

**HIV-RELATED STIGMA, DISCRIMINATION AND COPING  
STRATEGIES AMONG PEOPLE LIVING WITH HIV/AIDS RECEIVING  
TREATMENT AT THE UNIVERSITY COLLEGE HOSPITAL, IBADAN,  
NIGERIA**

**BY**

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## **DEDICATION**

This research work is dedicated to the Almighty God who paved the way for me to work among people living with HIV and AIDS. These individuals who, are infected and affected will have to live and cope with the associated but unwarranted stigma. May God grant them the will power to cope successfully with the condition.

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## ABSTRACT

Stigma complicates the prevention and control of HIV worldwide as it adversely affects the care seeking practices among People Living With HIV/AIDS (PLWHA). In Nigeria HIV stigma-related practices experienced by PLWHA have not been adequately investigated. This study therefore focused on HIV-related stigma, discrimination and coping mechanisms among PLWHA receiving treatment at the University College Hospital (UCH), Ibadan, Nigeria.

The study was a cross-sectional survey. Systematic random sampling technique was used to select 700 consenting clients at President Emergency Plan for AIDS Relief clinic UCH. A semi-structured questionnaire which included questions on stigma-related and discriminatory experiences, perceived consequences and coping strategies was used for data collection. In-depth Interviews (IDI), were conducted among eight consenting respondents who had experienced serious HIV-related stigma and discrimination such as loss of job, divorce and marital separation. Quantitative data were analyzed using descriptive statistics and Chi-square test. Qualitative data were analysed using thematic approach.

Respondents' mean age was  $40.0 \pm 9.4$  years, 60.8% were married, 67.7% were females, and 56.2% were traders. Majority (78.1%) had ever experienced self-stigmatization as a result of their HIV sero-positive status with 27.0% experiencing it within the three months preceding the study. A major indicator of self-stigmatization was the unwillingness to disclose HIV sero-positive status to family members (53.7%) and to friends (69.3%). Significantly more females (56.3%) than males (48.7%) were scared of disclosing their HIV positive status to family members ( $p < 0.05$ ). Nearly a third of respondents (30.3%) had ever experienced stigmatization from other people. Stigmatization experienced by PLWHA included treatment with disdain (67.0%) and restriction of social interaction (65.9%). Few (5.1%) respondents experienced at least one form of discrimination in the three months preceding the study. The experienced discriminatory acts included rejection by friends (1.3%), avoidance (1.7%), isolation (1.1%), gossips by members of the community (0.6%), loss of job (1.3%) and disclosure of status to others by health workers without permission (4.0%).

The perceived consequences of HIV-related stigma included sadness (68.0%), divorce (61.3%) and social isolation (58.9%). The coping strategies adopted by respondents included being unperturbed (53.7%), praying (45.9%) and ignoring acts of stigmatization (40.0%). Only 27.7% of respondents enrolled with a social support group for PLWHA. The most common benefits of being a member of a support group included sharing of discriminatory experiences (29.8%), counselling services (29.8%), sharing of condom (22.0%), other material support (18.4%) and acquisition of entrepreneurial skills (1.2%). Verbal assault was a key concern among majority of Indepth Interviewees. In addition, marital instability was disclosed to be a major social consequence of HIV among married persons.

Stigmatization and discrimination constitute major challenges among the People Living With HIV and AIDS. Psychotherapy, advocacy and public enlightenment are needed to address the problems.

**Keywords:** People Living With HIV, Stigma, HIV-related discrimination, Coping strategies  
**Word count: 445**

## CERTIFICATION

I certify that this study was carried out by Olusola Deborah OLUWASOLA in the Department of Health Promotion and Education, Faculty of Public Health, College of Medicine, University of Ibadan, Ibadan, Nigeria.

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## ABREVIATIONS

<b>Abbreviation</b>	<b>Full meaning</b>
ARV.....	Antiretroviral
ART.....	Antiretroviral Therapy
CDC.....	Centre for Diseases Control
FMOH.....	Federal Ministry of Health
FGN.....	Federal Government of Nigeria
G.O.P.D.....	General Out Patient Department
HIV/AIDS.....	Human Immune-deficiency Virus/Acquired Immuno-Deficiency Syndrome
ICRN.....	International Centre for Research and Women
IDI.....	Indept Interview
ILO.....	International Labour Organization
JAAIDS.....	Journalism against AIDS
NACA.....	National Action Committee on AIDS
NARHS.....	National HIV &AIDS and Reproductive Health Survey
PLWHA.....	People Living With and AIDS
SMOH.....	State Ministry of Health
SSA.....	Sub Sahara Africa
STI.....	Sexually Transmitted Infections
T.B.....	Tuberculosis
UNAID.....	Joint United Nation programme on Aids
USA.....	United State of America
VCT.....	Voluntary Counselling and Testing
WHO.....	World Health Organization

## CHAPTER ONE

### 1.0

### INTRODUCTION

#### 1.0 Background of the Study

Acquired Immunodeficiency Syndrome (AIDS) has killed more than 25 million people since it was first recognized in 1981, making it one of the most destructive epidemics in recorded history (Joint United Nations Programme on AIDS (UNAIDS)/World Health Organization (WHO), 2005). An estimated 38.6 million people worldwide were living with HIV in 2005. In 2006, an estimated 4.1 million became newly infected with HIV and an estimated 2.8 million lost their lives to the disease condition AIDS (UNAIDS, 2006). No country or region is immune or shielded from the pandemic, though the prevalence rates vary (UNAIDS, 2002a). In 2006, almost two thirds (63%) of all persons infected with HIV were living in sub-Saharan Africa. The number of people living with the virus worldwide continues to grow including sub-Sahara Africa. The total number of people living with the virus as at 2008 was more than 20% higher than the number in 2000, and the prevalence was roughly threefold higher in 1990 (WHO, 2009). The occurrence of HIV and AIDS has reached epidemic proportions in many communities around the world. The situation constitutes a global health crisis; it is the greatest threat to human well-being and public health in modern times (United Nations (UN) Assembly, 2001).

It is well documented that there are usually three phases to the AIDS epidemic in most countries. The first phase is the “epidemic of HIV infection”. This is when the HIV infection enters a community or country silently and unnoticed, without being widely perceived or understood. The second phase is the “epidemic of AIDS” which appears when HIV triggers off life-threatening health conditions and the associated consequences. The third phase of the epidemic is that of stigmatisation. This phase which is very challenging is characterized by discrimination, blame and denial (Mann, 1987). According to Mann (1987) social, cultural, economic and political responses hold the key to overcoming the HIV and AIDS problem. Nigeria appears to be in-between the full AIDS epidemic phase; and the stigma and discrimination phase. HIV and AIDS-related stigma and discrimination

provide opportunities for the spread of the infection (FMOH, 2003). The practice undermines prevention, voluntary counseling and testing, care and support; and also increases the impact of the infection on individuals, families, communities and nations (Population Council, Horizons; 2002). The stigma and discrimination attached to being diagnosed with AIDS is far greater than and significantly different from that linked to being diagnosed with other illnesses such as cancer and hypertension (Becky et al., 2009). This may be due to the fact that HIV is primarily transmitted through sexual intercourse and people sometimes erroneously link HIV infection with sexual promiscuity. Heterosexual intercourse remains a major route of HIV/AIDS transmission in three-quarters of HIV cases in developing countries (WHO, 2006). This is also the case in Nigeria.

Nigeria, the largest and most populous country in sub-Saharan Africa, is one of the countries that are highly affected by the HIV and AIDS scourge (Oyediran, Oladipo and Anyanti; 2005). The disease condition has spread rapidly since the first case was diagnosed in 1986. The adult HIV prevalence increased from zero percent in 1986 to 1.8 percent in 1991, then to 4.5 percent in 1996. It increased to 5.4 percent in 1999, and to 5.8 percent in 2001 (UNAIDS/WHO, 2006). The epidemic in Nigeria has extended beyond the commonly classified high-risk groups and is now common in the general population (FMOH, 2004). The 2007 National HIV and AIDS; and Reproductive Health Survey in Nigeria (NARHS PLUS) showed that the overall HIV prevalence rate was 3.6%. The prevalence rate of HIV was higher in females (4.0%) than in males (3.2%). Likewise, the HIV prevalence rate was slightly higher in urban communities (3.8%) compared to the rural communities (3.5%). Persons aged between 30 and 39 had the highest HIV prevalence of 5.4% (National Action Committee on AIDS [NACA], 2008).

In Oyo State the prevalence of HIV, based on the result of the national sero-surveillance studies conducted in 1992 and 2004, were 0.1% and 4.2% respectively (SMOH, 2004). It was also reported that there was no town or village that had not reported cases of HIV and AIDS; and about 85 percent of the infections were reported to have been contracted through unprotected heterosexual intercourse (SMOH, 2004). The disease condition always attracts social stigmatization and discrimination wherever it occurs. To properly address the

challenges of stigma in the society there is need to first understand its nature and the dynamics of its spread. It is necessary to explore stigma not only from the perspective of those who stigmatise, but also from the perspective of those who are stigmatised. The conceptualisation of HIV and AIDS as a shameful disease, and its link to immoral practices including sexual promiscuity, prostitution, homosexuality and drug use in many societies, contribute to HIV-induced stigma and discrimination. Self-stigmatisation which can manifest as self-blaming and shame can lead to psychological consequences such as depression, withdrawal and feelings of worthlessness (UNAIDS, 2002c). The effect of the stigmatization of HIV-infected persons and the effect of stigmatization brought upon oneself (self-stigmatization) all lead to social exclusion. In Nigeria and other countries in Sub-Saharan Africa (SSA), cultural diversity has potential for a diversity of stigma manifestations (Alubo, Zwandor, Jolayemi and Omudu, 2002; Bond, Chase and Agglenton, 2002). The exploration of the nature of HIV-induced stigma is useful in HIV/AIDS prevention programming; it is one of the pre-conditions for designing programmes aimed at promoting the de-stigmatization of the disease condition. In Nigeria, there is paucity of information relating to how People Living With HIV and AIDS (PLWHA) perceive stigma and discrimination which they are experiencing. This study therefore focuses on the exploration of stigma and discrimination from the perspective of the stigmatized.

### **1.2 Statement of the Problem**

The epidemic of AIDS has destabilized the health systems, social protection, education, industry, the agricultural sector, transport, political stability and civil society in many Sub-Saharan African nations including Nigeria. The devastating impact of the HIV and AIDS will continue to ravage African economies including Nigeria because of the absence of a cure, vaccine and affordable treatment. The problems of concern that face People Living with HIV and AIDS or those suspected of having HIV and AIDS in Nigeria have not been investigated extensively through a systematically conducted research or study. Studies conducted elsewhere have shown that people with HIV and AIDS are unfairly treated and



(or) discriminated against because of their actual or suspected HIV/AIDS status (Parker and Agglenton, 2003; Journalism against AIDS (JAAIDS), 2004).

Discrimination against people with or suspected of having HIV and AIDS is not a violation of their human rights alone; it also compromises effective public health measures aimed at tackling HIV and AIDS (WHO, 2002). The National Policy on HIV and AIDS is aimed at controlling the spread of the infection, and mitigating its impact including stigmatization and discrimination to a point where it would no longer be of public health importance. It is necessary to address HIV and AIDS-related stigma and discrimination before the goal and objectives of the National Policy on HIV and AIDS can be achieved. It had been revealed that people living with HIV/AIDS (PLWHA) are stigmatized, ostracized, rejected, and shunned. Many of them experience sanctions, harassment, and even violence because of their infection or association with persons with HIV and AIDS (Oyediran, Oladipo and Anyanti; 2005). Stigma and discrimination related to HIV and AIDS constitute a complex psychological and sociological factor which facilitates the spread of HIV by complicating care and prevention. There is, therefore, a need to understand the phenomenon of HIV and AIDS-related stigma and discrimination.

In Nigeria the prevalence of perpetration of HIV-related stigmatization and discrimination against PLWHA; the responses of PLWHA to the stigmatization; discrimination received and the perceived burden of stigmatization and discrimination on PLWHA have not been adequately explored. This study was therefore designed to determine the prevalence of perceived stigmatization and discrimination among people living with HIV and AIDS. The People Living With HIV/AIDS who are receiving treatment care at President Emergency Plan for AIDS Relief clinic, University College Hospital, Ibadan, constituted the captive population for the study.

### **1.3 Justification of the Study**

All over the world, lack of knowledge, fear and denial have engendered serious and often tragic consequences such as denying people living with HIV/AIDS access to treatments, services and support, as well as making it hard for prevention work to take place. The

epidemic of fear, stigmatization and discrimination first described by Jonathan Mann (1987) has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those infected (Merson, 1993). Despite numerous conferences and expert consultations on human rights prohibiting discrimination on the basis of HIV status, relatively little is known about the causes of these negative responses or how they can best be combated.

This study offers insight into the experiences of people living with HIV/AIDS and negative social responses encountered. The results of this study will be useful as baseline information for designing and implementing educational programmes. In addition they will be useful for making communities and various health care institutions health-promoting for PLWHA. A good understanding of the prevalence of the various forms of HIV-related stigma and discrimination experienced by PLWHA is worth investigating because the findings could be used for the design of de-stigmatizing programmes. This study is part of a concerted effort to rid the world of the stigma and discrimination that hamper efforts to reduce levels of infection and the provision of support for people living with HIV/AIDS. Furthermore, the findings of the study could be used for guiding the formulation of evidence-based policies geared towards promoting the health and wellbeing of PLWHA in communities and health institutions.

#### **1.4 Research Questions**

The questions framed to suite the study are as follow:

1. What is the prevalence of HIV-related stigma and discrimination experienced by PLWHA?
2. What is the prevalence of self-stigmatization among PLWHA?
3. What are the attitudes and beliefs of other people perceived to be stigmatising and discriminating by PLWHA?
4. What are the perceived psychological and social consequences of HIV-related stigma and discrimination endured by PLWHA?
5. What are the strategies for coping with HIV-related stigma and discrimination among PLWHA?

## **1.5 Objectives**

### **1.5.1 Broad objective**

The broad objective of the study was to determine the prevalence, consequences and coping strategies of HIV-related stigma and discrimination experienced by PLWHA.

**1.5.2 Specific objectives:** The specific objectives were to:

1. Determine the prevalence of HIV-related stigma and discrimination perpetrated against PLWHA by others;
2. Determine the prevalence of self-stigmatization among PLWHA;
3. Describe people's attitudes and beliefs perceived to be stigmatising by PLWHA;
4. Identify the perceived physical psychological and social burden of HIV-related stigma and discrimination endured by PLWHA and;
5. Document the strategies for coping with HIV-induced stigma and discrimination among PLWHA.

## CHAPTER TWO

### 2.0

### LITERATURE REVIEW

#### 2.1 Conceptual Clarifications, Typology and Nature of Stigma with Special Reference to HIV/AIDS

##### 2.1.1 Concept of stigma

Stigma a complex social phenomenon and results from an interplay of several factors including social and economic factors in the environment and psychosocial issues of affected individuals.

Goffman (1963) a pioneer in the field of stigma perceptions, describes three types of stigma: (1) “abominations of the body,” or stigma related to physical deformities; (2) stigma related to “blemishes of individual character,” such as people who are considered to be weak-willed, to have unnatural passions, or to be dishonest; and (3) “tribal stigma,” or stigma relating to race, nation or religion, or membership of a despised social group, everyone typically inherits membership to this last group, tribal stigma can equally adhere to and affect all members of a family.

According to Parker and Aggleton (2003) stigma is a social process that produces and reproduces relations of power and control. They noted that stigma can be used to turn differences into inequity (based on gender, age, sexual orientation, class, race, or ethnicity) allowing some groups to devalue others based on these differences. They submitted that stigma and discrimination are used by dominant groups to produce, legitimize and perpetuate social inequalities, and also to exert social control through the exclusion of stigmatized groups, limiting the ability of the stigmatized groups or individuals to resist or fight the stigma. Jones, Farima, Hastorf, Miller, Scott and French (1984) have presented six dimensions of stigma. These dimensions can pass for the attributes of stigma. They are concealability, course of the mark, disruptiveness, aesthetics, origin and peril. Concealability involves the extent to which the stigma is visible, and is Goffman's

distinction between being discreditable and discredited. Being discreditable involves having a stigma that can be hidden, and choosing not to disclose it. Being discredited involves having a visible stigma, or having disclosed a stigma that was previously hidden. The more visible a stigmatizing condition is, the greater the negative impact it will have on the sufferers (Crocker 1999; Goffman, 1963; Hebl and Kleck 2000; Katz, 1981). Even having a hidden stigma can have an impact on interactions, since knowledge of one's hidden stigma may change the way one behaves, thereby effecting the interaction (Goffman, 1963; Smart & Wegner, 2000). Course of the mark relates to whether the attribute changes over time, and how it changes over time. It also entails what the ultimate outcome is. Disruptiveness relates to the degree or extent to which the stigma interferes with social interaction. This attribute is often present in the definition of stigma, as stigmatization involves the process of excluding certain individuals that have certain attributes from certain social and culture context.

Aesthetics refers to subjective reactions to the "ugliness" of the stigma. Origin on the other hand connotes the circumstances in which the stigmatizing condition originated, and whether the stigmatized person is responsible for it or not. Perility of a stigma refers to the danger that stigma imposes on others, and to how imminent and serious the danger is perceived to be. Other theorists present similar dimensions or attributes of stigma. For instance according to Katz (1981) there are four dimensions of stigma; responsibility, threat visibility and sympathy. The dimensions that have been presented partly overlap each other, as origin and responsibility are stigma dimensions that refer to controllability, peril and threat make reference to real or perceived danger, and concealability and visibility refer to the degree a stigmatizing attribute is observable (Strangor and Crandall 2000).

The fear of AIDS induced stigma leads many to choose silence. Using Goffmans term, they assume a discreditable "identity". Psychological literature is replete with findings of how secrecy and not confiding in significant others results in mental and physical health consequences. (Pennebaker, 1995; Smart & Wegner, 2000). The fact that HIV/AIDS carries a stigma that potentially can become visible as the illness progresses, the individual may willingly or not, in time assume a discredited identity due to the course of the mark (Goffman, 1963). By choice, or by the potential visibility of the HIV/AIDS stigma, the

silence will be broken. When a stigma that has been knowingly concealed from others becomes revealed, the social life of the individual can become further burdened. The psychological distress can be greater when a hidden stigma is revealed, than when a stigma that has not been hidden is revealed (Smart & Wegner, 2000).

It has been pointed out that interactions between stigmatized and non-stigmatized individuals often are characterized by awkwardness (Crocker et al., 1998; Goffman, 1963; Hebl et al., 2000; Katz, 1981). This awkwardness reflects the dimension of disruptiveness. The interactions are frequently uncomfortable and stressful, to both the stigmatized and non-stigmatized (Crocker et al., 1998). This could pose a threat to social relations, as humans are highly motivated to avoid negative affects (Nathanson, 1992). This motivates PLWHA to keep silent about their HIV-status. The dimensions of visibility and disruptiveness illustrate the complexity of the HIV/AIDS-related stigma (Goffman 1963, Katz 1981). The dimension of responsibility is important with regards to HIV/AIDS-related stigma. The idea of illness as retribution for sin and a moral failing transgression is often part of the social construction of HIV/AIDS in some societies (Dageid, 2002; Lie, 1996). This coincides with the responsibility dimension of stigma.

Since HIV/AIDS often is conceptualized as something that happens to people who engage in deviant immoral behavior, the disease can be seen as something deserved (Jane, Chah, Igbokwe and Agwu, 2011). The dimension of responsibility corresponds to the stigma type “blemishes of individual character” enunciated presented by Goffman (1963). When HIV/AIDS is conceptualized as punishment for sins committed, the individual is seen as responsible for the conditions. This is more so because it is perceived as something that could have been avoided with correct and moral behavior. This has resulted in the belief that decent people do not become infected with HIV/AIDS (Dageid, 2002). This belief is not entirely correct. The social construction of HIV/AIDS could lead people to make inferences about responsibility, even if they have no knowledge about the underlying conditions of infection (Nyblade et al., 2008). When people are perceived as responsible for having contracted HIV/AIDS, the negative reaction in form of stigma increase (Hebl & Kleck, 2000). Ascribing responsibility for a stigmatized attribute, can lead to reduction of

sympathy. The dimension of sympathy can thus be seen as related to that of responsibility (Goffman 1963).

The interplay between dimensions of stigma can enhance HIV/AIDS-related stigma. Research has shown that stigmatized individuals who are believed to be responsible for their condition such as HIV/AIDS due to assumed sexual promiscuity, are more rejected and disliked, and receive more negative reactions, than individuals with stigmas that are perceived as outside their control such as contracting HIV/AIDS through blood transfusion (Crocker et al., 1998; Jones et al., 1981; Weiner, 1993). Threat is also a central dimension of the HIV/AIDS-related stigma. HIV/AIDS poses an obvious threat of contagion, disease and death, and is therefore highly feared (UNAIDS, 2002d).

In general, the stigma associated with a contagious disease that poses an obvious threat to others is greater than when there is no obvious threat associated with the stigmatized condition (Alonzo & Reynolds, 1995; Jones et al., 1984; Katz, 1981). With regards to HIV/AIDS-related stigma, threat can be seen as a fundamental dimension (Goffman, 1963).

Katz (1981) proposed that most of stigma probably hold an element of threat. The dimension of threat with regards to the HIV/AIDS-related stigma can be seen at two levels. Firstly, HIV/AIDS is a disease that threatens physical health and life itself. This type of threat has been termed tangible by Stangor and Crandall (2000). Tangible threats is when concrete and material goods such as health, social position, safety and wealth are threatened. Secondly, HIV/AIDS represents a threat to moral, beliefs and peoples understanding of how the world works. HIV/AIDS is often conceptualized as something that happens to “others”. Stangor and Crandall (2000) have termed this type of threat symbolical.

A symbolic threat is when values, beliefs and ideologies are threatened. “The others” are seen as individuals or groups who do not oblige to the values of society and in so doing they pose a threat to these values (Katz, 1981). This corresponds with the definition of stigma provided by Brown et al. (2001). They experienced that stigmatization is a process that results from the perception that there has been a violation of shared attitudes, beliefs

and values. It is not unlikely that threats that originally were tangible can become generalized to be symbolic, due to the social construction of HIV/AIDS.

The dimension of threat starts to highlight the function of stigmatization. When perception of threat leads to stigmatization, stigmatization can be seen as a way for the stigmatizer to avoid danger. Stangor and Crandall (2000) claim that the perception of threat appears to be a likely foundation for stigma. Thus the avoidance of danger can be seen as a function of stigma at least from the perspective of the stigmatizer. When humans are confronted with danger from which they cannot escape, a common response is to try to protect themselves by distancing themselves from the threat, by creating a distinction between “us” and “them” (Gilmore & Somerville, 1994). The relation between HIV/AIDS related stigma and threat will be further elaborated upon in the sections on the impact and functions of HIV/AIDS-related stigma.

According to UNAIDS (2003), HIV/AIDS-related stigma can be described as a “process of devaluation” of people. This stigma often stems from the underlying stigmatization of sex and intravenous drug use (two of the routes of HIV infection). Discrimination follows stigma and this is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Discrimination occurs when a distinction is made against a person that results in being treated unfairly and unjustly on the basis of belonging, or being perceived to belong, to a particular group. Others have defined stigma being a reflection of societal power structures (Link, 2001; Parker, 2001).

When stigma is acted upon, the result is discrimination. Discrimination consists of actions or omissions that are derived from stigma and directed towards individuals who are stigmatized. Discrimination, as defined by UNAIDS (2000) refers to any form of arbitrary distinction, exclusion, or restriction perpetrated against a person, usually as a result of an inherent personal characteristic or perceived belonging to a particular group: In the case of HIV and AIDS induced discrimination, discrimination perpetrated against a person as a result of or suspected HIV-positive status irrespective of whether confirmed or not there is any justification for the measure.



AIDS-related discrimination may occur at various levels such as family and community, institutional and national levels (McLeroy, Bibeau, Steckler and Glanz, 1998). Discrimination at these level will be discussed in greater detail.

*1. Family and community level:* There is discrimination occurring in family and community settings which has been described by some writers as ‘enacted stigma’ (Brown, Macintyre, & Trujillo, 2003; Jacoby, 1994; Malcolm et al., 1998; Scambler, 1998; Scambler and Hopkins, 1986; Swendeman, Rotheram–Borus, Comulada, Weiss, and Ramos, 2006).

This is what individuals do either deliberately or by omission which harm others such as denying them services or entitlements. Examples of this kind of discrimination against people living with HIV include: ostracization, such as the practice of forcing women to return to their kins upon being diagnosed HIV-positive, following the first signs of illness, or after their partners have died of AIDS; shunning and avoiding everyday contact; verbal harassment; physical violence; verbal discrediting and blaming; gossip; and denial of traditional funeral rites.

*2. Institutional level:* This is discrimination occurring in institutional settings such as workplaces, health-care services, prisons, educational institutions and social-welfare settings. Such discrimination crystallizes enacted stigma in institutional policies and practices that discriminate against people living with HIV, or indeed in the lack of anti discriminatory policies or procedures of redress. Examples of this kind of discrimination against people living with HIV include discrimination in the following settings:

- i. Health-care facilities: These manifest in terms of reduced standard of care, denial of access to care and treatment, HIV testing without consent, breaches of confidentiality including identifying someone as HIV-positive to relatives and outside agencies, negative attitudes and degrading practices by health-care workers.
- ii. Workplace: denial of employment based on HIV-positive status, compulsory HIV testing, exclusion of HIV-positive individuals from pension schemes or medical benefits.

iii. Schools: denial of entry to HIV-affected children, or dismissal of teachers on the ground of their HIV positive status.

iv. Prisons: mandatory segregation of HIV-positive individuals, exclusion from collective activities.

3. *National level*: At a national level, discrimination can reflect stigma that has been officially sanctioned or legitimized through existing laws and policies, and enacted in practices and procedures. These may result in the further stigmatization of people living with HIV and, in turn, legitimate discrimination. A significant number of countries, for example, have enacted legislation with a view to restricting the rights of HIV-affected individuals and groups. These actions include:

- Compulsory screening and testing of groups and individuals;
- Prohibition of people living with HIV from certain occupations and types of employment;
- Isolation, detention and compulsory medical examination, treatment of infected persons;and
- Limitations on international travel and migration including mandatory HIV testing for those seeking work permits and the deportation of HIV-positive foreigners.

Discrimination also occurs through omission, such as the absence of, or failure to implement, laws, policies and procedures that offer redress and safeguard the rights of people living with HIV.

### **2.1.2 The Typologies and Functions of Stigma**

There are three types of stigma broadly these are, felt stigma, enacted stigma and self-stigma. To fully understand the dynamics of stigma it is necessary to look at stigma from the perspective of both those who stigmatize, and from the perspective of those who become stigmatized (Brown et al., 2006).

From the perspective of the stigmatized, an important distinction has been made between *enacted* stigma and *felt* stigma. Enacted stigma refers to sanctions that are individually or

collectively applied to people on the basis of their belonging or perceived belonging to a particular group. (parker & aggleton 2003). Enacted HIV/AIDS-related stigma refers to the discrimination and violation of human rights that PLWHA or people assumed to be infected with HIV/AIDS may experience (Green, 1995). Felt stigma refers to the feelings an

individual has about his or her condition, and the fear of how others will react to this condition. Felt stigma can be seen as fear of, or anticipation of, enacted stigma (UNAIDS, 2000a).

Felt stigma can affect PLWHA's view of themselves, and of their surrounding community (Chen, Choe, Chen and Zhang 2005). This perception and the fear of enacted stigma, can lead to avoidance behavior. Felt stigma can be seen as a survival strategy to limit the occurrence of enacted stigma, such as when people deny their risk of infection or fails to disclose their status in order to avoid being banished (Brown et al., 2001). Felt stigma enables individuals to conceal their HIV-status. Felt stigma enables individuals to experience HIV/AIDS related stigma and suffer its impact, without having been an actual target of enacted stigma. Felt stigma and fear of rejection can impair the individual's perception of available support, and the individual can become vulnerable to signs of possible rejection, possibly misinterpreting the behavior of others as rejecting (UNAIDS 2000a).

Felt stigma can lead to an individual isolating him- or her-self, because he or she anticipates no support and possible rejection, thereby excluding him or herself from social support (Crandal and Coleman 1992). Again the dimension of disruptiveness becomes apparent. According to Jones et al.,(1984), several studies have linked felt stigma to depression and emotional distress. Feelings of shame and embarrassment are components of felt stigma, and may contribute to the inhibition of an individual's adjustment by maintaining focus on negative aspects of the stigmatizing condition (Mickelson, 2001).

Both felt and enacted stigma can have serious consequences for the individual. An individual can internalize stigma, resulting not only in the devaluation of one's identity in the eyes of society, but also in

the eyes of oneself (Crocker, 1999). Hiding one's stigma can be seen as a defense against enacted stigma, but does not necessarily exclude the experience of the HIV/AIDS-related stigma. The internalization of society's judgment can be seen as an act of self-stigmatization, which is defined as an individual's internalization of perceived or experienced societal attitudes (UNAIDS, 2001a). The negative attitudes of society towards PLWHA constitute an important source of stigma. Through awareness of cultural representations, PLWHA know that others devalue their social identity. This awareness can function as a strong motivator for keeping one's stigma hidden, and in some cases it can lead to the cultural representations becoming internalized (Goffman, 1963).

Self stigmatization can be seen as a way of discrediting oneself (Goffmans, 1963). The conceptualization of HIV/AIDS as a shameful disease, and its link to moral and sexual taboos in many contexts in Sub Saharan Africa, contributes to self-stigmatization and feelings of shame. Self-stigmatization can lead to depression, withdrawal and feelings of worthlessness (UNAIDS, 2002c).

## **2.2 Functions of Stigma**

Threat as a dimension briefly touched on the function of stigma. Stigma was portrayed as a reaction to both tangible and symbolic threat, involving the avoidance of danger (Katz, 1981). Stigma can be observed in every society, across time and cultures. This universality suggests that stigma may serve a function in society (Dovidio et al., 2000). Attributes that are stigmatized differ with time and between societies. Old age is an example. It is considered a stigmatizing condition in the U.S., while it is considered a valued attribute in Japan. There are, however, some attributes that seem to be universally stigmatized (Stangor & Crandall, 2000). Certain sexual identities, handicaps, facial disfigurements and diseases are some examples (Kurzban & Leary, 2001). These universal attributes have certain dimensions in common, some of which were mentioned earlier. HIV/AIDS and the dimensions of HIV/AIDS-related stigma lend strength to the notion of the universality of stigma. That stigma serves different functions has been well documented (Neuberg et al., 2000). From the perspective of the stigmatizers, some of the functions of stigma are; enhancement of self-esteem, enhancement of social identity, and justification and validation of social, economic and political world views (Crocker et al., 1998; Gilmore & Somerville,

1994; Neuberg et al., 2000). Although it is possible that stigma serves these functions, they do not shed light on who becomes stigmatized. According to the dimensions presented earlier, people who are perceived to present a threat are likely to become stigmatized.

The bio-cultural Approach to the Functions of Stigma is worth reviewing or discussing. Neuberg et al. (2000) argue that stigma has its root in the biological need for humans to live in effective groups. Living in groups characterized by reciprocity can be seen as a primary human survival strategy. People will therefore stigmatise those who threaten the successful functioning of the group to which they belong. They argue that this perspective elucidates the issue of why people stigmatise, whom they stigmatise, when and how. Group living is adaptive, with the fundamental benefits stemming from the sharing of individual efforts, resources and knowledge (Neuberg et al., 2000). Those who are identified as threats or obstacles to group functioning must be dealt with, and stigmatization serves the function of both identifying and dealing with these individuals. Stigmatisation identifies and excludes individuals who threaten group functioning (Katz, 1981). Individuals who do not adhere to the norms and values of the group will be considered a treat to the group. Stigmatization thereby preserves groups by dealing with both tangible and symbolic threat.

One approach to the function of stigma that also emphasizes disease is that credited to Kurzban and Leary (2001). They present an evolutionary approach to the function of stigma, and argue that the desire for social distance is predicted by instrumental concerns such as avoiding parasitic infections. Since the spread of a disease, like HIV/AIDS, will lead to a decrease in the group's efficiency, the spread must be hindered. This may be achieved through the process of stigmatization, and reflects a reaction to tangible threat (Katz, 1981). Stigmatization creates a barrier between the healthy and the unhealthy, the good and the bad, those who conform and those who do not. This is the well known "us" - "them" barrier, which is meant to ensure the continuation of the healthy, effective group. This distancing strategy seems to be an integral part of stigmatization (Ratele & Shefer, 2002). How the HIV/AIDS-related stigma has been seen as a way of reinforcing pre-

existing social inequalities, illustrates how stigma can strengthen the distancing process between “us” and “them” through multiple stigma ( Ratele & Shefer, 2002).

When stigmatization serves the function of ensuring the group’s functioning because it is a reaction to a real or perceived threat, on a tangible or symbolic level, the stigmatization

itself becomes justifiable. The perception of threat can also be escalated, e.g. through negative media propaganda. In many African countries, the media has associated HIV/AIDS with e.g. non-acceptable sexual behavior and death, and thus contributed to the production, maintenance and the legitimization of HIV/AIDS-related stigma (UNAIDS, 2002-2003). Doing the opposite, reinterpreting the perceived threat of HIV/AIDS, could reduce stigmatization. This is important to keep in mind with regards to the alleviation and prevention of HIV/AIDS-related stigma.

### **2.3 Stigma and Power**

Approaches to the function of stigma, indirectly highlight power aspects of stigma.

Stigmatization requires power, as one cannot stigmatize without having the power to do so. Stigma is linked to power and has its origin in the structure of society. Power is essential in the social production of stigma (Link, 2001). Stigma creates and is in turn reinforced by social inequality. Stigmatization is thus an exercise of power over certain people, underlining and reinforcing the differences between powerful and powerless, rendering the stigmatized disempowered (Gilmore & Somerville, 1994).

Parker & Aggleton (2003) highlight how stigma can be used to marginalize, to exclude and to control individuals who, through the process of stigmatization, are labelled as deviant, representing symbolic or tangible threats. Stigma can thus be used to strengthen a community’s values and functioning by metaphorically or actually excluding, or threatening to exclude, those who are different or unwanted (Gilmore & Somerville, 1994). The boundaries between “us” and “them” thus contribute to the order, structure and functioning of the community. The fact that HIV/AIDS-related stigma is closely related to other stigmatized attributes such as sexuality, poverty and gender shows how HIV/AIDS-

related stigma contributes to the reinforcement of social inequality (Parker & Aggleton 2003).

#### **2.4 Stigma-inducing Conditions with Special Reference to HIV/AIDS-related Stigmatization, Discrimination**

HIV-related discrimination and stigmatization may appear in a variety of contexts. Central among these are the family and local community, employment and the workplace, and the health care system (McGrath et al., 1993). In addition to an exercise of power, stigma can be a response to fear, risk or a threat of a disease that is incurable and potentially fatal (Gilmore and Somerville, 1994). The more rapid the spread of the disease and the greater the uncertainty of how the disease is transmitted, the more likely stigma will result (Sullivan, 2010). Epidemics that present an overt threat to the values of a community are especially likely to evoke stigma because stigma is used to “enhance or secure social structuring, safety and solidarity or reinforce societal or community values by excluding divergent or deviant [individuals]” (Gilmore and Somerville 1994). Stigma related to medical condition is greatest when the condition is associated with deviant behavior or when the cause of the condition is viewed as the individual’s responsibility. This becomes particularly strong when the illness is associated with religious beliefs and thought to be contracted through morally sanctioned behavior (Alonzo and Reynolds, 1995).

Stigma is also more evident when the condition is unalterable, incurable, severe, degenerative, and leads to readily apparent physical disfigurement or an undesirable and unaesthetic death (Alonzo and Reynolds, 1995; Cogan and Herek 1998). HIV and AIDS have all of the characteristics associated with heavily stigmatized medical conditions. They are associated with socially improper forms of sex and injection drug use, socially censured behaviors that are viewed as the responsibility of the individual. AIDS is incurable, degenerative, often disfiguring, and associated with an “undesirable death” (Nzioka, 2000). The disease condition is often incorrectly thought to be highly contagious and a threat to the

community at large. The general population, and some medical personnel, are not well-informed about the disease and so lack a deep understanding of its nature.

The fact that HIV/AIDS primarily is transmitted through heterosexual contact in Sub-Saharan African (UNAIDS, 2002e) coincides with Goffman's characterization of stigma as a blemishes of individual character. This mode of transmission therefore contributes to stigma, since sexual promiscuity is a stigmatizing practice (Bond, Chase and Aggleton, 2002). HIV/AIDS can be understood as proof of sexual promiscuity and it is often perceived as a "prostitute's disease" (Dageid, 2002). In Sub-Saharan African, sex workers and people living in poverty are particularly at risk for HIV-infection. These are already stigmatized groups, and their "identity" often contributes to making them experience multiple stigmas

### **1. *The Family and Community***

In the majority of developing countries, families are the primary care-givers to sick members. There is clear evidence of the important role that the family can play in providing support and care for people living with HIV/AIDS (World Bank, 1997; Warwick et al., 1998; Aggleton & Warwick, 1999). However, not all family response is positive. Infected and affected family members may still be stigmatized and discriminated against within the home. There is also mounting evidence that women (Bharat & Aggleton, 1999) and non-heterosexual family members (Castro et al., 1998a; 1998b) are more likely to be badly treated than children and men.

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 (Lwihula et al., 1993). The extent to which such strategies are successful may depend upon the wealth of the household concerned and its capacity to provide care without calling upon other community members for support. Fear of rejection and stigmatization within the home and local community may prevent people living with HIV/AIDS revealing their sero-status to family members (McGrath et al., 1993). Families may reject sero-positive



members not only because of the stigma associated with HIV/AIDS, but also because of the connotations of homosexuality, drug use and promiscuity that HIV/AIDS carries (Panos, 1990; Misra, 1999; Mujeeb, 1999).

## ***2. Employment and Workplace***

While HIV is not readily transmitted in the majority of workplace settings, the supposed risk of transmission has been used by numerous employers to terminate or refuse employment (Barragán, 1992; Gostin, 1992; Panos, 1992; Shisam, 1993; Hasan et al., 1994; Omangi, 1997). There is also evidence that where people living with HIV/AIDS are open about their serostatus at work they are likely to experience stigmatization and ostracism by others (Panos, 1990; Gostin, 1992; Gostin & Lazzarini, 1997). Pre-employment screening takes place in many industries – particularly in countries where the resources for testing are readily available and affordable. In poorer countries screening has also been reported as taking place, especially in industries where health benefits are available to employees (Parker, 1991; Jackson & Pitts, 1991). Some employers have used this pressure to deny employment to people living with HIV/AIDS (Whiteside, 1993; Williams & Ray, 1993). In the workplace, HIV/AIDS-related stigma manifests itself through negative interaction, unjust hiring and firing, unfair payment and benefits, limited employment security and health insurance, denial of medical absence and leave, and inconsistent promotion and training (UNAIDS, 2002-2003). Only few companies in developing countries appear to have developed strategies to combat fear, stigma and discrimination in the workplace, and an equally small number have begun to define the responsibilities of employers towards employees with HIV/AIDS (Jackson & Pitts, 1991; Bezmalinovic, 1996).

## ***3. The Health Care System***

The extent to which individuals are stigmatized and discriminated against by the health care system have been reported. There are, for instance accounts of withheld treatment to HIV positive persons (Bhedbhan Virdhi Andolan, 1993; Carvalho et al., 1993; Panebianco et al.,

1994); non-attendance of hospital staff to patients left lying in their beds (Daniel & Parker, 1990; Ogola, 1990; Masini & Mwampeta, 1993); HIV testing without consent, breaches of confidentiality, and denial of hospital facilities and medications (Panebianco et al., 1994). Contributing to such responses is lack of knowledge about HIV/AIDS transmission (Kegeles et al., 1989; Herek & Capitano, 1993; Herek et al., 1998); fear (Blendon &

Donelan, 1988; Tesch, Simpson & Kirby, 1990; Rosasco Dulato, 1992); moralistic assumptions of guilt (Cole, Zhang & Chen, 1993; Masini & Mwampeta, 1993); and the perceived incurability of HIV/AIDS. All of these conspire to make it appear pointless to offer good-quality care.

Lack of confidentiality has been repeatedly cited as a particular problem in health care settings. Wide variations in practice exist between countries, and between health care facilities within countries. In some settings signs have been placed near people living with HIV/AIDS with words such as “HIV-positive” and “AIDS” written on them. Elsewhere, registers of HIV-positive people have been compiled and their names released to media and police without permission (Panos, 1990; Singh, 1991). Principles of confidentiality also vary between countries and cultures. In some places, for example, confidentiality may be less of an individual issue than a community and collective concern. The term “shared confidentiality” describes a situation where family and community members feel they have the right to know the serostatus of family members, neighbours and friends (Campbell et al., 1997).

#### **4. Religious Sector**

In some instances the religious sector (churches, mosques, religious schools, lay groups, and religious community-based organizations) reinforce stigmatization of PLWHA through acting upon their attitudes towards sexuality, the use of contraceptives, multiple sexual partnerships and the notion that HIV/AIDS is a punishment by God (UNAIDS, 2002-2003). Some religious leaders and religious organizations have used their power to maintain the status quo, rather than to challenge and modify negative attitudes towards PLWHA. How

religious doctrines, moral and ethical positions have contributed to the perception that PLWHA have sinned and deserve their “punishment”, has been noted by the African Regional Forum of Religious Health Organizations (Parker & Aggleton, 2002). Such attitudes promote silence and stigma, and can make finding solace and support in religion difficult for PLWHA.

In the religious sector, PLWHA have been excluded, abandoned, condemned, and treated as “witches”. People have been denied spiritual assistance, and have been blamed for their HIV-status (UNAIDS, 2001a). In a Zambian study, some churches were reported to impose mandatory testing before allowing marriage, and said to refuse to discuss realistic HIV/AIDS prevention strategies (Bond et al., 2002). In Nigeria, PLWHA have been given different funeral rites. The mourning period has been shorter than for “normal deaths”, and it has been suggested that the graves of people who have died from AIDS should be much deeper than others’ to guard against any possibility of post-burial infection (Alubo et al., 2002). Quick and non-traditional funeral ceremonies for people that have died of AIDS have reportedly been conducted in Ghana (Mill, 2003). PLWHA have also been promised miraculous healing, and have in this manner been taken advantage of in mendacious propagandas (UNAIDS, 2001a).

### **5. The Media**

The media is a useful canal for campaigns communicating information on HIV/AIDS and HIV/AIDS-related stigma. From an international perspective, Garcia Gonzalez (2000) highlights how HIV/AIDS-related campaigns can be fear-arousing and based on cognitive rationale messages that tend to produce anxiety and confusion, rather than changing behavior or social norms. In many African countries the media has succeeded in associating HIV/AIDS with sexual promiscuity, death and minority groups like sex workers and homosexuals (Hutchinson, Mahlalela and Yukich, 2007). The media does not always have the necessary knowledge and background information when reporting on situations regarding HIV/AIDS and PLWHA. This can lead to inappropriate and negative journalism, which can include improper comments, the use of negative terminology and,

sensationalism. The use of terms like “innocent AIDS victims” implies that there are guilty ones responsible for their condition. The media has also violated confidentiality when reporting on PLWHA (UNAIDS, 2002- 2003).

#### **6. Political and Judicial System**

HIV/AIDS-related stigma can be manifested in the forms of laws, policies, regulations and administrative procedures, which are justified as necessary to protect the general population (Parker & Aggleton, 2002). In Nigeria, instances stigma has been manifested through compulsory examination and screening, compulsory testing and treatment, compulsory notification of HIV/AIDS cases, restrictions of the right to anonymity (Nigeria-AIDS eforum 2003). Due to their HIV-status, PLWHA have had problems obtaining insurance contracts and bank credits (UNAIDS, 2002e). Many countries have introduced policies restricting travelling and migration for PLWHA, because they are seen to represent a danger for public health or health budgets in the host country (Parker & Aggleton, 2002). Denial of entry and deportation, thereby restraining people’s freedom of movement, has been evident in West and Central- Africa (UNAIDS, 2002e).

In many countries, Nigeria inclusive, laws, policies, regulations and administrative procedures have contributed to a more supportive environment for PLWHA. Despite the existence of a supportive judicial system, lack of law enforcement contributes to stigma and discrimination. Documentation of discrimination is limited. Executive inaction further legitimizes stigmatization (Parker and Aggleton, 2002; UNAIDS, 2002-2003). The many ways HIV/AIDS-related stigma manifests itself within the society illustrate the complexity of HIV/AIDS-related stigma. This complexity renders it difficult to generalize about HIV/AIDS-related stigma as a phenomenon; at the same time as it poses a challenge to attempts aimed at alleviating and preventing HIV/AIDS-related stigma.

#### **2.5 Prevalence of HIV/AIDS-induced Stigma and Discrimination**

A plethora of quantitative studies confirm that HIV-related stigma and discrimination are highly prevalent and feature prominently in the lives of people living with HIV in settings with epidemics as diverse as the United States, Vietnam, and South Africa (Bogart et al., 2008). Comparison of prevalence across region or sample is complicated by the differences among stigmatizing incidents inquired about as well as different time-frames. The experience of stigma was universal among a small sample in Brazil, and nearly

universal among a sample of women in Vietnam (Melchior et al. 2007; Brickley et al. 2008). One study in the US indicated that 8 out of 10 families experienced discrimination (Bogart et al. 2008). In contrast, another study of women with HIV in the US found the prevalence of enacted stigma to be lower, at around 17% of the sample (Wingood et al. 2007). A large household-based study in Kenya found that 75% of HIV-positive respondents had experienced “enacted stigma” (Odindo and Mwanthi 2008). Slightly more than one-half of respondents experienced “enacted stigma” in a China sample (Li et al. 2009) as had one-third of respondents in South India (Subramanian et al. 2009). In the Dominican Republic, a study highlighted the importance of “verbal stigma”, with more than 60% reporting being gossiped about and between 25-30% reporting verbal abuse. Furthermore, the study found striking gender differences, with women experiencing more of nearly every form of “enacted stigma”—a pattern found in earlier work in Tanzania—and gender-based violence emerging as a prominent concern as well (MacQuarrie, Nyblade, Philip, Kwesigabo and Mbwambo, 2006; Urena, 2009).

In India, “perceived stigma” or fear of stigma were common, even where reports of “enacted stigma” were low (Priya and Sathyamala, 2007; Steward et al. 2008; Subramanian, Gupte, Dorairaj, Periannan and Mathai, 2009). This is the pattern also found in the U.S. (Bogart, Cowgill, Kennedy, Ryan, Murphy, Elijah and Schuster 2008). Where such data were elicited, respondents reported experiencing (or fearing) stigma by general community members or friends and acquaintances, followed by health providers (Cao et al. 2006; Yu et al. 2009; Zukoski and Thorburn, 2009). While most studies did not distinguish “enacted stigma” according to its source, several studies explored stigma and discrimination in particular institutional settings. Two separate studies in the US, one of housing project

clients and the other of ART clients, found that approximately 40% of their respondents had experienced discrimination in the health care system (Sohler et al. 2007; Thrasher et al., 2008). A multi-country qualitative study in Lesotho, Malawi, South Africa, Swaziland, and Tanzania documented “extensive” verbal and physical abuse and neglect in health services. (Dlamini et al., 2007). An Australian study highlights an important gender component: women reported significantly higher rates of discrimination in health services, though there was a decline in reports of incidents for both men and women (Thorpe et al. 2008). Studies of attitudes among health workers also found stigmatizing views to be high (Mahendra et al. 2006; Sadoh et al. 2006; Li et al. 2007; Li et al. 2007; Mahendra et al. 2007; Webber 2007; Oanh, Ashburn, Pulerwitz, Ogden and Nyblade 2008; Stein and Li 2008; Chirwa et al. 2009). A prospective study in France examined employment discrimination specifically and found that 149 out of 478 people living with HIV experienced employment loss over the duration of the study (Dray-Spira et al., 2008). Studies among employers in both China and Nigeria found strong reluctance to hire or retain employees with HIV ( Adeyemo and Oyinloye, 2007). This suggests that the workplace is a setting for potential discrimination regardless of region.

Numerous Household surveys which revealed extensive stigmatizing attitudes towards persons living with HIV cuts across various countries including the general population in China (Chen et a. 2005, Emler 2005), US (Bunn et al. 2008, Lau and Tsui 2005), Hong Kong (Hongjie et al. 2006 Stephenson 2009; Visser, Makin, Vandormael, Sikkema and Forsyth, 2009, ), South Africa (Mak et al 2006), Jamaica (Maughan-Brown 2006, Stein and Li 2008 ), Brazil (Norman et al. 2006), Genberg et al 2009), Nigeria (Babalola et al. 2009, Fatusi and Anyanti, 2009), Thailand (Visser et al. 2006), Tanzania (Chan et al 2007, Stein and Li 2008), Zimbabwe (Ndinda et al. 2007, Stephenson 2009), Burkina Faso (Lau and Tsui 2007), Zambia (Chiu et al. 2008, ; Stephenson 2009; Visser, Makin, Vandormael, Sikkema and Forsyth, 2009), and Ghana (Garcia et al. Stein and Li 2008). Furthermore, stigmatizing attitudes do not apply to all people living with HIV equally. One study of attitudes among women in Puerto Rico, for instance, found that there was significantly less sympathy for people living with HIV who were drug users, somewhat more for people

living with HIV described as homosexual, and the most sympathy for children and heterosexual women with HIV (Norman, Abreu, Candelaria and Sala 2009).

## **2.6 HIV/AIDS-related Stigma and Discrimination in Sub-Saharan Africa**

The prevalence of HIV/AIDS induced stigma in the Sub Saharan region is worth reviewing. This is so because the region accounts for a huge proportion of people affected by the

disease condition. There are widespread cases of stigmatization and discrimination of PLWHA in Sub Saharan Africa (Alubo et al., 2002; Bond et al., 2002; Mill, 2003; Muyinda et al., 1997; UNAIDS, 2001c; UNAIDS, 2002e; UNAIDS, 2002-2003). Some of the reported cases obtained for use have serious limitations with regards to their scientific and empirical quality. The information that has been collected on HIV/AIDS-related stigmatization is often of an anecdotal quality with a limited scientific utility. Parker & Aggleton (2002) point to how these limitations can be due to the unavailability and/or inadequacy of theoretical and methodological tools. The lack of scientific research on the manifestations of HIV/AIDS-related stigma in SSA presents a serious challenge to the understanding, alleviation and prevention of HIV/AIDS related stigma (UNAIDS, 2002-2003). Stigma manifests itself with great variation within the region of SSA. Stigma often leads people to do things, or omit to do things, that harm others or denies them services or entitlements (UNAIDS 2002e).

Discrimination with regards to HIV/AIDS occurs when negative thoughts and emotions lead people or institutions to take action that treat PLWHA unfairly and unjustly on the basis of their presumed or actual HIV-status. Because of the stigma associated with HIV/AIDS, and the discrimination that may follow from this, the human rights of PLWHA are frequently violated (UNAIDS, 2002c; UNAIDS 2002-2003).

Individuals can stigmatize and discriminate both in their personal and professional capacities. Systems and institutions can stigmatize and discriminate through practices and policies (UNAIDS, 2002-2003). Statistics in Ethiopia, Tanzania and Zambia indicate that people are largely unaware that their attitudes and actions are stigmatizing (International Center for Research on Women, [ICRW, 2002]. This highlights the need to put HIV/AIDS-

related stigma on the public agenda. The family is the main source of care and support for PLWHA in most SSA countries (Parker and Aggleton, 2002). Obligations to care for family-members with HIV/AIDS have been documented in Uganda (Muyinda et al., 1997). Amongst Zambian women, safe disclosure has been considered to imply telling their mothers about their HIV-status (Bond et al., 2002). This may illustrate the importance of family as a source of support for PLWHA. A recent study from Ghana indicates a

willingness amongst family-members to offer PLWHA care and support, though stigma also is evident (Mill, 2003).

Research from Tanzania has indicated that even when PLWHA have been cared for by their family-members, they have experienced stigma and felt that love has been withdrawn from them (Lie, 1996). Negative family responses to PLWHA are also common (Horizons, 2002). When a family learns that one of its members is HIV-positive, a tendency may be to isolate or to chase that person away. HIV/AIDS brings shame upon the entire family, and in many cases the family rejects family-members with HIV/AIDS (UNAIDS, 2002e).

Several women in a Ghanaian study reported that their families were no longer willing to share meals with them after the disclosure of the sero-status; some were told not to touch anything belonging to family-members (Bond et al., 2002). Bond (2002) reported that amongst women in Ghana, negative outcomes were experienced in the forms of being avoided and isolated. In Uganda, PLWHA have been blamed for domestic instability, and been given insufficient care and treatment. People have avoided places where PLWHA have been. It has also been reported that community members have stopped buying produce from PLWHA (Muyinda et al., 1997). In Zambia women have also reported experiencing blame, rejection, bitterness, anger, insufficient treatment and neglect (Bond et al., 2002). Common forms of stigma in Zambia are gossip, verbal abuse and name calling. The common humiliating practices which reflects stigma associated with HIV/AIDS include, people avoid sitting close to PLWHA, and avoid contact with items they have used (Bond et al., 2002). In Tanzania, people have avoided purchasing goods from PLWHA (Biswalo & Lie, 1995). PLWHA often find themselves in a position of weakness, abandonment and



extreme isolation in the community, a situation that is difficult to deal with (UNAIDS, 2002e).

In the education sector PLWHA have been refused enrollment or access to educational facilities. Schools and universities have excluded and expelled pupils or students perceived to be HIV-positive. In addition they received negative treatment by both peers and teachers, through teasing and violence (Parker & Aggleton, 2002). In Zambia, AIDS orphans have been taunted and called disparaging names, and sending HIV-positive children to school has been considered unsafe (Bond et al., 2002). Students and school children have also been segregated within the classroom (UNAIDS, 2002-2003). Women and children are particularly vulnerable to HIV/AIDS-related stigma in Botswana, Tanzania and South Africa, due to stigmatization in the education sector (France, 2001). In a study from Zambia, the stigmatization of teachers also became evident, as leave was imposed upon them thus making their illness visible (Bond et al., 2002). In Botswana, private companies have tested employees for HIV during regular health-checks without informing them it was a HIV test. If test results were positive, they were subsequently fired (Lie et al., 1996). There is prohibitions to enter certain occupations, and mandatory HIV testing as a requirement to obtain work permits have also been documented (Parker & Aggleton, 2002). Employees have reportedly been treated poorly and harassed by both business leaders and co-workers. Co-workers have refused to work next to PLWHA (Parker & Aggleton, 2002

In many instances, the institutions where one expects to obtain care and support is the first place where people experience HIV/AIDS-related stigma (UNAIDS, 2002-2003). Health care settings have been identified as the most frequently sited context for experiencing HIV/AIDS-related stigma in SSA (UNAIDS, 2001a). In health care settings, stigma may be expressed in terms poor quality medical care, restricted access to facilities, or denial of drugs and treatment. Conditional treatment, name tagging, lack of confidentiality, negative attitudes of health workers are some documented incidents (UNAIDS, 2002-2003). In Zambia, patients have reportedly been segregated, isolated, left in the corridors, been attended to last, been called disparaging names, and been discharged to go home or to go to

traditional healers so that people with “other” diseases could have the hospital beds (Bond et al., 2002; UNAIDS, 2002e). In some hospitals, HIV test results are not communicated to patients, and testing has been conducted without any pre- or post-test counseling (UNAIDS, 2002e).

In a Ghanaian study, women reported that information about their own HIV-status and their partner’s cause of death had been withheld from them (Mill, 2003). In health care settings, medical research on HIV/AIDS has also been conducted inappropriately and unethically. Research has been performed without informed consent and confidentiality. Some patients have been discriminatorily selected and misused for research projects, and non-equitable access to information and benefits of research has been given (UNAIDS, 2002e). HIV/AIDS-related stigma in health care settings poses a serious threat to HIV/AIDS prevention and care. HIV/AIDS-related stigma in health care settings can directly prevent people from attending HIV/AIDS testing, seeking treatment, care and support (France, 2001). Health care personnel have both a responsibility and a unique opportunity to deal with stigma within their professions and workplaces (Health and Development Networks [HDN], 2001). Courtesy stigma has also been reported in Uganda (Muyinda et al., 1997).

#### *HIV/AIDS related stigma in Nigeria*

In Nigeria, family-members express an obligation to take care of family-members with HIV/AIDS, though they mostly accept the status within themselves and tend to shamefully shield them away from the community (Alubo et al., 2002). When PLWHA become very sick, it brings shame upon their families, members of the family tend to stigmatize them, treat them with hostility and as less valuable members of the family. In many cases PLWHA often experience stigmatization at home and in the community through blame, rejection, abandonment, neglect, unjust treatment and punishment (Alubo, Zwandor, Jolayemi and Omudu, 2006). Expulsions, separation, confiscation of property and marital disharmony are documented (UNAIDS, 2002e). In Nigeria, it is not only PLWHA who are affected by the HIV/AIDS-related stigma, but also people affiliated to them.

In Nigeria, community members have encouraged family-members of PLWHA not to waste time or money on them, since the disease cannot be cured anyway (Alubo et al., 2002). Communities may shun, mock, and gossip about those who have, or are perceived to have HIV/AIDS and stigma may manifest itself in form of violence and murder (Adeyemo and Oyinloye, 2007). Community members have reportedly been treating PLWHA as if they were already dead, staring blankly at them, sitting far away, not paying them visits, spitting at them and not wanting to eat together or share pit latrines with them (Alubo et al., 2002).

Stigmatization of HIV infected and affected persons have been identified as a constraint to addressing the HIV/AIDS epidemic in Nigeria (Adeyemo and Oyinloye, 2007). Since HIV/AIDS related stigma and the resulting discriminatory attitudes create an environment that fuels the epidemic, programs targeted at educating people about HIV/AIDS can play a role in reducing the stigma and discrimination against people with AIDS. A study carried out by Oyediran, Oladipo and Anyanti (2005) found that majority of their respondents expressed discriminatory attitudes. The study also revealed that factors which significantly influence the likelihood of stigmatizing PLWHA include the following: belief by males and females that HIV could be contacted through sharing of meals; levels of educational attainment also play a significant role in influencing stigma. Younger people (15 -24 year olds) who were less educated, from the south west and south east zones and who had minimal exposure to radio and television messages were more likely to exhibit discriminatory attitudes to an HIV positive young child being allowed in school. Interestingly respondents who were more educated and from the north-east and north-west were most unwilling to disclose that a family member was HIV positive (Babalola, S.A Fatusi and J,A nyant 2009).

While the majority of respondents (88%) in this study have heard about HIV, misconceptions about the mode of transmission of the virus was relatively high and appears to be fueling the discriminatory attitudes expressed by both male and female respondents. Given also that younger and less educated persons were more likely to discriminate against people living with HIV, national information, education and communication programs need

to emphasize the correct modes of transmission of the virus so that fears can be allayed and people can relate compassionately with friends and relatives living with HIV/AIDS.

A study conducted by Oyediran, Oladepo and Ayanti (2005) has shown that people living with HIV/AIDS are considered as having no hope and therefore are viewed as economically unproductive people even though they may be physically fit. Programs need to educate the general public that while AIDS remains incurable, it is possible for people living with the virus to live functional and economically viable lives with adequate nutritional and psychosocial support, rest, treatment of opportunistic infections and antiretroviral therapy (Oyediran *et al.*, 2005).

### **2.7 Stigmatizing Attitude towards HIV/AIDS**

A recent study conducted in Cameroon among private plantation worker's attitude to HIV/AIDS and PLWHA (Jane, Igbokwe and Agioh 2011). The study revealed that on an average, 69.4% of the respondents in the plantations indicated positive attitudes towards HIV/AIDS. Although a high proportion of the respondents generally had a positive attitude towards HIV/AIDS, a good proportion of them also presented negative attitudes towards PLWHA. For example, 59.3% indicated that they would like HIV/AIDS patients in the plantation to be known while 47% of the respondents would not feel comfortable having PLWHA as neighbours. About 38% were not in favor of sharing room/office with or buying goods from a known HIV/AIDS patient while about 35% were in support of the idea that a law should be enacted to compel HIV/AIDS positive individuals to publicly disclose their HIV status. The results also showed that about 28% of the workers would neither want to work in the same plantation with PLWHA nor shake hands/hug an HIV/AIDS patient while 39.5% and 33.7% would not have an HIV/AIDS patient as a friend or be willing to eat together with HIV/AIDS patient, respectively. Many 30% of respondents indicated that they would want HIV/AIDS positive workers not to be allowed to work in the plantations. Some respondents believed that HIV/AIDS positive persons had gotten what they deserved as they were responsible for their illness by being sexually loose. The results showed that although there was a high positive attitude among respondents indicator of HIV/AIDS-

related stigma and discrimination still existed in the plantations. This stigmatization and discrimination would have a severe negative impact on the plantation as affected worker(s) may decide to quit their jobs before their status becomes common knowledge.

According to Odimegwu (2003), the stigma associated with HIV is promoted by various factors such as fear, the way the disease disfigures the patient, misconception of transmission routes and fatal nature of the disease. These sentiments may be translated into actions of avoidance of an infected individual. However, over 80% of the respondents Odimegwu study were willing to care for a family member who had HIV/AIDS. This probably reflects that no matter how stigmatized the disease is, people are willing to make sacrifices in order to care for their close relatives. According to Bharat, Aggleton and Tyrer (2001), misconceptions about how HIV infection may be transmitted tend to promote negative attitudes towards PLWHA. Consequently, respondents who believe that HIV infection can be transmitted through sex or sharing a meal with PLWHA are more likely to stigmatize and discriminate against PLWHA than other people. This might be indicative of the fact that negative response and attitudes towards PLWHA are strongly linked to general levels of knowledge about HIV/AIDS and in particular, to the causes of AIDS and to routes of HIV transmission. In other words, the perception of how HIV/AIDS is acquired is critically important to how people will relate with PLWHA (Bharat et al. 2001).

## **2.8 Stigma and Discrimination versus Human Rights**

Stigma and discrimination are interrelated, reinforcing and legitimizing each other (FMOH, 2003). Stigma lies at the root of discriminatory actions, leading people to engage in actions or omissions that harm or deny services or entitlements to others. Discrimination can be described as the enactment of stigma (UNAIDS, 2000). In turn, discrimination encourages and reinforces stigma. Discrimination is a violation of human rights. The principle of non-discrimination, based on recognition of the equality of all people, is enshrined in the Universal Declaration of Human Rights and other human rights instruments (Gostin and Lazzarini, 1997). The declarations prohibit discrimination based on race, colour, sex, language, religion, political or other opinion, property, birth or other status. Furthermore, the United Nations Commission on Human Rights has resolved that the term 'or other

status' used in several human rights instruments 'should be interpreted to include health status, including HIV/AIDS', and that discrimination on the basis of actual or presumed HIV-positive status is prohibited by existing human rights standards.

Stigmatizing and discriminatory actions, therefore, violate the fundamental human right to freedom from discrimination. This implies that discrimination directed at people living with HIV or those believed to be HIV-infected, leads to the violation of other human rights, such as the rights to health, dignity, privacy, equality before the law, and freedom from inhuman,

degrading treatment or punishment. There are many direct and indirect links between the HIV epidemic and lack of protection of human rights. Violation of rights may worsen the impact of HIV, increase vulnerability and hinder positive responses to the epidemic (Gostin, 1992). The effects will be briefly reviewed.

- **Impact:** The violation of human rights worsen the impact of HIV encapsulated in discrimination increases the impact of the epidemic on people living with HIV and those presumed to be infected, as well as their families and associates. For example, a person who is dismissed from his or her job because of being HIV-positive, beyond his illness, is faced with many additional problems, including lack of economic resources for his health care, as well as providing for any dependent family.
- **Vulnerability:** People are more vulnerable to infection when their civil, political, economic, social or cultural rights are not respected. For example, women's vulnerability to HIV infection is enhanced where they do not have the legal power to make choices in their lives and to refuse unwanted sex; or where children cannot realize their rights to education and information. Further, lack of access to appropriate HIV prevention and AIDS care services increases the vulnerability of other marginalized groups such as injecting drug users, refugees, migrants and prisoners (Ingstad, 1990; Peterson, 1990; Mushingeh, Chana and Mulikelela, 1991; Thant 1993).

• **Response:** Where human rights are not respected, for example when freedom of speech or freedom of association is curtailed, it is difficult or impossible for civil society to mobilize themselves to respond effectively to the HIV epidemic. In some countries, peer education is hampered by laws that refuse official registration of non-governmental organizations or groups with certain memberships (for example, sex workers) (Guskin, Hendricks, Tomasevski, 1996). Ensuring the protection, respecting and fulfilment of human rights is one important way of combating AIDS-related stigma and discrimination (Grant, 2003). AIDS-related stigma and discrimination and their consequential human rights violations may be addressed through the use of existing human rights mechanisms. This existing

framework provides a basis for accountability and an avenue for recognizing and enforcing the rights of people living with HIV who suffer discrimination on the basis of their actual or presumed HIV-positive status to challenge such action through procedural, institutional and monitoring mechanisms for enforcing human rights, and have recourse for countering and redressing discriminatory action.

International human rights principles provide a coherent, normative framework within which to analyze and redress AIDS-related discrimination (UNAIDS 2003). States are responsible and accountable, not only for the direct or indirect violation of rights, but also for ensuring that individuals can realize their rights as fully as possible. The *International Guidelines on HIV/AIDS and Human Rights*, published in 1998 by UNAIDS and the Office of the United Nations High Commissioner for Human Rights, clarify the obligations of states contained in existing human rights instruments and how they apply in the context of AIDS.

## **2.9 Consequences of HIV/AIDS-induced Stigmatization and Discrimination**

There are several levels at which HIV/AIDS-related discrimination and stigmatization may be experienced and felt. These include societal and community levels, in addition to the experience of individuals.

### ***Societal and community levels***

Societal laws, rules, policies and procedures may result in the stigmatization of people living with HIV/AIDS. A significant number of countries have enacted legislations aimed at controlling the actions of HIV/AIDS-affected individuals and groups (Tomasevski et al., 1992). These laws include the following legislation: compulsory screening and testing of groups and individuals; prohibition of people living with HIV/AIDS from certain occupations and types of employment; medical examination, isolation, detention and compulsory treatment of infected persons; limitations on international travel and migration; restriction of certain behaviors such as injecting drug use and prostitution (Gostin & Lazzarini, 1997).

International experience shows that such measures serve only to increase and reinforce the stigmatization of people living with HIV/AIDS and those at greatest risk of contracting the virus. In many countries, discriminatory practices such as the compulsory screening of certain populations or “risk groups” cause both the stigmatization of such groups and a misplaced sense of security among those who do not see themselves as belonging to these sections of the population.

Restrictive and coercive measures – frequently enacted to “protect” society from infection – discriminate against, or exclude, those who are already infected. Laws that insist on the compulsory notification of HIV/AIDS cases and the restriction of a person’s right to anonymity and confidentiality, as well as the right to movement of infected persons have been erroneously justified on the grounds that the disease constitutes a public health emergency (Mak et al., 2006). With some other infectious diseases such responses may be justifiable. However, in the case of an already highly stigmatized condition such as HIV/AIDS such discriminatory policies and legislates result in punitive measures that further discriminate against people living with HIV/AIDS and may drive those infected, and those most vulnerable, further underground (Gostin and Lazzarini, 1997). It is heart warming to note that several countries have enacted legislations to protect the rights and freedoms of people living with HIV/AIDS and to safeguard them from discrimination (Mann, Tarantola and Netter, 1992; Mann, Tarantola and Netter, 1996).



Much of the HIV/AIDS related legislations have sought to ensure the right to employment, education, privacy and confidentiality, as well as the right to information access, treatment and support (Gostin and Lazzarini, 1997). However, the failure of governments to protect people living with HIV/AIDS from discrimination, through legislation or through the active enforcement of such legislation, is a violation of their human rights (Gruskin, Hendricks, and Tomasevski, 1996). The apathy of some governments in providing effective systems of prevention, treatment and care may arise from more deep-seated stigmatization at a societal level (Milner, 1991). Governments and national authorities contribute to HIV/AIDS-related stigmatization in other ways. They may, for example, cover up and conceal cases or fail to maintain reliable and transparent reporting systems (Milner, 1991; Whiteside, 1993).

Ignoring the existence of HIV/AIDS, neglecting to respond to the needs of those living with HIV infection, and failing to acknowledge burgeoning epidemics as a result of perceived non susceptibility are some of the most widely reported stances (Daniel, 1991; Milner, 1991).

Stigma and discrimination, both real and perceived, may also arise from a variety of community-level responses to HIV/AIDS. The harassing and scapegoating of individuals suspected of being infected or of belonging to a particular group has been widely reported (Byrne, 1992). It is often stimulated by the need to blame and punish and can, in extreme circumstances, extend to acts of violence and murder (Nardi and Bolton, 1991). Attacks on men who are presumed gay have increased in many parts of the world, and have been associated with the growing HIV/AIDS epidemic (Peterson, 1990). Sex workers and street children in Brazil have likewise been singled out for violence and abuse (Peterson, 1990; Byrne, 1992). HIV/AIDS-related murders have been reported in countries as diverse as Brazil, Colombia, Ethiopia, India, South Africa and Thailand (Panos, 1990). In December 1998, Gugu Dhlamini was stoned and beaten to death by neighbours in her township near Durban, South Africa, after speaking out openly on World AIDS Day about her HIV status (Crandall and Coleman, 1992).

In a highly stigmatizing environment, people may withdraw from society as a means of self-preservation. This isolation can extend to exclusion from social and sexual relationships and – in extreme circumstances could lead to premature death through suicide or euthanasia (Gilmore & Somerville, 1994; Hasan et al., 1994). More often, however, stigmatization causes a kind of *social death* in which individuals no longer feel part of civil society, and are no longer able to access the services and support they need (Daniel and Parker, 1990). Who to tell, how and when, can be a potential source of fear and anxiety among many people living with HIV/AIDS and may prevent individuals from accessing treatment and care (Moynihan et al., 1995; Omangi, 1997). Even where laws have been enacted to protect the rights and confidentiality of people living with HIV/AIDS, few people are prepared to litigate for fear that it would become widely known in the process.

Those who are identified as belonging to marginalized and/or minority groups may also worry about the reactions of others, regardless of their sero-status. Fear of telling family members about their homosexual orientation has recently been cited by some Mexican men as equal to the fear of revealing their HIV sero-status (Castro et al., 1998a; 1998b). The impact of HIV/AIDS on women is particularly acute.

In many developing countries, women are economically, culturally and socially and educationally disadvantaged and lack equal access to treatment and financial support. Being outside the structures of power and decision-making, women are erroneously perceived as the main transmitters of Sexually Transmitted Infections (STIs). Together with traditional beliefs about sex, blood and other kinds of disease transmission, these perceptions provide a fertile basis for the further stigmatization of women within the context of HIV/AIDS (Ingstad, 1990; Peterson, 1990; Thant, 1993). There is clear evidence from UNAIDS-supported studies of household and community responses to HIV/AIDS in developing countries (Warwick et al., 1998; Aggleton and Warwick, 1999) that sero-positive women are likely to be treated very differently from men. Whereas men are likely to be “excused” for the behavior that resulted in their infection, women are not. In India, for example, the husbands who infected them may abandon women living with HIV/AIDS. Rejection by wider family members has also been reported as common (Bharat and Aggleton, 1999). In

some African countries, women whose husbands have died from AIDS-related infections have been blamed for the death. The diseased relatives may also evict the surviving spouse from her home (Henry, 1990). Fearful of such situations, some women may prefer to remain ignorant of their sero-status or may keep it a secret (Dunn, Green Hammond and Roberts, 2009).

Individual denial of risk and vulnerability is not an uncommon response to the epidemic (Crocker, 1999). Such denial may manifest itself in self distancing from the problem and, in extreme cases, can result in people misperceiving their vulnerability (Lie, 1996). Denial can also discourage voluntary testing among many people, particularly members of especially vulnerable groups. This, in turn, may increase the potential risk of HIV transmission within

the community (Lie and Biswalo, 1996). Such action undermines prevention, care and support (Muyinda et al., 1997).

### **2.10 Impacts of HIV/AIDS-related Stigmatization on the Individual**

Baumeister and Leary (1995) have proposed that the need to belong is a fundamental human motivation. This theory elucidates the impact stigmatization can have on individuals, at the same time as it coincides with perspectives on the functions of stigma. Stigma affects and disrupts relations, therefore this theory can be used as a framework for understanding the impacts HIV/AIDS-related stigma can have on PLWHA. The impacts this can have on PLWHA can be understood in light of the need to belong as a fundamental human motivation.

Baumeister and Leary (1995) reviewed the existing empirical evidence in order to evaluate the validity of ‘‘the need to belong’’ as a fundamental motivation, and conclude that the evidence supports ‘‘the need to belong’’ as a fundamental motivation. They proposed that the ‘‘need to belong’’ has two central features: *frequency* and *quality* of interactions and relations. People need to have frequent contacts or interactions with other people, and these need to be seen as stable, continuous and marked by affective concern. Thus, to satisfy ‘‘the need to belong’’, the person must perceive the other as one who cares for and is concerned about his or her welfare, and the interactions and contact should be of a certain frequency.

“The need to belong” as a fundamental motivation can therefore not elucidate the impact of stigma on the individual in all cases.

The need to belong can only elucidate the impacts of stigma in those situations where stigma disrupts relations based on frequent, stable, continuous and affective contact. As the need to belong is a fundamental motivation, loss of frequent affective care should provoke aversive reactions in the individual that go beyond negative affect (Baumeister and Leary, 1995). Disruption and fear of disruption of important relationships are major stressors for humans, negatively effecting psychological and physical well-being. The tendency for human beings to respond to distress and protest to the end of a valued relationship is nearly universal, even across cultures and across the age span (Baumeister and Leary, 1995).

Anxiety and distress at separation from important others can be seen during infancy (Mahler et al., 1975). Social exclusion may be the most common and important cause of anxiety and depression is linked to the degree to which one feels included and accepted by others (Baumeister and Leary, 1995). Changes in one’s “belongingness status” will produce emotional responses, with positive emotions linked to increases in belonging, and negative emotions linked to decrease in belonging. Many people even resist dissolving relationships that are harmful and destructive (Baumeister and Leary, 1995). General well-being and happiness in life seems to depend on having some close social ties. The connection between social support and psychological health is consistent in psychology (Orford, 1992). Social support is relevant to the need to belong because social support is based on positive relationships and interactions with others. Social support is health promoting and can also function as a buffer against stressful life events (Orford, 1992). People facing the challenge of coping with a life threatening disease condition like HIV/AIDS, are thus further burdened by the potential disruption of social relationships and the potential loss of social support. AIDS orphans are especially vulnerable. Due to their status as orphans, they may become overwhelmed by lack of belongingness (Mrumbi, 2000).

Rejection of PLWHA and the withdrawal of love from them can be seen as violations of their basic human need to belong (Baumeister and Leary, 1995). This violation may be one of the gravest consequences of HIV/AIDS-related stigma. Research on HIV/AIDS-related stigma carried out in Tanzania found that the experience of spouse stigma was predictive of depression, guilt and feelings of not having meaningful relationships (Lie, 1996). Research has shown that depression renders people more susceptible to illness and infection, as it negatively affects the functioning of the immune system and its ability to combat physical disorders (Gilbert, 1992). This illustrates the cyclic dynamics of the HIV/AIDS-related stigma, mental and physical health.

### **2.11 Consequences of Stigma for the Families of PLWHA (Secondary Stigma)**

The consequences of HIV and AIDS-related stigma do not begin and end with the HIV positive person, but extend to include their families, children, and even friends and caregivers (Alubo, Zwandor, Jolayemiand and Omudu, 2002). This phenomenon is generally referred to as “secondary stigma or stigma by association. Across all the research sites, the parents of the person with HIV were often held responsible for the “bad” behavior, which led to the HIV infection of their children. The following quotes illustrate this point: *Some people say that the father never taught him good manners so he has ended up getting the disease (Bond. Chase and Agneton, 2002).*

People tend to think that children get this disease when they become spoiled. People say that the family is to blame, not the infected one. Because of this attribution of blame, as well as the close shared physical proximity, family members of people living with HIV and AIDS experience many of the same expressions of stigma as do the those living with HIV and AIDS themselves, including being the subject of gossip, being socially ostracized and isolated, and even losing income, employment, or housing. The children of people living with HIV and AIDS may bear the worst impact of stigma, sometimes being denied a place in school or being taunted, teased, and rejected by peers (Mrunbi, 2000).

## **2.12 HIV Stigma as a Barrier to HIV Prevention, Treatment, Care and Support**

A substantial body of literature, both qualitative and quantitative, has emerged to convincingly support the hypothesis that stigma inhibits access to services and adherence to treatment (Bwambale, Sali, Byaruhanga, Kalyaango and Karamangi 2008). Indeed, HIV and AIDS-related stigma is a phenomenon that almost all respondents, whether or not they knew their HIV sero-status were aware of. The presence of stigma and the fear of experiencing its effects has a profound impact on the ability and willingness of people to access and utilize the services that are available for controlling the further development of the epidemic. For example, HIV/AIDS-related stigma inhibits people from seeking treatment for infections that are closely associated with HIV, such as TB, skin rashes, and certain types of diarrhoea, whether or not they have tested positive for HIV ( Mak, Cheung,

Cheung and Lee, 2006). As a peer educator in Zambia explained: *It is TB, skin rashes and cancer [that are most associated with HIV]. Most people who have these diseases are shy to talk about their diseases, which makes them stay away from the clinic or the hospital to receive treatment (Melchior, Nemes, Alencar and Buchalla 2007).*

### ***Impact of Stigma on Prevention***

Stigma served to distance the non-infected from people living with the HIV. Fear of casual transmission has the effect of shifting the focus on to mechanisms of transmission that are largely impossible and/or those modes that are the least risky, but over which people have the least perceived control (Murphy, Austin and Greenwell 2006). The moral judgment aspect of stigma allows the non-infected to deny their risk because if someone perceives him or herself to be at the greatest risk through means over which he or she has no control or if a person perceives no risk, then he or she probably will not take the measures necessary to protect against acquiring HIV (Alonzo and Reynolds, 1995, Jones et al., 1984; Katz 1991).

Stigma, therefore, operates in a number of ways to distance people from a sense of risk (Strangor and Crandall 2000; Gilmore and Somerville,1994). Stigma creates an obstacle to prevention. Stigma gets in the way of prevention in several ways. Even where there is a

fairly high sense of vulnerability to HIV, stigma seems to interfere with the ability of individuals or couples to discuss condom use and use condoms regularly and correctly (Khumalo-Sakutukwa, Morin, Fritz, Charlebois, Rooyen, Chingono, Modiba, Mrumbi, Visrutaratna, Singh, Sweat, Celentamo and Coates 2008). Condoms themselves have acquired a strong stigma through their close association with HIV in the press and health promotion campaigns. Thus, the mere suggestion of using a condom in any given sexual encounter can be interpreted as tantamount to admitting one's own infidelity, or that one suspects one's partner has not been faithful.

### ***Impact of Stigma on Testing***

The vast majority of data on the relationship between stigma and HIV testing comes from sub-Saharan Africa (Kalichman and Simbaya, 2007). While willingness to test for HIV was high (89%) among antenatal clients in Nigeria, women who were unwilling to be tested cited strong fears of stigma should they test positive for HIV (Adeneye et al., 2006). In contrast, only 33% of a sample of antenatal clients had been tested for HIV in Botswana. Women who declined to test did not believe stigma to be a substantial reason for refusing an HIV test, but concerns about the confidentiality of results were a substantial reason for refusing a test (Creek et al., 2009). Fear of stigma and discrimination were dominant reasons for the 60% of pregnant women who refused HIV tests in a Vietnam based study (Thu Anh et al., 2008). Stigma has been cited as a primary barrier to using VCT services in Botswana, South Africa, Tanzania, Thailand, Uganda, and Zimbabwe (Wolfe et al., 2006; Bwambale et al., 2008; Khumalo-Sakutukwa et al., 2008). "Perceived stigma" was a predictor for declining to test for HIV among both men and women in a study of Nigerian youth and adults in South Africa (Hutchinson and Mahlalela 2006; Babalola 2007). In South Africa, the effect of perceived stigma on avoiding VCT was stronger for women than it was for men (Hutchinson and Mahlalela 2006). South Africa study and in Brazil, one of the few studies on VCT and stigma outside of Sub-Saharan Africa (Kalichman and Simbaya 2007; Pulerwitz et al., 2008) Respondents' own stigmatizing attitudes were negatively associated

with likelihood of having tested for HIV in Cape Town. In contrast to the majority of literature on the relationship between stigma and testing, a study in Zimbabwe found that uptake of testing was significantly higher among those women and men who had observed enacted stigma, though the study could not determine whether observed enacted stigma occurred before or after testing (Sambisa, 2008).

### ***Impact of HIV on Uptake and Adherence to Anti-retroviral Therapy***

The role of stigma in reducing uptake of ART is unclear. Stigma emerged spontaneously as the second most frequently listed reason women do not begin ART in a qualitative study in Zambia (Samuels, Simbaya, Sama, Geibel, Ndubani and Kamwanga, 2008); but in a Nigeria study of men and women, less than 4% of respondents feared stigma (Murphy, Austin and Greenwell 2006). One explanation for such apparently contradictory findings

may lie with the gender of the respondents and the social and economic costs of accessing services, all of which are experienced differently by men and women (Nyirenda et al., 2006). A study of directors of NGOs providing HIV-related services in Zambia reported that a majority believed HIV-positive women were especially vulnerable to negative social consequences, which impedes access to a range of services (Benotsch, Seal, Stevenson, Sitzler, Kelly, Bogart and Gorefelton 2008). The evidence is much clearer that stigma and discrimination present barriers to good adherence to ART. Perceived stigma and internal stigma were inversely associated with adherence in the US, (Roberts, 2005); United Kingdom, (Samuels, Simbaya, Geibel, Ndubani and Kanwanga., 2008); Brazil, (Ware et al., 2006); Botswana, (Calin, Gree, Hetherington and Brook. 2007) and China, (Melchior, Nemes, Alencar and Buchalla 2007; Rao et al. 2007; Nam, Fielding, Avalos, Dickson, Gaolathe and Geissler 2008; Sabina et al. 2008; Thrasher, Earp, Golin and Zimmer 2008; Dlamini et al., 2009; Naidoo et al., 2009). In analyses using multi-variate models, this relationship persisted when controlling for other factors. In one US study, patients with high stigma concerns were 3.3 times more likely to not adhere to their ART regimen (Dlamini et al., 2009). However, a study in Peru demonstrated that stigma decreased and adherence improved with intensive investments in daily adherence support (France, 2001). A related finding from qualitative studies on the context of prevention of mother-to-child



transmission services in Malawi and South Africa is that fear of stigma and discrimination, along with fear of household conflict, divorce, and lack of support from husbands, were oft-cited as a reasons for women dropping out following their initial antenatal clinic visit (Bwirire et al., 2008; Varga and Brookes, 2008). Women also expressed concern about the focus on the health of the infant and worried about access to ART for themselves (Murphy, Austin and Greenwell, 2006).

### ***Impact of Stigma on Disclosure***

A related and extremely important consequence of stigma is its effect on people's ability and willingness to disclose a positive test result to others. People living with HIV struggled with the issue of disclosure (Hongjie, Zhi, Xiaoming, Stanton, Naar-King and Hongmei 2006). In some cases, as with one woman in Vietnam, people live with the knowledge that they have HIV for years without telling even their most intimate partners for fear of stigma and its consequences, which can include physical violence and/or abandonment. As was the case for a woman, who continued to have sexual relations with her husband without condoms, and who had another child without availing herself of mother-to-child transmission prevention services, this can mean that the necessary measures are not taken to prevent the further transmission of the virus (Nam, Fieding, Avalos, Dickson, Gaolathe and Geissler, 2008).

In some cases, people with HIV avoid making use of available support services out of fear that using those services would result in public disclosure of their status. As one woman living with HIV in Vietnam reported, *'The ward invited me [for counseling] several times but I did not go because I am reluctant to meet people there.... It is normal for a drug addicted person to be infected. But for me, people tell each other, "Look, such a girl but yet infected." So I feel reluctant. I do not want to go [to the ward's activities for those living with HIV]'* (Obermeyer and Osborn, 2007).

The study findings indicate that HIV and AIDS-related stigma is an important obstacle for prevention, impeding people from getting tested for HIV or from disclosing their HIV status to others. Although anti-retroviral treatment (ART) was not widely available in any of the research sites at the time these studies were conducted, evidence is now emerging

from a number of ART pilot sites indicating that there, too, stigma is an obstacle. It was certainly an issue for the use of prevention in mother-to-child treatment programs in Botswana and Zambia (Nyblade and Field, 2000). Indeed, HIV and AIDS-related stigma is a phenomenon that almost all respondents, whether or not they knew their HIV sero-status, were aware of.

The conceptualization of HIV/AIDS as a disease of shame, sexual promiscuity and immorality has consequences for disclosure and help-seeking behavior. The fear of HIV/AIDS-related stigma and its negative impacts force many PLWHA to face the dilemma of whether to disclose their status or not (Macdonald, 1998). Some people choose to disclose their HIV-status to one or a few significant others while others yet again go fully public. Some people choose to tell no one. These choices all have their different and

varying consequences. The fear people have in connection with disclosure of their HIV-status have been identified as the manifestations of felt stigma (Bharat et al., 2001).

Disclosure may be necessary to obtain social support. Some HIV-positive people who disclose receive a supportive network by so doing, gaining both emotional and instrumental support. Others become abandoned as a result of their disclosure. One cannot always know for sure what the reactions to disclosure will be, making the dilemma whether or not to disclose painstaking (Muyinda et al., 1997). The many examples of the negative consequences of disclosure are abundant, e.g. in Durban, South Africa, AIDS activist Gugu Dlamini was beaten and died of the injuries after revealing her HIV-positive status during a commemoration of World AIDS day in 1998 (UNAIDS, 1999). Episodes like this spread fear and shape perceptions and ideas of what will happen if PLWHA disclose. Wanting to protect significant others from worry is also a motivation for not disclosing one's HIV-status (Muyinda, Seeley, Pickering and Baron 1997). Major dilemma facing many HIV-positive parents is whether or not to tell their children (Lie, 2000).

Goffman (1963) noted how information control becomes very important to the individual who chooses to keep his or her stigma hidden. Individuals who try to keep their stigmas

hidden, can become obsessively preoccupied with thoughts around their stigma. This can be explained by Lane and Wegners' theory of the "preoccupation model of secrecy". According to this therefore, framework attempts at secrecy activate cognitive processes that lead to obsessive thinking about the secret (Smart and Wegner, 2000). The constant monitoring of the interaction, steering it in the direction that will best facilitate concealment of the stigma and the cognitive capacity this requires, is bound to influence how one interacts in the relationship. The effort and strain that secrecy requires can take its toll on both the psychological and physical well-being of the individual. Crandall & Coleman (1992) have found that PLWHA who do not disclose their status to significant others are likely to become more isolated, more depressed and more anxious than those who selectively confide in people they feel they can trust. Keeping one's HIV-positive status hidden from significant others can influence the quality of that relationship.

In summary, it is often fear of rejection that leads PLWHA to choose silence. This can leave them to live in constant fear of their status being revealed, and the perceived or real consequences disclosure could have. The constant risk of discovery can turn in to a major stress factor, creating a considerable amount of psychological distress, and negative impact on the physical condition. Choosing silence thus burdens the individual with secrecy, at the same time as it deprives the individual of potential sources of social support (Miller & Major, 2000). As illustrated, neither keeping ones stigma hidden, nor disclosing it comes without a price. However, disclosure has the potential to be beneficial both for PLWHA and the society.

Studies in New Mexico, Alabama and Mississippi, US found strong gender differences in the use of health services (Wingood, Diclemente, Mikhail, McCree, Davies, Hardin, Hook and Saag 2007). While the experience of stigma was implicated in avoiding care-seeking for all, women reported more stigma and avoided seeking health care more often than men, resulting in poorer health outcomes (Wingood, Diclemente, Mikhail, McCree, Davies, Hardin, Peterson, Hook and Saag 2007; Dunn et al., 2009). Delayed treatment-seeking among Zimbabwean men was also attributed to fear of stigma, particularly for sexual health concerns (Pearson et al 2008), A history of TB could prevent or discourage access to care

because TB could be a marker for HIV. This situation has been experienced in South Africa (Moller and Erstad, 2007).

### **2.13 Alleviation, Prevention of HIV/AIDS-related Stigma**

The tremendous impact of HIV/AIDS-related stigma, at both individual and societal levels, call for immediate actions aimed at alleviating and preventing it. HIV/AIDS-related stigmatization has for long been regarded mainly as an individual phenomenon. This accounts for why awareness raising and attitude-change campaigns, together with educative strategies based on behavioral psychological models, have consequently dominated attempts that have been carried out to counter the phenomenon. Understanding stigma as a phenomenon linked to group processes and functioning, to the production and reproduction of structural inequalities, and as central to the constitution of social order, has major

implications for how stigma and stigmatization should be investigated and responded to (Parker and Aggleton, 2003).

The control of HIV/AIDS should take into consideration the broader social, cultural and economic forces that facilitate its production and maintenance (Agadzi 1989; Garcia Gonzalez, 2000; Parker and Aggleton, 2003). A broader perspective or focus implies dealing with the social structures and power relations that allow stigma to prosper. Attitudes, misconceptions and fear associated with HIV/AIDS should also be challenged coupled with provision of care and support for PLWHA (Parker and Aggleton, 2003).

Stigma is a socially constructed phenomenon and can manifest itself differently across many settings or cultures. This poses ethical and methodological challenges to its control and prevention. No universal or correct way for alleviating and preventing HIV/AIDS-related stigma still. In order to effectively tackle HIV/AIDS-related stigma, some methodological and ethical perspectives need to be taken into consideration. Cultural sensitivity, empowerment and action research emerged as important components in any attempt to deal with HIV/AIDS-related stigma in SSA. These perspectives have been emphasized by several researchers working with HIV/AIDS-related challenges (Beeker et al., 1998; Dageid, 2002, France 2001; Krantz & Staugård, 1996; Lie, 1996; Lie, 2000;

Parker, 1996; Patel et al., 2002; Rakotonanahary et al., 2002; Shoepf, 1995; Skjelmerud & Tsubira, 1997; United Nations Development Programme [UNDP], 2000; Wang, 1992).

It is necessary to discuss the key concepts one after the other starting with cultural sensitivity.

- i. **Cultural sensitivity:** In order to understand how people and communities contribute to mental health suffering, like that of HIV/AIDS-related stigma, and to be able to offer appropriate mental health services, cultural factors must be studied (Swartz, 1998; Triandis, 1990). Cultural sensitivity refers to a professional's knowledge of culture and cultural differences. Knowledge of culture involves knowledge of how culture evolves, what constitutes culture, and how culture can change. It also implies an acceptance of diversity and a willingness to take culture into account when seeking to understand how others think, feel and behave within a certain context (Brislin, 1993; Sue & Sue, 1999). Gaussett (2001) highlights how one should not disregard African systems of belief that do not fit into Western discourses, but rather assimilate them when working with HIV/AIDS related challenges. Before any alleviative or preventive strategies can be planned or implemented, the assessment of stakeholders' needs, priorities, and cultural standards is necessary (Swartz, 1998).

Acquiring cultural sensitivity with regards to HIV/AIDS-related stigma means striving to take new patterns of thought and explanations for the phenomenon into consideration (Cresswell, 1998). It is important to keep in mind that people do not always behave according to the cultural standards. Taking a culture sensitive stance is therefore not sufficient in dealing with HIV/AIDS-related stigma in SSA including Nigeria. One must also strive to be sensitive to each and every individual. In this regard, phenomenological psychology holds an important point of view. Phenomenological psychology stresses people's understanding of the self and one's surrounding world as explanatory for reactions and behaviors. From the perspective of some phenomenologists, no objective or universal reality exists (Creswell, 1998; Egidius 2000; Graham, 1986). People's understanding is based upon their own reality, as it is lived and

experienced. This reality, however, is instituted in a cultural context. Both these perspectives are important to keep in mind when working in the cultural diversity of SSA.

- ii. **Empowerment**: Empowerment is a value orientation for creating social change in the community; it also conotes a theoretical model for understanding attempts to exert control and influence over decisions that affects one's life, at individual, organizational and community level (Zimmerman, 2000). The implicit assumption in empowerment is that people are believed to benefit psychologically from more awareness, participation and control (Zimmermann, 2000). People who have self-knowledge are believed to be more effective in making decisions in their lives, and education is therefore a critical component of empowerment (Swift, 1992).

In empowerment, opposition to the status quo becomes accepted, and generates objectives of change that expand to an ever-widening circle of self-induced change (Parker, 1996; Swift, 1992). Freire (1970) calls for a related collaborating approach involving liberating learning through co-generative dialogues. In such a process the professional change-agent assists, interacts and cooperates with the stakeholders in developing self-awareness. Such self-awareness can serve as a base for problem-definitions, goals and actions, and make change come into being. Through co-generative dialogues, empowerment activities have the potential to transform communities into positive circles of self-help and greater fulfilment (Swift, 1992). Garcia Gonzalez (2000) believes that the HIV/AIDS-epidemic will lead us to discover the importance of combining empowerment as a health promoting strategy with traditional prevention strategies. Empowerment as a health promoting strategy is a dialectic model (Parker, 1996).

The goal is a generative spiral of never ending empowering processes, as change is carried out through a holistic unit of analysis, interactively both in persons and environments. Swift (1992) stresses the importance of seeking the causes behind

the causes in preventive work. Combined prevention and empowerment strategies can address both the critical dangers threatening the wellness of society and the flaws and structures of society inhibiting positive transformation (Swift, 1992).

Van Uchelen (2000) points out how psychological theory is dominated by individualistic rejection of PLWHA and the withdrawal of love from PLWHA can be seen as violations of their basic human need to belong. This violation may be one of the gravest consequences of HIV/AIDS-related stigma. Research on HIV/AIDS-related stigma carried out in Tanzania found that the experience of spouse stigma was predictive of depression, guilt and feelings of not having meaningful relationships (Lie, 1996). Research has shown that depression renders people more susceptible to illness and infection, as it negatively affects the functioning of the immune system and its ability to combat physical disorders (Gilbert, 1992). This illustrates the cyclic dynamics of the HIV/AIDS-related stigma, mental and physical health.

#### Home-based Care and Support

Evidence from Kenya suggests that quality of care by family members is improved when stigma is low. Less expressed stigmatizing attitudes were associated with greater care and support knowledge and insights into the needs of children under their care. While provision of care activities within the home is sometimes an explicit attempt to avoid potential discrimination at formal services, families caring for an HIV-positive family member cite fear of stigma from community members as a dominant concern. Home-based care professionals also report stigma to feature strongly as a barrier to introducing home-based care services (Waterman et al. 2007).

#### Stigma-reduction Interventions

Documented evaluations of programmes to reduce HIV stigma and discrimination lag behind research on the prevalence of stigma or its relationship to uptake of services. Furthermore, the available evaluation data are unlikely to be fully representative of the range of anti-stigma interventions being implemented. For example, a search for

programmes on Popline search engine yielded more than 200 results since 2005, but only a half dozen of those met inclusion criteria of having stigma reduction as a primary or secondary objective and having conducted an evaluation with an outcome measure of stigma (Adams, 2009). An essential component to the effective response to HIV stigma are programmes working with and led by people living with HIV (Urena, 2009). Yet there were no published evaluations of these programmes' impacts on stigma to date, a glaring gap in the literature (Samuels et al., 2008).

Programme activities using the media and mass communications appear especially likely to have effective results. One Ghanaian programme that used religious leaders to convey compassionate messages showed that stigmatizing attitudes declined with exposure to the campaign over time (Boulay et al., 2008). Exposure to edutainment programs, such as serial dramas aired on TV or radio, was correlated with more accepting attitudes in Botswana and Kyrgyzstan, but no significant relationship was found with a similar programme in Malawi (O'Leary et al. 2007. Pappas-DeLuca et al. 2008; Rimal and Creel 2008; Adams, 2009). Another study in Nigeria that used a household survey found that personal exposure to HIV messages in the media was significantly and positively associated with accepting attitudes, but this effect worked predominantly through exposure's effect on increasing HIV-related knowledge (Babalola, Fatusi and Anyanti, 2009).

Several community-based interventions with multiple activities demonstrated significant changes in stigma at the community level in Thailand (Apinundecha et al., 2007); Tanzania (Nyblade et al., 2008); Vietnam and Zambia (Nyblade, MacQuarrie, Kwesigabo, Jain, Kajula, Philip,

Henerico Tibesigwa and Mbwambo 2008; Samuels et al. 2008). Each of these programmes focused on community participation and interaction. While all of these programmes included awareness-raising and sensitization and HIV knowledge awareness, the exact content and modalities of these programmes are too diverse to easily glean which approaches are most responsible for their success. Interventions studies in Vietnam and Tanzania suggest that opportunities for sustained dialogue about values and beliefs is



important for reducing more than fear-based stigma and tackling other drivers of stigma. Some community programmes included the provision of services, including home-based care, VCT, or ART (Attawell et al. 2005; Khumalo-Sakutukwa, Morin, Fritz, Charlebois, van Rooyen, Chingono, Modiba, Mrumbi, Visrutaratna, Singh, Sweat, Celentano and Coates 2008; Samuels, Simbaya, Sarna, Geibel, Ndubani and Kamwanga 2008).

Interventions to reduce stigma among providers in health care settings in India (Mahendra, Gilborn, George, Samson, Mudoji, Jadav, Gupta, Bharat and Daly 2006), Ghana (EngenderHealth, 2007), Tanzania Wu et al., 2008), Vietnam and China (Oanh, Ashburn, Pulerwitz, Ogden and Nyblade 2008) also showed improvements in stigmatizing attitudes and discriminatory care practices over time or in comparison to control groups.

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## **2.14 Conceptual Framework**

### **The Ecological Model**

The Ecological model explains the interaction between and within the network across various levels of the environment. The model highlights people's relationship with their physical and socio-cultural environments. There are two key concepts of the ecological model that help to identify intervention points for promoting health. The first is that behavior affects and is affected by multiple levels of influence, while the second is that individual behaviour shapes and is shaped by the social environment. McLeroy, Bibeau, Steckler and Glanz (1998) identified five levels of influence for health-related behaviours and conditions for the explanation of the first key concept of the ecological perspective. The levels include intra-personal or individual level, inter-personal level, institutional or

organisational level, community level and public policy level. These levels will be briefly explained.

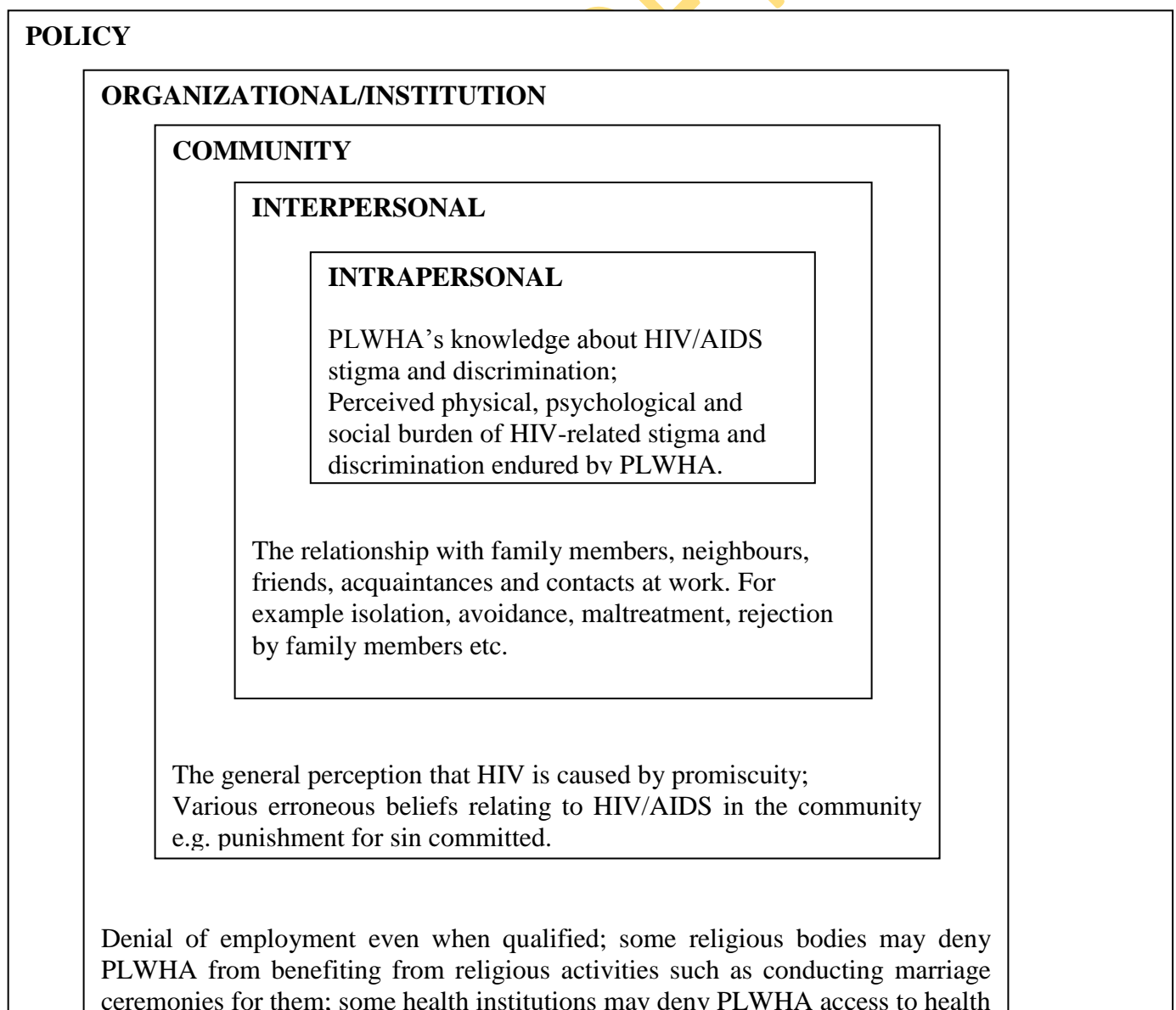
- i. *The intra-personal level:*** At this level the characteristics of an individual such as knowledge, attitude, perceptions and behavior come to play. For example, the

PLWHA's knowledge about HIV/AIDS stigma and discrimination; perceived physical, psychological and social burden of HIV-related stigma and discrimination endured by PLWHA.

- ii. *The interpersonal level:*** At this level the influence of (significant) others come into play. This involved the relationship with family members, neighbours, friends, acquaintances and contacts at work. For example, other people's actions or behavior perceived by PLWHAs to be stigmatizing and/or discriminating; and the various attitudes of other people perceived to be discriminatory or stigmatizing by PLWHA.
- iii. *The organization level:*** Organizations such as religious bodies, NGOs, workplaces, hospitals etc constitute groups that may promote stigma and discrimination towards PLWHAs. For example, some organizations may not employ PLWHA even if they are qualified; some religious bodies may deny PLWHA from benefiting from religious activities such as conducting marriage ceremonies for them; some health institutions may deny PLWHA access to health services.
- iv. *The community level:*** Various social networks and cultural norms or standards exist formally or informally among community members. Some of these social and cultural norms may be perceived as a form of stigma or discrimination. For example the general perception that HIV is caused by promiscuity; various erroneous beliefs relating to HIV/AIDS in the community.
- v. *The policy level:*** Local, state and federal policies and laws exists to regulate or support healthy actions and practices for disease prevention, early detection, control and management. Some of this policies and laws may be perceived by PLWHA as non-existence or ineffective in protecting their interests against stigma and discrimination. For example ineffective or non-existence national/state policy on HIV and AIDS in workplaces which promotes discrimination against PLWHA by making it compulsory for all workers or

- vi. applicant to undergo HIV tests in order to keep their jobs or be employed; denial of entry visa into some countries because of ones HIV positive status.

An ecological perspective shows the advantages of multi-level interventions that combine behavioral and environmental components. Furthermore the model depicts a holistic approach to problem identification and resolution. The ecological model adapted to facilitate the study on prevalence of perceived stigmatization and discrimination among people living with HIV is presented in figure 2.



**Figure 1.1: Ecological model applied to the Stigmatization and Discrimination among People Living with HIV**

Source: McLeroy, Bibeau, Steckler and Glanz (1898).

**CHAPTER THREE**

**3.0**

**METHODOLOGY**

**3.1 Study Design and Scope**

The study is a descriptive cross-sectional survey of persons living with HIV and AIDS, who were receiving care at the President Emergency Plan for AIDS Relief (PEPFAR), University College Hospital (UCH) Ibadan. The PEPFAR clinic is one of the many HIV treatment centres in Nigeria. The clinic was established in the 2004.

The study conducted between May and June 2010, was limited in scope to the attitude, beliefs, perceptions and behavior ever perceived to be stigmatizing or discriminating by persons living with HIV and AIDS. The study also includes the perceived psychosocial effect of HIV-induced stigma and discrimination.

It should be noted that the study was not limited to the stigmatizing and discriminating experiences endured at the PEPFAR clinic alone. Rather it entailed all the experiences ever endured in various social settings and in other health care settings before enrolling for care at PEPFAR. The PEPFAR clinic merely served as the setting where PLWHA were enlisted

for study. The findings of this study are not therefore necessarily a reflection of what happens to PLWHA at the PEPFAR Clinic.

### **3.2 Description of Study Setting**

University College Hospital Ibadan is one of the 15 Federal University Teaching Hospitals in Nigeria. The hospital is located in Ibadan, the largest city in West Africa. The hospital was established to serve as a teaching hospital for medical and allied professionals. The other functions of the Teaching Hospital include the provision of qualitative and affordable tertiary health care to Nigerians and also conduct clinical researches. Being a federal health care institution which is reputed for being a centre of excellence in medical education and clinical services, it is not uncommon to find patients from different parts of Nigeria at the hospital. The hospital consists of various clinics, including the PEPFAR clinic which is dedicated to the care and support for PLWHA.

The PEPFAR clinic UCH is jointly managed by the Government of the United State of America, the Nigerian government in collaboration with UCH, Ibadan and Harvard school of Public Health U.S.A. Some University College Hospital staff members are seconded to the clinic to provide care for persons living with HIV/AIDS. The clinic is situated behind United Bank for Africa (UBA) building within the UCH premises. The PEPFAR clinic has other service centres in the following locations within UCH and College of Medicine Upremises:

1. Antenatal clinic, UCH
2. HIV diagnosis laboratory of the Department of Virology, College of Medicine, University of Ibadan based in UCH premises
3. HIV and Voluntary counselling centres located in 1. The General Outpatient Department, 2. Heamatology department (Blood Bank), 3.Special treatment care unit and at the Children Outpatient unit, UCH.

The PEPFAR clinic what has a strong support group, serves as a place of refuge for many patients. Group meeting serve as a rendezvous for mutual social support and group counseling. The clinic also has six satellite stations in various neighbourhood in Ibadan

namely: Eleta, Oluyoro and Adeoyo (all in Ibadan metropolis). The other satellite service centres are located in Ogbomosho, Saki (all in Oyo state) and Ijebu –Ode (Ogun state).

### 3.3 Study Population

The adult persons attending PEPFAR clinic constituted the study population. They were persons living with HIV and AIDS. They were of different socio-demographic characteristic. They came from the different parts of Nigeria. The clinic, as at the time of the study admitted approximately 35 new patients per day.

#### The Inclusion criteria

These were respondents confirmed to be HIV positive and/ or having AIDS. In addition they should be aged 18 years and above and be willing to participate in the study.

#### Exclusion Criteria

People living with HIV and AIDS who were very sick, those on admission bed and unwilling patients were excluded from the study without any form of intimidation.

### 3.4 Sample size determination and Sampling Procedure

**Step 1** - In order to obtain an acceptable sample of the study population, an organizational diagnosis was first conducted to document the population of PLWHA registered at PEPFAR clinic in UCH. The diagnosis revealed that the clinic had approximately 11000 patients and that females constituted approximately 60% of the total population.

**Step 2** – This stage involved the calculation of the number of PLWHA to be sampled. The sample size was calculated at 95% confidence interval using the following formula:

$$N = \frac{z^2 * p(1 - p)}{d^2}$$

where N = sample size

$$\begin{aligned}
z &= \text{confidence level at 99\% (standard value of 2.578)} \\
p &= \text{reasonable estimate of key proportions 50\% or 0.50} \\
d &= \text{margin of error at 5\% (standard value of 0.05)} \\
n &= \frac{2.578^2 * 0.5 (1 - 0.5)}{0.05^2} \\
&= 665
\end{aligned}$$

The calculated sample size of 665 was increased to 700 in order to address possible cases of attrition or incomplete responses.

**Step 3** – Proportionate and stratified random sampling techniques were used in selecting the respondents. The PLWHA were stratified into two homogeneous groups of females and males. Female were 60% while the males were 40%. In view of the fact that the sample

size required was 700, the number of PLWHA in each category was calculated using the formula below:

$$\text{Category sample size} = \frac{\text{Percentage of group by sex} \times \text{Sample size}}{100\%}$$

For example the calculation of Category sample size of females was:

$$\frac{60\% \times 700}{100\%} = 420$$

Therefore 420 PLWHA that were females and 280 PLWHA that were males were recruited for study.

**Step 4** – This entailed the selection of PLWHA to be interviewed. It is to be noted that the total sample size to be selected was 700 out of approximately 11000 PLWHA attending the PEPFAR clinic. The sampling fraction for facilitating systematic random sampling was calculated using the formula below:

$$\frac{S}{K}$$

Where

S = sample size

K = total population

Therefore the sample fraction was:

$$\frac{700}{11000} = \frac{1}{16}$$

Therefore the first respondent was selected randomly between patient 1 and 16. Thereafter, every 16<sup>th</sup> PLWHA was recruited as a study respondent. If the first selected respondent was 10, then other respondents would be: 26, 42, 58, 74 and so on. Whenever any of the 16<sup>th</sup> person declined to participate, then the 17<sup>th</sup> person was selected. Purposive sampling procedure was also used to select eight participants with adverse discriminatory experiences such as divorce, dismissal from work and so on for in-depth interview (IDI). It is to be noted that all registered PLWHA were expected to come to the clinic for follow-up care at least once a month as recommended. Therefore, the study was carried out on all the clinic days for a period of two months.

### **3.5 Methods and Instruments for Data Collection**

Both qualitative (IDI) and quantitative (Semi-structured interview) methods were used for data collection. The instruments were designed after reviewing relevant literatures relating to HIV-related stigma and discrimination with special reference to pertinent variables relating to prevalence, attitudes and beliefs, perceived psychological and social burden and strategies for coping with HIV related stigma and discrimination. The design of the instruments was also facilitated by the use of the ECOLOGICAL model. (see chapter two)

#### **3.5.1 The Questionnaire**

A self administered questionnaire (Appendix 2) was used to obtain the necessary information from respondents. The questionnaire was developed by the researcher based on literature reviewed and the information obtained from in-depth interview together with inputs from the supervisor and health promotion specialists in the Faculty of Public Health, University of Ibadan. The questionnaire was divided into five sections. It was used to collect data from the respondents on experiences relating to HIV-related stigma and discrimination; perception relating to HIV-related stigma and discrimination; determination of respondents' attitude, consequences/effects of HIV-related stigma and discrimination;



and past and prevailing coping strategies to HIV-related stigma and discrimination experiences. The questionnaire consisted of both open-ended and close-ended questions and was administered. Purposive sampling procedure was used to select eight respondents with adverse discriminatory experiences who were interviewed on In-dept Interview.

Questionnaire Survey: The investigator and five RAs interviewed 700 PLWHA respondents that were eligible for the interview over a period of two months. Each interview began with an introduction and overview of the research including the objective of the study. Each respondent was informed that participation in the study was voluntary and that information disclosed by them would be kept confidential. The respondents were instructed not to write any names on the questionnaire. Each copy of the questionnaire was either interviewer-administered or self-administered depending on the respondents' level of education. Respondents were encouraged to ask questions on what they did not understand in the questionnaire. The interviewers encouraged the respondents to complete all sections of the

questionnaire applicable to them. Explanations were given to the respondents as required to aid their understanding of the questionnaire. The copies of the questionnaire were retrieved from the respondent's immediately after completion and reviewed for incompleteness and necessary correction.

### **3.5.2 Indepth Interview (IDI) Guide**

An Indepth Interview guide (IDI) developed by the researcher was used to obtain pieces of information that were included in the quantitative data collection tool(questionnaire). There were five major questions in the indepth interview guide.

The questionnaire was divided into five sections organized into sections A-E. Section A focused on respondents' demographic characteristics; section B was on experiences relating to HIV-related stigma and discrimination. Section C focused on respondents' perception of HIV-related stigma and discrimination. Section D was used to assess respondents' attitude, consequences/effects of HIV-related stigma and discrimination; while section E explored respondents' past and prevailing coping strategies to HIV-related stigma and discriminatory experiences (see Appendix 2 for details).

### **3.6 Validity**

Validity describes the ability of an instrument to measure what it is expected to measure. Several measures were taken to ensure that the instruments were valid. The instruments were designed in English and translated to Yoruba by someone vast in both English and Yoruba. This was later translated back to English by an expert who was equally vast in Yoruba and English so as to ensure that the instruments were well translated and the meanings of the items in the questionnaire were not lost during the process of translation. The In-depth interview guide and the questionnaire were reviewed in-house among experts in the Department of Health Promotion and Education, medical sociologists, and a medical statistician for face, construct and content validity.

### **3.7 Reliability**

The questionnaire was pre-tested to enable the researcher make final adjustments and to find out how reliable and consistent the questions were in enlisting the desired responses. The Cronbach's Alpha Model technique was also employed to measure the reliability of the instrument. This involves administering the questionnaire once to slightly more than 10% of study population and consequently the coefficient of reliability was calculated using the SPSS computer software. The result showed correlation coefficient was greater than 0.05. The result of the analysis of the data collected during the pre-test was 0.89 which showed that the instrument was reliable.

### **3.8 Pretest of Instruments and Training of Research Assistants (RAS)**

#### Training of RAS

Training was conducted for five recruited Research Assistants (RAs) using multiple training methods including lecture, role-play and brain storming. This ensured that they had adequate understanding of the instruments, prior to commencement of data collection. The training focused on the objectives and importance of the study, sampling processes, how to secure respondents' informed consent, interviewing skills and review of questions to ensure

completeness. The RAs were also involved in the pre-test of the questionnaire in order to create an experiential learning opportunity for them.

### The Pretest exercise

The two instruments (indepth interview guide and questionnaire) were pre-tested in other health care facilities with HIV/AIDS related activities in Ibadan. Indepth interview guide was pre-tested among HIV/AIDS related support group leaders at Adeoyo Hospital, Ibadan. The questionnaire on the other hand was pre-tested among PLHWA at Saint Mary's Catholic Hospital Eleta in Ibadan. A total of 10% of the sample size for the study was used for the pre-test. Both the researcher and supervisor assessed clarity, understandability and completeness of questions.

### **3.9 Data Collection Process**

Visits were made to the PEPFAR clinic and a letter was written to the Project Directors to seek official permission and to intimate them about the study (see appendix 3). The processes of data collection were as follows:

The IDI guide developed by the researcher was used to obtain information that was included in the quantitative (questionnaire) data collection tool. There are five major questions in the indepth interview guide that was used for the interviews. (see appendix 4)

### **3.10 Data Management and Analysis**

The following activities were carried out to ensure good data management and analysis:

- The quality of the data collected was checked by the researcher in the field. This entailed reviewing the pattern of responses of each respondents as recorded in the questionnaire. Problems discovered during data collection were resolved immediately in the field.
- A serial number was assigned to each of the copies of the questionnaire for easy identification and recall of any instrument with problems.

- Copies of the administered questionnaire were edited and coded by the investigator with the use of a coding guide. The data in each copy of the questionnaire were entered into a computer for analysis using the Statistical Package for Social Sciences (SPSS).
- The data were analyzed using descriptive statistics, Chi square and t-test.
- The findings of the study were summarized and presented in tables and figures in chapter four.
- The administered copies of the questionnaire were stored in a place that would be safe from destruction by any means and where unauthorized persons would not have access to them. They will be destroyed one year after the defense of the dissertation.

### **3.11 Ethical Consideration**

The study proposal was submitted to the UI/UCH Ethical Review Committee for evaluation and approval. This was to ensure that the study conformed with the generally accepted scientific principles and international ethical guidelines relating to researches involving human subjects. Official permission and approval was also obtained from the managements of University College Hospital, Saint Mary Catholic Hospital, Adeoyo Hospital and from the PEPFAR authority where the actual study was conducted.

Informed consent was obtained from study respondents. All respondents were informed that participation was voluntary and that they had the choice not to participate if they so wished without any penalty or loss of any privileges at any stage of the interviews. Respondents were assured that confidentiality of responses would be maintained during and after data collection. Only identification numbers were assigned to each copy of the questionnaire after data collection and no name or identifier was required on the questionnaire. The identification numbers were used to facilitate data entry and to recall of any copy of the

questionnaire with problems. No one can link the identity of any respondent with the identification numbers.

### **3.12 Limitation of the Study**

Since the treatment centre is located within a research institution, PLWHA might have been participating in one other form of research or the other. This could constitute research fatigue which could affect the quality of responses supplied. Effort was made to brief the respondents about the importance/benefit of the study and the long term benefit of participating in it to society and the depth of care and support programme. Also, Data may have been influenced by methods of interview adopted.

## **CHAPTER FOUR**

### **4.0 RESULTS**

#### **4.1 Socio-Demographic Characteristics**

The ages of respondents ranged from 14 to 79 years with a mean of  $40.0 \pm 9.4$  years and a median age of 39.5. Majority (71.3%) were aged 30-49 years. A large proportion (67.7%) of them were females. Respondents' occupations included trading (47.2%), artisan (10.9%) and teaching (7.4%). Some respondents (18.1%) were retired civil servants and 5.0% were unemployed. Christianity (62.2%) topped the list of the religions practiced by respondents followed by Islam (37.4%). Majority (69.0%) of the respondents were married. The singles and widows accounted for 12.1% and 10.4% respectively. Respondents with secondary education were 35.0% while those with tertiary education constituted 36.1%.

Majority (85.1%) of the respondents were Yoruba while 8.0% were Igbo, (see table 1 for details).

**Table 1: Socio-demographic Characteristics of Respondents**

N= 700

<b>Socio-demographic characteristics</b>	<b>N = 700</b>	<b>%</b>
<b>Age group</b>		
14 - 29	94	13.4
30 - 39	256	36.6
40 – 49	243	34.7
≥50	107	15.3
<b>Occupation</b>		
Trading	330	47.2
Civil Servant	190	27.1
Artisan	111	15.9
Unemployed	35	5.0
Students	29	4.2
(Clegy, king and politicians)	5	0.6
<b>Religion</b>		
Christianity	435	62.2
Islam	262	37.4
Traditional	3	0.4
<b>Marital Status</b>		
Married	483	69.0
Single	85	12.1
Widow	73	10.4
Separated	37	5.3
Divorced	19	2.7
Cohabitation	3	0.4
<b>Education Status</b>		
No formal Education	67	9.6
Primary Education	135	19.3
Secondary Education	245	35.0
**Tertiary Education	253	36.1
<b>Ethnic Group</b>		
Yoruba	596	85.1
Igbo	56	8.0
Others	36	5.1
Hausa	14	2.0

#### **4.2 HIV Screening-related Issues, Sexual Partners and Sexual Partners' Sero-status**

The research participants were first screened for HIV in several parts of Nigeria. Majority (86.9%) of them were, however, screened in Oyo state with those screened in Ibadan (78.6%) topping the list followed distantly by participants who were screened at Ogbomoso (4.1%). The details of the distribution of the respondents by location of place of screening are shown in table 2.

Sixty-four percent of the respondents were diagnosed to be HIV-positive in Federal Government owned institutions; others were diagnosed in private health care institutions (25.4%), NGO/CBO/FBO establishments (6.7%) and state hospitals (0.1%). (See details in table 3).

Thirty-nine percent of the respondents' partners were HIV negative while 36.9% of respondents' partners were HIV positive. A sizeable proportion (24.1%) did not know their partners' HIV status. (See Figure 2). A significantly higher proportions (78.8%) of males were more aware of their partners' HIV status compared with their female counterparts. (Details in table 4)

Majority (95.1%) of the respondents had sexual partners. Eighty seven percent of the respondents' sexual partners were their spouses and boy/girl friends constituted 12.4% of the respondents.



**Table 2: Locations where respondents were first diagnosed of being HIV positive**

**N=700**

	<b>No</b>	<b>%</b>
<b>Place of diagnosis/Screening</b>		
Ibadan	550	78.6
Lagos	14	2.0
Akure	25	3.6
Jos	8	1.1
Saki	12	1.7
Ogbomosho	29	4.1
Ijebu Ode	17	2.4
Other Oyo towns	53	8.4
Ondo	9	1.3
Abuja	3	0.4
Benin	4	0.6
Osun	12	1.7

Persons screened in Oyo state = 86.9%

Note: Proportion screened in South west geopolitical zone = 97.9%

**Table3: Ownership of screening centres used by respondents during the study period**  
**N= 700**

<b>Ownership</b>	<b>No</b>	<b>%</b>
Federal Government	448	64.0
Private	178	25.4
NGO/CBO/FBO	46	6.7
Mission	24	3.4
Local Government, Health Centre	3	0.4
State Government	1	0.1

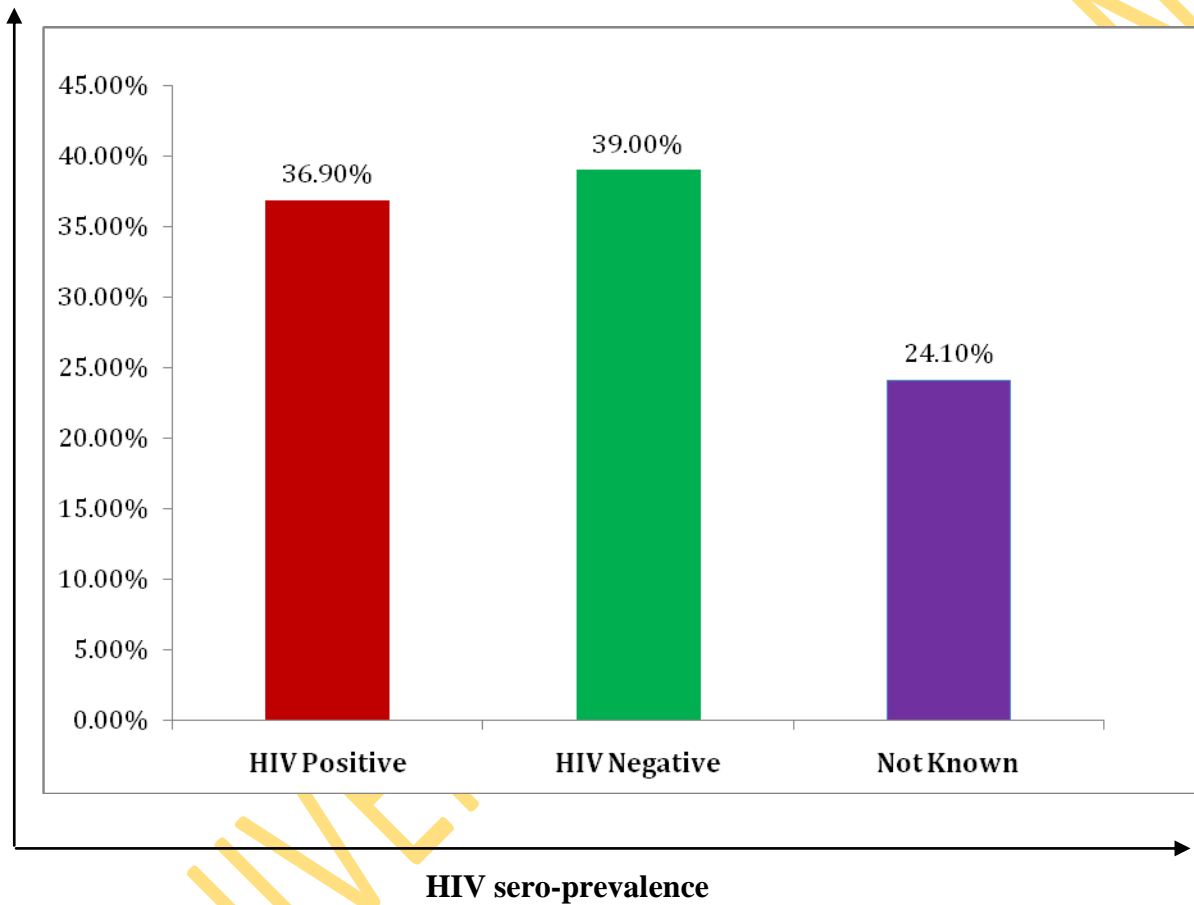


Fig 2 Reported HIV status of respondents' sexual partners

**Table 4 Awareness of partner's HIV status by gender**

**N = 700**

<b>Sex</b>	<b>Awareness</b>		<b>Total</b>	<b>X<sup>2</sup></b>	<b>p-value</b>
	<b>Yes (%)</b>	<b>No (%)</b>			
Male	178 (78.8)	48 (21.2)	226 (100%)	7.020	0.03
Female	330 (69.6)	144 (31.4)	474 (100%)		
<b>Total</b>	508 (72.6)	192 (27.4)	700		

### **4.3 HIV Stigma and Discrimination Experiences**

Some (30.3%) respondents' had ever been stigmatized, looked down upon or discriminated against as a result of their HIV status. (see figure 3). The proportions of male and female respondents who had ever experienced stigmatization/discrimination were (26.1%) and 32.3% respectively with no significant difference (See details in Table 5).

The HIV/AIDS induced-stigma and discrimination ever perpetrated against PLWHA took several forms; these forms included physical assault (24.1%), verbal abuse/insult (65.1%), subjection to ridicule (63.2%) avoidance by friends (42.0%) and not treated humanely like other patients (25.9%). The experiences of induced stigma within the three months preceding the study also included physical assault (13.7%), denial of job opportunities (15.2%) sack from job (14.7%) and refusal of medical care in a health care facility (20.0%) (See Table 6 for details). The gender differentiation of forms of HIV-induced stigma and discrimination perpetrated against the PLWHA included physical assaults, (male 7.1% ; female 16.9%), verbal abuse/insult male (16.5%) and female (48.6%), subjection to ridicule male (15.6%) and female (47.6%), denied job opportunity male (6.6%) and female (15.1%), avoided by friends male (11.8%) and female (30.2%), ejected from house male (3.8%) and female (12.7%) and refusal of medical care in a health facility (male 1.9%; female 9.9%). (See details in Table 7).

### **Experience of HIV/AIDS Stigma and Discrimination.**

Majority of the Indepth-interviewees reported ever been stigmatized. Perpetrators of HIV/AIDS stigma mentioned by Indepth-interviewees included husbands/wives, in-laws, friends, colleagues at work and even some health care providers. All the Indepth-interviewees were of the belief that HIV/AIDS induced - stigma is bad because anybody can as well be in their shoe. The following represents some of their verbatim quotes which expresses the experiences of stigma and discrimination endured by PLWHA:

*“I have been seriously stigmatized by my husband and in-laws. I am called different names, such as Iyawo oni Eedi”.*

*“My wife reported to church pastor about my sero-status and also exposed my status to her family members and she was advised to pack out. She push me out of bed before living my house claiming her parents said she can remain in my house if she wants to die”. “My own relatives also treated me badly by throwing food to me through the window”.*

An interviewee reported an experienced clinic-based stigmatizing treatment thus:

*“I was at x-ray unit of the hospital; one of the staff of the unit said rudely: E ma wuko siwa lenu” ( don’t cough into our mouth).*

Another young lady said pathetically:

*“I became sick and I was taken to hospital and my colleagues at work who came to the hospital to visit got to know that it was HIV/AIDS sickness. When I recovered, I was relieved of my job because they believed I would infect others by sharing cup with them. I told them I would bring my own cup but they did not listen to me’.*

Other quotes which reflect stigma experience included the following:

*“HIV/AIDS stigma is bad! I and my husband are both patent medicine vendors and after our marriage I conceived with twin pregnancy and I was diagnosed to be HIV positive. I told my husband and he said I should not tell anybody. When I delivered*

*the twins and nursed them for 3 months, I became very sick and my husband took me back to my family with the children and my parents really cared for me. After a year he came back and took the children away and he does not allow me to visit them; He does not allow them to received phone calls from me. His parents also did not want me to come near them at all. When I see them on the way and I greeted they will answer me with one word 'odabo' meaning bye-bye''.*

*'' I am a lawyer jilted by a boyfriend when he knew I am HIV positive. I also confided in a friend and disclosed my status to her but rather than being supportive she 'broadcasted' my status to other friends and she later packed out of the flat we were sharing together and ran away from me because she felt I may infect her''.*

*''HIV/AIDS stigma is the worst thing that can happen to someone. Can you imagine when the husband that vowed to live with you for the rest of his life ran away from you or asked you to leave and when you refused to leave he ran away and his family members also continue to fault you''.*

#### **4.4 Other Perceived Unpleasant Things People Living with HIV/AIDS Experience**

The other things experienced by PLWHA included poverty, abandonment, suicide, isolation, gossips, shame, blame for their predicament, sack from work, loneliness depression and rejection especially from the family. All these feelings or perceptions are among the consequences of HIV infection expressed by the indepth interview.

A female respondents disclosed for instance that:

*''we experience isolation, we are being gossip about and people avoid us; even some relatives send us out of the family compound''.*

*'' PLWHA are abused and exploited by traditional healers. When people in my village and my extended family members knew about the HIV status of my family and that I lost my daughter due to HIV infection they avoided us like leprosy. They did not visit or talk to us; they were waiting for the time that we will die but help came when the support group of people living with HIV/AIDS came to our rescue.*

*After our recovery from the deadly emergency state they still refuse to visit us. We sometimes force our-selves to visit them and when we visit them we will go with our bottle of water and our cup because they will not offer us anything and they will not allow their children to interact with us''.*

**Table 5 Respondents' who had ever experienced stigmatization and/or discrimination by gender**

**N=700**

Sex	Ever Experienced stigmatization		Total	X <sup>2</sup>	p-value
	Yes (%)	No (%)			
Male	59 (26.1)	167 (73.9)	226	2.761	0.097
Female	153 (32.3)	321 (67.1)	474		
<b>Total</b>	212 (30.3)	488 (64.7)	700		



**Table 6: Forms of induced-stigma and/or discrimination experienced by PLWHA**

Form of induced stigma and/or discrimination experienced by respondents	Ever experienced N= 212		Experienced within last three months N- 700	
	No	%	No	%
Physical assault				
Yes	51	24.1	7	13.7
No	161	75.9	44	86.3
Abused/insulted				
Yes	138	65.1	15	10.8
No	74	34.9	123	89.2
Subjected to ridicule				
Yes	134	63.2	16	12.0
No	78	36.8	118	88.0
Excluded religiously				
Yes	34	16.0	4	11.8
No	178	84	30	88.2
Sent out of the family				
Yes	39	18.5	4	10.3
No	172	81.5	35	89.7
Excluded from school				
Yes	24	11.3	1	4.2
No	188	88.7	23	95.8
Denied Job opportunity				
Yes	46	21.7	7	15.2
No	166	78.3	39	84.8
Sacked from Job				
Yes	34	16.0	5	14.7
No	178	84.0	29	85.3
Loose Promotion benefit				
Yes	32	15.1	4	12.5
No	180	84.9	28	87.5
Avoided by friends				
Yes	89	42.0	8	9.0
No	123	58.0	81	91.0
Refuse visa or Entry to any country				
Yes	18	8.5	3	16.7
No	194	91.5	15	83.3
Ejected from house				
Yes	35	16.5	2	5.7
No	177	83.5	33	94.3
Refused Medical care in a health care facility				
Yes	25	11.8	5	20.0
No	187	88.2	20	80.0
Refused Nursing Care in a health care facility				
Yes	30	14.2	8	26.7
No	181	85.8	22	73.3
Maltreated by health care personnel				
Yes	46	21.7	7	15.2
No	166	78.3	39	84.8
Disclosure of HIV status without consent by health personnel				
Yes	47	22.2	7	14.9
No	165	77.8	40	85.1
Not treated humanely like other Patients				
Yes	55	25.9	5	9.1
No	157	74.18	50	90.9
Humiliated				
Yes	99	46.7	10	10.1
No	113	53.3	89	89.9

\*This refers to last three months preceding the study

**Table 7 : Gender differentiation of forms of HIV induced stigma and/or discrimination**

Form of HIV-induced stigma and/or discrimination ever experienced by respondents	Sex	HIV-induced stigma/discrimination		X <sup>2</sup>	p-value
		Yes %	No%		
Physical assault (N=212)	Male	15(7.1%)	44(20.8%)	0.084	0.772
	Female	36(16.9%)	117(55.2%)		
Abused/insulted (N=212)	Male	35(16.5%)	24(11.3%)	1.199	0.274
	Female	103(48.6%)	50(23.6%)		
Subjected to ridicule (N=212)	Male	33(15.6%)	26(12.3%)	1.861	0.173
	Female	101(47.6%)	52(24.5%)		
Excluded religiously (N=212)	Male	10(4.7%)	49(23.1%)	0.050	0.822
	Female	24(11.3%)	129(60.9%)		
Sent out of the family (N=212)	Male	15(7.1%)	44(20.6%)	2.618	0.106
	Female	24(11.3%)	128(60.4%)		
Excluded from school (N=212)	Male	8(3.8%)	51(24.1%)	0.408	0.523
	Female	16(7.5%)	137(64.6%)		
Denied Job opportunity (N=212)	Male	14(6.6%)	45(21.2%)	0.198	0.656
	Female	32(15.1%)	121(57.1%)		
Sacked from Job (N=212)	Male	13(6.1%)	46(21.7%)	2.183	0.140
	Female	21(9.9%)	132(62.3%)		
Loose Promotion benefit (N=212)	Male	10(4.7%)	49(23.1%)	0.219	0.639
	Female	22(10.4%)	131(61.8%)		
Avoided by friends (N=212)	Male	25(11.8%)	34(16%)	0.005	0.943
	Female	64(30.2%)	89(42%)		
Refuse visa or Entry to any country (N=212)	Male	3(1.4%)	56(26.4%)	1.220	0.269
	Female	15(7.1%)	138(65.1%)		
Ejected from house (N=212)	Male	8(3.8%)	51(24.1%)	0.516	0.472
	Female	27(12.7%)	126(59.4%)		
Refused Medical care in a health care facility (N=212)	Male	4(1.9%)	55(25.9%)	1.975	0.160
	Female	21(9.9%)	132(62.3%)		

#### 4.5 Respondents' Experiences of Self-stigmatization

The indicators of the various forms of self-stigmatization ever experienced among respondents included fear of HIV status disclosure to family members (53.9%), fear of disclosing HIV status to friends (69.3%), stoppage of attendance to social functions

(17.7%), stoppage of visiting friends (19.6%), feeling ashamed of accessing medical care (29.4%) and limiting number of social functions or gatherings attended (25.3%). However, within the last three months preceding the study only 29.4% were afraid of disclosing their HIV status to family members and 26.4% were afraid of disclosing their sero-status to friends. (See details in table 8)

Table 9 highlighted the gender differentiation of experiences of self-stigmatization. The table shows that fear of disclosing their HIV status to family members is not significant. Only excluding oneself from religious activities because of HIV status is significant (See details in table 10).

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**Table 8: Respondents' experience of self-stigmatization**

Experiences of self-Stigmatization by stigma indicator:	Ever experienced N=700		Experienced within last three months N=700	
	No	%	No	%
Isolated self from family functions because of HIV status				
Yes	123	17.6	24	19.5
No	577	82.4	99	80.5
fear of disclosing status to family members				
Yes	377	53.9	111	29.4
No	323	46.1	266	70.6
Scared of disclosing status to friends				
Yes	485	69.3	128	26.4
No	215	30.7	357	73.6
Felt worthless because of HIV status				
Yes	137	19.6	32	23.4
No	563	80.4	105	76.6
Stopped social functions because of HIV status				
Yes	124	17.7	33	26.6
No	576	82.3	91	73.4
Excluded self from religious activities because of HIV status				
Yes	99	14.1	24	24.2
No	601	85.9	75	75.8
Stopped visiting some friends because of being looked down upon				
Yes	137	19.6	37	27.0
No	563	80.4	100	73.0
Stopped going to the office or to work because of HIV status				
Yes	83	11.9	16	19.3
No	617	88.1	67	80.7
Ashamed of accessing medical care				
Yes	206	29.4	50	24.2
No	494	70.6	156	75.8
Stopped applying for Jobs because of HIV status				
Yes	117	16.7	22	18.8
No	583	83.3	95	81.2
Limited the social functions or gatherings attended				
Yes	177	25.3	37	20.9
No	523	74.7	140	79.1
Stayed indoor most times because of my HIV status				
Yes	150	21.4	32	21.3
No	550	78.6	118	78.7

**Table 9 Gender differentiation in pattern of experience of self-stigmatization**

**N=700**

Indicator for self-Stigmatization	Sex	Self stigmatization		X <sub>2</sub>	p-value
		Yes	No		
Isolated self from family functions because of HIV status	Male Female	39(5.6%) 84(12%)	187(26.7%) 390(55.7%)	0.023	0.880
Scared of disclosing status to family members	Male Female	110(15.7%) 267(38%)	116(16.6%) 207(29.6%)	3.610	0.057
Scared of disclosing status to friends	Male Female	144(20.6%) 341(48.7%)	82(11.7%) 132(18.9%)	5.532	0.063
Felt worthless because of HIV status	Male Female	44(6.3%) 93(13.3%)	182(26%) 381(54.4%)	0.002	0.962
Stopped social functions because of HIV status	Male Female	45(6.2%) 79(11.3%)	181(25.9%) 395(56.4%)	1.105	0.293
Exclude self from religious activities because of HIV status	Male Female	43(6.1%) 56(8%)	183(26.1%) 418(59.7%)	6.586	0.010
Stopped visiting some friends because of being looked down upon	Male Female	44(6.3%) 93(13.3%)	182(26%) 381(54.4%)	0.002	0.962
Stopped going to the office or to work because of HIV status	Male Female	30(4.3%) 53(7.6%)	196(28%) 421(60.1%)	0.641	0.423
Ashamed of accessing medical care	Male Female	67(9.6%) 139(19.9%)	159(22.7%) 335(48.4%)	0.008	0.931
Stopped applying for Jobs because of HIV status	Male Female	40(5.7%) 77(11%)	186(26.6%) 397(56.7%)	0.233	0.630
Limit the social functions or gatherings attended	Male Female	59(8.4%) 118(16.9%)	167(23.9%) 356(50.6%)	0.119	0.730
Stay indoor most times because of my HIV status	Male Female	51(7.3%) 99(14.1%)	175(25%) 375(53%)	0.257	0.612

#### **4.6 Respondents' Perceptions Relating to HIV-related-induced Stigma and Discrimination and Stigmatizing Attitudes of People towards PLWHA**

The prevailing societal beliefs perceived by respondents to be stigmatizing or depicting an act of discrimination are shown in table 10. A large majority (73.9%) rightly disagreed with the view that anyone who has HIV is serving a punishment from God. A large proportion of the respondents (84.8%) did not share the view that anyone who is HIV positive does not deserve care and support because they are paying for their misdeeds. Eighty-three percent of the respondents disagreed with the view that it is not proper to employ workers who have HIV because of their low productivity. Few (7.3%) of respondents were in agreement with belief that anyone discovered to have HIV should not be allowed in religious gatherings.

Majority of the respondents (87.4%) disagreed with the views that anyone who is HIV positive should not be allowed to mix freely with other people. Similarly, a majority (87.4%) disagreed with the idea that People Living with HIV and AIDS should not be admitted into the same room with others in the hospital. Many respondents had the wrong perception of HIV with special reference to job opportunities. For instance, 40.1% did not support the view that People Living with HIV and AIDS should be given equal job opportunities.

Only 21.9% of the respondents were of the view that people living with HIV should avoid having sexual intercourse either protected or not. (See table 10 for details). More than half of the respondents (52.2%) perceived as stigmatizing the tendency by people to treat PLWHA as if it is their fault. Other half (51.8%) were of the opinion that people physically back away from or refuse to associate with person with HIV. A large proportion (61.1%) of the respondents were of the perception that some close relations were afraid of rejection by people when a family member has HIV. Fifty-nine percent of the respondents were of the perception that withdrawing from interacting or visiting a friend because of his or her HIV status is a stigmatizing attitudinal tendency. (See details in Table 11).

**Table 10: Respondents' attitudes to stigmatizing statements****N=700**

Stigmatizing statement	Responses		
	Agree (%)	Undecided (%)	Disagree (%)
Anyone who has HIV is serving a punishment from God	94 (13.4%)	89 (12.7%)	517 (73.9%)
Anyone who is HIV positive do not deserve care and support because they are paying for their misdeeds	85 (12.1%)	22 (3.1%)	593 (84.8%)
It is not proper to employ workers who have HIV because of their low productivity	79 (11.3%)	40 (5.7%)	581(83%)
Anyone discovered to have HIV should not be allowed in religious gatherings	51 (7.3%)	23 (3.3%)	626 (89.4%)
Anyone who is HIV positive should not be allowed to mix freely with other people	61 (8.7%)	27 (3.9%)	612 (87.4%)
People living with HIV should not be admitted into the same room with other in the hospital.	65 (9.3%)	23 (3.3%)	612 (87.4%)
A marriages should not be conducted for anyone discovered to have HIV	102 (14.6%)	47 (6.7%)	551 (78.7%)
People living with HIV should be given equal jobs opportunities as others in the society	407 (58.1%)	13 (1.8%)	280 (40.1%)
People living with HIV should avoid having any form of sex either protected or not	153 (21.9%)	26 (3.7%)	521 (74.4%)
People living with HIV should avoid having children	123 (17.6%)	24 (3.4%)	553 (79.0%)

**Table 11: Respondents' reaction to the stigmatizing attitude of other people towards PLWHA**

**N=700**

<b>Statement</b>	<b>Affected me a lot</b>	<b>Affected me to some extent</b>	<b>I can not tell</b>	<b>Affect me little</b>	<b>Does not affect me at all</b>
Treating PLWHA as if it is their fault	121/(17.3%)	244(34.9%)	35 (5.0%)	134(19.1%)	166 (23.7%)
Physically backing away from or refuse to associate with someone because of HIV	70 (10.0%)	292(41.7%)	57 (8.1%)	110(15.7%)	171 (24.4%)
Fear by close relations of rejection by society when a family member has HIV	99 (14.1%)	329(47.0%)	61 (8.7%)	96 (13.7%)	96 (16.4%)
Failure to be interacting or visiting friend after hearing that he/she has HIV	93 (13.3%)	20 (45.7%)	59 (8.4%)	109(15.6%)	119 (17.0%)
Avoidance of physical contact with an HIV positive persons by people	109(15.6%)	22 (40.3%)	52 (7.4%)	110(15.7%)	147 (21.0%)
Blaming HIV positive persons on their moral failings	101(14.4%)	297(42.5%)	70 (10.0%)	115(16.4%)	116 (16.7%)
Fear by people to relate with persons with HIV	159(22.7%)	302(43.1%)	48 (6.9%)	93 (13.3%)	98 (14.0%)
Treatment of people with HIV with HIV by society disdain or score	182(26.0%)	287(41.0%)	51 (7.3%)	91 (13.0%)	89 (12.7%)



#### **4.7 Respondents' Perceptions of HIV/AIDS Stigma and Discrimination**

Majority of the respondents believed that lack of knowledge about HIV and AIDS is the major factor which promotes stigmatizing attitude among people.

The following represents are some of their verbatim quotes:

*“People are afraid of coming closer to PLWHA because they fear that they can get infected if they move closer to us”.*

*“HIV/AIDS stigma is the number one killer before the death by HIV; if stigma is removed from HIV, many people would survive the disease condition”.*

*“People are just not knowledgeable about the disease and even some medical personnel are not helping matters; they also talk to PLWHA as if they are not human beings. Only a few health care providers show compassion”.*

*“People are just being wicked. Anyone who is still alive does not know what will kill him. People do not understand the nature of the disease and so discriminate against people infected and affected by the disease condition”.*

*“The sickness will naturally attract stigma and one can't fight with everybody. One just have to live with it or else one will run crazy”.*

*“HIV disease is just like any other disease like hypertension and diabetics. If people have this knowledge and our government makes the drugs available like ant-malaria drugs it will go a long way to help people living with the infection and the stigma attached to it”.*

#### **4.8 Respondents' Perceptions of Consequences/Effects of HIV/AIDS on Affected Persons**

The perceived consequences/effect of HIV/AIDS on affected persons are presented in table 12. The following were perceived by majority of respondents to be the consequences/effects of HIV/AIDS on affected persons: separation or divorce (61.4%), lowered immunity (61.0%), isolation/avoidance by people (58.8%) and sadness/depression (68.1%). The perceived consequence can be differentiated into three typologies-physical, psychological and social effects. (See foot of table for key). Slightly more than half (51.7%) did not regard feeling of being worthless to be an aftermath of HIV/AIDS. About half (50.1%) of the respondents did not regard refusal to go for HIV test as a consequence of HIV/AIDS. Many of the respondents regard low self-esteem (44.3%) and denial that one has HIV/AIDS (48.3%) as the challenges associated with HIV/AIDS.

**Table 12: Perceived physical and psychosocial effects of HIV/AIDS on PLWHAs**

N=700

Perceived Effects of HIV/AIDS on PLWHAs	Yes	No	Don't know
Hopelessness	300 (42.9%)	355 (50.7%)	45 (6.4%)
Divorce	429 (61.4%)	225 (32.1%)	46 (6.5%)
Suicidal tendency	321 (45.9%)	335 (47.8%)	44 (6.3%)
Lowered immunity (exposure to all kinds of diseases)	427 (61.0%)	210 (30.0%)	63 (9.0%)
Malnutrition (not feeding well)*	366 (52.3%)	288 (41.1%)	46 (6.6%)
Isolation/avoidance by people	412 (58.9%)	242 (34.6%)	44 (6.6%)
Low self esteem	310 (44.3%)	320 (45.7%)	67 (10.0%)
Feeling of being worthless	294 (42.0%)	362 (51.7%)	44 (6.3%)
Refused to go for HIV test	304 (43.4%)	350 (50.1%)	46 (6.5%)
Denying that one has it.	338 (48.3%)	307 (43.9%)	55 (7.9%)
Depression	476 (68.1%)	187 (26.7%)	36 (5.2%)
Reduced quality of life	317 (45.3%)	338 (48.3%)	45 (6.4%)

#### 4.9 Coping Strategies and Membership of Social Support Groups

Common strategies adopted by respondents for coping with stigma and discrimination included the following: unmoved (53.7%), ignoring the person(s) perpetrating discrimination/stigmatization (40.1%) and praying (45.9%). Few respondents challenged persons discriminating against them (9.3%), threaten perpetrators with legal action (3.9%) and report experience stigma/discrimination to support group (7.6%) Some respondents (12.4%) resort to crying as a defence mechanism (See details in table 13).

A small proportion (27.7%) of respondents were members of a social support group for people living with HIV/AIDS. (See Figure 3). The gender differentiation of respondents who belong to a social support group is shown in figure 4.5. By far more females (70.9%)

than males (29.1%) belonged to a social support group. Respondents' who belong to a social support group perceived benefits of social support groups to include sharing of experiences (29.84%), skill acquisition (22.9%) as well as care and support (physical & psychological) (18.4%). (See table 14).

The coping strategies shared at the social support group meeting included; not stigmatizing oneself (19.7%), living positively (38.1%) and not giving room for discrimination to occur (14.5%). The details of the other issues discussed at group meetings are contained in table 15.

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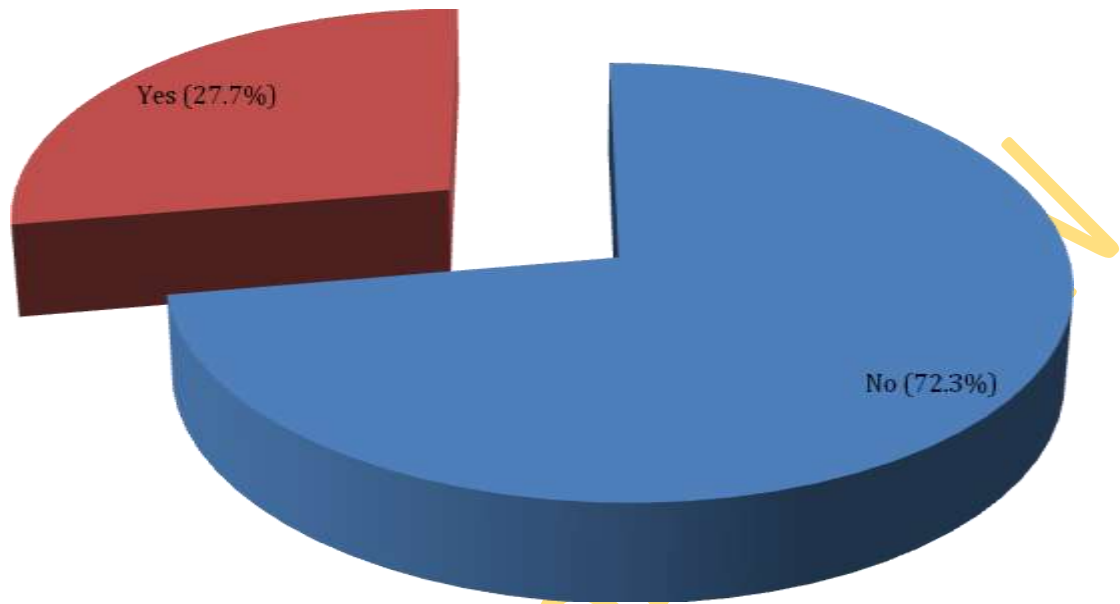
**Table 13 : Strategies adopted for coping with HIV and AIDS-related stigma/ discrimination by respondent**

**N=700**

<b>Coping strategies*</b>	<b>No</b>	<b>%</b>
<b>Unmoved</b>		
Yes	376	53.7
No	324	46.3
<b>Challenged/confronted the person</b>		
Yes	65	9.3
No	635	90.7
<b>Threaten legal action</b>		
Yes	27	3.9
No	673	96.1
<b>Report to support group</b>		
Yes	53	7.6
No	647	92.4
<b>Ignore the person(s) perpetrating discrimination/stigmatization</b>		
Yes	281	40.1
No	419	59.9
<b>Quarrel with the person(s)</b>		
Yes	15	2.1
No	685	97.9
<b>Praying</b>		
Yes	321	45.9
No	379	54.1
<b>Crying</b>		
Yes	87	12.4
No	613	87.6
<b>Singing</b>		
Yes	16	2.3
No	684	97.7
<b>Disclosure to partner</b>		
Yes	7	1.0
No	693	99.0
<b>Enlighten them</b>		
Yes	8	1.1
No	692	98.9

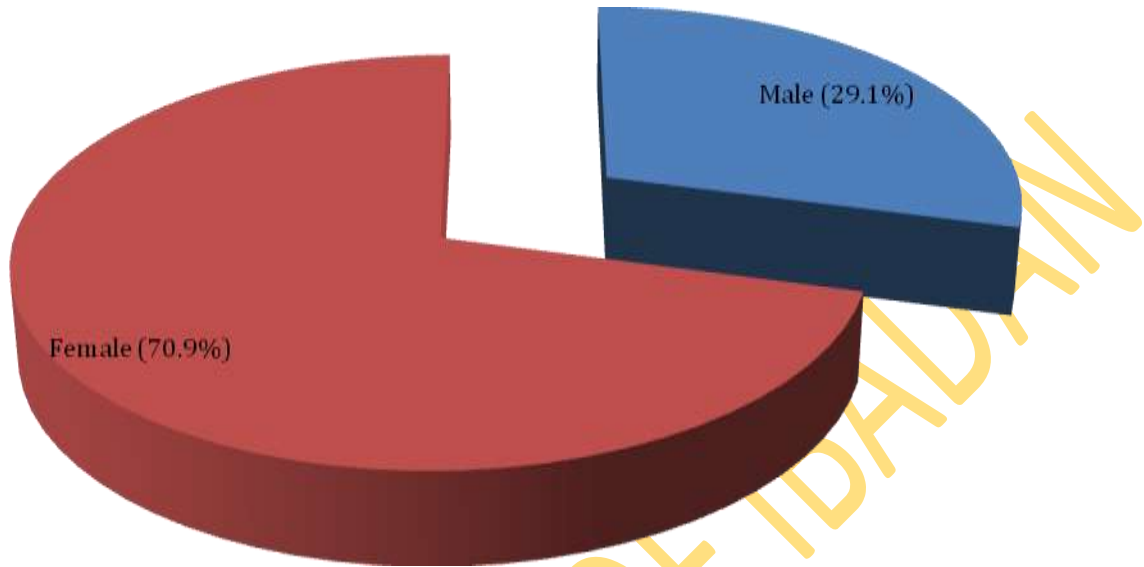
\*These are multiple responses

**N = 700**



**Figure 3: Respondents' membership of social support groups**

N= 223



**Figure 4: Gender differentiation of respondents who belong to a social support group**

**Table 14: Respondents' perceived benefits from social support groups**

**N = 245**

<b>Perceived benefits from support group</b>	<b>No</b>	<b>%</b>
Sharing of experiences	73	29.8
Skill acquisition	56	22.9
Care and support (physical & psychological)	45	18.4
Financial support	12	4.9
Distribution of ITN materials, buckets and condom		
Friendship	12	4.9
Loan opportunities	3	1.2
Home Based Care	3	1.2
Assist with Jobs	2	0.8
	1	0.4



**Table 15: Coping strategies for HIV and AIDS-related stigma/discrimination discussed among PLWHAs in support group meetings**

**N= 173**

<b>Strategies for coping with HIV stigma shared during support group meetings</b>	<b>No</b>	<b>%</b>
Living positively	66	38.1
Not stigmatize oneself	34	19.6
Not giving room for discrimination	25	14.5
Disclosing ones HIV status to kill stigma	14	8.1
Ignoring the person stigmatizing one	12	6.9
Be happy with everybody	10	5.8
Reporting to Support group	8	4.6
Reporting to legal authority	4	2.4

#### **4.10 What Support Group Organizations are Doing for PLWHA**

According to most social support group leaders, majority of organizations provide monetary support, shelter and training workshop on how to live positively for PLWHA and also share food items among them. Other forms of support included home visit to PLWHA, assistance in getting drugs at clinic and transport fare when coming to collect drugs at the clinic. Social support groups also take care of children orphaned by HIV/AIDS and remind PLWHA of their clinic appointments.

Typical verbatim quotes from three different support group leaders which reflect the forms of support provided by support groups include the following:

*“Whenever anyone of our member is very sick they will call on us and we will bring them to hospital for treatment. If the landlords harass them, we get them connected to a lawyer that will assist them and when they are forcefully ejected from their house, we house them and we also do home based care”.*

*“We do a lot of counselling, care and support, including advocacy. We assist people to come to hospital, visit them at home and also encourage them not to lose faith and that final solution would come one day.*

*“We shelter homeless PLWHA in our local office but recently the landlord has been kicking against it. Whenever PLWHA without relatives is admitted into the hospital ward, we act as the relatives. We care, support and render financial assistance within the limit of our resources We can not do everything; we advocate for assistance for our people”.*

#### **4.11 Challenges facing support group organizations**

Some of the challenges experienced by social support groups were provided by some of the Indept interviewees. The following quotation summarizes the perceived challenges:

- *“The challenges facing the support group were inadequate funding and lack of political support, unequal distribution of funds by National and State action*

*committee on AIDS. Other challenges are lack of volunteer staff, irregular attendance of support group meeting and lack of motivation for support group leaders''.*

#### **4.12 Strategies for Reducing HIV/AIDS Stigma in Our Society**

Support group leaders' perceived strategies for reducing HIV/AIDS stigma were formation of more support group, more funding support from the government to increase awareness programme in the cities and villages. In addition medical officers in private hospitals should be taught to show PLWHA more love and concern. Other strategies included all encouragement of peer educators, good government policy, empowerment programme for PLWHA, convenient access to treatment, and public education on impact of HIV/AIDS stigma.

#### **4.13 The Experienced Acts of Discrimination in the Workplaces and from Health Workers**

Few (9.3%) respondents had ever experienced an act of discrimination in the workplace: The discriminatory experiences included isolation/rejection (47.7%), mockery/ridicule (18.5%) and avoidance (13.8%) by other people. (See table 16 for details). The discrimination ever experienced from health workers since becoming HIV positive included; disclosure of ones status to other patients/health workers without permission (42.4%), maltreatment (15.2%) and avoidance (12.1%). The details are contained in tables 17.

**Table 16: Typical discriminatory acts experienced by respondents in the workplace  
N=65**

<b>Discrimination experienced in the workplace</b>	<b>No</b>	<b>%</b>
Isolation/Rejection	31	47.7
Mockery/Ridicule	12	18.5
Avoidance	9	13.8
Denied opportunity such as traveling/Promotion benefits	5	7.7
Gossips	2	3.1
Abuse	2	3.1
Loss of Job	2	3.1
Annoying comments such as HIV positive individuals are careless and greedy.	2	3.1

**Table 17; Acts of discrimination experienced by respondents in the hands of health workers.**

**N=65**

<b>Discrimination experienced from Health worker</b>	<b>No</b>	<b>%</b>
Disclosure of one's status to other patients/Health workers without permission	28	43.1
Maltreatment	10	15.2
Avoidance	8	12.1
Delay in rendering prompt attention	6	9.1
Gossips	5	7.6
Abuse	4	6.1
Isolation/Rejection	3	4.5
Mockery/Ridicule	1	1.5
Demanding for extra payment before treatment because of HIV status	1	1.5

\*Health worker referred to in the table are health care providers in the health facilities ever visited for care and not necessarily those of PEPFAR clinic alone.

## CHAPTER FIVE

### 5.0 DISCUSSION, CONCLUSION AND RECOMMENDATIONS

The presented results are discussed in this chapter. The chapter ends with a set of recommendations.

#### 5.1 Discussion

##### 5.1.1 Socio-demographic Characteristics

Seven hundred people living with HIV participated in the study and their age ranged from 14 to 79 years with many of them falling within the 30–39 years age group. The age profile shows that the infection cuts across young people, including adolescents, and adults of various ages. The results further revealed that it is the most economically productive segment of the society that is more affected. Findings relating to the age profile of the target population in this study are similar to the observations by the National Action Committee on AIDS-NACA (2008).

The study group was predominantly made up of Christians. This is to be expected because Christianity is a major religion in the southern parts of Nigeria (Kumapayi, 2005) including the geopolitical zone where this study was carried out. The study took place in South-Western Nigeria which is predominantly inhabited by the Yoruba; it is therefore not surprising that majority of the respondents were of the Yoruba ethnic group.

Disproportionately more females were affected by the infection. This result is similar to what has been noted in different parts of Nigeria (Ogbuji and Oke, 2010) and other parts of the world (International Centre for Research on Women [ICRW]; 2002). A number of factors may have accounted for the presence of more females in the study population. These include the anatomy of the female genital organ, poverty, gender differentials in health-seeking behaviour and gender differential in the pattern of utilization of health care services. HIV infection is more easily transmitted from man to woman because semen has a higher concentration of the virus than vaginal secretions (CDC, 2010). The large surface

area of the vagina and the fact that vagina mucosa is more prone to injury during sex create opportunities for infection than the skin of the penis (SMOH, 2004).

Women are relatively poorer than men in most societies (ICRW, 2002). Their low economic status therefore creates opportunities for them to be sexually exploited thus increasing their risk of HIV infection. Studies have shown that more females tend to visit health care facilities for health care than males (Peterson, 1990; Mushingeh, Chana and Mulikelela, 1991; Thant, 1993). This pattern of health seeking behaviour may have also applied to the differentials in the utilization of HIV/AIDS care centres in the study area. There is therefore more opportunities for females to be screened for HIV compared with their male counterparts.

The observation that most respondents were married raises a serious public health concern. This is so because of the possibility of infected married respondents passing the virus to their spouses. Children born by HIV-infected mothers also run the risk of HIV infection through the mother-to-child transmission mode (Panos, 2001). A possible burden of HIV among married persons is that when either the wife or her husband or both die as a result of the complications of the disease condition, their children automatically become orphans. In Nigeria, orphanage occasioned by HIV-induced death could lead to several adverse consequences. The consequences could be physical (Nardi and Bolton, 1991), economic (Lie, 1996) and social in nature as has been found to be characteristic of HIV and AIDS-related deaths (Oyediran and Anyant, 2009).

The presence of adolescents among the respondents is very instructive. It reinforces previous and prevailing beliefs that they are vulnerable (Ajuwon, Olley, Akin-Jimoh and Akintola, 2001) and so HIV prevention programming should start early to target them. A study by Alford (2003) on the influence of peer pressure on adolescents' sexual behaviour has shown that many adolescents were influenced by their peers to start having sexual intercourse as early as 15-17 year. Early sexual debut thus makes adolescents vulnerable to HIV infection (Dias, Matos and Goncalves, 2006).

### **5.1.2 Experiences Relating to HIV-Induced Stigma and Discrimination**

Several respondents claimed to have ever been stigmatized in one way or the other due to their HIV status. This could be attributable to the incurable nature of the condition as at today; the situation is compounded by lack of a vaccine against it. More over the condition is erroneously perceived as a death sentence for HIV patients (FMOH, 2003a).

Generally, deadly health conditions such as small pox (Goffman, 1963; Nzioka, 2000), incurable diseases such as epilepsy (Alonzo and Reynolds 1995; Cogan &Herek 1998), disfiguring diseases such as Hansen’s disease (Kurzban and Leary 2001), and sexual promiscuity-related ones such as STIs (UNAIDS, 2002-2003) are often stigma-inducing in many cultures. The HIV/AIDS belongs to this category of stigmatizing health conditions. The condition is incurable and leads to skin cancer that could be disfiguring.

In addition the disease condition is associated with indiscriminate sexual intercourse, a practice that is highly detested in several cultures (Goffman, 1963) including Nigeria.

Men who become infected, though less stigmatized, are seen as having had sex with prostitutes, or having been involved in prostitution themselves. Prostitution is a stigmatising practice in several societies (Dageid, 2002). Many women with HIV/AIDS are viewed as having been sexually “promiscuous,” or being prostitutes. In many cultures accusations of sexual promiscuity and prostitution are particularly very grave for women (Bond et al., 2002).

The society and its institutions perpetuate stigmatizing views or perceptions partly due largely to lack of knowledge of how HIV is contracted. The results of the study corroborate the findings of a very recent study by Ogbuji and Oke (2010). The study noted that persons living with HIV experienced one form of stigma and discrimination or the other. A large household-based study in Kenya found that 75% of HIV-positive respondents had experienced “enacted stigma” (Odindo and Mwanthi, 2008). In South India the prevalence of enacted stigma was about one-third of the study participants (Subramanian et al., 2009). Slightly more than half of respondents experienced “enacted stigma” in a study conducted



in China (Li et al., 2009). In contrast, a study of women with HIV in the US found the prevalence of enacted stigma to be low (Wingood et al., 2007). Another study in the US however indicated that 8 out of 10 families experienced HIV-induced discrimination (Bogart et al., 2008).

It could be concluded from the results of this studies and the reviewed literature that HIV-related stigma is a reality that cuts across several cultures. The prevalence and severity of the HIV-induced stigma may however vary from place to place within and between countries due to differentials in the social response to the condition.

Household surveys which revealed extensive stigmatizing attitudes towards persons living with HIV cut across various countries including the general population in China (Chen et al., 2005; Emler, 2005), the United States (Bunn et al., 2008; Lau and Tsui 2005), Hong Kong (Hongjie et al., 2006), South Africa (Mak et al., 2006), Jamaica (Maughan-Brown, 2006), Brazil (Norman et al., 2006; Genberg et al., 2009), Nigeria (Babalola et al., 2009), Thailand (Visser et al., 2006), Tanzania (Chan et al., 2007; Stein and Li, 2008), Zimbabwe (Ndinda et al., 2007; Stephenson 2009), Burkina Faso (Lau and Tsui, 2007), Zambia (Chiu et al., 2008), and Ghana (Garcia, 2000; Stein and Li, 2008). The results of this study is therefore a contribution to the acknowledgement of the universality of HIV-induced stigma and discrimination.

Few respondents reported the disclosure of their HIV status by health personnel without their consent. This is an unethical practice. Practices such as this could heighten stigmatization and discrimination perpetrated against PLWHA and can inhibit appropriate health-seeking behaviour among them. Instances of the unethical disclosure of the seropositivity status of patients have reported elsewhere (Cao et al., 2006; Yu et al., 2009; Zukoski and Thorburn, 2009).

Some of the respondents had ever experienced verbal assault because of their HIV status. Instances of verbal assault on PLWHA have similarly been reported in various countries including the Dominican Republic (MacQuarrie et al., 2006; Urena 2009). Striking gender differences in the experience of HIV/AIDS stigmatization were observed in this study. Women experienced more of nearly every form of enacted stigma than men. A similar

pattern was observed in Tanzania (Lie, 2006) the United States (Bharat and Aggleton 1999) and South Africa (ICRW, 2002). Many of the respondents were scared of disclosing their HIV status to their family members while few respondents had stopped going to the office or to work because of fear of stigma. Few respondents reported that they had stopped applying for jobs because of the fear of HIV-induced discrimination. These illness-related behaviours are indicators of self-stigma.

Previous studies have revealed the prevalence of HIV-induced stigma and discrimination in work places. A prospective study in France for instance examined employment discrimination perpetrated against persons living with HIV and AIDS. The study revealed that 149 out of 478 people living with HIV experienced employment loss over the duration of the study (Dray-Spira et al., 2008). Studies among employers in both China (Rao et al., 2008) and Nigeria (Adeyemo and Oyinloye, 2007) have found strong reluctance to hire or retain employees who are HIV positive.

A study in India also revealed common cases of “perceived stigma” or fear of stigma or stigmatization, even where reports of “enacted stigma” were low (Priya and Sathyamala 2007; Steward et al., 2008; Subramanian et al., 2009). Bogart et al. (2008) noted similar experiences in the USA. Self-stigmatization could be as burdensome as stigma perpetuated by others.

### **5.1.3 Perceptions Relating to HIV-Induced Stigma and Discrimination**

Various misconceptions existed among the respondents relating to HIV-induced stigma and discrimination. Some believed that anyone who has HIV is serving a punishment from God. This is a wrong perception. Perceptions such as this could be what had been learnt from the community as part of the social construct of HIV and AIDS (Goffman, 1963). According to Goffman (1963) stigmatizing conditions are often conceptualized as punishment for sins committed in which the stigmatized is seen as responsible for his/her condition because it is something that could have been avoided with appropriate behaviour. Inappropriate construction of HIV and AIDS could lead to self-blaming and traumatic psychological experiences such as feelings of low self-worth, low self-esteem and depression.

Some of the respondents were of the perception (opinion) that people who are HIV-positive do not deserve care and support because they are paying for their misdeeds. This is another inappropriate perception of HIV and AIDS. A similar wrong perception was noted by Jane et al. (2011) which revealed that people were of the believe that HIV/AIDS positive persons got what they deserve as they were responsible for their illness by being sexually promiscuous. People's general well-being and happiness in life depend on having some close social ties (Oxford, 1992). Therefore, people facing the challenges of coping with a life-threatening disease like HIV/AIDS need social support. Disruption in social relationships and loss of social support among PLWHA could engender a sense of hopelessness which can compound their quality of life.

Some of the respondents perceived that people believed that it is not proper to employ workers who have HIV because of their low productivity. This is a wrong perception as well. The HIV infection does not necessarily lead to low productivity. It may lead to low productivity if it is not well managed. The infection is like any other chronic conditions which require life-long management. If well managed, PLWHA could be as productive as persons not living with the virus.

Several of the respondents had appropriate perception of the HIV and AIDS condition. The view that people living with HIV and AIDS should be given equal job opportunities as others in the society and the conviction that PLWHA can engage in sexual intercourse as long as they protect themselves and remain with one partner are reflections of appropriate perceptions of the condition. According to International Labour Organization (ILO, 2010) The international labour organization states categorically that real or perceived HIV status should not be a ground for discrimination or prevention of the recruitment or continued employment of any one.

People's negative perception of HIV often arises from the social construction of the epidemic. According to Bunting (1996), "HIV-positive people are sometimes perceived as invasive agents in a 'healthy' society and this social construction of the disease condition fosters the social exclusion of PLWHA because they are seen as a threat to others".

This study shows that even close relations often entertain fear of rejection by other people when a family member has HIV. A previous study has shown that in some communities a

family with an HIV-infected person is derogatorily labeled “AIDS family” and the children of PLWHA are taunted as having AIDS parents (Alubo et al., 2002). Keeping a social distance from a person living with HIV by family members has potential for compromising the social support that he/she needs.

#### **5.1.4 Consequences/Effects of HIV/AIDS-Induced Stigma on Affected Persons**

The experience of isolation and other discriminatory practices suffered by PLWHA that are revealed in this study could possibly lead to denial and non-disclosure of their HIV sero-status. Discriminatory practices have potential for leading to several psychopathologies such as depressive illnesses (Subrmanian, Gupte, Dorairaj, Periannan and Mathai; 2009) and shame (Macdonald, 1998). As noted, isolation/avoidance (Bharat and Aggleton, 1999), sadness/depression (Lewis, 1998), mockery and shame (UNAIDS 2006) are usually the major concerns among PLWHA. Furthermore, non-disclosure and denial of their sero-status can lead to inappropriate health-seeking behaviour. The results of this study confirm instances of denial of sero-positivity earliest noted by (Muyinda et al., 1997) and non-disclosure of sero-positive status to significant others earlier reported by (Henry, 1990) among PLWHA for fear of the attendant social consequences.

The denial of job opportunities and other rights experienced by some respondents is one of the social consequences often experienced by PLWHA. The social rejection occasioned by avoidance by friends and the significant others could engender in PLWHA a feeling of worthlessness or devaluation. The experiences reported in this study are indicative of self-stigmatization. Self-stigmatization could compromise the psychological health of PLWHA (Herek's 1999; Esu-Williams, Puler, Mgilane and Stewart; 2005).

HIV is not readily transmitted in majority of workplaces. However, the fear of risk of transmission has been used by numerous employers to terminate or refuse employment to HIV-positive persons (Barragán, 1992; Gostin, 1992; Panos, 1992; Hasan et al., 1994; Omangi, 1997). It has been reported that pre-employment screening for HIV/AIDS takes place in many industries and the result is often used against PLWHA that are seeking employment (Panos, 1992).

### **5.1.5 Implications for Health Promotion and Education**

The stigma and discrimination observed in this study among PLWHA present major challenges to the successful implementation of HIV/AIDS control programmes. Health promotion and education have practical roles to play in the prevention, control and amelioration of HIV-induced stigmatization. Health education is a science which uses results obtained from systematically conducted measurements to design evidence-based interventions. This implies that health education interventions have great promise in addressing HIV-related issues including stigma and discrimination. Health Education is essential for PLWHA to know their rights and be more assertive. Awareness of the existence, magnitude, context and the experience of stigmatization among the PLWHA can be used to disseminate facts on stigmatization.

Counselling is a health education strategy which could be used to address the psycho-social challenges associated with HIV-induced stigma and discrimination. People Living With HIV/AIDS who are already in the treatment programme and are living positively can be made to counsel newly diagnosed persons. Professional counselors or health care workers should be trained to provide counseling services to PLWHA and their family members. Counselling services can be provided alongside health services provided at treatment centres. However, in Nigeria some clinic facilities may lack privacy and confidentiality needed for such counseling services. Both male and female PLWHA should be counseled on the importance of positive living. Education should target misconceptions and psycho-social consequences of self-stigmatization and how to prevent them.

Psycho-social issues such as fear of being stigmatized and self-blame which often prevent PLWHA from seeking appropriate help need to be addressed using appropriate strategies such as training on coping skills and psychotherapy. Health workers at federal, state and local government health centers including private clinics need to be trained on management of stigma-related issues and ethics of care including confidentiality (Skjelmerud and Tusubira, 1997). Health education programmes aimed at promoting the de-stigmatization of HIV/AIDS should be evaluated so as to determine what works and what does not. This is

more so because PLWHA are a heterogenous group of people who would naturally have varying needs and concerns.

Public enlightenment programmes including awareness campaigns have the potential for reaching large numbers of people. While public enlightenment campaigns can create awareness, influence knowledge, perception and attitudes as well as foster political will for action; evidence of their effectiveness in bringing about permanent change in behaviour remains insufficient (Whitaker, Baker and Arias; 2007). The mass media in Nigeria can be used to tackle HIV-induced stigma and discrimination. These media have their inherent strengths and weaknesses. However, the use of one or more of them could be very helpful as the weakness of one could be counter-balanced by the strengths of others.

The positive effects of behavioural change communication cannot be exaggerated. Well designed communication materials have important roles to play in tackling HIV-induced stigma and discrimination. Public enlightenment techniques could also involve the use of posters and leaflets, documentaries, drama, playlets and jingles. Relevant information should be provided in such a way that the messages can be passed across to the people. Simple local language could be used to facilitate the dissemination of messages destigmatization messages. Community mobilization could be used to target the misperception, norms and value that fuel HIV-induced stigma and discrimination. Community mobilization is a participatory process that focuses on the involvement of communities in health education interventions.

In additions there is a need to develop advocacy models to address HIV/AIDS-related stigmatization and discrimination, drawing on the experience of community mobilization, empowerment, and social transformation programmes. Advocacy interventions should target community-based organizations including faith-based institutions. Role models such as sports men and women, artistes and credible opinion leaders have important roles to play in this regards. Advocacy can be made more effective by using locally generated data from systematically conducted studies such as this study as baseline information. Advocacy has

been shown to be promising in contributing to the shaping of reforms and policies implementation (Alford, 2003).

## **5.2 Conclusion**

The research explored HIV-related stigma and discrimination, including self-stigmatization and perception relating to HIV-induced stigma as well as the adverse effects of HIV-related stigma and discrimination. There is a high prevalence of various forms of stigmatization and discrimination against people living with HIV/AIDS. There appears to be a general negative perception of HIV/AIDS even among some people living with the condition.

There is gender differentiation in the perception of stigma experiences, denial of seropositivity and non-disclosure of sero-status to significant others. This development adversely affects appropriate health-seeking behaviour, facilitates the spread of the virus and has potential for undermining HIV prevention and control efforts. There is therefore a need to respond to HIV/AIDS-induced stigma and discrimination through the use of a combination of well-designed health education strategies. Behavioural change communication, advocacy for positive perception of the disease condition by individuals and communities, counselling and community mobilization can be combined to reduce the burden of stigma and discrimination.

## **5.3 Recommendations**

The following recommendations are made based on the findings of this research:

1. In addition to drug treatment, People Living With HIV and AIDS should be provided with patient education and psychotherapeutic interventions aimed at addressing the HIV induced psychological complications which they experience;
2. Health care institutions should promote the development of staff on the ethics of care among their staff that stress the protection of the identity and dignity of PLWHA;
3. Sustained community-based educational interventions are needed to tackle the AIDS-related myths and misconceptions identified in this study which form the basis for the stigmatization and discrimination perpetrated against PLWHA.

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4. Programmes aimed at promoting the de-stigmatization of HIV and AIDS should involve the collaborative efforts of the following stakeholders within the context of an ecological model: the PLWHA, the family, community, public institutions, religious institutions, health care institutions and employers of labour and;
  5. The results should be used by stakeholders in HIV/AIDS prevention and control in designing and conducting the social marketing of de-stigmatization models that work.



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## APPENDIX 1: Semi-structured questionnaire

### PREVALENCE, PERCEPTIONS OF STIGMATIZATION AND DISCRIMINATION AMONG PEOPLE LIVING WITH HIV AT PEPFAR CLINIC IN IBADAN, NIGERIA

I am..... a student of the Department of Health Promotion and Education, Faculty of Public Health, University of Ibadan. This questionnaire is designed to enable you share your experiences with me concerning what people living with HIV/AIDS face in the hands of other people. Your views will be useful for designing educational programs for people living with HIV/AIDS and for soliciting for support and promotion of the dignity of persons with HIV infection. This study to the best of my knowledge will not expose you to any danger. Data collected from this study will be treated with strict confidentiality. For the avoidance of doubts your name will not be written down on this questionnaire or anywhere else and what you tell me will not be shared with any other person. Taking part in this study is voluntary. You are free to withdraw from the study at any time without any repercussions on you. Please feel free to answer the questions as honestly as possible. Do you have any question? Please feel free to ask questions as the interview progresses. Thank you.

FOR OFFICE USE ONLY  
Serial No.....

#### **SECTION A: - DEMOGRAPHIC DATA**

**Instruction:** For most of the questions in this section, please tick (✓) the appropriate alternative response(s); in some cases however simply supply the needed information in the blank spaces provided

1. **Age in years as at last birth day:**
2. **Sex:** 1. Male  2. Female
3. **Occupation:** \_\_\_\_\_
4. **Religion:** (1) Christianity  (2) Islam  (3) Traditional   
Others (specify) \_\_\_\_\_
5. **Marital status:** (1) Single  (2) Married  (3) Widow   
(4) Separated  (5) Divorced  (6) Cohabitation
6. **Highest level of education:** (1) No formal Education  (2) Primary education   
(3) Secondary Education  (4) Polytechnic (OND)   
(5) Polytechnic (HND)  (6) First degree   
(7) Postgraduate
7. **Ethnic group:** (1) Hausa  2. Igbo  3. Yoruba   
Others Specify) \_\_\_\_\_
8. (a) How long ago have you been diagnosed of being HIV Positive? \_\_\_\_\_  
(b) When specifically?.....
- 8.1 What made you to go for HIV screening when you did so?  
\_\_\_\_\_
- 8.2 How old were you when you were diagnosed? \_\_\_\_\_
- 8.3 Where were you diagnosed? (a) Town/Community \_\_\_\_\_  
(b) Centre/Institution \_\_\_\_\_

- (c) Ownship of centre 1. Government  2. Private  3. NGO
9. (a) Is your partner aware you have HIV? 1. Yes  2. No
- 9.(b) What is the HIV status of your sexual partner (i.e is he or she positive or negative)?  
 (1)Negative  2. Positive  3. Don't know
10. Who is your sexual partner? 1 Husband  2. Wife   
 3. Boy friend  4. Girl friend  5. Casual  
 Others specify \_\_\_\_\_
11. How long ago have you been accessing free medical services for the HIV infection at  
 PEPFAR clinic UCH?  
 \_\_\_\_\_

**SECTION B: EXPERIENCES RELATING TO HIV STIGMA AND DISCRIMINATION**

**Instruction:** Please tick (✓) the appropriate alternative option to the questions in this section; for some questions simply provide the needed information in the blank spaces provided.

12. Have you ever been stigmatized or looked down upon or discriminated against by someone as a result of your HIV status? Yes  No   
 (If No go to question 14)
13. If “Yes” to question 12 what form of stigma and/or discrimination have you experienced as a result of your HIV status? use the table below for your answer by ticking (✓) “Yes” if you have experienced such and “No” if you have not.

**TABLE 1**

	Forms of induced stigma and/discrimination perpetrated against PLWHA	Ever experienced (Tick) (√)		Experienced within the last three months (Tick) (√)	
		Yes	No	Yes	No
13.1	Physical assault (e.g. beaten, slapped, pushed, locked up etc.)				
13.2	Abused/ insulted because of your HIV status				
13.3	Subjected to ridicule (e.g. mocked, laughed at, scorned etc.)				
13.4	Excluded from religious activities because of your HIV status				
13.5	Excluded from family functions or gatherings because of your HIV status				
13.6	Excluded from school activities because of your HIV status				
13.7	Denied job opportunity because of your HIV status				
13.8	Sacked from job because of your HIV status				
13.9	Loose promotion benefits because of your HIV status				
13.10	Avoided by friends because of your HIV status				
13.11	Refused Visa or Entry into another country because of your HIV status				
13.12	Ejected from your house because of your HIV status				
13.13	Refused medical care at the hospital because of your HIV status				
13.14	Refused nursing care at the hospital because of your HIV status				
13.15	Maltreated by any health care personnel				
13.16	Disclosure of your HIV status by a health personnel without your consent				
13.17	Not treated like other patients because of HIV status/cared for in a discriminating way				
13.18	Humiliated because of HIV status				

14. Table 2 below contains a set of self-experiences relating to HIV self-stigmatization; for each tick (✓) “Yes” if you have experienced such and “No” if you have not.

TABLE 2

	<b>EXPERIENCES OF SELF STIGMATIZATION</b> e.g feeling that you do experience because of your HIV status	<b>Ever experienced (Tick) (✓)</b>		<b>Experienced withing the last 3 months (Tick) (✓)</b>	
		<b>Yes</b>	<b>No</b>	<b>Yes</b>	<b>No</b>
14.1	I isolate myself from family functions because of my HIV status				
14.2	I am scared of disclosing my status to my family members				
14.3	I am scared of disclosing my status to my friends				
14.4	I feel I am a worthless person because of my HIV status				
14.5	Stopped social functions because of my HIV status				
14.6	I exclude myself from religious activities because of my HIV status				
14.7	I have stopped visiting some friends because I am afraid of rejection or being looked down upon				
14.8	I have stopped going to the office or to work because of my HIV status				
14.9	I am ashamed of accessing medical care in other hospitals because of disclosure of my HIV status				
14.10	I have stopped applying for jobs because of my HIV status				
14.11	Limit the social functions or gathering I attend				
14.12	I stay indoor most times because of my HIV status				
Other experiences within last three months:					

**SECTIONC: RESPONDENTS ATTITUDES TO STIGMATIZING STATEMENT**

15. **Table 3** contains peoples's views/opinions to stigmatizing statement; for each tick (✓) whether you **Agree {A}**, or **Disagree {D}**; if you are not sure/have no idea, tick (✓) **{NS}**.

**TABLE 3**

	<b>Respondents attitudes to stigmatizing statement</b>	<b>Agree</b>	<b>Undecided</b>	<b>Disagree</b>
15.1	Anyone who has HIV is serving a punishment from God			
15.2	Anyone who is HIV positive does not deserve care and support because they are paying for their misdeeds			
15.3	It is not proper to employ workers who have HIV because of their low productivity			
15.4	Anyone discovered to have HIV should not be allowed in social gatherings			
15.5	Anyone who is HIV positive should not be allowed to mix freely with other people			
15.6	People living with HIV should not be admitted into the same room with others in the hospital or hostel			
15.7	A marriage should not be conducted if either man or woman is having HIV			
15.8	People with HIV should be given equal jobs opportunities as others in the society			
15.9	People living with HIV should avoid having any form of sex either protected or not			
15.10	People living with HIV should avoid having children			



**Table 4** reflect Respondents attitudes to stigmatization of other people towards PLWHA; for each state the extent to which you think it is stigmatising or not stigmatising by ticking (✓) whether **It affect me a lot, Affect me to some extent, I can not tell, Affected me little, Does not affect me at all.**

**TABLE 4**

	<b>People's attitudes that may be stigmatizing</b>	<b>Affect me a lot</b>	<b>Affect me to some extent</b>	<b>I can not tell</b>	<b>Affected me little</b>	<b>Does not affect me at all</b>
16.1	Persons with H IV are often treated as if it is their fault					
16.2	Physically backing away from or refusing to associate with someone because of HIV					
16.3	Close relation's fear of rejection by people when a family member has HIV					
16.4	Failure to be interacting or visiting friend after hearing that he/she has HIV					
16.5	Avoidance of having physical contact with an HIV positive person					
16.6	Finding faults in ones character because he/she has HIV					
16.7	Fear of relating with someone with HIV					
16.8	Looking at people with HIV with disdain or score					

17. (a) **Table 5** contains a set of perceptions of the effect of HIV/AIDS on sufferers; for each tick (√) “**Yes**” if it could be a consequence of HIV-related stigma and discrimination “**No**” if it is not; or “**Don’t Know**” if you are not sure/have no idea.

TABLE 5

	Consequences/ Effects of HIV/AIDS on affected persons	Tick (√)		
		Yes	No	Don’t know
17.1	Hopelessness			
17.2	Can separate husband and wife or ( Divorce)			
17.3	Suicide (killing oneself)			
17.4	Lowered immunity (exposure to all kinds of diseases)			
17.5	Malnutrition (not feeding well)			
17.6	Isolation/avoidance by people			
17.7	Low self – esteem			
17.8	Feeling of being worthless			
17.9	Refused to go for HIV test			
17.10	Denying that one has it.			
17.11	Sadness / depression			
17.12	Reduced quality of life			
17.13	Thought of killing oneself to end everything			
17.14	The end (death) is near.			

18. What are the other unpleasant things that people who are living with HIV experience just because of their HIV status? 16(List them below)

1 \_\_\_\_\_  
2 \_\_\_\_\_  
3 \_\_\_\_\_  
4 \_\_\_\_\_  
5 \_\_\_\_\_

**SECTION E: STRATEGIES FOR COPING WITH HIV INDUCED STIGMA AND DISCRIMINATION**

**Instruction:** Please tick (✓) the appropriate alternative option to the questions in this section; for some questions simply provide the needed information in the blank spaces provided.

19.. How do you normally cope when you experience stigma/discrimination as a result of your HIV status? (You can tick (✓) as many that applies to you)

- |                         |                          |   |                          |
|-------------------------|--------------------------|---|--------------------------|
| 1. Unmoved              | <input type="checkbox"/> | 2. Challenge/confront the person stigmatizing | <input type="checkbox"/> |
| 3. Treaten legal action | <input type="checkbox"/> | 4. Report to support group                    | <input type="checkbox"/> |
| 5. Ignore the person(s) | <input type="checkbox"/> | 6. Quarrel with the person                    | <input type="checkbox"/> |
| 7. Pray                 | <input type="checkbox"/> | 8. Cry  | <input type="checkbox"/> |
- Others specify

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

20. Are you a member of any social support group for people living HIV/AIDS

✓ Tick Yes  or No

21. If yes what do you benefit from membership of the group?

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

22 .If member of a social support are issues on how to cope with stigma and discrimination discussed at your meeting? 1. Yes  2 No.

23.. If issues about stigma and discrimination are discussed in your social support group what are the strategies or methods for coping with stigma and discrimination you do share among yourself?

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

24. Tell me in detail a typical discriminatory treatment you will never forget that was melted out to you by a member of your family because you have HIV

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

25. Tell me in detail a typical discriminatory treatment melted out to you by a friend or colleague because you have HIV which you will never forget.....

.....

26. Tell me in detail a typical discriminatory treatment melted out to you by a member of your community because you have HIV that you will never forget

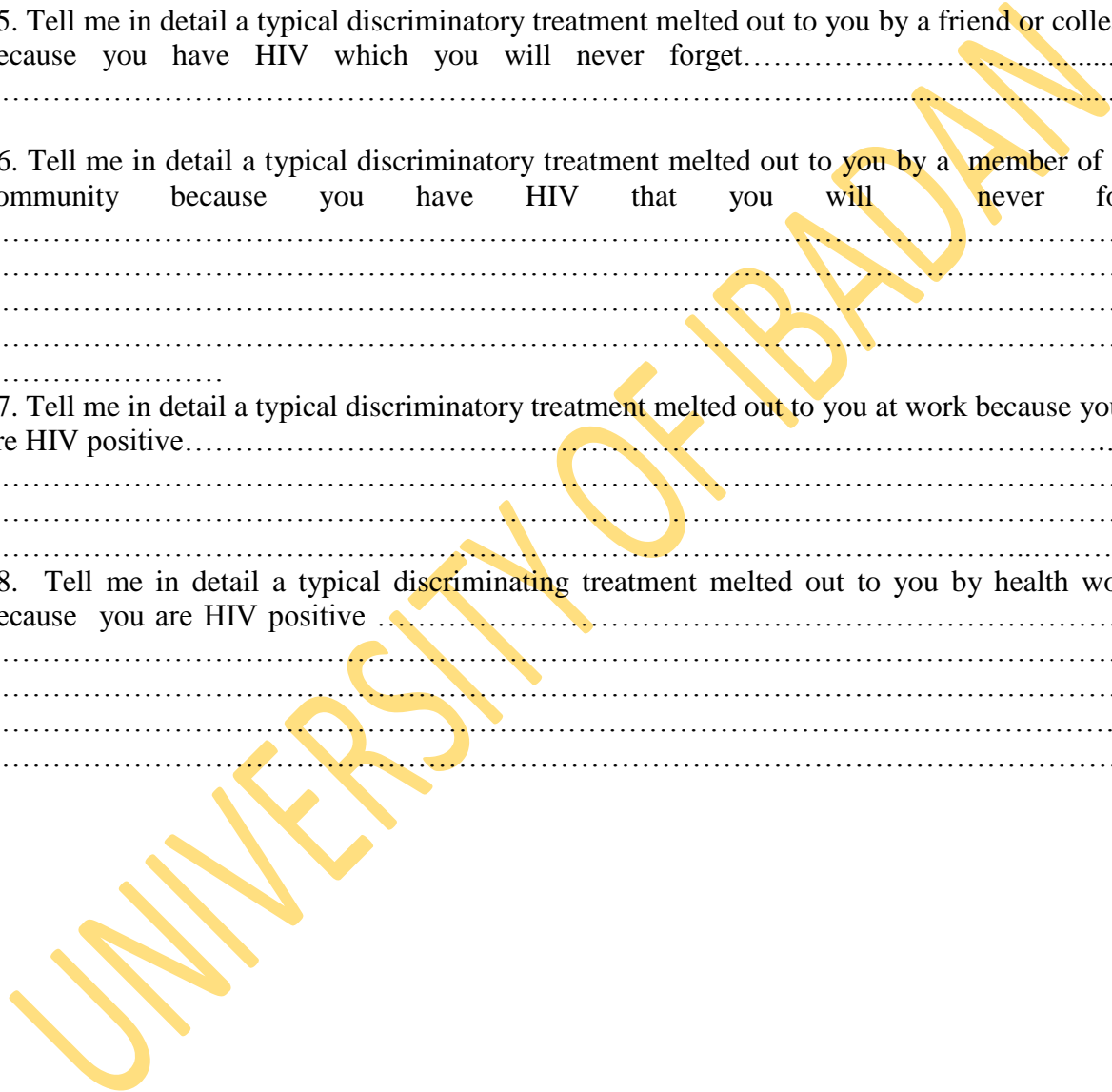
.....  
.....  
.....  
.....

27. Tell me in detail a typical discriminatory treatment melted out to you at work because you are HIV positive.....

.....  
.....

28. Tell me in detail a typical discriminating treatment melted out to you by health worker because you are HIV positive .....

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



**APPENDIX 11: Semi-structured questionnaire (Yoruba version)**

**WIWOPO, EROGBA IDEYESI ATI IDOJUKO LAARIN AWON ENIYAN TI O N GBE PELU KOKORO HIV ATI EEDI NI ILE-IWOSAN PEPFAR NI ILU IBADAN, NIGERIA**

Oruko mini..... Mo je akeko ile-iwe Yunifasiti ti ilu Ibadan. Eka ti Itesiwaju nipa eto ati imo ilera. A se Iwe ibere yii lati je ki o le jiroro pelu mi ohun ti awon eniyan n fi oju awon ti o ni kokoro HIV tabi aarun Eedi ri lawujo. Ero yin yoo wulo fun idanileko fun awon ti o ni kokoro HIV tabi aarun Eedi ati lati le beere fun iranlowo ati igbelaruge igbesi aye awon ti o ni aarun naa. Oadmiloju wipe abo wa lori lilowo ninu iwadi yii ati wipe ko si ewu kankan ti o ro mo kikopa ninu iwadi naa. Gbogbo alaye ti a ba gba lenu yin ni a o daabobo. Ki o le da yin loju oruko yin ko ni je kiko sile si ori iwe yii tabi ibomiran ati wipe ohunkoun ti a ba jo so ko ni je siso fun elomiran.

Kikopa ninu ayewo yii je lati okan yin wa , ko si tipatipa nibe. Eni anfani lati so pe e ko fe kopa ninu iwadi naa moo ni igbakugba laisi ewu kankan. Lati bi mi? E ni anfaani ati beere ohunkohun bi ijiroro se ntesiwaju. Mo dupe lowo yin fun ifowosowopo yin`

FUN LILO OFISI NIKAN Onka ni sisentele .....
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**ABALA A: -AKOSILE NIPA ARA ENI**

**Itosona:** Fun awon ibere to wa ni abala yi, fala si eleyi ti o ba bamu nibo miran eko idahun to ba ibere naa mu si alafo ti o wa labe ibere naa.

1. **Omo odun melo ni o ni ojo ibi ti o se gbeyin;**
2. 1. Okunrin  2. Obirin
3. **Ise wo ni o nse** \_\_\_\_\_
4. **Esin:** (1) Igbagbo  (2) Musulumi  (3) Esin Ibile   
Esin miran \_\_\_\_\_
5. **Ipo Igbeyawo:** (1) Omidan/ Apon  (2) Gbeyawo  (3) Opo   
(4) Ipinya  (5) Ikosile  (6) Gbigbepo laisegbeyawo
- 6.. **Iwe Kika to ga julo ti mo ka:** (1) N Ko lo si ile iwe rara  (2) Ile iwe alakobere   
(3) Ile iwe alakobere  (4) Ile iwe girama  (5) Ile iwe gbogbonise   
(6) Oye Onipokini  (7) Oye Onipokeji
7. **Eya wo ni e je** (1) Gamubari  2. Igbo  3. Yoruba
8. (a) Igba wo ni e ti mo pe e ni kokoro HIV? \_\_\_\_\_  
(b) Igbawo gangan?.....
- 8.1 **Kini o mu ki e lo se ayewo HIV ?** \_\_\_\_\_
- 8.2 **Omo odun melo ni e je nigba ti e lo se ayewo naa?** \_\_\_\_\_
- 8.3 **Nibo ni e ti se ayewo naa(a)Ilu/Agbebgbe** \_\_\_\_\_

- (b) Oruko Ile eto ilera \_\_\_\_\_
- (c) Awon wo loni Ibi ayewo naa (1) Ijoba (2). Aladani (3) Ile ise ti kii se ti Ijoba tabi taladani
9. (a) Nje ololufe re mo pe oni kokoro HIV? 1. Beni \_\_\_\_\_ 2. Beko \_\_\_\_\_
- 9.(b) Nje o mo ipo ti ololufe re wa ( boya oni kokoro HIV tabi koni)?  
 (1) Koni kokoro HIV  2. Oni kokoro HIV  3. N komo boya oni tabi koni
10. Tani Olubalopo/ololufe re ? Oko 2. Iyawo 3. Orekunrin 4. Orebinrin 5. Ore ojiji  
 Omiran \_\_\_\_\_
11. Ati igbawo ni o ti n gba itoju ofe fun kokoro HIV ni ile itoju PEPFAR UCH?  
 \_\_\_\_\_

**ABALA B: AWON IRIRI TI O TAN MO IDOJUKO ATI IDEYESI NITORI KOKORO HIV**

ITOSONA: Jowo, faala si eleyi ti o ba bamu nnu awon ibere ti o wa ni abala yii; fun awon ibere miran e ko awon ohun ti e ro pe o ye si awon alafo ti a ti pese sile.

12. N je o ti ni idojuko tabi kia fi oju tenbelure bi nitori pe oni kokoro HIV?

Beni  Beko

(Ti o ba je pe beko lo si ibere 14)

13. Ti o ba ri be si Ibere Kejila, kini idojuko tabi ideyesi ti o je iriri tire nitori pe oni kokoro HIV? Lo tabili ti o wa ni isale yii fun idahun nipa fifa ala si (✓) beni ti o ba ti ni iriri bee ati beeko ti e ko ba ni iriri bee.

**TABILI KINI**

	<b>IRUFE IDOJUKO ATI IDEYESI TI A FI WUWA SI AWON TI O NGBE PELU KOKORO HIV ATI EEDI</b>	<b>Se o se o ri(Faala) (√)</b>		<b>Se o se o ri laarin osu meta (Faala) (√)</b>	
		<b>Beni</b>	<b>Beeko</b>	<b>Beni</b>	<b>Beeko</b>
13.1	Itabuku ara (bii. Lilu, Gbigbalaju, Titilule, Titimole ati bebe lo.)				
13.2	Bu tabi tabuku nitori kokoro HIV				
13.3	Fisi ipo yeye (gege bii. moloju, firerin, tabuku ati bebe lo)				
13.4	Ya si oto lati ko ipa ninu esin nitori pe o ni kokoro HIV				
13.5	Yiya si oto ninu ibasepo ebi tabi ipejopo molebi nitori kokoro HIV				
13.6	Yiya si oto kuro ninu awon ojuse kan ni ile iwe				
13.7	KIko lati fun ni nise nitori kokoro HIV				
13.8	Daaduro lenu ise nitori kokoro HIV				
13.9	Fifi eto igbega dun eniyan nitori pe oni kokoro HIV				
13.10	Awon ore sa fun o nitoripe oni kokoro HIV				
13.11	A ko jale lati fun o ni iwe irinna si ilu okere nitori pe oni kokoro HIV				
13.12	A le o jade ninu ile nitoripe oni kokoro HIV				
13.13	A ko lati se itoju re ni ile iwosan nitori pe oni kokoro HIV				
13.14	Awon noosi ko lati se itoju to peye nitori pe oni kokoro HIV				
13.15	A fi iya je o lati owo awon osise eto ilera				
13.16	Awon osise eto ilera so ipo HIV re fun awon elomiran lai gba iyonda lowo re				
13.17	A ko lati se itoju re bi awon alaisan yooku/ a se itoju re ni ona iyasoto				
13.18	A gbogun ti o nitoripe oni kokoro HIV				

**14. Tabili keji(2) ti o wa nisale yi je akojopo awon iriri idojuko ti o tan mo ti ara eni, fun okanokan fa ala si beni (✓) ti o ba ti ni iriri yii tabi beeko ti oko ba ni.**

	<b>IRIRI IDUJUKO SI ARA ENI fun apere awon ifunra ti eniyan maa ni iriri re nitori kokoro HIV</b>	<b>Mo ti ni iriri yii ri ( fa ala si ) (✓)</b>		<b>Mo ti ni iriri yii ri laarin osu meta (3) (fa ala si)(✓)</b>	
		<b>Beni</b>	<b>Beeko</b>	<b>Beni</b>	<b>Beeko</b>
14.1	Mo ya arami soto kuro ninu ojuse ebi nitori kokoro HIV				
14.2	Eru n ba mi lati so fun awon ebi nipa ipo kokoro HIV mi				
14.3	Eru n ba mi lati so fun awon orei nipa ipo kokoro HIV mi				
14.4	Mo dabi eniti koja si ohunkohun nitori ipo kokoro HIV mi				
14.5	Mo da ojuse mi ni awujo duro nitori ipo kokoro HIV mi				
14.6	Mo ya arami soto kuro ninu ise esin nitori ipo kokoro HIV mi				
14.7	Mo da kiki awon ore duro nitori eru ikosile ati fifi oju tembelu eni nitori ipo kokoro HIV mi				
14.8	Mo da lilo si ofisi ati ise duro nitori kokoro HIV mi				
14.9	Oju ntimi lati gba itoju ni ile iwosan miran nitori fifihan ipo kokoro HIV mi				
14.10	Mo da wiwa ise duro na nitori ipo kokoro HIV mi				
14.11	Mo din ojuse mi ni awujo ati ipejopo ku				
14.12	Mo tilekun mori ni opo igba nitori ipo kokoro HIV mius				
Awon iriri miran ; Larin osu meta seyin					



**ABALA C:**

**ORO TI O TAN MO IDOJUKO ATI IDEYESI KOKORO HIV(HIV DISCRIMINATION)**

15. **Tabili keta (3)Yii** Je ero okan awon eniyan nipa ti dojukoo; fun okankan fa ala si (✓) boya mo faramo (A) tabi nko faramo (D) tabi ko da o loju ((✓) (NS)

**Tabili 3**

	<b>Erogba awon eniyan si oro ideye si ni</b>	<b>Fara moo</b>	<b>Ko dami loju</b>	<b>Nko fara moo</b>
15.1	Enikeni ti o ni HIV, Olorun lo nfi iya ese je e			
15.2	Eni ti o ni kokoro HIV ko ye ni eni ti o ye ki a toju tabi lati ran lowo nitori iya ise owo won ni won nje			
15.3	Ko to na ki a gba eni to ni kokoro HIV sise nitori ise won ko le kun oju osuwon			
15.4	Ko ye ki a gba eni to ni kokoro HIV laaye ni awujo			
15.5	Ko ye ki a gba eni to ni kokoro HIV laaye lati lo botife ni awujo			
15.6	Ko ye ki a gba eni to ni kokoro HIV si ori bedi ni yara kanna pelu eni ti ko ni			
15.7	Ko ye ki a se igbeyawo fun eniyan ti o ni kokoro HIV			
15.8	O ye ki a se igbeyawo fun eni ti o ni kokoro HIV si ise bi eniti koni			
15.9	Awon ti o ni kokoro HIV ko gbodo ni ibalopo kankan yala o ni idabobo tabi koni			
15.10	Awon to ni kokoro HIV ko gbodo bi omo			

16. Tabili (4) Fi iwuwa si awon eniyan to ni ideyesi ninu; fun okankan so ona ti o lero pe o ni ideyesi ninu tabi ko ni nipa fifa ala si (✓) O pamilara pupo, O pa mi lara die, Nko le so, O pamilara die, Ko pamilara rara.

17. **TABILI KERIN (4)**

	<b>Iwa awon eniyan ti o le ma mu ideye si ni dani</b>	<b>O pamilara pupo</b>	<b>O pa mi lara die</b>	<b>Nko le so</b>	<b>O pamilara die</b>	<b>Ko pamilara rara</b>
16.1	A ma n hu wa si awon ti oni kokoro HIV bi wipe asise won ni					
16.2	Awon eniyan ma sa fun eni ti o ni kokoro HIV tabi ki won ko lati ba eni to ni kokoro HIV se					
16.3	Awon ebi ma n sa fun eni to ni kokoro HIV					
16.4	Kikuna lati ni ajosepo pelu eni ti o ni kokoro HIV lehin ti a gbo pe o ni HIV					
16.5	Yiyago fun ifarakanra pelu eni ti o ni kokoro HIV					
16.6	Kika esun si ni lese nitori kokoro HIV					
16.7	Iberu lati ba oni kokoro HIV ni ajosepo					
16.8	Fifi oju tenbelu eni ti o ni kokoro HIV					

18. (a) **Tabili Karun(5)Je akojopo ero abayorisi HIV/AIDS; fun okankan faala si (√)**  
**“Beeni”** ti o ba je abayorisi Idojuko ati Ideyesi ti o tan mo HIV “Beeko ” Ti ko ba ri bee  
; Tabi **“N ko mo ti ko bad a e loju**

**TABILI KARUN (5)**

	Consequences/ Effects of HIV/AIDS	Fa ala si (√)		
		<i>Beeni</i>	<b>Beeko</b>	<b>Ko dami loju</b>
17.1	Isoretinu			
17.2	O le mu ipinya wa larin oko ati aya tabi (ikosile)			
17.3	O le mu ki eniyan fe pa ara eni			
17.4	O mu ki jagunjagun ara lole (fi aye gba orisirisi aisan)			
17.5	Ounje ti ko kun oju osuwon (Aijeun deede)			
17.6	Idaduro/ pipe awon eniyan sile			
17.7	Riri ara eni bii eni ti ko kun oju osuwon			
17.8	Ni ero si ara eni bi ai ja mo nkankan			
17.9	Kiko lati lo se ayewo fun kokoro HIV			
17.10	Siso wipe nkoni kokoro HIV			
17.11	Ibanuje/ironu			
17.12	Odin ojulowo igbesi aye ku			
17.13	Nini ero lati para eni lati mu opin de ba ohun gbogbo			
17.14	Opin (iku) sun mo to si.			

18. Kini awon ohun miran ti ko dara ti awon ti won gbe pelu kokoro HIV ma ni iriri re nitori ipo ti won wa pelu kokoro HIV (Ko won si ori ila isale yi)

- 1 \_\_\_\_\_
- 2 \_\_\_\_\_
- 3 \_\_\_\_\_
- 4 \_\_\_\_\_
- 5 \_\_\_\_\_

**ABALA E:AWON ONO LATI FARADA IDOJUKO ATI IDEYESI TI O WA PELU HIV**

**Itosona: Jowo fa ala si (√) eyi ti o ye ninu awon ibere ti o wa ni abala yii; fun awon ibere miran e ko idahun to ba ibere naa mu si alafa ti o wa labe ibere naa.**

19. Bawo ni e se ma farada awon iriri ti o wa ninu Idojuko ati ideyesi ti o waye nitori ipo kokoro HIV? (E le fa ala si (√) aimoye bi o ba se kan si yin)

- 1. Aibikita
- 2. Tako eni ti o ni idujuko/ideyesi
- 3. Pinu lati fale agbofinro
- 4. So fun awon egbe
- 5. Pa eni bee ti
- 6. Ni gbolohun pelu eni naa
- 7. Gbadura
- 8. Sukun
- 9. Onamiran \_\_\_\_\_

20. Are you a member of any social support group for people living HIV/AIDS

Tick Yes  or No

21 If yes what do you benefit from membership of the group?

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22 .If member of a social group are issues on how to cope with stigma and discrimination discussed at your meeting? 1. Yes..... 2 .No.....

23.. If issues about stigma and discriminatory discussed in your social support group what are the strategies or methods for coping with stigma and discrimination do you share among yourself?

.....

.....

.....

.....

24. Tell me in detail a typical discriminatory treatment you will never forget that was melted out to you by a member of your family because of you have HIV.....

.....

.....

.....  
25. Tell me in detail a typical discriminatory treatment melted out to you by a friend or colleague because you have HIV which you will never forget.....  
.....  
.....

26. Tell me in detail a typical discriminatory treatment melted out to you by a member of your community because you have HIV that you will never forget.....  
.....  
.....

27. So fun Tell me in detail a typical discriminatory treatment melted out to you at work because you are HIV positive.....  
.....  
.....

28. So fun mi ni ekunrere iwa ideyesini ti osise ilera kan ti hu si o nitoripe o ni kokoro HIV .....

