

“ONCE IT’S YOUR SISTER, THEY THINK IT’S IN THE BLOODLINE”: IMPACT OF
HIV/AIDS- RELATED STIGMA IN GHANA

by

GLADYS BARKEY ASIEDU

M.S., Kansas State University, 2007

AN ABSTRACT OF A DISSERTATION

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School of Family Studies and Human Services
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Abstract

The purpose of this study was to conduct a phenomenological inquiry into the impact HIV/AIDS-related stigma has on People Living with HIV/AIDS (PLHA) and their family members in Ghana and the overall relationship family members have with PLHA. The study explored the concept of stigma in the Ghanaian context, ways in which it is expressed, factors influencing HIV-related stigma and its consequences on both PLHA and their family members. Strategies that PLHA and their family members consider for effective HIV-related stigma prevention were also explored. The study further explored some of the gender-biased nature of HIV-related stigma in Ghana. Data was gathered qualitatively through interviews with five PLHA and their discordant family members. Interviews were transcribed and translated into English, coded and analyzed. After inductively establishing themes and categories, final confirmatory analysis was deductively established, by using the Bronfenbrenner's ecological model and Symbolic interaction theory to affirm the authenticity and appropriateness of the inductive content analysis. The study found that HIV-related stigma begins with serostatus disclosure. Stigma is manifested in myriad contexts including the family, community, healthcare institutions and gender. The major factors influencing stigma are insufficient knowledge of HIV transmission, fear and misconception of HIV created by the media, cultural and religious factors as well as poverty. Family members experienced similar stigma as PLHA, such as loss of jobs, loss of social network, loss of identity and self stigma. However extreme impacts such as suicidal thoughts were only experienced by PLHA. The impact of HIV-related stigma is worst for women because of beliefs and values relating to gender-role expectations. While women accept and support their husbands when they have HIV/AIDS, women are often neglected and abandoned by their husbands. To address this stigma, participants suggested house to house education, financial support from the government, revision of educational content especially discontinuation of negative images of HIV/AIDS used by the media. Implications for this study in the areas of research, practice and policy are provided.

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Approved by:

Major Professor
Karen S. Myers-Bowman PhD

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Dedication

To my dear father, Victor Nortey, who taught me that my gender should not be a barrier to what I want to do.

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Chapter 1 - Introduction

"When I make clothes people don't want to buy them because they think I might infect them" (Sakyi-Addo, 2004, ¶ 18). These words are from Ivy, a dressmaker in Ghana who has fallen on hard times as a result of being diagnosed with HIV/AIDS (Sakyi-Addo, 2004). Ivy's words present a challenge to researchers, practitioners, politicians, policy makers and communities at large who sometimes feel helpless to identify plausible solutions for the stigma associated with the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS). This is especially true in Africa and in most developing countries where the impact of HIV/AIDS-related stigma is enormous for People living with HIV/AIDS (PLHA) and their family members. Stigma makes the care and support for PLHA and those affected by HIV/AIDS a daunting challenge in Ghana, however, its impact is largely overlooked and there is little documentation of it. PLHA suffer emotionally, physically, economically, and socially. They may lose their jobs/livelihood, access to service, status, and their sense of self; creating anxiety, depression, loss of support, isolation and sometimes physical violence (Martin, & Logan, 2005; Ogden & Nyblade, 2005; Parker & Aggleton, 2003).

HIV/AIDS-related stigma does not begin and end with an individual; rather, it extends to family members. While family members of PLHA make major adjustments to care for PLHA, they are often times stigmatized by association and in many societies the impact of stigma on the family is enormous and far reaching (ICRW, 2006; Ogden & Nyblade, 2005; Parker & Aggleton, 2003). In many situations family members of PLHA experience the same stigmatization as the PLHA even though they do not have HIV/AIDS. This calls for an in-depth exploration of both the PLHA and their family members.

Although HIV/AIDS-related stigma is common in many countries and societies, it takes many forms in different countries. Specific groups that are stigmatized may vary across cultures and national borders (Herek, Mitnick, Burris et al, 1998). Studying HIV/AIDS-related stigma in different settings may not only provide an in-depth understanding of the phenomenon, but it also may highlight a focus for developing culturally sensitive programs for HIV/AIDS education. There have been some studies on HIV/AIDS-related stigma in Africa (e.g., ICRW, 2006; Ogden & Nyblade, 2005; UNAIDS, 2000), studies on AIDS education in the Ghanaian culture (NACP, 2004; Tsikata, 2007); and even on stigma in Ghana (Ulasi, Preko, Baido et al., 2009). However,

the impact of stigma on family members in the Ghanaian context has not been specifically explored; hence, this study fills that gap. Uiasi and others' study for instance determined the predictors of HIV/AIDS-related stigma and discrimination and also identified the perceptions of community members towards HIV/AIDS and PLHA in Ghana but the impact on PLHA and their family members were not explored. Also, a Ghanaian traditional belief is that "AIDS is a disease that affects cursed people. The people are cursed because of their immoral attitudes" (GNCC, 2000, p. 36). This belief, which may be intricately tied to why PLHA are stigmatized, may vary from culture to culture. Cultural differences in HIV/AIDS-related stigma may necessitate different intervention and prevention for reducing stigma in communities. Therefore, more research is needed to illuminate and understand the cultural context of HIV/AIDS-related stigma.

Also, there is a strong interaction between gender and stigmatization associated with HIV/AIDS (Hong, Van Anh, & Ogden, 2004; UNAIDS, 2000) that has not been explored in the Ghanaian context. Although there has been an overwhelming amount of research around the world that testifies to the increasing vulnerability of women to HIV/AIDS and its resulting stigmas (Anderson, Marcovici, Taylor, 2002; Brewer, Hasbun, Ryan, et al. 1998; Giffin, & Lowndes, 1999; Gupta & Selvaggio, 2007; ICRW, 2006; Mane & Aggleton, 2001; Mallow, Cassagnol, McMahon, et.al, 2000: UNAIDS 2002), in Ghana, only a few studies and anecdotal reports provide evidence of the interaction of gender and HIV/AIDS-related stigma. From my experience of working with PLHA in Ghana, I can say that Ghanaian women experience more stigma than men. Over 80% of the HIV/AIDS clients that I gave support to in Ghana between 2001 and 2004 were women. I witnessed that many of them were evicted by their landlords, abandoned and isolated by their husbands and family members, etc. I deem it necessary that these experiences be documented to provide empirical evidence to identify specific needs and resulting action to be taken at community and national levels.

Purpose and Significance of Study

The purpose of this study is to conduct an in-depth inquiry into the impact HIV/AIDS-related stigma has on PLHA and their family members in Ghana and the overall relationship family members have with PLHA. My professional rationale for this study is the enormous challenges that HIV/AIDS-related stigma poses for individuals and their families. The passion

for this research was reinforced by the experiences I had while working on the Eastern Regional AIDS Committee in Ghana and with families affected by HIV/AIDS.

Ghanaian society is a society that believes in collectivism, strong familial ties, and that an individual does not develop in isolation; hence, “it takes a whole village to raise a child.” What this signifies is that what befalls an individual is also in part a crisis for the entire family; therefore, the inclusion of family members in Ghanaian research is crucial. Thus conducting an inquiry into some of the challenges that HIV/AIDS related stigma poses to the individual, without considering the challenges of the family members may not be complete. After all most care givers of PLHA are family members.

Surprisingly many intervention programs and program content do not consider the stigma family members experience and the influence it has on their relationships with PLHA. Many policy makers, educators and the members of the society at large either are unaware of or feel helpless in dealing with HIV- related stigma. This is evidenced in the absence of a focused and culturally sensitive plan to fight HIV stigma. It is therefore imperative that HIV/AIDS- related stigma be studied in the context which it is manifested. Thus, this study examined stigmatization in the Ghanaian context and unveiled some of the important factors related to the phenomenon from ecological and symbolic interactionist perspectives. Questions about HIV/AIDS related stigma such as what is stigma, where it comes from, as well as how to confront it are fundamental issues that are important in the fight against HIV/AIDS. This study therefore presents a phenomenological perspective to HIV-related stigma in the Ghanaian context.

The findings from this study are beneficial not only because they add to existing knowledge of HIV/AIDS-related stigma, but also because they can be utilized in developing intervention and prevention frameworks for helping PLHA and their families. Stigma education that is culturally sensitive can prevent stereotyping and make other preventive and treatment measures (such as testing and safe practices like condom use with partners) more effective (Nyblade et al., 2003). I am optimistic that if educational programs are designed to include family members, many of the challenges of stigma will be prevented. Hence the inclusion of the thoughts, ideas, and experiences of HIV/AIDS related stigma not only from PLHA but also from family members in this study is significant.

The study will further explore some of the gender-biased nature of HIV/AIDS- related stigma to provide the basis for the educational programming needed to challenge stigma

associated with HIV/AIDS and gender in Ghana. Although there may be similarities in experiences of PLHA and their families in many African countries, there are unique aspects and factors that influence these experiences in different countries and communities. These factors include the preexisting beliefs and values surrounding sexuality, gender, and HIV/AIDS.

The study begins with an assumption that family members can play a significant role in the disclosure of PLHA's status and also, that the stigmatizing experiences of family members are in many ways similar to that of PLHA. Family members may give support, financially and emotionally or may refuse to provide such support. In either circumstance the relationship they maintain with the PLHA is significant to this study. The study further assumes that there are differences in stigmatizing experiences between men and women. Being a predominantly patriarchal society, it is expected that women will experience more stigma than men and the impact on women will be enormous for women compared to men. Information from this study will provide insight to family life education programming in Ghana.

Finally, I hope that the findings of this study will give voice to those brave families who were willing to share their stories with me. It is my fervent hope that the findings of this study, in some way, will encourage them as they live their lives with HIV/AIDS.

Chapter 2 - Literature Review

This study was to conduct an inquiry into the lived experiences of PLHA and their family members regarding HIV/AIDS related stigma in the Ghanaian context. The study does not only provide “a voice” to the participants but also consider its benefit to family life programming. This literature review presents an overview of some of the studies on HIV/AIDS-related stigma and the gaps in the literature. It begins by providing a global representation of HIV/AIDS and its occurrence and then briefly explains the terms, definitions of words and the concepts associated with the phenomenon. Furthermore, the literature on the consequences of HIV- related stigma is presented. The literature on gender and HIV/AIDS-related stigma will be discussed and a background to HIV/AIDS in Ghana will be provided.

HIV/AIDS Pandemic

The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS) epidemic has become a serious health, social and developmental challenge in many countries around the world. Since the first cases of HIV/AIDS were identified more than 25 years ago, millions of people around the world have become infected with the disease, and the epidemic has claimed millions of lives. Globally, there are an estimated 33 million people living with HIV/AIDS (PLHA) up from 29.5 million in 2001 (UNAIDS, 2008), including more than one million in the United States. While cases have been reported in all regions of the world, most people living with HIV/AIDS reside in low and middle-income countries, particularly in sub-Saharan Africa (UNAIDS, 2008). Sub-Saharan Africa, the hardest hit region, is home to two-thirds (70%) of people living with HIV even though it makes up only 11–12% of the world’s population (UNAIDS, 2008). Almost all of the region’s nations have generalized HIV epidemics: that is, their national HIV prevalence rate is greater than 1%. Also, more than half of the global HIV/AIDS cases are women in sub-Saharan Africa (UNAIDS/WHO, 2008a; Seager, 2009).

HIV is a leading cause of death worldwide and the number one cause of death in Africa. Over 2 million people died of AIDS in 2007, up from 1.7 million in 2001 (UNAIDS/WHO, 2008a; UNAIDS 2008b), but deaths are now declining due in part to antiretroviral treatment (ART) scale-up. While there have been successes in addressing the epidemic on many fronts, multiple challenges remain in the areas of prevention, care and treatment. One of the many issues

that is common to all these challenges is stigmatization of PLHA and their families. In most developing countries, particularly in Ghana, HIV/AIDS-related stigma fuels the transmission of the disease and has greatly increased the negative impact associated with the epidemic.

Definition of Terms

What is HIV/AIDS?

There has been much controversy over the origin of HIV and AIDS for many years. According to Center for Disease Control (CDC) (2008), in 1999, an international team of researchers reported that they had discovered the origins of HIV-1 (the predominant strain of HIV in the developed world). A subspecies of chimpanzees native to West Africa was identified as the original source of the virus. The researchers believe that HIV-1 was introduced into the human population when hunters became exposed to infected blood of the chimpanzees. Over several years, the virus slowly spread across Africa and later into other parts of the world.

Human Immunodeficiency Virus (HIV) is the virus that causes Acquired Immune Deficiency Syndrome (AIDS). HIV is different from most other viruses because it attacks the immune system and progressively destroys a type of white blood cell (T cells or CD4 cells) that the immune system must have to fight diseases (CDC, 2007). It leaves individuals susceptible to opportunistic diseases such as Tuberculosis (TB) and pneumonia. A person infected with HIV can carry the virus for a lengthy period of time before damage is done to the immune system, for AIDS to develop, or even to show any symptoms of the disease (CDC, 2007). AIDS is the final stage of HIV infection, and is defined in terms of how much deterioration of the immune system has taken place as seen by the presence of opportunistic infections (CDC, 2008). At this stage, the virus has weakened the immune system to the point at which the body finds it difficult to fight infection. When people have one or more specific infections (or a very low number of T cells) they are considered to have AIDS. Although there is no cure for HIV and AIDS, there are treatments purported to reduce the amount of virus in the body with Anti-Retroviral Treatments (ART) which dramatically slow the destruction of an infected person's immune system (CDC, 2008).

According to the CDC (2008), HIV is primarily found in the blood, semen, or vaginal fluid of an infected person and is transmitted in three main ways:

- Having sex (anal, vaginal, or oral) with someone infected with HIV.
- Sharing needles and syringes with someone infected with HIV.
- Being exposed as a fetus or infant to HIV before or during birth or through breastfeeding (mother-to-child transmission).

Because a person can carry HIV for a long time without any symptoms, many patients are identified at the end of the final stage when they have AIDS.

What is Stigma?

The standard citation for defining stigma is Erving Goffman's (1963) study on stigma related to mental illnesses, physical deformities and what were perceived to be socially deviant behaviors. Goffman (1963) defined stigma as an "attribute that is deeply discrediting" that reduces the bearer "from a whole and usual person to a tainted, discounted one" (p. 3). Goffman (1963) described three types of stigma:

First there are abominations of the body - the various physical deformities. Next there are blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behaviour. Finally there are the tribal stigma of race, nation, and religion, these being stigma that can be transmitted through lineages and equally contaminate all members of a family. (p. 4)

Because one typically inherits membership to this last group, tribal stigma can equally adhere to and affect all members of a family.

While Goffman focused on the individual aspects of stigma, Parker and Aggleton (2003) offered a framework that emphasizes stigma as a social process that produces and reproduces relations of power and control. According to Parker and Aggleton (2003), stigma is used by dominant groups to legitimize and perpetuate inequalities, such as those based on gender, age, sexual orientation, class, race or ethnicity. By applying stigma, dominant groups effectively limit the ability of stigmatized groups and individuals to resist subordination because of their entrenched marginal status. Furthermore, stigmatized individuals and groups often accept the norms and values that label them as having negative differences (Goffman, 1963). As a result,

stigmatized individuals or groups may accept that they deserve to be treated poorly and unequally, making resistance to stigma and its resulting discrimination even more difficult.

In addition to an exercise of power, stigma can be a response to fear or risk or a threat of a disease that is incurable and potentially fatal (Gilmore & Somerville, 1994). The more rapid the spread of the disease and the greater the uncertainty of how the disease is transmitted, the more likely that stigma will result. Epidemics that seem to present an overt threat to the values of a community are especially likely to evoke stigma because it is used to “enhance or secure social structuring, safety and solidarity...or reinforce societal or community values by excluding divergent or deviant individuals” (Gilmore & Somerville, 1994, p. 1342).

Stigma related to medical conditions is greatest when the condition is associated with deviant behavior or when the cause of the condition is viewed as the individual’s responsibility (Alonzo & Reynolds, 1995). This becomes particularly strong when the illness is associated with religious beliefs and thought to be contracted through morally unacceptable behavior (Alonzo & 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 & Reynolds, 1995; Cogan & Herek 1998; de Bryun, 1998).

Stigma can be either “internal” (felt) or “external” (enacted) (Falobi, 2004; UNAIDS, 2002). External or enacted stigma refers to “actual experiences of discrimination” (UNAIDS, 2002, p. 9). This may include the experiencing of domination, oppression, the exercise of power or control, harassment, categorizing, accusation, punishment, blame, devaluing, prejudice, silence, name calling, denial, anger, a sense of inferiority, social inequality, exclusion, ridicule, resentment or confusion (Falobi, 2004;UNAIDS,2002). Additionally, external stigma has a powerful capacity to produce internalization and acceptance of inferiority by the stigmatized individual or group and sometimes justification of discrimination by the dominant group (Falobi, 2004; UNAIDS 2002). Internal or felt stigma is the shame PLHA experience when they internalize the negative responses and reactions of others (Falobi, 2004; Ogden & Nyblade, 2005). This can lead to depression, withdrawal and feelings of worthlessness, loss of hope, inferiority, and the belief that they no longer have a future (Falobi, 2004; Fife & Wright, 2000). Felt stigma has an important role to play in “policing” the behavior of PLHA, causing some to deny their serostatus, others to conceal it, and all to experience anxiety about telling others and seeking care.

The consequences of stigma as noted by Goffman (1963) reduce the life chances and social situation of the stigmatized through discriminatory actions. Stigma and discrimination are interrelated, reinforcing and legitimizing each other. Stigma lies at the root of discriminatory actions, and may lead people to engage in actions that harm or deny services or entitlements to others (UNAIDS, 2005). Discrimination is defined as any form of arbitrary distinction, exclusion, or restriction affecting a person, usually by virtue of an inherent personal characteristic or perceived membership to a particular group (UNAIDS, 2000). Thus discrimination is the enactment of stigma or the negative acts that result from stigma and that serve to devalue and reduce the life chances (opportunities that PLHA may have to improve the quality of their lives) of those stigmatized. In turn, discrimination encourages and reinforces stigma. Therefore, for the purpose of this study, I do not conceptualize discrimination as separate from stigma, but as the end result of the process of stigma.

Types of stigma in relation to HIV/AIDS.

PLHA encounter each of the three types of stigma described by Goffman (1963):

(i) *Stigma associated with abominations of the body: various physical deformities.*

People diagnosed with HIV/AIDS are susceptible to opportunistic infections, which are caused by microbes that usually do not cause illness in people with healthy immune systems (CDC, 2008; Sowadsky, 1999). These opportunistic infections spread rapidly and can result in physical deformities that are often degenerative and disfiguring (Gilmore & Somerville, 1994; Goffman, 1963; Ogden & Nyblade, 2005; Sowadsky, 1999). Depending on the stage of the disease, some PLHA may lose weight, have rashes, or may have a serious illness (like blindness), but these symptoms do not always mean that one is HIV positive. Many PLHA are stigmatized because of these physical deformities on their bodies.

(ii) Stigma associated with blemishes of individual character perceived as weak will. This type of stigma included those persons who are perceived as *domineering or having unnatural passions, treacherous and rigid beliefs, and are dishonest* (p.4). According to Goffman (1963) these traits were “*inferred from a known record of for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior*” (p. 4). HIV/AIDS has been associated with perceived flaws in individual characters that come with negative responses in society

(homosexuality, injection drug use and promiscuity) (Aggleton, 2000; Marshall, O'Keefe & Fisher, 1990; Milan, 2005; Ogden & Nyblade, 2005; Smart, 2005). Many people believe that PLHA are responsible for their predicament and that the disease is a punishment for bad moral behavior. In many societies, HIV/AIDS is seen as a disease of morally irresponsible people, a disease that belongs to "them" or "others," a disease of drug addicts, prostitutes, and homosexuals. As a result of this, people who contract HIV often are blamed and stigmatized for their condition.

(iii) *Tribal stigma of membership in socially devalued groups such as racial and ethnic minorities or gender, nation and religion.*

Stigma is linked to power and control throughout society as a whole. Ultimately stigma creates and reinforces social inequality. Stigma associated with gender is the common aspect that fits this third type of stigma regarding HIV/AIDS related stigma. Originating deeply from within the structure of society and the norms of values that govern everyday life, stigma causes some groups to be devalued and ashamed and others to be superior. For instance, the long-standing ideologies of gender have resulted in women being blamed for the transmission of sexually transmitted diseases (HIV in this case). It is not surprising that many communities react to women who are seropositive in a different way from men with the same status. For instance in Ghana many women are blamed for the disease for which they and their husband suffer, when, in fact, men are often the promiscuous partner within the relationships.

Goffman's concept of stigma presents some of the basis for understanding why many people with HIV/AIDS are stigmatized. It also shows the complexity of stigma that involves interplay between society and the individual.

What is HIV/AIDS-Related Stigma?

HIV/AIDS-related stigma has been seen all over the world, although it manifests itself differently among countries, communities, religious groups and individuals. HIV/AIDS-related stigma embodies a set of shared values, attitudes and beliefs that can be conceptualized at both cultural/contextual and individual levels. At the cultural level it is manifested in laws, policies and the social conditions of the PLHA. At the individual level it manifests in the form of behaviors, feelings and thoughts that are prejudiced against PLHA. It also reinforces fears of outsiders and otherwise vulnerable groups. HIV-related stigma is multi-layered, tending to build

upon and reinforce negative connotations through the association with already marginalized behaviors, such as sex work, drug use, and homosexuality (behaviors often considered socially unacceptable). UNAIDS (2003) described HIV/AIDS-related stigma as a “process of devaluation of people either living with or associated with HIV and AIDS. This stigma often stems from the underlying beliefs about sex and intravenous drug use, two of the primary routes of HIV infection” (p. 1).

Diseases associated with stigma share common attributes: often the person with the disease is seen as responsible for having the illness because he/she deviated in some way from a norm, the disease is both progressive and incurable, the disease is not well understood by the public, and the symptoms cannot be concealed (Goffman, 1963; Herek & Capitanio, 1999; Seaton, 2003). HIV/AIDS corresponds to all of these characteristics: contracting of the disease is associated with flaws in individual characters such as homosexuality, prostitution and drug use, the disease is both progressive and incurable and in the course of the disease PLHA may face physical deformities such as growing lean and having rashes all over the body. Although some communities have made efforts to educate people on HIV/AIDS, many people are ignorant about the transmission of the disease and therefore the fear of contracting the disease leads them to stigmatize. Individuals living with HIV are often believed to deserve their HIV-positive status as a result of having done something wrong. This perception creates us-and-them differences; reinforcing the feeling that HIV belongs to a particular group of people (them) - because of their immoral behaviors - and not to us. Consequently, there is the tendency of “us” (often the dominant group) to exercise power and social control over “them” through stigmatization, hence limiting the abilities of the stigmatized groups to fight the stigma. By attributing blame to particular individuals and groups that are different from the majority, others can absolve themselves from acknowledging their own risk, confronting the problem and/or caring for those affected.

HIV/AIDS-related stigma has been defined in many ways and has been expressed as a complex social process resulting from the interactions between social and economic factors in the environment that create unfavorable attitudes, beliefs and policies directed toward people perceived to have HIV/AIDS as well as toward their families, close associates, social groups and communities (Brimlow, Cook & Seaton 2003; Ogden & Nyblade, 2005). It can result in PLHA

and those associated with them being rejected from their community, shunned, discriminated against or even physically hurt.

PLHA and HIV/AIDS-Related Stigma

Stigmatization of PLHA has been documented in the United States (Crandall, 1991; Crandall & Moriarty, 1995; Herek & Capitanio, 1993, 1999; North & Rothenberg, 1993; Rothenberg & Paskey, 1995; Sowell et al., 1999; Zierler, Cunningham, Andersen et al., 2000) and in numerous reports from developing countries (Bond & Nubani, 2000; Hutchinson, 2003; ICRW, 2002; Nyblade & Field, 2000; Ogden & Nyblade, 2005; UNAIDS, 2000). Probably one of the most publicized events occurred South Africa in 1998, when Gugu Dlamini, a female volunteer fieldworker for the National Association of People living with HIV/AIDS, was stoned and stabbed to death by neighbors soon after she disclosed that she was HIV positive on radio as part of South Africa's commemoration of World AIDS Day (Piot, 1999). Unfortunately, this is not an isolated event, and it highlights the potential severe consequences of HIV/AIDS stigma on PLHA. It points to the collective, communal and individual levels of HIV/AIDS-related stigma.

Stigma intensifies the emotional pain and suffering of PLHA (Nyblade et al., 2003). For instance, they are unable to find employment, are denied health care, cannot access services in their communities, and they sometimes lose respect and power, their social network and even their marriage.

Many PLHA find it difficult to find lucrative and stable jobs, or may report of being dismissed from work or being refused jobs. For instance a woman in Hong, Van Anh, and Ogden's (2004) study recounted that: *"Now they are afraid of me so they do not hire me [to wash clothes]. People like me cannot ask for any job. Now I do only do some agricultural laboring that is all I am doing for my living now"* (p.36). A mother of PLHA in the same study expressed how her daughter is not able to find a stable job:

This girl now does work such as catching shellfish and snails or drying rice, but she cannot apply to work in factories, as they will not accept her. They don't say it is because of HIV, they say that they do not accept, that's all. They may feel disgusted when they see her. So she lives such a lonely life. She catches snails for three to five thousand dong [US25 cents] per day when she can, probably to buy rice. If she cannot work, she stays at home, so we eat whatever we, her parents, can afford (p. 36).

In some societies PLHA in formal employment who are open about their serostatus (testing positive to HIV) sometimes find themselves being dismissed from their jobs. In Urwin's (1988) study on the impact of HIV on the family, for instance, 'James' (one of the respondents) was given a permanent leave of absence when his employer learned of his AIDS diagnosis. At the end of the Fifteenth International AIDS Conference in 2004, Sonia Gandhi and former South African President Nelson Mandela both urged political leaders to make stronger efforts to reduce the stigma that surrounds HIV/AIDS. According to Gandhi, "I have seen people who have lost jobs and who have been ostracized, and the orphans not adopted because of stigma, and I have seen people fading away in front of their helpless families" (Gandhi & Mandela, 2004, ¶ 2). Loss of employment due to discrimination may leave PLHA with no option other than relying on family members for assistance or to depend on public assistance which is little to nothing at all in many countries, considering the cost of treatment and medication for HIV/AIDS. This requires them to interact with various agencies, which may also discriminate against them.

Accessibility to service such as health care, education, housing and insurance has been one of the many areas of discrimination towards people with HIV (Brimlow, Cook & Seaton, 2003; Ferreira, 2004; ICRW, 2006; Urwin, 1988). Although health care facilities provide care for PLHA, they sometimes stigmatize them. Studies reveal the reality of withheld treatment, nonattendance of health care professionals and support staff to patients, denial of hospital facilities and medicines and sometimes being insensitive to concerns from PLHA (Aggleton, 2000; ICRW, 2006). For instance, a service provider described a physician in Manhattan, Kansas, who does not work with children with HIV because he is not "comfortable" attending to children with HIV/AIDS. Instead, the children are referred to Salina for care (D. Hart, personal communication, February 26, 2006). In a similar circumstance, a person living with HIV in Ethiopia recounted the following experience: "I went to a dentist... and told him I am HIV-positive. When he heard this he told me that he cannot help me and asked me to leave his clinic" (Ogden & Nyblade, 2005 p. 31). Mahendra, Gilborn, George and others (2006) identified the strengths and limitations of existing services for HIV infected individuals in hospitals and found that many PLHA are denied care, experience delay in treatment, or referred to other hospitals because of their diagnosis. Some participants expressed: "*we are often refused treatment in...hospitals. They tell us 'we have no bed, we have no empty bed'. Another thing that they say*

is *'we don't have facilities for treating HIV.'* They then refer us to other hospitals." (p.18). One participant also expressed how a doctor gave an excuse:

The doctor refused to examine me for almost two months. Even stopped doing my dressing. He just told me to continue with my medicines. He also referred me to another hospital for an operation that he wouldn't do as it would be very costly for me (p. 18).

Similarly, PLHA lose power, respect and identity through the taking away or diminishing of their roles, responsibilities and social standing within the family and larger community. (Belsey, 2005; Deacon & Myers-Walls, n.d; Fife & Wright, 2000; ICRW, 2006; Link & Phelan, 2001; Macklin, 1988; Marshall, 1990; Ogden & Nyblade, 2005). This expression of stigma is probably due to the perceptions people have about HIV as contracted through inappropriate behaviors or behaviors that are not acceptable by society. Therefore anyone who has HIV is seen as immoral and irresponsible and not fit to be respected or given authority in society. In addition to this is the belief that HIV means immediate disability and death because of the nature of the disease, so PLHA can no longer be productive members of the society. They are called names and are labeled. Most African countries for example have expressions in indigenous language to identify PLHA. For instance among the Akan tribe in Ghana, they are called "tease wuo" and the Ga tribe in Ghana call them "gbele wu" which literally translates "the living dead" and "skeletons" respectively. These expressions are demeaning and throw light on how people perceive HIV/AIDS.

Many PLHA especially children are refused education because of their serostatus. In a recent study in Nigeria to determine what elementary school teachers in Nigeria know about HIV/ AIDS, most of the teachers interviewed (76 percent) said that they will not admit a child known to be HIV positive into the class with other children. (Okafor and Aranotu, 2002).

PLHA often find that they are no longer welcome at important family and community events, such as parties, weddings, etc. In the realm of daily life, they often find that neighbors, friends and relatives are reluctant to visit or be close to them. In Ogden and Nyblade's study (2005), a woman in Vietnam explained that she terminated all contact with a childhood friend because *"people told me I should stop spending time with her. They said things like, 'I know you have been close with her from childhood, but now she goes on that track (sex work) so don't play with her"* (p. 28). Similarly in a phenomenological study (Okafor, 2002), a participant explained why she cannot disclose her status:

The reason I cannot tell anybody that I have this disease is because I will be cut off from everybody, people will not even buy things from me in the market, and nobody will allow me to buy goods from them because they will not touch my money.

The loneliness and isolation as a result of testing positive to HIV/AIDS is also expressed by a catholic sister who used the symbolism of the Stations of the Cross to describe the pain and isolation of the PLHA in her Uganda hospital (Okafor and Holder, 2004). The Stations of the Cross reads:

He cannot stand alone, the abscesses are too painful. Peter is too weak. With help he makes it home and to bed where he begins the difficult task of regaining strength so he can pick up the cross of living with AIDS and continue his journey alone.”

(Okafor and Holder, 2004, p.30).

This imagery based on the suffering of Jesus Christ signifies the pain and suffering that is associated with AIDS, especially the loneliness, sense of isolation and despair that go hand in hand with the infection. It is not surprising that when PLHA are subjected to discriminatory and hurtful acts, they internalized all those acts and stigmatize themselves. They usually will isolate themselves from the rest of the family or the community.

Internalized Stigma

One of the major aspects of stigmatization is internalized stigma. Many PLHA drop out of school and work, avoid social settings, friends and family; some even lose hope of having family on their own or avoid sexual relationships as a means of self-preservation (Fife & Wright, 2000; Gilmore & Somerville, 1994; Guni, 2005; Herek & Mitnick, 1996; Ogden & Nyblade, 2005) because of the shame, or fear of being stigmatized. For instance, a woman in Ogden and Nyblade's (2005) study explained:

I do not want to have close contact with people because I know that I have HIV... I am the one who should isolate myself from others. Some people who know me well want to have a good relationship with me, but I do not want to be close to them. (p. 32).

Also, as recounted by counselors in a focus group discussion in Aggleton's (2000) study:

Some people are not very supportive because the PWA him/herself may not be cooperative to other members (of the family). He/she may stigmatize him/herself, hence repelling the would-be help from other people. (p. 30)

Some studies show that internalized stigma related to HIV/AIDS appears to be more intense than it is for individuals with other life-threatening diseases or conditions. For example, Fife and Wright (2000) compared self-stigma associated with HIV/AIDS to that of cancer and discovered that self-stigma is worse for PLHA than cancer because of the nature of transmission. Overall, the negative perception of PLHA – reinforced by the language and expressions of HIV/AIDS – has caused many affected individuals to avoid families and friends and to isolate themselves from their communities. They hesitate to pursue new employment or promotions at current jobs, continued education or higher levels of vocational training, or health care and they give up on scholarships or travel (Nyblade et al., 2003). Internalized stigma causes a kind of “social death” in which PLHA no longer feel part of their families and society and are no longer able to access the services and support they need. This may be a challenge for educational programs because self-stigma may limit participation of PLHA in educational programs and services that will be beneficial for them and the society at large. For instance, Nyblade and others (2003) found that when PLHA participate in educational programs and services they not only reaffirm a sense of purpose and hope for their lives, but they also take an active role in HIV/AIDS education and counseling. In other words, self-stigma or internalized stigma does not end with the individual infected with HIV, but is also a loss to society in general.

Stigmatization Within the Family

Within the family there are major changes that take place when a person has HIV/AIDS. Family members may sometimes refuse to provide care for PLHA. Ogden and Nyblade (2005) found that family members and close friends stigmatized PLHA and refused to provide care "out of fear of transmission, out of anger, judgment and moral condemnation, fear of experiencing the stigma of others, or a combination of these factors" (p. 31). The family's judgment, moral condemnation and fear of being stigmatized are undoubtedly derived from the larger society, cultural values and ideologies.

When people are diagnosed with HIV/AIDS they can be isolated and separated from their families and public places (Nyblade et al., 2003; Ogden & Nyblade, 2005; Parker & Aggleton, 2003). Common expressions of stigma within the home include separating household items such as cooking and eating utensils, clothes, bed linens and making PLHA sleep in separate quarters (Nyblade et al., 2003; Ogden & Nyblade, year; Parker & Aggleton, 2003). In

public places, expressions of stigma include not sitting or standing near PLHA in public transport, in places of worship, while waiting in a queues and not greeting PLHA (Belsey, 2005; Fife & Wright, 2000; ICRW, 2003; Ogden & Nyblade, 2005). From my personal experience of working with PLHA, I realized that many individuals were “separated” from their family routine: they were given different rooms, different plates and cups to eat from, etc. Separation from the family routines is a difficult issue that the PLHA have to deal with. This is because at the center of Ghanaian society is the institution of family. It is acknowledged as the bedrock of all social life.

In a recent study done by the Health and Development Network (HDN, 2006) in Swapna Majumdar, India, it was found that stigmatization of PLHA starts at home, especially for Indian women. When one woman, Urmila, tested positive for HIV in her fifth month of pregnancy, she thought her in-laws would give their full support as even her husband was diagnosed as HIV positive. However, after a few months when her husband died, her in-laws ostracized her. They also tricked her into signing away her and her son’s rights to her husband’s share of the property.

Loss of marriage and childbearing are other consequences of HIV/AIDS-related stigma within the family. In some cases spouses are deserted upon disclosure of their HIV status because often the first person to become tested in the relationship is considered as the one who brought the disease into the family (Health and Development Networks, 2006; Ogden & Nyblade, 2005). The GSHRDC conducted an inquiry into the relationship between gender norms/domestic violence, human rights and HIV/AIDS and found that one of the impacts of disclosure of one’s serostatus is separation or divorce. A 31 year old woman in the recounted: *“it has been four years now since we separated. He said it is because of the disease. When they told me that I had the disease, I told him and he said he cannot stay with me”* (p.75). Similarly a 25 year old woman explained (in the same study), how her husband “vanished” when he heard of her serostatus: *“that was what I told you about that when I told him, after two weeks, he told me that he was going to his hometown and will be back but has not come back ever since”* (p. 75).

Furthermore, PLHA may find that marriage and childbearing are no longer an option for them because the family of the PLHA discourages it and in some cases family members take sanctions against PLHA if they bear children (Mbwambo, Kilonzo et al., 2004, in Ogden & Nyblade, 2005).

Secondary Stigma: Family Members of PLHA

In a phenomenological study (Okafor, 2002) of PLHA in Nigeria, a participant recounted her stigmatizing experience as worse than leprosy of the biblical time. She felt guilty of giving the disease to others and ashamed of imparting disgrace on the family name. She was particularly concerned that her sisters might never marry and that the whole community would feel disgraced and betrayed by her. The participant's concerns illuminate the impact of HIV/AIDS related stigma on family members of the PLHA.

While the PLHA are the ones who have the disease, their family members are often stigmatized by association. Family members (parents in particular) and their perceived lack of vigilance and engagement may be held responsible for the "misbehavior" of their children. As a result, it is believed that a person who has HIV/AIDS was not raised up properly by his/her parents. For instance, Nyblade et al. (2003), who conducted a study in Tanzania, Zambia and Ethiopia, interviewed a woman who said in a focus group discussion: "Some people say that the father never taught him good manners so he has ended up getting the disease" (p. 34).

Also, if a family member is known or assumed to be HIV-positive, there is a sense of transference of HIV-positive status (and the "immoral" behaviors assumed to have caused it) to the entire family. When this happens the family loses its reputation and social status which are usually closely tied to the behavior of the family members (Ogden & Nyblade, 2005). Thus, when someone becomes HIV-positive, it can reflect poorly on the entire family. As expressed in Nyblade et al (2003),

Because their son died due to AIDS, they will think every member is infected. In families it is the same like a thief. If there is a thief in the family everybody is a thief. So, if there is someone with the disease, then everyone also is a prostitute. Everyone has HIV/AIDS. No one gets good remarks when you have AIDS; everything is insults. (p. 35)

In Ghana, for instance, family members are ultimately responsible for the behavior of each household member and the family is either blamed or praised for the behavior of its members (Hintz, 1987). An individual is linked to a long chain of living and deceased members in his or her family, town or village (Hintz, 1987). Thus, family members of a person with HIV/AIDS often are held responsible and are stigmatized. Sometimes, in an attempt to preserve the family, family members may encourage PLHA to hide their HIV status to prevent gossip and

social rejection. Also, family members encourage relatives with HIV/AIDS to minimize social contact in order not to be stigmatized.

In many respects family members experience the same forms of stigmatization as the PLHA, such as losing their jobs, access to services, etc. For example, Ogden and Nyblade (2005) recounted the story of a woman in Vietnam who lost her job because her daughter was diagnosed with HIV. This woman provided care for neighborhood children. When people heard the news of her daughter's positive serostatus, all the children were withdrawn from her care and she had to seek another job of selling lottery tickets, which is less lucrative. In situations where the PLHA is the sole breadwinner of the household and loses his/her job as a result of stigma, the financial repercussions are often overwhelming for the family (Hong et al., 2004).

In many societies the impact of stigma on the family is enormous and far reaching. In my work with PLHA, I observed that due to the sub-standard health care delivery system and unavailability of routine health screening in Ghana, many people who were diagnosed with HIV/AIDS were in the advanced stages of the disease and did not live long enough to face much stigmatization. Instead, their family members were the ones to answer for the PLHA's "bad behavior." As a result, their family members bore the brunt of stigmatization from their communities.

Children of PLHA most often bear the most severe impact of secondary stigma such as isolation, rejection and taunting by their peers. In a study by Deacon and Myers-Walls (n.d) in the 1990s in the U.S., one woman who was caring for a younger sister reflected on the discrimination of her family members because her mother died of AIDS. She recounted that, after her son was born, he was isolated from the other babies. She also was isolated from the other mothers and was interviewed by social workers, even though she was completely healthy and showed no indication of HIV or complications during her pregnancy. In a study done in Zambia, Nyblade and others (2003) found that children of PLHA are often stigmatized and are often blamed for their parents' behavior. A woman who had tested positive to HIV said "my neighbors are not willing for my children to watch TV in their house" (Nyblade et al., 2003, p.35) despite the fact that the children do not have HIV/AIDS. In Hong, Van Anh and Ogden's (2004) study for example a 69 year old woman whose daughter has HIV/AIDS recounted how her daughter's child was stigmatized at school:

When her child went to school, her friends in the alley called her “SIDA child.” She cried then and did not want to go to school. I just heard that they said “do not play with a SIDA child. If you play with her you will get infected.” She cried again and ran home to tell me, her grandmother. I said to her, “Don’t mind them. Your mother has SIDA, not you. Do not mind what they say to you” (p. 36).

As a result, children may internalize the negative reactions and in cases where they are orphans they can blame themselves for the death of their parents (Nyblade et al., 2003). Expressions such as “its my fault because I don’t have parents” and “I was not suppose to be born” (Nyblade et al., 2003) are very common. Children are often reminded (by their guardians) of their parents’ behavior and death whenever they make mistakes(Nyblade et al., 2003). Children, therefore, bear the brunt of family stress.

Gender and HIV/AIDS

Since the diagnosis of the first HIV/AIDS case, the disease has had a gendered dimension to it. According to the UNAIDS and WHO (2008a), more than half of the global HIV/AIDS cases are women (UNAIDS/WHO, 2008a) who live in sub-Saharan Africa. In fact 75% of young PLHA in Africa are women and girls (Amnesty International, 2005). In Ghana, for example, the disease was initially considered as a women’s disease and AIDS was explained as standing for “Akosua Is Dying Slowly” (Ampofo, 2003) because of the overwhelming number of women (80% of PLHA) who had the disease in the late 1980s. (Akosua is a name among the Akan tribe given to a female born on Sunday). It was not until the mid 1990s that the ratio between women and men begin to narrow although currently the rate is still higher among women. Out of the 600,000 PLHA in Ghana, 61% are females and 39% are males. Several factors, mostly social and biological, have been provided as contributing to women’s vulnerability to HIV/AIDS infection.

Women’s Vulnerability to HIV/AIDS

It was not until recently that a growing number of researchers began to explore the biological factors that make women more vulnerable to contracting the HIV virus. The WHO (2004) published a report that indicated that the biological differences between men and women make women more susceptible in any given heterosexual encounter. According to the report, there are three factors that account for this. First, women have a greater area of mucous

membrane exposed during sex. This mucous membrane is a soft tissue in the female reproductive tract which can tear easily during intercourse which then produces a transmission route for the HIV. Second, during sexual intercourse more fluids are transferred from men to women than from women to men. Finally, male sexual fluids have a higher viral content than vaginal fluids. Thus, vaginal tissue absorbs fluids more easily, including sperm, (which has a higher concentration of the HIV virus than female vaginal secretions) which remain in the vagina for hours following intercourse, hence increasing the chance of having the virus. Therefore, male-to-female transmission of the disease is estimated to be eight times more likely than female-to-male transmission. Why then are women blamed more than men when they have HIV/AIDS?

A growing number of studies have looked at the social factors that make women (particularly African women) more vulnerable to HIV/AIDS than men (Dunkel, Jewkes, and Brown, 2004; GSHRDC, 2009; Mill, 2000; Opong & Agyei-Mensah, 2004). Some of these social factors are violence against women, inequalities within families, and lack of opportunities for women in patrilineal societies that prevent females from inheriting land and property.

Research by Dunkel, Jewkes, and Brown, 2004 shows that women who are victims of violence are at a higher risk of being exposed to HIV. The research was carried out among 1,366 South African women who attended health centers in South Africa. After adjusting for factors that could skew the outcome, such as whether interviewees had engaged in casual sex or sex work, the result showed that women who were beaten by their husbands or boyfriends were 48% more likely to become infected by HIV than those who were not. Those who were emotionally or financially dominated by their partners were 52% more likely to be infected than those who were not dominated. Domination, and physical abuse is often accompanied by rape: the lack of condom use and the forced nature of rape mean that women are immediately more vulnerable to HIV infection.

In many African societies, women have few rights within sexual relationships and the family (United Nations Development Program [UNDP], 2009). Often men make the majority of decisions, such as whom they will marry, how many and whether the man will have multiple sexual partners. On such polygamous relationships, power imbalance means that it can be more difficult for women to protect themselves from getting infected with HIV. For example, a woman may not be able to insist on the use of a condom if her husband is the one who makes the decisions.

In many societies women do not have the same property rights as men and the denial of a woman's inheritance and property rights can increase her vulnerability to HIV (UNAIDS, 2002; UNDP, 2009). In sub-Saharan Africa, for instance, property is typically owned by men and even when married, women still do not have as many property rights as their husbands and inheritance rights are just as discriminatory. For example, when a husband dies, his property often goes to his side of the family and not to his wife (UNAIDS, 2002; UNDP, 2009). Not being able to own property means that women have limited economic stability. This can lead to an increased risk of sexual exploitation and violence, as women may have to endure abusive relationships or resort to informal sex work for economic survival.

High illiteracy rates among women have also been recognized as a factor that adds to women's burden of risk for HIV/AIDS (Seager, 2009). Girls are more likely than boys to fail to complete secondary or higher level education because of social economic factors. Factors such as early marriage, pregnancy, and care duties at home are some of the challenges for girls and women. For example a 2006 statistics, (Seager, 2009) show equal proportion of males (93%) and females (94%) enroll in basic primary education; however at the university level women make up only 34% of the students. On the whole more women (about 50%) are uneducated as compared to 34% of males in Ghana as of 2006 (Seager, 2009). These high levels of uneducatedness leaves a majority of women working in the farming and other informal activities (such as trading, vending etc) with the least of women found in administrative and managerial jobs. This creates economic dependency for women as they seek to exchange sex for money or favors or depend solely on their partners.

Virginity puts young girls at risk of rape and sexual coercion in high HIV/AIDSs prevalence countries. Men are always seeking young girls, specifically virgins, as sexual partners, because of the erroneous beliefs that young girls are safe from the HIV infection (Seager, 2009) and sex with a virgin can cleanse a man of infection (Gupta, 2000). This pattern is evidenced both locally and internationally by the trafficking of young girls. This, however, puts women at risk at a rather young age, five to ten years younger than men (Seager, 2009).

Gender and HIV/AIDS-Related Stigma

While women constitute a larger percent of HIV/AIDS cases and vulnerable to HIV/AIDS, they are often times blamed and stigmatized more than their male counterparts.

'She died after passing her HIV to her husband'. This is an often-repeated sentence in Zimbabwe. The echoes can be heard in homes in workplaces and in graveyards, at times shrill, at times in a hushed whisper. The tone, though, is always accusatory... The corollary to this statement, i.e. 'He died after passing HIV to his wife', is seldom heard. (Nath, 2001, p. 36)

Findings from various research studies indicate that gender also plays a part in the ways HIV-related stigma is expressed, and the intensity with which it is experienced (Gupta & Selvaggio, 2007; Hong et al., 2004; Lesko, 2005; Nyblade et al, 2003). In developing countries women and men are not dealt with in the same way when they have HIV/AIDS (GSHRDC, 2009; Gupta & Selvaggio, 2007; Hong et al., 2004; Lesko, 2005; Mill, 2003; Nyblade et al., 2003; Ogden & Nyblade, 2005). It is evident that men with HIV/AIDS are more likely to be accepted by family and community than women. Consequences of stigma are more severe for women, and they are more frequently sent away from their families and separated from their children than men are. For instance a phenomenological study of PLHA in Nigeria, Okafor (2002) found that the stigmatizing experiences of women with HIV/ AIDS is made worse by pre-existing stigma on women as agents of all sexually transmitted diseases. Women who discover their serostatus after the death of a husband from AIDS are blamed by the relatives of their husbands.

Nyblade et al. (2003) found that the reasons given for blaming men or women for being responsible for bringing HIV infection into the partnership, home, or community are intricately tied to socially accepted norms regarding gender specific roles, responsibilities, and sexuality in the three countries studied. Both men and women who transgress these norms face blame. However, when men are blamed (by women or by men) it is with an underlying assumption that the behavior is to be expected, in tune with social perceptions of men's proclivity for multiple sexual partners. This was expressed by a man from Zambia: "We men are to blame because we normally say that you don't need to have the same kind of meat every day, meaning that despite your real girlfriend, you have other multiple girlfriends somewhere else" (Nyblade et al., 2003, p. 26). According to Hong and colleagues (2004), in Vietnam, social expectations are that women should uphold the moral integrity of the family and society while men can be more self-indulgent and so it is regarded as normal for men to "like indulging in pleasures" or to "prefer rare and new things." Therefore, when they have HIV people are not always surprised or angry.

On the other hand, if Vietnamese women, who are always expected to be careful, get HIV, it is a shock for their families.

Hong et al. (2004) further reported that the family is at the center of Vietnamese culture, and one is meant to act in ways that support and reinforce the well being of one's family. Those who violate this norm are often harshly criticized and simply not tolerated. However, these norms do not apply to men and women equally. This is reflected in many Vietnamese proverbs, such as: "no matter how wise, she is still a woman; no matter how silly, he is still a man." (p. 34). A female participant in their Vietnam study expressed:

I think it is no problem for a man to get HIV/ AIDS and he could be talked with, but people hate a woman who gets infected. I say the truth. Why is that so? Because work is available for women—they should have good employment. So if a woman indulges in play too much, people would hate it. For example, people do not hate a drug addicted man nearly as much as a drug addicted woman. To say frankly, if men are still young and they indulge in play and get [HIV] infected, that's the general story of the society. If a girl gets this disease, no one would like to get close to her, because it is a problem of her conduct and her morality. It is not tolerated in females compared to males.

(Nyblade et al., 2003, p. 34).

Thus, as part of their social functions women are expected to do all the house chores and take care of their husbands and the rest of the family. Simply put, there is no time for the woman to engage in "play" (so called illicit behaviors such as prostitution or having multiple partners) that will result in getting infected with HIV/AIDS. HIV is regarded as evidence that women have failed to fulfill this important social function. To phrase the problem another way:

Women living with HIV and AIDS (or more often, suspected to be living with HIV and AIDS) are regarded as everything they should not be—sick and slim when they should be healthy; being cared for when they should be caring for others; sexually deviant when they should be sexually righteous. To be HIV-positive is not to be a proper woman (Bond, Chilikwela, Kafuma et al., 2003, p. 29).

HIV/AIDS-Related Stigma and AIDS Prevention

Stigmatization of PLHA still remains one of the most significant challenges in developing countries for all HIV/AIDS programs, across the continuum of prevention and care.

In 1987, the late Jonathan Mann, then director of the World Health Organization (WHO) Global Program on AIDS, identified three phases of the HIV/AIDS epidemic: 1) the epidemic of HIV, 2) the epidemic of AIDS, and 3) the epidemic of stigma, discrimination, and denial. He noted that the third phase is “as central to the global AIDS challenge as the disease itself” (Mann 1987). Mann recognized that stigma, discrimination, blame and collective denial were potentially the most difficult aspects of the HIV/AIDS epidemic to address, and that addressing these is key to overcoming it. Despite international efforts to tackle HIV/AIDS since then, stigma and discrimination remain among the most poorly understood aspects of the epidemic. In 2000, Peter Piot, the executive director of UNAIDS, identified stigma as a “continuing challenge” that prevents concerted action at community, national, and global levels (Piot, 2000).

People living with HIV/AIDS often fear the stigma that may result if others know their serostatus. This fear has a profound impact on the effectiveness of HIV/AIDS prevention, treatment and care programs (Brimlow, Cook, & Seaton, 2003; Brown, Trujillo & Macintyre, 2001; ICRW, 2006; Mahendra, et al., 2006; Parker & Aggleton, 2002). For instance the moral dimension and judgment aspect of HIV/AIDS stigma creates a difference between “us” (good moral community) and “them” or “others” (homosexuals, sex workers, injection drug users). This allows the “us” group to deny their risk of becoming infected and therefore, fail to take the necessary step to protect against acquiring HIV (ICRW, 2006; Ogden & Nyblade, 2005). Thus stigma can distance people from a sense of risk, which may in turn create an obstacle to prevention. Even so when people are already infected, they may fear that disclosing their HIV status or using condoms may result in partner rejection, limit sexual opportunities or increase risk for physical and sexual violence.

Because HIV transmission is associated with behaviors which are considered immoral and negative, and are not acceptable in many societies, attention to HIV/AIDS and its related issues may not be welcomed in some institutions such as churches, workplaces or schools (Gilmore & Somerville, 1994; Herek & Capitanio, 1999; Ogden & Nyblade, 2005) even though it is generally accepted that HIV prevention should be incorporated in community programs. Also in some societies, stigma has been shown to be associated with delays in HIV testing and even when they get tested, because they fear a positive result, which in their minds is linked to the stigma and social repercussions, they might not return for the results (ICRW, 2006). It is apparent that many people are living and dying with HIV/AIDS that have not been reported and

diagnosed because they did not get tested. This may discourage governments from acknowledging or taking timely action against HIV/AIDS.

Thus, stigmatization deters individuals from finding out about their HIV status, and inhibits those who know they are infected from sharing their diagnosis and taking action to protect others, and from seeking treatment and care for themselves.

Gaps in the Literature

In reflecting upon the personal moments in my life which influenced my interest in exploring the meaning and impact of HIV/AIDS related stigma in the lives of PLHA and their family members and to focus on Ghanaian women with HIV/AIDS, I became cognizant of my insufficient knowledge of what it means to have HIV/AIDS and to be stigmatized as a result of the diagnosis in the Ghanaian. I am neither HIV positive nor AIDS diagnosed. Furthermore, I have not lost a loved one to HIV/AIDS. Yet I have seen the struggles of PLHA, their family members and women who struggle with the diagnosis daily and sometimes I wondered what they would have said if they had the opportunity to be asked questions like: what is it like to have HIV/AIDS and to be stigmatized; what does it mean; how does it impact your lives? The desire to gain insight into the struggles of not only the PLHA but also family members led to me making the issue of HIV/AIDS as well as its related stigma a focus for my graduate work. By focusing on this issue, I also realized that it is a problem area amenable to family research and practice.

Few studies have been conducted in Ghana regarding HIV/AIDS and most recently, the issue of stigma related to the disease has emerged. Perry (1997) conducted a phenomenological study into the experiences of women with HIV/AIDS in Ghana. The study reported three major experiences of women; pre-illness experiences, the experiences of living with HIV/AIDS and transformation of self. Among other themes the women's experiences were captured by themes of loss, secrecy, fear and isolation, worry, symptoms, pain and disability, faith and hope. Another study was an in-depth interview with health care workers in the Cape Coast municipality in Ghana (Awusabo-Asare and Marfo, 1997). The study revealed that there was general fear of infection among health care workers that resulted from inadequate supply of basic protective items and insufficient information on the serostatus of some patients. Fear among health care workers resulted in refusal to treat HIV patients and refusal to work in HIV facilities.

Furthermore, Mill (2003) explored the experiences of HIV positive women in Accra and Agomanya. The study was carried using participatory action research. In-depth interviews and focus groups with 31 HIV-positive women, 5 HIV-positive men, 8 nurses, 10 professionals, and 2 traditional healers were used to collect the data. The need for secrecy in “breaking the news” emerged as an important theme. Secrecy affected the women’s access to treatment and to financial and emotional support from families. The secrecy surrounding breaking the news of HIV infection is one manifestation of AIDS stigma in Ghana. The study suggested both educational prevention and interventions to eliminate AIDS stigma among health care professionals, including nurses.

A more recent study (Ulasi, Preko, Baidoo et.al, 2009) have employed a cross sectional survey of 104 adults from Kumasi and looked at the predictors of stigma and the perception (knowledge, attitudes and behaviors) of community members towards PLHA in Kumasi. Four stigma constructs, employment-based discrimination, screening and identification of HIV positive people, revelation of HIV status and social contact stigma were determined based on reliability measures from responses to the questionnaire. The results showed that participants with higher educational attainment were more likely to favor policies denying employment to PLHA but disapproved of revealing HIV serostatus. Also Muslims were more likely than Christians to agree with identifying PLHA and more likely to advocate revealing HIV serostatus. The study also reported that males were more likely to favor revealing HIV status than their female counterparts.

The Gender Studies and Human Rights Documentation Center (2009) in Ghana have recently reported the findings of a national study on the *Gender norms, domestic violence and women’s vulnerability to HIV/AIDS* in Ghana. The study employed a qualitative research approach and recruited 389 women to participate in the study. They reported that various gender norms and domestic violence have a role to play in women’s vulnerability to HIV/AIDS. Gender norms reported included but limited to women’s general lack of sexual knowledge, women’s acceptance of male promiscuity within marriage, practice of polygyny, the notion of sex as women’s marital obligation, the view that infertility is solely a woman’s problem and the practice of widow inheritance. The study also reported some of the experiences of women as a result of testing positive to HIV/AIDS.

Although the studies discussed above have documented the presence of HIV/AIDS related stigma in Ghana, few have explored in detail what it means to the PLHA and the impact it has on family members of PLHA. Nor did the studies also explore the differences in experiences of stigma between men and women. For instance Mill's (2003) study only looked at secrecy as a manifestation of stigma whereas literature suggests that there are many ways in which stigma is expressed. The study did not include family members of the women who were interviewed and so we do not know anything about their experiences. Although Ulasi, Preko, Baidoo and others' (2009) study included some family members of PLHA, however they were included as part of the community and as "stigmatizers" but did not specifically explore their actual stigmatizing experiences as family members of HIV patients. The GSHRDC (2009) study's focus was to explore the relationship between gender norms/domestic violence and HIV/AIDS. Although some of the women's experiences were reported, it lacked a detailed exploration of stigma. Also, it did not include family members in the study.

Therefore this study is to fill in the gap of previous studies by seeking the stigmatizing experiences of PLHA and their family members and by adding a Ghanaian outlook to a literature which is overwhelmingly dominated by Eastern and Southern African evidence. The study does not only seek the experiences of stigma but also what stigma means to them, how it impacts their lives and how they cope with it. The differences between men and women's experiences of stigma which is lacking in the literature will also be reported.

Summary

The review of literature elucidates the impact of HIV/AIDS and its related stigma on individuals, family members and educational programs. The literature attests to both external and internal stigmatization that people experience when they have HIV/AIDS. PLHA face stigmatization in various contexts from within their households, communities, workplaces and health settings etc. They suffer emotionally, physically, economically and socially: they lose their jobs/livelihood, access to service, status and sense of self. Much of this stigmatization is as a result of HIV/AIDS been associated with perceived "immoral sexual behaviors."

It is also evident that the impact of HIV/AIDS –related stigma do not end with the individual but the family members and close relatives of PLHA are also stigmatized by association. In many cases family members experience the same stigmatization as PLHA such as

loss of livelihood, loss of status etc. In many societies like Ghana, the impact is felt more by family members than the PLHA. However, many studies have focused on PLHA, with little to no focus on the experiences of their family members and their relationship with PLHA.

Furthermore, research indicates that there are gender differences with regards to the way HIV-related stigma is expressed, and the intensity with which it is experienced. Biologically and socially women are more susceptible to HIV/AIDS than men, statistically more women have HIV/AIDS than men and are more likely to be blamed and stigmatized than men. However, the differences in gender regarding HIV/AIDS related stigma has not been specifically explored in the Ghanaian context.

Stigmatizations have made the fight against HIV/AIDS more difficult. In most cases PLHA are afraid to get tested even when they test positive they do not report their status and do not seek treatment for fear of stigmatization. This becomes a challenge to the fight against HIV/AIDS. When people do not disclose their status or take precautions, they end up infecting many more people. Much of this can be attributed to the absence of a focused and culturally sensitive plan to fight HIV stigma. Evidence from a study conducted by ICRW (2006) shows that HIV/AIDS- related stigma is context specific and, therefore, it is imperative that AIDS- related stigma be studied in its context in order to design educational programs that are culturally sensitive.

The study in Ghana was to make inquiry into the concept of stigma in the Ghanaian context, the stigmatization experiences of PLHA and their family members and its impacts and seek ways to confront the phenomenon. Further inquiry was conducted into the significance of gender to HIV/AIDS-related stigma which presents an in depth understanding of HIV/AIDS-related stigma in a way that considers the socio cultural aspects of the phenomenon. This will in turn help in generating culturally sensitive educational programs on HIV/AIDS-related stigma in Ghana. Stigma education that is culturally sensitive not only prevents stereotyping but also makes other preventive and treatment measures possible.

Background to the Study in Ghana

Before the methods and findings of the study, it is important to establish the context within which the study was conducted. This section presents the geographical location of Ghana,

the social context and traditional aspect and the role of women in the Ghanaian context. A background to the HIV/AIDS epidemic is also presented.

Geographical location

Ghana is located within sub-Saharan Africa on the west coast of Africa on latitude 4.5 north of the Equator and occupies a total land area of 238,537 square kilometer. It is bordered by Côte d'Ivoire to the west, Burkina Faso to the north, Togo to the east and the Atlantic Ocean to the south. The main stay of the economy is agriculture, but the country is also rich in mineral deposits such as gold, diamonds, bauxite and manganese. Cocoa and gold constitute the main export commodities in the country. Ghana is the second largest producer of cocoa in the world and is also home to Lake Volta, the largest artificial lake in the world. There are ten regions in Ghana: Greater Accra, Eastern Region, Western, Central, Ashanti, Volta, Northern, Brong Ahafo, Upper East and Upper West Regions. It is home to more than 100 different ethnic groups, which speak over 200 languages and dialects. Ghana is an ethnically diverse country; thus, Ghanaian culture is a mixture of all its ethnic groups, the Asante, Fanti, Akyem, Kwahu, Ga, Ewe, Mamprusi and Dagomba, among others. Fortunately, Ghana has not seen the kind of ethnic conflict that has created civil wars in many other African countries (Oppong, & Agyei-Mensah, 2004).

Ghana's population, estimated at 23.008 million in 2006 (Seager, 2009), is growing at a rate of 2.7% per year (World Factbook, 2009). Forty-six percent of Ghana's population is under the age of 15 years, indicating momentum for further growth. The population over 65 years accounts for only 5% of the total population. This large and youthful population is potentially vulnerable and at risk for HIV/AIDS and other sexually transmitted infections.

Social Context of Ghana

Although there is not enough space in this thesis to discuss Ghanaian culture and to explore the complexities of its concept of kinship and the ways in which rules of conduct are ascribed for both individuals and groups, I believe a basic understanding of the social context and the basic concepts which relate to marriage and family will be significant in providing a context within which to examine the issue of HIV/AIDS related stigma.

At the heart of Ghanaian society is the family which is considered the foundation of all social life. Not only is the family the foundation for social life but it is also the major source of

“social security” both financially and emotionally as well as caretaker of the young, old and the sick. A traditional Ghanaian family is much more than the nuclear family and includes distant relatives. The term “*family*” is therefore used to refer to both nuclear and extended family, most commonly reference is made to the latter. The family (extended family) is usually based on lineage ties. Matrilineal and patrilineal families are the major family systems in Ghana. The major difference is that with matrilineal, a child is considered to belong to the mother’s side of the family. For instance, in a typical matrilineal family system the brother of a child’s mother (uncle) is considered as the “father” of the child who is expected to take full responsibility of his “nephew.” And so in this type of family system, the brother of a child’s mother is the one who inherits the mother’s property if any. The patrilineal system on the other hand considers that children belong to the father’s side of the family. Therefore it is very common for Ghanaians to call their uncles “father.” Even though these family systems are distinct, one thing that is common to them is that irrespective of which system type being practiced by a particular tribe, a child often belonged to a male other than a female. For example, even in a matrilineal society a child is a responsibility of her mother’s brother and for patrilineal system, he or she is a responsibility of her father.

In Ghanaian society kinship is sustained through marriage. Marriage and child birth are very important in the Ghanaian society as it is a way to ascribe roles (economic and noneconomic as well as reproductive roles) to individuals. Because of this belief system, some women who are not married are viewed differently. There is variability in marriage in Ghana within the different tribes and ethnic groups; however there are various commonalities as portrayed in the literature (Nukunya, 1992 cited in Perry, 1997):

1. Traditional Ghanaian marriages involve a union of two families rather than two individuals;
2. Polygyny, the marriage of one man to two or more women, is commonly practiced;
3. Extra-marital affairs by husbands are common; extra-marital affairs by wives are prohibited and may prompt divorce;
4. Traditional Ghanaian marriage involves some form of marriage payment made by the bridegroom in return to her father and the rest of his family for the rights to have guardianship of the bride;

5. Within the confines of marriage, both partners are expected to treat each other with compassion and to fulfill each other's sexual desires;
6. A husband assumes responsibility for his wife's economic well-being, as well as authority over her sexual behavior; in return, a wife is expected to perform domestic duties, make financial contributions to the family, and to defer to her husband's authority; and
7. Marital conflicts arising from either spouse's failure to fulfill her/his marital obligations are resolved within the context of the extended family.

A common African adage goes "it takes a village to raise a child." This adage provides an understanding of the belief of reciprocity and the labile nature of Ghanaian society which is important for the understanding of this study. The involvement in a whole village in raising a child is with the expectation that the child will grow up and be a responsible adult to give back to the community. In many respects it is an obligation of adult children to take care of their elderly parents or family members as it is for adult family members to take care of the young ones. In fact, children are the main source of old age support and social security. An adult child who is being cared for by his or her mother is abominable in the Ghanaian society and seen as irresponsible. The labile nature of Ghanaian society is obvious within the extended family system where mothers are mothers to all children, elderly parents are grandparents to all children and uncles may be seen as fathers. It is common for a niece or nephew to be raised by his or her aunt or uncle. Thus a Ghanaian child grows up depending upon various members of the extended family rather than solely upon his or her birth parents.

Role of Women in Ghana

In Ghanaian society women's roles are entrenched in tradition and bounded by circumstances surrounding their birth (Perry, 1997). For most women, these circumstances include being raised in rural areas, having less education, and living lives that are tied to marriage and childbirth (Perry, 1997). In recent years a growing number of women, are being raised in the urban areas by economically advantage families and therefore are exposed to all the advantages of urban living, such has having good education, jobs, health amenities and fulfilling their life's aspirations. Consequently Ghanaian women own businesses, work as medical officers, nurses, professors, government officials and civil service appointees.

Within Ghanaian society, the contemporary roles of women are inextricably linked to traditional roles such as wife, mother and worker (Perry, 1997) and revered through these roles. It is a traditional belief that Ghanaian women are never independent and therefore must be under the guardianship of a man, her husband. As her guardian, the husband provides for all her needs, rights over her, and expects her domestic services in return. A Ghanaian wife is expected to be obedient and “respectful” to her husband and overlook his infidelities. For example a man may only be accused of infidelity if he has sexual relations with a married woman. On the other hand a woman may be considered as an adulterer if she is touched by other men other than her husband and receives gifts from them (Perry, 1997). These acts as well as the act of “disobedience” can be a basis for divorce.

Bearing children is very crucial to the Ghanaian family as it defines her role (as a mother) and her social esteem. As a result the social pressure to bear children is huge in the traditional Ghanaian society. Ghanaian women are expected to provide basic needs such as care, food and shelter for their children, those of others and sometimes strangers. Because of these obligations, there is a cultural expectation for women to work and most importantly to engage in work that does not interfere with their domestic duties of cooking, cleaning, caring for their children and their husbands. Hence Ghanaian women are often involved in the informal sector (often low and irregular pay). Working as hairdressers, dressmakers, trading etc. are very common. In the urban areas it is common to find (usually, less educated) women selling foodstuff along the streets, with their babies wrapped around them or sleeping nearby.

In rural areas women work the land and the financial benefit goes to the upkeep of the household. In pre-modern Ghana, the wealth of men was reinvested in an enterprise that was often perceived as belonging to his extended family. This traditional division of wealth had placed women in positions subordinate to men. The persistence of such values in traditional Ghanaian society may explain some of the resistance to female education in the past.

Transition into contemporary modern society has been slow for Ghanaian women. Although the Education Act of 1960 expanded and required elementary education, some parents were reluctant to send their daughters to school because their labor was needed in the home and on farms (US, Library of Congress, 2010). Resistance to female education also stemmed from the conviction that women would be supported by their husbands. In many respects, there was even the fear that a girl's prospect of marriage is dimmed when she became educated.

History of Stigma in Ghana

Tribal stigma associated with isolation and labeling has long been part of the history of Ghana. People from specific tribes and lineage have been labeled, although education and western civilization have impacted many of this labeling in recent years. There have been certain stereotypical characteristics that have been associated with the different tribes in Ghana for a long time.

The Akans for example have been long characterized as the powerful tribe, most dominant tribe and on top of the social hierarchy in present day Ghana. The history goes far back between the 15th and 17th century where the Akans fought many battles against the European colonists to maintain autonomy. As a result they dominated gold mining and the gold trade in Ghana, which made them acquire more wealth than any other tribe in Ghana. The Akans are therefore characterized as aggressive, hardworking and the “lords” of the land. In fact their language (Twi) is the widely spoken language in Ghana. They employed specific groups of people from the Northern part of Ghana as slaves and custodians. These groups of people are known to belong to the bottom of social hierarchy in present day Ghana. Also there is a long-standing ideology that Ewes do not have resources and so without being educated they are not respected. They have popularly been considered and feared for believing and practicing supernaturalism like juju (voodoo).

These stereotypes have enabled certain tribes especially the (Akans) to see themselves as more important than others, and therefore, to exert power over those tribes. Until recently, the Ewes were a secluded group of people who only married within their tribe and in fact many people outside their tribe do not marry them. Also, in present day Ghana jobs like security officers, cleaners are only given to people from Northern part of Ghana. Such societal prejudices make it possible for some group of people to dominate other groups of people.

The social context of the Ghanaian society has been provided to give some kind of understanding into the expectations of individuals and family members as well as women in the Ghanaian society. Hopefully this will help you understand the expectations of both PLHA and their family members with issues of care and support as well as the impact of HIV- related stigma.

Background to HIV/AIDS in Ghana

The first official reported AIDS case in Ghana was in 1986 (GAC, 2001). By the end of December 2003, a cumulative total of 76,139 AIDS cases had been officially reported (Gender Studies and Human Rights Documentation Centre [GSHRDC], 2009). Currently it is estimated that approximately 600,000 adults are living with HIV/AIDS in Ghana (GSHRDC, 2009). The country is currently experiencing a generalized epidemic. The major forms of HIV transmission in Ghana are:

1. Mother-to-child transmission (MTCT), accounts for 15%,
2. Blood and blood products accounts for about 5% and
3. Heterosexual intercourse accounts for 80 % of new infections (GAC, 2006).

Although there are homosexuals in Ghana, known by gay websites (Attipoe, 2004; Prince, 2004), the only form of sexual transmission that is recognized in Ghana is heterosexual transmission (GAC, 2001; National AIDS/STI Control Programme, 2004). International organizations reporting on HIV transmission often times do not report on HIV transmission by homosexual or bisexual groups in Ghana.

HIV prevalence is not uniform across Ghana's regions. There are important regional variations in report AIDS cases. These variations can be attributed to factors such as the composition of regional populations. The 2006 regional prevalence rates ranged from 1.3% in the Northern region to 4.9% in the Eastern region as shown in appendix A. HIV prevalence at regional level is calculated by aggregation of samples from all sites per regions (HIV Sentinel Survey Report 2006 NACP/ GHS). The Eastern region has consistently reported the highest levels of HIV infection. The high rate is attributed to the return migration of female sex commercial workers from neighboring West African countries, particularly Cote D'Ivoire. Studies show that many of these women came from the Eastern Region particularly from the Krobo ethnic group who constitute the majority of Ghanaian commercial sex workers in Cote d'Ivoire (Anarfi 1999; Oppong & Agyei-Mensah, 2004).

The HIV prevalence rate in Ghana decreased from 3.6% in 2003 to 2.3% in 2005 (GSHRDC, 2009) and HIV prevention and treatment programs have been working aggressively to combat the AIDS epidemic. However, reports from the United Nations Integrated Regional Information Networks (IRIN) on Africa indicate that the Ghanaian government's AIDS program is in danger of failure due primarily to stigmatization (IRIN, 2005). In fact, the Ghana AIDS

Commission estimates that about 90% of Ghanaians are aware of HIV/AIDS; however, stigmatization of PLHA remains the biggest challenge to the fight against the disease (GAC, 2004) This hinders all efforts to prevent the spread of the virus and mitigate the social and economic impacts of the epidemic (GAC, 2004).

Theoretical Framework

The research literature has identified several concepts that shape HIV/AIDS-related stigma. This section looks at two concepts which shape my understanding of HIV/AIDS related stigma among Ghanaians: symbolic interactionism; and Bronfenbrenner's ecological theory.

Symbolic Interaction

Symbolic interactionism (SI) is a sociological perspective based on the ideas of George H. Mead (1934), Charles H. Cooley (1902) and W. I. Thomas (1931). The term *symbolic interactionism* was created by one of Mead's students, Herbert Blumer (1969). Blumer articulated this perspective and specified its three basic premises: (1) humans act toward things on the basis of the meanings that things have for them; (2) the meanings of things are derived from social interaction; and (3) these meanings are dependent on, and modified by, an interpretive process of the people who interact with one another. In sum, people act based on symbolic meanings they find within any given situation (Ingoldsby, Smith & Miller, 2004). As human beings we thus interact with the symbols, forming relationships around them. The goals of our interactions with one another are to create shared meaning.

In particular, the meaning of objects, events, and behaviors comes from the interpretation people give them, and interpretations vary from one group to another (Ingoldsby, et al., 2004: White & Klein,2002). The words we use to describe our behavior and the behavior of others are particularly important, according to this theory. According to Symbolic interactionism, because we live in a world that is socially constructed some behaviors are rewarded and respected while others are condemned or punished (Ingoldsby, et al., 2004: White & Klein, 2002).

Exploring the issue of HIV/AIDS-related stigma through the lens of symbolic interactionism gives insights into society's attitude towards PLHA by taking into consideration how society perceives HIV/AIDS and what it means. Symbolic interactionism is a very complex

theory with many concepts and assumptions. For the purposes of this work three of them will be highlighted: 1) importance of meaning, 2) situational definitions, and 3) self concept formation.

The basic premises that SI elucidates is that meaning is an important aspect of human behavior which cannot be ignored (Ingoldsby et al., 2004). This basic premise leads to the assumptions that 1) people react to things according the meaning the thing has for them, 2) meaning is learnt through interaction with others, and 3) people interpret things according to what they learn through their experiences (Ingoldsby et al., 2004). Within a given culture, there is a general consensus on the meanings associated with various words or symbols. The explanation of this entails the concept of *role-taking* in SI: the cognitive ability to take the “role of the other” and the “generalized other” (White & Klein, 2002, p. 65). This is a significant process in communication because it enables actors to interpret one another's responses and in so doing bring about greater consensus on the meanings of the symbols used.

The importance of meaning is reflected in the saying that if situations are real they are real in consequences (White Klein, 2002). Defining a situation shows that people act in situations on the basis of how they are defined. For instance, if people see HIV/AIDS as a curse for some improper behavior, then obviously they will isolate themselves from the PLHA. Defining a situation is not a static process but depends on past experiences or cultural expectations and hence may be changed in the process of interaction.

A review of the literature on HIV/AIDS and its related stigma shows that PLHA are stigmatized as a response to the images and symbols that society have created for HIV/AIDS as well as the meaning people give to the disease. This is also linked to society's expectation of individuals in society. To many people, HIV/AIDS is a symbol of moral improprieties such as drug use, men having sex with men, promiscuity, etc. (Aggleton, 2000; Belsey, 2005; Brimlow, Cook & Seaton, 2003; Breitkopf, 2004; Brooks, Etzel & Hinojos, 2005; Brown, Tujillo & Macintyre, 2001; Castro & Farmer, 2005; De Palomo, 2006; Ferreira, 2004; Hong, Van Anh & Ogden, 2004; International Center for Research on Women [ICRW], 2006; Ogden & Nyblade, 2005; Parker & Aggleton, 2002). As a result of this, people experiencing stigma are seen as personally responsible for their situation which possibly invokes anger and resentment in the person attributing responsibility, which then turns into social rejection and stigma (Breitkopf, 2004).

HIV/AIDS is also seen as a threat, a disease that is incurable and can be deadly and a danger to society. Stigmatization associated with HIV/AIDS does not occur naturally. Instead, it is created by individuals and communities who, for the most part, generate the stigma as a result of their own fears of contracting the disease. For instance in Ghana, beliefs about the causes of HIV/AIDS enable PLHA to be stigmatized. In the traditional healing system in Ghana, disease is believed to result from natural or supernatural causes (Awusabo-Asare & Anarfi, 1997; Senah, 1997; Wyllie, 1983). Diseases that are degenerative, resulting in deformity, contagious, etc., are more likely to be defined as supernaturally or spiritually caused (Warren, 1979). HIV/AIDS has the potential to be classified as supernatural on the basis of one or more of these characteristics and has, in fact, been given a supernatural meaning by Ghanaians (Awusabo-Asare & Anarfi, 1997). In some cases, the infection is perceived as a punishment given by God to perpetrators of sins like prostitution, promiscuity, drug use or homosexuality (Ulasi, Preko, Baidoo, et al, 2009). For example, a study done by Ghana National Commission on Children (GNCC 2000) to ascertain the views of young people concerning HIV/AIDS revealed that some of the participants believe that AIDS is a disease that affects cursed people. These people are cursed because of their immoral attitudes. Because of the meaning that the disease has for Ghanaians, PLHA or people who are associated with the disease are often stigmatized.

One of the many expressions of HIV/AIDS-related stigma in Ghana is labeling of PLHA. Labeling is a result of the physical appearance of PLHA (especially those in the advanced stage) and can be related to society's beliefs and definitions of how people contract AIDS as well as the nature of HIV/AIDS itself. In Ghana expressions like "tease a wuo" and "gbele wu" which literally translates "living dead" and "death skeleton" respectively, are among some of the labels used to describe PLHA.

Along with symbols and meaning, the *formation of self concept* is an important concept in SI. This concept emphasizes that the self is a reflexive phenomenon, founded on symbols and consciousness which enables humans to see themselves as subjects and objects (White & Klein, 2002). The importance of others in the formation of self-concept is found in the "*looking-glass self*" which explains that to some extent individuals see themselves as they think others see them (Ingoldsby et al., 2004). Thus, one imagines how s/he appears to others as well as the judgment that others may be making regarding that appearance. Also, one develops a self-image through one's reflection; that is, the judgments or critique of others. In the area of HIV/AIDS, the

literature shows many people do not disclose their serostatus because of what others might think of them and how they might be stigmatized. When PLHA are constantly subjected to the stigmatizing and discriminatory actions of others, they also start to stigmatize themselves, because they usually share the same basic belief systems as the rest of the community and are constantly subjected to the hurtful and discriminatory actions of others (Aggleton, 2001; Castro & Farmer, 2005; Fife & Wright, 2000; Ogden & Nyblade, 2005; Smart, 2005). The negative perception of PLHA – reinforced by the language and expressions of HIV/AIDS - cause individuals to avoid families and friends and to isolate themselves from their community. When PLHA internalize the negative responses and reactions of others it can lead to depression, withdrawal and feelings of worthlessness, loss of hope, inferiority, and the belief that they no longer have a future.

Throughout my work in the area of HIV/AIDS and stigma, I have always wondered why many societies stigmatize PLHA and why they cannot understand that having HIV/AIDS does not mean dying and rather accept PLHA as “normal” people. As I look at the issue from the SI perspective, I have begun to understand that there is more to why PLHA are stigmatized. For example, one of the many issues that the literature on HIV/AIDS-related stigma has noted is the lack of confidentiality that the PLHA has to deal with, particularly where a person’s serostatus is revealed through a member of the family or a close friend. As I look at it in the Ghanaian context from the SI perspective I have an in-depth understanding of it. Obviously there are some health workers who reveal the serostatus to the public for their selfish gains, but in the Ghanaian culture in order to show respect to a person and provide support, “bad news” is not revealed directly to the person but through another family member or a close friend. As a result, many people who test positive for HIV/AIDS are asked to come with any of their closest family members before the results are given to them. In other settings this may mean a violation of confidentiality, but in the Ghanaian context it may not be. Exploring the area of HIV/AIDS-related stigma through the lens of SI will provided insightful understanding in the Ghanaian context. It provided an understanding of how Ghanaians see HIV/AIDS, the meaning they have for the disease and how that contributes to stigmatization.

Ecological Theory

Bronfenbrenner's ecological model of human development provides a useful framework for examining HIV-related stigma. The model acknowledges that human development involves transactions between human beings and the characteristics of the environmental system within which they interact (Bronfenbrenner, 1979; Bronfenbrenner, 1986). Thus a person is affected by the settings in which he or she spends time and in like manner, a person also has effects on the settings. He identified five system levels: the microsystem, mesosystem, macrosystem, exosystem and chronosystem. But for the purposes of this study three (Microsystem, mesosystem and the macrosystem) will be utilized. The rationale is that these three systems focus on the individual and the immediate environment (the family in this case) while emphasizing the importance of the socio cultural consistencies such as values, norms that influences the individual and his or her environment.

Microsystem - the interaction a person has with his or her immediate environment.

These structures include family, neighborhood, school, childcare etc. At the microsystem level the relationship is bi-directional. For example, while a child's parents may affect his/her beliefs and behavior, the child may also affect the behavior and beliefs of the parent.

Mesosystem- the connections or inter-relations between the Microsystems. (e.g. connections between a person's family and school). E.g. events at home can impact a child's performance at school.

Macrosystem- the larger cultural context within which one lives (e.g. developed and non developed countries, socioeconomic status, ethnicity etc). Thus the beliefs, cultural values, customs and laws defined by the macrosystem have influence throughout the interactions of all the other layers. For example commonly the reason behind women's experience of more stigma than men can be explained by the culture and societal norms.

Bronfenbrenner's model is important in looking at the impacts of HIV and its related stigma on family members of PLHA. It emphasizes that the individual does not grow/develop in isolation. In other words what befalls a person is also felt and experienced by the people/settings around him. Secondary stigma is one of the many aspects of stigma related to HIV/AIDS. Stigmatization does not begin and end with the individual, but it extends their families, friends caregivers, etc. (Ogden & Nyblade, 2005; Van Anh & Ogden, 2004). The macrosystem also has

a major role in explaining why people stigmatize. For example, the common thoughts that HIV/AIDS is a disease resulting from “immoral behavior,” is intricately tied to cultural values and laws in the broader society. These behaviors have been associated with HIV/AIDS transmission, and therefore a person who contracts HIV is seen as immoral and irresponsible.

The effects of the larger principles defined by the macrosystem have a cascading influence throughout the interactions of other system levels described by Bronfenbrenner (1986). For example, the standards and ethics set by the society regarding proper behavior, acceptable behavior, and moral principles are the same standards that exist in the family, school and work as well as are accepted by an individual (Stein, n.d). Therefore, if HIV/AIDS has always been regarded as a danger to society, obviously people who acquire it will be regarded as a danger to society. Also, if society regards HIV/AIDS as a disease caused by violation of social norms, especially those related to sexual behaviors, it is obvious that society will stigmatize people who acquire it. Thus, while the various systems in the ecological model could provide the basis of support for individuals and families affected by HIV/AIDS, it usually works in the opposite direction. Schools, peers, family, work (society at large) dictates behaviors that are “right” or “wrong.” More importantly, if a person does not fit the criteria for “right,” he/she is considered an outcast (Stein, n.d). PLHA undisputedly does not fit into the “right.” Thus in order to understand the concept of HIV/AIDS related stigma, the macrosystem needs to be explored.

I chose this theory to guide my research in order to focus on the fact that PLHA do not live in isolation. They live in an ecosystem which impacts their growth and development. The bi-directional influence that Bronfenbrenner’s theory emphasized gave an understanding of how secondary stigma impacts family members of PLHA and in what ways those impact influence the relationship between family members and PLHA.

Chapter 3 - Methodology

This study explored the concept and meaning of stigma in the Ghanaian context, the impact of HIV/AIDS-related stigma and the factors influencing it. The issue of gender differences regarding HIV/AIDS-related stigma was also addressed and finally ways to challenge the phenomenon were explored. Five PLHA and their family members from the Eastern Region of Ghana were chosen for interviews to share their experiences.

Rationale for Qualitative Methodology

With the objective to render an in-depth depiction of day-to-day realities of how HIV/AIDS-related stigma impact Ghanaian families, this study adopted a qualitative design. The rationales for the choice of this method are several. First, I believe that human behavior is significantly influenced by the setting in which one lives and in which the behavior occurs. The physical setting (e.g., location) and the internalized notions of norms, traditional roles, and values are important contextual variables that must not be taken for granted. Research must be conducted in the setting where all the contextual variables are operating. Qualitative inquiry makes use of interviews and observations so the researcher has the opportunity to meet the participants being studied in their own environment. Becker (1992) emphasized that: *to understand people, we must understand their contexts- the worlds or situations in which they live. To separate person and world is false; to be a person is to be in a world* (p. 13). For me, observing and interviewing the participants in their own settings is a great way to understand the issue of stigma and the reality of families affected by HIV/AIDS in Ghana. Patton (2002) explained that if mathematical models of sciences, surveys and experiments do not provide the satisfaction in understanding the world, then the only way to understand it is by entering it. He wrote:

Live among the peoples of the world as they live. Learn their language. Participate in their rituals and routines, Taste of the world. Smell it. Watch and listen. Touch and be touched. Write down what you see and hear, how they think and how you feel. (p. 259)

Many studies (e.g., ICRW, 2006; Pequegnat et al. 1992) have shown that stigma, and especially those related to HIV/AIDS, are context specific and vary from culture to culture. Therefore, common/universal indices of stigma often utilized by quantitative methods may not

give the detailed understanding of the impacts and effects of the stigma under examination. In order to design culturally sensitive educational programs on the phenomenon for Ghanaians (one of my objectives for this study), it is imperative that AIDS-related stigma be studied in this cultural context. Pequegnat et al. (1992) commented on the dangers of AIDS research conducted in absence of context: *“If intervenors disregard social context factors or attempt to impose value systems inconsistent with or counter to the values of a community [culture], their efforts can produce interventions that are irrelevant and ineffective”* (p. 3).

The setting of the inquiry also related to the context of the study calls for a qualitative rather than quantitative approach. From my experience of working with families with HIV/AIDS, many of the affected families are unable to read English and, in fact, are not able to read their local languages. It happens that those who are able to read the local language are those who have had some kind of formal education and therefore can read English as well. From my opinion, generating a survey for families that are unable to read would require interpreters or someone being with them and explaining the questions as well as writing it for them. This would be cumbersome and very time consuming. I deemed it more appropriate to be with the participants in person, identifying with them and interviewing in the language that they are comfortable with.

Secondly, the use of qualitative methods provided depth not possible with quantitative data. Although the sample size was relatively small, qualitative method provides the opportunity to gather details about each participant. Qualitative methodology is designed to look beyond the percentages to gain an understanding of the participants' feelings, impressions and viewpoints, thus seeing the world through the eyes of the participants. In this inquiry I was able to see the world (stigma) through the eyes of the participants (Ghanaian families) and I am hopeful that my presence and the interviews gave them a voice, enlightened and encouraged them. One of the objectives of this study was to present the stories of the families, as they reported and hopefully their stories will impact policy makers and area workers to find a way of dealing with the issue of stigma. This objective could not have been accomplished without qualitative method because qualitative inquiry is a way of presenting real concerns of people: it contains quotations and real stories from people: their experiences. I included quotations and words in the local language to add to the richness of the data. The result is rich, in-depth data laden with insights unobtainable from quantitative research techniques.

Many studies on HIV/AIDS-related stigma in the U.S. have been quantitative in measuring stigma attitudes and knowledge about HIV/AIDS through surveys (Parker & Aggleton, 2003). In my search of literature, I found a considerable number of studies using surveys and attitudinal measures to study AIDS-related stigma (e.g., Herek & Capitano, 1999; Kalichman & Simbayi, 2003; Mahendra et al, 2006; Research Triangle Institute, 2000; Shapiro, 2005). The use of quantitative surveys in measuring stigma, to gauge the severity of the problem has resulted in generation of measurement tools like stigma indices, and standardized survey questions. The use of these instruments is readily available and is not as time consuming as qualitative methods; however, these instruments do not make it possible to explore in detail people's unique experiences with regards to HIV/AIDS stigma nor do they provide an in-depth meaning for the concept of stigma in the Ghanaian concept.

Phenomenological Perspective

One way of using qualitative method is by using phenomenological perspective to gain an in-depth understanding of the meaning of experiences (Patton, 2002). An approach, which aims at describing how people experience a particular phenomenon, "*how they perceive it, describe it, feel about it, judge it, remember it, make sense of it and talk about it to others*" (Patton, 2002, p.104). This study employed phenomenology as a philosophy to guide the inquiry into PLHA and family members experience with HIV-related stigma as well as provide a structure for uncovering the essence of the phenomenon for professionals and researchers. The inquiry represents an effort to uncover and describe the phenomenon of HIV-related stigma as it is experienced by PLHA, their family members and particularly women.

As a research methodology, phenomenology is "*grounded in existential philosophy and seeks to uncover meaning and essences in experience so that understanding is facilitated. It focuses on lived experiences with human phenomenon and their transactional relationships*" (Lauterbach, 1993, p. 136). Thus, philosophically, phenomenology differs from the positivist or natural science approach to research which may not focus on meanings "*but rather focuses on statistical relationships among variables or on the occurrence or frequency of certain behaviors*" (Van Manen, 1990, p. 11). The natural science approach is usually viewed as reductionistic in that its focus is on reality as defined by objective and measurable facts. Phenomenological approach on the other hand is considered to be holistic in that its focus is on

the subjective, contextual meanings of phenomenon or lived experiences. Hence phenomenology is directly a methodology and a philosophical approach.

It should be noted that by using phenomenology as the philosophy for this study, I do not mean to categorize people's behavior towards PLHA and their family members, but it is to present a holistic approach to the phenomenon. Therefore the study was influenced by both ecological and symbolic interaction frameworks. By this, interpretations and discovery of meanings in the lived experiences will offer an appropriate platform for developing context specific programs for individuals and families in Ghana.

Ecological theory was helpful in understanding the concept of secondary stigma in the Ghanaian context and emphasized how much participants relied on each other within and outside of the family for care, support as well as coping with the issue of stigma. Understanding the concept of reciprocity among Ghanaians was an important concept that ecological theory brought to light. While children depend on adult for care and support in their daily lives, they in turn become a source of social security for adults when they grow up. However in times of sickness like HIV/AIDS this concept is compromised as adult children are not able to perform their expected roles, thereby creating relational problems within the family. While family members make adjustment to care for the PLHA they are in fact stigmatized just by their association with the PLHA. Understanding the beliefs and values of the Ghanaian society was vital to this study and ecological theory was helpful in understanding that the reasons why people stigmatize both PLHA and their family members are entrenched in the beliefs and value systems of the society, a society in which the participants are part of. Of utmost importance to this theory is how rules and regulations surrounding provision of ART impact the lives of the PLHA.

As discussed earlier in this study, Symbolic Interaction emphasizes how people act based on symbolic meanings they find within any given situation (Ingoldsby, Smith & Miller, 2004). By interacting with the symbols, thus, we form relationships around them. This theory assisted in looking at some of the imagery and beliefs behind the issue of HIV/AIDS and why PLHA and their family members are stigmatized. Most importantly these imagery and beliefs are those that the PLHA and their family members also share. The meaning of stigma as PLHA and their family members shared was also significant to this study.

Research Questions

Evident from the literature is the notion that stigma is a complex and contextual phenomenon and its impact on both PLHA and their family members have not been specifically explored in the Ghanaian context. Therefore my overarching question was “what are the lived experiences of PLHA and their family members regarding HIV-related stigma in the Ghanaian society” and “what are the unique stigma experiences of women with HIV/AIDS in Ghana.”

The research questions for this study were:

1. How do PLHA and their family members conceptualize HIV/AIDS-related stigma in the Ghanaian context?
2. What are the experiences of HIV-related stigma for PLHA and their family members?
3. What are the impacts of HIV/AIDS-related stigma on PLHA and family members, and how do these impacts influence their relationships?
4. How do PLHA and their family members cope with HIV-related stigma in Ghana?
5. What are the differences between men and women with regards to stigma experiences in Ghana and how do these differences impact the lives of women in Ghana?
6. What are the factors influencing HIV-related stigma among Ghanaians?
7. What strategies do PLHA and their family members feel will be effective for stigma prevention?

Setting

The location for the inquiry was the Eastern Region of Ghana and the rationale for this includes first, the region has a high HIV prevalence, both historically and currently as explained in the background to HIV/AIDS in Ghana. According to the HIV Sentinel Survey Report (NACP/GHS) in 2006 the Eastern Region stood at a prevalence rate of 4.9%, highest in the country. Second, as a result of my previous work in the region, good working relationships and networks was established with the Regional AIDS project, AIDS workers, NGOs and community-based organizations, as well as the Associations of PLHA. I believe that these established relationships gave me the opportunity to collect data without having to create new relationships.

Sample Recruitment

The study was a purposeful sampling and employed a combination of critical case, criterion and homogeneous sampling techniques (Patton, 2002). The Eastern region has the highest prevalence rates both historically and currently, and so it was chosen to present a critical case for the rest of the country. Although making logical generalizations from the findings to other parts of the country, it may be inferred that whatever experiences families have in the Eastern region could also be experienced by other families affected by HIV/AIDS. Although Ghana is ethnically diverse, the ethnic locations are not confined to specific ethnic groups and so many people live in different ethnic locations other than their own. Also the beliefs about issues pertaining morality, HIV/AIDS related stigma is homogenous. Therefore, even though the study was conducted in the Eastern Region, the result is not confined to a specific group of people.

The criteria for participation in the study were that, for PLHA, they should have been diagnosed at least 5 years ago and family members should have at least one member of their family with HIV/AIDS. The rationale is that 5 years is an ample time in the life of the PLHA to ascertain how the progression of the disease is impacting their lives. Also, 5 years is good amount of time to have different and many experiences with stigma. Family members of PLHA were only considered if they knew of the PLHA's status. Participants who met these criteria were chosen for the interview. The initial goal was to recruit four PLHA and at least 2 members of their families each but we experienced a setback in recruiting family members and so we recruited one family member for four of the PLHA and two family members for one of the PLHA.

Contacts with PLHA were made in two forms. The first form of contact was made with PLHA during their Association meeting in Koforidua. The focal person of the Regional AIDS project introduced me to the group and gave me the opportunity to introduce my study. Many of the PLHA expressed interest in the study but most of them did not meet one or more of the criteria so out of nine people who expressed interest at the meeting, I had two PLHA who included their family members. One included his parents and the other included her sister.

The second form of contact was done by the Eastern Regional AIDS Project's Focal Person who identified and contacted potential subjects (who were not present at the meeting) to inform them about the study and to introduce me as the one who will be contacting them, should they decide to participate in the study. Individuals who were interested in the study were asked to

contact the office of the Regional AIDS Project and leave their address or how best they could be reached. A total of 23 PLHA expressed interest in the study. I then contacted them and explained to them into detail what the study is about and if they will be willing to include their family members. Five of the PLHA expressed that their family members were not aware of their diagnosis but they were suspicious and so they were excluded. Nine out of the 23 PLHA said their family members were aware but they would be willing participate in the study because they were not on good terms with them. The other nine expressed that their family members would be willing to be contacted and participate in the study. Out of the nine PLHA, three participants were selected to participate as the family members of six PLHA turned down their participation. They included one member of their family each. Participants were asked to confirm with their family members of their participation.

After recruiting the PLHA for the study, I contacted them on the telephone to set dates, times and locations for their interviews as well as that of their family members and to request their addresses to formally mail them their invitation. All of them declined to receive anything in the mail but requested that I bring it to them on the date of interview together with the informed consent. I also confirmed that they all met the criteria for the study. PLHA provided telephone numbers of their family members and convenient times to call. Family members were then contacted and briefed about the study and to confirm the dates and times of the study.

Procedure

Participants were given the option to interview together as a family or separately. All of them opted to be interviewed separately in order to provide honest answers to the question. Participants and their family members were informed of the use of digital recorder; one family member chose not to be recorded so the interview was hand written.

Interviews

Interviews were conducted in various locations depending on the PLHA or the Family member's choice. Some participants invited me to their homes where the interviews were done. Others preferred their work place while others preferred to be interviewed in a different town. Interviews were carried out in various locations in and around participants' place of resident. For family A, the interviews were done in different towns. For the PLHA interview was done in her dressmaking shop. Her sister's interview was done in her home. Family B and C's interviews

were done in the same town but different places. The PLHA in family B and C chose to be interviewed in a resort close to their towns. Their mothers were interviewed in their own homes. For family D, interviews were done outside their home, in a classroom of one of their high school where the PLHA teaches. They took turns to be interviewed. Family E were interviewed in their home but took turns for the interviews while they went about their household duties at the same time. All interviews were done in Twi, the widely spoken language in Ghana. One participant occasionally switched between Twi and Ga (another popularly spoken language).

Interviews included combinations of standardized open-ended questions and an interview guide. The use of standardized open-ended question was to ensure that all participants had the opportunity to answer the same questions throughout the process and to minimize variations. The interview guide, on the other hand, provided topic areas to probe during the interview process, in order to provide a systematic and comprehensive interview (Patton, 2002). The combination gave me some flexibility in probing participants' responses and topics in great depth (Patton, 2002). Because questions were asked in a language other than English, I translated the questions from English into Twi, at the same time I used different expressions to get to the point of the questions. Sometimes, depending on the level of understanding and knowledge of the participant, I had to use examples and different expressions to enable them understand the questions. For instance the interview with Yebson was quite straightforward because he is a teacher and well educated, and so he understood my questions and even at some point answered them in English.

Two interview protocols were prepared to serve as a guide for interviewing PLHA and family members differently (appendix B) to enable participants give honest responses. I was the only person who did the interviews and so while I was recording participants' narration, I made observations too. Great effort was made to ensure that the recorders were working and extra batteries were fully charged and there were no distractions. When I needed to check on the recorder, I sought permission from participants to check on it and then we continue with the interview. All interviews begun with the purpose of my "visit" and a reference to previous conversations about the study. Informed consent was signed by each participant. Where Participants could not write, they marked X on the signature portions. Participants were informed that their participation was voluntary and they could decide not to answer any question if they were not comfortable with it. One family member declined to answer some of the questions that she was not comfortable with.

An interview was handwritten for one participant who refused to be tape recorded. She explained that she has always been “afraid to hear her own voice on tape.” I therefore requested that she give me some time to write her narration. I explained to her and other participants that I was the only one who will hear their voices since I will be translating the scripts alone. I also assured them of their confidentiality as pseudonyms will be utilized.

I listened to interviews and reviewed them the night of interview dates and compared it with my field notes. If there were any gaps that needed to be filled, I made notes and contacted participants to discuss that. Because I was the only one writing observations and asking questions at the same time, the second contact to the participants was very important. Post-interview note-taking was also significant, it gave me the opportunity to reflect and note my thoughts and impressions of the interviews, including the surrounding environment as well as my observations about the participants’ responses and also gave me the opportunity to reflect and ask specific questions on my second contact with the participants (Patton, 2002). One of the observations that struck me was that PLHA talked undertone when they heard foot steps or saw someone coming their way. Most of them also referred to HIV as “the disease” instead of mentioning the name AIDS. They were all to prevent passersby from hearing what was being discussed.

Interviews were then translated into English and transcribed. Because the interviews were done in a language other than English, it was important that I make meaning of what participants said before translating it so that it will be meaningful and so by the time I completed the translation and transcription, I had a sense of the emerging themes and categories. Interviews were translated and transcribed, by noting the dates, time, and location of interviews. Pseudonyms were used so the transcripts do not have the real names of participants. A naturalized approach (Oliver, Serovich, and Mason, 2005) was employed so the transcript reflects a verbatim depiction of language that represents the real experiences of PLHA. Some indigenous terms were used.

Description of Participants

Participants for the study included three female PLHA and two male PLHA. Two of the female PLHA family members included their mothers in the study. The other female included her sister. One male included his parents and the other included his wife. In all 11 people

participated in the study and they lived in different cities throughout the Eastern region. The respondents are discordant families (a situation where one person tests positive and the rest of the family members test negative to HIV/AIDS) and heterosexuals. A brief description of the participants is presented.

Family A

Yaa and her sister, Opokua

Yaa is 36 years old woman who tested positive to HIV about 5 years ago. She and her husband divorced two years after her diagnosis. They have two children together, a boy and a girl, 5 years and 8 years respectively. Before her diagnosis she sold clothes but she used all her capital for medications so she is a dressmaker now. Currently she is living with her mother and father. Yaa confided in her mother and her older sister (Opokua) so they are aware of her HIV/AIDS status, but her father does not know. Yaa's husband and their children tested negative to HIV. Yaa finished Junior secondary school (a three year pre –high school education) and was not able to further her education. She also relies on a local NGO for her medications.

Opokua is a 40 year old woman (whose husband died about 4 years ago). She lives a few miles from her sister. She has two boys and a girl. Opokua is currently unemployed. She wanted to sell food at her husband's work place but was asked to do HIV test and she did not do it and so was refused to sell her food. She is waiting for her brother-in-law (husband's brother who she calls her husband) to help her put up a shop so she can sell provisions. Opokua finished primary school class 6 (6th grade). Opokua and Yaa do not live in the same town; they live about 8 miles apart but Opokua visit her mother and sister often.

Family B

Vickie and her mother, Daavi

Vickie is a 36 year old female who was diagnosed about 8 years. She is currently not working. She used to sell shrimps but stopped because of the gossip from her colleagues. She later went into selling biscuits but people stopped buying her biscuits due to speculations of her diagnosis. She is currently being taken care of by her mother (Daavi). She is not married and has no children but is looking for a partner. According to Vickie, it is difficult to find to a partner because of her diagnosis. She was in elementary school (an old- system of pre high school, that faded out in the early 90s) but did not finish.

Daavi is a 63 year old woman who never had any formal education. She has been selling Kenkey (fermented corn meal made into balls and cooked) and fried fish for 40 years now. She has not tested for HIV but she believes she is negative. Since her daughter informed her of her diagnosis she has been supportive. Her husband died several years ago but never remarried. Daavi has 6 children, Vickie is the second born. According to Daavi, prior to her daughter's diagnosis, she had never seen an HIV patient before. She does not have a television or radio and so the only source of information about HIV is her daughter's doctor and social workers.

Family C

Ida and her mother, Dede

Ida is a 38 year old female who was diagnosed about 10 years ago. Ida used to work on a cruise boat as a waitress. Ida worked on the cruise as a temporary employee for 15 years. She was denied permanent status and laid off because of her diagnosis. Even though she sought the help of her supervisor to reinstate her job position, things did not work out. She moved in with her mother after her diagnosis but she could not bear her mother's behavior towards her so she moved out. She is not married and has no children. She sells phone cards. Her boyfriend, who is married, helps her out financially but she is looking for another partner, someone she can marry. Currently her boyfriend has rented an apartment for her and she is living on her own. Ida finished elementary school.

Dede is a 57 year old woman who has not tested for HIV but believes she is negative. She has 4 children, Ida is her oldest. She is been married for 25 years after the death of Ida's father. Her husband is blind and so she is the bread winner of the household. She bakes bread for a living. Dede was not happy about her daughter's diagnosis. She believes Ida is responsible for her diagnosis. She heard of Ida's diagnosis from the community even before Ida informed her formally. She finished 3 years in high school (out of 5 year high school program).

Family D

Yebson and his wife, Faustie

Yebson is a 48 year old man who was diagnosed about 8 years ago. He is married for about 16 years now and they have 3 children together. All of them including his wife tested negative to HIV. Yebson finished high school and has a diploma in education. Currently he is

teaching at one of the high schools in his community. No one in his community knows of his diagnosis. Yebson informed his mother about his diagnosis who also informed other members of her family. His mother refused for him to live with her because she feared people might know of his diagnosis and stop patronizing her clinic. But he has a supportive wife who takes care of him. His children are unaware of his diagnosis.

Faustie is a 40 year old who has been supportive of her husband since his diagnosis. Her husband did not inform her directly of his diagnosis but she heard it from a prayer camp where he had been for some time about 5 years ago. She was the breadwinner for the household before her husband was put on ART and started working. Currently she is a hairdresser and owns her own beauty salon. She has not informed her family members of her husband's diagnosis because of fear of being stigmatized. She finished elementary school.

Family E

Paul and his parents, Leticia and Jacob

Paul is a 27 year old male who has been diagnosed for HIV about 6 years ago. He is not married and has no children. Paul said he is a virgin and therefore surprised at his diagnosis. He is currently living with his parents and siblings who are very supportive of him. He finished junior secondary school and learnt a trade in electrical work. He used to work with an electrical contractor but stopped working because of his diagnosis. The contractor stopped giving him contracts. His immediate community does not know of his diagnosis but they have been suspicious as to what kind of disease he has.

Leticia is a 58 year old woman who remembers being married for over 20 years. She has 4 children, Paul is the second born. She had little formal education and currently working as a farmer with her husband. They grow different kinds of grains and vegetables depending on the season. He and her husband support their son very much both financially and emotionally. Their biggest problem is how their son got infected because according to them he had not engaged in any of the perceived behaviors that results in HIV.

Jacob is almost 60 and finished elementary school. He used to be a bead maker but now farming with the rest of his family. Both Jacob and Leticia said their son informed them of his diagnosis and they accepted him. But their community does not know of his diagnosis. Paul said he has had an affair during their marriage but that was a long time ago when Leticia was going to

deliver Paul at the hospital and so he is not sure whether that was where his son's diagnosis came from. He has been abandoned by some of his friends because of his son's diagnosis.

Both parents do not want to do the HIV test anyway. Their biggest fear is that when their church (Jehovah's Witness) members become aware of their son's diagnosis, they will lose their reputation as good parents and as church members so they do not want to inform anybody of their son's diagnosis.

Analysis

Data Management

All the interviews were downloaded from the digital recorder to a computer and then back-up copies were made to CDs and flash drives for safe keeping. They were listened to several times. Field notes and interviews were then transcribed and saved directly to Nvivo. Interviews were saved in Nvivo 7 and each group of family was created as a separate case to manage, explore and analyze.

Coding and Classification

As explained earlier by the time I finished the translating and transcription I had an inclination of the themes and categories. Initial lists of coding categories, patterns and themes were established via inductive analysis. Coding begun with convergence and ended with divergence. I looked for items in the data that fit together by looking at themes and how often they recur in the data. Then all the items and themes from the data that fit together were categorized. After familiarizing myself with the data, I created tree nodes in Nvivo which was made up of the major broad categories and then each case (family interviews) were coded separately into the tree nodes. New categories were created as they emerge from the data, without the restraints imposed by structured methodologies (Thomas, 2003). By developing categories inductively from my data, I used the constant comparison method to stimulate thoughts, and highlighted differences between categories.

To make sure each item fits specifically in a certain category I considered the extent to which the items in that particular category cohere and make sense (internal homogeneity), and made sure that the differences among categories were clear (external heterogeneity), (Patton, 2002). Thus there were several themes and quotes that belong to more than one categories but I

prioritize the quotes into the best fit categories. However, when specific quotes best explained different categories I used that and explained them differently. Also, to test for credibility and to make sure the categories make sense, I involved two colleagues in the process of coding.

The next step involved divergence: the process of extension (Patton, 2002). I built on the items of information which are already known from the literature and other studies. I then made connections among different items and categories and provided new information that was found (Patton, 2002).

Confirmatory Stage of Analysis

After inductively establishing themes and categories final confirmatory analysis was deductively established (by using the Ecological model of human development and Symbolic interaction) to interpret the data to affirm the authenticity and appropriateness of the inductive content analysis. Findings were compared to the existing literature on the issue of HIV-related stigma and then, the research questions which developed from the literature were utilized as a guide in presenting the results.

Although the Regional AIDS project was involved in the research, the organization was not involved in the analysis. My major professor was involved in the design and the analysis to verify the substantive significance, the credibility and understandability of the categories and whether the inquiry made senses and met the institutional requirements.

Triangulation

Triangulation is using different ways of looking at a study to make it reliable. According to Patton (2002) triangulations is “the attempt to get a ‘true’ fix on a situation by combining different ways of looking at it or different findings” (p. 177). In this study I employed multiple data sources and involved colleagues as well as some of members of my dissertation committee including my major professor to check the coding to facilitate the validation of the data. Multiple data sources included interviews with multiple PLHA, as well as their family members, written field notes, observations, audio recordings as well as telephone conversations.

Two of my colleagues were involved in the coding of the data. One of them has a family studies background and the other was from the sciences and had no idea of the topic or my area of study. They were intentionally considered to assist in the early stages of coding and analysis and to enhance the accuracy and validity of the findings. One of the committee members was

also involved to provide a feedback on the categories and themes that emerge from the findings. She is an Assistant Professor who has an experience in international research. My major professor also reviewed the coding and categories that emerged.

I also employed theoretical triangulation by using symbolic interaction and ecological theories. Although these theories are different they complemented each other by providing an holistic approach to the study. Symbolic interaction was useful in looking at the meaning of stigma, why it happens and why there are differences in gender. Ecological theory on the other hand helped in looking at the impact of the phenomenon on both PLHA and their family members. The findings were also compared to existing literature on HIV-related stigma.

Researcher as a Measurement Tool

Qualitative inquiry considers the role and credibility of the researcher as significant to the study. In order to establish credibility, it is imperative that a qualitative study include information about the researcher that could have influenced data collection, analysis, interpretation, and conclusions. This may include the personal connections that the researcher has with the participants, the issue, and the context. The task of the researcher is to maintain *intellectual rigor* while making sense of all the information collected (Patton, 2002). As a researcher I recognized that it is important to realize my own characteristics and biases and how they may influence the study

I viewed this research as a learning experience and putting into practice what I have read and the knowledge that I have acquired in qualitative study so far. I consider my experience of working with people living with HIV/AIDS (PLHA) in Ghana as important to this study. During my work with PLHA and their family members in Ghana, I observed the pain and suffering of PLHA, how they are abandoned by the community, their families, friends etc. I also observed the courage they have (especially women) in the face of society's stigmatizing behaviors. However, interviewing the participants for this study brought home to me how passionate I am about the area of HIV/AIDS in Ghana and about women with the disease

Conducting interviews in my own language was an advantage for this study as I was able to connect very well with them. Participants were aware that I could speak most of their dialects and so I believe they were able to identify with me. For instance one of the participants responded to questions by making switch between English and Twi. For one of the participants

when she was talking about issues that were uncomfortable for her, she would use my indigenous language (Ga). The knowledge I have about the topic areas also helped me ask pertinent questions about the issue under discussion. Not only did I interview the participants, but the whole process was also helpful as I answered questions on HIV/AIDS from the participants. It made me realize how much work there is to be done about the topic.

Chapter 4 - Results

As discussed in previous chapters the objective of this study was to conduct a phenomenological inquiry into the concept of stigma in the Ghanaian context, the stigmatization experiences of PLHA and their family members, its impacts and seek ways to confront the phenomenon. Further inquiry was conducted into the significance of gender to HIV/AIDS-related stigma. Symbolic Interaction Theory and Ecological Theory provided the lenses through which the data was viewed, and the research questions are utilized as the framework for presenting the resulting themes.

Research Question 1:

How do PLHA and their family members conceptualize HIV/AIDS-related stigma in the Ghanaian context?

This question seeks to understand what stigma means for PLHA and their family members. Participants revealed several themes regarding their perception of stigma and what it meant to them. Their expressions reveal how complex stigma is and how complex it is to make meaning out of it. Perceptions from PLHA and family members are presented. For them, stigma is: betrayal, death, fear, disgrace, isolation and the feeling of otherness. Others described stigma as total rejection and a way to make the PLHA feel worthless.

For Yaa it is a simple “betrayal” and Ida said: *“Hmm, Not good, betrayal and it really shows what people think of you. I believe its isolation too. It also shows what your family thinks of you and whether their love for you is a true love or money love and also how selfish they are.”* Daavi, Vickie’s mother, believes that, *“it’s their way of showing how scared they are of the disease. Who knows, I may have done that to someone else if the doctor had not explained it to me.”* For Vickie stigma means death because, *“Yes death, because what people will do to you when you have this disease, you will always wish you were dead.”*

Stigma can be an expression of “otherness” where HIV/AIDS is perceived to have resulted from membership in a certain group of people creating a difference between “them” and “us.” This makes it difficult for people to accept that what happens to one person could happen to them and in fact we are all at risk. Vickie expressed that not only does stigma mean rejection and disgrace, but *“how much as humans we are always in denial that anything can happen to*

us.” She added, “*Oh, yes you know you treat people badly and you forget that you could be in the person’s shoes one day.*” For Paul it simply signifies, “*the fact that we always think we are different from other people.*” Paul’s father, Jacob shared the same: “*I guess it means we are different from them so they look down on us. It’s total isolation because they are afraid they will also get the disease and people will treat them the same way.*”

Sometimes stigma can be a tool that people employ to fit in society as disclosed by Opokua, Yaa’s sister:

Oww, I believe we are all human and people will choose to behave in a certain way to fit in society. But the thing is, this disease is very scary and now we don’t even know ways in which people get it. So if someone knows that this person has it, that’s it. Anything or anybody that has something to do with the person is out.

Participants also revealed that stigma means outright rejection or a way for people to tell that you don’t belong. Yebson said: “*Well, it’s like rejecting you, throwing you away or you become an outcast in everything because you are considered as worthless.*” His wife expressed that: “*it’s absolute rejection and making the person feel that he is worthless; he is not human anymore because he is going to die. Yes, that is how we feel.*” For Paul: “*Owww, for me, it’s rejection, outright rejection, because of their suspicion...also it means I am worthless and may be they don’t consider me a human being anymore.*”

Participants’ perception of stigma and how they conceptualize stigma unravels some of the complexities of HIV/AIDS related stigma. Their perception of stigma brings out how stigma is negative.

Research Question 2:

What are the experiences of HIV-related stigma for PLHA and their family members?

Participants were asked to share some of their experiences since they or their family members were diagnosed with HIV/AIDS. The data show that stigmatization begins with diagnosis and disclosure of one’s serostatus. The experiences of PLHA and family members are presented.

Experiences of PLHA

Three categories emerged from participants' experiences: diagnosis and reactions, disclosure of PLHA's serostatus and expressions of stigma in their daily lives.

Diagnosis and Reactions of PLHA

All of the PLHA had similar stories surrounding their diagnoses: they had been sick and admitted at the hospital several times and several lab tests were recommended by medical doctors. The data for this study show that stigma begun during diagnosis as PLHA were not informed of the kinds of tests until the results were out. For example, Yebson expressed how his doctor insisted that he do a lab test:

I remember I used to get sick all the time and so I went to the hospital and the doctor asked that I have to do a test; he didn't mention the name of the test to me. But he insisted that I do it otherwise he will not take care of me.

Vickie recounted how she was diagnosed:

Okay, well it started like fever. I got sick all the time and so I went to a clinic here and so the health practitioner told me to go for some lab works. So when the results came he asked me, "do you have money?" and I asked him, "why?" Then he asked again, "do you have money?" and so I asked him, "how much?" and then he said, "the medication is expensive" and I asked him what the problem was and he said I have gotten the disease called HIV.

Similarly, Ida expressed:

I told him [doctor] the symptoms I have been having. So he told me he will recommend some lab work for me. But he didn't tell me what kind of test it was. So when the results came, he called me and inform me that I have HIV virus in my blood.

Many PLHA go through a process, from the initial feelings of shock, despair, grief and sometimes denial to an eventual acceptance and understanding that they have a life to live. Denial, disbelief, worry and thoughts of suicide were the major themes that emerged as PLHA's reaction to their diagnosis. For example Vickie expressed her reaction: "*Shock, surprise, I was very worried. I cried when I came home. I did not believe it, even when I was in the hospital in Accra I did not believe it.*"

PLHA did not believe the diagnosis either because they did not think it could happen to them or they were not involved in any of the perceived behaviors that are associated with HIV/AIDS. Ida said: *I didn't believe it. I didn't believe it. I told one of my aunties but she also did not believe it so the two of us we never believed it. I guess we all did not believe it could happen to us.* Paul's disbelief was associated with his good moral behavior and the fact that he is a virgin. To Paul the diagnosis hurts:

Oh, the day I heard it, I wasn't happy, I was very very sad. I was devastated and I was surprised that it happened that way. I wished I were dead, yes that would have been better because when I heard the results I wasn't happy in any way. I thought about it and became depressed. I even lost tremendous weight and became like a broom stick. It wasn't easy. Because it hurts, it hurts so much and I was very surprised.

Being devastated and wishing for death because of a diagnosis is not related to the actual disease but rather the perceived stigma that will be experienced by the PLHA when the community finds out about their serostatus. Paul recognized that his diagnosis will put him in a place of being stigmatized and so being dead will be the end to that humiliation. What makes it more painful is that he has *"...never slept with a woman in my life. I can swear that I have never seen the thighs of a woman before."* Like Paul, Yaa was so worried that she thought of committing suicide after she learnt of her serostatus:

As for that, initially, I was very very worried and honestly planned to drink poison and die. But I also thought about the children too, and thought that I had to check the status of the children too, may be they will show negative. So my plan was that if I check and there is nothing in them[test negative] I will choose to live and take my medications and tell my husband about it so that he can also go and check his. So he also went and checked his and so when they did not find anything in him, I was very happy and decided that I will keep on taking my medication and live with him.

Yaa's initial thought of suicide can be attributed to the stigma that is associated with HIV as well as the humiliation from within the home and the community. For her, if her husband and children had tested positive to HIV, then that would have been a disgrace for her family.

Serostatus Disclosure

Disclosure of PLHA's status took five forms: voluntary disclosure, involuntary disclosure, implied or perceptible disclosure, third party disclosure and nondisclosure. Voluntary disclosure takes place when the PLHA chooses to disclose their status of their own free will. Depending on the PLHA's ability to keep his/her status secret, s/he could control how many people s/he chooses to inform. The decision to disclose one's status on one's own terms depends on how one perceives the reaction of the person to whom the information will be revealed and its impact. Usually it is to receive some kind of support. According to Ida, she informed her supervisor so she could help her:

From there I went to my supervisor and informed her of the situation, so that she can help me out or tell me what to do. So she took me to the authorities but they refused, and let me go, but at that time I didn't have much education about this disease and I didn't even know my right so what they gave me was one month salary and they released me.

Involuntary disclosure, on the other hand, is where the PLHA is asked by health workers to share their status with one other relative prior to receiving Anti-retroviral treatments (ART) as explained by Yaa:

Part of the rules is that if a person is diagnosed with HIV/AIDS he or she has to come with a relative or friend for support and also as a witness, who will make sure that the patient adheres to his or her medications.

Involuntary disclosure is to enable support for the PLHA and to ensure that their medications are adhered to. However, sometimes the "guarantors" may refuse to provide guarantees for their support. In Yaa's case for example, after disclosing her status to her husband so that he could give her a guarantee for the ART, he refused it because he said he did not believe the diagnosis. She had to beg him to guarantee the medications for her.

Implied or perceptible disclosure takes place when the PLHA's status is inferred from his/her poor health, physical appearance and weight loss. In this form of disclosure the true status of the PLHA is not known for sure and s/he can choose not to affirm people's suspicion even when confronted about it. Paul expressed:

I don't know. I have not told them but I know they are suspicious, that is why they are not on talking terms with me. You know, I have been sick on and off so they suspect that

disease. None of them have been able to ask me anything but they are not talking to me, and don't visit as they used to do.

For Vickie, her landlady's husband inferred her serostatus from her frequent use of toilet:

Vickie: So, I used to stay in a compound-house before I moved here, where you came to meet me.

Gladys: Okay.

Vickie: And I used to go to the toilet frequently and so my landlady's husband asked his wife to evict me from the house because he thinks I have that disease.

Gladys: How did he know?

Vickie: Ah I don't know, he said the way I used the toilet frequently, he suspects it's that disease, so around that time the coordinator sent me to a catholic hospital, in Accra which treats most HIV patients.

Some family members, also were suspicious of the PLHA's status before they were 'formally' informed. Opokua tells how she suspected her sister's serostatus before she informed her:

Yes, she told me herself, but I kind of suspected it because she was getting sick all the time and made frequent visits to the hospital, and one of their co-tenants informed me that she used the toilet often, so I was very suspicious. But one day after one of her frequent visits, she called and said that she was going to tell me something and that she is begging me not to tell anybody, not even my children and my father.

The introduction of Anti-Retroviral Treatment (ART) helped the PLHA gain weight. This confounded many people who relied on physical appearance as signs of one's status. Vickie said, she goes to the hospital, takes her medication regularly and so when she gained her weight back, people started doubting:

They doubted if it is really the disease, so they started talking. Some will say: "oh it's not the disease [HIV/AIDS]." And then others will say: "it's the disease. Now they say there is medication for it." So it went on that way.

Yebson simply put it, "because if you will take it [ART] consistently you have no problem."

Sometimes, some medical workers and religious leaders abuse their power and share the status of the PLHA with other people. Also, in many situations PLHA's friends, co-workers and family members share PLHA's serostatus with other members of the community. However, like

perceptible or implied disclosure, for third party disclosure the true status of the PLHA is not known for sure, and s/he can decide to affirm it or deny it. For Ida, her colleagues did not know about her status until a nurse (who was in the consulting room with the doctor) informed them. Similarly, Faustie said she was prepared for the worst of her husband's illness until she found out from a pastor about his status: *I heard if from a prayer camp, where he was when he got ill. I went to visit him and the pastor told me.*

The PLHA revealed that if it had not been their family members who disclosed their status to other people, it wouldn't be known. For instance, Vickie recounted how her disclosure to her brother snowballed in her family. With tears rolling down her cheeks Vickie said:

Yes, the man that I trusted, he went to tell my father that this is what is happening. In fact I was very sad, I had never been sad... so my father also went and told the rest of the family that I have gone for the bad disease so they should come and look at me.

Similarly, when Yebson expressed:

Yes, so when I informed my mother she also informed my uncle about it. I guess she did that for sympathy. Out of "okra mouth" my uncle also spread the news to everyone we knew in their community. So our family relationship changed.

For Yaa, it was her husband who made it known to other people:

What made people know my problem was my husband's behavior. When he came to dissolve the marriage, he intentionally got drunk so he could say what he wants to say. And he told all the people gathered that I have this disease. Also at the WAJU [Women and Juvenile unit] he made it known to the people there. Even when he is coming to WAJU he brings his friend. So as am speaking I know three of his friends know that I have this disease.

For many PLHA, disclosure of one's status is the beginning of stigmatization. As a result PLHA are sometimes compelled to conceal their serostatus. Yaa expressed: *"So what I have noticed is that if you tell this problem to someone else it is not good."* She shared how some women in her association will not share their serostatus to anyone because of inevitable stigmatization. When Ida decided to inform her parents about her serostatus, she was surprised to find out that they knew already. According to her: *"they said people from my work place had come to inform them already so all they have been waiting for is for me to confirm."* Yebson and his wife chose nondisclosure of his serostatus to their immediate community including their

children because of their experience with their disclosure to his mother's side of the family. Similarly Paul and his parents prefer to keep his serostatus to the nuclear family.

Expressions of Stigma

The manifestations of stigma appeared in multiple ways and vary from overt and blatant to covert and subtle manifestations. Overt experiences were those that participants explicitly experienced (verbal and physical) from friends, other family members and from the community in which they live. Covert experiences were those subtle, nonverbal and indirect stigmatizing experiences shared by PLHA and their family members. Both results are presented.

Overt experiences

Two categories of overt expression of stigma were identified: physical expressions and verbal expressions. Both forms of overt expression are presented.

Physical Expressions

For most of the participants, stigmatizing experiences started within the family. While some family members accept PLHA, some do not. Even those who accept them do not do so whole heartedly. Ida puts it this way: *"I also realize that even those who seem to be nice to me are not 100% nice. They are pretending."* Within the home PLHA are separated in several ways from the rest of the family members. According to Yaa, before her diagnosis her sister and the rest of the family ate together, but things changed with her diagnosis:

So from that day onwards when I cook nobody eats in the house, my mother, my sister's daughter except my father. Even our youngest sister who is the same age as my son, they don't want to eat with my son. When I cook and give them some, my children will ask me if my mother will allow my brother to eat. It hurts (Yaa cries) very much.

She also shared how she went to take her bath at her sister's house and how her things were treated:

One day, I went there to have a bath and I forgot and left my dress and my sponge there. The next time I went there she had put my dress outside and I could not find my sponge so I asked her about it but she said she didn't know where she put the sponge. So I realized that maybe she trashed the sponge, but I did not say anything to her.

In many situations family members do not share household items with the PLHA or even want to sit near them. Yaa shared:

What is happening? Even the room that I live in right now, it's a family room, so anyone who comes to visit is supposed to sleep in that room, but you see because of my problem the room has been left for me and when they come visit they don't sleep in the room. They sleep in my parents' room.

No, all my utensils are in the kitchen, but they don't use it. My only item they use is the fan, to fan the fire. And they also use my bucket.

For Vickie, when her paternal family heard of her diagnosis they gave her food in different plates. She said: *"from that time when they are giving me food, they put it in a broken plate or leaking bowl and push it to me (Vickie cries)."* Vickie's mother also shared how her daughter was not allowed to sit in the family car when she (Vickie) went to visit her paternal family: *"Oww, her father's family, I wasn't there but they went to Easter celebration in their father's hometown and they found out that she was sick of this disease so they refused to sit in the family car with her."* Faustie also shared how her husband's family stopped visiting them after her husband's diagnosis: *"All his family members who used to visit us stopped visiting us, even once in a while when they come to a funeral and they come by to say hello, you offer them water they will refuse."*

In many situations the experiences extended to abuse, terrible beatings and sometimes poisoning from family members: With tears, Ida shared how she was forced to drink a concoction that a fetish priest prepared: *"So she forced me to drink, but I said I won't drink and she told me that if I won't drink then she was going to leave me at the priest's house. So that night I drank the concoction."* For Yaa, her husband withheld money from her so she could not go to the hospital to buy her medications. Also she recounted that one day she went to the public toilet and remained sometime. When she came back her husband accused her of going out to sleep with another man and so he beat her up terribly. He threatened Yaa to remove her things from the house otherwise he will beat her to death. Fearing for her life, Yaa did as her husband said; she packed her belongings and moved out of the house.

Physical expressions from friends and the community are no different from expressions from family members. For Paul, although he never told his boss about his diagnosis his boss refused to touch anything that Paul might have touched at their electrical shop, things like

electrical cords or spoons and plates. Yaa expressed how she was not allowed to try on a dress because of her “sweat”:

Yaa: I used to buy shirts from a lady near my husband's house, one day I saw a nice shirt in her shop so I said, “ O this is a nice shirt, can I wear it and see if it fits” What she said to me was that because of sweat she will not allow it. But before my husband broadcast my disease, I used to buy clothes from her, I was one of her good customers and I used to fit in any dress that I want to in her shop. When that happened she gave me 2 of the shirts to take home and try them on. When I came home, she did not bother to ask if they fit well on me.

Gladys: So what if it had not been your size and you needed to return it?

Yaa: O I know she would not have accepted it.

Sometimes when people are suspected of having HIV/AIDS they are ejected from their homes. According to Vickie: “*And I used to go to the toilet frequently and so my landlady's husband asked his wife to eject me from the house because he thinks I have that disease.*”

Verbal Stigma

Verbal stigmatizing of PLHA is the second category of overt experiences. PLHA described how their family members, relatives, friends, coworkers and the community gossip, speculate and spread rumors about whether they are suspected to have HIV and how they are assumed to have contracted HIV/AIDS. This leads to insults of PLHA, talking behind their backs, laughing and mocking, labeling, name calling and blaming. Yaa narrated how she responded to her husband's insults and name calling:

I realized what my husband has decided is what he has decided because sometimes when he meets me in the street he insults me: “prostitute, whore, go and find somewhere to heal yourself.”

Yaa also received insults from her niece after she had confronted her disrespect towards her. For Vickie, not only does her paternal family gossip about her but members of the community she lived in called her names and labeled her: *When they [paternal family members] see me they will start talking, that I have gone for that disease, and then when they see other members of the family they will be gossiping about me.* She added:

They [community] will say: “ ei she is the one going, AIDS woman, she is the one going”

and sometimes when they see me talking to someone, they will wait when we finish talking then they will go behind my back and talk to the person that I have AIDS and warn the person that if they don't stop befriending me they will get the disease.

It's not easy oh, my sister, hmm, especially the community where my mother sells the kenkey. Oh, sometimes the guys in the area, when they see me coming, they will start saying, "there she comes, AIDS woman, there she comes." Then they will start laughing.

Sometimes PLHA are referred to as "Eight" just because of the similarity of pronunciation to AIDS. Vickie recounted:

Vickie: Then there was a guy who works at the health center who showed interest in me, so we started dating. Somebody took a taxi and went to the guy's house and told him that "that girl is 1+7"

Gladys: What is 1+7?

Vickie: eight, AIDS

Gladys: aaaaaaaaaaaaaah, I didn't even think about it that way.

Vickie: Exactly, so that is what the girl does, she will go to the guy's home and tell him, "the girl you are dating is 1+7." Sometimes she will say, "4+4" or "6+2" and so on but the guy did not understand until another person told him point blank that I have HIV.

This second person is an elderly man.

Gladys: O really?

Vickie: Yes, he is old and he told my boyfriend that if he wants a serious relationship, he will offer his daughter to him so my boyfriend should forget about me.

Vickie also shared how her colleagues will gossip about her when they see her, they will say "*ei this girl if she lives another day then God loves her,*" literally meaning she is not worth living.

Ida told of how her own mother insulted her and blamed her for her serostatus: "*So the rest of my family accepts me except for my mother. Sometimes when we have argument she will insult me and make mention of my disease.*" She described how her mother insulted her in public during one of their hospital visits. Ida felt embarrassed and went back into the doctor's consulting room.

Sometimes PLHA are confronted indirectly about their status to confirm others' suspicions or what they have heard. Ida expressed that:

Oh yes, some of the men will intentionally express that they want to date you, just to test you, they will want to sleep with you, if you don't allow it then they will go and broadcast that they have a confirmation that I have the disease.

Vickie shared similar experience:

It's not easy. It's not easy at all living in this community, sometimes some of the men will come and try me like, one guy showed interest in me and then when it was time to be intimate, I insisted on using a condom, then he said, "why are you insisting on condoms, I know you have AIDS, that is why all along you don't want to be intimate with me, you think I don't know, I know" hmm.

For Paul, even though people do not know for sure what his diagnosis is, he said if people knew about it, they will start pointing fingers at him:

So, we don't talk to anybody about my condition, otherwise, Sister Gladys, they will start pointing fingers at me. They will say: "look at him, the sick person, because of his immoral behavior he has gotten this disease, he deserves it." Although it may not be the way they think about it.

In some situations the "talk" in the community is about uncertainties surrounding PLHA's status. Vickie said:

They doubted if it is really the disease, so they started talking, some will say: "oh it's not the disease" and then others will say: "It's the disease, now they say there is medication for it" so it went on that way. Then there was a guy who works at the health center who showed interest in me, so we started dating.

Hmm. They even told him that I was in the hospital and the doctor did surgery to put food in my stomach that is why I have grown big so that no one will notice I have AIDS.

Covert Expressions of stigma

Some actions may be very subtle, but clearly recognizable as being out of the ordinary. As recounted by Yaa:

As for my mother, because the Father [Anglican father] counseled her about the disease when I cook she eats. But sometimes too when I cook and give her some, she will say: “O I just ate, I’m full.” What she does is by the time I close from work and go home she would have cooked already, so when I start cooking she will say: “just cook what you can eat, I have eaten already.” As for my father he doesn’t know my problem so he always eats it.

She added that “Some people when they see you they will stare at you in a way that you feel judged, and then when they see that you stare back at them then they turn away” and “verbally they do not say anything to me but the way they will behave towards me hmmm, it’s very difficult for me, and it hurts a lot.”

Many will not say anything to you but they will call you prostitute in your absence. Even some people, for instance, yesterday a lady passed by my shop and asked me why I did not come to work the previous day. I told her I travelled and then she said: “Oh I see, if you have strength, then there is no problem.” Meanwhile I haven’t told her I am sick. Oh even sometimes when you meet someone and greet the person, they will ask how am doing. If I say I am doing fine, they will ask: ‘Are you sure you are fine, do you have strength, are the children okay?’ And so on. In fact, the way they will ask you questions, you recognize that they have heard something (Yaa).

A more subtle form of physical exclusion is described by Vickie: “Also my church members started behaving differently towards me. I was very nice with all of them but after I had this sickness, there has been a distance between me and the church members.” The experiences of stigma for PLHA appear in multiple ways as shown from the data and vary from overt and explicit to the more hidden and subtle. Many times family members also experience these forms of stigma.

Experiences of Family Members

Diagnosis and Response of Family Members

The reaction of family members to the news that one of their own has been diagnosed with HIV/AIDS was quite similar to that of the PLHA themselves and ranged from anger and blame, disbelief and denial to acceptance. Two family members in the study expressed anger and blame regarding the PLHA’s diagnosis of HIV. The anger and blame was due in part to the

perceived irresponsibility of the PLHA and especially for how they, as family members (even though they do not have HIV/AIDS), will be treated differently.

When asked her reactions to her daughter's diagnoses, Dede, Ida's mother, expressed:

Dede: Oww, I did not do anything, I was very surprised and not happy because she should have known better.

Gladys: What do you mean?

Dede: Well, if you know that AIDS is coming, you don't go out and meet it and bring shame to your family.

Gladys: But how will one know?

Dede: By sleeping around with men.

The blame that is associated with the diagnosis of HIV/AIDS is related to the perception that one has engaged in a behavior that is "morally improper" and therefore should be held responsible for it. Similarly, Opokua, Yaa's sister, who had witnessed her husband's co-worker's experience, expressed her initial anger:

Why she has that disease, but I believe my anger subsided when I learnt her husband and children are all negative. I also became angry because I thought of what people will think of us, I mean the family, you know this disease when it comes into your family people look down on you. One of my husband's co-workers got one and her husband's family treated her badly and so I was kind of scared of what will happen to her and what people will think of us, eheee, [yeah] that's why.

Opokua's initial anger was due in part to the fact that her sister, had "brought home" HIV to her family members. Thus when she learnt that her husband and children were negative, her anger lessened. However, she recognized that HIV-related stigma is also an issue for the family members of PLHA even though they were not diagnosed. As a result she feared of what might happen to them as family members.

Some family members also expressed disbelief at PLHA's diagnosis. Jacob, Paul's father said:

For me I was really shocked and surprised, because my son is a good boy and I didn't believe it. That day, I couldn't sleep because I didn't believe it; I realized that our lives will change forever, especially how people will behave towards us if they know of it.

For Paul's parents, their disbelief is as a result of the good moral behavior that their son had led and therefore did not "deserve" to have HIV/AIDS. His parents attested to his good behavior, hence their surprise and disbelief. According to Leticia, his mother: "*as for me I was very sad, because my son is a very quiet person. I don't know how he got this disease...hmm, because he doesn't like women, he hasn't even slept with a woman before.*" Thus Paul does not fit into the category of people who are perceived to have HIV; he does not have multiple partners. In fact he had never been involved in any sexual relationship before. Not only did Paul's father, Jacob, have doubts about his son's diagnosis but he also realized that their lives will change forever, specifically, the way people will treat them if the community finds out.

Family members' disbelief could also stem from PLHA's denial of their serostatus. When Yaa's husband informed his family and her family about her status, Yaa's father did not believe it. She denied her serostatus when her father inquired. Similarly, Vickie described how her boyfriend never believed the speculations of her serostatus:

O yes they said many things so the guy told them that it is not true and that, that is not possible, he did not believe it. So every time the guy will ask me anything about the disease, I will deny it. Fortunately for me when I go to sleep at his house he doesn't see me taking any medications so he believed me.

This study shows that when family members deny the serostatus of the PLHA, it is to protect the PLHA as well as themselves from being stigmatized from the community. Vickie, recounted: "*but as for my mother, if anybody asks her about my sickness, she will never tell, hm, hm, never ever, she will deny it.*" Even though Opokua, Yaa's sister believes her sister is in denial that many people know of her serostatus, she does well to protect her sister: "*O yes, people know, many people have asked me on several occasions but I tell them it's not true, but she thinks many people don't know.*"

Denial can also take the form of nondisclosure as in the case of Paul's family. Paul's family chose not to inform anybody outside their nuclear family, to protect both Paul and them from the inevitable stigma that is associated with the disease. Therefore when confronted about Paul's illness, they provided other diagnoses like stomach ulcer and headaches.

Sometimes family members themselves are in denial of PLHA's serostatus for obvious reasons, and may refuse to take precautions to protect themselves. Faustie does not accept that

her husband's serostatus is true because she is negative and her husband is not a womanizer. She said:

Even when we go to counseling they ask us to use condoms, but I always tell him that I don't like the condom and he also doesn't feel comfortable doing it without the condoms so we do it once a while, like once in two months or three months.

Thus her husband does not fit in any of the "categories of people who are at risk for HIV/AIDS." Faustie's denial of her husband's serostatus is also associated with the fear of being stigmatized by the community and her own fear of the disease.

In general, family members accept PLHA's status and provide some kind of support for them irrespective of their responses towards the PLHA's diagnosis. Although some of their behaviors may be stigmatizing for PLHA, all family members in this study explained that they have accepted the PLHA, live with them and support them.

Disclosure

This study gathered that family members reveal the serostatus of PLHA to other relatives to gather support and sympathy for the PLHA and themselves. However, the objective of the disclosure are usually not met as the "news" of the PLHA's serostatus snowballs within the family or community. For example when Yebson's mother shared the news her son's serostatus to her brother, to gain some kind of sympathy, he in turn shared it with other relatives. Also, sometimes when family members disclose the serostatus of PLHA to other relatives, it is a way of showing their fears of the disease and making other relatives aware of the diagnosis so that they will also be cautious. Vickie explained how her brother initiated the "news" of her diagnosis and how all the family members became aware. As a result they took steps to separate her from the rest of family.

Expressions of Stigma for Family Members

The expressions of stigma for family members also took two forms: Overt and Covert expressions of stigma. Overt expressions consist of physical and verbal expressions.

Overt- Physical Expressions

In many respects, family members of PLHA experienced similar physical stigmatizing behaviors from other relatives and the community in which they live. Faustie expressed how her

mother-in-law's sister-in-law who accepted them for some time, later gave them separate cooking utensils:

Ow she was nice to us, but human beings, you stay with them for some time and they change. It got to a point that she gave us our own plates, knives, and other cooking utensils, even we never used her bathroom, I used the public bathroom and clean my husband everyday in his bed. I remember during those times when I used to visit them, I will do groceries and try and cook to help out, but this woman will never touch any of the food that I prepare.

For Jacob, Paul's father, the friends he used to visit changed their attitude towards him:

Jacob: Oh I used to go there every evening after we return from the farm, even my wife was angry that I spend too much time there. When I go there we will talk and play draft [kind of board game]. Sometimes they will give me water when I am thirsty, oh his wife will give me a glass of water or some juice or something, but it got to a point when they all changed their attitudes towards me.

Gladys: What did they do?

Jacob: Sometimes, when I asked for water they will say their water is finished or they will send someone to go and buy bagged water for me, uh, so I didn't understand and then it got to a point that when I go there he wouldn't want to play the draft with me anymore. He will tell me, oh he has to go somewhere or someone has come to borrow the game. Ei hmm, so that went on for a long time, when I try to confront him he will say: "oh it's nothing, there is nothing wrong" so gradually I stopped going there because I didn't feel welcomed anymore.

Family members also found themselves being rejected by friends: Opokua expressed how her friends avoided her because of her sister's diagnosis:

There are two ladies here that I used to attend every funeral with, Ow I mean, sometimes we even sew the same cloth for the funerals we attend. Now if they are attending any funeral they won't even tell me, so I have also decided not to ask them anything.

Overt-Verbal Expressions

Some of the PLHA's family members are interrogated in an indirect way to confirm suspicions of the PLHA's diagnosis. Vickie narrated how she responded to one of the "interrogators":

Sometimes I think of my mother and I pity her a lot. Some of them say nasty things to her. One time, I was in my room one day, and a woman came to our house, very early in the morning, I guess she didn't know I was in the house so she started, "auntie [referring to Vickie's mother], I heard your daughter has AIDS. So where is she? Then is she going to die?" Then I got out of my room and she felt ashamed, and I asked, "Congratulations. Are you done? Are you done doing your inquiry? Go, go to your house and broadcast it to everyone that I will die in 3 days because I have AIDS. I will die so you can attend my funeral." Then she walked away. Up till now we are not on talking terms.

Jacob, Paul's father, recalled how some of his friends inquired about his son's health:

Yes, they suspect it and so there has been some occasions where my friends have commented on his illness. Oh like one time one of them asked me how he was and I said, he was fine. And then he asked again, "Are you sure he is fine?" And I said, "Oh yes he is fine" And then he asked, "So your son, what at all is wrong with him? What is his sickness?" and then another friend responded that, "I hear AIDS can do that too." And then they looked at each other in a way that made me realized that they know. But I told them the doctor said it's a stomach ulcer. Later on, one of them said, "Oh but we hear he is blind in one eye, AIDS can do that." But I told them that it's because of the frequent headaches he has.

Family members also expressed how they are verbally stigmatized in their absence. When Faustie, Yebson's wife was asked to share some of her verbal experiences of stigma she simply said: " *Ow, they will never say anything in front of you but they will insult us in our absence.*"

Also, this study shows that even though family members may not have HIV/AIDS, they are usually labeled and called names. Opokua, Yaa's sister recounted:

One day something happened. I got into an altercation with one of her [referring to her sister] husband's family. She also lives in this area. So we exchanged insults back and forth on the market. Then she went, "you prostitutes, that is why you are sick of AIDS,

you prostitutes.” I know I don’t have AIDS but I knew what she was referring to so to prevent other people from hearing it at the market, I stopped and came back home.

Sometimes a whole house (family) is labeled. For instance, Vickie explained how her younger sister’s ex-boyfriends labeled them, *“Oh I hear, your house is HIV house.”*

Covert expressions

The family members in this study expressed how they experience stigma in an indirect and subtle manner. Opokua, Yaa’s sister shared her experiences: *“My sister, some of these things people don’t tell you in the face but you could see from their behaviors, what they are thinking.”* Or sometimes when people meet her they will ask about her sister in a way that shows what they are thinking: *“So how is your sister? Is she well now?” So many questions. Meanwhile you haven’t told them your sister is sick.”* According to Opokua, sometimes people do not verbalize their suspicions, but you can infer from the way they will act towards you: *“Oww, madam, sometimes people don’t talk about it in front of you, but the way they will behave towards you, said it all.”*

Research Question 3:

What are the impacts of HIV/AIDS-related stigma on PLHA and family members, and how do these impacts influence their relationships?

HIV- related stigma has enormous impact on both the PLHA and their family members. One of the participants’ responses shows the magnitude of the impact: *“so my sister, this disease if you get it and you don’t take care, you will lose everything. You will lose your family, your friends, you will lose your job, you will lose your relationship, if you are not strong”* (Ida).

The major category identified by participants is socio-economic impacts: Loss of access to resources and livelihood. Also reported were, loss of friends, loss of identity, loss of spouse or partners, impact on family cohesion, and self stigma. While much of the data paints a rather grim picture of deeply-embedded stigmatization against PLHA and the family, the findings also show that the complexity of stigma includes positive impacts for both PLHA and their family members. These impacts also are presented.

Loss of Livelihood and Resources

Many PLHA and their family members lose their livelihood as a result of stigmatization. The major themes identified for loss of livelihood and resources were job loss, decreased client base, unemployment due to a person or family member's serostatus and eviction from homes.

Job loss

Loss of employment can occur after an employer learns of an employee's serostatus. For example, Ida recounted how a group of her colleagues had been working as casual workers for a long time and so they wanted to be made permanent staff. One of the requirements for permanent status was to do a thorough medical exam. According to Ida:

So every one of my colleagues got their results but they asked me to come to the hospital the next day. The next day very early in the morning, I went to the hospital and the doctor told me that the reason why they did not grant my permanent status is because I have HIV... so what they gave me was one month salary and they released me.

For most people who are independent workers like vendors, they are compelled to quit their jobs due to the community's stigmatizing behaviors. When asked about her work life Vickie said:

Vickie: Oh as for my work life, I stopped going to the market and the bus station to sell shrimps.

Gladys: Is it that you didn't have the strength to go or...?

Vickie: Oh no I had the strength although it wasn't like the first but it's my colleagues.

Gladys: What did they do?

Vickie: They started talking about it, gossiping and sometimes insulting me, so I stopped.

For Yebson, his community does not know his status so he still teaches. Asked what would have happened if they knew of his status, he said:

Yebson: My sister, hmm I would have been dead by now.

Gladys: Why?

Yebson: If they know, I don't even think they will even allow a single soul to sit in my class.

For some employers, suspicion that an employee has HIV/AIDS is enough to let them off. Paul recounted his experience with his boss:

Gladys: Yes, but how about your work life?

Paul: Oh I used to be a hardworking person and my boss liked me very well. But now here I am, I don't even have the strength to do anything. My boss used to go on treks with me; sometimes we will go for weeks or several days.

Gladys: I see.

Paul: Oh yes when he gets big contracts. But now he doesn't call me for work

Gladys: Why?

Paul: Well, you know everybody is suspicious now. You know the way I have lost weight and my frequent visits to the hospital. He thinks I don't have the strength to work and I also believe he is afraid because he is uncertain of what kind of disease I have. But I know he is suspicious because when I used to go to the shop he made sure he does not touch anything that I touch.

Decreased Client-Base

Furthermore, many PLHA or their family members lose their livelihoods through decreased client base. Jacob shared how her daughter's client base decreased and therefore had to change jobs due to the community's doubt about his son's illness:

I remember my older daughter used to sell waakye (rice and beans) in town but she had to stop because the market was not good anymore and most of her customers will ask her what kind of disease her brother has. Oh they asked her that every time they buy waakye. So we asked her to stop it. So she helps us on the farm now.

Gladys: So you think the market was not good because of your son's disease?

Jacob: Oh yes, you can easily tell from the questions they ask.

Vickie also recounted how her people stopped buying her mother's kenkey:

But people started talking that I have AIDS and I am the one who helps my mother to prepare the kenkey before she takes it to the market to sell. So my mother will always come home with the kenkey. They don't buy it and my mother didn't understand. But they say it at her back on the market.

Things were not easy for them as her mother expressed: *"It wasn't easy at all, when people stopped buying my kenkey, I was very worried because I am a single mother and that is what I have done for several years to take care of my children so."*

Yaa also expressed how things were tough for her because she does not get many customers after her husband disclosed her status in the community: “*and so the little money I get from my dressmaking I use it to take care of the kids. But now I don’t get many customers so sometimes things are very tough with us.*” When asked about her work life she said:

Yaa: As for my work, I am the only person in my shop so..

Gladys: So do people bring you things to sew for them?

Yaa: Well, they bring it, but it is not many as it used to be. Because I used to live with my husband, they [clients] go there and when they don’t see me the people in the house tell them I have moved. You know, people talk a lot and they tell them why I moved and so on. So they also end up not coming to me anymore.

Denial of Employment

Employment also can be denied if an application requires an HIV test. For instance, Yaa’s sister, Opokua was not allowed to sell food at her husband’s work place canteen. When asked about some of her experiences, she recounted:

Opokua: I don’t recall any other thing but I quite remember that my husband decided that he was going to help me to get a spot at their canteen to sell food. So he talked to the one in charge and he also went to inform the big men at the work place.

Gladys: Okay.

Opokua: So when the time came for me to get the paper work and all that, the officer-charge said that the boss said I should go and do medical exam including AIDS test.

Gladys: But don’t the Health and Sanitation officials require that for everyone selling cooked food for the public?

Opokua: They do, but when you find something small [money] for them they usually will push you through without the medical exam. And I talked to most of the women at the canteen. They said they never did any medical exam. So you may ask yourself, why me?

Gladys: I see.

Opokua: My sister, some of these things people don’t tell you in the face but you could

see from their behaviors what they are thinking.

Gladys: Hmm, so what happened?

Opokua: Yes, so my husband did the best he could to push it through, but they did not accept it. He even gave the boss and the one in charge of the canteen something [money], but they never accepted it. They insisted that I do the medical exam because the district requires it. But I know that most of the women there did not do it, even after that incident they took another young lady who also never did any medical tests.

Gladys: So you think it's because of your sister's problem?

Opokua: Very much so, otherwise what will it be? So we gave up on that.

Gladys: But you could have done it to prove them wrong?

Opokua: Ow these people they will get something else to say. My sister, once they know that my sister has disease, they will never allow me. But I thank God because even if they had allowed me, maybe they will tell all the other workers and no one will buy my food.

Eviction from Home

Eviction by landlords is one of the many challenges that PLHA and their family members face. Vickie and her mother, Daavi recounted how their landlady evicted them from their home because the landlady's husband suspected Vickie has HIV/AIDS: *“And I used to go to the toilet frequently and so my landlady's husband asked his wife to eject me from the house because he thinks I have that disease.”* Daavi said:

When she was sick and was on admission at Ashaiman, the landlady came to me for her keys because she said her husband said my daughter has AIDS so he cannot live with her. But I refused to give the keys to her and we fought over it. So one of my daughters, Nora, came from Accra and she was very angry to hear what the landlady was doing so. She paid the rest of our rent and we moved from that house.

Loss of Friends

PLHA and their family members face physical and social isolation from friends outside the home. Participants described a distancing where friends no longer visit, or in many cases

avoid PLHA or their family members. Ida shared how difficult it was for her when her friends literally “ran” away from her:

Ow, for that I went through difficult times, my sister. It wasn't easy, I have to tell you that. Hmm Akosombo is a small town, so the news spread. But before that I used to live with my friends. They were not working so I was the one taking care of them and doing everything for them. But when they heard the rumor about my condition they moved and left me. Even one of them told me that the hospitals have published the names of all the HIV patients on their notice boards. So she wanted to go and look at it.

Paul's friends do not visit him anymore:

Well, like I said earlier, now I do not have any friends. All my friends don't visit me anymore. But I am okay with it because in this world no one knows what the future holds. One day they will find themselves in my situation and they will understand it more.

Also some of them “won't even shake my hand. So it's better for me to be by myself than being with them.” His father also recounted how the friends changed their attitude towards him. They no longer welcomed him. Opokua, Yaa's sister also recounted how her friends avoided her because of her sister's diagnosis.

Loss of Identity

PLHA identified that they are seen and treated by the community as if they have no future. They lose their identity. They are called names and are automatically associated with “social evil” and are not respected. For instance, Ida's mother who was angry about her daughter's diagnosis automatically has the idea that her daughter knew where she had the disease from: “*By sleeping around with men.*” Vickie also recounted how she was called prostitute by a man in her community: “*you prostitutes, look what you brought on yourselves, you are always changing partners, look how ugly you look now*”, and how someone told her boyfriend that “*that girl is 1+7*” or “*4+4*” or “*6+2*” referring to her as she is the “eight,” a word which is close to the pronunciation of AIDS.

Sometimes the community may show disrespect for PLHA if she is a woman by suggesting other women to partners. In the Ghanaian society, for someone to offer a woman to a man, knowing very well that the person has a partner is total disrespect to the partner. Vickie recounted how an old man offered to give her daughter to her boyfriend at the time: “*yes, he is*

old and he told my boyfriend that if he wants a serious relationship, he will offer his daughter to him so my boyfriend should forget about me.”

Sometimes a whole family may lose its reputation and identity because one family member has HIV/AIDS. For Vickie her house was named the “*HIV house*,” symbolically referring to her family as an HIV family. When Opokua had an altercation with one of her brother-in-law’s relatives the expression used was, “*prostitutes, that is why you are sick of AIDS, you prostitutes*” meaning she and all her family members are prostitutes just because of her sister’s diagnosis of AIDS. Meanwhile she (Opokua) does not have HIV/AIDS. When asked what she thinks people will say if they disclose their son’s status, Leticia said they will be blamed for their lack of vigilance because their son is very young: “*Ow, they will insult us and will even tell us we are bad parents, because look, he is 27 and he had this disease when he was very young so hmm.*”

Loss of Spouse or Partners

For many, having a steady relationship even sometimes marriage is not an option when they or relatives have HIV/AIDS. Yaa recounted how she and her husband divorced after her diagnosis. Although her husband accepted to live with her after the diagnosis, he later informed Yaa’s mother that he is no longer interested in the marriage. Traditionally, Yaa’s husband was supposed to perform the customary rites and present a reasonable reason for dissolving the marriage. His reason was that Yaa is a prostitute but he could not substantiate his accusations with any evidence. Yaa was the one who presented drinks to her husband’s family to dissolve their marriage.

Similarly, Vickie decided to end her relationship with her fiancé because she could not continue denying her serostatus to him all the time even though people informed him that Vickie is HIV positive.

So he kept asking me all the time especially when he is drunk, but I always deny. So from the look of things I decided to end the relationship, but he still calls me. Sometimes when he calls and I tell him I am sick he will ask if it’s that disease but I will tell him it’s asthma, he knows I am asthmatic. So when he ask me those questions I try to defend myself by asking me if he ever saw me taking any medications and so on and so we ended that relationship.

Sometimes inviting a male to visit even isn't an option. Vickie expressed that:

Also, my other problem is finding a partner to be in a relationship, because now if I bring any man to my community, they will call him and tell him that this is my condition. So where I am, I don't invite any man to come and visit me.

While women with HIV/AIDS are encouraged to date men with HIV/AIDS, some men prefer to date women who do not have HIV/AIDS or even sometimes take advantage of the women who are living with AIDS. Ida recounted:

But because they counsel us to date people who also have the disease, I decided to look for someone who also has the same problem. So I was introduced to a certain guy who is also in the same problem, but he doesn't behave as if he has the disease. Oh he came to me like four times, I felt confident and I was not scared that someone will call and tell him because we all have the disease. So he came to me on four occasions but I never heard from him again.

Vickie also expressed similar concerns:

Gladys: What if you meet someone in the association?

Vickie: I don't think so.

Gladys: Why is it not possible?

Vickie: Not that (laughs) but what the men do in the association is terrible. They date several women, may be two or three in the same group. Hmm

Gladys: Awwwww

Vickie: Even some of them will agree to be with you while they have other girlfriends who do not have the disease

Gladys: I see.

Vickie: Even some of them, you date them and then they will leave you. Move to another city without telling you. You will never see them. If you call them, they will never respond.

While some believe that you can find someone who will understand and marry you even if you inform them you are HIV positive, some people would rather not disclose it. For example Yaa, recounted how her friends in the Association blame her for informing her husband. However, she expressed that it is the right thing to do. If she finds someone who is interested in her she will inform him of her serostatus. For other women like Vickie and Ida, they will never

inform anyone who wants to marry them because of the resulting stigma. They acknowledge that marriage is the solution to most of their stigmatizing problems. Ida expressed that:

It's not easy, oh my sister, for me. I believe if you are diagnosed with this disease and you are able to marry, it solves half of your problem, because people in this community will sometimes walk to me and ask , " so now who is your partner or who is your boyfriend. I haven't seen you with a male. What is the problem, or do you have any problem?"

The experience of losing a relationship is quite similar to that of their family members. Vickie recounted of her younger sister who never had a steady relationship and had to relocate:

Vickie: My younger sister never had a steady boyfriend because of that. As soon as she starts dating someone, people will call to inform the person and so the guys also will quit the relationship. But they will not tell my sister why they quit, she will only find out later when the relationship is over. Some of the guys will make comments like, "Oh, I hear your house is HIV house."

Gladys: Oh, ho.

Vickie: So my sister became very sad, so she moved to Accra recently but she visits us regularly.

Other family members may even think their adult children who have HIV/AIDS cannot pursue their life's aspiration of getting married. Leticia, Paul's mother expressed:

Hmm, I get worried all the time, all the time, for me and for him, young boy. was hard-working. He has his own room. We were hoping that he might get someone to marry and also have his family, hmm.

Impact on Family Cohesion

The bulk of the care for PLHA is given within the context of the household, generally by family members and specifically by women. However, HIV/AIDS-related stigma can result in the refusal of family members to provide this care either out of anger, or moral condemnation or both. In terms of behavior towards PLHA, family members fell into two camps: those who continue to support and treat PLHA as though nothing had changed and, those who behaved differently towards them.

Acceptance of People living with AIDS

On the whole, most family members in this study provided some kind of support for PLHA. The forms of support included emotional support, room and board, and financial support. Regarding acceptance and support, there were some family members who fully accepted and supported the PLHA upon disclosure, there were some family members who partially accepted and supported the PLHA and there were those who accepted the PLHA but later changed their minds. For example, Paul recounted how his family accepted and supported him and kept his diagnosis a secret from the community:

“Well, nothing much has changed. My parents have been very supportive and caring. Both of my parents know [about my serostatus], my sister and my brother [also know], but they don’t have to tell anybody. We do everything together. For Paul his family has been his source of strength: “I would say indirectly yes, my family has been my source of strength. For me, I really know, I am always sad, full of sorrow. But my family, especially my mother, she always encourages me and consoles me.”

Similarly, Vickie recounted how the maternal side of her family, especially her mother and her younger sister, fully accepted her and support her emotional and financially. Her mother is a single mother and she is the one who provided for most of her financial needs. She has been supportive from the day of her diagnosis. Her mother’s denial of Vickie’s serostatus is also to support her emotionally. Her younger sister has also been supportive. She recalled how her sister would not eat if they don’t eat together.

Although some family members pledge their support for the PLHA, some of them do not honor it. They provide some kind of support, but they also behave in ways that show their partial acceptance and support. Yaa recounted how her mother supported her by providing her with accommodation but behaved differently towards her. Similarly, Yebson and his wife expressed how his mother supports them financially, but according to Faustie:

Faustie: O yes, in fact he [her husband] has even realized that he cannot rely on his family members for anything. You know, money can help, but in this society we value physical presence than money.

Gladys: I know that.

Faustie: Ehee,[yeah,] so his mother can bring a house full of money, that is not enough.

Her son needs her presence too, and for her to say that she cannot allow her own son in the house because she will lose her patients, is something to think about.

Vickie's father (step father) accepted her and supported her emotionally even when her mother did not after she disclosed her status. She recounted how her father will argue with her mother the whole day, sometimes because of her and how he even insulted her for being a bad mother. However, according to Vickie, it got to a point where her step father changed his attitude towards her and so she had to move from the house: *"My step father, it got to a point that he also started doing what my mother was doing, and because my mother didn't support me, it was terrible for me."* Similarly, Faustie recounted how her mother-in-law's sister-in-law accepted to stay with them but later behaved in ways which were stigmatizing to them.

Rejection of People living with AIDS

Within the family, PLHA expressed how their relationship with their family members changed in different ways. Some family members treated PLHA with anger, blame and disrespect. Exclusion of PLHA from family activities and separating household items also was common. Sometimes family members relocate as a way of "running away" from the PLHA and in many situations may even refuse care for PLHA. Ida, for instance stated how her mother's anger was reflected in the way she treated her throughout her diagnosis. On an occasion Ida expressed her dislike for the food her mother brought to her during one of her hospital visits, and her mother expressed her anger and blame towards her:

Ida: Yes, but that is what I did. So she will bring me food whenever she is coming, but she always brings food that she knows I don't like.

Gladys: What kind of food don't you like?

Ida: I had nausea so I didn't feel like eating anything. So I told her that the food she brings to me, I am not able to eat. So if she can bring me foods that go with pepper soup or something, that will be fine. My goodness, as soon as I said that she went crazy then she started: "Eh if you cannot eat the food, leave it. You can die. In fact, you have to die. You are disturbing me. Why, why have you gone in for this kind of disease? Why did you go in for this disease, and now you want to choose your own menu? I don't have time. I don't have time."

Yaa also described how her niece's behavior changed towards her. When she confronted her about it, Yaa said: "*O my God, I regretted for asking that. She insulted me very well and she said something that made me suspect that her mother has told her something about my problem.*" Her niece's misbehavior came as a surprise: "*I was surprised because that girl used to respect me very well.*" Yaa's sister Opokua expressed how angry she was at her sister's diagnosis and especially when she was denied her job:

But I hope you understand me. I am human and it's not like I blame my sister for what she has brought into the family. But I am also human. In fact when I didn't get the canteen job I was very annoyed.

She added that

Not really with the authorities who denied me. If my sister has AIDS, it's not me who has the disease. So why should I be denied anything? But anyway it's all good. But like I said I am a human and so sometimes when I think about it I get mad and there are many times that I have not been in the mood to talk to her because of those issues. But I have learnt to get over it. After all, what if it had been me?

Exclusion of PLHA from family routine includes but is not limited to exclusion from family visitation; exclusion from family activities and decision making; separating of household items and even exclusion from family membership and refusal to provide care. For instance, Yebson and his wife, Faustie, described how his side of the family stopped visiting them after his diagnosis:

Eheee, [yeah] so they rejected me outright. But it wasn't like that before. They used to visit me all the time. I go there at least once a month and so on. But now, no, I don't go there and they don't come here. (Yebson, PLHA)

Owww, those who know, like I said earlier, don't come close to us anymore. They don't visit so we also don't go there anymore. (Yebson, PLHA)

Yaa also narrated how she was excluded from visiting her sister's husband when he was sick. Her mother and sister did not want her to visit him:

Later on her husband became very sick, they hid it from me, so I did not know the kind of sickness. Even when I asked where he was, so that I can go and visit him, they never told me. Her husband was so kind but when I asked about him my mother will never tell me,

but they always inform me when they are going to visit him. Hm, but they won't tell me and the man died.

In certain situations family members do not include PLHA in their decision making even if it is regarding the PLHA's health. For Paul it was because he is no longer in a position to contribute financially and so his family members might have considered it as unnecessary to consult with him. When asked why he thinks his family members do not consult him, he said: *"Honestly I don't know, but I think the truth is now I am not working so they think it is not necessary to consult me on that."* Furthermore PLHA sometimes lose the power to decide the care they want because family members make it for them. With tears in Ida's eyes, she narrated how her mother took her to a fetish priest and was forced to drink a concoction. She drank it because her mother insisted that if she doesn't drink it she was going to leave her at the priest's house.

Furthermore, for some PLHA, their family members refuse to use their items, or share things with them. Because of her diagnosis, Yaa's family members do not eat any food she prepares except her father who does not know her true serostatus. She also recounted how her sister had refused for her daughter to wear her (Yaa's) shoes. Similarly, Vickie recounted how her paternal side of her family put her food in a separated bowl and plate and would push it to her. They even refuse for her to sit in the family car with them.

Yet for some PLHA, when family members refuse to provide care for them it is a big rejection. Ida, for example described how she was the 'caretaker' before her diagnosis how her relationship with her mother was before she was diagnosed:

Oh, my sister, we were very nice. At that time when I was working on the cruise, I took care of them. Yes I was the one who did everything for them. Christmas times I do everything for them as parents. I have two other sisters who were very young at the time. I took care of them before this happened.

My sister tells her [mother] that she vividly remembers those times when my mother comes to me early in the morning for money. So they all accept me, except for my mother. I used to shop for food, clothes and send to them. I did everything for them. So today if it is time for her to take care of me, she tells me she doesn't have time, hmm.

Asked if her diagnoses had strengthened her relationship with her family Ida said:

Oh my God, not in any way, not at all, hm [nodding]. It has divided us, because I was the one who was holding the family together, caring for everyone and making sure that everybody is fine. And since I became sick, my sister ran from home, my mother rejected me and so on.

Her mother refused to provide care and stopped going to the hospital with her. For Ida, her mother's rejection was part of the reason why she was not put on ART right away because the health officials were not sure if her mother would help her in adhering to the medication. She said: *"because of my mother's behavior they were not convinced that if I was put on the ART she would make sure I take the medication consistently."*

For many, exclusion from family visitation, exclusion from family activities and decision making, separating of household items and refusal to provide care means exclusion from family membership. For instance, when Ida was asked what she thinks has been some of her family members' challenges she said:

Well, probably the time and patience to care for me, and the money too. And at a point I believed they found it difficult to admit that I was a member of the family because my younger sister, she stopped calling me "sister" and my mother was prepared for me to die.

For others like Faustie who felt rejected by her husband's family, they are the ones who do not consider themselves as family. She stated: *"oh for me I really don't consider them as my family anymore. Even my husband, he doesn't talk about them anymore. It's just the two of us and our children."*

Well, it's sad, because, who doesn't want family? We all do. But then if they reject you, what do you do? Sometimes I think about it because that is not the kind of relationship I will like to have with my in-laws but they have also taught us a lesson. Apart from that, everything is fine (Faustie, Yebson's wife)

Irrespective of whether family members accept PLHA or reject them, one common reality that all of them face is role and responsibility change.

Role and Responsibility Change

Stigma is also expressed through the diminishing or change of the roles, responsibilities, of PLHA as well as their family members within the family and larger community. Role and

responsibility change is one of the major issues that PLHA and their family members had to deal with whether they are accepted or rejected. PLHA are perceived as no longer being productive members of the family. In many respects this leads to lack of respect from family members. In a society that believes in adult children caring for their parents, when illness results in role change it creates tension within the family. Ida expressed how her role as a daughter changed because she was not able to work and care for her mother anymore due to her diagnosis. She further stated that she was no longer the “big sister” to her siblings as one of them ceased addressing her, as sister and her mother was even prepared for her to die. For Paul:

I am 27, and I believe I should be responsible. But here I am still being taken care of like a child, and it hurts but... hmm, what can I do? I feel worthless. Everything is money, which is our biggest problem, because whenever the doctor writes a prescription it's money, money. Even before they admit you at the hospital they have to get money first. The medications are very expensive too.

Perhaps that is why his family members do not consult him in situations when they have to find money to take him to the hospital.

Self- Stigma

One of the profound consequences of HIV-related stigma on PLHA and their family members is the occurrence of self-stigma or internalized stigma. PLHA and their family members experience self-stigma or internalized stigma as a result of facing overt and subtle stigma. Self-stigma does not happen as a surprise because PLHA and their family members who experience it share the same cultural and social values and norms as the stigmatizers in their communities. Therefore, they have the same ideas of what HIV/AIDS means. For example, Ida expressed how she responds to people's behavior towards her:

If they are nice and want to be close to me, I accept that and live with it. If they treat me bad and want to isolate themselves, I do the same. Like one of my sisters, for years when she wasn't calling me or talking to me, I also didn't bother to talk to her. But when I became well and she realized that I am her sister, I also became close to her.

Similarly, Yebson said: ‘oh, like they don't visit me anymore, I don't hear from them and because of that I also felt reluctant to go to them.’ Thus PLHA's isolation is a response to people's reaction towards them.

There are many expressions of self-stigma but those found in this data ranged from feelings of worthlessness to self isolation or withdrawal and even to the extremity of having thoughts of suicide. However, feeling worthless is mostly a result of the PLHA's inability to contribute financially. Paul also described how he feels worthless because he is not able to contribute financially since he lost his job. With tears Paul said:

I feel sad that I am not able to contribute. Whether they consult me or not, the truth is I do not have the money, so it doesn't worry me so much, what worries me is that I am not able to provide anything.

For many of the PLHA withdrawal starts from within the home. Yaa narrated how her children sometimes become withdrawn and quiet because the rest of the family members do not want to eat with them. While some PLHA like Vickie despised themselves and are simply not "comfortable" eating together with their family members because of weight loss and physical appearance, for some others self isolation is a way of taking precautionary measures because of their uncertainties surrounding the transmission of the disease. Paul expressed:

Oh yes, my family has not abandoned me, but I am the one who makes sure that I do not use some of their items. No, they have not abandoned me at all. But I am the one who feels I have to be careful in the things we share.

When asked why he does not share household items with his family he said: "because of the disease, the way the disease is even me I don't know how I got it so I am only trying to be careful not to give it to anybody."

Yet many PLHA isolate because of predicting stigmatizing behaviors from friends and the community at large. Ida narrated how she no longer participates in social events:

Because at those events, I will meet the same people who are talking about me. And I hardly go to the market because that nurse who spread the news, anytime I meet her at the market she points fingers at me and gossips to other people in the market. So I don't go anywhere. I don't attend any party, I don't attend any funeral. Even if I know the person who is organizing the event, I will not go because I will sit in the same bus with them and the humiliation will be too much for me. So it's enough. Even when I go by myself I will not feel okay, so I won't.

Similarly Paul said: *“Oh I mentioned that my friends don’t come to me and I have also decided not to go visit them because even when they see me the way they will behave, is very sad. Some of them won’t even shake my hand. So it’s better for me to be by myself than being with them.”*

Also: *“I used to go on outreach programs, but now I would rather stay at home because you see, people talk, people talk a lot.”* Yaa also expressed how she used to participate in church activities until her husband disclosed her serostatus to “everyone.” For her, disclosing her serostatus was a disgrace and so she felt ashamed.

For me, if it hadn’t been my husband who had disgraced me all over this place, I would never be ashamed if I am in public. But he has disgraced me so much so I don’t go to places that I know he has disgraced at.

Well, I used to go to church even with my husband before my problem. But when he started disgracing me and telling people that I am a prostitute, one of the elders in our church called him and told him to stop doing that because I am not a prostitute. But he did not stop, so I felt like he had disgraced me in the church and many other places so I don’t feel happy/comfortable going to church.

Yet some PLHA are able to overcome their self-stigma as recounted by Yebson:

Yes, from the initial stages, yes. That time I really did isolate myself. Like after I came from the doctor’s office, that week I really felt like not going near anybody. But with time as I read more about the disease and got to know from the educators that I was not going to die “tomorrow,” I started doing my normal things.

For many PLHA self-stigma goes beyond the feeling of worthlessness to thoughts of suicide:

Faustie recounted how her husband thought of committing suicide:

One day he told me that because of his sickness he will kill himself with a knife. That time I think I had told him that if his mother does not come to help out I will be leaving. I was fed up because there was no help from his family.

For Vickie, her thought of suicide was as a result of her mother’s stigmatizing experiences:

So I hear they exchanged words at the market like that and later my mother heard it. In fact when I heard it I was sad, very sad and I had a thought to commit suicide but my younger sister was all out for me. She gave me all the attention I needed, comforted me and always talks to me so I forgot about it and continued with my life.

Yaa also thought of committing suicide. For Yaa it was the status of her children that changed her mind.

The most profound expression found with family members is isolation or withdrawal from family life and social interactions. None of the family members expressed that they felt worthless or wished they were dead. Thus the intensity of self-stigma is stronger with PLHA than family members. For example, Opokua, Yaa's sister, described how she withdrew from her friends and social events because of stigmatizing behaviors from people.

In fact, because of that I don't want to get involved with other people, because in this community the more people you get involved with the more people will talk about the situation. So I really don't go anywhere, except, for instance, if the funeral is someone in my church or very close to me or if it will be held in my hometown.

And the fact that my friends neglected me was a big issue for me. So I really don't have any social life any more. In fact, whenever something comes up that I feel I can attend, I think of how people will gossip about me and then I will decide not to go.

Where family members expressed a sense of hopelessness, it was expressed for the PLHA's inability to fulfill their life's aspirations. Leticia, Paul's mother, recounted:

For me, my problem is that he is young, and it was my wish that he will also get married and have children one day, but now see.

Positive Impact

While stigma is pervasive, the data provides instances of PLHA and their family members surmounting the stigma and revealed how the diagnosis has strengthened them as individuals and as families in various aspects of their lives. For example, participants shared that they have become stronger individuals and families and are more self-reliant than they used to be. For Jacob, his son's diagnosis and their experiences "*has made us [nuclear family] realize that we can only rely on ourselves.*" Similarly, Yaa recounted how she has become independent and realized that she cannot rely on her friends. With tears she said: "*Oh Yes definitely, I have become a stronger person and independent. If I hadn't been sick I wouldn't have known how human beings are.*" Then with a big sigh she said: "*because if you are not sick, you have many friends and loved ones, but it's when you get sick that you come to know your friends and haters.*"

For some participants their diagnosis and experiences have strengthened them spiritually or religiously and morally. As Ida put it:

And sometimes I also thank God for where I am now, because those times that I didn't know my status, I wasn't that spiritual. I used to attend church once a while, but this disease has made me become closer to God than I used to. So now I don't party, don't attend funerals. I rather participate in church activities so it's all good, but there is only one thing left that I want God to do.

In a similar way Yebson expressed:

Gladys: In what ways have these challenges strengthened you as an individual and as a family?

Yebson: O yes, morally and spiritually it has strengthened me.

Gladys: How so?

Yebson: Well now I attend church every Sunday. I pray all the time and I do not have any girlfriend now.

For the couple in the study their challenges have enhanced their relationship, the communication and brought them together. Yebson, proudly expressed that: *"Honestly, I think it has brought us together now especially me and my wife. We go to church together, pray together and I really really respect her more for being with me."* His wife affirmed what her husband said:

Oh, now I am the one who encourages him and I have made him understand that if his family rejects him I will take him to my family. I always tell him that so that he doesn't think too much. Now he listens to me so much. Previously he did not take any suggestions I made.

Also she recounted that: *"Oww, now we go to church together. We pray together and I believe he respects me more than the first...no, the fact that his family behave differently towards me even encouraged me to be there for him more."*

Overall most of the PLHA and their family members recounted that their challenges have strengthened their togetherness as a family. Paul simply said his family has been supportive and they do everything together: *"Well, nothing much has changed. My parents have been very supportive and caring. Both of my parents know, my sister and my brother [also know of my*

serostatus] *but they don't have to tell anybody. We do everything together.* Paul's father expounded on what his son said:

Also now we all do the same work. So we go to the farm, come back, cook and eat and I don't get to go out anymore. If I am going out then it's for some church program, outreach but not to sit with friends or play 'draft' with friends. And now we make decisions together, like how much money will be spent on medications, food and stuff like that, which is good. Previously, my son took care of himself and my daughter took care of her own business, but now we are one family and we do everything together and we don't talk to outsiders about our problems too because they may use it against us.

Research Question 4:

How do PLHA and their family members cope with HIV-related stigma in Ghana?

PLHA and their family members develop various strategies to cope with stigma.

Sometimes decisions around disclosure depend on whether or not disclosing one's status would help to cope (through care) or make the situation worse (stigmatize). Four major themes emerged as coping strategies: Anti-Retroviral treatment as coping mechanism; social support; denial and nondisclosure as coping mechanism; and religious and belief systems.

Anti Retroviral Treatment as coping mechanism

The PLHA expressed that the ART helped them to conceal their status which somehow confounded people's thought hence minimizing stigmatizing behaviors. Vickie recounted that:

Yes, so they put me on the medication, the ART, and I got a lot of support from Josephine, she always talks to me; consoles me and so on till I came back to myself. Hm, if you had seen me at that time, you will run from me, very skinny.

For Vickie, gaining weight or coming back to her normal weight is a way to prevent the inevitable stigma that is associated with HIV/AIDS. Yebson expressed that the ART is the solution to all the problems.

Social Support

There were two major categories that emerged from this study as ways through which PLHA and their family members get social support. They are formal and informal support.

Formal support includes participating in networks of PLHA and counseling from health workers. Informal support on the other hand, was mainly from family members and friends.

Formal Support: Participating in PLHA Network

Sharing how she copes with day-to-day experiences, Yaa recounted with a laugh:

As for me right now because of the association that I belong to, when we go for meetings they talk to us. They encourage us and teach us many things and that consoles me because when I attend meetings I see people who are just like me, even some who are more beautiful than me.

One of her biggest fears and worries, apart from financial difficulty is getting bedridden and not being able to care for herself and her children so she runs to the clinic with any little medical problem. She said:

One thing that scares me is that maybe I can get very sick and could not do anything by myself or even work to take care of my children. So every time I have pain in some part of my body, I run to the clinic in order that I don't become bedridden.

Participants expressed how they cope with their experiences through counseling from health workers and other HIV/AIDS area workers. Vickie and Ida shared how their district AIDS coordinator and some health officials helped them through counseling, emotionally and financially:

Vickie: Oh like I told you, initially I cried, but before they will put you on this medication, the nurses and the health workers will counsel you and talk to you, so I am fine and my sister too has been a great comfort for me so, yes I am okay.

Ida recounted that before she was put on the ART she had support from a private practitioner who saw her monthly and treated all her symptoms and gave her assurance:

I always go to a clinic in Juapong, it's a private clinic, the practitioner told me at the time that there was no treatment at the time, but she assured me that there will be treatment in the near future so I should be patient. So every month I go there, then she treats me for all the sickness, malaria and whatever symptoms I have that makes me weak.

Informal Support from Family Members and Friends

Support from family members is a major issue for the PLHA. While some family members stigmatize them, some help them cope. For Paul, his family has been a great strength for him: *“I would say indirectly yes, my family has been my source of strength. For me, I really know, I am always sad, full of sorrow but my family especially my mother, she always encourages me and console me.”* His mother and father expressed their support for him respectively:

We talk to him; I encourage him all the time, because I don't want him to be depressed. He is our son so we do what every parent will do for a son. So we eat together, drink from the same cup and use the same plates. He is the one who asked that he wants to use his own plates and spoons and so on (Leticia, Paul's mother).

Ow, we have each other, now we don't talk to anybody about my son's disease. Everything is within the family, and we support him too both financially and emotionally. What else can one do? (Jacob, Paul's father).

Vickie's source of encouragement has been from her maternal family, especially her mother and her sister and some friends, who have always been there for her. They console her and feed her. She recounted how much help her boss (who is also her friend) has been:

She also consoles me all the time. She always ask me to forget about what people say and she tries not to be judgmental, because she has not done the AIDS test so she doesn't know whether she has it or not. So I shouldn't worry about what people say. When they find themselves in my shoes they will stop talking. Sometimes she comes to visit me.

When I came home my mother would cook and give me some to eat but now she said she cannot do that anymore. But there is this woman, auntie Josephine who is the coordinator, she helps me out a lot. She takes me to church, counsels me and so on. In fact she has helped me very much; sometimes she comes home to counsel my mother too. She talks to her to accept me instead of blaming and insulting me because already, I feel bad for the condition that I am in so if she also adds insults to injury, it will not help. Sometimes she even gives my mother money to cook for me. So she's been helpful. She is an angel in my life (Ida, PLHA).

Denial and Nondisclosure as Coping Mechanism

Denial, non-disclosure of status and hiding away the PLHA can also be a way of coping, a strategy that PLHA and their family members use protect against stigma.

Yebson, feels comfortable in his community because he has not disclosed it to anyone and his wife is very supportive. He said: *“Well, so far as no one knows in this community, I am okay and I have a good wife who has helped me throughout all these years.”* Similarly, his wife expressed: *“No, in this community nobody knows the kind of illness he has so we are free. Otherwise, my sister, we couldn’t have lived here. Ei, this community, they talk a lot.*

Nondisclosure also is a tool for most family members to cope with the stigma of being blamed. Paul and his family said they have not told people in their community because they will be insulted when people know for sure that he has HIV/AIDS. Paul said:

So, we don’t talk to anybody about my condition, otherwise, sister Gladys, they will start pointing fingers at me. They will say: “look at him, the sick person, because of his immoral behavior he has gotten this disease, he deserves it” Although it may not be the way they think about it.

As a way of coping with inevitable stigma, family members either hide-away PLHA or encourage them to hide away from the community. Faustie described: *“those times I remember I would take him to the bathroom around 3am to bathe him because I didn’t want people to see him.”* And for Paul, his family suggested he stay home for some time: *“O and my family also suggested that I stay home for sometime so if I gain weight I can go back because the more people see me the more they talk.”*

Relocation can be another way of coping with stigma. Ida’s plan is to move out of town, *“because now if I bring any man to my community, they [people from her community] will call him and tell him that this is my condition. So where I am, I don’t invite any man to come and visit me.* She plans to move to live with one of her aunts in a bigger city than where she is. Similarly, Vickie’s sister had to move out of town because she was not able to have a steady relationship with men.

Religion and Belief system

Many PLHA turn to religion and prayer for comfort, solace and support. For example, as Ida previously explained, her illness has increased her faith and she now regularly attends church

and participate in many church activities. Yebson also described how he became more spiritual than he used to be; he goes to church every Sunday and prays with his family regularly. Similarly, Ida expressed how she has become involved in church activities more than she used to.

Many cope by searching for explanation for the HIV infection other than sexual transmission. This data reveal that an explanation of witchcraft provides some kind of protection against stigma, and a way of coping for both PLHA and family members, because then the source of infection is outside the control of the individual and the family. Faustie reveals that if her family members knew of her husband's true status they would not have helped her. She said: *"my family members do not know what kind of sickness he has, in fact they believed its witchcraft or juju."* She recounted how her husband's illness started after having a dream.

Well, before the sickness started he went to a choir conference at Aflao and he came earlier than the scheduled date, so when I asked him he said it was nothing. It was later that he told me that when he went to the conference he had a terrible dream. He said someone hit him with an iron rod in the dream, but the person turned his back towards him so he couldn't see the face. After that dream he lost his voice, he couldn't sing anymore so he did not participate in the competition.

So all this illness started after that dream, but you see he never told me until he got sick. So that is what I told my family about his illness.

Asked whether her family would have supported her if they knew her husband has AIDS, she answered: *"Of course not, no way."*

Paul and his family believe that he got the disease through witchcraft. Many Ghanaians believe that someone can be bewitched for two reasons: when the person has done something wrong or out of mere envy. In Paul's case, he and his family believed it was the latter because he is hard working and has a promising future. So for them, bewitching him with AIDS is a way of *"slowing him down."* Leticia shared: *"We are Jehovah's Witness so we don't want to find the root cause other than believing in Jehovah, otherwise we can also visit some other supernatural powers to get answers."*

Like PLHA, family members also cope by holding on to their faith and through counseling from health officials and other officers working in the area of HIV/AIDS. Daavi,

Vickie's mother, said: *"There is a lady who also came to visit me like you have come here. She assured me not to worry that my daughter will die because there are medications and so she will not die."* Like Paul's family, she hangs on to her faith for everything.

Most of the time, these coping strategies are employed consecutively or simultaneously. Some PLHA may gain support through disclosure and joining an association that is at a distance from their place of residence, while simultaneously employing nondisclosure with their immediate neighborhood. While these coping strategies do not all necessarily contribute to the broader aim of reducing the spread of HIV/AIDS, they are an individual and the family's way of coping with the stigma associated with HIV/AIDS

Research Question 5:

What are the differences between men and women with regards to stigma experiences in Ghana and how do these differences impact the lives of women in Ghana?

Although most participants initially said that they did not believe there were differences in stigma experiences between men and women, when asked what would have been the experiences of their opposing gender, most of them expressed that experiences of women are worse than men. As much as it may seem contradictory, it may be as a result that most participants shared the same beliefs and values of society about gender roles and responsibility, so that where there are differences, it may seem "normal" to them. The data also show that much of these differences are as a result of the society's expectation of women and men. Women are labeled more than men, their roles change when they are diagnosed and the impact is felt more by women than men. In their quest to stop their stigmatizing experiences many women are adopting the trend of nondisclosure.

Differences in Disclosure

One of the major differences between men and women's experiences is the differences in disclosure. Most participants expressed that women are stigmatized more than men because they usually disclose their status whereas men do not. Even when participants believe that there are no differences between men and women regarding stigma, they expressed that most men do not disclose their status in the first place. For example, Ida believes that depending on the kind of community, men and women experience stigma: *"I believe so, if the community is the type that*

pokes into people's business they would. But the thing is, my sister, most men don't tell, so probably I wouldn't have told anybody."

The data shows that women disclose their status to get support, financially and emotionally whereas men are too proud to disclose or in many respects have the money to buy their medications. Vickie recounted some of the reasons why women disclose their serostatus more than men:

Well, maybe they [men] have the money to buy the medications or maybe they think it's a disgrace to let other people know of their status. And you know how men are, proud. And you know how men are able to keep secrets than women. But most of the women in the association are traders and they are now out of jobs.

Similarly, Yebson agreed that women experience more stigma than men because they disclose their serostatus too often to too many people:

Well I think it depends on how they tell other people about their status. In our association, for instance, there was a lady who sells "koko" (cornmeal porridge). She told people of her status so eventually she lost all her customers. You know, I believe women talk much more than men. Maybe that is why they are stigmatized more.

While women are "known" to share their diagnosis easily, ironically they conceal their husband's diagnosis. Men, on the other hand, conceal their diagnosis but reveal their spouses' diagnosis. For example Yaa recounted how her husband has disgraced her by revealing her status: *"For me, if it hadn't been my husband who had disgraced me all over this place, I would never be ashamed if I am in public. But he has disgraced me so much so I don't go to places that I know he has disgraced me."* Faustie, on the other hand, said she had never shared her husband's diagnosis with any of her family member because that will result in withdrawing their support for them. She asked: *"You see how I have kept it a secret from my family?"* When men disclose their spouse's status to family members it is justification to dissolve the marriage or to find another woman. Yaa expressed that: *"he even told his family members about my situation during one of our meetings to dissolve the marriage."* Yaa's sister explained:

Well, I believe many women whose husbands have this disease do not tell their relatives. The problem is when women have it, they tell their husbands and because their husbands too for one reason or another will want to go in for other women, they inform their family members just so they can have their support for going in for another woman. And the

family members too when they hear that, O my goodness, they will say all sorts of nasty things about you and sometimes evict you from your marital home. But madam, you know that when you have this disease people think of you as a prostitute and so being a woman prostitute is a big deal too.

Differences in Response

Another major difference between women's and men's experience is their responses to HIV/AIDS, especially to a spouse who has been diagnosed. The data show that people react to women's diagnoses differently. Also, most women are forgiving, compassionate and supportive of their spouses, no matter their serostatus. Men, on the other hand, lack compassion and usually neglect their spouses who are HIV positive. Yaa expressed:

Well, I think that when a married woman gets this , she is neglected by her husband and most of the time the men even leave the children with the women, knowing very well that she would not have money to take care of them. But when it is the man who has the disease, the woman will stay with him no matter what and take care of him. That is what I think.

Asked whether he would have experienced the same rejection from his friends if he were a woman, Paul said:

Paul: Oh that would have been worse, worse, worse.

Gladys: Why?

Paul: A woman? Hmm, I don't think even my parents would have believed me if I told them I were a virgin. You know, when a woman has this disease her situation is worse because people think she did more than double what the man did.

Support Verses Neglect

Yaa recounted that he doesn't have a husband because of her diagnosis but things would have been different if he were the one who tested positive: "Yes because now I don't have a husband, but if he was the one who had the disease, I would have stayed with him." Asked why it happens that way she said: "well, because we women think of the children more than anything, and when you leave, that will be it, he will not take care of the children. I would have stayed. I would have stayed." Some men will rather go in for another woman said Vickie: "I also think when men are sick the women stay with them and take care of them but what kind of a husband

will stay with her wife and nurse her? No, they won't do that; they will rather go for another woman."

Vickie further recounted that it is easy for a man to find someone to care for him than it is for a woman:

Yes because they [men] will always get someone to care for them, their wife or mother or sister or someone. Now I think most of us are learning from them, that is why I don't want to tell any man I meet about my condition.

When Yebson was asked his opinion on the differences between men and women's experiences he also attributed it to a good characteristic of women:

Yebson: You know naturally women have compassion than men. Women are very sympathetic so they tend to stay in the marriage to care for their husbands.

Yebson's wife affirmed that his husband would have left her if she were the one that is HIV positive. She expressed: *"Yes, absolutely, do you think if I were the one who has the disease, he would have gone through what I went through for me, no way, I believe he would have left me long ago."* When asked why, she also referred to a characteristic in men: *"because that is what men do. They are not compassionate like women. Only few women will leave their husbands, but most men will go find other women."*

Other Differences Related to Social Norms

On the other hand, there are strong beliefs about the reasons why women experience more stigma, blame and shame than men when they have AIDS. In fact most of the reasons participants gave for the differences are related to the perceived extent of "immoral" sexual behavior that men and women engage in as well as gender roles and responsibilities. When women and men have AIDS, it is attributed to having multiple partners, as Yebson expressed: *"It's true that many people say that, if you are a woman then it's because you are a prostitute and if you are a man it's because you are promiscuous. Even some pastors believe that way too."* However, it is a natural propensity for men to have multiple partners, as Opokua expressed sarcastically:

Opokua: Oh, but madam, all men are promiscuous, how many men in this world will stick to their wives only? I believe there is no man. So somehow we already know that all men have multiple partners. But that is what it is, there is nothing wrong with

it. Why do we say that when a married woman sleeps with another man, she has committed adultery but if a married man does it, no one thinks of it as adultery? It's the norm.

Gladys: So why do you think we think that way that it's normal for men and not normal for women?

Opokua: Like I said, men are men and women are women.

Even when men have HIV/AIDS, women are the ones to blame. Vickie said, "And you know, I can tell you that there are many men who have this disease, but they always say it's women's disease." She added that,

You see we don't see men having multiple partners as a new thing but if it's a woman, oh my God, everybody will hear it. In the same way, when a man have the disease, even though people will believe that he had had multiple partners, they don't usually refer to that fact or even say it in public. Sometimes they will even say it is so-and- so woman who gave it to him, recounted Vickie.

Similarly, Daavi and Leticia affirmed that when men have AIDS, they make reference to where they contracted it (usually from a woman):

Gladys: I see, so what do you think people think of a woman who has AIDS?

Daavi: Ow that she has led an unacceptable life.

Gladys: What if it's a man?

Daavi: Ow, that he got it from one of his multiple partners and you see, naturally men always have multiple partners but if you are a woman you cannot do that otherwise people will not respect you.

Gladys: So what do you think people think of women who have AIDS?

Leticia: Oww, may be they had multiple partners, prostitutes.

Gladys: What about men?

Leticia: Oww, may be they got it from a prostitute or maybe they also had multiple women.

Labeling

As part of women's blame for their serostatus, they are labeled and called names. Many Ghanaians call them "Ashawo" meaning whore or prostitutes, as Faustie said: "*they are also usually left with the burden of taking care of the children, they are called names, "ashawo" and so on.*" They rain insults on women more than men. For example, Vickie recounted how people perceived her:

Well, in this society, hmmm you know, in my situation when I got it people started saying that I am a prostitute, I have had a bad life, that I have slept with many men that is why I got. But if it were a man, well they will insult him but it wouldn't be so much as they did to me.

For Ida, people's perception of her is "*one thing, prostitute, multiple partners, that's it and nothing will convince them that their thinking is wrong.*" However, if men are labeled they are called "men" because "*You see a woman cannot be a prostitute because it is not acceptable but a man can be a womanizer because it is acceptable*" said Faustie sarcastically. Although Daavi did not think there are differences between women's and men's experiences she thinks most men do not disclose their status and also referred to the physical characteristics of men:

Gladys: So do you think the way people behaved towards your daughter, they would have done that to her if she were a man?

Daavi: O yes, or maybe I hear most men don't say it so then he would have gotten a wife.

And see people will not talk about a man who has this in public.

Gladys: Why do you think so?

Daavi: Because he is a man (laughs) and so people are afraid of him.

Yet for some others, women are blamed more than men because it is believed that there are more women than men. Paul recounted that: "*but you see sister Gladys, in this society if you have this disease then it means you have had multiple partners and there are more women than men so...*" Thus the dedominance of women in terms of the number infected makes it easier for them to be blamed.

The data also showed that although men are sometimes called "womanizers" they are seldom talked about. When asked what people think of men who have AIDS Jacob said: "*people think he's also had multiple partners or he is a womanizer. But you see in the case of the man,*

people don't really talk about it more like the case of the woman" and he further explained that it is also as a result of multiple issues:

Jacob: Honestly, I am a man but I will say this, I think there is nothing wrong with it when a man has multiple partners, but when a woman has multiple partners, hmm it's not good.

Gladys: Why is it not good, if you can have multiple partners, why can't I?

Jacob: Oww, you are a woman so you don't have to do that otherwise you will not get a husband and people will not respect you. Even some men will take advantage of that and come and propose to you but they won't marry you. They will want to sleep with and leave you.

Gladys: So what is the difference between us?

Jacob: Oww, I think people accept men more easily than women because you see, it is believed that when you have this disease then you have not done something right. And when men sleep with many women there is nothing wrong, but if it is the other way people will never forgive you.

Gladys: So you think it's okay for you to do that?

Jacob: No, it's not okay, but what I am saying is it's not a big deal, I can have multiple women and choose one to marry. But for a woman, if you do that you may not have a husband. But, my daughter, who will know if I had slept with 100 women or 200 women, but if you are a woman and you sleep with a 100 or 200 men, we will know. See we come in all sizes and shapes. (We all laughed out loud). So you see, that is what I mean. Uhuuuh.

Role change

The reasons given for blaming and stigmatizing women more than men are intertwined with social roles regarding gender specific roles and responsibility. Traditionally women are expected to be the care givers, providing care for men and children and the elderly. When a woman (depending on the age) has HIV/AIDS and she is not able to provide care then it means she has "violated" a norm and may not be forgiven. In cases where the woman is married it becomes difficult for the man to accept his new role. Therefore he may choose to neglect his wife. Ida said:

And one thing that I also notice is that, sister Gladys, being a woman itself is a problem because women are the ones that take care of everyone. We take care of children and men. So, if a man has this disease it is not a new thing that a woman takes care of him but if the woman becomes sick, then who takes care of her? So I believe people ask why they should be taking care of you when according to the norm you should be taking care of them.

When women are taken care of, it is in exchange for what they had once given. When Ida was reminded that her mother used to take care of her, she said:

In that case, I was the “supplier” of the house so when everything changed and I couldn’t supply any more she will have to take care of me but you see later she was looking for avenues to get rid of me.

One major norm in the Ghanaian society is that adult children must take care of adult or elderly parents. In this respect, when a young woman like Ida or Vickie has HIV/AIDS, and is being taken care of by her parents, it does not resonate well with the society. It is a significant role change which society frowns upon. Ida described her role change:

O yes of course, since I was not able to supply anymore, my family started looking down on me, my role as a daughter who cared for her parents, like everyone expects, changed. And I was no more a daughter, but a burden to my mother. For my sister I believed she did not respect me because maybe in her mind she thinks I have led a bad life that is why I have this disease. But it’s all good, because I know them now.

When men have AIDS and are not able to provide for the family, it is a big change for the family but their spouses always find other avenues or take on multiple jobs to support the family. When Yebson was asked whether his role as a father has changed he responded: “no. I don’t know what will happen if my children know, but for now they don’t know so everything is normal.” His wife, Faustie, recounted likewise:

Well, I don’t think so because my husband is still my husband and he is the same father to his kids. But, well I think in terms of caring for the family financially, it changes because like my husband he was the main breadwinner, and so when he became sick, things were tough. But apart from that I don’t see any changes, no matter what, that respect is there even if the person is sick. It doesn’t make him less of a husband.

Also it is socially expected the wife must stay with her ill husband and take care of him:

Most men will not do that, they would have informed all their family members and the family members would have found another woman for him. But since he is the one who has the disease, his family expect me to take care of him and do all that stuff.

Some participants also shared that women's roles as mothers and wives do not change much.

Oh, I believe the big issue is when you are bedridden and you cannot work, then it makes it difficult to perform your role as a wife or mother, otherwise if you have the strength to work and care for your children and your husband, things don't change much.

Impact on the Lives of Women

It is obvious that women bear a stronger brunt of stigma, blame, shame, labeling, name calling, and rejection than men. The reasons can be tied to society's expectations of women to act and behave in a certain way. When women have HIV/AIDS, it simply creates the impression that they have failed to honor those expectations, even though it may not be the truth. This makes the impact of HIV/AIDS-related stigma on women tremendous. For most married women, especially discordant couples, if it is the woman who tests positive, then that is the end of her marriage.

Women who test positive are usually rejected by their spouses. Being rejected by a husband is a huge problem for a Ghanaian woman because most women depend on their husbands financially. It also means that the children will be taken care of solely by the woman sometimes with little or no help from the husband. Therefore the economic impact is huge. Yaa explained that her biggest worry was money:

As for me, right now in my life, what I worry about is to get some money and do some business, buy things and sell. Previously I used to sell things, store shirts, materials and so on; my hangers are even there as am talking. But because of this sickness, I lost all my capital so I don't have anybody who will give me money to begin the business again.

Opokua affirmed what her sister said when she was asked to describe the experiences of women who have AIDS:

Opokua: Oh, they suffer very much, because if they are not lucky, and their

husbands leave them like my sister, they will have to care for their children by themselves and if they are not lucky they will never get husbands.

Gladys: How about men who have AIDS?

Opokua: Oh, they, they do not have any problem. Their wives or sisters or mothers will take care of them and most of the time they won't even tell they have that disease.

Similarly Vickie shared her opinion: *“Oh yes, some of the women when they tell you their stories you will cry. Their husbands have abandoned them because of this disease and they don't have any help.* Many times husbands had to make decisions regarding the woman's health; when to get medication and when not to. This could be detrimental to the health of women. In Yaa's case she had to beg her husband to be a guarantor before she was put on ART.

When we go to hospital the doctors ask us to bring a relative to support us so he [husband] was the first person I informed. So he went with me to the doctor's office, when he was told about my diagnosis, he did not believe. He said this disease is a supernatural disease so he refused for me to accept the medication from the hospital. And so that first day I had to beg him to be my witness before the medication was given to me.

In many respects economic independence results in the inability of the woman to finance her health. Yaa recounted how she had to rely on the services of NGO to pay for her medications:

My husband stopped giving me money for my medications so I stopped going to the hospital. One day I got money from my mother so I went to the hospital and the nurses asked me why I have not been coming for my medications and I told them I don't have money so they wrote a note for me to take to Father Benson (An Anglican father who has an NGO that helps PLHA). The father accepted me (Yaa cries) and so every month I go there to take a form before going to the hospital. So my medicine is given to me at a subsidized price. I was very happy because I used to pay 100 Ghana Cedis but now I pay 50 Ghana Cedis.

Also, a woman's serostatus could heighten violence in her relationship: beating, rape accusations and so on. Yaa described how her husband sometimes forcibly has sexual intercourse with her and beat her. One day she went to the public toilet and stayed quite while because she had to join a queue. When she returned, her husband beat her up until some neighbors came to her rescue.

Some men who have HIV/AIDS take advantage of the diagnosis of their fellow women. Vickie expressed that it is not possible that she could date someone in their association because the men in the association take advantage of them. With a laugh she said: *“not that, but what the men do in the association is terrible, they date several women, may be two or three in the same group.”*

Avoiding Stigma by Nondisclosure

Because of the stigmatization associated with the disclosure of HIV/AIDS and the impact it has on women, many women are changing the trend of disclosing their status and adopting the nondisclosure method used by their male counterparts. For many, the only way to avoid being stigmatized is nondisclosure. The women shared the experiences of some women in their associations who do not disclose their status to their husbands and in fact some of them (participants) were not prepared to share their status to their future husbands. For example, Yaa referred to a woman who was abandoned by her husband because of her serostatus. She remarried but never disclosed her status to her new husband:

Imagine that if I was not working, and my husband left me, what will happen. I can go and find other men to take care of me and be spreading the disease. Honestly, I know someone whose husband treated her the same way and left her. She has found another man who is going to wed her. Do you think this is right and fair? No it's not because the new man doesn't know she has the disease. I really object to it. So me, if I find a man, I will tell him the truth. If he really cares about me, he will understand....Many of them..... like when we go for meeting we talk about our lives, some women have it but have not told their husbands and they are not prepared to tell them. Sister Gladys, do you think it's fair?

Similarly, Vickie shared: *“If you tell them they will go and never come back. I know some women who say they will never tell their husbands, so they come to the meeting, get their medications and go home, who knows?”* Paul also expressed that many women do not disclose their status because of the fear of being abandoned. Because of inevitable stigma associated with serostatus disclosure, two of the women explained that they will never reveal their serostatus to any man who wants to date them:

For me if I meet someone who wants to marry me, I will never tell him of my condition. There is a lady in the association who informed her husband of her condition, the husband informed every person in his family about his wife's condition and they started misbehaving towards the lady. They eventually sacked her from her marital home. So do you think if many people see this, they will be willing to tell anybody of their condition, even their husbands? No!

Whether or not women are blamed for bringing HIV/AIDS into the family, the impact of its related stigma was more profound for women than men. For many women, being stigmatized because of HIV/AIDS diagnosis is an experience of multiple stigmas. First, being a woman itself is belonging to a marginalized group which is often stigmatized. Second, being HIV/AIDS positive means being stigmatized and third, being abandoned or divorced results in another stigma.

Research Question 6:

What are the Factors influencing HIV-related stigma among Ghanaians?

Participants expressed several factors that influence stigma in the Ghanaian context. The factors they identified as influencing stigma were issues of morality, fear, as well as the power of language. For family members, their stigmatizing experiences are because of their association with the PLHA.

Morality

HIV/AIDS in Ghana has been associated with behaviors that are perceived to be “immoral.” These strong beliefs make people dissociate themselves from people who they perceive to engage in such activities thus making them reluctant to associate with HIV/AIDS in anyway. Opokua recounted that: *“I also believe if you have this disease, then many people will think you have led a bad life and so they will not want to associate themselves with you and many people feared that in fact they will die if they have this disease.”*

Irrespective of how PLHA may have been infected, PLHA do not agree to the assertions that people get HIV because of the “immoral life.” For instance, Yebson identified the common perception: *“It's true that many people say that, if you are a woman then it's because you are a prostitute and if you are a man it's because you are promiscuous. Even some pastors believe that*

way too.” Then explained how he perceives it: *“But my sister it is not true because we went for a program in Koforidua and they told us of a man who had never slept with a woman before, he got married and got the disease. His wife is negative, so how will you explain that too?”* Thus one can be infected by HIV/AIDS through other means other than sexual intercourse and therefore we are all at risk, irrespective of our “proper” or “improper” behaviors.

Some of the participants have their own doubts about the issue of HIV/AIDS and perceived immoral behaviors. Leticia said sarcastically: *“Aaaah, they say this disease is the disease of prostitutes and womanizers so maybe our son slept with someone and got it. But I know he has never slept with anyone.”*

Sometimes people talk of how they do not believe what other people perceive of how they or their family members might have been infected. However at the same time they do not recognize when their words, or beliefs are stigmatizing. Despite believing that their son did not engage in any of the so-called illicit behaviors, Paul’s family still described how people who get HIV/AIDS indulge in unacceptable behaviors and need to change their lifestyle. Leticia, Paul’s mother, said: *“Well, maybe because of my son, I will say to some extent it’s not true but most of the people who have it have also led some kind of unacceptable life. I also hear that some witches too are responsible for it. Some people can use that to bewitch you.”* For Jacob, Paul’s father, *“lifestyle is the biggest thing everyone needs to consider, the choices we make in our lifestyle, immoral behaviors...”*

Gladys: So you believe that people get this disease because they slept with multiple partners?

Jacob: Maybe? Is it not what people say?

Gladys: What about your son?

Jacob: As for my son, it’s only Jehovah who knows.

Fear

There are three themes surrounding the issue of fear when it comes to HIV/AIDS as presented by participants in this study. Fear due to insufficient knowledge of HIV/AIDS transmission, fear due to the media presentation of the disease and fear of the disease itself and what it symbolizes.

Fear Caused by Insufficient Knowledge of HIV Transmission

Many people are of the view that HIV is only acquired through sexual intercourse. Therefore it is a disease of prostitutes or womanizers. Consequently it was difficult for Paul and his parents to believe his diagnosis. Both parents strongly affirmed their son's good moral behavior and virginity, and ruled out other natural cause of his diagnosis. Faustie on the other hand did not believe his husband's diagnosis is truly HIV: *Well, for me I don't believe he has that disease, because we've been together for several years, but I don't have it and my husband is not a womanizer so I don't believe it's that disease.* This provides evidence of the misinformation or the lack of sufficient and correct information about the transmission of HIV/AIDS. Thus many people are unaware that there are several ways of getting HIV/AIDS other than being a "prostitute" or "womanizer." And in fact there are several discordant cases like Faustie and her husband. Ida recounted:

Oh yes many people think that way. Even my own mother tells me I saw the disease and went in for it, but it is not that way. I have not led a bad life, but this is a disease and anybody can get it because you wouldn't know whether "Kwesi or Kofi" has it. It is not written on anybody's forehead, but once a man asks to date you, you accept and wouldn't know whether he has it or not.

Ida's mother shared how she was surprised of her daughter's diagnosis because for her, one can literally see HIV and can make a choice to have it or not. She said: *"Well, if you know that AIDS is coming, you don't go out and meet it and bring shame to your family."* According to her, her daughter knew where she had the disease from. Asked where she had it from, Dede said: *"By sleeping around with men... my daughter knows right from wrong and she chose to go in for the wrong thing so."* Dede's perception is not very different from many people, specifically many Ghanaians who have been misinformed about HIV/AIDS transmission. This misinformation makes it difficult for one to realize that HIV/AIDS is not a disease that one can see on other people.

Although some PLHA say people stigmatize due to insufficient knowledge of the transmission of HIV, they themselves exhibit those kinds of perceptions that people have about the transmission of the disease. Asked why people stigmatize Yaa responded:

Yaa: I believe they think that if someone has this disease and they eat with the person they will also be infected.

Gladys: So you think they don't have sufficient knowledge of the disease.

Yaa: At all. They don't know it and they fear it too.

However, when she suspected that her sister had informed the daughter of her diagnosis she called her and said: *“So I told my sister that one day she may find herself in my situation because once they buy food from outside and eat they can as well be infected one day.”* Thus, many people (including PLHA) do not have the correct information on the transmission of HIV/AIDS even though they think they do. Ida's mother believes that one can literally see HIV: *“What kind of foolish disease have you brought to us, why did you go in for this foolish disease, why did you see the disease and went in for it, don't give me work at all.”*

This data also show that sometimes the correct information can make a difference in the area of HIV- related stigma. Daavi, Vickie's mother explained;

But for me, the doctor told me that we can eat from the same bowl, sleep on the same bed, but I will not be infected unless may be she uses a blade to cut her finger nails and then I also use it. Even that unless she has a cut from the blade and I have a cut too but I will never get it from eating with her.

This information that Daavi received from the doctor provided the basis for the acceptance of her daughter's diagnosis.

Fear Caused by Media Reports

For the participants in this study the media has played a tremendous role in portraying HIV/AIDS as something that needs to be feared. When Yaa was asked if there are other reasons why people stigmatize, she said: *“owww, not really, but I think the way the media advertised the disease is like it's a bad disease: you will die if you have this disease and so on. It also got people scared of the disease and do not want anything to do with it.”* Similarly Vickie recounted that:

Hmm, you remember when this disease first came and the media was showing it to the public, it was scary and most of the patients they showed were dying, skeletons. So people were really scared of the disease, like if you have it you will die the next day.

Also for Yebson, *“if you learn you have that disease you will be scared... I think it's because of the way the media portrayed it from the onset. The way they placarded it. That is why people behave that way towards the disease.”* According to Yebson because the media has “polluted”

people's minds of those negative images, "it will be difficult to correct" and the only knowledge people have about the disease is "death."

Paul also shared:

Oh yes. The way they show it on TV, talk about it on the radio, how deadly it is and how it's killing people. People fear that if they come close to you they might get it, which is why many people behave that way towards us. So as soon as people suspect that you have this disease, ow they will never come near you at all.

When people are given in-depth education it makes a big difference. When Daavi,

Fear as a Result of Nature of Disease

There is also the fear that the disease itself is degenerative: it poses apparent physical defacement or an undesirable and unaesthetic death. Faustie recounted how her husband lost weight and could not do anything on his own before he was put on ART, so she hid him from public because:

He had lost so much weight and had become weak, especially after each TB injection. So I will lift him up by myself and dress him and clean him up. He ate a lot but was still weak and could not do anything.

Similarly, Paul shared:

You see, I think it's because of the way I have lost weight, maybe I look ugly and worthless to them...even some people say that this disease is deadly so they will even not come near you because if they do they will die. So maybe that is why they don't come near me.

For Yaa, the symptoms are important: "Yes, I think the symptoms the disease presents is a big thing, when you have this disease, at a certain stage the way you will lose weight uhh and become so skinny too." Because of that many people are afraid of what they will go through before they die, said Ida. Yet to some PLHA the uncertainties surrounding how people may have gotten the disease are enough to put fear into them and other people. Paul said: "because of the disease, the way the disease is. Even me, I don't know how I got it so I am only trying to be careful not to give it to anybody...you know the way I have lost weight and my frequent visits to the hospital, he [Paul's employer] thinks I don't have the strength to work and I also believe he is afraid because he is uncertain of what kind of disease I have."

Even some family members think the disease is unpleasant. Jacob, Paul's father, said: *“and you know, I guess may be because of the way the disease is, everybody is afraid of it. They think if you get it today you will die the next day so... It's all the disease, the disease. It's not a pleasant thing.”*

Power of Language

People recognize the negative power of language as a stigmatizing tool. Terms with negative connotations are part of daily conversation and even the media. Often, speakers are not aware that their words are stigmatizing or even damaging. Many people are influenced by this language and act on it by stigmatizing. Ida gave an example of the imagery used in the media:

I also believe the media too has a big role to play. In fact, the way presenters sometimes talk about it is not good. Sometimes they use bad imagery like they can even say, something is like an AIDS patient just because of the size of that thing, which is not good. They are the educated people but they don't do well at all. I remember one time one radio presenter said he went to buy sardines and the sardines were so tiny and skinny like someone suffering from AIDS.

For her, it is sad when such language is used by educated people:

Up till now, public education about the disease is going on but there are many of us, Blacks that still have a negative concept about this disease, sometimes you meet some people who are very much educated but the kinds of things they will say about this disease, you will ask yourself what schooling has done for them.

Sometimes the use of such negative language comes as a surprise when it is coming from a doctor and makes the consequence severe. Yebson collapsed when the result of his test was revealed to him. For him it was both the diagnosis itself and the words of his doctor. *“You have gone for this disease that the whole world has rejected.”* As much as that language is stigmatizing in itself it also adds to why people should fear the disease and the basis for not wanting to have anything with it and the fact that it came from a medical doctor affirms the basis for stigmatizing against PLHA.

Words like “ashawo” (a woman having more than one partner) or “prostitutes” that are used to insult PLHA, especially women with HIV/AIDS, also go a long way to provide the basis for people's stigmatizing behaviors. Prostitutes or “Ashawo” are considered to be behaviors that

are “immoral” and “unacceptable,” and so its association with HIV/AIDS makes it acceptable for people to stigmatize PLHA and their family members.

Family Members’ Association with PLHA

The major reason why family members of PLHA are stigmatized, even though they do not have HIV/AIDS, is because of their association with the PLHA. In one of the interviews, one PLHA’s sister explained why her friends avoided her.

Opokua: O yes, indeed, I know they feel like if people see them with me, they will categorize them in some way so they will rather avoid me to please people. But I am okay with it.

Gladys: But your sister doesn’t even live with you.

Opokua: Yes, but once it’s your sister, it’s everybody in your family, they think it’s in the bloodline.

Similarly, Daavi, Vickie’s mother said: *“I think they are afraid of the disease and maybe they think since my daughter has it I may also have it because I am the only one taking care of her.”* Faustie sarcastically puts it: *‘Well I am the one who takes care of him. I am his wife, so they assume that if he has, I have it too. I eat with him. We drink from the same cup, so I have it too. Up till now no one has visited us.’*

Summary

The concept, causes, impacts and gender differences of HIV/AIDS- related stigma is complex as seen from the results presented. The ideas, thoughts and beliefs about the phenomenon have been presented. The data reveal that responses to diagnosis are not very different for each participant and their family members. Usually disclosure of one’s serostatus is the beginning of their or their family members’ stigma experiences. Disclosure could be voluntary or involuntary, perceptible or third party disclosure. PLHA and their family members’ stigmatizing experiences are both covert and overt. Both PLHA and their family members find ways to cope with those experiences at home and within their communities. Participants provided the reasons for stigma being related to morality, fear, beliefs in the supernatural causes of HIV and the power of language. The major reason for family members being stigmatized even though they do not have HIV/AIDS is only by associating with the PLHA.

As seen from the data the impact HIV/AIDS has on both PLHA and their family members is tremendous. Be it personally, within the home, or outside of the home, participants socio-economic lives may change as a result of the diagnosis of HIV/AIDS of a person in their family. Many times, they lose their livelihoods, lose friends, lose their identity, lose their spouse or partners and the impact it has on their family relationship is huge. Both PLHA and their family members suffer these impacts and in many circumstances internalized their experiences. Apart from the negative impacts of HIV/AIDS related stigma, it also has its positive sides such as PLHA becoming independent, religious, and bringing the family together on the whole.

The differences between men and women regarding stigma experiences have also been presented. The data shows that women disclose their status more often than men do and they are more supportive of their spouses if they are the ones who have HIV/AIDS. However, most men neglect their wives when they learn of their diagnosis. Because of this some women who have HIV/AIDS (like Ida and Vickie) and are looking for partners, plan on using nondisclosure as a tool to avoid being stigmatized. Participants suggested both intervention and prevention strategies to deal with the issue of stigma associated with HIV/AIDS. These strategies are discussed as implications for practice.

Chapter 5 - Discussion

The purpose of this study was to examine the concepts and meaning of HIV-related stigma, factors influencing stigmatizing behaviors and how it impacts PLHA and their family members as well as their relationships in Ghana. The study also looked at some of the differences between men and women when they have HIV/AIDS as well as some of the strategies that can be used to prevent HIV-related stigma. This chapter will discuss the key findings of the study, present interpretations as well as the limitations of the study. It will conclude with implications, suggestions and recommendations for future research and practice.

This study employed ecological and symbolic theories to understand the concept and meaning of HIV/AIDS in the Ghana, some of the numerous challenges that both PLHA and their family members face, and how they live with those challenges in their daily lives. The study brought to light that the impact of HIV-related stigma could be problematic to the PLHA, their family members as well as to HIV/AIDS programming. The study also revealed that the differences in stigmatizing experiences between women and men when they have AIDS are intertwined with cultural norms relating to gender- role expectations.

Stigma as a Concept

Stigma is a complex phenomenon that is deeply intertwined with social values and beliefs, fears around disease and death, as well as gender and social inequity. It has been defined in many ways by different people (Gilmore & Somerville, 1994; Goffman, 1963; Parker & Aggleton, 2003). Stigma as defined by these scholars reflects a single concept: that, it is a negative concept with a resulting negative action. It generally comes from cultural stereotyping which develops into prejudices and then to emotional reaction. Overall the concept is applied in situations where labeling, separation, stereotyping, status loss and negative behaviors occur. One of the objectives for this study was to provide PLHA and their family members the chance to define stigma from their own perspective. This is because when perceptions of people are not recognized, misunderstandings of experiences may occur, leading to unsubstantiated assumptions. In other words if people are not given the chance to include their own perceptions and ideas in a given phenomenon, studies could only be conducted from the vantage point of theories that are not informed by the experiences of the people they study (Falobi, 2004).

According to SI, meaning is learned through social interaction and therefore “*people make value judgments about which symbols are positive or negative and react to them based on their values*” (Ingoldsby, Smith & Miller, 2004 p. 84). In this study, stigma was defined in terms of the negative feelings, actions and differential treatment that PLHA and their family members receive from other relatives and from the community at large. Betrayal, fear, death, disgrace, isolation, rejection, “something which is not good” and the “feeling of otherness” were how PLHA and their family members perceive stigma. These definitions are not different from those of scholars and researchers in terms of its content as they refer to negative behaviors and are in fact based on societal values which have been created through social interaction. When stigma is perceived as betrayal, isolation and rejection it is in fact, tied to the PLHA’s expectations of his/her family member. As family members, they are expected to keep PLHA’s serostatus as “secret” within the family or even to themselves. It is also expected that they will be supportive and protective of them. For PLHA, such unfulfilled expectations from the family members are a conduct of disloyalty to them as part of the family.

Stigma has been defined as a response to fear or risk or a threat of a disease that is incurable and potentially fatal (Gilmore & Somerville, 1994). This study reveals that participants perceive HIV/AIDS as “fear.” Fear is a result of misinformation and the nature of the disease. For instance, one of the family members said that “*it’s their way of showing how scared they are of the disease. Who knows, I may have done that to someone else if the doctor had not explained it to me,*” drawing from the concept that stigma originates from society and anybody can stigmatize given the circumstances. The origination of stigma from society explains why it is used as a mechanism to fit in society. When PLHA and their family members are rejected, it is the stigmatizers way of denouncing what society disapprove, hence making them fit and accepted in the society in which they live. At the same time, it is their way of taking precautionary measures against being stigmatized by association.

When participants described stigma as death it is symbolic in portraying the maltreatment they receive from other relatives or the community, which for them is equivalent to death. It is equivalent to death because they are treated as if they do not exist. Also, the meaning of death is their way of expressing that they cannot endure or even survive society’s behavior towards them.

It is apparent that many PLHA go through a process, from the initial feelings of shock, disbelief, grief sometimes accompanied by denial to an eventual acceptance and understanding

that after all they have a life to live for. Many of them even have thoughts of suicide. The study shows that many people's reaction or response to HIV/AIDS (disbelief, denial shock etc) is mainly related to cultural beliefs of right and wrong behavior and the fact that HIV/AIDS has been associated with "wrong behaviors." They were either in disbelief or did not want their family members to know that they were aware of their diagnosis. Because HIV/AIDS is associated with behaviors that come with negative responses in society (Aggleton, 2000; De Bryun, Milan, 2005; Ogden & Nyblade, 2005; Smart, 2005; Urwin, 1988), many people believe that if a person has HIV/AIDS then it was his or her own choice to engage in such "immoral behaviors" and therefore they must be held responsible. Participants in the study were in denial because they expressed differently how they were not involved in any of the perceived "improper behaviors." The 27 year old participant, Paul, expressed how shocked and surprised he was when he was diagnosed because according to him he has never been sexually involved with any woman. For him and his family his disease is attributed to a supernatural cause rather than a physical one but they have still been stigmatized because practically who makes the distinction between how one got infected? Undoubtedly some of the participants in the study did two or more HIV test even though they were aware of their positive diagnosis.

The separation of "them" and "us" enables people to deny that they personally are likely to be infected. When people are in denial that they can be infected, they may refuse to take precautions to prevent infection. For instance, even though Faustie was advised to ensure condom use with her husband she sometimes refused to do so. This is because she believes her husband does not belong to the group of people who indulge in "improper behaviors." Family members on the other hand also go through a similar process of anger, denial and disbelief to eventual understanding that there is hope. Some of them do well to protect PLHA from stigmatization by denying their serostatus when confronted.

As revealed by the study, HIV-related stigma begins with disclosure of one's serostatus. Disclosure usually takes the form of voluntary, compulsory, third party or implied. When PLHA's serostatus are revealed in any of these forms the ultimate result is stigma from the family, friends and the community. Voluntary disclosure is mostly to gain support, emotionally, physically and financially but depends in part on how PLHA perceive the reaction and response of the person being revealed to. Compulsory disclosure on the other hand also is for receiving ART. The question as to whether it is necessary to reveal one's status before they can be put on

medication is quite unanswerable. For the PLHA, it is a regulation that needs to be conformed to. Many health practitioners think that it is a way of letting the PLHA gain support from their family members and friends and a way of making sure that PLHA adhere to their otherwise expensive medications. It is difficult to come to terms with this “regulation” and many studies (as discussed in the literature review) have reported that it is a problem of confidentiality for the PLHA. This “regulation” is intertwined with both medical effects of the ART when used inconsistently, as well as cultural norms of the Ghanaian society and the negative image of HIV/AIDS.

Once started, it is necessary that antiretroviral treatment be taken every day for life. With every missed dose one increases the risk that the drugs will no longer work. It is therefore imperative that people receiving antiretroviral treatment get all the help they need to minimize the impact of side effects. Medical professionals therefore provided that “regulation” to ensure that PLHA adhere to their medications by involving their family members. Also there is the traditional belief among Ghanaians that “bad news” must be shared with the presence of another person, be it family members, friends etc. For instance when someone dies in a family and other relatives are been informed, it is only done in the presence of other family members with the idea that they can provide both immediate and long term support to the one who is affected. This is due in part of the characteristics of the Ghanaian culture which is “narrow socialization” (Arnett, 1995) or collectivistic in nature.

Narrow socialization holds “*obedience and conformity as the highest values and discourage[s] deviation from cultural expectations*” (Arnett, 1995 p. 617) and emphasize family and work group goals. In a collectivistic culture each person is encouraged to conform to society, to do what is best for the group but not to express opinions or beliefs that violate those conformities. Hence a right for the common good is a priority relative to that of the individual. In this kind of culture rules that promote stability, obedience, order and conforming to the society are requirements. Cooperating with others is the norm and therefore refusal to cooperate and wanting to be independent is frowned on. Simply put, everyone must rely on others for support. Because of this, matters concerning an individual does not mean, decisions must be made individually but it must include the family. Every decision that is made must be considerate of the repercussions on both individuals and family members. In many respects the consequences on the other person (be it friend, family member etc) must be the priority. Because of this belief

the family (be it nuclear or extended) is involved in the individual's "life" be it good or bad to make sure that the individual conform to the society's expectation. The involvement of relatives and family members in the diagnosis of HIV is seen as necessary in the Ghanaian culture. Regardless of the purpose and the objective of this "regulation" it is necessary to review it because in many situations it causes more harm than good and it does not work as PLHA do not inform their relatives, but bring other PLHA to serve as their guarantors. Ida revealed how she was not put on ART because of her mother's disapproval of her diagnosis. In my opinion waiting for a parent's approval or acceptance of her adult daughter's diagnosis before she is put on medication leaves much to be desired.

When family members, friends and health workers reveal PLHA's status to other people, it becomes problematic because then the whole community learns of their serostatus and stigmatizes them. Putatively, these groups of people, family, friends and health workers, are the trusted people in the PLHA's lives and so when they lose their trust it is betrayal for most PLHA even though some of them reveal the PLHA's status in order to "gather" sympathy for them. For health workers to reveal the status of their patients to other people, especially in the market place is an absolute breach of confidentiality and calls for attention.

Causes of HIV-Related Stigma in Ghana

As discussed in an earlier chapter tribal stigma associated with isolation and labeling has been part of the history of Ghana. HIV/AIDS has only built on a system that readily stigmatizes and discriminates as a way of preserving the norms of society when misconceptions prevail. In Ghana, certain illnesses and behaviors have usually been regarded as disgraceful and are therefore stigmatized. Diseases such as leprosy, mental illness, epilepsy, tuberculosis, sexually transmitted diseases are among those that have long been stigmatized. Particular behaviors such as prostitution, sex work or women having multiple partners are also considered disgraceful. Even though these prejudices have influenced HIV-related stigma there are many other factors which promote it. HIV/AIDS like many other stigmas may be attitudinal phenomenon with a cultural context to the stereotyping process (Falobi, 2004).

One of the premises of SI is that people's attitude towards situations or events are as a result of the meaning that, that the particular situation, event or thing has for them (Ingoldsby, Smith & Miller, 2004). The foundation for the reasons behind HIV/AIDS-related stigma is the

negative imagery surrounding HIV/AIDS. Evidenced from this study and the literature is the notion that HIV/AIDS is a symbol of moral impropriety, death, something that must be feared, a curse etc. Hence it must be feared and frowned on. This negative imagery has been perpetuated as a result of social interaction including the media. The attitudinal concept of the causes that emerged from this study were insufficient knowledge of HIV transmission, fear and misconceptions of the disease, cultural and religious beliefs. Also, the media as well as poverty has played a rather significant role in promoting the propagation of HIV-related stigma.

Studies have shown association between stigma and ignorance (Brown, Trujillo & Macintyre, 2001; MMWR weekly, 2000; Shapiro, 2005; Susenblick, 1988). It is often true that educational programs provide information on HIV/AIDS and AIDS transmission to communities and individual which show that people have some kind of knowledge about HIV/AIDS and its transmission. However, people still fear the disease. Evidence from this study is the complexity of the HIV-related stigma phenomenon and therefore understanding the possible factors that influence or causes stigmatizing behaviors is crucial in both intervention and prevention of the phenomenon.

Insufficient Knowledge of HIV transmission

Despite the effort of prevention and educational programs many people including PLHA (as in the case of this study) do not really understand the transmission of HIV/AIDS. Most people know some basic facts about the HIV and the transmission of the disease but many lack adequate information. An example from this study is when a PLHA, Yaa, was talking about how her sisters' relationship had changed towards her. She told her sister that: *“one day she may find herself in my situation because once they buy food from outside and eat they can as well be infected one day.”* Also, in one of her reactions to her husband's insults she said: *“if he said I am sick, he and our children are also sick because it is the two of us who gave birth to the kids.”* This illustrates how people, including HIV patients lack adequate and correct information about the transmission of the disease.

There is still much gap between what people hear in educational programs and what people actually do. Much needs to be done to ensure that people, including HIV/AIDS patients, understand what they hear from prevention and intervention programs and act on them.

Fear and Misconceptions

Fear and misconceptions also fuels stigma in Ghana. The misconceptions about the disease make people afraid of contracting the disease and dying. The media has played a significant role in this. Many people are often afraid of being identified as having led “inappropriate” lives, destroying the family’s reputation, losing their jobs, being rejected by their spouses and family members, losing their reputation and respect in the family, and being denied care and treatment. For many other PLHA, being considered an irresponsible person is enough to be afraid of.

The macrosystem refers to the larger cultural context within which a person lives (Bronfenbrenner, 1986). A person is therefore is influenced by the beliefs, norms and values of their society. The general belief that HIV is as a result of a lifestyle, which is not in conformity with the norms of society, promotes stigma. Sometimes this general belief is also shared by PLHA and their family members who are often stigmatized themselves. Even though one of the participants shared that his son (PLHA) has not led an “improper” lifestyle, when asked what he feels should be done, he suggested that people must change their lifestyle. This often stems from the fact that stigma is often created by society, a society which the “stigmatized” is part of and therefore share the same beliefs as the rest. Also the fear of death from a disease that is often incurable further reinforces stigmatizing those with HIV or suspected to have HIV.

Cultural and Religious Beliefs

Some traditional, cultural and religious beliefs have also influenced stigmatizing behaviors associated with HIV/AIDS. As discussed earlier, Ghanaians believe in supernatural causes of disease which predispose persons with HIV/AIDS to stigmatization (Senah, 1997; Wyllie, 1983; Awusabo-Asare & Anarfi, 1997; Warren, 1979). Diseases that results in deformity, or are contagious like leprosy, etc, are more likely to be classified as supernaturally or spiritually caused.

It is often believed that the disease is a punishment from a supernatural force as a result of a person’s sin. It is then considered as a curse or witchcraft except in cases where men have HIV as a result of having more than one sexual partner. Although a cultural perception such as witchcraft was identified as a cause of HIV/AIDS, it was not recognized as a basis for stigmatizing. In fact, where participants revealed that they or their family member’s serostatus

was believed to have caused by witchcraft, it is a way for individuals and family members to gain support from other family members and not to be stigmatized or to provide an explanation for the uncertainties surrounding how the person got the disease.

Also, the religious belief that HIV is a sin and punishment from God further creates a difference of “them” and “us.” Except in cases where the person is seen as an “upright” person, then the disease is seen as a result of envy. In this study, Paul and his family believed that his HIV was caused by witchcraft on the basis of envy because he has led a “good” life-never had sexual intercourse with a woman. Also he is a good boy who has not done anything wrong to anybody. His only “problem” is that he is hardworking and therefore envied.

Media Reports

For many Ghanaians the mass media has been an important source of information on HIV/AIDS since the emergence of the disease. Radio, TV and the print media are the major commercial mass media sources in Ghana. As they can be used to reach large groups of people, many organizations and agencies, (both government and nongovernment) involved in HIV/AIDS have made considerable use of the mass media for their educational campaigns against HIV/AIDS and to disseminate information about HIV/AIDS prevention. The uses of the commercial media as well as contents of educational campaigns have played a significant role in propagating HIV-related stigma.

Since the emergence of the HIV epidemic in Ghana both media commercials and educational campaigns reported negative information about HIV/AIDS, which has not helped in changing the misconceptions about HIV and reducing its related stigmas. For example, the early representations and metaphors of HIV/AIDS as a sexually transmitted disease rather than a viral communicable disease as with hepatitis B contributed to its stigmatization as an illness. As a result of this many people started discriminating against PLHA instead of fearing the virus itself. Sometimes the language of commercial media reporters is in fact a reflection of the attitude and prejudice of the reporter. Many journalists, radio and TV hosts use imagery that are in themselves very stigmatizing. For example, Ida recounted how a radio presenter compared sardines he bought to HIV patient. All of the participants in this study expressed that the TV commercials, contents of educational campaigns have created an environment in which people fed on their fears and misconceptions about HIV.

One of the powerful realities that this study reveals to me is how damaging the commercial media is to the knowledge about HIV/AIDS education. One of the main purposes for media programs for HIV/AIDS in Ghana was to educate people or make people have knowledge of HIV/AIDS, its transmission and prevention. However, methods that were used inadvertently led to stigmatizing behaviors from the public. During the data collecting I was astounded at what I realized about one of the participants. Daavi, whose daughter has been diagnosed with HIV/AIDS for the past eight years, is one of the many Ghanaians who do not have formal education, do not have TV and usually conforms to the old, traditional ways of getting information (through oral source and community meetings). She explained that there is no need to be afraid because her daughter's doctor had explained to her that, she will not die, that she can eat and do several things with her daughter but will not contract HIV. She explained vividly to me how HIV is contracted through fluids. For Daavi, her only source of information about HIV/AIDS is the doctor and that information is what she works with. I wondered what would have happened if she had also been influenced by the media. Thus although the purpose and objective of the educational campaigns on TV, radio and the print media is to prevent the spread of HIV, often times the content of the message creates fear in people which enables the stigmatizing behaviors.

Poverty

There are myriads of other structural issues that influence people's stigmatizing behaviors and enable gender differences in HIV-related stigma, including poverty. PLHA who have low socioeconomic status are neither able to pay for their medications even under the government subsidized rates nor eat well. When one is put on ART it is a necessity that they eat very well. These factors compel people to disclose their status and rely on family members, relatives and friends who most of the time stigmatize them and disclose their status to other people. Results from this study shows that women are often times the ones who reveal their status (because of their socioeconomic needs) more often than their male counterparts.

Several scholars have emphasized the relationship between gender and poverty (Nyblade et al., 2003, Ogden & Nyblade, 2003); including how poverty plays a role in driving people to disclose their status and depending on the rest of the family for support. Evidenced from this study is that most of the members of the Association of PLHA are women because they needed

all the help they could find. A primary factor contributing to women's poor socioeconomic status is lack of formal education. Reports (Seager, 2009) show that equal proportion of males (93%) and females (94%) enroll in basic primary education. However most females drop out of school and by the time they get to college, they make up only 34% of the population (Seager, 2009). Those who drop out are not able to pursue good paying jobs but work in the informal sector, mostly combining less lucrative jobs such as vending, dressmaking, and hair dressing with their domestic chores. Because of this, most Ghanaian women do not have economic independence and are compelled to rely on their husbands or other available resources. Therefore being diagnosed with HIV or other life threatening disease, compounded with abandonment from their husbands can be quite frustrating: hence the use of public or governmental assistance (which also means revealing one's status) is very common. Most men, or people who (usually have some kind of economic stability), are able to buy their medication without government assistance and therefore do not need to disclose their serostatus.

Poverty may also affect treatment for PLHA. For instance one of the participants expressed how hungry and weak she becomes after taking her medications, and so on days that she does not have money to buy food she skips her medications. This could be detrimental to her health as missed doses increase drug resistance. It is no doubt that if PLHA are economically empowered (as expressed by all participants in this study) and able to take care of themselves they can be less susceptible to HIV-related stigma.

HIV-related stigma has been known to be triggered by many factors, including insufficient knowledge about the transmission of the disease as well as the misconceptions and fear associated with a disease that is life threatening. Many people do not understand that HIV cannot be transmitted through everyday contact. Other factors such as the belief system, cultural values coupled with the long history of stigmatization among Ghanaians have also promoted the propagation of HIV-related stigma. In addition, irresponsible media reporting, as well as poverty are other factors that trigger HIV-related stigma.

Context and Impact of Stigma Expression Towards PLHA

Stigmatization is expressed in many forms in the Ghanaian society; it could be expressed overtly, subtly or it could be "felt" or enacted depending how it is approached. Whichever way one chooses to look at the expressions of stigma, the context within which it is perpetuated is

significant. Employing Ecological theory, the microsystem, mesosystem and macrosystem provided the structure for organizing this section to reflect the individual PLHA and their immediate environment and how they are impacted by their environment. Stigma and discrimination may occur at different levels of context. Varied contexts of stigma expression for PLHA were identified during this study: self stigma, the family, community, workplace, healthcare institutions and gender. Its impact on the PLHA are also discussed.

Self Stigma

One of the prevalent consequences of HIV- related stigma for PLHA is self stigma, also referred to as, “internalized stigma” or “felt stigma.” The *formation of self* as described earlier, is an important concept in SI which emphasizes that one develops a self-image through one’s reflection; which is the judgment and critique of others (White & Klein, 2002). As explained in previous chapters self-stigma occurs when a person imposes stigmatizing actions or behaviors on themselves: usually the feelings they hold about their condition and their reactions to others’ negative behaviors (Falobi, 2004; Ogden & Nyblade, 2005; UNAIDS, 2002). Individuals who stigmatize themselves are also part of the larger society who ascribe to the same cultural norms and values of society and therefore have the same ideology about HIV/AIDS. When they become the objects of hurtful and cruel actions from their communities, they usually react negatively with feelings of shame and guilt resulting in self isolation and sometimes depression.

Self-stigma is often expressed through depression, withdrawal and feelings of worthlessness, loss of hope, inferiority, and the belief that they no longer have a future (Falobi, 2004; Fife & Wright, 2000). The commonly expressed forms of self-stigma in this study are: loss of hope, feeling of worthlessness and sometimes suicidal thoughts. Withdrawal from social and family events was also expressed by PLHA. Self-stigma is more intense for individuals affected by HIV/AIDS in Ghana than in other societies. This is as a result of the collectivist nature of Ghanaian culture where individuals are defined as part of families rather than as independent identities. Self-stigma can persist for a long time if not for life and deplete the already weakened strength of individuals.

The Family

The family is the immediate environment that provides care and support for the PLHA. However, there are circumstances in which family members refuse to provide care for PLHA and

even isolate themselves from PLHA (Nyblade et al., 2003; Ogden & Nyblade, 2005; Parker & Aggleton, 2003). In this study, PLHA and family members had different opinions on acceptance and care for PLHA. All the family members in this study stated that they accepted the PLHA even though some of them had resentment and anger towards them. PLHA on the other hand expressed that they were initially accepted and cared for by family members but that support did not last. This conflicting claim can be explained by the fact that either family members unconsciously stigmatize PLHA or they do so knowingly, but refuse to admit because it is unacceptable to reject one's own family member.

Stigma expressed by family members towards PLHA was either open or private. With open rejection, family members made it known to the PLHA and the community about their anger and disapproval of their HIV diagnosis. Ida's mother for instance was not happy about her daughter's diagnosis and she made it known to her and the community. When rejection is private, family members often create an impression to the community that they are "normal" while they stigmatize PLHA within the home.

Findings from this study affirm earlier conclusions (Hong, Van Anh, & Ogden's 2004; Nyblade et al., 2003; Ogden & Nyblade, 2005; Okafor & Holder, 2004, Okafor, 2002) that PLHA may lose their social network, such as friends and family members. Lives in Africa and Ghana derive meaning from social interactions ranging from singing, dancing and hugging one another in the church, to social interaction in the market place (Okafor, 2004) as well as living with family members, eating together among other familial activities.

Within the family, husbands often abandon their wives or partners when they have HIV/AIDS (GSHRDC, 2009; Health and Development Networks, 2006; Ogden & Nyblade, 2005). Even though the story of only one participant from this study affirms this, all participants expressed that most men abandon their wives when they have HIV/AIDS. Often, the abandonment is accompanied by blame and accusations of infidelity especially if the other spouse (often the husband) tests negative. While these accusations may or may not be true, they are all linked to the association of HIV/AIDS to "improper behaviors."

It has been reported (Mbwambo, Kilonzo et al., 2004, in Ogden & Nyblade, 2005) that sometimes family members discourage and sanction PLHA not to bear children of their own because of their serostatus. From this study, even though family members did not sanction or prevent PLHA from having children, they questioned the chance of PLHA having children who

will not be infected. This is probably due to the fear of passing on one's HIV positive status to the unborn child and the lack of insufficient knowledge of mother to child transmission.

Family members often stigmatize because of the fear of transmission, or moral condemnation or even the of fear of experiencing the stigma from others (Ogden & Nyblade 2005). Firstly, the finding from this study confirms some of the known reasons for stigmatizing of PLHA by family members as fear of transmission and moral condemnation. Secondly, family members behave differently towards PLHA because of exhaustion from care giving, particularly as PLHA's illness advances and the burden of care becomes increasingly demanding. Thirdly, family members stigmatize due to role change within the family. In Ghanaian society individuals in the family have different roles. For example, a wife is expected to take care of her husband, children and the extended family while a husband provides the financial needs of the family. An adult child is expected to care for their parents and the elderly in the family. The diagnosis of HIV/AIDS changes some of these roles as family members take up new roles and responsibilities. Typically family members (usually parents) take up roles of caring for their adult children. This role change becomes difficult for family members and therefore they may refuse to provide care for PLHA. For some (especially men) taking up new roles and responsibility may not be an option, as they often abandon their wives.

Community

People living in the same communities share common beliefs and ideals, about HIV/AIDS which are usually passed on through generations. These beliefs are what perpetuate HIV-related stigma. The less supportive and stigmatizing attitudes towards PLHA held by people in the community is a product of exposure to a shared environment. Tackling HIV from the community level will play a significant role in the fight against HIV-related stigma.

Expressions of stigma from the community include avoiding relationship with PLHA, gossip, isolation, labeling, name calling and accusations of promiscuity and prostitution. Eviction from one's apartment or house is also common within the community. The main areas of this research are eviction from homes; loss of social network; verbal abuse such as gossip, labeling and insulting; and exclusion from community activities. Perhaps the gravest form of mockery is another stigmatizing experience from the community which involves mostly women. It is described by women as an increase in visits or proposals from men for dating where the specific

intent is to confirm the suspicions of the community of PLHA's diagnosis and report back to the community.

Social events such as funerals, naming ceremonies, and marriage ceremonies are important aspect of the Ghanaian culture. All community members are expected to participate in these events to celebrate and to mourn. Living without these social interactions often affect the individual, and for many living without it is not an option. Strong traditional ties are the main source of coping in any life event for Ghanaians and so being "out of touch" with the community members often has emotional effects on the PLHA. Many people withdraw from PLHA because of the fear of contracting the disease. In this regard PLHA do not reveal their serostatus to prevent been disconnected from their social network. In a phenomenological study (Okafor, 2002) done in Nigeria, one of the participants explained why she does not want to disclose her status:

The reason I cannot tell anybody that I have this disease is because I will be cut off from everybody, people will not even buy things from me in the market, and nobody will allow me to buy goods from them because they will not touch my money (Okafor, 2002).

In addition to losing their livelihood and social network, many PLHA lose their identity as they are usually labeled, given names and not respected in their communities. When people have HIV, they are called names, such "ashawo" (prostitutes), "tease awuo" (living dead) and from this study, they are called "Eight" or any number that adds up to the number eight (4+4, 7+1 etc) to reflect its close pronunciation to AIDS. Generally that is how they are "known" or called in public and in the communities in which they live. Being called other names may not sound as derogatory in other cultures as it is in the Ghanaian culture. This is because Ghanaian names are chosen carefully, they are all symbolic, they all have meanings or represent something or somebody and in fact they provide information as to which tribe or clan one belongs to. Labeling or calling someone a name that has a negative connotation other than their indigenous names are often not welcomed. Likewise labeling a whole family "HIV house" other than the name of the family is also unwelcoming and casts a negative reputation on the family.

Workplace

Stigmatization and discriminatory behaviors in the workplace as discussed in previous sections include pre-employment and on the job screening, and termination or refusal of jobs

because of one's serostatus (Falobi, 2004; Hong, Van Anh, & Ogden's, 2004; Ogden & Nyblade, 2005; Urwin, 1988). The main areas of stigma documented in the work place in this study include: job loss, mandatory HIV test before re-employment, decreased client base; gossip, avoiding contact with items that PLHA touch etc. Many PLHA also quit their jobs because of the numerous questions and accusations from the community. Job loss can be devastating especially for adult PLHA who are expected by the society to care for their extended family.

In Ghana, there are laws and regulations that protect HIV patients against discrimination of all kinds especially in the workplace. In general, the 1992 Constitution of Ghana, the labour law, 2003 (Act 651) and the International Labour Organization's code of practices, oblige all to respect the rights of all staff and the general public irrespective of their HIV/TB status. Chapter 5 Article 17 of the 1992 constitution guarantees the fundamental human rights and freedom for all persons in the country. According to this law (The Tripartite committee and Ghana AIDS commission, 2004), "*A person shall not be discriminated against, on grounds of gender, race, colour, ethnic origin, religion, creed, and social or economic status*" (p.5). Also Article 24 states that, "*every person has the right to work under satisfactory, safe and healthy conditions and shall receive equal pay for equal work without distinction of any kind*" (p.5). Specifically, the Ghana National Workplace HIV/AIDS policy states that HIV/TB testing should not be required at the time of recruitment or as a condition of continued employment. Therefore the denial of employment to HIV infected or affected persons constitute a breach of their fundamental human rights.

Many organizations, both governmental and private, are required to, and in fact, have launched HIV/TB workplace policies in their work places in Ghana, to educate, inform and communicate with staff and their families on issues related to their HIV status. However, in practice, the implementation of these policies and laws has been a challenge. Many organizations require HIV testing and will not employ HIV patients. Because most Ghanaians work in the informal sector it becomes even difficult as there are no proper rules governing workers in those areas. Many HIV patients accept their release from work without contesting and exercising their rights, because of the difficulty associated with the bureaucratic process as well as the financial drain. Already most PLHA and their family members have financial difficulty and do not have the excess money to engage in law suits.

Health Care Institutions

During the early period of the AIDS pandemic, there was a general resort to legislation, particularly in the developing countries, as a measure to protect the public against the disease. In the absence of successful behavior change or scientific intervention at that time, there was increasing pressure on public health officials to introduce legislation, which imposed coercive restrictions on the liberty, autonomy and privacy of PLHA. For instance the requirement that PLHA disclose their status to relatives as a requirement for treatment has in no doubt increased stigmatizing experiences for many PLHA. It should be noted that those regulations were put in place in order for PLHA to adhere to their expensive, subsidized medications, and to gain support emotionally, physically and financially from relatives. Also, it was implemented by the organizations of health workers to prevent PLHA from spreading the disease. However the disclosure of one's serostatus has become a challenge for PLHA and their family members. As a result of this many PLHA do not disclose their status to the family members or friends to receive treatment. In fact they prefer to bring other PLHA who know of their status to clinics and hospitals who then serve as guarantors in order to receive the ART treatments. Unfortunately, in Ghana there is no way to check whether the so called "relative" is in fact a relative who lives at home with the PLHA. The review of the regulation is therefore imperative since its objectives are not being met.

Many times, health care workers do not inform PLHA of the kind of testing they recommend. All participants in this study recounted that they were not informed of the kind of test recommended by the doctors. This is a breach of privacy. However, most health workers are of the view that when the patients are informed of the test, they will neither go ahead with the test nor go for the results because of stigma and social repercussions. Thus confirms what earlier studies (Kalichman & Simbayi, 2003; Ogden and Nyblade, 2005) have shown: the social stigma associated with HIV/AIDS might be a more powerful deterrent to testing than attitude towards the disease itself. Some healthcare workers also deny care and treatment of PLHA and disclose their status to the community. For example when the health care provider who gave Vickie shots for her tuberculosis heard that she had HIV, he refused to go ahead with the shots. In such a situation the PLHA had to deny her serostatus in order to receive care and treatment.

Many health workers abuse their authority and violate the privacy and autonomy of PLHA by informing other people about PLHA's serostatus. In this study one of the PLHA, Ida,

described how a nurse in the doctor's office disclosed her status to the community, in the market place. Such behaviors are appalling and such professionals should be sanctioned.

Gender

Actually, women are the most affected by stigma in the community. Ghanaian culture and value system as discussed in previous chapters increases women's vulnerability. The perception that women are the direct transmitters of sexually transmitted diseases (STIs) influences the way people behave towards women with HIV/AIDS. Even though most PLHA, especially men receive care and support from their wives and other family members, many women are ill treated by their husbands when they have HIV/AIDS. Most participants in this study expressed that women experience more stigma than men with AIDS.

For many Ghanaian women stigma related to HIV/AIDS is an addition to already existing stigmas. For instance most women are marginalized for being women. Regardless of HIV, women are considered to be of lower social status and are often marginalized relative to men in the family and the community. In fact they receive the harshest insults as a result of their diagnosis and receive additional stigmas when HIV is involved. One of the female participants explained that her diagnosis resulted in a divorce. In the Ghanaian context her stigma experience is multi-layered because she is a woman and has HIV, which means she is a prostitute, she was rejected by her husband, which means she has failed as a "proper" woman.

Regarding gender and HIV/AIDS in Ghana, there exists a fundamental double-standard. Men are generally expected to have multiple partners, be reckless, adventurous making them more likely be exposed to a whole host of STIs including HIV. Women and on the other hand, are expected to be sexually faithful, proper, and not engage in any "improper" behaviors. Consequently, women are the ones who are blamed and rejected more than men.

Gender- role expectation also explains why women received blame more than men. Generally, women are the care-givers in the society, caring for their husbands, children, the old and the sick. For married couples HIV present a shift from women as care givers to women as care receivers. Because of the demanding nature of the disease and the effect of the medications women are not able to execute their domestic duties or their normal active life. Most men whose wives have HIV would rather find other women to fill that gap.

A significant aspect of gender related stigma is the issue surrounding disclosure of PLHA's serostatus. Many PLHA feel obligated to disclose their status to their aspiring partners or spouses. However it is widely known that women are more likely to disclose their status to their partners even before marriage, whereas men conceal their status, get married, infect their wives and sometimes even turn around to blame their wives. A typical example of such story is about a woman in the US who appeared on the *Oprah Winfrey* show recently. Bridget married a man who had HIV but never disclosed it to her. Then she became sick and went to see her husband's doctor. Bridget requested to be tested for 'everything'. The results showed that she was HIV positive. When she informed her husband, he was neither upset nor angry. The husband went to test and his results came back positive. Bridget's husband and his doctor blamed her for infecting her husband. She lived with that guilt for two years before she found out that it was rather the husband who infected her with the disease. She apparently sued him for \$12.5 million. Bridget's story is one in many cases where women are sometimes falsely blamed and accused of "bringing HIV home" to their husbands, who eventually abandon them. Thus in theory, even though women and men have a potential of being deserted by their partners, in practice women are often the ones who are abandoned.

A recent study in Ghana (Ulasi et al., 2009) found that males were more likely to be in favor of disclosure of HIV positive status than females. The study confirmed that about 86% of the participants had not been tested for HIV, or knew their status. The findings of the study contradict the actual disclosure between men and women which is that women disclose their status more than men: the reason behind women experiencing more stigma than men. Thus even though men favor the idea of disclosing one's serostatus than women do, in practice women are the ones who disclose their status more often. Participants in the current study expressed that women are the ones who experience more stigma than men, because they disclose their status more often than men. The females explained that they usually need support especially financial support that is why they disclose their status. However, their male counterparts, do not disclose their status because they have the economic means to afford their medications. Hence there is a relationship between gender and poverty with regards to HIV-related stigma which has been discussed under the factors that influence stigma.

Evidence of stigma from this study is the issue of violence against women followed by abandonment and neglect. Even though there are laws and regulations that protect women

against discrimination and domestic violence, often times the implementation of these laws have not been successful. The Domestic Violence and Victims Support law was passed in 2007 in order to bring to justice the perpetrators of domestic violence. However, most women who are abused hesitate or are not able to press charges against their abusers or take them to court. This stems from the fear of divorce and its repercussions and the fact that most women are economically dependent on their abusers. When abusers (usually men) are taken to court, most of them end up abandoning their spouses and refuse to support the children. Therefore most Ghanaian women stay in abusive relationships, which make them more vulnerable to HIV/AIDS and its related stigma.

In sum, the cultural values, and norms set by the larger society are the same values that exist within the PLHA's family, workplace and health care institutions hence PLHA experience stigma in those contexts. This confirms the concept of Ecological theory (Bronfenbrenner, 1986) that principles defined by the macrosystem have a cascading influence throughout the interactions of other systems such as the microsystem and the mesosystem.

Effect of Stigma on Family Members of PLHA

In a phenomenological study of PLHA in Nigeria (Okafor, 2002), a participant recounted her stigmatizing experience as worst than leprosy of the biblical time. She felt guilty of giving the disease to others and ashamed of imparting disgrace on the family name. She was particularly concerned that her sisters may never marry and that the whole community would feel disgraced and betrayed by her. The participant's concerns illuminate the impact of HIV/AIDS related stigma on family members of the PLHA even though they may not be HIV positive. One of the major purposes of this study was to inquire about how HIV-related stigma is experienced by family members of PLHA which has otherwise been given little attention in the Ghanaian literature. The study found that family members were stigmatized because of their association with the PLHA. Because Ghanaian culture is collectivistic, individuals are defined as part of a group. A HIV/AIDS diagnosis negatively reflects on the group (in this case the family) and not only on the individual. In Ghana, family members are considered ultimately responsible for the behavior of individuals and the family. Stigma as experienced by family members of PLHA is therefore attributed to collectivist nature of Ghanaian culture. While there are many similarities

regarding stigma experiences for PLHA and their family members, there are few areas that are distinct.

Studies (Van Anh & Ogden's 2004; Ogden & Nyblade, 2005; Nyblade et al., 2003) show that although family members do not have HIV/AIDS they experience similar forms of stigma such as losing their respect and identity, their jobs and friends. The finding from this study confirms this conclusion. For instance, a family in this study was labeled "HIV house." (In this case "house" has been used symbolically for family). Also, family members were denied employment, experienced decrease in client base and lost their friends because of the serostatus of their relative. Losing a job or being denied a job because of a relative's diagnosis can be as devastating to the family member as it is for the PLHA.

One of the profound experiences of HIV-related stigma for family members which has not been otherwise reported in the literature is loss of partner. One of the PLHA described how her sister did not have a steady relationship because of her diagnosis. It is surprising and unthinkable to abandon a relationship because of a person's relative's serostatus. This could probably be explained by the "collectivist" nature of Ghanaian culture. Thus when a person is diagnosed with HIV/AIDS there is a sense of transference of HIV-positive status (and the "immoral" behaviors assumed to have caused it) to the entire family (Ogden & Nyblade, 2005; Nyblade et al. 2003). One of the participants in this study stated that "*once it's your sister, it's everybody in your family: they think it's in the bloodline.*" While this statement is symbolic of the fact that what is experienced by PLHA is also experienced by family members, it also presents a literal meaning of the insufficient knowledge surrounding HIV/AIDS transmission as well as how people perceive HIV/AIDS as a family disease in the Ghanaian context.

Internalized stigma is a form of stigma that is experienced by many PLHA as well as their family members. In Nyblade et al.'s study (2004), family children often stigmatize themselves and blame themselves for the death of their HIV positive parents. While children were not included in this study, one of the parents described how her children internalize the experiences of isolation from friends and other relatives. Many of the participants also shared that they isolate themselves from social events, friends just like PLHA. It should be noted that internalized stigma was profound for family members who "accepted" and supported PLHA, thus the idea of *we are in this together* is possible. One of the family members, who openly

expressed anger towards her daughter for her diagnosis, reported that she did not experience self stigma. Putatively, this could mean her conformity to society's negative attitude toward PLHA.

Perhaps the major difference of self-stigma between family members and PLHA as identified in this study, has to do with thoughts of suicide and the feeling of worthlessness. While PLHA expressed that they thought of committing suicide, none of the family members expressed such thoughts. Also, none of the family members expressed that they felt worthless or wished they were dead. Thus, although PLHA and family members experience similar kinds of stigma, it is more intense for PLHA than family members. It is quite understandable since PLHA are the ones who have the virus.

Family members in this study did not experience blame for their lack of vigilance and engagement as a result of their child's serostatus, as shown in the literature. However, family members revealed the potential for parental blame. Non disclosure of PLHA's status was a means to prevent such parental blame.

Many of the family members however, did not inform PLHA of their stigma experiences as they saw it as unnecessary. However, their experiences of stigma by association often have tremendous impact on their relationship with the PLHA. For instance Opokua expressed that her sister was not aware of how she has been denied work. Although she feels it was not necessary to inform her sister, she sometimes gets angry at her sister for her diagnosis. Another probable factor that may have contributed to family members' nondisclosure of their experiences is that they did not want to compound the burden of the PLHA's stigmatizing experiences.

Because family members experience stigma even though they do not have HIV, they sometimes encourage relatives with HIV/AIDS to conceal their HIV status (as in the case of Paul) to prevent the resulting labeling, gossip, social rejection etc. In some cases, family members isolate relatives with HIV (as in the case of Faustie and her husband Yebson) to minimize social contact and prevent stigma. These measures are also ways for family members to prevent being stigmatized even though they do not have HIV/AIDS. The perceptions and experiences of family members with regards to HIV-related stigma are therefore important in designing stigma averting interventions and educational programs.

Significant to Ecological theory is the principle that individuals do not live in isolation but are influenced by their environment. The theory also emphasizes a bidirectional relationship. The stigma experiences of family members of PLHA authenticate this assumption. Thus even

though family members of PLHA do not have HIV/AIDS, they experience stigma because of their association with PLHA. Hence HIV-related stigma does not only impact the PLHA but it also impacts their family members.

Impact of Stigma on HIV/AIDS programs

Probably the most profound consequence HIV-related stigma has on the community level is its impact on the activities to mitigate HIV/AIDS. One of the participants' in this study expounded on that:

I have met many men who have the disease but their wives are still with them so why do the men leave if it is the women who have it. Right now the government is trying to prevent the spread of the disease but the truth is if there are no measures to make the men be responsible for their wives and children it is not going to work. Imagine that if I was not working, and my husband left me, what will happen, I can go and find other men to take care of me and be spreading the disease. (Yaa, PLHA).

There are many factors that undermine HIV programs and enable the spread of HIV. It has been reported that HIV-related stigma inhibit people from testing and even participating in HIV prevention programs (Brimlow, Cook, & Seaton, 2003; Brown, Trujillo & Macintyre, 2001; ICRW, 2006; Mahendra, et al., 2006; Parker & Aggleton, 2002) and so there is the need to work towards curtailing the negative consequences of the phenomenon. Evidence from this study is that many people refuse to test for HIV because of the fear of testing positive and its consequential stigma. According to Paul's parents they have had enough with their son's diagnosis and therefore will not test for HIV. Many people like Paul's family are afraid of finding out about their serostatus because of its associated stigma. This however does not help prevention or intervention programs for HIV/AIDS.

Also, in some societies, stigma has been shown to be associated with delays in HIV testing and even when people get tested, they do not return for the results (ICRW, 2006) because of the fear of testing positive and its resulting stigma. Because of this and the impact it has on the spread of HIV/AIDS, many healthcare workers in Ghana do not inform PLHA when they are being tested for HIV as revealed in this study. Although the objective of this is to slow the spread of HIV in some way, the failure to inform people of what they are being tested for is in fact a violation of basic human right for PLHA and needs to be addressed.

Although studies show that stigma often prevent PLHA from receiving treatments (Brimlow, Cook, & Seaton, 2003; Brown, Trujillo & Macintyre, 2001; ICRW, 2006; Mahendra, et al., 2006; Parker & Aggleton, 2002), this current study found that in fact Ghanaians participate in treatment programs except in cases where they are not able to afford. For many Ghanaians suffering from HIV/AIDS, ART has played an important role in their lives, helping them come back to their “normalcy” and therefore concealing their diagnosis and preventing them from stigma.

Disclosure often results in stigmatization and therefore many PLHA and family members conceal the serostatus of PLHA. From this study, while some women were ready to disclose their status to their future partners, others were not prepared to do that. For instance Vickie said: “*For me if I meet someone who wants to marry me, I will never tell him of my condition.*” While this may be a way for PLHA to avoid being stigmatized, non disclosure may result in the spread of HIV thus diminishing the objectives of HIV education. Many PLHA who relocate do not disclose their serostatus in their new community. Most of them marry and have children, a behavior which increases the spread of the disease. But how do we keep track of such people? Unfortunately in Ghana, there is no proper record keeping on individuals and so there is no way of tracking PLHA who may relocate. There remains so much to be done in finding a balance between disclosure and nondisclosure, to minimize the experience of stigma as well encouraging people to disclose their status.

The moral dimension of HIV/AIDS which seems to separate “them” from “us,” may prevent people from taking precautionary measures. For instance, even though Faustie was counseled to ensure condom use to prevent her from contradicting the disease from her husband, she seemed adamant. She does not believe her husband’s diagnosis is HIV because according to her, he had not engaged in any of the so called “promiscuous” life. Related to moral dimension is the disbelief in discordant situations and the belief in witchcraft as a cause of HIV/AIDS. The perception that Faustie and her husband married for over 16 years but she and her children tested negative to HIV, further reinforced the denial of her husband’s diagnosis.

Many PLHA find ways to by-pass the “regulation” that has been set as requirement for ART because of the associated stigma that comes with the “regulation.” Even when they are required to bring relatives to the hospital to guarantee their medication, they bring other PLHA

who are aware of their serostatus. One of the objectives of the “regulation” which is to inform other relatives, who will then hold PLHA accountable for spreading HIV, is defeated.

Coping with HIV-related Stigma and Positive Impacts

Many PLHA and their family members use different methods and strategies for coping with their experiences. While some cope by disclosing their status to get support from their family members, friends, colleagues, others cope by choosing to conceal or deny their serostatus. Family members also do likewise, they either disclose their relative’s status to other family members or friends to gain or gather support for them. On the other hand they may choose to conceal or deny the status of their relatives. Whichever strategy the PLHA or family members choose depends on how they feel the PLHA’s serostatus may be welcomed and the repudiation which will be experienced by the family as a whole.

Some PLHA join associations and area networks or support groups where they feel belonging and share their similar stories. Coping with HIV also means being able to gain support especially financial support from these networks and support groups. Most associations, depending on the district, provide ART for their members at a further subsidized cost. Because membership of the associations is not mandatory, many PLHA who have high economic status do not participate in social network programs, thus minimizing their susceptibility to stigmatization. ART has been a great mechanism of coping for the PLHA as they are able to conceal their status, confounding the thoughts of the public. One participant expressed that her fear is being bedridden and not being able to work and care for her children and so she literally runs to the clinic every time she is sick.

Nondisclosure and relocation are other strategies used by both PLHA and their family members to cope with the harsh treatment from the rest of the family or the community within which they live. Relocation is a freedom and having “a fresh start” of their lives as no one is aware of their status or relative’s status in the new place. When relocated, PLHA and their family members are able to find jobs, participate in social events and make friends which otherwise is not possible in their old communities. One explanation that many PLHA and their family members (evidenced in this study) provide for HIV diagnosis, is witchcraft. An explanation of witchcraft provides some measure of protection against stigma, as the cause of infection is now outside the control of the individual. This explanation usually offers hope for cure. These coping

strategies do not inevitably contribute to the broader aim of reducing the spread of HIV. However, they are the PLHA's and family members' defense mechanism against stigma. And some may provide a good basis on which to build programs to enhance skills to challenge stigma.

Ironically, the mechanisms that help PLHA to cope or strategies that people utilize to cope with their diagnosis are the same medium through which they are stigmatized. In this study most participants depended on their family and some colleagues for support, however some of these friends and family members are the same people who disclose PLHA's serostatus and often stigmatize them too. Healthcare personnel who otherwise provide counseling for PLHA are also the same people who sometimes disclose PLHA's serostatus to the public. Interaction with area network and support groups also makes it possible for PLHA's serostatus to be known. Being put on ART, which is a way that many PLHA cope, also means disclosing one's status to at least one person of the family, who in turn may reveal "the news" to other family members.

In spite of all the shortfalls of coping mechanisms and strategies as well as the negative experiences they have, PLHA and their family members acknowledged that they have been positively impacted in their individual and family lives. For most individuals, having HIV/AIDS make them realize the positive aspects of individualism, being independent and self reliant. They realize that they can only rely on themselves for their "new life."

Being individualistic in a culture that is predominantly collectivist is often tough but most PLHA and their family members survive. For some, this calls for bonding with their nuclear family as in the case of Yebson's family, or even relying on themselves as in the case of Yaa and Ida. Most of them find strength within their already "weakened strength" and take consolation in the fact that after all having diagnosis does not mean "dying the next day." For some, it is the recognition that they must answer to a higher authority (often supernatural: God), where they find happiness and strength. Most participants said they participate in religious activities more than traditional social events. Also, the realization that a person's diagnosis has enhanced the relationship they had with the rest of the family members is a positive impact. For some families nothing has changed and for others togetherness and respect are new ingredients in their marriage and families.

Strengths and Limitations of study

A major strength of this study is its contribution to the literature with a special focus on the Ghanaian context, specifically considering the ideas and perspectives of not only PLHA but their family members too. Studies in the area of HIV-related stigma have focused on the individual experiences without paying much attention to the ecological context within which those experiences take place. Thus this study confirms Becker's (1992) argument that "*to understand people, we must understand their contexts- the worlds or situations in which they live. To separate person and world is false; to be a person is to be in a world*" (p. 13).

The meaning of stigma from scholars are very important in serving as the basis for reference, however the meaning as expressed by those who experience it is equally important, if not more important. Thus one of the strengths that this study highlights is the shared meaning of stigma. Being informed of the "stigmatizees'" own experiences provided understanding of those experiences which in turn enables substantiated assumptions, which is significant for both research and practice. Of utmost importance to the meaning and experiences of stigma are the factors that are responsible for those actions. I share a general principle that if a person wants to offer help to an individual or group of people get out of a problem, s/he can only do so appropriately and effectively by understanding the reasons for the problem. This study has brought to light some of the complexities surrounding why people stigmatize in our society. Therefore, the next step forward would be how to tackle those factors.

The use of qualitative method further enhanced the strengths of the study. Qualitative methods of inquiry provide an in depth, detailed information of a phenomenon as opposed to quantitative methods which use large scale surveys and instruments. One of the advantages of qualitative methods of data gathering is the ability to use the indigenous language of the participants instead of using surveys which are usually standardized in languages other than the primary language of the participants being studied. In this study participants felt comfortable especially knowing that they are free to express themselves in any of their languages.

There were, however, a few setbacks during the recruitment phase of the study. There was general reluctance of PLHA to include their family members in the study either because most of their family members were not aware of their status or do not approve of their status. This is seen from a couple of interviews that were rescheduled several times and later cancelled. Data was primarily gathered from family members who supported PLHA as those who did not

approve of their relative's diagnosis refused to share their stigmatizing experiences. One of the family members who did not approve of her daughter's diagnosis chose not to answer all the questions.

This study is also limited by the small sample size, restriction of sample to the Eastern region, the use of discordant families and only members of the PLHA associations. These factors may limit generalization. However most of the participants in the study were not originally from the Eastern region, and in addition to the homogenous nature of beliefs about issues relating to morality and sexuality in Ghana, inferences could be made from this study that many PLHA and their family members, given the same or similar socio economic status, experience similar kinds of stigma. Further research which will take all these factors into consideration is needed.

Implications of Findings

Findings from this study have provided a philosophical understanding of the concept of HIV-related stigma in the Ghanaian context as well as some of the experiences from both PLHA and their family members. Of utmost significance to the issue of HIV-related phenomenon are the factors influencing it, and its impact on PLHA and their family members. The strength of this study is that the issue of HIV-related stigma occurs in a much broader context/environment than one can imagine. Ecological and symbolic factors weigh heavily on the expressions of stigma related to HIV/AIDS. In addition there are differences in gender regarding how HIV-related stigma is experienced in the Ghanaian context. These differences are as a result of cultural norms and expectations regarding gender roles.

The findings from this study elucidate the complexities of HIV-related stigma as a phenomenon, the challenge and dilemma it poses to professionals working in the field. There are many issues that arise in the area of research, intervention, prevention, and policy with the phenomenon. Some of the many questions that arise from these issues have to do with disclosure, counseling and educating discordant families, gender disparities, beliefs about HIV/AIDS, etc. As I analyze the data, I asked myself several questions, such as: How do we encourage people to disclose their serostatus to their partners without breaching their privacy and without being stigmatized? How do we make men responsible and take care of their ailing wives and children when policies that address those issues don't work? How do we explain to people that HIV does not necessarily mean having multiple partners and at same time how do we

prevent people having multiple partners? What ways can be used to test HIV/AIDS without violating people's privacy? How do we encourage women to stand up for themselves in the midst of HIV/AIDS and domestic violence? In general how do we prevent people from stigmatizing? All these questions and concerns prove the implication of these findings for research, intervention and prevention.

Implication for Future Research

One of the major limitations of the study was the sample. The participants for this study were recruited from the associations of PLHA in Ghana specifically in the Eastern Region. Including sample from outside the Associations can provide differing perspectives about stigma. Questions like whether they disclose their status to friends and relatives and how they cope with their diagnosis could provide valuable information. It is known that most PLHA who join the association, do so to get support, emotionally and financially to be able to pay for their medications. It is no doubt that the participants of this study were from low socioeconomic backgrounds and therefore the data captured the experiences and understanding of stigma from their perspectives which may not be a generalized reflection of the general population. While participants had opinions about those who can afford their medications and therefore do not join the association, data were not gathered from those groups of people. In their positions as leaders or "wealthy," these groups of people influence social norms and their actions can either ease or enable stigma. Further research is required into how socioeconomic status may impact stigma in the Ghanaian context. A focus on the rest of the HIV population who are wealthy will be a good sample to study, to inquire about their stigmatizing experiences if there are any at all.

A further research to include family members who have HIV/AIDS would also be interesting to inquire if they might bring a different perspective to the issue of HIV-related stigma. This study was only able to recruit discordant family members or family members who have not tested for the disease. Research show children of PLHA bear the worst brunt of stigma, sometimes being denied a place in school or rejected (Ogden & Nyblade, 2005). Including children of PLHA can also throw more light on the impact of the phenomenon on children.

This study also had a special focus on gender and the differences of stigma experiences between women and men when they have HIV. This research highlighted some of the differences and possible factors influencing it. However a larger sample size of both women and

men could further provide valuable information and more insights into the phenomenon. The relationship between gender, poverty and HIV could further be explored. Inquiring more about whether women who have HIV/AIDS (and are economically independent) are abandoned by their husbands for example.

Although there are men having sex with men (MSM) in Ghana, there are no working documents in Ghana on them. Known gay websites reports (Attipoe, 2004; Prince, 2004) show that there many MSM in Ghana for economic reasons. However both national and international working reports, advocacy materials (like the Ghana HIV/AIDS strategic framework) fail to identify MSM as a potential mode of transmission of HIV. Studies that inquire into HIV/AIDS among MSM is also an area that needs research in Ghana. It will be enlightening to inquire the relationship between their stigmatizing experiences (if any) and that of heterosexuals in Ghana.

Finally, Ghana has prospects to curb the spread of HIV/AIDS and to mitigate the impact of the epidemic. There has been considerable political commitment over the years, and government have moved to create the National Strategic Framework through multi-sector collaborations. In addition, there are established organizations, at the governmental and nongovernmental level (such as Ghana AIDS Commission, National AIDS Control Programme, Ministry of Youth and education, NGO/CBO) to provide leadership over coordination of the national response. With the decentralized system of government, Ghana also has the prospects to operationalize HIV/AIDS response strategies at the community and grassroots levels. However, these strategies and activities of these organizations or institutions are not always evaluated, creating the absence of information on intervention and educational evaluations hence making it difficult to determine the true impact of prevention and intervention programs. Evaluation research is therefore necessary in assessing the contributions of various strategies and programs relating to HIV/AIDS and its related stigma, as well as where they need to be improved upon. Evaluation and monitoring structures can follow up on trends in the area of stigma throughout the implementation stages. When the levels and forms of stigma are considered throughout the response to the epidemic, the chances of understanding these social constructs would improve resulting in the ability to counteract them.

Implication for Intervention

PLHA and family members presented different intervention strategies and techniques, to handle the issue of HIV-related stigma. Some of those interventions could also be used as prevention strategies. Thus professionals can design intervention programs that support PLHA as well as educate family members and the community on HIV/AIDS, its transmission and its related stigma.

One approach that participants suggested is the house-to-house intervention support. Involving home-care visitors, “friends,” training them on hands-on support techniques help both PLHA and their family members. Yaa described:

I think it works. So if the government can employ people to do that, go from house to house to teach people about the disease, it will help a lot. And those of us who have the disease we should also be visited so that our families and friends who know we have the disease will know that we haven't been left out and that we also have important people in our lives.

This intensive face-to-face contact may provide support for the PLHA, reduce the isolation and withdrawal of PLHA and limit the stigma and discrimination that often result from fears of close contact. At the same time, it could stimulate reflection of vulnerability and risk, compelling home-visitors to confront HIV as a problem that affects their families and communities. This realization through- action could reinforce messages of precaution in a way that education alone cannot. Similarly, Leticia affirmed that more house-to-house education is needed: “*like you have done with me today. Some of us don't really know much about the disease.*” Contact has been shown to result in significant improvements in people's attitude as it provides the tendency to interact on a daily basis with PLHA. This creates familiarity which in turn confounds people's thoughts about HIV/AIDS resulting in less prejudice. When contact is maintained over time behavior may change (Falobi, 2004).

There is also the need to empower PLHA as well as their family members to stand up for their rights. Often times when issues related to HIV-related stigma are been discussed, PLHA and their family members are portrayed as helpless victims. In a way this could heighten some of the features that form stereotypes about PLHA and their family members. Intervention programs that include empowerment can increase the self esteem of individuals to have positive beliefs and

hope about their future. This will go a long way to encourage PLHA and family members to advocate for themselves.

It is imperative that health workers, area workers, social workers who also provide counseling for PLHA, exercise caution when counseling. It's been acknowledged that stigma is a social problem that needs to be addressed within the context of society. This may involve PLHA having to disclose their serostatus. Even though disclosure may provide a sense of empowerment, it promotes the propagation of stigma. Health workers and area workers should therefore make an effort to weigh the advantages and disadvantages of making a decision to disclose one's status with PLHA

Economic empowerment of PLHA (especially women) and their family members who are stigmatized, is a major intervention that needs to be embarked on. The findings from this study indicate that financial difficulties are major issues for both PLHA and their family members as they lose their livelihoods and spend so much on care and treatment. Most participants expressed that they need support from the government. Many PLHA believe that if they gain financial support from the government, they would be able to take care of themselves and become less susceptible to stigma. Both government and non-government agencies can provide micro-financing programs for PLHA and if necessary their family members to assist in establishing themselves financially. Yaa narrated that:

I know that some of the AIDS patients do not practice very good hygiene and so people look at them in a different way. But it all boils down to the financial difficulties, if they have money they will take care of themselves very well. So if the government can help us by giving us some money to start trade, that will be very helpful. Because our family members betray us too much but if we have money and are not dependent on them, that will not happen but they will see us and regret.

Similarly, Paul expressed that money is their biggest issue: *“Oh I think money is the biggest issue. If the government can give out loans to us to trade, then we wouldn't have to rely on many people.”*

Government support may also be in the form of help for PLHA and their family members to find jobs: Opokua, Yaa's sister, who was refused to sell food at an institutional canteen shared that: *“I also think the government should help PLHA and their families,*

especially those like us who can't get a job because of our situation.” Participants felt it was time for the government to step up to take some kind of action to help married couples, especially discordant couples otherwise its efforts to fight HIV/AIDS will be fruitless.

Participants further suggested that intensive education and counsel is required for men to be responsible and stay with their wives: Yaa said:

Well I think the men should be educated very well, that if their wives have this disease they should stay with them. I have met many men who have the disease but their wives are still with them. So why do the men leave if it is the women who have it? Right now the government is trying to prevent the spread of the disease, but the truth is if there are no measures to make the men be responsible for their wives and children it is not going to work. Imagine that if I was not working, and my husband left me. What will happen? I can go and find other men to take care of me and be spreading the disease.

Implication for Family Life Education Practice

Although there are complexities surrounding the issue of HIV-related stigma, the findings of this study can be utilized by family life educators in designing programs not only for PLHA and their families but also the communities at large. As educators, professionals and NGOs continue to design programs for families in Ghana; there is the need to examine the ideas about the characteristics of the cultures within which the programs will be implemented. For instance, it was clear from this study that an individual from a culture that holds collectivist values is compelled to conform to societal expectations and beliefs of the group. Therefore, it is important for program developers and educators, and a host of professionals in the area of family life education be aware of the ecological context of stigma. Participants in this study strongly recommended that more needs to be done about HIV educational programs and the media to prevent HIV- related stigma in Ghana. In particular, educational programs and media platitudes need to be revised. Also, professionals and organizations need to define their purpose clearly and the context of HIV-related stigma education should not be limited to one context.

Educational Programs

Participants in this study specified the need to intensify public education on HIV/AIDS.

Ida said:

Right now my suggestion will be that you intensify public education. If it's possible there should be a program everyday about this disease, because I believe that in the early times when the disease came, the way people died from it and the symptoms they had, have really scared the public. So things should change.

Specific public education could be house-to-house education to give general information on HIV/AIDS. Yaa recalled that the government used to do that and it was effective:

Gladys: So how does it work, because your mother knows about your status but your father does not know. So what do your "visitors" talk about to them?

Yaa: they give us general information about the disease. When they come, they disguise themselves as my friends and then they come to talk to us and the family about the disease, so my family learns so much from those sessions.

Although this house-to-house education is an intervention for PLHA, its preventative power cannot be underestimated because the entire household (including those who are not aware of the PLHA's status) are involved.

Furthermore, educational content and messages need to be revised. Findings from this study indicate that many people worry about HIV transmission through casual encounters in their daily lives. These speculative fears clearly suggest that ambiguous (and often negative) information contained in HIV -related educational programs can have inadvertent, and usually undesirable, consequences. Thus, programs must ensure that people (including PLHA) have an in-depth understanding of what HIV is and how it is transmitted to enable them form the correct opinion of actual HIV risk in any given life situation they encounter. For example, providing information that HIV is unable to survive for long outside the body will reassure people that HIV cannot be transmitted through casual contact such as sitting next to a person with HIV on a bus or sharing utensils.

Program contents need to disassociate HIV from the often tabooed social issues that are associated with its transmission, particularly sex. Professionals and educators can discuss factors that lead to HIV/AIDS transmission, without directly and necessarily referring to specific individuals or groups, to ensure that specific groups are not singled out as transmitters. When

educational content include implicit value judgments about a behavior, it legitimizes stigma by implying that HIV/AIDS is a matter of individual choice.

Also, educational content must be broadened to include information on HIV/AIDS beyond transmission, specifically what it means to live with HIV; how individuals can prevent its transmission; and if diagnosed with HIV, how to live healthy and productive lives. Participants expressed the need to include information on longevity of PLHA or that opportunistic infections are treatable. Paul expressed:

And also they should educate people about the disease because many people think if you have this disease then that is the end of your life. So maybe if they can tell people that this disease is not about death, but it's like any other disease you can think of, maybe people will stop behaving cold towards us.

In addition to expressing the longevity of PLHA, public education that supports human rights and freedom must be intensified. Vickie expressed that:

I believe you have to educate people and really talk to people that if someone has this disease it doesn't mean that is the end of their life. There was a lady I met at one of our programs in Kumasi. She was fired from her work and evicted from her house because she has this disease. You see, but for me I have come to understand that having HIV is not the end of my life. We are human beings and we need to be treated as such. No one has the right to take our freedom away from us. Although we may be weak in some areas of our work life, we still can work in other areas so nobody should trample on our freedom. So for me, I believe you should help us in many ways so that when people are against us you can defend us. So that they would not behave that way towards us.

Creating the awareness and understanding of HIV-related stigma, including what it is; the harm it present to us, family members and community, emphasizing the significant role each individual has to play in reducing it, will help to prevent inadvertent stigma. While not dealt with in-depth, the findings of this study indicates a gap between participants' opinion of stigma as something which is not good and their own opinions which are stigmatizing. This indicates a lack or limited recognition of stigma. Creating the awareness of what stigma is and how harmful it is would help stop this unintentional stigma from occurring.

Furthermore professionals and educators must provide safe spaces and environments in which to discuss values and beliefs that trigger stigma. Values, norms and beliefs about issues

like sex, behavior, and moral judgment are often ingrained and usually unconscious. Open discussions on issues like these should be encouraged to help people develop tolerance and acceptance for lifestyle differences. Open differences should reflect our judgments and its negative impact which keep us from accepting and caring for PLHA and their close relatives; the fact that we are all at risk and how the distinction of “them” and “us” puts us at a greater risk. Although it is difficult to change the ideologies surrounding gender in a dominantly patrilineal culture, discussions on gender issues focusing on how women are marginalized and, specifically how the double standards of men lead to women’s vulnerability can be encouraged. The house to house or home visit program will be a great place to discuss such issues.

Media

The data show that language and information has a tremendous influence on HIV-related stigma. The media is a powerful tool because it reaches a wide group of people and influences people’s opinions with its content, style and delivery of its messages. Utilizing positive images of PLHA in the media, by journalists and program hosts, rather than and negative images will combat the fear that propagate stigma. The findings from this study confirm that the use of negative messages that associate HIV infection with disfigurement, suffering, and death, and images of sick and dying people with AIDS only promote fear of HIV/AIDS, PLHA and their close associates. Eliminating the negative imagery will increase positive images of PLHA and combat the fear which may in turn reduce stigma. Participants emphasized that the media must change its messages about HIV and death. Yebson suggested: *“And the media too should stop putting into people’s minds that if you get this disease then that is the end of your life.”* Opokua said for the media to inform her that HIV means death and for her sister to be well and alive are contradictory:

Owww, for me I think if people are educated that there are medications for this disease and that it doesn’t kill like it used to be, many people will look at the disease differently. And probably will one day consider it as malaria. But now all you hear is, “if you have AIDS, you will die. If you have AIDS, you will die,” but my sister is still alive and I know other people too who are alive. So what is the government doing about it?

Similarly, Ida shared that the media should include positive images about the disease in everyday programming:

The media should also show to the public how everything have changed and how people on ART look very much like any other person. Then many people will accept those who have the disease. I believe we should all be accepted like how the Ugandans have accepted HIV patients. They live with them. They work and do everything with them. So every day there should be something, maybe a program, something in the news, TV and so on so that things will change, and people will not stigmatize, so that we can be free and you the professionals will also be successful in your work.

Likewise Yebson shared that the media should clear all the negative images it has created about HIV/AIDS and present it in positive way:

The best thing is that the way the media started presenting it in a bad way; they should come back in a positive way to tell people that the disease is not deadly if you take care of it. There are medications that can help. That will solve the problem because they have now polluted the minds of the society.

Yebson's wife shared the same opinion. Faustie said: *"the media is the main issue... oww, I believe if the media change their presentations on the disease, that it is deadly, people will change."*

Media professionals can modify their language to be non-stigmatizing, provide facts and up-to-date information on HIV while limiting myths and misperception about HIV/AIDS and PLHA. Given their potential to shape the attitudes, values and perceptions of large numbers of people, communicators have a responsibility to create clear messages about HIV/AIDS, to report accurately, and to do so in a sensitive, non-stigmatizing manner. Local, national, Internet, public and private media can provide opportunities for PLHA to share their experiences with the public. Exposure to personal experiences of PLHA can have impact on perceptions of HIV/AIDS, increase cultural exposure to AIDS and may reduce HIV-related stigma. The mass media has a responsibility to build skills and capacities for journalists, editors, producers, AIDS activists, communicators and people working in the field of HIV/AIDS and also provide resources for sustained communication about HIV/AIDS that effectively reduces stigma. There should also be standards for reporting on HIV/AIDS in a non-stigmatizing manner.

Professionals

Educators and professionals in the field must acknowledge their own fears about the disease, in order to overcome it. We must all begin the process of self-reflection on values, morals, and judgment. Professional bodies have both a responsibility and an opportunity to overcome stigma within their professions and workplaces. They should be encouraged to adapt professional codes of ethics and conduct with respect to HIV/AIDS. These bodies have social and professional authority, and their ability to act as educators and role models for their communities gives them the opportunity to act as “change agents” for reducing stigma.

Finally, professionals must disclose their true intentions and purpose for conducting any form of interviews or programs with PLHA. During the process of this inquiry, I gathered from the participants that many professionals and HIV/AIDS area organizations take advantage of PLHA for their individual or organizational benefits. One of the PLHA, Ida shared a concern:

So what I want to tell you is that, don't let this interview drown with this river, but please do well to fight hard for us so that everything we have said here will work for us. Because many people come to talk to us like you have come here. Sometimes we even hear they are sponsored, but they don't give us the amount they are supposed give to us. So for me, I told sister Golda [Regional AIDS Project, focal person] that I have stopped interviewing with people but she told us yours is for a study, so I agreed to do it.

Ida's concern poses a challenge to researchers, practitioners and policy makers. That research findings must not be over looked, but must guide policy and practice. It is important to note that the claims of the PLHA may or may not be true. However, revealing the clear and true purpose as well as significance of interviews and programs with PLHA, their roles and expectations, will provide adequate information for them to make decisions about voluntary participation.

Integrating Contexts

Because individuals are members of groups throughout their lives, projects should do well to look beyond any one context of stigma. An ecological approach should be employed in integrating stigma education in HIV/AIDS programs. Even activities that focus on a particular context of stigma almost exclusively can still strengthen their impact by acknowledging links with other social arenas.

Programs could maintain a high-profile public image through media-friendly events, using local and traditional leaders, religious authorities as promoters of compassion, and to demonstrate care activities to families. Involving key institutions and opinion leaders to take the lead in programs to reduce HIV-related stigma is crucial. These leaders are the authorities that shape and reinforce the values in our culture. They can do this by encouraging and supporting non-stigmatizing philosophy like compassion and equal treatment for all.

Organizations or institutions irrespective of whether they are HIV/AIDS oriented or not can address relevant HIV/AIDS issues within its activities. Although this can be seen as a vague recommendation, the specific message in terms of stigma is that a multipurpose approach will most likely have the biggest impact. The corollary of this finding is HIV-related stigma is a multi- context phenomenon and therefore organizations; whether they address education, the environment, economic or any other developmental issue, can contribute significantly by adding AIDS to their agenda and contributing their specific strengths from other contexts. The role for HIV-focused projects in this regard will be to provide information, technical assistance, networking links, and policy advocacy to facilitate the integrated approach to reducing stigma in the community.

Implication for Policy

In order to minimize stigma related to HIV/AIDS, it is also imperative that programs address poverty, economic marginalization, tribal stigma, unequal gender-based power relations and norms in Ghana. This may call for a cultural reform. A culture that labels is a culture that readily fuels stigma. Without changing the deeply held beliefs about sex and morality as well as the beliefs surrounding HIV/AIDS, the programs to mitigate HIV/AIDS and its related stigma will not be effective. Women are the most affected by HIV/AIDS related stigma because of the societal beliefs about sex, gender and HIV. This must not be taken for granted in designing and implementing programs.

Policies should review strategies to hold men accountable to be responsible for their children even when they choose to divorce their spouses. Legally, the Women And Juvenile Unit (WAMU) and the Social Welfare were charged to ensure that men pay child support and alimony in situations like this, the implementation of their policies have been quite challenging.

Policies that empower individuals especially women must be addressed. However, policies that are implemented through the use of cultural tools rather than foreign ones can be useful. Cultural tools are inherited and transformed by generations. Cultural tools are formed as a result of groups working together, adapting symbolic methods and materials that were used by predecessors, building on that to generate new ones (Rogoff, 2003). A specific example that we can draw from is the domestic violence Act 2006 (Act 732) passed in parliament in Ghana which was finally passed into law in February 2007. The implementation of the law has faced many challenges. When the policy was implemented, it did not take into account the impact that a simple domestic violence claim could have on families and women. Policies that empower women will help them to be economically independent and have high self esteem and will eventually help them in making informed decisions.

In Ghana, most governmental and nongovernmental organizations which are involved in HIV/AIDS programs fail to address the cultural and societal factors that promote the spread of HIV/AIDS. There is therefore the need to make organizations strategize their programs to address stigma through their various prevention and educational programs.

A combination of both intervention and prevention programming is the best practice to increase disclosure and improve community attitudes. Specific example is TASO (The AIDS Support Organization) in Uganda, which has been central in encouraging greater openness about HIV/AIDS as well as improving support and care for PLHA, family members and the communities at large. While many organizations have created work place policies on HIV/AIDS, more needs to be done especially in the area of implementation the policies.

Conclusion

The phenomenological inquiry into the experiences of HIV-related for PLHA and their family members has been conducted in the Ghanaian context. A focus on gender differences regarding HIV-related experiences has been presented. Ecological and symbolic interaction theories were employed to guide the study. The corollary of this study is that stigma is certainly complex and affected by context. The symbol and beliefs surrounding HIV/AIDS have led to stigmatization of PLHA and their family members. Stigmatization as defined by PLHA and their family members provided insights into the negative treatment people experience when they or

their family members are diagnosed with HIV/AIDS. Those experiences connote that stigma is a negative concept with corresponding negative actions.

The experiences of stigma could be internal, within the individual or the family and external, from the community, work place and health institutions. Stigma is often manifested overtly or covertly by PLHA and their family members. While some family members stigmatize PLHA within the home, they are also stigmatized outside of their home. However it is manifested, stigma has negative impacts on individuals, family members, and the spread of HIV/AIDS. While PLHA and family members experience similar kinds of stigma, the impact is more intense on the PLHA than the family members as they (PLHA) often feel worthless and have thoughts of suicide. The impact of HIV-related stigma is also more intense for women than men, as they experience multiple stigmas. They are often times neglected and abandoned by their husbands when they have HIV/AIDS. Women's roles as wives and caregivers often change which poses great difficulty for them, their husbands and their family members.

Putatively, the expressions of stigma, the meaning of stigma, how it impacts people's lives and most importantly how it influences the differences in the way women and men are treated when they have AIDS, are assumed to be a consequence of deeply held beliefs about sexuality, gender- role expectations, human behavior and disease. In turn, these beliefs are largely ascribed by PLHA and family members who are also stigmatized. Values and beliefs about appropriate behavior and fears about death, as well as entrenched social inequity, fuel stigma and therefore there is the need to consider a broader and holistic approach of the phenomenon in all programs.

The findings of this study pose a great challenge to researchers, policy makers, practitioners and professionals in the area of HIV/AIDS in Ghana. Like many social problems, the issue of HIV-related stigma should be addressed within multiple contexts. The integration of these contexts irrespective of their orientation will help mitigate some of the issues that propagate stigma, while serving as prevention against HIV-related issue.

The uniqueness and the major contribution of this study is its focus on family members of PLHA. While there are many studies on PLHA, family members of PLHA have been given little attention. The findings from this study highlight the stigma experiences of family members of PLHA and how those experiences impact their lives. As it was clearly articulated by one of the family members of PLHA in this study, *"once it's your sister, it's everybody in your family; they*

think it's in the bloodline," a person's serostatus diagnosis is often transferred to the rest of the family members even though they may not have HIV/AIDS. The inclusion of family members gave valuable insights about HIV and its related stigma. In addition, this study highlighted the strengths of both PLHA and their family members. Often times when HIV-related is being reported in the literature, the main focus is on the negative impact. The findings of this study brought to light the strengths and the positive impact HIV-related stigma has on the individual and the entire family. While participants recounted their difficult experiences with stigma associated with HIV/AIDS, some of them emphasized how strong they have become and how their relationship with the rest of the family members have been enhanced. Most have precluded the traditional extended Ghanaian family and adapted a nuclear family system.

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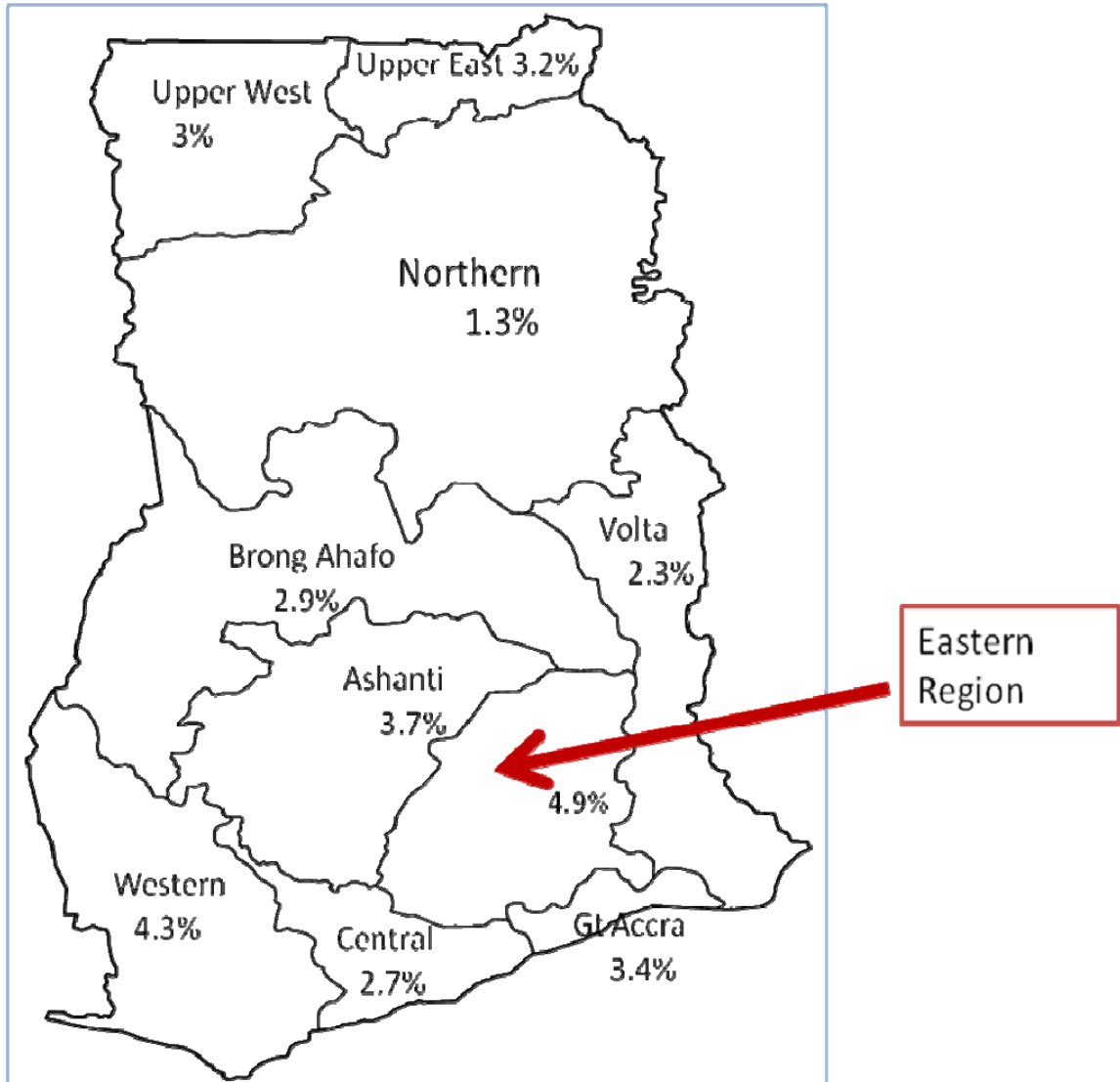
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Appendix A - PREVALENT RATE OF HIV/AIDS IN GHANA BY REGION



Appendix B - Interview Guide

This interview guide assisted me in conducting interviews with people living with HIV/AIDS and their family members in Ghana. The interview guide addressed issues such as the concept of stigma in the Ghanaian context; stigma experienced by PLHA and their family members, its impact on their lives, how they cope with it and the factors influencing it. In addition, gender differences in the experience of HIV/AIDS-related stigma were addressed. The guide offers both structured interview questions and probes to participants' responses. This interview guide is divided into two: (A) Interview schedule for PLHA and (B) Interview schedule for family members of PLHA.

Interview Guide for PLHA

Opening Questions:

After I introduce myself and the purpose of my study, PLHA introduced themselves and told me about themselves: their ages and educational background occupation, children, married etc.

Introductory question

- Please tell me about when you tested positive for HIV/AIDS?

Transitional Question

- What was your first reaction/response when you were told you had HIV/AIDS?

Key Questions

How do PLHA conceptualize HIV/AIDS-related stigma in the Ghanaian context?

- Please can you tell me what stigma is and what it means to you?

How do PLHA families experience HIV/AIDS-related stigma in the Ghanaian context?

- How have people treated you differently since your diagnoses?

-Can you share some of your experiences with me?

-The expressions of stigma like verbal, physical etc

What are the impacts of HIV/AIDS-related stigma on PLHA and family members, and how do these impacts influence their relationships?

- What areas of your lives have been affected by stigma related to HIV/AIDS?

-Family life

-Social and community life

-Work life

-School life

-Life on the whole

- What areas of your family's life have been affected by HIV/AIDS-related stigma
- How have these experiences affected you as an individual? Please explain.

-Self-stigma

-self-isolation

- Comparing your life before you tested positive and now, what are the differences and challenges?
- What do you think have been some of your family's challenges as a result of your diagnoses?
- In what ways have these challenges strengthened you?
- Can you tell me how your relationship with your family has been?

-Have your interactions changed?

*-How did you used to interact with them (as
mother/father/wife/husband/sibling/child)?*

-How do you interact now?

How do PLHA cope with HIV-related stigma in Ghana?

- You have told me about your experiences and ways in which you have been stigmatized now can you tell me how you cope with those experiences daily?

What are the gender differences with regards to stigma experiences in Ghana and how do these differences impact the lives of women in Ghana?

- Do you feel men and women are treated differently when they have AIDS? Please explain.

-Comparing yourself to your male/female counterpart, how are you treated differently?

-What are your experiences as a woman/man who has AIDS?

-What are your experiences as mother/wife, father/mother?

*-How is your experience different from your
husband/wife/mother/father/sister/brother etc*

-Has your role as mother/wife, father husband changed? If yes please explain.

-How do you think people see you as a woman/man or as mother/wife or as

father/husband who has AIDS?

- What do you think are the factors that contribute to gender differences with regards to stigmatization?

What are the factors influencing HIV-related stigma among Ghanaians?

- What do you think may be some of the reasons why people stigmatize you even though you do not have HIV/AIDS?

-Moral judgment

-Cultural norms

-Fear of the disease

-Images of the disease

-Insufficient knowledge of the disease

- Are there any other factors that contribute to people's behavior toward you as family members of PLHA?

What strategies do PLHA feel will be effective for stigma prevention?

- What do you think can be done to address the issue of HIV/AIDS-related stigma?
- What do you want people to know about HIV/AIDS and its related stigma?

Interview Schedule for Family Members

Opening Questions:

After I introduced myself and the purpose of my study, family members introduced themselves and told me about themselves: their ages and educational background, occupation, children, marital status etc.

Introductory question

- Please tell me about when and how you learnt that (name of PLHA) has HIV/AIDS.

Transitional Question

- What was your first reaction/response to it?

Key Questions

How do Family members of PLHA conceptualize HIV/AIDS-related stigma in the Ghanaian context?

- Please can you tell me what stigma is and what it means to you?

How do Family members of PLHA HIV/AIDS-related stigma in the Ghanaian context?

- How have people treated you differently since (PLHA's name) diagnoses?
 - Can you share some of your experiences with me?*
 - The expressions of stigma like verbal, physical etc*

What are the impacts of HIV/AIDS-related stigma on PLHA and family members, and how do these impacts influence their relationships?

- What areas of your life have been affected by stigma related to HIV/AIDS?
 - Family life*
 - Social and community life*
 - Work life*
 - School life*
 - Life on the whole*
- What areas of your family's live have been affected by HIV/AIDS-related stigma
- How have these experiences affected you as an individual? Please explain.
 - self-stigma*
 - self-isolation*
- Comparing your life before (PLHA's name) tested positive and now, what are the differences and challenges?
- What do you think have been some of your family's challenges as a result (PLHA's name) diagnoses?
- In what ways have these challenges strengthened you?
- Can you tell me how your relationship with your (PLHA's name) have been?
 - Have your interactions changed?*
 - How did you used to interact with them*
 - (*as mother/father/wife/husband/sibling/child*)?
 - How do you interact now?*

How do PLHA cope with HIV-related stigma in Ghana?

- You have told me about your experiences and ways in which you have been stigmatized now can you tell me how you cope with those experiences daily?

What are the gender differences with regards to stigma experiences in Ghana and how do these differences impact the lives of women in Ghana?

- Do you feel there are gender differences in the way people are stigmatized? Please explain.
 - *How do you think people see women/men who have AIDS?*
- What do you think are the factors that contribute to gender differences with regards to stigma?

What are the factors influencing HIV-related stigma among Ghanaians?

- What do you think may be some of the reasons why people stigmatize you even though you do not have HIV/AIDS?
 - Moral judgment*
 - Cultural norms*
 - Fear of the disease*
 - Images of the disease*
 - Insufficient knowledge of the disease*
- Are there any other factors that contribute to people's behavior toward you as a family member of PLHA?

What strategies do PLHA feel will be effective for stigma prevention?

- What do you think can be done to address the issue of HIV/AIDS-related stigma?
- What do you want people to know about HIV/AIDS and its related stigma?