# FACTORS THAT INFLUENCE STIGMATISATION AND DISCRIMINATION AGAINST PERSONS LIVING WITH HIV IN THE HEALTHCARE DELIVERY SYSTEM OF GHANA

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# Factors that Influence Stigmatization and Discrimination against Persons Living with HIV in the Healthcare Delivery System of Ghana.

A thesis submitted in partial fulfilment of the requirement for the degree of Master of Public Health

By:

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#### List of abbreviations

AIDS Acquired Immune Deficiency Syndrome

ART Antiretroviral Therapy
GAC Ghana AIDS Commission
GDP Gross Domestic Product
GHS Ghana Health Service
HCW Healthcare worker

HIV Human Immunodeficiency Virus HTC HIV Testing and Counselling MDG Millennium Development Goal

MOH Ministry of Health MR Mortality Rate

MSM Men who have Sex with Men

NACP National AIDS and STI Control Programme

NGO Non-Governmental Organization
NHIS National Health Insurance Scheme

PLHIV Person Living with HIV

PMTCT Prevention of Mother to Child Transmission

PWID People who inject drugs

SRH Sexual and Reproductive Health

SW Sex Worker

THE Total Health Expenditure

UNAIDS Joint United Nations Programme on HIV/ AIDS

USAID United States Agency for International Development

VCT Voluntary Counselling and Testing

WHO World Health Organization

# Glossary

Definitions of commonly used terms in this study are provided. The definitions related to the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) are from the revised version of the Joint United Nations Programme on HIV/ AIDS (UNAIDS) terminology guidelines, 2015 (1). They have been adapted for the purpose of this study. Other definitions related to Ghana have been formulated for the purpose of this study.

**Anti-retroviral therapy (ART)**: Triple or more antiretroviral drug combination which is highly active and suppresses replication of the Human Immunodeficiency Virus. It reduces viral load in the blood to undetectable levels and slows down the progress of HIV disease.

**Ghana AIDS Commission**: Commission in Ghana mandated to oversee the national response to the HIV epidemic.

**Healthcare**: Preventive, curative, palliative services and interventions delivered to individuals or populations.

**Healthcare delivery system**: In this study refers to the healthcare setting, the health workforce, the HIV policies, protocols and guidelines with which they operate.

**Healthcare workers (HCW):** This term will be used in this study to refer to doctors, nurses, pharmacists, dispensary technicians, biomedical scientists and all professionals involved in the provision of health services and care to clients.

**Human Immunodeficiency Virus (HIV**): The virus that weakens the immune system, ultimately leading to AIDS.

**Key populations**: Those most likely to be exposed to HIV or to transmit it. Men who have sex with men, transgender persons, people who inject drugs, sex workers and their clients, and seronegative partners in serodiscordant couples.

**Person Living with HIV (PLHIV**): A person who has tested sero-positive for HIV.

#### Abstract

**Background:** HIV-related stigma and discrimination have been recognized as obstacles to healthcare and quality of life of persons living with HIV. Paradoxically, stigmatisation and discrimination also occur in the healthcare delivery system where individuals undergo HIV counselling and testing and persons living with HIV receive care and treatment.

**Objective:** To critically analyse the factors influencing continued stigmatisation and discrimination against persons living with HIV in their interaction with the healthcare delivery system of Ghana and propose recommendations to curb this phenomenon.

**Methodology:** A narrative literature review of published literature on HIV-related stigma and discrimination in the healthcare delivery system of Ghana was conducted. Stangl et al's "HIV stigma reduction framework" was used to analyse the findings.

**Findings:** Findings were grouped into conceptualizations of stigma and discrimination; underlying reasons; manifestations; impact and interventions to address stigma and discrimination within the healthcare delivery system of Ghana. HIV-related stigma in the healthcare delivery system was related to individual attributes of health workers, institutional policies, sociocultural and structural environment. Multiple stigma was experienced socially marginalized populations who were HIV-positive.

**Conclusion:** The study demonstrates that HIV-related stigma and discrimination in the healthcare delivery system are reinforced by broader social processes, organization of service delivery, policies, societal beliefs and norms. Stigma-reduction interventions should incorporate these inherent factors to make them effective.

**Recommendations:** HIV-related stigma interventions in the healthcare delivery system should be multifaceted and take into consideration individual, social and structural factors such as legislation and policies contributing to it. Stakeholder involvement in the design of interventions is key to its effectiveness.

Key words: HIV, AIDS, Stigma, Discrimination, Healthcare, PLHIV

**Word Count:** 13181

# **Introduction and Organization of Thesis**

HIV-related stigma and discrimination have been described as a barrier to responses aimed at addressing the HIV epidemic in Ghana. Eliminating stigma and discrimination in the healthcare delivery system is an important first step to reducing stigma in the larger society and the general population. This is because health workers are important stakeholders in their communities.

Having worked as a general nurse and more recently in the HIV Testing and Counselling Department of my hospital as a coordinator, I observed several instances of stigma and discrimination by colleagues and other members of staff against persons living with HIV. Most patients were unable to seek redress when these incidents occurred. I noticed how pervasive the problem is, the little attention that it was accorded and the negative effects it had on the persons living with HIV; hence my motivation to undertake this particular study. My interest lies in identifying evidence-informed interventions that can be utilized to address this challenge; as similar circumstances prevail in many other healthcare facilities in Ghana.

This study utilizes the elements of a narrative literature review to analyse the factors that influence HIV-related stigma and discrimination within the healthcare delivery system of Ghana. It critically analyses literature on the drivers, facilitators, manifestations, outcomes and impact on persons living with HIV.

The thesis is organized in five chapters:

- 1. Chapter one provides background information about Ghana with regards to the country's state of health and its health system
- 2. Chapter two presents a description of the problem, significance, objectives, methodology and conceptual framework used for this study
- 3. Chapter three analyses the findings with regards to theories and concepts of stigma; drivers and facilitators of HIV-related stigma in the healthcare delivery system; intersectionality of stigma; manifestations; outcomes and impacts of HIV-related stigma
- 4. Chapter four presents findings on interventions that have been implemented to reduce HIV-related stigma and discrimination as well as gaps in the current interventions
- 5. Chapter five discusses the findings, presents a conclusion and provides recommendations for the reduction of HIV-related stigma and discrimination in the healthcare delivery system.

# **CHAPTER 1: Background Information about Ghana**

This chapter provides background information about Ghana, the state of health and the health system. It also presents an overview of the HIV epidemic, the context and extent of HIV-related stigma in Ghana.

# 1.1 Geography

The Republic of Ghana is located in West Africa and shares borders with Burkina Faso in the north, Togo in the east, Cote D'ivoire in the West and the Atlantic Ocean in the south (2). Majority of Ghana's landmass is made up of lowlands with mountainous ranges on the eastern border (2). It has a tropical climate with an annual average temperature of 26°C and two major seasons: rainy season and dry season (2). Ghana is divided into three ecological zones; a sandy coastline, thick forests from the south and west to the middle belt and savannah areas in the north (2).



Figure 1: Map of Ghana; Source: Ezilon Maps, 2015 (3)

# 1.2 Demography

Ghana's population is estimated at 24.7 million with an estimated 2.5% annual growth rate (4). 51.2% of the population is female and 38% of the general population is below fifteen years of age. More than 51% of the population lives in urban areas (2).

#### 1.3 Political and Administrative Structure

Ghana practices a multi-party democratic system of governance with three organs of government; executive, legislature and judiciary (2). The country is decentralized into ten administrative regions which are sub-divided into 216 districts (2).

#### 1.4 Socio-economic Situation

Ghana is a lower middle income country with gross domestic product (GDP) per capita of \$1427 in 2014 (5). The services sector is the largest and contributes 49.6% of the country's GDP, followed by the industrial sector (28.4%) whilst agriculture contributes 22% (6). The agricultural sector employs 45% of the economically active population whilst the services sector employs 41% (2).

#### 1.5 General Health Profile

Life expectancy is estimated at 63.5 years and 68.6 years for males and females respectively (4). Current maternal mortality ratio is estimated at 380 per 100,000 live births (7). The country was unable to achieve the Millennium Development Goal (MDG) target of 54 per 100,000 live births by 2015 (7). Ghana showed improvements in infant and under-five mortality rates (MR) but was unable to meet the MDG targets (8). Infant MR reduced from 80 in 1990 to 52 per 1000 live births in 2013, whilst under-five MR reduced from 128.2 in 1990 to 78.4 per 1000 live births in 2013 (7). Malaria accounted for 29% of under-five deaths whiles leading causes of mortalities in neonates prematurity, birth asphyxia, birth trauma and sepsis (9). Epidemiological transition in Ghana has resulted in a change in disease patterns with an increasing double burden of communicable and noncommunicable diseases (10). Human Immunodeficiency Virus (HIV) infections and Acquired Immune Deficiency Syndrome (AIDS) as detailed later contribute a significant portion of the communicable disease burden with an estimated national prevalence of 1.5% in the adult population (11). Table one presents the top ten causes of mortalities in 2012.

Condition	Number of Deaths (*1000)	Percentage (%)
Lower respiratory infections	22.4	10.7
Stroke	18.3	8.7
Malaria	17.4	8.3
Ischemic Heart Disease	12.1	5.8
HIV/ AIDS	10.3	4.9
Pre-term birth complications	7.9	3.7
Diarrheal Diseases	7.6	3.6
Birth asphyxia and birth trauma	7.3	3.5
Meningitis	6.3	3
Protein-Energy Malnutrition	6.2	2.9

Table 1: Top 10 causes of deaths in Ghana, 2012. Source: Ghana-WHO Statistical Profile (12).

# 1.6 Overview of the health system

The Ministry of Health (MOH) is responsible for policy formulation, mobilization of resources, monitoring and regulation of healthcare delivery (13). Health services in Ghana have been decentralized to improve access and community participation in planning (14). The Ghana Health Service (GHS) under the MOH provides majority of public health services to the population through primary and secondary facilities while the four teaching hospitals managed directly by the MOH provide tertiary and specialist care services (15). Private provision is through faith-based institutions, Non-Governmental Organizations (NGOs) and private for-profit facilities (16).

Service delivery, based on the principles of primary healthcare, is organized around the three-tier system: primary, secondary and tertiary (14). However, secondary and tertiary facilities occasionally provide primary care services as well (17). Figure 2 presents a schematic of the organisation of service delivery.

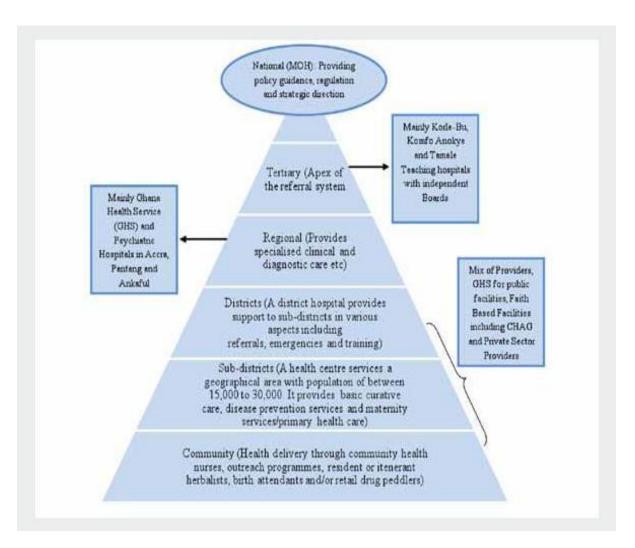


Fig 2: Organization of public health services in Ghana Source: Adjei S et al, 2011 (17).

The Food and Drugs Authority regulates food, medicines and medical products in the country (18). The major sources of financing for health services are Government of Ghana expenditure, National Health Insurance Fund, internally generated funds of institutions, donor funds and direct out-of-pocket payments (14). The National Health Insurance Scheme (NHIS) was formed in 2003 to facilitate achieving universal health coverage (19). Active subscription is estimated at 10.5 million (20). Total Health Expenditure (THE) as a percentage of GDP in 2014 was 4% (21). More than 70% of highly skilled healthcare workers (HCW) is found in urban areas with the rural areas extremely disadvantaged (14).

# 1.7 Epidemiological overview of HIV and AIDS in Ghana

HIV remains a significant public health challenge in Ghana. HIV in the country was initially found among women who engaged in sex work in neighbouring

countries and had returned home in 1986 (22,23). Currently, prevalence in the adult population between 15 to 49 years is estimated at 1.6% (11). According to the Joint United Nations Programme on HIV/ AIDS (UNAIDS), an estimated 270,000 people were living with HIV in Ghana in 2015 with an estimated 19,000 being children between 0-14 years (11). New infections have seen a steady decline from 15,000 in 2012 to 13,000 in 2015 (11).

Although Ghana is experiencing a generalized epidemic, the burden of HIV is higher amongst certain population groups (24). HIV prevalence has been estimated at 11.1% for sex workers (SW) and 17.5% for men who have sex with men (MSM) (11,24). Prevalence of HIV in Ghana varies with geographical location with the Eastern and Ashanti regions having the highest prevalence of 3.7% and 3.2% respectively (25,26). Prevalence is also higher in urban areas compared to rural areas (25). Figure three shows trends in new HIV infections from 1990 -2015.

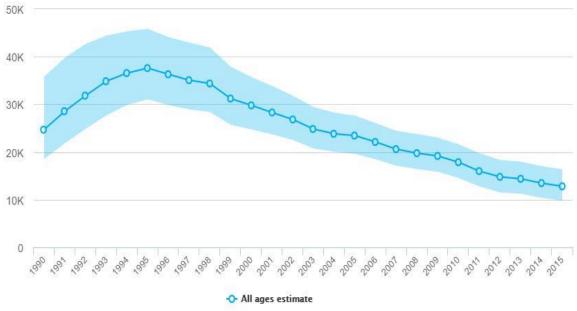


Fig 3: New HIV Infections from 1990 - 2015, Source: UNAIDS/ AIDS Info (11)

The highest prevalence is seen in females aged 15 years and above who represent 56% of all cases (11). Males aged 15 years and above constitute 36% whilst children between 0-14 years account for the remaining 8% (11). Aside biological and physiological predisposition, women in Ghana are disproportionately affected because of gender inequality and inability to negotiate for protected sex with their partners due to sociocultural norms (27,28). Many women potentially acquire HIV from their husbands who may be culturally permitted to have multiple partners (27). HIV Type I is the commonest and constitutes 97.1% of all infections in Ghana (25) whilst the commonest mode of transmission among adults is through heterosexual

intercourse (29). As detailed later, stigma and discrimination against Persons Living with HIV (PLHIV) is a major problem in the Ghanaian society (30,31). Selected indicators on HIV epidemiology are presented in annex 1.

# 1.8 Context and Extent of HIV-related stigma and discrimination in Ghana

PLHIV in Ghana face several challenges in relation to stigma and discrimination in their daily lives (32,33,34). Three decades after HIV was discovered in Ghana, HIV-related stigma¹ still persists despite the availability of ART (23). The introduction of ART was expected to change perceptions about HIV as a fatal condition to a chronic manageable one; which would have positively influence HIV-related stigma (35). "HIV-related stigma refers to the negative beliefs, feelings and attitudes towards PLHIV, groups associated with PLHIV and key populations at higher risk of HIV infection, such as persons who inject drugs (PWIDs), SWs, MSMs and transgender people" (36). This underlying stigma leads to discrimination wherein PLHIV are treated unfairly due to their HIV-positive status (36).

The fear of stigma leads to self-stigma where PLHIV and their families blame and isolate themselves (37,38). PLHIV and their family members may resort to keeping their status secret; in the process negatively affecting access to preventive measures, treatment, and quality of life of PLHIV (39). At the societal level, stigmatisation and discrimination against PLHIV in Ghana take many forms. PLHIV are subject to overt and covert social isolation, distancing, ostracism from the community, workplace, churches and their interaction with public health services (29,40,41,42).

In Ghana, stigmatisation has been attributed to lack or insufficient knowledge about HIV, inaccurate media reportage, religion, culture and societal norms which associate HIV with deviant behaviours (29,43). The initial association of HIV with sex work in 1986 when it was first discovered in Ghana contributes to this phenomenon (44,41). Similarly, in all Ghanaian communities, SW and homosexuality are considered disgraceful whilst laws Ghanaian laws criminalize SWs, PWIDs and MSMs (45,46). These norms fuel stigmatisation and tacitly condone discriminatory attitudes and behaviours (45). In Sub-Saharan Africa, religion which moulds societal beliefs has been found to play a crucial role in reinforcing stigma (47). Religious organizations covertly promote stigma through their moralistic stands and support for conservative social norms (47).

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<sup>&</sup>lt;sup>1</sup> HIV-related stigma is used in this study interchangeably to refer to both stigma and discrimination associated with HIV.

This study focuses specifically on HIV-related stigma and discrimination in the healthcare delivery system<sup>2</sup>. As indicated earlier, healthcare delivery in Ghana is made of three hierarchies with each facility providing services to PLHIV according to its level.

<sup>&</sup>lt;sup>2</sup> Healthcare delivery system in this study refers to the healthcare settings or facilities, their HIV policies, guidelines and protocols with which they operate as well as the healthcare workers.

# **CHAPTER 2** Problem Statement, Justification, Objectives and Methodology

This chapter first describes the problem of HIV-related stigma in the healthcare delivery system; the significance and the consequent study objectives are articulated. Thereafter, the methodology used to achieve the objectives is presented including a description of the conceptual framework used for the study.

#### 2.1 Problem Statement

The healthcare setting has been recognized as one of the places where PLHIV encounter widespread stigma and discrimination in their quest to access healthcare (48,49). The improved knowledge about HIV, its transmission and the introduction of ART in Ghana in 2003 has enhanced substantially health outcomes for PLHIV (35). One would have expected that this would have reduced the stigma associated with HIV. However, HIV-related stigma is still pervasive in Ghana; including the healthcare delivery system where individuals receive HIV Testing and Counselling (HTC) and where PLHIV receive care, treatment and support (31,33). These have been associated with a negative impact on effective responses to the HIV epidemic in the country (41).

Healthcare workers (HCW) with their professional training and ethics are expected to play a major role in health promotion programmes to reduce HIVrelated stigma and discrimination in the society (33). However, studies have shown that HCW including doctors and nurses are also involved in acts of stigma and discrimination against PLHIV in Ghana (31,34). Stigma studies among Ghanaian pharmacists showed that only 17% had accepting attitudes towards PLHIVs (49). In the same study, only 19% of HCW expressed accepting attitudes towards PLHIV (49). Although statistics about the actual prevalence of HIV-related stigma in the healthcare delivery system are unavailable, anecdotal evidence shows that, as a result of stigma, many individuals are unwilling to go for HTC in some facilities and seek treatment late when their conditions have deteriorated leading to poor prognosis (34). Individuals have refused to undergo HTC because of lack of confidentiality and judgmental attitudes from HCW (34). In the HIV Stigma Index Study in Ghana (2014), 8% of participants reported of non-consensual disclosure of their statuses to third parties by HCW (41).

Laar (2013), found that some HCW in Ghana found the provision of sexual and reproductive health (SRH) information to PLHIV inappropriate and withheld such essential information from them (50). Although forced sterilizations and abortions have not been documented in Ghana like other Sub-Saharan African countries (51,52), research has shown that in Ghana that PLHIV do not receive comprehensive SRH education due to inadequate knowledge about reproductive rights and options for PLHIV by HCW (50). It

has also been documented that some HCW have refused to assist in surgical procedures for HIV infected patients whilst some physicians and nurses have also indicated their unwillingness to provide services to PLHIV in Ghana (53). Dako-Gyekye, et al. showed that in some health facilities in Ghana, measures are in place to segregate HIV-infected patients from others (31).

HIV-related stigma in healthcare settings also affects prevention programmes such as HTC and prevention of mother to child transmission (PMTCT) programmes (30). In spite of NACP's programme to increase HTC in Ghana, uptake of this service is not commensurate with service provision (34). Although 90% target was set for PMTCT coverage in 2013, only 76% was achieved (24). According to the NACP, uptake of HTC dropped from 1.15 million clients in 2011 to 669,000 in 2013 (24). Studies have found that aside absence of HIV testing kits, geographical inaccessibility and financial constraints among others, stigma and discrimination in health facilities could be a contributory factor to the decreased utilization of HTC and PMTCT programmes (34,54). Apanga et al (2015) in their study on the factors influencing uptake of voluntary counselling and testing services found that 53% of respondents indicated their unwillingness to utilize HTC services due to fear of stigma (30).

#### 2.2 Justification

HIV-related stigma in the healthcare delivery system has deleterious effects on programmes aimed at addressing the HIV epidemic (53). Prevention begins in the healthcare delivery system through HTC while PLHIV receive care and treatment in the healthcare setting (55). It is crucial that providers of care to PLHIV have a positive attitude in any HIV programme (56). Consequently, stigma and discrimination in this environment negatively affects the prevention of HIV as well as quality of treatment, care and lives of PLHIV (34).

HCW are important stakeholders in their communities (53,57) and therefore addressing HIV-related stigma the healthcare delivery system influences positively stigma reduction in the community (53). Research conducted by UNAIDS has shown that responses in healthcare settings are capable of eliciting positive or negative outcomes at homes, communities and workplaces; therefore it is absolutely necessary that HIV-related stigma in healthcare setting is addressed (58).

Several reasons underlie the continuous existence of stigma and discrimination in the healthcare delivery system in Ghana. Given the significance of eliminating HIV-related stigma in the response to the HIV epidemic, it is important that stigma and discrimination in the healthcare delivery system are critically analysed and addressed to ensure the successful implementation of HIV programmes. This study will also facilitate the

understanding of the linkages between healthcare related stigmatisation and social processes.

# 2.3 Objectives

# 2.3.1 General Objective

To critically analyse the factors influencing the continued stigmatisation and discrimination against persons living with HIV in their interaction with the healthcare delivery system in Ghana and to propose recommendations to curb this phenomenon.

# 2.3.2 Specific Objectives

- 1. To describe the theoretical underpinnings of HIV-related stigma and discrimination
- 2. To explore the reasons underlying and the manifestations of HIV-related stigma and discrimination in the healthcare delivery system in Ghana
- 3. To analyse the consequences of stigma and discrimination in the healthcare delivery system in Ghana
- 4. To examine current strategies addressing HIV-related stigma and discrimination and identify gaps in the current responses
- 5. To formulate evidenced-informed recommendations for addressing HIV-related stigma in the healthcare delivery system of Ghana.

# 2.4 Methodology

Stangl et al's "Stigma reduction framework" (59) was used to conduct a narrative review (60) of published literature on healthcare-related stigma and discrimination against PLHIV. This sub-section delineates the process for identifying literature for the study.

#### 2.4.1 **Search**

Electronic search was conducted from December, 2015 on Pub-Med, Science Direct, Biosemantics, Google Scholar and VU e-library to obtain published articles on HIV-related stigma with findings on healthcare. The following keywords; HIV, AIDS, stigma, discrimination, PLHIV, healthcare and Ghana were used to perform an initial broad search in different combinations. Further search was conducted using keywords related to each specific objective in different combinations with Boolean operators "and"/ "or" to generate more results. *Table 2* below presents the search words.

Article titles and abstracts obtained were reviewed for relevance to identify articles which reported findings on healthcare. The availability of the full text article and fulfilment of the inclusion criteria then determined its addition or not. Reference lists of journal articles retrieved were searched manually to identify potential related articles following the initial search. Specific websites of ministries and organizations working in the HIV field such as World Health Organization, Ghana AIDS Commission (GAC) and UNAIDS were also searched

to obtain statistics, programme reports and policy documents related to the topic.

For the analytic framework, the corresponding author was contacted in the quest to obtain the original poster presentation. Though the original frame work was not obtained, she provided links to her published articles which utilized and explained the framework. No starting date limit was assigned on the literature to be used for this study to allow for the inclusion of older literature that were still relevant.

Source	Search words used per objective				
	Objective 1	Objective 2 & 3	Objective 4	Objective 5	
PubMed Biosemantics VU e-library Google Scholar	"Stigma, healthcare"; "Stigma, theory"; "Stigma, concept"; "Stigmatisation, healthcare"; "Stigmatisation, theory"; "Stigmatisation, concept"; "Discrimination, healthcare"	"Stigma, healthcare setting, Ghana"; "Stigma, healthcare delivery system, Ghana; "Stigma, health" "Stigmatisation, healthcare setting"; "Stigmatisation, healthcare delivery system"; "Stigmatisation, health"; "Discrimination healthcare" "Stigma, self" "Stigma, internalized"	"Stigma, interventions"; "Stigma, programmes"; "Stigma, strategies"; "Stigma, responses"; "Stigma reduction"; "Stigma, guideline"; "Stigma policy"	"Stigma, interventions"; "Stigma, programmes"; "Stigma, strategies"; "Stigma, responses"; "Stigma reduction"; "Stigma, guideline";	
Websites of Ministry of Health Ghana AIDS Commission UNAIDS WHO		"Stigma, PMTCT"; "Stigma, VCT"; "Stigma, HTC"; "Stigma, ART"	"HIV, Policy"; "HIV, Programme"; "HIV, response"; "Stigma, policy"; "HIV, law" "HIV, legislation"	"HIV, Policy"; "HIV, Programme"; "HIV, response"; "Stigma, policy"; "HIV, law" "HIV, legislation	

Table 2: Search table

#### 2.4.2 Inclusion Criteria

The criteria for inclusion were:

- 1. Studies of any design that reported findings on HIV-related stigma and healthcare
- 2. The full text article was available
- 3. The article was written in the English language.

# 2.4.3 Limitations of the Study

Literature and publications on the subject in the Ghanaian context are limited; therefore studies in other countries with similar contexts to Ghana were used to support findings. This study has a limited scope in terms of its review of HIV-related discrimination which was done based on its relationship with HIV-related stigma.

For some relevant abstracts found, in spite of having extensive access to literature through the VU library, the full texts articles could not be retrieved and are therefore not included in this study. The study may have excluded potential relevant articles written in different languages aside English.

## 2.4.4 Analytic Framework

Several studies have underscored the diversity and complexity of HIV-related stigma and analysed it from different perspectives (61). Parker & Aggleton (2003), proposed that stigma and discrimination be understood in terms of power, differences and culture as they influenced the wider social processes which reinforced social inequalities (61). This, they suggested, provided a better understanding of stigma resulting in improved interventions to tackle them (61).

Holzemer et al (2007) identified two components of stigma: contextual factors which had an effect on stigma (environment, healthcare system and agents) and actual stigma process (62). They analysed the concept of stigma in terms of triggers, stigmatizing behaviours, types and outcomes of stigma (62). In their model, the concept is presented in a linear manner, projecting a causal relationship; but they also suggest that it is an iterative and interactive process (62).

Whilst Holzemer et al's (2007) model considers the dynamics of HIV-related stigma, Stangl et al in 2010 (as cited by Nayar et al, 2014) (59) present an "HIV stigma reduction framework" that scrutinizes the fundamental reasoning underlying stigma and its consequences in terms of cognitive and social processes; which can appropriately be applied to stigma in the healthcare delivery system. It takes into consideration the structural dimensions of stigma by incorporating policies and legislations into the framework.

The "HIV stigma reduction framework" is preferred for this study because it is comprehensive and captures details about social processes, individual factors

and structural components as well as the dynamic nature of HIV-related stigma. It also incorporates the notions of culture, power and inequalities proposed by Parker and Aggleton (2003) which influence stigma and discrimination experienced by PLHIV within the healthcare system. This research adapts and utilizes this framework for the analysis of literature using the specific objectives as a guide.

# 2.4.5 Theoretical Background of the Stigma Reduction Framework, Terminologies and the Stigmatisation Process

The stigmatisation process in this framework comprises six domains namely drivers, facilitators, intersecting stigma, stigma manifestations, outcomes and impacts presented in figure 2 below (59,63).

- 1. **Drivers** affect the stigmatisation process on the individual level in a negative way (59,63). They include lack or inadequate knowledge about HIV, misconceptions; insufficient awareness about stigma and its repercussions, fear of being infected through casual contact with PLHIV and social judgement (58,62,63,64).
- 2. **Facilitators** influence stigma and discrimination at the societal level and include institutional, cultural, and community factors such as legislation, policies, beliefs and norms (61,63,65). The combination of drivers and facilitators determine how stigma is applied to PLHIV (63).
- 3. The interrelationship that exists between HIV status and social marginalization such as gender, migration, poverty, social class, PWIDs and sexual orientation result in **intersecting** or **multiple** stigmas (63,66) which lead to several manifestations of stigma.
- 4. **Stigma manifestations** are usually negative and include
- **Anticipated stigma** fear of negative experiences and treatment due to HIV status (67):
- **Internalized or self-stigma** the degree to which negative beliefs and feelings related to HIV of society are accepted by PLHIV which prevent them from seeking the needed help (67);
- Experienced or enacted stigma discrimination faced by individuals based on their HIV status or association with PLHIV outside the scope of the law (67);
- Discrimination unjust treatments faced by PLHIV within the scope of the law (67) and resilience – the ability to prevail over experiences of stigma and discrimination (63). Drivers, facilitators and manifestations of stigma are influenced by the social and structural environments. Discrimination is considered as a manifestation of stigma instead of an end-product of the stigmatisation process in this framework (68).

- 5. The manifestations of stigma result in several stigma **outcomes** such as delay in HTC, PMTCT and seeking care, loss to follow-up and poor adherence to treatment which eventually leads to;
- 6. Long term **impacts** include increased morbidity and mortality, poor quality of lives for PLHIV, depression and suicide (63). Resilience and activism have been identified as the positive impacts of stigma in this framework (64,68).

The framework provides five socioecological levels at which HIV programmes can be focused and implemented:

- **Individual**: knowledge, skills and attitude
- Interpersonal : social networks, family and friends
- Organizational: institutions and workplace policies
- Community: societal beliefs, norms and values and
- **Public policy**: national laws and policies (59).

# 2.4.6 Adapted Framework for the Study

This study utilizes all the components of Stangl et al's, (2010) "HIV stigma reduction framework" (59). However religion has been included as part of the facilitators as it plays a key role in determining the occurrence or otherwise of stigma in the Ghanaian context; this adaptation was done during the course of the review as evidence highlighting the role of religion in Ghana emerged. The stigma reduction framework is presented schematically in figure 4.

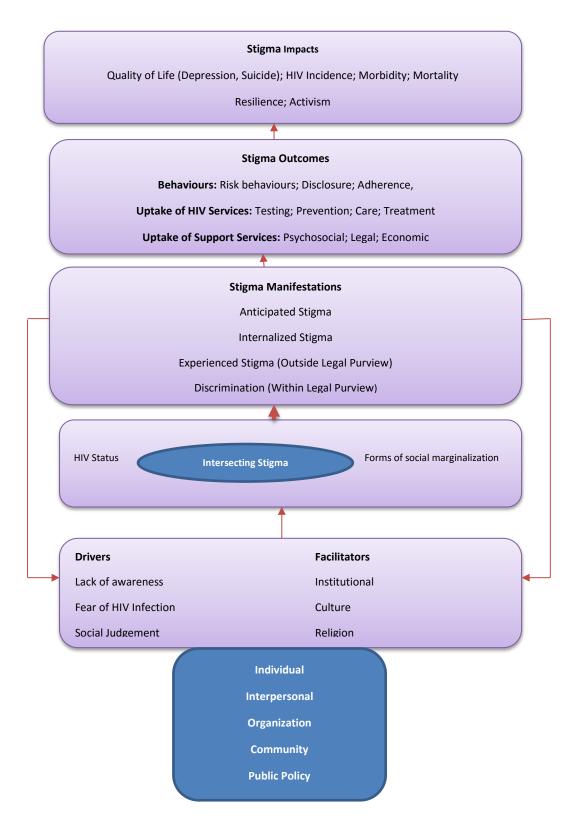


Fig 4: Stigma Reduction Framework; as cited in Nayar et al, 2014 (59)

# **Chapter 3: Literature Analysis**

This chapter begins with an overview of theories on stigma, discrimination and HIV. This is followed by a review of literature from Ghana, using the domains of the "HIV stigma reduction framework" specifically examining the drivers, facilitators, intersectionality, manifestations, outcomes and impacts of HIV-related stigma in the healthcare delivery system.

## 3.1 Theories on the Concept of Stigma and Discrimination

Sociologists and anthropologists have viewed the concept of stigma from individual and societal dimensions and underscored its relevance in preserving inequalities in the society (61,63,66). Stigma has existed for many centuries and have related to diseases such as leprosy, mental illness, tuberculosis among others (37,46).

Goffman, proposing the social identity theory in 1963 (69), described stigma as "an attribute that is deeply discrediting" which an individual possesses (also alluded to by Gilmore and Somerville, 1994 (64). Goffman argued that stigma occurred when an individual's perception of himself ("actual identity") was different from societal expectations ("virtual identity") resulting in unacceptable differences ("spoiled identity") (69). He suggested that individuals may possess physical (deformities), behavioural (individual character) or social traits (tribe, race) which may be different from societal norms (69). These attributes undermine the individual's status from the societal viewpoint (69). Although Goffman's theory placed emphasis on individual attributes that distinguished a person from those perceived as "normal" by society, he also highlighted the need to understand stigma in terms of social relationships (69).

There have been extensive studies on the concept of stigma after Goffman's initial concept. Link and Phelan widening Goffman's concept examined stigma from the sociocognitive perspective and the broader social processes involved (70). In this theory, stigmatisation is exclusively subject to the presence of underlying social, political and economic power (70). It begins with an initial labelling of human differences by society (64,70). Labelling here, highlights the importance of categorization assigned to stigmatized individuals by others instead of just the individual attribute (70). This labelling results in the creation of negative stereotypes against individuals who possess perceived unacceptable traits; leading to categorization of labelled persons and separation of "us" from "them" (70). This culminates in an eventual loss of status and discrimination for such persons (70). They associated the occurrence of stigma to the convergence of these five complemental components (70).

In recognition of the social processes involved, other anthropologists analysed the concept of HIV-related stigma by associating it with complex cultural, power, and control systems which are intrinsically linked to social and structural inequalities (61,64). In the view of Parker & Aggleton (2003), stigma occurs when "culture", "power" and "difference" combine and therefore understanding this relationship is crucial to analysing the concept of stigma and discrimination (61). Stigmatisation therefore provides a mechanism of preserving inequalities, exercising power and social control through marginalization of those with real and perceived differences (61,64).

Deacon (2006), acknowledged the individual and social dimensions involved in stigma and suggested that the concept of stigma be separated from discrimination to allow for wider examination of the repercussions of stigma including other forms of disadvantages such as self-doubt and internalization of stigma (68). She also challenged Link and Phelan's concept about stigmatisation as eventually and exclusively leading to loss of status and discrimination, suggesting instead that stigmatisation could also lead to positive outcomes including resilience, self-empowerment and activism (64,68).

The conceptualizations of stigma and discrimination have an effect on the design of stigma-reduction interventions and their effectiveness; highlighting the need for the development of a comprehensive concept. Based on the concepts of stigma and discrimination described above, the next section reviews theories explaining HIV-related stigma.

# 3.2 Understanding HIV-related Stigma

Persons with different diseases experience varying degrees of stigma with some attracting higher degrees of stigma than others (71). There is a high level of stigma attached to HIV and several theories have been used to understand HIV-related stigma.

UNAIDS (2000) citing De Bruyn (1999) outlined five attributes of HIV and AIDS that contribute to its stigmatisation (58); also suggested by Gilmore and Somerville (1994) (64). They included peoples' perception about the perceived incurability and fatality of HIV before the introduction of ART (58,64). Metaphors used to describe HIV at the onset portrayed it as "horror", "death", and "punishment" thereby providing a form of veracity to the stigma associated with it (58). Religious beliefs generate assumptions that HIV is a punishment for immoral behaviours (58,64). Inadequate knowledge, misconceptions and fears about the contagiousness of HIV have an influence on stigma (58,64). Furthermore, HIV has been linked with behaviours already stigmatized in the society such as SWs, MSMs and PWIDs (58). This association with perceived morally unacceptable behaviours intensifies HIV-related stigma (29,58). From the societal perspective, people who live irresponsibly (23); outside the values of society should be blamed for getting infected (72). As a result, PLHIV are held responsible for the behaviours that

led to contracting HIV; the consequence of which is stigma (58). Ogden and Nyblade (2005) identified efforts by society to distinguish PLHIV who get infected through perceived deviant behaviours and those considered as "innocent victims" such as HCW who get infected during their work, children who are infected through vertical transmission, and persons infected through procedures like blood transfusion (73).

Castro and Farmer using a structural violence framework to explain HIV related stigma examined the importance of broad social forces which influence its occurrence (72). The forces identified included racism, sexism, political violence, poverty, other social inequalities as well as economic and historical factors (72). For example, based on this construct, women who are PLHIV living in societies where gender inequalities are highly prevalent will experience more stigma while poor PLHIV living in societies where economic status is important will experience more stigma (72). They stressed the need to address these social forces in stigma reduction programmes (72).

Gender based studies, utilizing the socio-psychological perspective delineated the importance of gender inequalities and power relationships, alluded to by Parker and Aggleton (61) in HIV-related stigma (66). They have proposed that socially constructed relationships that devalue women are highly essential in understanding and tackling HIV-related stigma and discrimination in many societies (66). In societies where women are socially disadvantaged, females living with HIV receive higher intensities of blame and judgement than males (66). Conversely, other studies have reported men experiencing higher stigma than women in societies where men are disadvantaged (74).

Theories on HIV-related stigma highlight the multifaceted nature of stigma experiences which may vary from individual to individual across different contexts (75,76). Different concepts are thus needed to understand the domain of HIV-related stigma comprehensively.

# 3.3 Drivers of HIV-related Stigma and Discrimination

This section analyses the drivers of HIV-related stigma in the healthcare delivery system of Ghana. The fear of infection; lack of awareness and social judgement are analysed.

#### 3.3.1 Fear of HIV infection

Research has identified lack or inadequate knowledge of HIV and its transmission by HCW resulting in irrational fears of contagion as important contributors to HIV-related stigma (23,53,77). Although this description has been attributed to persons with little education on HIV, HCW have also demonstrated limited knowledge and understanding about HIV transmission (31,77). This results in use of excessive precautions like masking and double gloving in their interactions with PLHIV; even in situations of casual contacts (23,33,34,78). These actions to manage their fears were sometimes based on

the individual HCW's personal attributes and perception of what constituted a risk (33).

Hesse et al (2006) found that in one of Ghana's tertiary facilities, contrary to 92% of medical doctors claiming adequate knowledge about HIV, only 72% had actual comprehensive knowledge about its transmission whilst 36% would hesitate in performing invasive procedures on PLHIV due to fears of infection (77). Medical personnel in this study also lacked sufficient knowledge about universal basic precautions (77). Similar findings were reported by Awusabo-Asare (1997) a study in another facility in Ghana (53). However, Awusabo-Asare (1997) again found that some medical personnel were hesitant in treating PLHIV notwithstanding of adequate knowledge (53). The fears exhibited by HCW in this study could also be attributed to the unavailability of protective equipment (53). Dako-Gyekye et al (2015) and Mill (2003) have also documented similar findings in their studies (31,39). One participant in the study by Dako-Gyekye et al (2015) described how her doctor became apprehensive when she disclosed her HIV status and his discomfort in treating her whilst another remarked about relative lack of exposure and understanding of HIV transmission by HCW in another facility (31).

However, the above studies did not review the nature and quality of training provided on HIV to HCW which could have had an influence on the knowledge gained. Studies conducted among HCW in other countries have produced similar results (79,80). Several studies have recommended that equipping HCW at all levels with sufficient knowledge on HIV to reduce the stigma associated with it (31,53,77).

#### 3.3.2. Lack of Awareness about Stigma

Many studies have highlighted the lack of awareness and insight by HCW into their own stigmatizing attitudes against PLHIV and their consequences (79,81). Although empirical studies on awareness of stigma amongst HCW in Ghana are unavailable, findings from other studies on HIV-related stigma in the healthcare setting in Ghana indicate that many HCW lack sufficient awareness about their stigmatizing attitudes (34) and its effects PLHIV (34). This was corroborated in the research by Rogers et al on "layered stigma among healthcare and social service providers toward key affected populations (81). Here, it was found that although HCW exhibited negative attitudes toward PLHIV, they did not regard such behaviours as stigmatizing (34).

In Ghana, HCW routinely reinforced secrecy and discouraged PLHIV from disclosing their status to relatives; that inadvertently fuelled the stigma associated with HIV (39). Mill (2003) found in certain instances that, even when patients had voluntarily decided to disclose their status to relatives, doctors had recommended that they kept their status a secret; reinforcing the

shame associated with HIV (39). In certain situations, HCW did not disclose patients' diagnoses to them with the notion that patients' condition would deteriorate further if they knew their diagnosis (39). Although HCW viewed secrecy of HIV diagnosis as way to protect their patients from stigma, this conversely, but not unexpectedly undermined self–worth and increased self-stigma among patients (31,39).

While these studies were not explicit about HCW insight into stigma, inference from the findings demonstrate a crucial lack of awareness which can be linked to inadequate training about stigma, norms, absence of clear policies on stigma and personal attributes of HCW such as inexperience and beliefs (33,50). Dawson-Amoah (2015) found that only 56.6% of respondents in a teaching hospital in Ghana had received any training on stigma and discrimination whilst 22.4% had training on key populations' stigma and discrimination (33). Although the details in other primary, secondary and tertiary facilities are not available, Dawson-Amoah (2015) and Dako-Gyekye et al (2014) observe that the situation in most facilities is probably as unsatisfactory (31,33).

# 3.3.3 Social Judgement

HCW are members of society who may ascribe to religious and socially conservative beliefs, values, and norms (33). Dawson-Amoah (2015) suggested that the judgmental attitudes of HCW was a reflection of society's perception of HIV infections being a consequence of immoral behaviours (33). As a result, HCW exhibited attitudes that seemingly put blame on PLHIV for getting themselves infected (34). Moral judgmental attitudes documented included negative comments by HCW about lifestyle, lack of respect, neglect, and being treated ignominiously (37).

HCW because of their education, profession and respect by the society (57) assumed a position of power that somehow legitimatized their passing judgement on the perceived moral integrity of PLHIV (31,34). This substantiates the unequal power relations between HCW and patients in HIV-related stigma alluded to by Parker and Aggleton (61). An HIV-positive MSM in a study in Ghana described how his doctor screamed at him and threw him out when he told him about his sexual orientation (40). Rutledge et al (2009) found similar results in a study in the Caribbean where some HCW use their positions of power to condemn patients for their behaviours as though they were providing health education (82).

Differential treatment of PLHIV has been documented with key populations infected with HIV receiving greater stigma from HCW than others in Ghana (33). SWs and MSMs experienced more stigma than those perceived to be at a lower risk (33). These relate to symbolic stigma associated with behaviours perceived by society as a deviation from normal.

## 3.4 Facilitators of Stigma

The following section proceeds from the drivers of stigma to analyse organizational level factors that facilitate HIV-related stigma in the healthcare delivery system. They include institutional policies, service delivery and human resource factors.

#### 3.4.1 Institutional Policies

The literature revealed that some institutional policies and practices in health facilities may foster stigma against PLHIV (83). Although some of these practices were initiated to protect PLHIV from stigma, they may in some instances exacerbate HIV-related stigma (83). For example, segregation is used by health facilities to separate HIV-infected patients from non-HIV infected patients; often this is done to protect HIV-positive patients from acquiring opportunistic infections (34). According to Goffman (1963), segregation also enhances coping by enabling individuals newly diagnosed with a stigmatized condition (for example HIV) to associate with persons with a similar diagnosis (69).

In Ghana, segregation has been reportedly employed to deliberately distinguish PLHIV from other patients (31,34). Studies show that PLHIV in some hospitals received treatment from designated places known as "Fevers Unit" (23,31,39); or were isolated on side wards when they were on admission (34). This practice served as a way of demarking PLHIV as anyone receiving treatment there was instantly suspected as being HIV-positive (34). Conversely, PLHIV who were admitted in the same wards as other patients complained about the possible of disclosure of their status to other in-patients (34). Such clients felt that being segregated from the general population enabled them to effectively keep their status a secret from others (34,84). Studies to assess the impact of segregation on PLHIV in health facilities in Ghana will be prudent.

Dako-Gyekye et al (2015) observed that PLHIV in their study expressed reservations about the size and colour of their folders which were different from other patients as well as Wednesdays designated for them to receive treatment (31). These policies led to unintended disclosure of their statuses to other people (31). In certain health facilities in Ghana, the designated places for PMTCT are boldly labelled thereby revealing the status of pregnant women who went there (85). According to HCW, some of these practices were aimed at alerting their colleagues on the status of patients in their care to protect them from the risk of infection (34).

Whilst policies and guidelines on the treatment of PLHIV were absent in some facilities (50), Mensah (2012) and Laar et al (2014) found that institutional and structural arrangements with respect to ART clinic locations in some facilities in Ghana again did not provide the privacy expected by clients

(34,85). In this situation, clients viewed the location of services as "open" potentially exposing them to stigma (34). Conversely, medical personnel felt that such locations allowed for the easier accessibility for everyone especially very sick clients (34).

In understanding the different perspectives by PLHIV and HCW, Lin et al (2009) argue that stigmatising intent may be different from actual stigmatizing behaviours (86). According to them, stigmatizing behaviours occur as a result of a mixture of factors such as personal attitudes, societal norms and situational cues (86). Also, the interpretation of certain behaviours and practices by HCW as stigmatizing or not by PLHIV may be influenced by previous experiences and societal norms (86).

Notwithstanding these, the literature has shown that behaviours and practices that may seem harmless to health providers may be stigmatizing to PLHIV (31). Practices such as segregation although done with a good intent may lead to the unintended disclosure of the status of clients in health facilities to third parties possibly exposing them to stigma (31).

# 3.5 Service Delivery and Human Resource Factors that Promote Stigmatisation

Studies have shown that personal attributes of HCW such as entrenched beliefs may influence their attitudes towards PLHIV whilst service delivery factors may influence the willingness of HCW to provide services to PLHIV due to their perceptions of risk (53). The next sub-section examines these factors.

# 3.5.1 Culture and Religion

In Ghana, religious and sociocultural beliefs were found to be influential in determining what society perceived as right from wrong (42,43); and these may have an influence in stigma and discrimination practices in health facilities (87). Mill (2001) found that some HCW, based on their religious beliefs; also attributed HIV to immoral behaviours (87). One of the participants in Mills (2001) study described how her doctor informed her that she had contracted the "bad" disease; indicating the stigma associated with HIV (87). While this study was done 15 years ago, based on my experiences, such views remain common, and it would not be inaccurate to suggest that many patients continue to have the kind of experiences described by Mill (2001) fifteen years ago (87).

# 3.5.2 HCW apprehensions about HIV and occupational risk

In many studies, HCW have expressed their own anxieties about HIV and their ineptitude in dealing with PLHIV; which may have resulted in unintentional discrimination against PLHIV (50,88). According to Laar et al (2013), older nurses in a Ghanaian study had argued that their training had not equipped them with requisite competencies to handle PLHIV and expressed the need for further training (50). One participant remarked that:

"I completed midwifery school about 21 years, when we were in midwifery school HIV was not in the curriculum we didn't hear much about the HIV" (50)

This has resulted in the lingering fears they have in their interactions with PLHIV (50). The absence of clear policies and guidelines in many facilities on the treatment of PLHIV contribute to this (50).

### **3.5.3 Service Delivery Factors**

Asare and Marfo (1997) identified inadequate supply of protective equipment in poorly resourced facilities leading to perceived high risk for infection are some of the reasons contributing to stigma and discriminatory attitudes from HCW (53). This results in HCW perhaps justifiably using protective equipment only when working on PLHIV (53).

## 3.6 Intersectionality of HIV-related Stigma

Crenshaw (1989), invented the term intersectionality to delineate the multidimensional nature of oppression experienced by individuals (89). She emphasized on understanding discrimination against black women on the basis of the simultaneous operation of sexuality and racism; and not either one alone (89). Subsequently, the concept of intersectionality has been used to understand the concurrent interactions between biological, social and cultural identities in different contexts (90)

In the field of HIV-related stigma, this has been referred to as double, layered, multiple or compounded stigma to acknowledge the connection that exists between HIV-related stigma and other manifestations of social marginalization related to gender, caste, ethnicity, sexual orientation, social class, socioeconomic status and disability among others (61,83,91). Studies have found that individuals and groups who are already marginalized by society experienced stigma differently from those who come from otherwise not marginalized groups (33,81,83,92). In Ghana, SWs, PWIDs and MSMs are populations that face a lot of stigma (81,91). The laws of Ghana criminalize MSMs describing them as "unnatural canal knowledge" which potentially legitimatizes stigma against them (29,93)

Rogers et al (2014) found that there is a relationship between already existing prejudices in the society and the stigma faced by PLHIV in health facilities (81). They found that notwithstanding HCW assertions that PLHIV, SWs and MSMs had the right to quality healthcare, they still demonstrated prejudices and blame towards them (81,94). PLHIV who were MSMs and SWs received the highest levels of stigma (81). In Ghana, it has been found that women experienced higher levels of stigma than men because of gender inequalities, lower status and socially ascribed gender roles (28). While men may be culturally permitted to have multiple partners, women are disallowed; therefore unmarried women diagnosed with HIV were perceived to have breached a social norm (28).

Figure 2 depicts the innocence-guilt continuum (73) which shows the extent of stigma faced by different categories of people. From the societal perspective, it projects that key populations are guiltier of contracting HIV than for example children who get infected from their mothers or HCW who are infected in the course of their work (73).

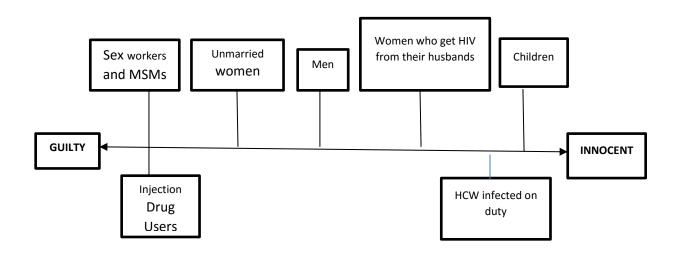


Fig 5: Schematic of the Innocence-Guilt Continuum (adapted from Ogden and Nyblade 2005 (73)

HCW are part of society and may be influenced by societal norms, values and religious beliefs (42,43). Their inability to decouple these norms and beliefs from their professional obligations results in stigmatizing and discriminating attitudes at work.

Again Dawson-Amoah (2015) found that among HCW in one tertiary facility in Ghana, 75.6% had not received any training on key populations' stigma and discrimination occurrence (33). However, in another tertiary facility, where respondents reportedly experienced no stigma or discrimination from HCW at the "Fevers Unit", it was found that the HCW had received extensive training on stigma and discrimination (31). This indicates that the level of training of HCW on stigma and discrimination has an influence on the occurrence of stigma and discrimination.

According to Chambers (2015), stigma in health facilities reflect societal views on HIV transmission, the personalities and professions of people that get infected (83). As a result healthcare settings become places where the views and perceptions about HIV by society are reinforced with the healthcare workers as the main protagonists (83). Also, healthcare settings in Ghana provide an avenue for the institutionalization of societal norms, values and

domination as clients occupy a subordinate position compared to HCW as identified by Parker and Aggleton (57,61,83).

# 3.7 Stigma Manifestations

The literature identified several ways by which stigma and discrimination are experienced by PLHIV in the health environment categorized in into anticipated stigma, internalized stigma, experienced stigma and discrimination (31,83). The next section describes the manifestations of HIV-related stigma.

# 3.7.1 Anticipated Stigma

The fear of stigma from HCW may lead to the non-disclosure of HIV status by PLHIV when they access healthcare services (31). Dako-Gyekye et al found that expectations of poor treatment from HCW prevented many PLHIV from disclosing their status in hospitals (31). According to Collymore (2002), PLHIV might not utilize health services because of the fears that individuals who are HCW in their societies that had shown negative attitudes towards them might blatantly discriminate against them in healthcare settings (91).

Dako-Gyekye et al (2015) also found that PLHIV commuted to hospitals and health centres very distant from where they resided for treatment to avoid stigma and discrimination from HCW who were also members of their own communities (31). In situations where PLHIV had not been stigmatized against in facilities in their communities, they were still unwilling to attend those facilities; some of them partly due to previous bad experiences from medical personnel whilst others are due to fears of stigma from the community (31). Again, fears of stigma by HCW might prevent or delay individuals from getting tested and utilizing health services altogether (30,83).

# 3.7.2 Internalized Stigma

Internalized stigma is characterized by feelings of blame, shame and worthlessness by PLHIV (73). This occurs when PLHIV ascribe stigmatizing beliefs from their communities unto themselves (73). According to Mensah (2012), PLHIV described situations where they could not complain about the poor quality of healthcare they received in some Ghanaian hospitals due to the fact they believed they deserved such treatments because of their HIV status (34).

Mill (2003) also found that societal perceptions about HIV and AIDS being associated with deviant behaviurs led to individuals feeling a sense of disgrace when diagnosed (39). Relatives as well felt a sense of shame when providing care to their HIV-positive family members and therefore put in great effort to hide this care giving from others; a situation compounded by the negative treatment from HCW (37). Internalized stigma potentially leads to psychological distress which has a negative effect on the utilization of health services and adherence to treatment (39)

As discussed earlier, the secrecy promoted by health works in the disclosure of HIV-positive status enhanced internal stigma among PLHIV (39).

#### 3.7.3 Experienced Stigma and Discrimination

The literature discussed the poor quality of services received by PLHIV in certain health facilities (31,33,34). Participants in a Ghanaian study described how they were the last to be seen in out-patients clinics when their status is known by HCW (31) while in-patients described how they were neglected while on admission as well as the little time spent by their bedside relative to other patients by HCW in comparison with other patients (34). In certain situations, HIV tests were done without the consent of patients (53). Some nurses confirmed that some of their colleagues gave poor nursing care including verbal abuse and gossiping to PLHIV admitted in the wards once they knew their status whilst another study found occasional refusal by physicians and paramedics to perform surgery on PLHIV (34,53).

The literature also identified violations of confidentiality by HCW as part of the stigma faced by PLHIV in health facilities (31,34,41). Nurses sometimes consciously or unconsciously disclosed the status of PLHIV in their care to their colleagues who may not be directly involved in their care as well as other patients and relatives; attributing it to the need to alert their colleagues to take precautionary measures (34). Some HCW were also found to reveal the status of their clients to relatives and people in the community (28,40,41,34,84).

Asiedu & Myers-Bowman reported that in certain HTC centres, it was obligatory for clients to disclose their status to relatives as a prerequisite for the initiation of ART (28) as was corroborated by Mensah Dapaah (2012) in another study (34). This compelled PLHIV to reveal their status even when they did not want to. It has also been documented that in certain health facilities, initiation of certain forms of contraception was required before ART was provided to women (41). According to Dako-Gyekye et al, PLHIV reported that attitudes of HCW in some facilities including doctors and nurses became unfriendly towards them when they disclosed their status (31).

Breaches in confidentiality of PLHIV in healthcare settings had a negative effect on the health seeking behaviours of PLHIV (34).

## 3.8 Stigma Outcomes

The stigma associated with HIV has been linked with negative outcomes for PLHIV. The adapted framework highlights three key areas where the outcomes of HIV-related stigma are experienced including behaviours; uptake of HIV services and support services (59). Findings in the context of Ghana are presented in the next section.

#### 3.8.1 Behaviours

Non-disclosure of HIV status to medical staff is used by PLHIV to avoid stigma and discrimination (31). Dako-Gyekye et al found that clients refused to disclose their HIV-status to HCW in health facilities fear of potential embarrassment (31).

Fears of stigma in health facilities may also have affected the health seeking behaviours of patients as some patients reported to the health facilities late when their conditions had deteriorated (34). These fears may have a negative effect on health promotion programmes spearheaded by HCW such as HTC (63). In health settings where ART centres are labelled, clients devised means to sneak in and out of the facility; to avoid being seen which affected access to HTC and adherence to treatment (39).

#### 3.8.2 Uptake of HIV Services

The literature suggested that stigma in health settings may be one of the key reasons for the under-utilization of health services such as HTC, PMTCT and accessing care and treatment when diagnosed (31,34). In the study by Apanga et al (2015), whilst 91% were aware of HTC services, 53% perceived stigmatisation as a barrier that would prevent them from using the services (30). Again, previous experiences of stigma in health facilities discouraged PLHIV from using services (34). A participant in a research described how nurses in a maternity ward discriminated against her and also disclosed her status to her partner which led to the breakdown of her marriage (34). She decided not to use the facility again and to discourage other pregnant PLHIV from going there (34). These are potential obstacles to accessing ART and adhering to treatment regimen (41,83).

It has also been documented that experiences of stigma and discrimination in health facilities reduced good adherence to antiretroviral therapy (95). Mensah (2012) found that in many instances when clients were discriminated against in health facilities, they were not likely to return or adhere to their medication (34). Stigma associated with segregated units for PLHIV in many facilities have resulted in patients refusing treatment as their status will be known by anyone who saw or visited them there leading to poorer outcomes (39).

#### 3.8.3 Uptake of Support Services

Support services available to PLHIV include legal support to seek redress and social support groups (32,34). Studies have shown that perception and experiences of stigma and discrimination may discourage PLHIV from using such services (32). In respect of utilizing legal support, one participant in the study by Wright and Mwinituo, (2010) remarked that:

"Who am I to go about reporting people? If the people don't want me, what else can I do (in a very sad mood)? You see, the more I pursue these things about discrimination, the more I am exposed to the public" (32).

PLHIV are thus discouraged from using support services.

#### 3.9 Stigma Impacts

The occurrence of stigma in health facilities and in communities may have very negative long term impact on health (33). PLHIV who experienced remarkable stigma and discrimination have reported psychological distress symptoms including anxiety, depression, low self-esteem, isolation and suicidal ideation (31,32,34) which impact negatively on the quality of lives of PLHIV and adherence to ART medication (31,34). Non-adherence to ART medication and delays in seeking treatment resulted in increased morbidity and mortality among PLHIV (31,34)

However, some PLHIV continued to use health services in spite of stigma because of the benefits they obtain from treatment (34) whiles some become advocates and role models for change in their communities (31). "Models of Hope" initiative in Ghana train PLHIV to provide care, support and inspiration to other PLHIV (41,96). This highlights the resilience and activism that can be derived from stigma and discrimination.

# 4.0 Chapter 4: Evidence-Informed Interventions to Reduce HIV-related Stigma

This chapter presents a review of policies and interventions utilized to address HIV-related stigma in Ghana. In the process, gaps are identified in the current policy, programme and service delivery processes. The final section presents a review of evidence-informed intervention to address the gaps identified in the Ghanaian context.

#### 4.1 Policy-response to HIV-related stigma and discrimination

The Ghana AIDS Commission working in collaboration with the MOH and NACP is the body mandated to co-ordinate the national response to the HIV epidemic (25). It works in active partnership with NGOs, community-based organizations, private sector, faith-based organization, PLHIV and civil society organizations to implement HIV programmes in the country (25). The revised National HIV and STI Policy, 2013 was developed by these stakeholders in accordance with the National Public Health Act, 2012 (97). This policy acknowledges the need to protect the inalienable rights of PLHIV and their families and advocates for the passage of *HIV and AIDS Prevention and Control Law* which addresses different aspects of the HIV-epidemic including stigma and discrimination (97). Specific programmes and strategies utilized to address stigma in the community and healthcare delivery system are presented below.

#### 4.2 Education Programmes

Education programmes are aimed at providing accurate information to the public and improving their knowledge on HIV transmission, stigma and discrimination (41).

## 4.2.1 Sensitization and Media Campaigns

Ghana's first national mass media campaign on HIV and stigma was the "Stop AIDS, Love Life" campaign launched in 2000 to "shatter the silence" surrounding HIV and AIDS (98). This campaign aimed at increasing national dialogue on HIV. Serial dramas, radio, television spots and handouts were used to raise awareness about HIV, stigma and discrimination (98).

### 4.2.2 Training of HCW

The NACP working in collaboration with the GHS through the LINKAGES programme provides training to peer educators and HCW providing ART and HTC and to enable them care in a stigma free environment (99). In addition to these, outreaches are done in the communities as well as phone-in help-lines (99).

## 4.3 Involvement of PLHIV in Stigma Reduction Programmes

The GAC has actively engaged PLHIV to spearhead programmes aimed at reducing stigma and discrimination in the community, work place and health institutions (41).

#### 4.3.1 Engagement of PLHIV in Service Provision

PLHIV have been trained and engaged in health facilities to provide services at ART centres (31) while others served peer educators known as "Models of Hope" (34). They trace treatment defaulters and provide counselling to PLHIV (96).

# 4.3.2 Involving PLHIV, Religious and Community Leaders in Advocacy

The GAC has involved PLHIV as well as community and religious leaders in programmes aimed at reducing stigma and discrimination in Ghana. These include the "Anti-Stigmatisation Campaign Project" (23,100) and the "Heart to Heart" Campaign (24).

#### 4.4 Social Support

Peer support groups have been formed in hospitals and communities to provide PLHIV with practical support when they are newly diagnosed, treatment adherence and handling experiences of stigma and discrimination they are confronted with in their daily lives (31,83). Many PLHIV found the support from these groups which form the Network for Persons Living with HIV and AIDS, Ghana as key in helping them adhere to treatment and enabling them to overcome internal stigma (31,101). Non-judgmental and empathetic attitudes from the HCW were also found to be important sources of support for PLHIV (31,34)

#### 4.5 Legal Redress

The Commission for Human Rights and Administrative Justice and the Legal Aid Scheme are mandate to assist PLHIV in cases of stigma meted-out against them (97). However, the operation of these two bodies have been hindered by inadequate resources for them to function effectively; this has limited their impact (41).

## 4.6 Gaps in the current interventions

Findings show that while they are responses to address HIV-related stigma amongst the general population, explicit interventions targeted at the healthcare delivery system are limited. This has resulted in gaps in interventions at the healthcare delivery system which are presented below

## 4.6.1 Social Prejudices of HCW and Legislation

The policy options that have been used to address stigma and discrimination against key populations such as MSMs, SWs and PWIDs do not reconcile with the social and legal environment. In addition to sociocultural prejudices against PLHIV and key populations which are still widely held among Ghanaians, the laws of the country criminalize key populations (46) which makes the implementation of these policies untenable.

Again, health programmes and life skills education for schools do not include awareness creation about stigma. This would have initiated stigma reduction interventions from childhood resulting in a bigger impact in adulthood. As a result, interventions to address HIV-related stigma against key populations have been largely ineffective (41).

#### 4.6.2 Service Delivery

Certain service delivery arrangements facilitate the occurrence of stigma in the healthcare delivery system which have not been addressed with the current interventions. These include factors related to the unavailability of protective supplies for HCW to enable them practice universal precaution in poorly resourced settings (53).

#### 4.6.3 Institutional Policies

The interventions do not address the absence of clear policies and guidelines in on the care and provision of services to PLHIV in many health facilities (33,50).

#### 4.6.4 Knowledge and Role Capacity of HCW

Stigmatization in the healthcare delivery system has been linked to the lack of comprehensive knowledge of HCW about HIV (31,34). This results in weak capacity to fulfil the roles expected of them in their interactions with in a manner that is not stigmatising. Although some training has been done for HCW working directly with PLHIVs in ART centres (99), these interventions do not address the knowledge and training needs of all HCW including hospital guards, cleaners and other support staff who also interact with PLHIVs.

4.7 Evidence-Informed Interventions to Address HIV-related Stigma Systematic reviews which have been conducted on HIV-stigma reduction interventions globally have identified evidence informed intervention to reduce HIV-related stigma (63,88,102). Brown et al. (2001) and Sengupta et al (2011) broadly categorised the interventions into information-based approaches, skills building, support and contact with affected groups (88,102). In addition to these, Stangl et al (2013) included structural and biomedical intervention categories (63). Evidence from these reviews suggest that a combination of interventions was more effective in reducing HIV-related stigma than single interventions (63,88).

While the focus of this study is limited to HIV-related stigma in the healthcare delivery system, evidence will be drawn from the systematic reviews and empirical studies used in these reviews to address the gaps identified in the Ghanaian healthcare delivery system. Their applicability to, and feasibility in the Ghanaian healthcare delivery context is reflected upon.

#### 4.7.1 Interventions to address social prejudices

Drawing evidence from the review conducted by Brown et al (2001) interventions to reduce prejudices and fears against PLHIV included training on HIV co-facilitated by PLHIV (88). Findings after the implementation of these interventions showed that participants re-examined their negative attitudes towards PLHIV (88). A classic example is seen in findings from a quasi-experimental study on HIV stigma reduction among HCW in Vietnam which utilized a participatory training approach on HIV and social stigma with PLHIVs as co-facilitators (103). It showed a significant decline in judgmental attitudes towards PLHIV from 56% to 31% in one facility and 31% to 17% in another facility (103). It is however notable that this intervention was combined with interventions at the organisational and service delivery level which may have had an influence on the result. In spite of this, such an intervention can be adapted and applied in the Ghanaian healthcare delivery system to reduce HIV-related stigma. Details of this intervention are presented in Table 3

#### 4.7.2 Interventions to address service delivery gaps

Based on insights from this study, it has been suggested that knowledge and skills development alone will not be effective HCW do not have the requisite information and protective supplies to practice universal precaution (53). Evidence of interventions at this level has shown that provision of information and supplies required for the practice of universal precaution by HCW such as gloves, sufficient water and soap significantly reduced the fears of occupational risk in caring for PLHIVs (103). Oanh et al (2008) found that after this intervention irrational use of barrier precautions by HCW decreased from 42% to 17% and 43% to 11% (p>0.001) respectively (103). However, it is also likely the gains in this intervention may have been influenced by the other interventions that were implemented simultaneously (103). Such an intervention can be adapted in combination with other interventions in Ghana.

## 4.7.3 Interventions to address institutional policy gaps

Evidence of interventions in this area shows interventions targeted at organisational change with health facilities enacting their own policies on the provision of care to PLHIVs for all categories of HCW with sanctions for recalcitrant HCW (67). Facility specific policies developed in a participatory manner with inputs from hospital managers, PLHIVs, clinical and non-clinical staff have shown a significant improvement in stigma reduction (103).

The study in Vietnam (103) used in the systematic review (63) offers an interesting practical example of how the above three evidence-informed interventions have been operationalized in the healthcare delivery system under a single programme. Here, facility specific interventions were developed

together with inputs from hospital managers, PLHIVs, clinical and non-clinical staff. Facilities developed their own policies and guidelines related to infection control, HTC, confidentiality and care of PLHIVs. Interactive training and skill development programmes were organized while policy booklets in simple language were distributed to all cadres of staff. The intervention resulted in health facilities acknowledging their own stigma practices and instituting measures to address them. Findings after this intervention showed significant improvement in understanding about universal precautions, HIV transmission, HTC and stigmatizing attitudes toward PLHIVs. (*Details are presented in table 3 below*).

Area of Intervention	Type of Study/ Stigma domains/ Socio- ecological level targeted	Intervention	Impact
Service delivery and Institutional Policies	Quasi- experimental with no control group  Stigma Domain Drivers Facilitators Manifestation  Socioecological level targeted Individual Organisational	Situational analysis by hospital managers to analyse discrimination practices in their hospitals;  Instituting a hospital steering committee  Development on action plans with clinical and non-clinical staff to address HIV-related stigma;  Developing and instituting a hospital HIV Care and Management Policy;  Developing a hospital universal precaution and infection control policy and education materials;  Hospital managers ensuring availability of supplies for universal precaution; (posters on handwashing, soap, water, alcohol dispensers, sharp containers)  Disseminating policies in simple language to all staff;  Training of all staff on HIV transmission and skills on universal precautions by experienced trainers  Training co-facilitated by PLHIVs with additional training on social stigmas;  Monthly monitoring and observation visits as well as feedback to managers	Policies instituted to address HIV-related stigma and discrimination.  Infection control procedures developed.  Significant decline in judgmental attitudes of HCW.  Percentage of HCW reporting judgmental attitudes decreased from 56% to 31% and 31% to 17% in the two hospitals respectively.

Table 3: HIV-related stigma reduction in Vietnamese hospitals Source: Oanh et al, 2008 (103)

Ghana can draw from this evidence and learn from Vietnam experience to implement these interventions in the country.

# 4.7.4 Interventions to address knowledge and role capacity of HCW gaps.

Further evidence from the review by Brown et al (2001) showed that interventions to improve knowledge through the provision of comprehensive and factual information on HIV resulted in increased knowledge about HIV among participants as well as significant change in negative attitudes as well as an increased willingness to provide treatment for PLHIV (88).

A randomized control trial in Nigeria which utilized this information-based approach showed that there was significant improvement in knowledge on HIV transmission, clinical skills related to providing care for PLHIVs, increased willingness to provide care for PLHIVs, reduction in stigmatization practices (104). Details are presented in Table 4 below.

Type of Study/ Stigma Domains/ Socioecological level targeted	Intervention	Impact
Randomized Control Trial	Assessing the knowledge of clinical staff	Improvement in knowledge on HIV transmission
<u>Stigma Domains</u> Drivers	Developing an interactive training module on HIV transmission, stigma and discrimination with inputs from initial assessment	Improvement in clinical skills related to providing care for PLHIV
Socioecological level Individual	Sensitization and training of trainers with experienced trainers using lectures, role plays, workshop, seminars and group discussions in an intervention group.  Trainers replicating trainings in the facilities for a period one year	Increased willingness to provide care for PLHIV  Reduction in stigmatization practices
	Stigma Domains/ Socioecological level targeted  Randomized Control Trial  Stigma Domains Drivers  Socioecological level	Stigma Domains / Socioecological level targeted  Randomized Control Trial  Randomized Control Trial  Stigma Domains Drivers  Developing an interactive training module on HIV transmission, stigma and discrimination with inputs from initial assessment  Sensitization and training of trainers with experienced trainers using lectures, role plays, workshop, seminars and group discussions in an intervention group.  Trainers replicating trainings in the facilities for a period one

Table 4: Evidence of knowledge-based intervention implemented in Nigeria. Source: Ezedinachi et al, 2002 (104).

#### 4.7.5 Responses proposed by UNAIDS

The UNAIDS makes key recommendations for governments to include programmes HIV-reduction in their national HIV responses (105).

- Stigma and discrimination reduction through community interactions with PLHIV, media campaigns, involvement of religious and community leaders, peer mobilization by PLHIV, anti-discrimination policies in institutions and the measurement of HIV-related stigma with the People Living with HIV Stigma Index.
- Legal representations for PLHIV to seek redress
- Updating laws, regulations and policies on HIV and human rights
- Education of PLHIV and those affected on laws and their rights
- Engagement of legislators and law enforcement agencies on human rights protection for PLHIV
- Training for the HCW on HIV, human rights and professional ethics and
- Reduction of gender-based discrimination against women in the context of HIV (105)

The UNAIDS makes specific recommendations for training on HIV-related stigma for health providers as follows (105):

- Raising awareness of individual HCW on HIV-related stigma as well as addressing the drivers and manifestations the earlier findings.
- Healthcare administrators addressing the facilitators of HIV-related stigma discussed earlier.
- Regulators of healthcare regulators ensuring that policies that protect the safety of HCW and clients and protecting the rights of PLHIV and key populations are passed and enforced (105).

#### **Chapter 5 Discussion, Conclusion and Recommendation**

This chapter presents a discussion of the major findings that emerged from the literature analysis categorized into concepts; factors underlying HIVrelated stigma; manifestations, consequences and interventions that have been implemented. This is followed by a summary of the findings and concludes with recommendations based on the findings.

## 5.1 Conceptualizations of Stigma and the "HIV Stigma-Reduction Framework"

HIV-related stigma has long been recognized as one of the obstacles to addressing the HIV epidemic. The continued presence of stigma in the last three decades has highlighted the fact that stigma-reduction interventions have not been completely effective or well implemented. Conceptualizations about stigma have evolved from a focus on individual attributes to the social processes that facilitate its occurrence. The stigma associated with HIV constitutes a part of entrenched social processes that result in social inequalities. They include poverty, culture, gender inequalities, racism and power differences, alluded to by Parker and Aggleton (2003) (61). While several conceptual frameworks have been used to understand stigma and to propose interventions to reduce it, many have ignored the inextricable structural factors such as legislation and policies closely aligned with stigma and which reinforce its occurrence. Ultimately, stigma is both a cause and a result of inequalities that permeate the society.

HIV, since its discovery has been linked socially marginalized behaviours such as SWs, PWIDs and MSMs. These have implications for interventions seeking to address stigma in the general community or sub-portion of the community such as the health care delivery system. HIV-related stigma in the healthcare delivery system is a manifestation of wider inequalities, stigma and discrimination in the general society. Any well-developed model on HIV-related stigma reduction must take a holistic view of the social contexts and the structural factors such as legislation and policies which are intertwined with inequalities and equity. The inputs of the socially marginalized are highly essential in any intervention strategy.

The "HIV stigma reduction framework" proposed by Stangl et al and utilized in this study recognizes these facts and incorporates the social and structural dimensions of HIV-related stigma such as legislation and institutional policies. It proposes various socio-ecological levels at which interventions to reduce stigma can be implemented and demonstrates a good starting point for a comprehensive framework to address HIV-related stigma. While a lot more research is needed to understand the complexities of social marginalization and HIV stigma, this framework integrates and acknowledges the significant role it plays in reinforcing inequalities. An evaluation of this framework in the

future will assist in determining its effectiveness in the reduction of HIV-related stigma.

# **5.2** Factors Underlying HIV-related stigma in the healthcare delivery system

Stigma and discrimination negatively affect the quality of life of PLHIV and their families. The stigmatisation process begins with factors which trigger the onset of stigma and are discussed below.

#### The role of societal values, culture and religion

The findings from this review indicate that comprehensiveness of knowledge about HIV transmission, universal basic precautions and HIV-related stigma by the HCW had an influence on occurrence of stigma in health facilities. Comprehensiveness of knowledge however varied across different categories of HCW with medical doctors exhibiting more in-depth knowledge than other HCW (33,53); consistent with studies done in Ethiopia (80). There were however disparities in the influence knowledge had on stigma; while some studies showed that knowledge influenced HIV-related stigma negatively (31,33), others showed that HCW exhibited high stigmatizing attitudes irrespective of comprehensive knowledge (77). These findings are supported by Brown et al (2001) in their systematic review of interventions to reduce stigma who found that information and education alone may not be adequate to reduce stigma due to deep-seated prejudices (88). Whilst information may provide knowledge; knowledge may not necessarily translate into behaviour change unless life skills to translate knowledge to behaviour are available.

In the Ghanaian context, the above findings underscore the broader relationship that exists between HIV-related stigma in the health system and entrenched societal values and norms; which play a significant role in the psyche of individuals. Culture and religion form a major part of an individual's development from childhood and through this certain values and beliefs may become entrenched in an individual. Attributing HIV to immorality and promiscuity could provide a basis for stigmatisation (106). As found by Mill (2001), HCW attributed HIV to deviant behaviours (87). These findings are consistent with findings from studies done in Zambia, Tanzania and Ethiopia (73). According to Chambers (2015), HCW may exhibit attitudes based on a pre-judgement of the characters of PLHIV which may manifest as stigma and discrimination (83).

While education and training may increase knowledge about HIV transmission among HCW, the sociocultural and religious dimensions will nevertheless persist. As a result, HIV stigma reduction programmes in the health system should must move beyond the conventional training and education programmes for HCW by taking a comprehensive approach that addresses sociocultural and emotional attributes of HCW as well.

## <u>Intersection of HIV-related stigma and the stigma associated with</u> <u>being from a marginalized group</u>

HIV was found to be attributed to behaviours that were deemed morally unacceptable to society such as MSMs, SWs and PWIDS. It shows the complex and dynamic nature of intersectional stigma when HIV-related stigma is linked with social prejudices. The healthcare setting therefore became the place for reinforcing dominant societal values so that groups that are already marginalized by society encountered further stigma in health facilities. Findings from this research reveal that key populations infected with HIV suffer higher levels of blame and judgement from health providers (33).

Multiple stigma in this study also emphasizes the important roles of culture, religion and societal values examined earlier. There is the inherent perception that HIV is self-inflicted and that infected persons consciously chose to engage in these unacceptable behaviours that put them at risk and must be punished (87). Laws that criminalize key population such as MSMs, IDUs and SWs provide some form of legitimacy to stigma. Whilst literature on the intersections of HIV-related stigma with socially marginalized populations are limited (especially in the Ghanaian context), findings in this review suggests a synergistic association between HIV-related stigma and other forms of social marginalization.

Further research on the relationship between HIV-related stigma and socially marginalized populations is necessary.

#### The role of institutional factors

Findings from this study also indicate that institutional factors like the availability of protective equipment as well as policies, logistic barriers and guidelines on the management of HIV in health facilities influenced the perceived risks of acquiring infection by HCW in their interactions with PLHIV (53). For example, the availability of gloves or not in poorly resourced setting may have influenced the decisions of HCW to selectively use universal precautions for only treating PLHIV or to essentially avoid them altogether. These findings resonate with findings by Vaishali et al (2007) who found that the unavailability of gloves and running water led to the selective use of universal precautions with PLHIV (55). More so, policies like segregation and isolation of PLHIV resulted in the inadvertent disclosure of HIV-status potentially putting them at risk for stigmatisation and discrimination. These findings show that stigma-reduction interventions in the healthcare delivery system may not work if the necessary supplies for HCW to practice universal precautions are not available.

## 5.3 Manifestations and Consequences of HIV-related stigma in the health delivery system

This literature review categorized the manifestations of stigma into four; anticipated stigma, internalized stigma, experienced stigma and discrimination with different examples across health facilities in Ghana (28,30,31,34). The findings indicate that while experienced stigma and discrimination have a negative impact on access, utilization of services and health seeking behaviours of PLHIV, internalized stigma impacted negatively on the mental and general health of PLHIV. Both may simultaneously have a negative effect on adherence to ART medication and subsequently quality of life of PLHIV. These findings are consistent with studies done in other contexts (55,56).

In order to circumvent stigma, PLHIV resorted to avoiding the utilization of health facilities, non-disclosure of their HIV status and non-adherence to ART. These behaviours led to increased morbidity and mortality among PLHIV as well as poor quality of life. On the contrary, other studies have found that behaviours to avoid stigma such as non-disclosure of HIV-positive status are survival strategies that may result in immediate benefit of preserving the self-esteem and reducing the stress and anxiety in PLHIV (107). In the longer term, however, it would still result in poor quality of life for PLHIV. PLHIV may be confronted with the dilemma of choosing to safeguard their health or circumventing stigma through non-adherence and preserving their self-esteem in the society. The decision lies in the priorities identified by PLHIV. These findings highlight the need to understand healthcare decision making by PLHIV from intrapersonal, interpersonal and social environment where they find themselves.

Other positive consequences of stigma such as activism and resilience were also identified where PLHIV overcome the stigma and become advocates in their communities. Findings on interventions for HIV stigma reduction have highlighted the importance involving PLHIV to ensure their effectiveness.

# **5.4 HIV-reduction interventions in the healthcare delivery system** Findings from the study suggests the need for HIV-stigma reduction interventions to target multiple domains and multiple socioecological levels. The contexts in which these interventions are expected to be implemented are also essential. While strategies aimed at improving knowledge, awareness and skills of HCW are essential, policies and legislations protect rights of PLHIV and ensure their ability to seek redress when these rights are violated are critical to the success of these interventions. The UNAIDS advocates that appropriate legal structures be established to ensure that these strategies

work while measures are put in place to enable to ensure that HCW feel safe in their working environments. Findings reveal that a combination of one or more interventions may be needed in this respect and a concerted effort from all stakeholders is needed to help reduce stigma. Evaluation studies are needed to analyse these effectiveness intervention strategies.

Several feasible interventions have been illustrated in this study. What is required now is the availability of funding and political will to ensure that these interventions are implemented.

#### 5.5 Conclusion

HIV-related stigma in the healthcare delivery system has been recognized to impact negatively on the health seeking behaviours, quality of treatment and lives of PLHIV. It is also known to affect the preventive strategies aimed at addressing the HIV-epidemic. The review of literature on HIV-related stigma in the healthcare delivery system has shown that its occurrence in the health environment is shaped by social processes and structural factors across different contexts. The study examined theories that have been used to understand HIV-related stigma and found the crucial role played by power, culture and differences that promote inequalities in the society.

HIV-related stigma in the health care delivery system is shaped by individual health worker factors and institutional factors such the absence of clear policies and guidelines on universal precautions and HIV-stigma in health facilities. The manifestations of stigma within the healthcare delivery system shows the dynamic relationship that exists between HIV-stigma and the stigma faced by marginalized groups in the society. The study also identified strategies used by PLHIV to circumvent stigma in the healthcare delivery stigma in the health care setting.

The study also presented several interventions that have been used to address HIV-related stigma and discrimination. It identified the importance of including PLHIV in formulating intervention to address HIV-related stigma and discrimination in the healthcare delivery system. The importance of legal and policy reforms that decriminalize key populations such as MSMs, PWIDs and sex workers in addition to legal representations for PLHIV to seek redress during instances of stigma and discrimination were established.

#### 5.6 Recommendations

The recommendations for programmatic actions to reduce HIV-related stigma in the healthcare delivery system in Ghana are made based on the findings of this study. They are categorized into the roles expected to be played by the various stakeholders involved in HIV-programmes in Ghana

# **5.6.1** Recommendations for policy makers (Government, MOH, GAC NACP, Donors)

 Anti-stigma and discrimination policies in the National HIV and STI policy should be strengthened and enforced across all institutions especially the health care delivery system. This policy should be disseminated to networks of PLHIV, key populations, HCW and the general public to increase awareness about the basic human rights of all people. The National HIV and STI policy can be simplified into a simple language and translated into the various local languages to ensure easy comprehension amongst all people.

- HCW and PLHIV should be actively involved in the development of specific policies for targeted at reduction of HIV-related stigma in the healthcare delivery system
- There should be regular evaluation and updating of the policies to ensure that they are abreast with changes that occur along time.
- Funding for HIV programmes should be increased to get stigma back on the agenda.
- Institutions mandated to assist PLHIV to seek redress when their rights are violated should be provided the materials and means to work effectively to improve confidence in the system while PLHIV should be empowered to seek redress where the need arises.
- The curriculum of all health training institutions should be revised to include a component on stigma and discrimination in the training of HCW. Since the values and beliefs of HCW have been recognized as contributing to HIV-related stigma, these values and prejudices should be assessed and addressed during professional trainings. To start stigma-reduction programmes from childhood, school health programmes and life skills for primary schools should include stigma awareness.
- The "Model of Hope" concept and the involvement of PLHIV in service provision in health facilities should be strengthened.

#### **5.6.2** Recommendations for health managers

- Health managers should ensure the availability of policies, guidelines and educational materials for the treatment of PLHIV, HIV-stigma and universal precaution. The development of these policies should use a participatory approach with inputs from HCW to ensure a sense of ownership. The policies should include sanctions for health who flout the policies.
  - All HCW should be made aware of the contents of these policies and guidelines
  - Opportunities should be provided for all categories HCW to regularly improve their knowledge on HIV and stigma through refresher trainings. Trainings should include the sensitization of HCW on the rights of PLHIV. HCW should strive to improve their knowledge on HIV and stigma

- Health managers should ensure the constant availability of protective supplies to enable HCW practice universal precautions. Protocols and guidelines on the use of universal precautions should be made available and enforced in all health institutions.
- Health managers should consider the integration of service provision to PLHIV together with all services depending on the contexts.
- Health facilities should institute systems that enable clients to lodge complaints about services they receive.

#### **5.6.3** Recommendations for further studies

- Findings from this review have demonstrated the multidimensional nature of the stigma encountered by socially marginalized groups, there is the need for further qualitative studies on HIV-related stigma and its intersection with socially marginalized behaviours in the Ghanaian context
- Further studies should be conducted to evaluate the effectiveness of HIV-related stigma interventions in healthcare delivery settings.

#### **5.6.4** Recommendations for support groups

- Support groups and life skills trainings for PLHIV should be strengthened.
- Community programmes involving PLHIV, religious and community leaders should be strengthened to nip the myths surrounding HIV transmission in the bud.

Finally, a concerted effort by all stakeholders; government, HCW, members of the community, national and international NGOs, community and religious leaders as well as PLHIV are needed to address the challenge of HIV-related stigma.

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## 6 Annexes

# **6.1** Annex 1: Selected Indicators on HIV epidemiology in Ghana, 2015

Indicators	Estimate
Adults aged 15 and over living with HIV	260,000
Women aged 15 and over living with HIV	150,000
Men aged 15 and over living with HIV	100,000
Children 0 to 14 living with HIV	19, 000
HIV Prevalence rate (Adults aged 15-24)	1.6
HIV Prevalence (Young men 15-24)	0.3
HIV Prevalence (Young women 15 – 24)	0.6
New Infections (Adults and Children)	13000
Coverage of pregnant women who receive ARV for prevention of MTCT (%)	63
Coverage of people receiving anti-retroviral therapy (%)	34
Proportion of ever-married or partnered women aged 15-49 who experienced physical or sexual violence from a male intimate partner	20.02
	Source: DHS 2008
Percentage of women and men aged 15-49 who	67.7
report discriminatory attitudes towards PLHIV	Source: DHS 2014

Table 5: Selected Indicators on HIV epidemic in Ghana Source: UNAIDS, AIDSInfo, 2015 (11)