our society?

1. ....
2. ....
3. ....
4. ....

*Thank you very much for your time and contribution*

## Appendix 2

### INTERVIEW GUIDE FOR COMMUNITY MEMBERS

I am Patience Akomah, a Master of Arts student of ISSER, Legon, conducting a research on “stigmatization and discrimination of people living with HIV/AIDS and its implications for prevention and spread. The study is purely for academic purpose, therefore information and identity of respondents will be treated as confidential if respondents consent is given.

Date: .....

#### PERCEPTIONS ABOUT HIV/AIDS

1. Have you heard about HIV/AIDS?
2. Can you tell me any means through which HIV is transmitted?
  - a. Through handshaking with an infected person [ ]
  - b. Eating from the same plate with an infected person [ ]
  - c. Through unprotected sexual intercourse with an infected person [ ]
  - d. Through breastfeeding [ ]
  - e. Through curse [ ]
  - f. Sleeping on the same bed with an infected person [ ]
  - g. Mosquito bite [ ]
  - h. Touching an infected person [ ]
  - i. Other (specify) .....
3. Have you seen a person living with HIV before?
  - i. How did you know the person is HIV positive?
  - ii. What is your impression about a person who has the disease?

#### AWARENESS ON STIGMA AND DISCRIMINATION

4. Can HIV related stigma and discrimination prevent people from testing and disclosing and why?
5. If your partner happens to be HIV positive but refuses to tell you but later found out that he/she infected you, what will you do? Please give reason(s)
  - i. Why would you take such an action?
6. In case you are tested for HIV positive, would you disclose to someone?

- I. If yes, whom would you disclose to and why?
- II. If no, why would you do so?
7. What is your view on PLWHA being stigmatized and maltreated due to their HIV status?
8. Why do you think people stigmatize and discriminate against PLWHAs?
9. Would you drink/eat from the same cup/plate with an HIV positive person?
- 9B. If no, why?
10. How would you treat a friend/ relative who is HIV positive?
11. Would you like people to treat you the same way in case you are HIV positive?
12. What do you think can be done to address stigmatization and discrimination of PLWHAs in our society?

*Thank you very much for your time and contribution*

### Appendix 3

#### INTERVIEW FOR HEALTH WORKERS/COUNSELLORS

I am Patience Akomah, a Master of Arts student of ISSER, Legon, conducting a research on “stigmatization and discrimination of people living with HIV/AIDS and its implications for prevention and spread. The study is purely for academic purpose, therefore information and identity of respondents will be treated as confidential if respondents consent is given.

Date: .....

Position of respondent:.....

#### SECTION A

1. Have you recorded any reported case of stigma and discrimination of PLWHA?
  - b. If yes, tell me about them
2. Why do you think PLWHA experience stigmatization and discrimination?

#### SECTION B

#### EFFECTS OF STIGMA AND DISCRIMINATION ON SPREAD AND PREVENTION

3. As an HIV/AIDS health worker, have you experienced any form of stigma and discrimination yourself?
  - i. Please tell me about your experiences
4. What are the implications of stigmatizing and discriminating against PLWHAs?
5. What have been some of the consequences of stigmatization and discrimination of PLWHAs?
6. Do you have special support for PLWHAs when they face discrimination and stigmatization?
  - a. If yes, can you tell me what support systems you have?
7. How can HIV related stigma be eliminated in the society?
8. What can PLWHAs who suffer stigmatization and discrimination do to cope with the situation?

**Appendix 4****INTERVIEW GUIDE FOR NGOS AND HIV SUPPORT GROUPS**

I am Patience Akomah, a Master of Arts student of ISSER, Legon, conducting a research on “stigmatization and discrimination of people living with HIV/AIDS and its implications for prevention and spread. The study is purely for academic purpose, therefore information and identity of respondents will be treated as confidential if respondent’s consent is given.

Date: .....

1. Job title of interviewee: .....
2. What is the name of your organization?
3. For how long have you been operating in this municipality?

**PROGRAMMES ON HIV/AIDS**

4. Do you embark on HIV/AIDS related work in the community?
  - a. Can you give me some of the activities you have embarked on since your establishment in the community?

**MEASURES ADOPTED BY ORGANIZATIONS IN FIGHTING STIGMA AND DISCRIMINATION**

5. Have you had any reported cases of any of stigmatizing or discriminating against in the society?
6. What form did it take?  
.....
7. What support was offered?  
.....
8. What do you think is the cause of stigma and discrimination towards PLWHAs?
9. Do you agree to the statement that stigmatization and discrimination can lead to non-disclosure of one’s status?
  1. Strongly agree
  2. Agree
  3. Don’t agree
- 9a. If you agree, why?
10. Do you agree that non-disclosure perpetuates spread of the disease?
  1. Strongly agree

2. Agree
3. Don't agree
4. Don't know

11a. If you agree, how would this perpetuate spread?

11. As an organization, do you have any programmes through which people are educated on the dangers of stigmatizing and discriminating against PLWHAs in the community?

i. If yes, kindly give me some of these programmes

12. As an organization, what are some of the measures you have adopted to mitigate stigma and discrimination in the society to achieve an HIV free generation in the near future?

*Thank you very much for your time and contribution*