An Exploratory Case Study of HIV/AIDS Related Stigma in Rural Ghana

by

Farouq U. Ayiworoh

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This thesis is an exploration of the nature of HIV/AIDS related stigma in the rural community of Wa, Ghana. The research study seeks to describe attitudes within the community about the disease, describe existing de-stigmatization approaches used by relevant bodies, and also examine in a preliminary manner, the effectiveness of these approaches in reducing HIV/AIDS related stigma in the community. Despite the significant progress made in the reduction of new HIV infections, HIV/AIDS related stigma still remains one of the main challenges faced by rural communities globally. The epistemological approach used was based on social constructivism theory. Findings indicate that knowledge is not synonymous with behaviour change and is insufficient to effectively reduce stigma hence there is the need for more funding to embrace a broader and more effective stigma reducing strategies. This study suggests that, HIV/AIDS related stigma is severe in rural Ghana due to rural social interaction and the implications of rural economics. Strengthening the rights of the infected and affected would consequently reduce the effects of HIV/AIDS related stigma.
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TABLE OF CONTENTS

Acknowledgements iii
Table of Contents iv
List of Tables vii
List of Figures viii
Abbreviations ix

CHAPTER ONE ........................................................................................................................................ 1
INTRODUCTION TO THE STUDY .................................................................................................... 1
  1.0 Background and Rationale ........................................................................................................ 1
  1.1 Research Objectives .................................................................................................................. 3
  1.2 Significance of Research ............................................................................................................ 5
  1.3 Limitations .................................................................................................................................. 6
  1.4 Thesis Overview ......................................................................................................................... 7

CHAPTER TWO .................................................................................................................................. 10
LITERATURE REVIEW and CONCEPTUAL FRAMEWORK ................................................... 10
  2.0 Introduction ............................................................................................................................. 10
  2.1 Brief Overview - Understanding the Disease ............................................................................. 11
  2.2 HIV/AIDS in Ghana .................................................................................................................. 12
  2.3 Understanding Stigma ............................................................................................................... 20
  2.4 Stigma and HIV/AIDS .............................................................................................................. 24
  2.5 HIV/AIDS, Stigma in sub-Saharan Africa ............................................................................... 27
  2.6 HIV/AIDS Related Stigma in Ghana ....................................................................................... 40
  2.7 Conceptual Framework ............................................................................................................. 43
  2.8 Summary .................................................................................................................................... 47

CHAPTER THREE .............................................................................................................................. 48
METHODOLOGICAL APPROACH ................................................................................................. 48
  3.0 Introduction .............................................................................................................................. 48
  3.1 Epistemological Approach ....................................................................................................... 48
  3.2 Standpoint perspective: Connecting the Researcher to the Research .................................... 50
  3.3 Study Site and Community Details .......................................................................................... 51
  3.4 Research Design ....................................................................................................................... 53
  3.5 Methodology ............................................................................................................................ 53
  3.6 Interviews ................................................................................................................................... 55
  3.7 Participant Observation ............................................................................................................. 57
  3.8 Secondary Data and Project Documentation .......................................................................... 57
APPENDIX ................................................................................................................................. 142

Appendix A: GAC HIV/AIDS M&E system linked with M&E data flows ................................. 142
Appendix B: Photographs of the GAC Office (posters, charts, etc.) ...................................... 143
Appendix C: Photographs of the RCC Office HIV and AIDS Educational Campaigns .......... 147
Appendix D: Sample Participant Consent Form ......................................................................... 149
Appendix E: Sample Interview Guides ..................................................................................... 152
LIST OF TABLES

Table 1.1: Research Design Matrix 4

Table 2.1: Modes of HIV Transmissions in Ghana 14

Table 2.2: Ghana HIV Prevalence & AIDS Estimates Report for 2013 17

Table 2.3: Ghana HIV Prevalence & AIDS Estimates Report for 2014 18

Table 5.1: Distribution of participants based on specific attributes and values 74

Table 5.2: Distribution of participants’ educational levels 75

Table 5.3: Do participants think HIV/AIDS related stigma causes more HIV infections 76

Table 6.1: Summary of a list of HIV and AIDS related stigma sources 109
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td>Estimated Ghana HIV populations</td>
<td>19</td>
</tr>
<tr>
<td>2.2</td>
<td>Link between HIV/AIDS and pre-existing Stigma</td>
<td>26</td>
</tr>
<tr>
<td>2.3</td>
<td>Effects of HIV/AIDS on population</td>
<td>30</td>
</tr>
<tr>
<td>2.4</td>
<td>Impact of HIV/AIDS on Smallholder Farmers</td>
<td>31</td>
</tr>
<tr>
<td>2.5</td>
<td>Understanding HIV/AIDS in the Context of Agricultural Livelihoods</td>
<td>33</td>
</tr>
<tr>
<td>2.6</td>
<td>Stigma as the intersection of our culture, difference, and power</td>
<td>38</td>
</tr>
<tr>
<td>2.7</td>
<td>Adapted Conceptual Framework</td>
<td>44</td>
</tr>
<tr>
<td>2.8</td>
<td>Linkage between the affected and infected of HIV/AIDS related stigma</td>
<td>47</td>
</tr>
<tr>
<td>3.1</td>
<td>Location of Wa on the Ghana map</td>
<td>51</td>
</tr>
<tr>
<td>3.2</td>
<td>Map of Wa</td>
<td>52</td>
</tr>
<tr>
<td>3.3</td>
<td>Structural diagram of the research</td>
<td>54</td>
</tr>
<tr>
<td>4.1</td>
<td>Summary of Priorities of the NSP 2011 – 2015</td>
<td>63</td>
</tr>
<tr>
<td>5.1</td>
<td>Distribution of participants based on gender</td>
<td>75</td>
</tr>
<tr>
<td>5.2</td>
<td>HIV/AIDS stigma triggers and outcomes for community members</td>
<td>77</td>
</tr>
<tr>
<td>5.3</td>
<td>Distribution of participants perceived stigma by numbers and percentages</td>
<td>79</td>
</tr>
<tr>
<td>5.4</td>
<td>Distribution of participants experienced stigma by numbers and percentages</td>
<td>84</td>
</tr>
<tr>
<td>6.1</td>
<td>Stigma reduction approaches as identified by participants</td>
<td>118</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>AFHS</td>
<td>Adolescent Friendly Health Services</td>
<td></td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
<td></td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal care</td>
<td></td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
<td></td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral drugs</td>
<td></td>
</tr>
<tr>
<td>CHRAJ</td>
<td>Commission on Human Rights and Administrative Justice</td>
<td></td>
</tr>
<tr>
<td>BCC</td>
<td>Behaviour Change Communication</td>
<td></td>
</tr>
<tr>
<td>CBO</td>
<td>Community Based Organization</td>
<td></td>
</tr>
<tr>
<td>EPP</td>
<td>Estimation and Projection Package</td>
<td></td>
</tr>
<tr>
<td>FAO</td>
<td>Food and Agriculture Organization</td>
<td></td>
</tr>
<tr>
<td>FSWs</td>
<td>Female Sex Workers</td>
<td></td>
</tr>
<tr>
<td>GDHS</td>
<td>Ghana Demographic Health Survey</td>
<td></td>
</tr>
<tr>
<td>GAC</td>
<td>Ghana AIDS Commission</td>
<td></td>
</tr>
<tr>
<td>GNA</td>
<td>Ghana News Agency</td>
<td></td>
</tr>
<tr>
<td>FGC</td>
<td>Female Genital Cutting</td>
<td></td>
</tr>
<tr>
<td>GHS</td>
<td>Ghana Health Services</td>
<td></td>
</tr>
<tr>
<td>GLBT</td>
<td>Gay, Lesbian, Bisexual, Transsexual</td>
<td></td>
</tr>
<tr>
<td>HBC</td>
<td>Home-based Care</td>
<td></td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
<td></td>
</tr>
<tr>
<td>HRSB</td>
<td>High Risk Sexual Behaviour</td>
<td></td>
</tr>
<tr>
<td>HTC</td>
<td>HIV Testing and Counselling</td>
<td></td>
</tr>
<tr>
<td>IGA</td>
<td>Income Generating Activity</td>
<td></td>
</tr>
<tr>
<td>IDUs</td>
<td>Injecting Drug Users</td>
<td></td>
</tr>
<tr>
<td>KYS</td>
<td>Know Your Status</td>
<td></td>
</tr>
<tr>
<td>MARP</td>
<td>Most At Risk People</td>
<td></td>
</tr>
<tr>
<td>MDGs</td>
<td>Millennium Development Goals</td>
<td></td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
<td></td>
</tr>
<tr>
<td>-------------</td>
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<td></td>
</tr>
<tr>
<td>MoH</td>
<td>Ministry of Health</td>
<td></td>
</tr>
<tr>
<td>MTCT</td>
<td>Mother to Child Transmission</td>
<td></td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
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<tr>
<td>NHASP</td>
<td>National HIV &amp; AIDS, STI Policy</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
<td></td>
</tr>
<tr>
<td>OVC</td>
<td>Orphans and Vulnerable Children</td>
<td></td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
<td></td>
</tr>
<tr>
<td>PLWHA</td>
<td>People Living with HIV/AIDS</td>
<td></td>
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<tr>
<td>PITC</td>
<td>Provider Initiated Testing and Counselling</td>
<td></td>
</tr>
<tr>
<td>RCC</td>
<td>Regional Coordination Council</td>
<td></td>
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<tr>
<td>SRH</td>
<td>Sexual and Reproductive Health</td>
<td></td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
<td></td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
<td></td>
</tr>
<tr>
<td>UPPEP</td>
<td>Universal Precaution and Post Exposure Prophylaxis</td>
<td></td>
</tr>
<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
<td></td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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</tr>
<tr>
<td>WB</td>
<td>World Bank</td>
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</tr>
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<td>WHO</td>
<td>World Health Organization</td>
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</tbody>
</table>
CHAPTER ONE

INTRODUCTION TO THE STUDY

1.0 Background and Rationale

Despite the increased access to HIV and AIDS antiretroviral therapy (ART) and also governmental, non-governmental (NGO), and community based organization working to fight the spread of the HIV virus, AIDS has become the leading cause of death for ages between 15 and 59 worldwide. Due to its strong ties with sexual and societal stigmatized behaviour, HIV/AIDS is one of the most complicated and bewildering social challenges faced by contemporary societies. In sub-Saharan Africa alone, AIDS has rendered millions orphans, increased levels of poverty significantly, increased the need for medical and emotional support, and also reduced life expectancies drastically (UNAIDS, 2015). Stigma associated with HIV and AIDS is considered detrimental to HIV prevention activities in Ghana and sub-Saharan Africa generally. Stigma has been identified as a major barrier to the success of both primary and secondary HIV/AIDS prevention and care activities. Parker & Aggleton (2003) argued that HIV/AIDS related stigma can interfere with reducing the spread of the disease and improving access to testing and treatment.

Ghana, a sub-Saharan African country has about 250, 232 people living with the HIV virus with an estimated 11, 356 new infection recorded in 2014; there were about 9, 248 HIV/AIDS related deaths recorded that year (UNAIDS, 2015; GAC. 2015). And stigma which is one of the aspect of the socio-psychological perspective of HIV/AIDS is arguably one of the most important components in minimizing the spread of the disease and its impact on the lives of
AIDS has reduced life expectancies for many more in Ghana. In Ghana, there has been tremendous efforts by governments and developmental agencies to fight the spread of HIV/AIDS but stigma is still the greatest enemy of the fight against this global epidemic. Millions are unable to share their pain because there is either no one to listen to them or they fear to be subjected to stigma and discrimination (Block, 2009).

HIV/AIDS related stigma is influenced by factors such as cultural constructions, misinformation and stereotypes, traditions and beliefs systems, religion and religious backgrounds, sexuality, and gender. It is shaped by not only the individual’s perceptions and interpretations of their micro interactions but also by the larger social, economic, and political forces of where they find themselves. Its social construct is that which has the significant impact on the life experiences of individuals both infected and affected by HIV/AIDS (Mbonu et al. 2009).
Although HIV/AIDS affects both rural and urban communities in Ghana, this research project focuses on only one rural community – Wa in north western Ghana. Through an exploratory case study this thesis examines the issue of HIV/AIDS related stigma and how prevention programs and support groups address the issue of stigma in this rural Ghanaian community. This study is conducted in collaboration with relevant bodies in the Wa community such as the Regional Coordination Council (RCC) and Ghana Health Services (GHS).

1.1 Research Objectives

The goal of this research project is to gain an understanding of HIV and AIDS related stigma, how this impacts the rural community of Wa, and how stigma is addressed through programs of relevant organizations like the GHS and RCC under the supervision of the Ghana Aids Commission (GAC). The research seeks to accomplish three main objectives:

1. To describe attitudes within the Wa community about HIV and AIDS related stigma
2. To describe existing de-stigmatization strategies and approaches used by relevant bodies in Wa
3. To examine in a preliminary manner, the effectiveness of GHS & RCC strategies in Wa for reducing HIV and AIDS related stigma

These objectives are presented with related research questions in the Research Design Matrix (Table 1.1.).
<table>
<thead>
<tr>
<th>Research Objectives</th>
<th>Research Questions</th>
<th>Source(s) of Data</th>
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<tbody>
<tr>
<td>Objective 1:</td>
<td>1.1. What are the different types of stigma?</td>
<td>Interviews</td>
</tr>
<tr>
<td>To describe attitudes within the Wa community about HIV/AIDS related stigma</td>
<td>1.2. Where is the stigma coming from in the Wa community?</td>
<td>Participant Observations</td>
</tr>
<tr>
<td></td>
<td>1.3. In what ways do the participants feel stigma can be reduced?</td>
<td>Key Informants Radio Interview on 01-12-15 on HIV/AIDS related stigma in Wa – World Aids Day program</td>
</tr>
<tr>
<td>Objective 2:</td>
<td>2.1. What are the current programs offered by GHS &amp; RCC?</td>
<td>Interviews</td>
</tr>
<tr>
<td>To describe existing destigmatization strategies and approaches used by relevant bodies in Wa</td>
<td>2.2. What are the current GHS &amp; RCC issued policies and guidelines on HIV/AIDS-related stigma?</td>
<td>Ghana Health Services (GHS) Documentation</td>
</tr>
<tr>
<td></td>
<td>2.3. How is stigma being addressed by the GHS &amp; RCC?</td>
<td>Key Informants Radio Interview on 01-12-15 on HIV/AIDS related stigma in Wa – World Aids Day program</td>
</tr>
<tr>
<td>Objective 3:</td>
<td>3.1. How do the existing GHS &amp; RCC approaches address the perception of stakeholders about stigma in Wa?</td>
<td>Interviews</td>
</tr>
<tr>
<td>To examine in a preliminary manner, the effectiveness of GHS &amp; RCC strategies in Wa for reducing HIV/AIDS related stigma</td>
<td>3.2 To what extent are GHS &amp; RCC programs and</td>
<td>Ghana Health Services (GHS) Documentation</td>
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<td></td>
<td></td>
<td>Key Informants Radio Interview on 01-12-15 on HIV/AIDS related stigma in Wa – World Aids Day program</td>
</tr>
</tbody>
</table>
This matrix includes two major components: HIV/AIDS related stigma and GHS and RCC organizational approaches. By considering different sources of data and the various research questions, this project first seeks to understand the nature of the stigmatization process as it relates to this rural community and how the various stakeholders seek to address these issues. The types of stigma and potential reduction strategies are also investigated by interaction with the stakeholders, namely the people living with HIV and AIDS (PLWHA), Wa community members, and employees of the GHS and the RCC.

1.2 Significance of Research

As discussed by Jarvis (2009), Peter Piot, executive director of UNAIDS in 2000, said stigma is a challenge that is preventing agreed action on HIV/AIDS reduction (Piot 2000 as cited by Parker & Aggleton, 2002). Problems of HIV/AIDS related stigma in Africa has been cited as a barrier to HIV testing, treatment, care and adherence, as well as reducing the quality of life of PLWHA. Even though there is an increase in researches on HIV/AIDS related stigma in sub-Saharan Africa, a better understanding of the cultural and social context in which stigma exists is
needed for the effective treatment and care strategies of the disease (Mbonu et al., 2009). The reduction of HIV/AIDS related stigma and discrimination is included in one of the nine priority areas identified by the UNAIDS Outcome Framework 2009-2011 (UNAIDS, 2009).

In Ghana, stigma has been the greatest enemy in the fight against the HIV/AIDS epidemic. People living with HIV and AIDS (PLWHA) and individuals suspected of a possible positive status are unable to share their pain because of the fear of being subjected to stigma and discrimination (GAC, 2012). Without the acknowledgement of one’s HIV status, reducing the rates of infection is very difficult, especially in a closely-knit society such as Wa.

The aim of this research project is not to reduce HIV transmission rates but rather contribute to available literature and recommendations in order to assist in slowing the rate of new infections in rural Ghana and sub-Saharan Africa generally. By further understanding the contributing factors and barriers related to HIV/AIDS related stigma encountered by the GHS, RCC, and the Wa community under the supervision of the GAC, steps will be made towards determining the effective and efficient methods and best practices in terms of reducing and ultimately, eliminating stigma as it relates to the HIV and AIDS crisis.

1.3 Limitations

A number of limitations should be born in mind in reviewing this study. Due to the relatively small sample size of participants; the relatively small rural Ghanaian community, a single NGO, and the comparatively few employees of the RCC and GHS who acted as key informants, the strengths of the research lie predominantly in identifying specific outcomes as they relate to policies and directives of the GAC rather than general conclusions. However,
overall conclusions about the nature and impact of HIV/AIDS related stigma generally are included in the concluding chapter.

In addition, the findings of the study, particularly the data gathered from the stakeholder group of PLWHA are representative of only a small population of the Wa community. Given the nature of the material being researched, the researcher interviewed only individuals who were interested in participating, rather than actively seeking respondents. The reason being that the sensitivity associated with HIV/AIDS in this closely-knit rural Ghanaian is substantial and the researcher and willing participants had to be very careful with the way the research data were collected. As a result, the number and diversity of respondents for this stakeholder group was limited due primarily to being stigmatized. Furthermore, due to the challenging and sensitive nature of the research topic, there is a higher than normal chance that participants in the interviews conducted either withheld or filtered some of their responses. The primary assumption of this research project is the openness and trustworthiness of the stakeholder groups; although this could be a limitation, the researcher assumed that information gathered from key informants and community members was honest and accurate.

Finally, this study faced significant financial and temporal restrictions that should be taken into account. A time constraint of approximately 12 weeks and an upper financial limit of approximately $5,000 were barriers to the expansion of data collection in the work.

1.4 Thesis Overview

This thesis is presented in six chapters with the following topics: Introduction, Literature Review, Conceptual Framework, Methodology, Context, Findings and Discussion, Final
summary, and Conclusions and Recommendations. Chapter two provides a brief review of HIV and AIDS, relevant literature on stigmatization and discrimination, and selected theories of HIV/AIDS related stigma. The chapter concludes with the conceptual framework on which this research project is based.

Chapter three provides the epistemological approach and methodology of the study including details concerning the case study selection, provides information on the researcher’s connection to the research, and details around the study site and its geographical location. This chapter outlines the research design used and describes the methods used for both data collection analysis. Chapter four highlights background information, context of the research, and the strategic plan of the relevant local organization. The chapter also outlines a description of stigma-reducing programs currently in operation in Ghana under the supervision of the GAC and provides an overview of the national policies and guidelines of stakeholders in relation to HIV and AIDS.

Research findings are presented in chapter five, identifying the study results in terms of types and sources of stigma and potential stigma-reducing strategies. A summary of GHS and RCC’s local approaches are included in this chapter and connects the findings to that of this research project’s objectives. Chapter six discusses findings of the research exercise through a process of interpretation, analysis, and description of the attitudes of participants and the impact of the process of stigmatization as it relates to HIV and AIDS. Chapter five also discusses triggers of stigma, stigma outcomes, and stigma reducing strategies found within the process of stigmatization.

Chapter seven provides the final summary, conclusions, and recommendations for this research and also revisits the conceptual framework, academic literature used, mentions the
methodological approach adapted, and matches the objectives of the study to the findings of the research. Salient findings then summarized in the conclusions followed by recommendations of the study and further research.
CHAPTER TWO

LITERATURE REVIEW and CONCEPTUAL FRAMEWORK

2.0 Introduction

This chapter begins with a brief overview of HIV/AIDS and also a global perspective of the HIV epidemic, before moving on to discuss the HIV/AIDS situation in the sub-Saharan Africa and a look at the impact of the disease in rural Ghana. A review of literature regarding stigmatization and HIV/AIDS related stigma is then explored, followed by an explanation of the conceptual framework designed and utilized for this research project.

Since its discovery in the early 1980’s, the human immunodeficiency virus (HIV) and the resulting acquired immunodeficiency syndrome (AIDS) has become a global emergency, threatening and ending lives globally. As a result, the United Nations in September of 2000 adopted the Millennium Development Goals (MDGs) which included a specific goal to reverse the spread of HIV/AIDS, Malaria, and Tuberculosis. One of the key goals of MDG was to address the tremendous global impact of HIV and AIDS and it stipulated a target of halting and reversing the spread of the disease by year 2015. Despite these bold steps and progress made, increased access to HIV/AIDS antiretroviral therapy (ART), governmental, and non-governmental organization working to fight the spread of the HIV virus, World Health Organization (WHO), estimated that there are approximately 36.9 million people worldwide currently living with HIV/AIDS. Of these, 2.6 million were children (<15 years old) and an estimated 2.0 million individuals worldwide became newly infected with HIV in 2014. The vast majority of people living with HIV are in low to middle income countries, particularly in sub-Saharan Africa (WHO, UNAIDS, 2015).
2.1 Brief Overview - Understanding the Disease

HIV/AIDS has been considered an epidemic for many years since the early 1980’s, the term referring to the widespread occurrence of an infectious disease in a community at a particular time and spreading to other communities. However, due to its cataclysmic nature and widespread existence, HIV/AIDS has now reached pandemic levels, beyond local and national boundaries to virtually every corner of the globe.

Human Immunodeficiency Virus (HIV) is a virus that gradually attacks the human immune system, which is our body’s natural defence against illness. HIV attacks the human immune system and if a person becomes infected they will find it harder to fight off other infections and diseases. The virus destroys a type of white blood cell called T-helper or CD4 cell and makes copies of itself inside them. The HIV virus is a micro-organism that is spread through bodily fluids such as blood, semen, vaginal fluids and breast milk. There are two main known types of the HIV virus; HIV-1 is the most common type found worldwide and HIV-2 is found mainly in Western Africa, with some cases in India and Europe. The HIV virus has the ability of rapid replication at a rate of one billion new viral particles each day. A person’s CD4 cell is primarily responsible for helping the body’s immune system fight off disease and infection. When the HIV virus enters the bloodstream, it attaches, binds itself to the CD4 cell, and becomes integrated with the genetic material called deoxyribonucleic acid (DNA) of the host cell. The virus then takes over the CD4 cell following the integration and creates a viral messenger called ribonucleic acid (RNA) cells. These RNA cells gears the production of significantly more HIV cells and ultimately results in the infection of additional host cells (Kalichman, 1998).
As HIV replicates itself and enters the CD4 cells, it eventually reduces the amount of healthy or un-effected CD4 cells. However, these CD4 cells are not destroyed until there is significant amount of the HIV virus in the bloodstream, thereby causing an explosion from within that ultimately destroy the host cell and the human immune system. At this point a person gets Acquired Immune Deficiency Syndrome (AIDS). This is the point where the human immune system declines rapidly and eventually loses its ability to protect the body from infections and diseases that would normally be controlled by the immune system. The body is unable to protect itself from common infections and eventually surrenders to AIDS related deaths (Kalichman, 1998).

This is the last stage of HIV infection where the body can no longer defend itself and untreated diseases and infections leads to death. There is currently no cure for HIV or AIDS however, with the right treatment and support, people can live long and healthy lives with the HIV virus. The only treatment for HIV/AIDS is to control or suppress the virus by not allowing it to multiply with a treatment called antiretroviral therapy or ART. If taken the right way, every day, ART can dramatically prolong the life of an individual infected with the virus, keep them healthy, and greatly lower their chance of infecting others. Before the introduction of ART in the mid-1990s, people with HIV could progress to AIDS in a few years. To prevent this, it is especially important to take treatment correctly and deal with any possible side effects.

2.2 HIV/AIDS in Ghana

Even though there has been significant progress on a global scale in the fight against HIV/AIDS, the decease is still the world’s most serious health and development challenges. By
the end of 2015, the World Health Organization (WHO) reported that there were approximately 36.9 million people living with HIV/AIDS worldwide, 2.6 million were reported to be children of the age of 15 years and below. Sub-Saharan Africa alone accounts for about 25.8 million people living with the HIV virus in 2014 and also has almost 70% of the global total new infections (WHO, 2015).

According to the WHO, there has been some significant successes though in the fight against the disease in the years to 2015. Currently, it is estimated that approximately 150 million children and adults in 129 low to middle income countries, mainly sub-Saharan countries have received HIV testing services. By the middle of 2015, about 15.8 million people living with HIV were receiving antiretroviral therapy (ART) globally and between 2000 and 2015, new HIV infections had fallen by about 35% to 40%, from an estimated 3.5 million new infections to 2.1 million. These figures are the result of international efforts that led to the global achievement of the HIV targets of the Millennium Development Goals (MDGs). According to UNAIDS (2008), the main mode of transmission in sub-Saharan Africa is heterosexual intercourse but this varies significantly from country to country. Table 2.1 below shows the various modes of new HIV infections by risk groups and percentages in Ghana:
Table 2.1: Modes of HIV Transmissions in Ghana

According to the National HIV & AIDS Strategy Plan for 2011 to 2015 (2010), the key sources of HIV infections in Ghana include Female Sex Workers (FSWs), Men who have Sex with Men (MSM), and Injecting Drug Users (IDUs) and should be labelled as the HIV epidemic’s Most at Risk Population (MARPs) since they contribute to the bulk of new HIV infections. Men and women who have “casual heterosexual sex” with more than one partners and Mother to Child Transmission (MTCT) have also been reported as a source of HIV transmission in Ghana.

Mother to child transmission of HIV is practically the only way that children who are under five years of age in Ghana can acquire the virus. Without any interventions to reduce
vertical transmission, about 30% of infected pregnant and breastfeeding women in the country every year would add children to the pool of those already infected. This would make the comprehensive prevention of HIV transmission and the attainment of Millennium Development Goals 4, 5, and 6 in Ghana a challenge (PMTCT, 2010). The population of FSWs is not known and the magnitude of commercial sex workers in Ghana has also not been comprehensively studied but this category of HIV transmission is one of the main modes of transmission and is one of the key most at risk groups. FSWs in Ghana has an HIV prevalence rate several times higher than the national average and contributes significantly to higher proportions of new infections. The NHASP, (2010) reported that FSWs accounted for the bulk of new infections with about 2.4% among sex workers, 6.5% among clients of sex workers, 22.2% among partners of clients of sex workers.

Ghana has limited data on MSM. Among 360 MSM in Accra, the Ghanaian capital in 2006, the Academy for Education Strengthening HIV and AIDS Response Partnership study reported a higher prevalence of 25.3% for this group with 62% being bi-sexual, 66% reporting paying for sex with men, and 48% using condoms. The findings show that MSM constitute a small population but contribute significantly to the spread of HIV in Ghana. This category of most at risk account for about 7.2% of new infections (NHASP, 2010). Data available on IDUs in Ghana is mainly from the prisons. In 2008, a survey carried out among prison inmates found that 11.4% of IDUs were HIV positive but the same survey reported that these prison inmates were also exposed to tattooing and MSM. It is estimated that about 0.1% of HIV new infections result from IDUs. Ghana has an HIV prevalence rate of more than 1% in the general population. A WHO definition for a generalised epidemic is when the prevalence rate is 1% or greater in the general population (NHASP, 2010; GAC, 2012).
The last population based survey on HIV prevalence carried out in Ghana was through the Ghana Demographic Health Survey (GDHS) in 2003 and the results indicated that 2% of adults aged 15 to 49 were HIV positive, this included 2.7% of women and 1.5% men. Since then estimates of HIV prevalence in Ghana has been undertaken based on the sentinel surveillance of pregnant women attending Antenatal care (ANC) and more recently through the Estimation and Projection Package (EPP) Modelling.

For countries like Ghana with a generalized HIV prevalence rate, the EPP model has been designed as a tool to construct national and sub-national epidemic curves indicating levels and trends of the HIV epidemic. Estimating and projecting national HIV/AIDS epidemics, requires the methodology and models of UNAIDS and WHO approaches. This approach to national HIV estimates requires the use of two specialized computer models, the EPP and Spectrum packages which are provided on CD-ROMs and are also available for download from the websites at UNAIDS. The epidemic curves are produced in EPP which is already in-built into the Spectrum projection package to estimate through a stepwise process, the national prevalence, incidence, mortality, and treatment needs by age group and sex.

According to a GAC country HIV/AIDS progress report in 2012 for the period January 2010 to December 2011, there were an estimated 230,348 people living with HIV in 2010, consisting of 102,713 males, 127,635 females, and 32,057 children. The same report indicated a 14,165 new infections and 17,230 annual AIDS deaths of which 2,472 were children. There was a slightly decrease in the number of people living with HIV in 2011 from 230,348 to 225,478, comprising 100,336 males and 125,141 females with 12,077 new HIV infections of which 10,373 were adults and 1,707 children. The number of new infections was slightly decreased due in part to increases in access to antiretroviral drugs and changes in life style.
The National HIV Prevalence & AIDS Estimates Report for 2013-2020 compiled in June of 2014, estimated the adult HIV prevalence rate in 2013 to be 1.30%. This is made up of about 224,488 people living with HIV/AIDS comprising 189,931 adults and 34,557 children. The report also estimated an adult incidents rate of 0.04% with 7,812 new infections and 10,074 deaths. Annual AIDS deaths amongst children 0 to 14 years was estimated at 2,248 (22% of total deaths), of which 472 occurred in children 1 to 4 years of age. A total of 2,407 new child infections (31% of all new infections) were estimated to have occurred with an HIV prevalence rate of 0.36% amongst children 0 to 14 years old. The 15 to 24 year group accounted for 1,673
of new infections (22% of new infections), of whom 64% were females. The report also estimated the number of AIDS orphans at a staggering 184,168 children. Tables 2.2 and 2.3 shows a summary of HIV prevalence statistics for the year 2013 and a summary of the estimated outlook of HIV prevalence for the year 2014 respectively.

Table 2.3: Ghana HIV Prevalence & AIDS Estimates Report for 2014

<table>
<thead>
<tr>
<th></th>
<th>Lower 2.50%</th>
<th>Median 50%</th>
<th>Upper 97.50%</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Adults + Children</td>
<td>166,799</td>
<td>219,983</td>
<td>294,397</td>
</tr>
<tr>
<td>HIV population-Children (0-14)</td>
<td>23,094</td>
<td>31,973</td>
<td>43,390</td>
</tr>
<tr>
<td>HIV population-Adults (15+)</td>
<td>142,729</td>
<td>188,010</td>
<td>252,635</td>
</tr>
<tr>
<td>Prevalence Adult (15-49)</td>
<td>0.92</td>
<td>1.24</td>
<td>1.7</td>
</tr>
<tr>
<td>HIV Prevalence- Children (0-14)</td>
<td>0.24</td>
<td>0.33</td>
<td>0.45</td>
</tr>
<tr>
<td>Number of new HIV infections</td>
<td>1,584</td>
<td>5,971</td>
<td>13,093</td>
</tr>
<tr>
<td>New HIV infections- Adult</td>
<td>698</td>
<td>4,093</td>
<td>11,684</td>
</tr>
<tr>
<td>New HIV infections- Children</td>
<td>736</td>
<td>1,078</td>
<td>1,563</td>
</tr>
<tr>
<td>Annual AIDS deaths</td>
<td>4,952</td>
<td>8,789</td>
<td>12,699</td>
</tr>
<tr>
<td>Annual AIDS deaths- Adult (15+)</td>
<td>3,782</td>
<td>7,076</td>
<td>10,195</td>
</tr>
<tr>
<td>Annual AIDS deaths- Children (0-14)</td>
<td>1,159</td>
<td>1,713</td>
<td>2,446</td>
</tr>
<tr>
<td>Annual AIDS deaths - Adults (15-24)</td>
<td>494</td>
<td>668</td>
<td>859</td>
</tr>
<tr>
<td>Annual AIDS deaths- Children (1-4)</td>
<td>138</td>
<td>356</td>
<td>710</td>
</tr>
<tr>
<td>Need for ART- Adult (Dec 31) (15+)</td>
<td>99,326</td>
<td>121,584</td>
<td>154,873</td>
</tr>
<tr>
<td>Need for ART- Children (Dec 31) (0-14)</td>
<td>14,546</td>
<td>20,268</td>
<td>27,675</td>
</tr>
<tr>
<td>Mothers needing PMTCT</td>
<td>7,718</td>
<td>10,937</td>
<td>15,536</td>
</tr>
<tr>
<td>AIDS orphans</td>
<td>121,255</td>
<td>173,812</td>
<td>240,701</td>
</tr>
<tr>
<td>HIV population (15-49)</td>
<td>120,908</td>
<td>162,053</td>
<td>220,662</td>
</tr>
<tr>
<td>Incidence Adults 15-49</td>
<td>0.01</td>
<td>0.04</td>
<td>0.09</td>
</tr>
<tr>
<td>HIV+ pregnant women with CD4 counts &lt; 350</td>
<td>4,697</td>
<td>7,060</td>
<td>10,078</td>
</tr>
<tr>
<td>New HIV infections - Males aged 15 to 24</td>
<td>77</td>
<td>540</td>
<td>1,323</td>
</tr>
<tr>
<td>New HIV infections - Females aged 15 to 24</td>
<td>143</td>
<td>960</td>
<td>2,294</td>
</tr>
</tbody>
</table>


The HIV prevalence rates and incidence as projected by the National HIV Prevalence & AIDS Estimates Report: 2013 – 2020 in 2014 is expected to drop gradually from 1.30% and 0.04% in 2013 to 0.99% and 0.01% in 2020 respectively. The overall HIV/AIDS population in
Ghana is also projected to decline slowly due to an increase in the use of Antiretroviral Therapy (ART) as the prevalence rates decreases. There is also an expected steeper decline in new infections for the population of children aged between 0 and 14 years as compared to the population of ages between 15 and 24 years due to the effective interventions for the Prevention of the Mother-to-Child Transmission (PMTCT) programmes in the country. AIDS deaths though, according to the report will gradually increase up to the year 2020 due to other factors such as inaccessibly to care and HIV/AIDS related stigma, causing infected people to not come forward for treatment.


HIV/AIDS related stigma and discrimination, according the National HIV & AIDS Strategic Plan: 2011 – 2015 reported in December of 2010 is one of the most significant determinants of the spread of the HIV virus in Ghana. According to the report, “HIV stigma and discrimination is a significant factor in Ghana and is a hindrance to accessing HIV prevention
services resulting in exposure to HIV infections” NHASP pp 26. In Ghana, as in many countries in sub-Saharan Africa, HIV/AIDS epidemic has become an openly contested area of intervention. A majority of the HIV/AIDS interventions are now in the hands of not only doctors and governments but the activism of people living with HIV/AIDS themselves. Traditional groups and chieftaincy institutions are now getting NGOs to bring them on board in the fight against HIV/AIDS but their capacities have not expanded to take a more assertive role in community and local level campaigns like championing education on HIV/AIDS related stigma and getting rid of traditional beliefs that aid the spread of the HIV virus (Crentsil, 2015).

2.3 Understanding Stigma

Goffman (1963) was one of the first scholars to write about stigma in his world-renowned book entitled “Stigma, Notes on the Management of Spoiled Identity”. Goffman (1963) defined stigma as an attribute or “mark” that is deeply discrediting and is used to humiliate or dishonour a person or group of people in any given society or social setting. He maintains that stigma is socially constructed and used to either disgrace or devalue those who fall short of some kind of social expectations; “Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for the member of each of these categories. Social settings establish the categories of persons likely to be encountered there” (Pg. 2). Goffman did not appear to emphasize or focus on the stigmatized individual but rather stigma as a social process based on the construction of social identity. Goffman’s definition of stigma includes society’s fear for social judgment thereby causing people to behave in a certain way to be accepted in the community in which they find themselves. This definition also embraces the risk
of social exclusion that exists for members of a community, especially because of an unwelcome influence or physical effect.

Emphasizing and building on Goffman’s idea of stigma as an attribute and social construct, Kurzban & Leary (2001) argue that “the process of stigmatization revolves around the exclusion of particular individuals from certain types of social interactions” (Pg. 201). Kurzban & Leary explicitly ignores the “psychological states of the person being stigmatized” but rather insist on an evolutionary analysis of stigma, an attempt to link stigma to evolution and social stratification. Kurzban & Leary offer a new perspective on the process of stigmatization and attempts to answers the question of why social species with the need for “strong” social acceptance “should be so inclined to reject members of its own kind”. Stigma is used as an effective tool of social stratification; community level stigma and discrimination is used to create differences and structure social hierarchy. Societies achieve conformity by contrasting who is normal, deviant, or different by their sexuality, gender, race and ethnicity, or class (Parker & Aggleton, 2002).

Social rejection appear to be based on the shared values and or preferences of groups of people hence, despite an individual’s best efforts to be accepted in a community, rejections result from the characteristics of the social life of the community to which they want to belong. An individual’s personal characteristics must match a set of shared values such as religious, cultural, tradition, and norms in a community for them to be deemed as ‘normal’ (Kurzban & Leary, 2001). Social psychologists, Jones et al. (1984) and Crocker et al. (1998) both describe stigma as a situational threat and argue that stigma is: (1) an attribute that marks or defines people or group of people as different and leads to social devaluation; and (2) is socially constructed and gradually progresses from an individual’s focus towards the larger social setting that they find
themselves hence, what may constitute or seem as normal in one society may be abnormal in another.

Building upon other social psychological definitions and notions of stigma being a social, interpretive, or cultural process, Yang et al., (2007) argues that “stigma exerts its core effects by threatening the loss or diminution of what is most at stake, or by actually diminishing or destroying that lived value.” (Pg. 1524). Yang et al. maintains that stigma is an essential moral issue in which “stigmatized conditions threaten what is at stake for sufferers” (Pg. 1524) or the stigmatized. What is at stake in a particular local social setting allows us to understand the behaviors of both the stigmatizers and stigmatized with respect to what is threatened and what matters.

Etymologically, the word stigma can also be traced back to Christianity and denotes bodily marks which resemble those of the crucifixion of Jesus Christ, signifying or attributed to the divine favour of God. Secularly though, stigma denotes a mark of disgrace or discredit towards an individual or groups of people in society (Mbonu et al. 2009). Psychologically, stigma embraces the actions of individuals or group of people towards other individuals of groups to enhance their social statuses or create some kind of social stratification for economic, political, or social gains. Their social environment defines what is accepted and provides the bedrock and context in which defining who is whole is evaluated and expressed (Jones et al. 1984; Crocker et al. 1998).

According to Holzemer et al. (2007), our environment or any kind of setting that we find ourselves at any point in time, be it in our local communities, schools, hospitals, or even our workplaces usually has factors such as the law and policies, traditions, culture, religion, or even norms that defines the way we conduct ourselves. These factors are usually what triggers our
behaviour and the actions to either label others as belonging or not belonging. These are the very factors that triggers stigmatizing behaviours in the form of avoidance, blame, or even actions that can be relatively minor such as refusing a hand shake to severe actions such as physical abuses. Holzemer et al. (2007) classify three main types of stigma: received stigma being all types of stigmatizing behaviour towards a person as experienced by themselves or others, internal stigma as thoughts and behaviours from a person’s own negative perceptions about themselves, and associated stigma as stigma that is as a result of an association of a person with someone.

Nyblade (2006) identified and grouped stigma into three main categories: perceived stigma, experienced stigma, and internalized stigma. Nyblade explained that perceived stigma involves a person’s perceptions about how they would be treated by their community members, friends, or family and upon learning of their sickness. Experienced stigma involves all stigmatizing thoughts, attitudes, and beliefs that are acted open within the community or environment that an affected person finds themselves. Experienced stigma comes in the form of refusal to rights such as employment, education, healthcare, physical abuses, harassments, or even assaults. Internalized stigma includes feelings of shame, blame, self-isolation, or even withdrawal. It can also be referred to as self-stigma when the affected person blames himself for his situation.

People who are stigmatized can experience preconceived opinions that are not based on reason or actual experiences indirectly and directly and in a community repeated negative social interactions usually causes the individual to expect similar interactions in future situations causing them to have feelings of rejection, shame, and also further confirms their perceived negative stereotypes. Particularly in threatening environments or in unwanted community settings, individuals who are extremely sensitive to status based rejections are more likely to
perceive devaluation and in some cases anticipate it the reaction of their surroundings or social settings as threatening environments. According to Miller (2006), when an individual of group of people identify and or experience stigma, they should resort to three critical components to coping with their stigma: appraisals of stigma-related state of mental or emotional strain, coping responses, and identification of prejudice.

The process involves conducting an evaluation of the coping resources that are available to them and then determining whether their experienced stigma is as a result of a specific stigmatized characteristic such as belief systems, culture, or traditions. A stigmatized individual is then able to experience a response to the situation they find themselves. Miller (2006), maintains that there two categories of coping responses namely: primary or secondary. Primary coping responses are intended to change the situation and secondary coping responses involves the individual adapting to the given situation by altering their personal feelings or emotions to accommodate the situation. The final component of coping responses, according to Miller (2006) is identifying prejudice, that is determining whether the perceived threat is in fact as a result of discrimination or prejudice.

2.4 Stigma and HIV/AIDS

The complexity and diverse issues of HIV/AIDS related stigma in many different cultural, traditional, and religious settings globally has made it very difficult to both effectively and efficiently address and possibly eradicate stigma associated with the disease. This complex phenomenon has also led to difficulties and agreement on the definition of stigma associated with the disease and its related concept of discrimination. Disagreement on the definition,
measurements, assessments, and the impact of HIV/AIDS related stigma has hampered local and global efforts to address HIV/AIDS associated stigma (Mahajan, et al., 2008). According to AVERT (2015), a global online information and advice on HIV and AIDS, stigma related to HIV/AIDS includes negative attitudes and prejudice directed at people living with HIV and AIDS. HIV/AIDS related stigma manifest itself usually in the community or local setting in which it is being experienced and it is built on pre-existing forms of stigma and discrimination associated with gender, race, sexuality, and poverty (Parker & Aggleton, 2007).

Because HIV/AIDS has no cure and is a life-threatening illness, people should and are afraid of contracting it but the fear of contracting the disease for most part has been based on myths, misconceptions, and inaccurate information on its transmission. Fears surrounding the disease and its mode of transmission in the early 1980s still exist today, making it a significant contributing factor for the stigma and discrimination associated with it (Kalichman, 1998; Parker & Aggleton, 2007). Early HIV/AIDS metaphors like referring the disease as a death sentence, as punishments, as guilt, and as shame has also been a contributing factor and re-enforced the legitimacy of stigma associated with the disease. Later stages of the disease if not treated, when the infected has full-blown AIDS also attracts a lot of fear due to the fact that the person becomes physically disabled and unable to take care of himself (Kalichman, 1998).

To understand the ways in which HIV/AIDS related stigma appear and the contexts in which they occur, we need to understand how they interact with pre-existing stigmas in their respective environments. The figure below shows a link between pre-existing stigma and HIV/IADS related Stigma.
Parker & Aggleton (2007) maintains that because HIV/AIDS is mainly transmitted through sex it is reasonable to say that stigma associated with the disease are closely related to sexual stigma. In most communities or areas of the world, the epidemic initially affected populations whose sexual identities and or practices are different from the ‘norm’. Stigma associated with HIV/AIDS therefore appropriated and reinforces the already existing stigma associated with sexually transmitted diseases, promiscuity, prostitution, and homosexuality. In some communities today, the belief that homosexuals are to be blamed for the HIV/AIDS epidemic and the only risk groups is still common.

Gender related stigma is also closely linked to HIV/AIDS related stigma. Parker & Aggleton (2003) argues that in communities where heterosexual transmission of the HIV virus is significant, the spread of the disease has been associated with female sexual behaviour that is not
consistent with gender norms. Parker & Aggleton maintains that because prostitution is usually widely perceived as a non-normative female behaviour, female sex workers are often identified as a vital means of HIV infections and they put their clients’ sexual partners at risk for infections. Men are also equally blamed in many settings for heterosexual transmission due to the assumptions that men prefer or usually have multiple partners in some traditions and religious communities.

Because the HIV/AIDS epidemic became widely known and developed during the period of rapid globalization and growth, gaps between rich and poor (Castells 1996, 1997, 1998) as cited by (Parker & Aggleton, 2003) new forms social exclusion has reinforced social inequalities and stigmatization of the poor, the homeless, and the jobless. As a result, poverty increases vulnerability to new HIV infections and HIV/AIDS exacerbates poverty hence HIV/AIDS related stigma interacts with and reinforces pre-existing stigma associated with social and economic marginalization. In some contexts and communities, Parker & Aggleton (2003) argue that the HIV epidemic and its associated stigma has been characterized by certain assumptions of the rich and is associated with affluent lifestyles. Race and ethnicity also interacts and gears HIV/AIDS related stigma because the epidemic is characterized by both racist assumptions about “African sexuality” and also by perceptions in the developing world that the disease is as a result of the western world’s “immoral behavior”.

### 2.5 HIV/AIDS, Stigma in sub-Saharan Africa

HIV/AIDS has significantly impacted the region of sub-Saharan Africa than any other part of the world and scholars globally have written about the alarming infection rates,
prevention strategies, care and support, and more importantly the implications of the disease in the region. Quite recently, there has an increase in the need for an understanding and dealing with HIV/AIDS related stigma in the African context due to its complexity and difficulty in dealing with. There has been government guidelines, projects, and policies like the Ghana National HIV/AIDS, STI Policy and the South African project of Siyam’kela that was purposefully designed to explore HIV/AIDS related stigma through the consideration of the South African government guidelines in conjunction with an interactions with infected individuals and faith based organizations.

In the context of HIV/AIDS in Africa generally, Mofolo (2010) argue that the role of culture has been very problematic in the fight against the disease mainly because of the patriarchal society in African communities. Mofolo in defining culture in the context of HIV/AIDS wrote “In simple terms, culture basically refers to the traditions and customs upheld by societies and communities because of their belief systems and values. Culture is defined as the learned, shared and transmitted values, beliefs, norms and life ways carried by groups of people, which guides their decisions, thinking and actions in patterned ways. The individual in society is bound by rules of his/her culture. Cultures are different in that the same events that may be fear-inducing in one culture may be anger-inducing in another.” (pp.3), hence sub-Saharan African traditions, religion, norms, and belief systems is also to be blamed for the spread of the HIV virus.

In examining HIV/AIDS in sub-Saharan Africa, Sovran (2013) also argued that culture and HIV/AIDS in the region are linked and that association of the two are very difficult if not impossible, to isolate. Sovran explains that the onslaught of HIV/AIDS in sub-Saharan Africa provides an important and unparalleled opportunity to examine the complex and intertwined
relationship between culture and the disease. Cultural practices such as early marriage and coital debut, widow inheritance and sexual cleansing rituals, gender relations and norms, female genital cutting (FGC), and male circumcision were all identified as factors that increased the possibilities that the HIV virus would be transmitted because they all involved blood or other body fluids especially if performed on groups (Sovran 2013; Feldman 1990; Hrdy 1987). In the early years of the epidemic, culture was invoked in sub-Saharan Africa to explain the spread of HIV in a mostly heterosexual population at a time when infection in the developed world predominantly associated with injection drug users and homosexual men (Sovran, 2013; Mofolo, 2010).

HIV/AIDS has a significant impact on the sustainable development efforts of sub-Saharan African counties because it mainly infects and kills mostly healthy and productive members of the community or society. As shown in figure 2.3 below, in the 38 hardest infected and affected African countries, projections are that there will be about 19 million additional deaths due to AIDS between 2010 and 2015 (Sandkjaer, 2007). According to Sandkjaer, these deaths would be among the productive and age groups thereby reshaping the population structure to such an extent that the most infected and affected region will have far fewer adults to take care of the disproportionate numbers of children and the elderly. The increased mortality rates resulting from HIV/AIDS in the region would significantly impact the life expectancy levels, a common measure and indicator of development. The figure below shows deaths with and without AIDS in 38 African countries in millions.
Although HIV/AIDS was considered primarily an urban issue in the early years of the disease, as the epidemic matures it penetrates rural areas because AIDS patients usually migrate to rural areas to seek family and community support not readily available in urban areas. In sub-Saharan Africa most people live in rural communities and most of them depend on agriculture for their livelihood; subsistence farmers and seasonal farm workers constitute the bulk of the population in these areas. Also, countries that have been hit hardest by the disease in the region are dependent on agriculture for their livelihood; more than seven million agriculture workers in sub-Saharan Africa have died of HIV/AIDS since 1985 and about one-fifth of the agricultural workforce will most probably die by 2020. Because of the extent to which AIDS makes people ill, disables them when very ill, and then causes deaths, it places considerable strain on rural agricultural production (Kupfer & Pilgram, 2005).
The impact of HIV/AIDS on smallholder agriculture in sub-Saharan African can be summarized as food insecurity which is caused by the reduction of agricultural production; absenteeism and loss of agriculture labour, loss of financial and physical assets, loss of relevant indigenous agricultural skills, impact on farming land size, and disruption of agriculture service delivery for rural institutions (ECA/SA, 2006; UNDESA, 2013; Parker et al., 2009). Figure 2.3 below is a summary of the impact of HIV/AIDS on smallholder farmers in sub-Saharan Africa.

![Flowchart showing the impact of HIV/AIDS on smallholder farmers](image)

Figure 2.4: Impact of HIV/AIDS on Smallholder Farmers: Source: ECA/SA, 2006; UNDESA, 2013; Parker et al., 2009

Family members provides the majority of support and care for people living with the disease and in sub-Saharan African, smallholder agricultural households rely on family members for agriculture labour. Because the disease mostly affects young adults, usually the most active and productive group of their communities, absenteeism of farm labourers and their managers is rampant and a huge issue due to the limited use of agriculture farm inputs in the region.
According to a survey conducted in Zimbabwe by the Zimbabwe Farmers’ Union, agricultural output generally declined by nearly 50 per cent in households affected by AIDS, specifically maize production declined by about 61% as a result of illness and deaths from AIDS (Kwaramba, 1997).

Costs associated with prolonged illnesses and the loss of income may force households to sell some of their assets to meet the additional health costs. These expenses may reduce smallholder household’s available capital, since cash is required for drugs, health care, hospital stays, and special highly-nutritious foods that are recommended to be eaten with HIV drugs. The burden of direct health care costs, transportation costs, lost time and wages due to waiting at health centers, and side effects can reduce adherence to antiretroviral drug regiments and contribute to negative treatment outcomes. According to an FAO studies done in Eastern Africa, poor households incur debt in order to meet additional health costs and funeral expenses when family members die (FAO, 2004).

Age and experience are synonymous with knowledge and skill in the African production environment. In sub-Saharan Africa, the indigenous farming knowledge system is very important in addressing many agricultural production problem – weeding, pest control and storage practices. The illiteracy of the African smallholder farmer ensures that the most potent practices are hardly ever recorded hence HIV/AIDS may amplify loss of such skills and knowledge if the elderly succumb to the disease. The intergenerational transfer of knowledge is being disrupted due to HIV/AIDS because parents die before passing on their knowledge to their children. The context-specific local agricultural knowledge that people use to respond to risks is lost (Kormawa, 2006). A study conducted in Swaziland on the impact of HIV/AIDS and drought on local knowledge confirmed that the pandemic erodes gendered-local knowledge. The death of a
“man of the house” or the “woman of the house” usually meant the disappearance of knowledge and skills related to agricultural production (ECA/SA, 2006).

As a result of HIV/AIDS illnesses and death in sub-Saharan Africa households, diversity of crops grown is declining. Family members infected with the disease can no longer contribute to agricultural production to the same extent hence there changes in cropping patterns; cash crops are being abandoned for less labour-intensive subsistence crops (Adetutu et al., 2012). As noted by Slater & Wiggins (2005), smallholder cropping patterns may switch towards food crops to assure survival and also farmers would cultivate crops for which there are lower peak demands for labour; for example, farmers would switch from maize to cassava and sweet potato due to labour shortages. A study conducted in Burkina Faso in 1997 revealed that as a result of the HIV/AIDS epidemic, two villages, Sanguié and Boulkiemdé, shifted their agricultural work patterns and that resulted in an overall reduction in food production (UNDESA, 2013).

Figure 2.5: Understanding HIV/AIDS in the Context of Agricultural Livelihoods: Source: Gillespie, 2006. International Food Policy Research Institute. www.ifpri.org
Figure 2.5 above shows the conceptual linkages between HIV/AIDS and household agricultural production in sub-Saharan Africa. The main goals of households in sub-Saharan Africa is to maximize well-being. The morbidity and mortality of one or more members of the household affects the entire extended family’s livelihood by reducing the ability of the household to produce and adjust to future shocks. The result usually manifest itself in a multitude of adverse consequences such as lower nutritional status, depletion of productive asset base, poorer health, and reduced schooling of children (Economic Commission for Africa/South Africa (ECA/SA), 2006). The “hardest-hit” countries in regions are in southern and eastern Africa; namely Botswana, Lesotho, Namibia, South Africa, Swaziland, Zimbabwe with HIV prevalence rates exceeding 20 percent and Cameroon, Central African Republic, Malawi, Zambia, and Mozambique has HIV prevalence rates between 10 and 20 percent (UN Census Bureau, 2003; Jayne et al, 2006). The epidemic with its direct and indirect effects on agriculture has manifested in a set of interrelated economic, social, and psychological dimensions that could ultimately impact on the health and well-being of the most severely affected regions in sub-Saharan Africa. In Africa generally, stigma associated with HIV/AIDS has been identified as a complex issue and is interfering with reducing the spread of the disease and improving access to testing and treatment (Parker & Aggleton, 2003).

In addition, it is generally accepted that stigma is a process rather than a stagnant or independently occurring event and the general consensus is also that stigma and discrimination must be understood as separate entities. Deacon (2006) cautioned that defining discrimination as a result of stigmatizing behaviours should be avoided because stigmatization can occur without discrimination, just as discrimination is not a prerequisite for an individual to feel stigmatized.
Discrimination is enacted stigma and it is the carrying out of individual or societal thoughts, actions, beliefs, perceived truths, behaviours, and communication techniques and occurs when an action takes place but in some cases not always present in the process of stigmatization (Deacon, 2006).

Link & Phelan (2001), in explaining the definition and understanding of both stigma and stigmatization, described stigmatization as a phenomenon and maintains that it is dependent on social, political, and economic power which ultimately lead to potential discrimination and loss of status with reduced opportunities in a community. Although, both those in or with power and those without power create stereotypes and labels, it is the influence on community or society as a whole that distributes power to ultimately lead to the negative consequences of the stigmatization process.

The problems of HIV/AIDS related stigma in sub-Saharan Africa has been raised in a number of researches and has been identified as a barriers to HIV testing and treatment, care and adherence, and has negative impact on the quality of life of both the infected and affected. According to Deacon (2006), it is important to understand HIV/AIDS stigma in relation to the broader political, economic, social, and cultural context and to also address stigma as one of a number of causes of discrimination. Deacon maintains that it is essential to clarify the meaning of HIV/AIDS related stigma and how it arises, and also how it operates in order to suggest ways of reducing its negative impact on society but researchers have found it difficult to develop a common theoretical perspective on stigma associated with the disease (Link & Phelan, 2001). HIV/AIDS related stigma refers to any kind of prejudice, discrediting, discounting, and discrimination directed at people perceived to have HIV or AIDS and the groups and
HIV/AIDS related stigma in Africa generally is influenced by factors such as cultural constructions, misinformation and stereotypes, traditions and beliefs systems, religion and religious backgrounds, sexuality, and gender. It is shaped by not only the individual’s perceptions and interpretations of their micro interactions but also by the larger social, economic, and political forces of where they find themselves. Its social construct is that which has the significant impact on the life experiences of individuals both infected and affected by HIV/AIDS (Mbonu et al. 2009).

Emphasizing on the social and cultural factors of HIV or AIDS related stigma in sub-Saharan Africa, both Herek et al., (1998) and Mbonu et al., (2009) argue that an individual’s thoughts, behaviours, and feelings that are projected onto people living with HIV/AIDS (PLWHA) are shaped by beliefs, traditions, norms, religion and also social structures of their community and should be considered from two perspectives, namely the target and the perpetrator. People or individuals who participate in discriminatory and stigmatizing behaviours through their actions, negative attitudes, feelings, or beliefs towards PLWHA and those with whom they associate are perpetrators of HIV/AIDS related stigma and targets of HIV or AIDS related stigma are individuals who are either infected with the disease or socially connected to PLWHA. This targeted group of stigma include PLWHA and their family members, spouses or partners, friends, and community members who provide services such as healthcare, employment, or volunteer in any shape or form for the betterment of PLWHA (Herek et al., 1998).
HIV/AIDS related stigma has been recognized as the crux of HIV voluntary testing, prevention, treatment, and counseling worldwide. According to Tomaszewski (2012), stigma affect an individual’s decision to get tested, access health care, or even the disclosure of their statuses to family members, friends, and care providers. Tomaszewski argues that societal stigma emerges in the form of laws, regulations, and policies that single out people living with HIV/AIDS. For example, the criminalization of HIV transmission and forcible segregation of HIV positive prisoners. Stigma associated with HIV virus and AIDS in sub-Saharan Africa is a collective whole of a set of shared values especially in closely-knit societies. These set of values are intertwined with culture and also an individual’s perceptions of laws, policies, and social conditions of the environment in which they find themselves (Tomaszewski, 2012).

Human difference, power struggles, and culture in our societies, together shapes our perceptions of each other and needs to be considered and examined through the understanding of social inequalities in our respective societies. According to Parker & Aggleton (2003), stigmatization generally and more specifically HIV or AIDS related stigma should be examined and conceptualized through the understanding of our social inequalities. Parker & Aggleton argue that “social processes that can only be understood in relation to broader notions of power and domination” (pp. 16). Stigma and HIV/AIDS related stigma, Parker & Aggleton maintain, is a process that occurs at the intersection of our culture, power, and our difference hence the principles of our social order has many implications for the ways in which our society respond to the stigma associated with PLWHA. Because the HIV/AIDS epidemic became widely known during the period of rapid globalization and growth with its associated gaps between the rich and poor (Castells 1996, 1997, 1998) as cited by (Parker & Aggleton, 2003) new forms social exclusion, reinforced social inequalities and stigmatization of the poor, the homeless, or the
jobless in our communities. The figure 2.6 below depicts the process of stigma as it occurs at the intersection of our cultural difference and power.

Figure 2.6: Stigma as the intersection of our culture, difference, and power Sources: Jarvis, 2010, (an adaptation from Parker & Aggleton, 2003)

Nyblade (2006) identified and grouped stigma into three main categorized namely perceived, experienced, internalized stigma. Perceived stigma, according to Nyblade is PLWHA perception of how they would be treated by members of their communities mainly because of their illnesses. This includes how family members, friends, neighbours, their community or even uninfected individual might react upon learning of their HIV/AIDS statuses. Perceived stigma goes beyond community members learning about their HIV/AIDS status to include perceived answers to what actions they would take, like any kind of rejection, blame, or even exclusion.
from social activities and loosing employments (Nyblade 2006). Experienced stigma is when discrimination actually take place against PLWHA, more of an action against them than just perceived thought. This happens in the form of denial of rights to healthcare, employment, education. It also includes exclusion by family and community members, verbal or physical abuses, and harassment. Internalized stigma according to Nyblade, is the negative feelings of PLWHA just because of their illness and includes the feeling of guilt, shame, self-blame that usually results in self-isolation and concealment of their HIV or AIDS statuses (Nyblade 2006).

A community’s reaction to a person living with HIV can have a huge effect on that person’s life; if the reaction is hostile a person may be forced to leave their home, or change their daily activities such as shopping, socializing, schooling, or seeking medical attention. Without the acknowledgement of one’s HIV status, reducing the rates of infections in sub-Saharan Africa is difficult and because of the huge social stigma associated with HIV/AIDS, people living with disease globally hide their HIV status (Block 2009; Ulasi et al., 2009). A research conducted by Stephenson (2009) among three sub-Saharan African countries, Burkina Faso, Ghana, and Zambia on community factors shaping HIV related stigma among young people demonstrated a clear influence of community environment on shaping HIV related stigma among young people. The results also indicated two important points; “that interventions must address HIV related stigma in order to encourage behavior change, and must take into account the social, economic and cultural environments in which young people exist.” (pp. 409). Reducing HIV and AIDS related stigma in sub-Saharan Africa would enhance health care delivery for PLWHA. Reducing stigma would also strengthen people living with HIV by helping them overcome self-stigma, cope with stigma, rebuild their self-esteem, and develop skills to take leadership roles in anti-stigma education and action (UNAIDS, 2007). The impact of stigma on young people including
isolated, dropping out of school, feelings of shame and thoughts of suicide would potentially be eradicated or reduced (Stephenson, 2009).

2.6 HIV/AIDS Related Stigma in Ghana

Stephenson (2009)’s research on community factors shaping HIV related stigma among young people in three African countries including Ghana, maintained that “understanding of the factors associated with attitudes toward HIV/AIDS is essential for the creation of community-based interventions that aim to dissolve stigmatizing perceptions” (pp. 403) and concluded that intervention of the epidemic must address HIV related stigma to encourage behaviour changes since social, cultural, and economic factors among young people is the bedrock on which stigma is built in sub-Saharan Africa and must also be considered.

In Ghana, HIV/AIDS related stigma is a huge issue, considering the fact that the Ghanaian community is a closely-knit religious society with predominately Christians in the south and Muslims in the northern regions. According to a survey conducted in Ghana by Raingruber et al. (2010), about 98% of Ghanaians have some kind of religious affiliation, with approximately 82% reporting as regular church goers and religion has also been cited as a major constraining force preventing individuals from seeking medical care for HIV/AIDS just because they don’t want to be associated with the disease.

The prominent role that religion plays in the lives of sub-Saharan Africans and Ghanaians particularly, reinforces the belief that HIV/AIDS is a punishment from God for “sins” like drug use, prostitution, promiscuity, and homosexuality hence most would do whatever they can to not associate with PLWHA. In Ghanaian communities, living with HIV and dying from AIDS brings
unwanted stigma to a family (Ulasi et al., 2008; Raingruber et al., 2010) and both the immediate and extended family members are disgraced and shun if a daughter or a son is either living with the HIV virus or has a full blown AIDS (Raingruber et al., 2010). The three categories of stigma as identified by Nyblade (2006), namely perceived, experienced, internalized deters the majority of Ghanaians to either conceal their HIV/AIDS statuses or stay away from members of their communities with the disease.

It is no secret that tradition is a contributing factor to the spread of HIV/AIDS in sub-Saharan Africa. For example, Mofolo (2010) argue that understanding traditional norms and practices, specifically Female Genital Mutilation would help reduce spread of the HIV virus. Expanding on culture or traditions in Ghana to re-enforces gender-based stigma and discrimination usually associated with the lack of power of women compared to men in a typical Ghanaian society (Raingruber et al., 2010). In Ghanaian societies, a woman would not be free to ask her husband to wear condom without risking the loss of her marriage, even when the relationship is polygamous. The first thought or utterance of the man is going to be “why do you think I’m sick” even if they are HIV positive.

Traditional norms and culture re-enforces gender-based discrimination, which also increase HIV/AIDS related stigma (Ulasi et al., 2008; Raingruber et al., 2010). In a research conducted by Mill (2003), titled shrouded in secrecy: breaking the news of HIV infection to Ghanaian women, Mill cited Anarfi (1995)’s report that about 25% of HIV/AIDS patients didn’t disclose to anyone their diagnosis and more than 90% did not also inform their spouses. The findings of Mill’s research is an indication that Ghanaian PLWHA use secrecy as a strategy and coping mechanism of their illnesses just to minimize the negative impact of HIV or AIDS related stigma on their loved ones and families, and also to maximize the support and care they need.
from their families and community. HIV/AIDS related stigma in Ghana is one of the main reasons for new infection even though there are enormous efforts by government, CBO’s, and NGO’s to reduce the spread of the disease. According to Mill (2003), a female participant interviewed during a study did not receive her diagnosis directly “following diagnosis, it was common to be told by their HIV counselor that to avoid stigma they should keep their diagnosis secret. The women experienced, or anticipated, many negative outcomes in relation to HIV disclosure. Some women were no longer permitted to share family meals, were isolated by community members, or were forced out of their homes. These outcomes were extremely stressful for the women and acted as powerful motivators for the women to keep their diagnosis secret” (pp. 14).

Stigma associated with HIV or AIDS in Ghana can further be explained or associated with cultural beliefs on sex. Majority of the Ghanaian society view PLWHA as individuals being punished by supernatural forces for their indecent and promiscuous behaviours and therefore deserves to be avoided and stigmatized. Traditional Ghanaian societies have taboos about sex such as fornication and adultery (sex before marriage, sex outside marriage, or even certain sexual acts) and belief that the payment for such actions are punishments by the “gods” of the land hence people “serving” those punishments should be avoided. PLWHA are generally seen in this category, the violators of sexual misconduct have committed crimes against the supernatural forces of the land and don’t deserve to be associated with, thereby re-enforcing stigmatization PLWHA (Mwinituo & Mill, 2006).

HIV/AIDS related stigma has had a profound and negative impact on the lives of both formal and informal caregivers in Ghana. Most formal caregivers are stigmatized just because they associate with PLWHA and even these caregivers themselves also have a certain amount
stigmatization behaviours towards PLWHA. There are still traces of stigma from physicians and health care workers, for example, according to a research conducted by Owusu-Daaku & Buanya-Mensah (2010) on Ghanaian pharmacists’ perception of people living with HIV or AIDS, only 17% reported an acceptable attitudes towards PLWHA. Some physicians and health care workers in Ghana are still hesitant in the treatment and care for PLWHA without outright stigma and discrimination. Researchers in Ghana experienced setback in recruiting family members of people living with HIV/AIDS (PLWHA) for fear of stigma and discrimination in their respective communities. Even though Kumasi is an urban community, family members of PLWHA were reluctant to come forward and be identified with HIV/AIDS (Ulasi et al., 2008).

2.7 Conceptual Framework

This paper broadly embraces some of Parker & Aggleton (2003) suggesting of a conceptual framework that incorporates the interaction of pre-existing stigma like sexuality, gender, or differences within a broader cultural setting and the fear of contagion of the disease. HIV/AIDS related stigma is partly a problem of individual ignorance and part of a complex social process that is linked to an existing social mechanism of exclusion and dominance in any particular social setting (Kurzban & Leary, 2001; Parker & Aggleton, 2003; Deacon, et al., 2005; Nyblade, 2006; Yang et al. 2007).
There is no doubt that HIV or AIDS is a life-threatening and life-altering illness that people globally should be afraid of contracting. Various metaphors and myths associated with disease has contributed to the perception that the HIV virus infects and affects the ‘other’ especially those that are already stigmatized because of pre-existing stigma like their sexuality or gender in our societies (Parker & Aggleton, 2003). The concept of fear of contagion and its associated attitude and ‘lack’ knowledge, and myths of the HIV virus is part of the conceptual framework of this study. Stigma associated with HIV/AIDS naturally comes with the fear of the contracting the disease because of the logical fear of death and living with a terminal illness (Kalichman, 1998; Parker & Aggleton, 2003) which is usually based on inaccurate and or misunderstood information about the disease. The unfortunate misunderstanding and misconceptions of HIV/AIDS such as the belief that the disease is transmitted through mosquito bite and proximity still lives-on today. Because the contraction of the HIV virus inevitably leads
to AIDS and in many cases is characterized by long and painful death, unaffected people including family members, think about their own mortality and disassociate with PLWHA.

The second concept that is of considerable importance when it comes to HIV/AIDS related stigma is the concept of difference with its associated issues of sexuality and gender. This pre-existing stigma of gender and sexuality re-enforces stigma associated with the disease by labelling individuals as “others” mainly because they are different hence are perceived as ‘carriers’ of the disease. These are merely metaphors associated with HIV/AIDS (Parker & Aggleton, 2003). In most areas of the world, especially in Ghana, HIV is mainly sexually transmitted, the virus mainly affected people or populations whose sexual practices, preferences, or identities are different from the ‘norm’, and therefore stigma associated with the disease is usually associated with homosexuality and prostitution. This metaphor re-enforces pre-existing sexual stigma associated with individuals with different sexual preferences and practices. Also, in settings where heterosexual HIV transmission is significant, the disease has been associated with female sexual behaviour, especially female prostitution.

In Ghana for example, prostitution is widely perceived as non-normative female behaviour hence female sex workers are often identified as transmitters of the disease who put at risk their clients and their clients’ sexual partners (Ulasi et al., 2008; Raingruber et al., 2010) The conceptual framework for this study considers a strip-down version of Parker & Aggleton, 2003 suggesting of the key component to be considered in an HIV/AIDS related stigma and discrimination to suite the context of the research.

HIV/AIDS related stigma is a process, according to Bos et al. (2008) and Nyblade (2006) that starts with certain triggers which usually results in stigmatization behaviours with outcomes. Parker & Aggleton (2003) argue that this stigmatization process is initiated at the intersection of
culture, power, and difference, and is as a result of societal behaviour. Parker & Aggleton maintains that stigma is used to produce and reproduce social inequality and also creates difference based on pre-existing stigma of gender and sexuality. Society’s perceptions based on certain social, cultural, and traditional values creates stigma in any particular context therefore it is important to understand HIV or AIDS related stigma in relation to the broader social cultural context. As discussed by Deacon (2006), “researchers need to measure stigma across the full range of domains (e.g. knowledge, attitudes, discriminatory behaviours, perceived stigma, experiences of stigma), and to establish why people are thinking and behaving in certain ways” (Deacon, 2006. Pg. 419). For the purpose of this study though, a conceptualization of HIV/AIDS related stigma would broadly include some of these key components but narrowly consider the cultural context of the research site with its associated religion and traditions.

In societies where cultural and traditional systems place greater emphasis on collectivism, for example in a closely-knit society like Ghana, living with HIV or AIDS may be perceived as bringing disgrace and shame to the family and community (Parker & Aggleton, 2003). Our cultural systems “and where it fits along the continuum of individualism and collectivism will therefore influence the ways in which communities respond to HIV/AIDS and the ways in which S&D are manifested” (pp. 7). Our beliefs and the explanations of the causes of HIV or AIDS contributes to our perceptions of the disease and also re-enforces our pre-existing stigma associated with the disease. The figure below is a representation of stakeholder interaction in the rural community of Wa. In addition to the theoretical approaches to understanding HIV/AIDS related stigma, this study considers the three stakeholder groups; collaborating organization, PLWHA, and community members as illustrated in figure 2.8 below. Relevant organizations/institutions in the community (GHS and RCC) work with community members
and PLWHA to coordinate with both governmental and non-governmental institutions to map out strategies to educate health care providers and the community on issues of stigma. Stigmatization takes place between PLWHA, their families, and the community hence the interaction between these stakeholder groups are very important and represents the greatest challenge for stigma reduction.

![Diagram showing linkage between affected and infected of HIV/AIDS related stigma](image)

**Figure 2.8**: Linkage between the affected and infected of HIV/AIDS related stigma

### 2.8 Summary

The purpose of this chapter is to provide background information and knowledge on issues of HIV/AIDS, and to provide a summary of literature in the fields of stigma and HIV/AIDS related stigmatization and discrimination. By first presenting an understanding of ideologies and frameworks of HIV/AIDS related stigma, the chapter provides conceptual framework for this study and the analytical approach to the research findings and discussion.
CHAPTER THREE

METHODOLOGICAL APPROACH

3.0 Introduction

This chapter provides an explanation of the epistemological approach, the methods of data collection used and its limitations, and also the approach to data analysis of this study. In addition, the chapter provides background information of the researcher and the geographic location of both the country and the study site and relevant information of the collaborating organization.

3.1 Epistemological Approach

The epistemological approach of this research is based on social constructivism and it was exploratory and descriptive in nature. This research focuses on the nature of HIV/AIDS related stigma as identified by respondents in the rural community of Wa and de-stigmatization approaches associated with the disease by local CBO’s and the GHS under the supervision of GAC. Social constructivism is a worldview in which society or “individuals seek understanding of the world in which they live and work” (Creswell, 2007, p.20). Social constructivism worldview is one that is interconnected with stigma and discrimination and since this study focusses on stigma as it relates to HIV or AIDS, it is reasonable to approach the research from a constructivism point of view. Understanding the links and interconnectedness of any community, its cultural settings and social dynamics are necessary to explore and try to understand the process of stigmatization in the context of HIV/AIDS.
Also, socio-cultural factors hugely influences the relationships between stigma and HIV/AIDS and as Sovran (2013) argued, culture and HIV or AIDS in sub-Saharan Africa are so closely linked such that it almost impossible if not difficult to discuss stigma and HIV/AIDS without considering factors such as culture and traditions. This is particularly important in the context of this study because the social, traditional, and cultural setting of Ghana directly influences the viewpoints of community members with regards to HIV/AIDS related stigma. Stigma is a socially constructed phenomenon that emerges through the interaction of individuals. Views of community members are formed and created based on their behaviours, communication, and social circles therefore, to understand the process of stigmatization it is necessary to understand the social dynamics and cultural settings within their communities and how they attach meanings to their traditional and cultural beliefs. The objectives and goal of this research is to rely as much as possible on the views of community members of the study site, focusing on the contexts in which they live to understand their traditions and culture and how this influence HIV or AIDS related stigma.

The epistemological approach of this study was also based on social constructivism because “stigma surrounding AIDS in Ghana may also be associated with cultural beliefs about sex. Society views AIDS patients as individuals who are being punished by supernatural forces for their promiscuous behaviour and therefore deserve to be stigmatized and avoided.” (Mill & Mwinituo, 2006, p. 371).
3.2 Standpoint perspective: Connecting the Researcher to the Research

As a Ghanaian-born Canadian who obtained both his primary and secondary school education in Ghana, my interest in HIV/AIDS and understanding of the repercussions of the disease grew soon after I started graduate school at the University of Guelph. For me, it was personal because I learned that members of my extended family are PLWHA. As someone who grew up in Ghana with intimate knowledge of the culture, traditions, and social norms of the country influenced the epistemological approach that was used for this study because I understand issues in the Ghanaian context of gender and sexuality as it applies to the socio-culture of the Ghanaian communities. I was also privileged to be part of a research team who conducted a community-wide survey and key informant interviews in order to ascertain the misconceptions associated with the use of contraceptives in northern Ghana. This research exercise gave me a vivid understanding of stigma associated with the use of contraceptives in the Ghanaian culture, more importantly how community members were labelled for using contraceptives.

My interest in stigma generally and more specifically in relations to HIV and AIDS grew even more when I heard stories about a well-educated and respected member of my family being stigmatized for living with HIV. This person was someone I looked up to growing up because of his zeal for learning and successes in life but the power of stigma associated with HIV and AIDS drove him out of his community to go back to the United Kingdom just to try and reduce the ‘shame’ associated with HIV/AIDS on himself and his family. Prior to the commencement of this study, I spoke with him of my intentions and he thanked me for my efforts to contribute to the body of literature and research work on HIV/AIDS related stigma.
3.3 Study Site and Community Details

Ghana is a West African country with an estimated population of about 27.9 million people and spans a land mass of about 238,535 km2. The capital city of Ghana is Accra and the country is bordered by the Ivory Coast in the west, Burkina Faso in the north, Togo in the east, and the Gulf of Guinea and Atlantic Ocean in the south (see figure 3.1). Wa is the regional capital of the Upper West region of Ghana, Upper West region being one of the 10 regions of Ghana.

Figure 3.1: Location of Wa on the Ghana map: Source: Google maps

The Municipality of Wa is located in the north-western corner of Ghana and according to the 2010 Population and Housing Census, has a population of about 107,214 representing 15.3 percent of the region’s total population. Wa attracts migrants from the surrounding towns, Burkina Faso, and Cote d'Ivoire due to the availability of some basic infrastructural facilities.
The Municipality of Wa is considered as a low-income rural community with one government hospital, three banks, and a market that serves the town and its surrounding villages. The average household size is about 5 persons per household and children constitute the largest proportion of the household structure accounting for 42.0 percent of the household population. According to the 2014 Ghana Statistical Service, the social and cultural structure shows that 80.4 percent of the people in the Wa Municipality belong to the Mole-Dagbani group which comprises of the Waalas who are the indigenous people, Dagaabas, and the Sissalas making it a closely-knit cultural and traditional society. The majority of households in the municipality are engage in subsistence agriculture with about 82.9% of the agricultural households involved in crop farming. Religion plays a major role in the culture of the people of Wa and has a significant influence in the lives of the people that live there. The adoption of Islam by the Waalas on one hand and Christianity by the Dagaabas on the other remains a factor of value differences between the two major groups in the municipality. Nevertheless, education and the continuous influence of information technology is fast promoting tolerance and eroding the dividing forces.
3.4 Research Design

A period of approximately six weeks was used for data collection for this research by using a combination of 3 different data acquisition methods, semi-structured interviews for both community members and key informants, participant observation through the use of a reflective journal, and secondary data from GHS’s project documentation.

Due to the very sensitive nature of this research study, PLWHA were not interviewed separately, they were interviewed as community members with specific follow-up questions asked when they identify themselves as PLWHA. Targeted participants who are PLWHA however, were recruitment at the GHS offices but this research did not explicitly ask to interview PLWHA. The research design for this project is represented in the flow chart shown in figure 3.3.

Participant observation was recorded throughout the research process in a reflective journal kept by the researcher and was used to augment the findings of this research. Once all the interviews were completed, this research study then collected project documentation from a local GHS office. These documentation included public literature on HIV and AIDS in the district and region and also stigma reduction brochures and policies. Some of GAC’s photographs of stigma reduction posters are shown in appendix B.

3.5 Methodology

In order to describe attitudes about HIV/AIDS related stigma and existing de-stigmatization strategies, approaches used by the GHS and support groups, research was conducted and data collected in collaboration with stakeholders. The methods of data acquisition
are illustrated below (see figure 3.3) and were conducted for three stakeholder groups namely, PLWHA (most participants of GHS programs), employees of GHS and community members.

![Figure 3.3: Structural diagram of the research](image)

The main source of recruiting participants was through opportunistic and snowball sampling. This research relied on chain referral sampling; participants or informants with whom contact has already been made used their social networks to refer the researcher to other people who could potentially be interested in the study. The reason for relying on this qualitative method of data sampling is because of the culture sensitive nature of the community. The researcher also approached shop owners and community members at random to ask if they were interested to be participants of the research.

There were three main forms of data collection utilized in this research, participant observation, in-depth interviews, and secondary data collected from a stakeholder groups and relevant bodies. There was an initial observation and interaction period between the researcher and community member to try and build a rapport pending the commencement of the actual research. The researcher kept a reflective journal which was used to take notes throughout the
entire period of the research. The reflective journal allowed the researcher to note his presuppositions, choices, experiences, and also his actions during the entire research process. The reflective journal was also used to document how participants show emotions and reactions, and their mannerism to questions during interview process. The journal was used to document research processes, the researcher’s practices as a researcher, and also critical reflection on those processes and practices; this allowed for an increase self-awareness and professional competence in the entire research process. The reflective journal was also used to augment coded semi-structured and key informant interview results.

Interviews of both community member which also included PLWHA and employees of GHS and the local CBO were digitally recorded and detailed notes taken. Written consent was obtained from each participant and a numerical coding using the time of the interviews was written on the consent forms (the only link of participants to the research) hence participants will have to provide their consent forms for the researcher to delete recorded interviews based on times on the form if they wanted to opt out of the research.

3.6 Interviews

There were three main types of interviews used in this research; key informant interviews, semi-structured interviews of community members, and recording of a community-based radio station interview conducted to commemorate the World AIDS Day for the year 2015 on December 1st 2015. Participants of the local radio station interview were key stakeholder members of the community and the theme was HIV/AIDS related stigma in the municipality.

Interviews were the main sources of data collection for this research. There were key informant interviews with each interested and willing employee of the GHS, a community based
organization called WAPCAS SHARP, the Assistant Director of the Wa Reginal Coordination Council (RCC), and community leaders to get input on HIV/AIDS related stigma in the community. The key informant group also included nurses of GHS and an outreach worker of WAPCAS SHARP, a community-based organization. There were 14 key informant interviews conducted (9 female, 5 male).

Interviews with various community members were conducted in order to obtain an overall community’s perspective on HIV/AIDS related stigma. Interviewees for this group were found through opportunistic and snowball sampling strategies. Most of the community members were recruited through leads from people we met at the GHS, shops, neighbours, and restaurants where I went to eat. The majority of community members interviewed were individuals who were acquaintances of people I had already interviewed. The total number of community members interviewed was 31 (20 female, 11 male). Community members who were PLWHA were isolated based on their responses to specific questions asked about their HIV or AIDS statuses during the interview process. The bulk of PLWHA were also interviewed at the GHS clinics where they either came for counselling or to receive their antiretroviral medication. Due to the sensitivity nature of this research, PLWHA were not given the impression that they were the only people being interviewed, they were categorized as community members. In total, this research had 17 PLWHA interviews with 10 female and 7 male participants.

Audio recordings of the World AIDS Day for the year 2015 on December 1st 2015 was also used in this research and classified as interview since participants were interviewed on a local radio station broadcast. Interviewees were key stakeholder members of the community and the theme was stigma as it relates to HIV and AIDS in the community.
3.7 **Participant Observation**

Participant observation was conducted throughout the entire research process to achieve triangulation in the research study. The researcher used a reflective journal for notes. Keeping and using a reflective journal in this qualitative research process allowed me to talk about my presuppositions, choices, experiences, and also my actions during the entire research process. The reflective journal was used to document how participants show emotions and reactions, and their mannerism to questions during the interview process. The reflective journal was used to document research processes, the researcher’s practices as a researcher, and also critical reflection on those processes and practices. This allowed an increase of self-awareness and professional competence in the entire research process. Personal identification of participants were not be recorded in the journal and the contents was kept confidential. The reflective journal was also used to augment semi-structured and key informant interviews results. Community members who agreed to participate in the research, selected a venue for the interview and the additional data was collected through the observations of participants in their own environment.

3.8 **Secondary Data and Project Documentation**

Project documentation from the GHS and a local CBO from the community were collected, reviewed, and analyzed. These documentations, including the Ghana Health Services 2014 HIV Sentinel Survey Report, Ghana National HIV and AIDS, STI Policy, Ghana National HIV & AIDS Strategic Plan 2011-2015, and the Ghana National HIV Prevalence & AIDS Estimates Report for 2013-2020 was reviewed to understand the past and current program approaches to reducing stigma.
3.9 Process of Data Analysis

Data collected from all the interviews, participatory observation notes from the journal kept, and all secondary data was analyzed using QSR NVivo 10 software and Microsoft Office 365. Coding was done based on the conceptual framework of Kurzban & Leary (2001), Parker & Aggleton (2003), Deacon et al., (2005), Nyblade, (2006), and Yang et al., (2007), who argued that HIV/AIDS related stigma should be measured from a broader perspective of culture, traditions, religion, and the environments in which we find ourselves because these factors shapes our individual and societal perceptions of any situation that we find ourselves. Microsoft Office 365 was used for charts and diagrams based on selective codes used to categorize the data under broad themes.

The term ‘node’ in QSR NVivo 10, is used to represent a collection of references about specified themes, places, or other areas of interest, some of the nodes were used to represent the identified codes. The software provided a count of the number of sources that were coded to a node and the frequency of references. As the transcripts of interviews and field observation notes were reviewed, responses and observations were placed in appropriate nodes and the references were verified against other responses within the node to ensure consistency. Interview transcripts from the journal notes were reviewed and used to examine and match the connections among the codes to explore the relationships that emerged.
3.10 Limitations of the Methodology

The most obvious of the methodological limitations were both time and financial restrictions. The researcher had time restrictions because he had to travel back to Canada to attend to a personal matter before going back again to Ghana to continue his field work, hence there was a break in the process of data collection which was stressful to both the researcher and participants of the study, especially due to the very sensitive nature of data to be collected and also the break in the process of data collection. Also the study site is a closely-knit and culturally sensitive rural community so leaving the entire data collection process to be continued reduced the amount of trust required to be able to collect as much information as possible and the transparency, honesty, and availability of people willing to participate in the research study reduced. The number of participants willing to be interviewed during the researcher’s first visit depleted because the researcher could not find them and had to work with a very strict time line to collect the required data.

An increased number of PLWHA participants, would have assisted in gaining a more in-depth understanding of the stigma process and also because participants of the stakeholder group was strictly voluntary and dependent on their willingness to participate, this research study was limited in terms of the number of subject-matter expects in the community. This research was not funded hence the researcher had to rely on family and friend to help cater for the huge financial requirement that was needed for the study. This research would have recruited more participants if there was a financial token to be given out after interviews were conducted to motivate participants and also help in recruiting other community members to participate.

Finally, there was a limitations of documentations and secondary data required for this study. GAC oversees and enact rules and regulations required to oversee and coordinate the
activities of the GHS, the RCC, and all local CBO’s in the country as whole. Due to strict bureaucracies in the country and the sensitivity of the research being undertaken, the researcher couldn’t get a clear cut organizational structure of the GAC other than the fact that it regulated and enacted rules of engagement on issues of HIV/AIDS and its related stigma in the country. And also, because of confidentiality, GHS could not release all the required secondary data this research study needed to augment its findings. Although statistics and figures came from reputable sources such as the GHS and RCC under the supervision of the GAC, the reliability of such information was unclear as it is not known exactly who was involved in the data collection and what is omitted in the gathering of the content. The GAC is a ministerial and multi-sectoral body established under the office of the President of the Republic of Ghana to provide support, guidance and leadership for the national response to the HIV and AIDS epidemic in the country.
CHAPTER FOUR

CONTEXT

4.0 Introduction

This chapter begins with the background information of GAC and how it coordinates and works with relevant bodies at the regional and district levels to implement its strategies and approaches to dealing with issues of HIV and AIDS in the country. The chapter then summarizes some of the current national and regional strategic plans for combating HIV and AIDS generally and also specific strategies and approaches of the GHS and RCC in dealing with HIV/AIDS related stigma in the community.

4.1 GAC and National HIV & AIDS Strategic Plan

In Ghana, the GAC is the highest policy making body on HIV/AIDS and is responsible for providing effective and efficient leadership for all programmes and activities of other stakeholders in the country. GAC is also responsible for coordinating the affairs of stakeholders like the Ministry of Health (MoH), GHS, RCC, CBO’s, and Non-governmental Organizations (NGO’s) in their efforts to fight against HIV/AIDS (GAC, 2013). Responsibilities of GAC include:

1. The formulation of comprehensive national policies, strategies, and establish programme priorities relating to HIV & AIDS
2. Providing a high level advocacy for HIV & AIDS prevention and control
3. Expanding and coordinating the total national response to HIV & AIDS
4. Mobilizing, controlling, and managing resources and monitor their allocation and utilization
5. Fostering linkages among all stakeholders in the country
6. Promoting researches, information, and documentation on HIV & AIDS issues
7. Monitoring and evaluation of all on-going HIV & AIDS activities in the country

Appendix A depicts the monitoring and evaluation (M&E) diagram of the GAC and also how it uses decentralized institutions in Ghana to carry out its mandate. To effectively fulfil its mandate of providing support, guidance and leadership for the national HIV and AIDS epidemic response in Ghana, the GAC collaborates and works closely with a wide-range of organizations and also delegates most of its duties to decentralized institutions to perform. Ghana though, has made significant progress towards achieving Universal Access to HIV/AIDS service through the implementation of her National HIV & AIDS Strategic Framework for 2006 – 2010. To further continue to sustain this program, the GAC in collaboration with key stakeholders and partners developed the National Strategic Plan on HIV and AIDS (NHASP) 2011 – 2015 to direct the implementation of HIV/AIDS response over a period of 5 years.
The NHASP mapped out its priorities based on the analysis of the epidemiology and behavioural data and analysis of the national HIV response that is geared towards achieving a universal access to comprehensive HIV/AIDS services. There were specific population groups targeted that included Female Sex Workers (FSW), Men having Sex with Men (MSM), clients of FSW, and injecting drug users because these members of the Ghanaian population were identified by the epidemic analysis indicators to significantly contribute to new HIV infections. Youth were also a priority target population group in Ghana’s quest to create a generation free of HIV and AIDS. Prevention of new HIV infections, HIV treatment, care and support, mitigation of social and economic effects of HIV/AIDS, health systems strengthening, community systems strengthening, and public sector response were the key goals and priorities of the NHASP for 2011 – 2015 as depicted in the figure 4.1 above.
4.2 Prevention of New HIV Infections

The strategic plan’s target is to reduce new HIV infections in Ghana by 50% by the end of 2015. The prevention of new infections, according to the NHASP should be through the following: the implementation of the Prevention of Mother to Child Transmission (PMTCT) of HIV, HIV Testing and Counselling (HTC), Blood Safety, Universal Precaution and Post Exposure Prophylaxis (UPPEP), Behaviour Change Communication (BCC), High Risk Sexual Behaviour (HRSB), Sexually Transmitted Infections (STI’s), and Most at Risk Population (MARPs).

In Ghana, Mother to Child Transmission (MTCT) of the HIV virus is the only means through which children under the age of 5 years acquire the disease. According to the NHASP, without any intervention to reduce vertical transmission of the HIV virus, there would be about 30% of new infections of the virus from infected pregnant and breastfeeding women in the country to add up the pool of those already infected. Based on the ERP modelling, the rate of mother to child infections was estimated at 30% in 2010 hence the National HIV & AIDS Strategic Plan for 2011 – 2015 targeted a reduction of MTCT from 30% to 5% by 2015 to try and enable Ghana eventually move towards a 0% HIV infection from MTCT thereby totally eliminating MTCT in the country.

The number of pregnant women attending Antenatal Care (ANC) counselled and tested for HIV annually increased from about 381, 874 (40%) in 2009 to 1, 023, 150 (95%) in 2015 hence there was a scale up of the number of pregnant women to be tested for HIV to 95%. This increase the number of pregnant women attending ANC will require additional equipment and trained health care staff to conduct HIV Counselling & Testing (HCT). As a result, a standardized package of PMTCT services was identified and following strategies were mapped

The strategy of increasing awareness of and generating demand for HCT services among communities with specific targeting of women in reproductive age and their partners is one that is most directly connected the RCC, the main collaborating institution of this research study. Strategy 1 seeks to scale up the demand for PMTCT services in both rural and urban communities in the country to increase the awareness of MTCT of the virus. Community-based programmes and promoting social transformation of an HIV/AIDS competent society is crucial to attain this goal especially in culturally sensitive and closely-knit societies. The first strategy address the issue of stigma reduction because it involves awareness campaigns of HIV infections to be implemented through community wide systems in a sustainable manner to support the increasing access to HTC by women in the reproductive ages and their partners. Civil societies including NGO’s, CBO’s, faith-based organizations, and community leaders would champion this strategy. According to the NHASP, the interventions to be implemented include media and community based awareness on HTC including couple testing, counselling and the promotion of male involvement of PMTCT.

Testing and counselling is viewed as an entry point to HIV treatment. According to the NHASP, HTC services has been scaled-up to and available to about 793 health care facilities in Ghana throughout their outreached programmes. Programmable data from NHASP indicates that there 865,058 people counselled and tested for HIV in 2209 and the number is expected to
increase to about 1,740,000 by the end of 2015. The HIV & AIDS strategic plan for 2011–2015, reports that HIV counselling and testing is provided as a walk-in service as part of the PMTCT at service delivery points including facilities providing Adolescent Friendly Health Services (AFHS) within health services facilities in the country. Most of these services are being carried out the GHS in Ghana. In addition, HIV testing and counselling is provided as outreach services in urban and rural communities through the Know Your Status (KYS) campaigns and as part of HIV Workplace Programmes. To increase the effectiveness in the context of low HIV prevalence, there is a targeted testing and counselling of population with high vulnerability to HIV infections in an effort to increase the detection rates of PLWHA in the country. Targeted outcome is to increase the percentage of men and women tested for HIV by 10% by the year 2015.

4.3 HIV Treatment, Care, and Support

In an effort to reduce morbidity and mortality rates among PLWHA, the NHASP 2011–2015 initiated an HIV/AIDS treatment, care, and support strategy to focus on treatment as a preventive strategy aimed at maintaining and ultimately minimizing the spread of the virus. Care and support is characterized among other issues by ignorance, fear, stigma and discrimination, inadequately trained and motivated staff, and weak referral networks hence efforts are needed to improve treatment, care and support for PLWHA at both community and institutional level by way of education. Care provided to the infected and affected individuals in Ghanaian communities and or their own environment form an important link in the continuum of health care for terminally and chronically ill people. This specific strategic plan was selected based on its relevance and effectiveness in addressing the key characteristics of the HIV/AIDS epidemic
and also a key factor necessary to promote Ghana’s universal access to HIV services. For the
treatment of HIV/AIDS, Ghana aimed at achieving the universal access target by increasing the
number of PLWHA on ART from 30.5% to 85% by the year 2015. The scale-up, according to
the strategy would require a rapid investment in Ghana’s health care systems to cater for over
100,000 PLWHA by 2015 because the number of eligible PLWHA increased from 54,894
adults and 4,851 children in 2009 to about 110,494 adults and 13,600 children in 2015. Scaling
up ART sites from 138 in 2009 to 300 by 2015, accreditation and certification of ART sites and
laboratories, improving referrals to Antiretroviral treatment sites, strengthening HIV drug
resistance monitoring, and strengthening drug and HIV commodity supply to ART sites were
mapped out achieve to achieve the HIV/AIDS treatment plan.

Home and support would be provided through home and community based care
according to the national HIV & AIDS strategic plan. There is however no Home and
Community Based Care (HCBC) policy and guidelines but there are some interventions that has
been initiated and put in place to cater for about 59 districts. HCBC policies and programme
guidelines according to the NHASP 2011 – 2015, will be developed and will include
psychological support to not only PLWHA but their care givers. There is a proposed increase in
the percentage of PLWHA accessing care and support services from 30% to 75% with a
 corresponding increase in the number of districts with functioning HCBC programmes to 170 by
the year 2015.
4.4 Mitigation of the Social and Economic Effects of HIV and AIDS

The spread of HIV new infections and the impact of HIV/AIDS in Ghana are influenced by socio-culture, legal, and economic factors. Households, community members, and both the private and public sectors are all feeling the worsening burden of caregiving and increased cost associated with HIV/AIDS (NHASP, 2010). Some of the key areas targeted for action in the national HIV & AIDS strategic plan 2011 – 2015 are a) Reduction of stigma and discrimination b) Increase access to PLWHA and Orphans and Vulnerable Children (OVC) in Ghana.

Mitigation of social and economic effects of HIV/AIDS is one of the key strategies geared towards the reduction of stigma and discrimination in Ghana. One of the main outcome objective of the NHASP 2011 – 2015 is to increase the percentage of people in Ghanaian communities with acceptable attitudes towards PLWHA from 11% in females and 19% in males in 2008 to 50% by the year 2015 because “widespread stigma and discrimination towards PLWHA in the general population adversely affects uptake of HIV services including HTC, adherence to antiretroviral therapy and access to supportive services” (NHASP, 2010, pp 77). According to the national HIV & AIDS strategic plan 2011 – 2015, stigma associated with HIV and AIDS goes beyond PLWHA; it affects their families, caregivers, health workers, and MARPs in Ghana hence stigma and discrimination interventions would target community members, individual, and institutions and would also seek to create an enabling environment to effectively address issues of stigma. These interventions would address key drivers of HIV/AIDS related stigma like lack of knowledge, fear, and negative cultural norms and practices in the country with regards to the disease.

To reduce HIV and AIDS related stigma in Ghana, the national HIV & AIDS strategic plan proposed to increase coverage of stigma reduction programmes in all districts and the
programmes will address issues such as lack knowledge on HIV and AIDS, fear of contagion of the disease, negative cultural norms and practices, and weak enabling environment in the country about issues of HIV and AIDS. Strategic plans such as the development of comprehensive interventions for all drivers of stigma and strengthening the capacity of implementers in stigma reduction programmes were identified as key initiatives in this regard. Interventions would include incorporating HIV and AIDS messages in national events such as national farmers’ day, independence day, awards and ceremonies, and general meetings of regional and district ministries to provide education on HIV and campaigns against HI related stigma. In addition, the strategy will sensitize community-based workers, health care workers, traditional leaders, opinion leaders, religious leaders, and policy makers on HIV and AIDS related stigma for them to champion stigma reduction education in the country.

Capacity development for association and supports groups of PLWHA and capacity building of the media and human rights organizations working with PLWHA associations were included in the national HIV & AIDS strategic plan for 2011 – 2015 to augment national efforts towards the reduction of HIV/AIDS related stigma. The plan is to train identified support groups and associations on stigma reduction strategies and on protecting the rights of their members. The inclusion of the media is necessary according to the plan to protect the rights of PLWHA through print and electronic media.

4.5 Community Systems Strengthening (CSS)

The national HIV & AIDS strategic plan for 2011 – 2015 acknowledges that community linkages, networks, partnerships, and coordination systems and mechanism that support services
delivery and advocacy are weak. Formal linkages exist between CBO’s and NGOs that receive funding from the GAC through their regional and district assemblies but other organizations that receive funding from different sources are not linked with any effective coordination in terms of having a common goal. For this reason, there are overlaps in project implementation leading to difficulty in coordination of activities among the various players and stakeholders at the community level. The NHASP therefore, places emphasis on the strengthening all community systems for the delivery of HIV and AIDS services in the country. Key strategies for strengthening the capacity of CBO’s and NGO’s to create enabling environment and undertake advocacy on HIV/AIDS policies include the monitoring and documentation of community and government interventions, advocacy communication and social mobilization, building community network linkages and partnerships, building skills for CBO’s and NGO’s in service delivery, advocacy and leadership, develop mechanism for funding CBO’s and NGO’s to implement community level activities, improve community based HIV services availability use and quality, and improve monitoring and reporting on community based HIV services.

4.6 Upper West Regional Coordination Council (RCC)

All the above proposed strategies and expected outcomes are initiative of the GAC and stakeholders in the country to spell out a working framework that would effectively and efficiently deal with issue of HIV and AIDS but because GAC does not have physical offices at the regional and district levels institutions such as the regional and district coordination council and the GHS coordinate and implement the expected goals and objectives. One such institution is the Upper West Regional Coordination Council (RCC), the collaboration institution for this research project. The RCC maintains an office in Wa and coordinates the activities of all the
districts in the region, it is more of a coordinating administrative body in the region, responsible for providing leadership and coordinates activities of local CBO’s, NGO’s, stakeholders, and also the GHS on HIV/AIDS activities and issues at the district and regional levels with a dedicated focal person to oversee these activities. The RCC’s activities on HIV and AIDS are funded primarily by GAC and other donor agencies to lead the health sector especially GHS’s response to HIV/AIDS. Promoting education and services to reduce the number of new infections and enhancing the living standards of PLWHA through by improving their home-based care services dominated the activities of the RCC in 2015.

Expansion and improvement of HIV/AIDS education across the length and breadth of the region is critical to preventing the spread of HIV and stigmatization of PLWHA according to the RCC. The overall program goals and strategic plans of the RCC for the 2012 – 2015 is to prevent new HIV infections and reduce stigmatization and discrimination of PLWHA in the region. Their specific program objectives for HIV/AIDS included the following:

1) Increase HIV/AIDS awareness especially among the youth in the region
2) Increase appropriate STI care-seeking behaviours
3) Reduce number of sexual partners for community members
4) Increase perception of risk and change attitude towards the use of condoms
5) Increase the demand for HIV/AIDS services
6) Create demand for information on HIV/AIDS

The RCC’s HIV/AIDS activity report for the last quarter of 2015 centered mainly on effective education on HIV transmissions, reduction of HIV/AIDS related stigma, and also involvement of stakeholders and community members in Wa and the surrounding districts on general HIV/AIDS awareness education. According to the report, fear of contagion of the disease
is fuelled by myths, misinformation, and misunderstanding of HIV/AIDS and is breeding stigma associated with the disease. A discussion on local radio broadcast organized by the RCC for last year’s World AIDS Day centered on issues of HIV and AIDS related stigma in the Wa municipality.

Behavioural Change Communication (BCC) and the effective management of HIV/AIDS cases were the methodologies adapted to curb new infections and these centered on abstinence from sex, promotion of communities own advocacy on early sex, the act of being faithful to one faithful sexual partner, correct and consistent use of condoms, reduce incidence of alcohol-related sexual encounters, and the use sharp material by multiple people. Some of the communication strategies employed by the RCC includes hanging of posters, giving lecture on HIV/AIDS in schools and community centres, involving community leaders, and peer education by encouraging the youth to volunteer with CBO’s and NGO’s to discuss issues of HIV/AIDS. The current national context is characterized as one having detailed guidelines with extensive attention to the issues of stigma or the process of stigmatisation in Ghana. Both the national and regional context understand that the issues of stigma and stigmatization is blended and geared by misconceptions, misinformation, and the cultural and traditional practices of the Ghanaian community.
CHAPTER FIVE

FINDINGS

5.0 Introduction

This chapter provides a summary the findings of the research project. These findings are based on the results of interviews conducted on the stakeholder groups (key informants, community member, PLWHA) and observations of participants of the research. The first section provides a very brief overview of respondents. The second sections presents the three main types of stigma (perceived, experienced, and internalized) and sources of stigma as identified by this community. The third section consider de-stigmatization approaches of the RCC and GHS under the directives and supervision of GAC. The fourth and final section provides a summary of the effectiveness of de-stigmatization strategies used in the community for reducing stigma.

5.1 Research Participants Profile

The study sample size comprised of 62 (n=62) participants, interviewed as community members and 14 as key informants. Due to the very sensitive nature of this research and also considering the fact this research was conducted in a closely-knit and culturally sensitive community, PLWHA were identified and classified based on their answers to specific questions asked during the interview process and the 14 key informants were recruited from the two main relevant bodies (RCC and GHS), a community-based organization, and from community leaders. The 17 PLWHA participants (see table 5.1) were recruited from an HIV testing and counselling
centre, interested community members living with HIV and AIDS, and at a local CBO involved with HIV/AIDS issues in the community.

Table 5.1: Distribution of participants based on specific attributes and values (n = 62)

<table>
<thead>
<tr>
<th>Classification</th>
<th>Attributes</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key Informants</td>
<td>CBO</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>RCC</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>GHS</td>
<td>5</td>
</tr>
<tr>
<td>Community Members</td>
<td>Christian Leaders</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Muslim Leaders</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Shop owners</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Teachers</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Interested Participants</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>PLWHA</td>
<td>17</td>
</tr>
<tr>
<td><strong>Total Number of Participants</strong></td>
<td></td>
<td><strong>62</strong></td>
</tr>
</tbody>
</table>

Table 5.1 above further illustrates the distribution of the participants according to the specified attribute values for each classification. This research project did not classify participants according to their ages, recruitment was based solely on willing community members who had the capacity to consent. Of the total 62 participants, 39 were females and 23 were males as illustrated in figure 5.1 below and they were all recruited in the community. 37% of the total number of participants were males and 67% were females.
Participants were asked to share their thoughts on HIV/AIDS and a follow-up question designed to ascertain their levels of education indicated that about 26% did not have any formal education, 47% had some level of secondary education, and 27% had at least a college or university level education as depicted in table 5.2 below. Participants had a fairly-good knowledge of HIV and AIDS and some of the modes of transmission of the HIV virus; about 80% of participants knew the various modes of HIV transmissions and also indicated that there is stigma associated with the disease in their community.

Table 5.2: Distribution of participants’ educational levels

<table>
<thead>
<tr>
<th>Educational Level of Participants</th>
<th>Number of Participants</th>
<th>Percentage of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>No formal education</td>
<td>16</td>
<td>26%</td>
</tr>
<tr>
<td>Secondary school level education</td>
<td>29</td>
<td>47%</td>
</tr>
<tr>
<td>University/College level education</td>
<td>17</td>
<td>27%</td>
</tr>
<tr>
<td>Total</td>
<td>62</td>
<td>100%</td>
</tr>
</tbody>
</table>
Table 5.3: Do participants think HIV/AIDS related stigma causes more HIV infections

<table>
<thead>
<tr>
<th>Responses</th>
<th>Number of Participants</th>
<th>Percentage of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>50</td>
<td>81%</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>11%</td>
</tr>
<tr>
<td>No Response</td>
<td>5</td>
<td>8%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>62</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

As depicted in table 5.3 above, majority of participants indicated that HIV and AIDS related stigma causes more HIV infections in the community; 81% of participants answered yes to stigma causing more infection, 11% answered no to stigma causing more infections (they do not believe that HIV/AIDS related stigma causes more infections), and 8% did not either answer or did not know if stigma caused more HIV infections in their community. The 19% of participants who either answered no to the question of HIV and AIDS related stigma causing more HIV infections or those that abstained from answering the question, did indicate in their final thoughts that HIV/AIDS is as a result of immorality, promiscuity, or prostitution.

5.2 **Attitudes within the Community about HIV/AIDS Related Stigma:**

**Objective 1**

PLWHA’s experiences of stigma in the community is categorized as either perceived, experienced, or internalized. Perceived HIV and AIDS related stigma involves a person’s perceptions about how they would be treated by others, especially their close associates - community members, friends, and family; and also what preconceived reactions they expect, especially learn of their HIV status is positive. Experienced stigma involves all stigmatizing thoughts, attitudes, and beliefs that are acted open within the community or environment that an
infected HIV/AIDS person finds themselves. Internalized stigma includes feelings of shame, blame, self-isolation, or even withdrawal of a PLWHA from their community due to their HIV/AIDS status.

Figure 5.2: below depicts how HIV and AIDS stigma impacts both the infected and affected community members. Participant responses indicate that people who are uninfected with the HIV virus and do not have family members living with the disease employ efforts to distance themselves from PLWHA and their families. However, the triggers and outcomes illustrated in figure 5.2 applies to both the infected and affected members of the community. Through the triggers of impending death, physical deterioration, HIV being a punishment and sin, HIV being as a result of prostitution and infidelity, and misinformation comes the outcomes of stereotypes, prejudice, social exclusion of PLWHA, refusing HIV testing, emotional and verbal abuse of PLWHA, abandonment of PLWHA, and the denial of rights of PLWHA.

Figure 5.2: HIV/AIDS stigma triggers and outcomes for community members
The spread and impact of the HIV and AIDS in the community of Wa, according participants of this study is influenced by the socio-cultural, economic, and legal settings. Stigma and discrimination, together with its associated issues of sexuality, gender, differences in cultural practices, and socio-economic statuses across this community is undermining efforts to address the HIV and AIDS epidemic. To effectively and efficiently reduce and even eradicate HIV and AIDS related stigma in this community is to address issues of cultural gender norms and stereotypes, strengthen and utilize legal and policy resources to empower rights-based HIV/AIDS groups, and to address the impact of HIV/AIDS caregivers.

5.2.1 Perceived Stigma

Fear of death, community social interaction (exclusion), cultural and traditional beliefs, and individual morality were the main findings of this research under perceived stigma. The fear of death which was the strongest incidents of perceived stigma among participants of this research is closely linked to the fear of contagion of the disease.

Fear of Death

Some participants indicated that death is certainly an ultimate end for every human but “most people don’t know how and when they would die” one participant noted and added that the “fear of being left alone” when you most need company in itself is death especially when you “see your physical appearance” deteriorating. Almost all PLWHA interviewed are aware that HIV/AIDS is not curable, at least as at the time of this research hence their perception is that once HIV is contracted an individual is immediately assumed to be a “walking corpse” as one
participant said and that dying is going to come quicker that anyone else in a harshest form and situation. Apart from PLWHA in the community, participants also attributed the fear of death as the main trigger for their stigmatizing behaviours in the community.

Figure 5.3: Distribution of participants perceived stigma by numbers and percentages

Fear of death accounted for about 35 percent of participants interviewed. The fear of deteriorating physical appearance was also identified as one of the main perceived stigma of PLWHA because it is one of the physical attributes, according to participants, of the disease and also one of the ways by which community members would point fingers at infected persons and label them as AIDS patients. The deteriorating of physical appearance of AIDS patients usually occurs at the time when they need support but because of stigma, family and community members would shy away from them. It is this fear of isolation and eventual death that scares participants and also increases their perceived stigma associated with HIV and AIDS. PLWHA’s perceptions about how they would be treated by others, especially their close associates such as their family, community members, and friends is what gears perceived stigma. One participant who was living alone in an uncompleted building, a building he was trying to put up when he
Community Social Interaction (exclusion)

Some of the findings of this study indicate stories of PLWHA being rejected and ejected from their family homes, losing friends, and basically living in isolation. One participant who basically lived under a baobab tree outside her family house could not find somewhere for her interview to be conducted, she said she had nowhere to go and we had to conduct the interview in my vehicle; this participant did not have full-blown AIDS, she was HIV positive and her family members rejected her. This is what she had to say during interview, when asked if she felt sorry for herself. “Yes, I feel sorry for my situation because I have HIV and my husband died with AIDS, my children will not come to me because they don’t want people to say that they also have HIV”. This was very interesting and speaks volumes about how stigma can divide families; her children wouldn’t visit her because they did not want to be perceived by the community as having or living with HIV by association.

There were three participants who asked to be interviewed outside the Wa municipality, we obliged and asked during the interview why they wanted their interviews to done in about 25 kilometres away. They answered with the same reason, they didn’t want members of their community to know that they have HIV or AIDS and they did not even receive their antiretroviral medication in community because of the community’s perception about PLWHA. Rejection and avoidance was perceived by PLWHA in various situations, most common is in relation to eating or even sharing cutlery. PLWHA in the community have the perception that

worked in Accra, Ghana indicated in fluent English that “I knew this day will come when I would be alone so I tried to build a place like this but could complete it”.

Community Social Interaction (exclusion)

Some of the findings of this study indicate stories of PLWHA being rejected and ejected from their family homes, losing friends, and basically living in isolation. One participant who basically lived under a baobab tree outside her family house could not find somewhere for her interview to be conducted, she said she had nowhere to go and we had to conduct the interview in my vehicle; this participant did not have full-blown AIDS, she was HIV positive and her family members rejected her. This is what she had to say during interview, when asked if she felt sorry for herself. “Yes, I feel sorry for my situation because I have HIV and my husband died with AIDS, my children will not come to me because they don’t want people to say that they also have HIV”. This was very interesting and speaks volumes about how stigma can divide families; her children wouldn’t visit her because they did not want to be perceived by the community as having or living with HIV by association.

There were three participants who asked to be interviewed outside the Wa municipality, we obliged and asked during the interview why they wanted their interviews to done in about 25 kilometres away. They answered with the same reason, they didn’t want members of their community to know that they have HIV or AIDS and they did not even receive their antiretroviral medication in community because of the community’s perception about PLWHA. Rejection and avoidance was perceived by PLWHA in various situations, most common is in relation to eating or even sharing cutlery. PLWHA in the community have the perception that
their illness does not warrant them to eat or even use cutlery in ‘chop bars’, local restaurants because community members think they can easily get infected with the virus if they share cutlery or eat from the same plates. One participant noted whiles sharing her perception of how the community perceived PLWHA, answered that “I don’t buy food or eat from one particular restaurant in my neighbourhood because the owner said I should not come there again after she saw me at the clinic to collect my medicine, she said I can send someone to buy me food but not come there myself”.

This research discovered that some of the members of the community had preconceived opinions that are not based on reason or actual experiences or facts about their perceptions of PLWHA. One of the participants, a teacher when asked what he thinks should be done to reduce HIV/AIDS related stigma in the community answered, “they (PLWHA) should be quarantined” so there was a follow-up question to try and ascertain whether he really understood the question and he said “yes, so that the community would not feel threatened by the disease and would not stigmatized PLWHA”. Either indirectly or directly, negative social interactions causes PLWHA in the community to confirm their perceived negative perceptions of their plight.

Cultural and Traditional Beliefs

In this community, culture and traditional beliefs and the interpretations of HIV and AIDS is that the disease is a curse and PLWHA are to be blamed, the disease according participants of this research is that PLWHA and their families are being punished for either displeasing the ‘gods’ of the lands or a witch doctor or a traditional spiritual leader in the community casted the disease on the infected and their families as a punishment for wrongdoing
in the community. A female participant when asked whether she is living with HIV or AIDS answered “yes, I’m and I got it from a witch doctor in our village as a curse because he was fighting with my family and wanted to teach me a lesson”. She did not disclose the cause of the fight but the idea that her illness is a curse gave her the perception that she is not ‘whole’. Perceived HIV/AIDS related stigma that is triggered by traditional and cultural beliefs is common in the community. Another participant mentioned that her family members “insisted that she moves out of the family house because she is a witch and her sickness is a punishment from their ancestors” and she actually believed her family’s understanding and perception of her sickness. Not everyone though, in the community perceives HIV and AIDS as a punishment from the ‘gods’ but in a closely-knit and culturally sensitive society, perceptions eventually becomes reality.

Shame associated with HIV or AIDS in the cultural and traditional context is usually as a result of the community’s belief that to be cursed is shameful for the individual, their family members, and in some cases the entire community. A cursed person and their family should be blamed for their ‘burden’ of being cursed. Because blame is placed on PLWHA in the community for contracting the disease they are usually ignored to suffer the consequences of their ‘curses and misfortunes’. An infected individual is responsible for contracting the disease and the family blames the individual, insisting that they look after themselves. One participant noted that she “got infected with HIV by my rivals”, a belief that the HIV virus can be transmitted spiritually, stating that “my husband used to love me more that than his other wives and they bought the disease for me” so that her husband wouldn’t came close to her any longer. Literally, she is being blamed for her husband’s love in a polygamous society; she is sick because she did not share her husband.
Individual Morality

An individual’s moral behaviour is another source of perceived stigma by the infected and affected. In this community, an individual’s morality becomes questionable as soon as they contract HIV because of the assumption that the disease is transmitted mainly through sexual intercourse. There were several female participants who stated that their family and community members believe the contraction of HIV is as a direct result of immoral behaviours, usually associated with sex workers or prostitutes. As one female participant stated, her uncle called her and said “you see the shame you have brought to the family, your immoral behaviour has caused this, and now, what would you do because you’re going to die and you should go back to where you got it (HIV) from and die there”. Another participant shared her family’s perceptions of her as a person living with HIV and stated that according to her family, she “behaved in a wrong way and that she had several male partners so that is her punishment”. An unmarried female who contracts HIV in this community is immediately branded as a commercial sex worker and deserves her punishment for immoral activities. Questionable behaviour of PLWHA as an assumed method of contracting HIV was identified as a significant component of perceived stigma.

5.2.2 Experienced Stigma

Experienced stigma involves all stigmatizing thoughts, attitudes, and beliefs that are acted open within the community or environment that an affected person finds themselves. This type of stigma comes in the form of refusal to employment, education, healthcare, physical
abuses, harassments, or even assaults. Experienced stigma as identified and encountered by participants, can be categorized and understood within one of three main sub-categories of fear of death, community social interaction (exclusion), and cultural and traditional beliefs.

Figure 5.4: Distribution of participants experienced stigma

**Fear of Death**

The first type of experienced stigma, fear of death is connected to a fear of contagion of the HIV virus. Participants indicated that some of their family and friends often fear physical contact and in some cases fear proximity by not having firm handshakes with them. The fear of death by AIDS complications with its associated physical deterioration increased the precautions uninstructed community members took to not get infected with the HIV virus. One participant
described a situation and experience about his brother refusing to sleep in his room when he
travelled, telling him that, “I’m scared of the mosquitos in your room because they would pump
your blood into me to get infected” with HIV. The fear of death by AIDS - fear of contagion of
the HIV virus is connected to all the types HIV or AIDS related stigma that this study uncovered.

Community Social Interaction (exclusion)

Even though, only eight of the 17 PLWHA interviewed, explicitly stated in more than
four sentences of their experiences of stigma that was of community social exclusion nature, they
all stated that they have had some kind stigmatization experience in the form of finger pointing,
verbal abuses, harassments, or even community members talking in a condescending manner to
them because of the illness. The most common form of experienced stigma was avoidance of
community members and friends. All 17 PLWHA indicated that they lost friends not because
they wanted to but because of living with HIV or AIDS; their friendships became more of mere
acquaintances. Incidents of avoidance was a much better way of telling an infected friend that
they either fear to contract the virus or fear to be labelled as someone who could possibly have
the disease. Participants indicated that both family and community members avoided having to
interact and associate with an infected individual.

One female participant said her extended family member refused to allow her to live with
them in the family house because she was tested HIV positive, according this lady “they said the
sickness has no cure and you will die soon” so it better for her to go and die somewhere no one
knows her, her family members think she is going to die and dying in the family house would
attract the attention of community members, they saw that as tarnishing the image of the entire
family. Another participant said his friend would not “call me to go play soccer, so I will also not go to the park because I didn’t want them to tell me I have HIV”. One participant said she had to stop selling ‘masa’, a traditional dough-like pastry made from blended beans and spices because “no one will buy my masa”.

Family members particularly would reject PLWHA, would not involve them in decision making processes, or even invite them to attend funerals together. One participant said his family members did not want him to attend his uncle’s funeral because he is living with HIV/AIDS “but I went there and only spoke with the government workers”, referring to his uncle’s co-workers. There was one participant who experienced total neglect because she had full blown AIDS before attempting her antiretroviral medical and was living alone with her dog. Her family members wouldn’t visit her or even talk to her and there was only one community health nurse who came to see her and also brought her medication. She said “my family sacked me to come and live here alone thinking I would die but I’m still alive because the nurse started bringing me medicine”.

Abuse, either directly or indirectly, verbal or nonverbal was reported by program participants. Several of the participants said they couldn’t go to the corner store because community members made funny gestors at them. A female participant said she was spotted by a neighbour at the clinic where she went to collect her medical and the following day this neighbour tried to provoke her to get the chance of insulting her that “I’m HIV positive, she kept asking me what I went to the clinic do and added, oh I can see you are putting on weight now, I know you are one of them” referring to PLWHA. Participants recounted their experiences with gossip and indicated that experienced community members “laughing and pointing fingers at them” as they passed by.
Cultural and Traditional Beliefs

Another type of experienced stigma as reported by participants is that of negative cultural and traditional beliefs. Cultural and traditional beliefs always had to do with using traditions and culture to blame PLWHA for causing their own plight and in some cases being the cause of some unrelated misfortunes in the family or community. One of my key informants indicated that his brother died from HIV/AIDS complications and left behind two uninfected wives “and for four years no one in the community wants to even date either of them because they think the ladies are also cursed” and now he has the burden of their up keeping.

5.2.3 Internalized Stigma

Internalized stigma includes feelings of shame, blame, self-isolation, or even withdrawal. It can also be referred to as self-stigma when the affected person blames himself for his situation. Internalised stigma has an enormous damaging effect on the mental wellbeing of PLWHA and breaks down the confidence to seek help and medical care. Internalized stigma was categorized into three sub categories as social withdrawal, fear of death, and negative self-image.

Social Withdrawal

All 17 PLWHA interviewed indicated levels of internalized stigma and identified with some sort of social withdrawal by isolating themselves from social gatherings or interactions with the community. One female participant explained that, "I am afraid of giving my sickness to
my family members, I don’t know how I got sick and I don’t want my children to get it so I stay in my room and cry sometimes”. Another male participant noted that upon receiving an HIV positive diagnosis, “my church members would look at me up and down to see if I’m growing thin, I think. And they would not tell me to pray again, so I decided to always stay in my room and pray alone”. While answering question about the effectiveness of his antiretroviral medication, a participant said, “I go to Tumu to get my medicine and I don’t stay in my area because they know I have AIDS”. There were a number of participants who felt guilty for being HIV positive and one of them had this to say: “sometimes am disgraced, I can’t talk to my children and everybody thinks that I am useless and a bad person, so I stay outside always where people don’t know me. I don’t want them to look at me always, when I greet them some people don’t say anything, it is better they don’t see me”.

**Fear of death**

Fear of dying from a long and painful AIDS related complications or sickness was a huge concern for PLWHA. One female participant who is a nursing mother, said, “I am aware that I have the disease so I do not touch by son too much. I don’t want him to die soon, I want him to grow and marry, so the nurse said he is not sick and I am happy”. There was one particular participant who said, “I don’t want to die now, the doctor said my medicine won’t make me die quick but I’m still afraid”. Another participants noted, “I don’t want to die now and leave my children because it will be hard for them, they can’t go to school and my family will just insult me”.

88
Negative Self-image

Negative self-image is the final aspect of internalized stigma as identified by PLWHA. One of the participants said, “Yes, I feel sad for myself and AIDS people because they don’t respect them, and everybody thinks you are a bad man” when asked if he feels sad for PLWHA.

5.2.4 Sources of Stigma

Sources of stigma, as identified by participants included fear of contagion, education, misinformation and stereotypes, and cultural and traditional beliefs. Above all, fear of contagion was identified as the main source of stigma in the community and it manifested itself in a number of different forms. Fear of contracting the HIV virus was noted by almost every single participant to be the reason why PLWHA are stigmatized in the community. One participant lamented that “my friends and even my wife does not want to eat with me again……..she said I can have cut on my fingers when cutting my finger nails and she will get the sickness”. Another participant, interestingly stated that, “you see, if you get accident and die you are dead but AIDS, you would be sick, slim. You cannot go out. Everybody would leave you and insult and you still die”. One’s deteriorated physical appearance coupled with living with a terminal illness is very scary for both PLWHA and unaffected members of this community.

The second main source of stigma according to both PLWHA and community members was lack of education, misinformation, and stereotypes associated with HIV/AIDS. As indicated earlier, this community associates HIV and AIDS to immoral behaviour such as promiscuity or prostitution. Some participants don’t know of all the modes of transmission of the HIV virus, one community member when asked of the mode of transmission of the virus said, “If a mosquito
bites AIDS person and bites you, you will get the sickness”. Others just think that they can’t be infected but there was one female participant who noted that, “People think I got AIDS because I’m a commercial sex worker, I don’t want to think about it, I got the sickness because my mother has AIDS before I was born and she died”. Lack of education was also identified as one of the sources of stigma in this community. One of the key informants of this research project lamented that, “We have increased our efforts to educate this community about modes of transmissions of the virus and the importance of being very sensitive to stigma because stigmatizing PLWHA causes people to hide their status, and we know this can cause more infections”.

Another source of stigma, as indicated by both infected and uninfected community members is cultural and traditional beliefs of this society. Some members of this community still believe that people get infected with HIV because they are either cursed by a traditional spiritual leader, being punished for breaking a taboo, or simply because the ‘gods’ are angry with something a member of their family did. Findings of this study indicates that even educated members of this community still clinch to some of these traditions and beliefs. An educated member of the community, actually one of the key informant of this study when asked if traditions and cultural practices is a factor for the spread of the HIV virus did not answer the question but said, “the traditional spiritual leaders can either buy the disease for someone or even cause someone to be infected with HIV……….the family would see this and not involve the person in any family matters because they know he has done something wrong”.

There was one female particular participant who did not seemed concerned and was indifferent when discussion the issues of stigma; whether she has ever been stigmatized, and what she thinks are the sources of stigma in the community. She was more concerned about the
antiretroviral medical and she asked questions about cures for HIV/AIDS, she was really different and said, “My husband is not sick and still love me, he reminds me to take my medicine every night” in fluent English. When asked specifically if she fears to die, she said, “No, everyone will die, I just hope to always have my medication”.

5.2.5 Stigma Reduction Strategies

HIV/AIDS related stigma reduction strategies as suggested by participants through interviews are education, healthcare and support, and community involvement in the campaign. According to this community, educating people on the modes of transmission of HIV and general high level understanding of the disease will help reduce stigma. One Community member, a retired nurse practitioner noted that, “people in this community don’t even know that Asthma kills quicker than being HIV positive, but when someone is HIV positive they think he is a dead person, we need to educate people to let them know that being HIV positive is like being sick like any other sickness”. Another community member who lost his brother to AIDS complications said, “It is about awareness, letting people know how HIV is transmitted…..we need to accept HIV/AIDS people (PLWHA) as human beings and pray that one day we have a cure for it”. Community members suggested that education is the key to reducing stigma and more importantly involving Muslim, Christian, and traditional leaders to preach and talk against stigma.

One key informant pointed out that, “leaders in this community should be involved and I think the regional coordination council must lead this initiative….imams and pastors should preach against stigma”. Some of the community members indicated that PLWHA should be
educated to boost their self-esteem and they should not allow people to put them down after their HIV status becomes public. One participant suggested that PLWHA can “create a local organization to be their voice in the community………also teach them how cope with stigma”.

During a community radio program to mark the 2015 World AIDS Day, three of this research’s key informants were invited to speak. Commenting on the topic of HIV and AIDS related stigma in the community, all three speakers re-emphasized the need for the community to get involved with the education of HIV/AIDS issues, more importantly stigma associated with the disease. One of the speakers reiterated the point that, “we are all affected by the HIV/AIDS epidemic, whether you an infected person or have a friend or family member living with the disease”.

Healthcare and support is another stigma reduction strategy by participants. According to one participant, “the antiretroviral medication is helping. I don’t feel sick like before and all the rashes are gone. Nobody is going to look at me twice”. Community members noted that looking healthy gives PLWHA confidence to come out. One of our key informants spoke about the possible need to empower PLWHA by “helping them with subsistent income generating activities to support themselves and keep them busy”. Counselling support services even though already in place was mentioned by one participant, stating that “talking to family member of PLWHA and their husbands or wives can also reduce stigma”.

The community’s involvement in HIV/AIDS related stigma reduction campaigns was identified as one of the best stigma reduction ideas by participants. All three panel members of the 2015 World AIDS Day radio discussion, spoke of the need for the community to get involved when they are approached to help with HIV and AIDS educational activities. The Assistant Director of RCC indicated that his institution is “reaching out to community leaders and role models of the community” to help with HIV/AIDS reduction activities. The Assistant Director
also warned that, “This country has an HIV and AIDS prevention and control law that criminalizes any form of discrimination against PLWHA”.

5.3 De-stigmatization Strategies & Approaches used by Relevant Organizations: Objective 2

De-stigmatization strategies used are considered in terms of the activities of relevant organizations in the community. Given the multisectoral nature of the response to HIV and AIDS activities in Ghana, GAC has the mandate to coordinate, monitor, and evaluate all HIV and AIDS issues including de-stigmatization activities in the country. GAC has a free hand to implement de-stigmatization strategies and policy as it sees fit. Ghana has a National HIV and AIDS, STI Policy for created by the GAC in collaboration with the Ministry of Health (MoH), National AIDS and STI Control Programme (NACP) of the GHS and other key stakeholders to provide useful information on the status of HIV/AIDS, its consequences and interventions necessary to adequately respond to the epidemic and the policies and organisational structures that have been put in place to comprehensively address the epidemic.

In this community, GAC has empowered the GHS, RCC, and the Center for Human Rights and Justice (CHRJ) to implement de-stigmatization strategies and approaches in an effort to reduce HIV/AIDS related stigma. The National HIV and AIDS, STI Policy’s specific goals and objective pertaining to HIV and AIDS related stigma includes the alleviation of the social, cultural, and economic effects of HIV/AIDS at individual, household, and community levels by reducing HIV and AIDS related stigma and discrimination through the provision of information, basic needs, and legal and community safety nets for PLWHA and key vulnerable populations. Another specific goals and objective pertaining HIV/AIDS related stigma is to identify
components that ensure that the basic human rights of each person in Ghana, especially persons infected with HIV and AIDS are respected, protected, and upheld. The policy has other goals and objective generally geared toward the overall reduction of HIV new infections but above are specific stigma reduction goals and objectives.

5.3.1 Current Programs offered by the GHS & RCC

The RCC, GHS, and CHRAJ are working under the supervision of the GAC to implement national HIV and AIDS de-stigmatization strategies and approaches and also map out their own individual local strategies to curb stigma in the communities. In this community, the RCC, CHRAJ, and GHS have teamed-up to address issues of HIV/AIDS together hence the de-stigmatization strategies of the RCC, CHRAJ, and GHS complement each other. The GHS deals with de-stigmatizations activities such as managing care and support in terms of providing and distributing antiretroviral medication and counselling. The RCC handles issues such as educational campaigns and getting the community involved in HIV and AIDS activities and issues whiles CHRAJ is responsible for protecting the rights of person living with HIV or AIDS, the families, and loved ones to limit abuses. The current HIV/AIDS related stigma reducing programs are summarized as education, care and support, and promoting and protecting the rights of PLWHA.

Legal Protection from Stigma & Discrimination

The first and most important de-stigmatization strategies is the protection of PLWHA, making it illegal to stigmatize or discriminate against a person because they are HIV positive or
have AIDS. This is where CHRJ comes in because the policy states that, “Human rights violations and related stigma and discrimination of persons infected with and affected by HIV is pernicious and pervasive” (National HIV and AIDS, STI Policy, 2013, p. 8). Also, individuals or community members who suffer HIV/AIDS related stigma and discrimination will have free legal representation if they to choose to sue because discrimination is illegal, “The Commission on Human Rights and Administrative Justice (CHRAJ) may remedy or call for the correction and reversal of instances of abuse of power and human rights through fair, proper and effective means. A public interest organization may represent an individual or group of PLHIV and key and vulnerable populations where discrimination has been demonstrated. CHRAJ and the Legal Aid Scheme should develop guidelines to provide assistance to PLHIV and key and vulnerable populations who require the services of CHRAJ” (National HIV and AIDS, STI Policy, 2013, p. 9).

Even though stigmatization is not explicitly mention, the Regional Director of CHRAJ in a local radio program on World AIDS Day clarified that, “this provision is for people who are living with HIV or AIDS and also those who have been stigmatized and discriminated against”. Legal protection from HIV and AIDS stigma and discrimination is further elaborated under the discussion of the current GHS and RCC issued policies and guidelines on HIV/AIDS related stigma.

*Education*

Education is the most common de-stigmatizing strategy in this community to essentially reduce HIV and AIDS related stigma. Both the national and local goal is to provide accurate
information, address fears, misconceptions, and myths about HIV and AIDS generally. The reason is to reduce new HIV infection in the country by increasing the knowledge and understanding of the consequences of stigma and its effects on HIV vulnerability. Emphasizing on the need for educating the community on issues of HIV and AIDS and more specifically stigma and discrimination of PLWHA, the National HIV and AIDS, STI Policy (2013) clearly stated that, “Stigma and discrimination, together with issues of sexuality, gender and differences in cultural practices and socio-economic status across regions, continues to undermine efforts to address the HIV and AIDS epidemic. Unequal gender relations, which include gender-intensified situations and gender-imposed constraints, call for a holistic approach for change in the nature of development beyond mere gender, sexuality and vulnerability of women. This should involve each sector of the economy and address barriers presented by masculine and feminine gender norms and stereotypes. In the past, the international community has focused mainly on HIV prevention in developing countries, but there is now a global consensus that a strategic approach to the HIV epidemic must integrate prevention, care and support with mitigation” (National HIV and AIDS, STI Policy, 2013, p. 26).

The educational goal here is to effectively provide accurate HIV and AIDS information to reduce fears, address misconceptions, and myths about HIV and AIDS to the community in an effort to reduce stigma associated with the disease. Education is also intended to increase the understanding of the consequences of stigma and its effects on PLWHA. One of such educational campaigns was organized by the RCC in collaboration with GHS and CHRAJ to discuss HIV and AIDS issues in the community in efforts to reduce stigma on World AIDS Day, December 1st 2015 on a local FM radio station, WFM 93.5.
The purpose of this FM radio station discussion was to commemorate the activities of World AIDS Day, educate the community, and also to spell out services available to PLWHA in the community. A representative from the GHS who is the HIV/AIDS Coordinator in the region, educated the community on the role of MoH/GHS and specifically spoke about services available to both PLWHA and the community with regards to HIV testing and diagnosis, care and support, counselling, and the available of free HIV/AIDS medication to infected individuals. The Coordinator also indicated that one of the key objectives of the GHS is to reduce HIV related stigma and discrimination towards persons infected or affected by HIV and AIDS and also draw attention to the compelling public health rationale to overcome stigmatization and discrimination against PLWHA in the community. The Coordinator clearly indicated that it is against the Ghanaian law to stigmatize or discriminate against either someone living with the disease or someone suspected of living with the disease.

The GAC issued national HIV and AIDS, STI Policy clearly encourages education as a means of reducing HIV/AIDS related stigma by this statement, “The Government should ensure that each person has equal access to culturally acceptable and age appropriate formal and non-formal HIV and AIDS, STI information and education programmes that are adequate and sound. This should include free and accurate information on mother-to-child transmission, breastfeeding, treatment, nutrition, change of lifestyle and safer sex and the importance of respect and non-discrimination of persons living with HIV and STIs, as well as key and vulnerable populations. This policy advocates that age-appropriate, sound adolescent sexual and reproductive health education that includes HIV and AIDS, STI be integrated into school curricula as subjects that undergo regular student assessment” (National HIV and AIDS, STI Policy, 2013, p. 27).
A representative from the RCC on the FM radio station discussion emphasized that the community’s misconceptions about HIV and AIDS still influences peoples’ perceptions about the disease and contributes to some level of continued stigma at the community level. The RCC representative called on the community leaders to dis-associate cultural and traditional beliefs with HIV or AIDS as part of the educational campaign to enlighten the community on the disease. There are other forms of educational initiatives in the community to reduce HIV/AIDS related stigma such as group training sessions, hanging of posters, giving lecture on HIV/AIDS issues in schools and community centres, and encouraging the youth to volunteer with CBO’s and NGO’s to be abreast with issues of HIV and AIDS.

**Care and Support**

The continual survival of PLWHA remains the rationale for the provision of care and support services in the community. HIV Testing and Counselling (HTC) is linked to care and support to encourage and assure people tested positive that even though there is currently no cure for the disease, there are medications available that can prolong their lives. The reason here is to reduce internalized HIV and AIDS related stigma and also encourages the creation and functioning of community support groups, care groups, and other organizations for people living with or affected by HIV/AIDS.

HTC primarily involves individuals who are actively seeking HIV testing and counselling at facilities offering the service; these services are offered especially in non-health settings such as the community, mobile and stand-alone services. Counselling is an integral part of the comprehensive care and support. It enables infected and affected individuals to talk about, share,
cope, and deal with issues related to HIV and AIDS such as stigma in the community and also open an atmosphere of acceptance and trust.

Due to the complex interactions between nutrition and HIV/AIDS, the provision of adequate food and nutrition is needed for people living with or affected by the disease in this community. Nutrition assessment and support that includes food assistance to PLWHA is available in this community to help to promote adherence to antiretroviral treatment and ensure that the nutritional status of the vulnerable and at-risk population does not decline. Households and caregivers of food insecurity are benefitting from household rations to ensure that PLWHA obtain the needed nutrition for their regimen through food assistance programmes to improve their nutritional status. PLWHA are also linked with community-based food security and economic strengthening opportunities such as income generation activities in this community.

5.3.1 Current GHS and RCC Issued Policies & Guidelines on HIV/AIDS Related Stigma

GHS and RCC do not have their own issued policies and guidelines on HIV and AIDS related stigma, these institutions uses policies and guidelines of the GAC found in the National HIV and AIDS, STI Policy of 2013 in this community. The National HIV and AIDS, STI Policy for Ghana provides useful information on the status of the HIV and AIDS epidemic, its consequences and interventions necessary to adequately respond to the epidemic and also policies and organisational structures that have been put in place to address the epidemic comprehensively. In this community, the RCC, GHS, and CHRAJ are the relevant institutions that has been put in place to comprehensively address matters of HIV/AIDS and its associated issues of stigma.
HIV/AIDS related stigma policies and strategies in this community are aimed not only at addressing HIV and AIDS related stigma and discrimination but also issues of sexuality, gender, differences in cultural practices and the socio-economic status of the infected and affected. The main objective is to reduce stigma and the strategy is to target key and vulnerable populations and draw attention to the compelling public health rationale to overcome stigmatization and discrimination especially at the individual, household and community levels. This HIV and AIDS related stigma policy is also intended to address gender norms and stereotypes and its impact on households, especially women, children and the aged. The policy identifies a role for government and non-governmental institutions to mitigate stigma and discrimination through information collaborative multisectoral advocacy.

The National HIV and AIDS, STI Policy for Ghana has created an enabling environment that is regulated by the legal and policy framework already in place in the country. Although there are no explicit laws protecting the rights of PLWHA, there are several laws already in place to address issues of discrimination and protecting the rights of Ghanaians including PLWHA. These include the 1992 Constitution of the Republic of Ghana, the Labour Act, Criminal Code, and Social Security Act 1991 (PNDCL 247). These laws generally opposes the violation of a person’s human dignity, support privacy of a person, and oppose the unfair termination of a worker’s appointment.

There are also various mechanism in place to ensure that these laws are effectively implemented, this includes CHRAJ, the National labour Commission, the Domestic Violence and Victims Support Unit of the Ghana Police Force and of course the Judiciary. All these institutions have been specifically trained to have a better understanding of HIV and AIDS so as to apply the laws as they relate to stigma and discrimination associated with the disease. A key
informant from the RCC when answering an interview question on the policies of HIV and AIDS related stigma in the community noted that, “there are no explicit laws about stigma and discrimination…but the laws are clear when someone is abused because of their sickness and that is enough because the judicial systems understands that”.

During the World AIDS Day local FM radio station discussion in the community, a representative from CHRAJ reminded listeners that, CHRAJ has been tasked with the responsibility of promoting and protecting the rights of PLWHA on specific issues of stigma and discrimination and they also manage complains of stigma and discrimination to the extent of recommending to law enforcement and the judicial service appropriate action to be taken. The following are some of the HIV and AIDS related stigma intervention guidelines and priorities of the RCC and GHS:

1. Incorporate appropriate HIV and AIDS messages in national events such as Independence Day, Farmers Day, Republic Day, awards and ceremonies and general meeting of Ministries, Departments, and Agencies (MDA’s) to provide education on HIV and campaign against HIV related stigma

2. Sensitize traditional, opinion and religious leaders and policy makers on HIV related stigma to enable these leaders lead the stigma reduction education

3. Sensitize health and community-based workers on HIV related stigma to minimize stigmatization of PLWHA as well as reduce stigma against health workers providing HIV services

4. Integrate stigma reduction in work place HIV programmes to enable public and private sector institution including the large informal sector to develop policies that protect the rights of PLWHA
5.4 Effectiveness of HIV/AIDS Related Stigma Reducing Strategies (Preliminary Manner): Objective 3

This section examines in a preliminary manner, the effectiveness of GHS and RCC’s strategies and approaches in the community for reducing HIV and AIDS related stigma. This community recognizes that stigma and discrimination is linked to the violation of rights of PLWHA. The protection of human rights of people living with HIV/AIDS as well as the rights of women, children, and members of key populations has been their starting point. According to one key informant interviewed, “…..to reduce the personal suffering of a person living with the disease is to protect his rights not to be stigmatized and abused”. Human rights protection, according to another participant of this research project, “…should be linked to HIV treatment, care, and support to halt or reverse new infections”.

In this community, activities and programmes aimed at reducing stigma against people living with HIV/AIDS and people at risk of HIV infection are addressed through education of community members on HIV/AIDS and its associated stigma and discrimination, involving community leaders in campaigns against stigma associated with the disease, and promoting and protecting the rights of infected and affected individuals of the community. GHS instituted an initiative called the HIV preventive commodities that was geared not only to preventing new HIV infections but also stigma reduction in this community. The HIV preventive commodities encourages community members to use condoms and lubricants, discourages early sexual experience by the youth, and HIV treatment. The GHS uses counselling of infected individuals and their family members as its main tool to address the perception of community members.
about stigma associated with the disease and the RCC is more focus on empowering PLWHA and the affected community members with knowledge about the disease and rights available to them. The Assistant Director of the RCC in the community explained that, “…ignorance about the harmfulness of HIV and AIDS stigma and fear about getting infected with the virus” is a major driver of HIV/AIDS related stigma in the community. The Assistant Director, indicated that the following programmes are in place in the community to address issues of stigma and discrimination:

- Use of media including advertising campaigns, entertainment integrated with non-stigmatizing messages on TV and radio shows
- Engaging religious and community leaders to preach and talk against stigma and discrimination
- Involving CHRAJ in educating members of the community of their rights and encouraging non-discrimination as part of workplace policies in employment and educational settings
- Peer mobilization and support among people living with HIV and AIDS aimed at promoting health, well-being, and human rights

Through knowledge dissemination, counselling services, and involving community leaders in HIV and AIDS reduction programs, both the GHS and RCC are able to provide information and prevention measures to reduce stigma and discrimination in the community. The problem with measuring stigma in this community is the fact that there are very few tested and validated measures from which indicators can be developed. This research project did not find any documented statistics from relevant bodies in the community to either augment or disprove the effectiveness of stigma reduction strategies in this community. Therefore, this preliminary
findings of the effectiveness of programs and strategies offered by the GHS and RCC in this community are based solely on interviews conducted.

This community is a culturally sensitive, religious, and closely-knit society hence the involvement of community leaders such as traditional spiritual leaders, pastors, and imams is effective in addressing issues of stigma and discrimination. The interaction with, and involvement of PLWHA is also an important and effective stigma reducing strategy. This community, through the CHRAJ has formed an organization of PLWHA with a leader who is primarily responsible for teaming up with CHRAJ to advocate for the rights of members who are facing issues of rights violation generally in the community. This organization of PLWHA, according to the RCC is also responsible for educating its members of the rights as provided in the constitution of Ghana. Strengthening the rights of people living with HIV and AIDS in Ghana generally and to overcome these obstacles, a web-based reporting mechanism was launched in December 2013 where PLWHA can directly report to the Commission through the reporting system’s website and they can choose to remain anonymous. This triggers an investigation involving CHRAJ and lawyers. This tool is used by members who have access to a computer and the Internet and is still in its infancy; by September of 2015, about 32 cases of discrimination cases were recorded and about 13 of them were resolved of complaints involving violence, blackmail, and denial of employment.

The involvement of community leaders is effective in addressing issues of stigma and discrimination in this community. Even though, one participant reported being stigmatized by church members, the majority of participants mentioned that their pastors or imams preached sermons about being tolerant and accepting PLWHA. One community member said that their imam spoke about the modes of transmission of the HIV virus in the mosque and now he knows
that, “people can get the disease through car accidents and some people can be born with it”, disproving the accepted belief in this community that living with HIV is a curse. Furthermore, the inclusion and encouragement of PLWHA to attend community events by community leaders is paying-off; one participant said that, “I was at the NDC rally and one of them (PLWHA) looked healthy and strong, he was even bigger than me”, further emphasizes the fact that infected individuals are normal and willing to contribute to the community if community leaders preach their inclusion.

Counselling services of PLWHA is also another effective programs used in reducing HIV and AIDS related stigma in this community. Every single person who was interviewed at the HIV testing and counselling clinic went through some sort of counselling and had something positive to say about the services provided. There was a gentleman whose wife was tested positive hence he was invited to also come in for testing and counselling but was tested negative and he had this to say, “Now I know this sickness can get anyone, my wife is sick but am not and I won’t leave her, maybe I can be sick tomorrow who knows”. Counselling at the HIV testing and counselling clinics is the first point of stigma reduction campaign in this community and it is effectively reducing the burden of the infected to talk to their loved ones about the modes of transmission and its associated stigma. Counselling is effective in reducing internalized and experienced stigma of infected individuals and their very close family members. Another participant whose husband tested negative explained that, “my children and my husband are not sick...my husband came here and the doctor spoke to him, now he doesn’t argue with me and he always ask me to take my medicine in the night...you see, I don’t look like I’m sick because I take my medicine”.

105
Knowledge dissemination is by far the most efficient and effective strategy in addressing issues of stigma and discrimination in this community. Providing HIV/AIDS related awareness to community members and infected individuals offers opportunities for stigma reduction that target several of the stigma outputs. This community uses peer education, giving lectures and discussions, using posters, and using local community radio broadcast for knowledge dissemination and it is very effective. The World AIDS Day 2015 celebration in this community had a local radio station broadcast that was used to educate community members on a wide range of HIV and AIDS issues and specifically discussed stigma. Community members heard first-hand information from community leaders about stigma and how it affect the entire community. PLWHA were also reminded of their rights and everyone was encouraged to visit HTC clinic to be tested if they felt there is a possibility they may have the HIV virus. Radio programs such as the World AIDS Day radio broadcast are able to reach rural areas that may be missed by television and newspaper articles.

Traditional HIV and AIDS awareness campaigns including transmission facts and prevention strategies are effective stigmatising strategies. Knowing the facts is important for self-protection from infection and these general knowledge approaches are needed especially in a closely-knit and culturally sensitive community such as this one. The dissemination of facts about the disease helps to eliminate stigma triggers of lack of information and inaccurate knowledge. About all the participants interviewed mentioned knowledge dissemination in the form of HIV and AIDS awareness campaigns should be encouraged and used to educate the community on issues of stigma and discrimination.
5.5 Summary

This findings chapter summarizes the data collected through the semi-structured interviews, participant observation, and review of relevant documentation to describe the attitudes of community members about HIV and AIDS related stigma. Research participants description of the types (perceived, internalized, and experienced) of stigma and sources of stigma has also been presented, followed by the sources and reduction strategies stigma suggested by stakeholder groups. This chapter also summaries de-stigmatization guidelines and polices used by relevant bodies in the community to address issues of stigma and discrimination and the effectiveness of these strategies and campaigns for reducing stigma is described in a preliminary manner.
CHAPTER SIX

DISCUSSION OF FINDINGS

6.0 Introduction

This chapter is divided into three main parts to provide an in-depth look at the major findings that emerged out of the findings of this research study. The first two parts would identify and discuss triggers of stigma and stigma outcomes and the third part would discuss stigma reducing strategies found within the process of stigmatization.

6.1 Triggers of Stigma

Stigma associated with HIV and AIDS is the greatest barrier to preventing new HIV infections, providing adequate care support, treatment, and reducing the impact of the disease. The stigmatization process usually begins with an action that becomes a consequence or reaction. These actions or triggers of the stigmatization process as identified by participants or members of the community are summarized broadly in table 6.1 below. Fear of death, cultural and traditional beliefs, and education, misinformation and stereotypes are the main sources of these triggers. The stigmatizing process involves community and family members; neighbours, shop owners, coworkers, employers, teachers, friends, health workers, and even siblings and parents. The corresponding triggers of stigma are physical deterioration, impending death, curse to the individual or family, blame and shame, punishment of the ‘gods’, assumed status by association,
method of contraction, result of prostitution or infidelity, lack of education, and inaccurate information.

Table 6.1: Summary of a list of HIV and AIDS related stigma sources

<table>
<thead>
<tr>
<th>Main Source of Stigma</th>
<th>Triggers of Stigma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of Death</td>
<td>Impending death</td>
</tr>
<tr>
<td></td>
<td>Physical deterioration</td>
</tr>
<tr>
<td></td>
<td>Losing a loved one (family member)</td>
</tr>
<tr>
<td>Cultural and Traditional Beliefs</td>
<td>Curse to the individual and the family</td>
</tr>
<tr>
<td></td>
<td>Blame and shame</td>
</tr>
<tr>
<td></td>
<td>Contraction is a sin</td>
</tr>
<tr>
<td></td>
<td>Punishment of the “gods”</td>
</tr>
<tr>
<td>Education, Misinformation, and Stereotypes</td>
<td>Assumed status by association</td>
</tr>
<tr>
<td></td>
<td>Method of contraction</td>
</tr>
<tr>
<td></td>
<td>The result of prostitution or infidelity</td>
</tr>
<tr>
<td></td>
<td>Lack of education</td>
</tr>
<tr>
<td></td>
<td>Inaccurate information</td>
</tr>
</tbody>
</table>

_Fear of Death_

As mentioned earlier, the fear of death being the main source of HIV and AIDS related stigma is associated with various stigma triggers. Death is an ultimate end for humans and it would come when it comes but knowing that a particular circumstance is ultimately going to end one’s life and is ‘avoidable’, makes the fear of HIV infection an obvious and easily identified main trigger of stigma. The reason is simple, HIV/AIDS is not curable hence the fear of contraction the disease becomes a concern among most community members for disassociating themselves from PLWHA.

It is interesting that, though the fear of death is the main reason why some community members would visit a Voluntary Counselling and Testing (VCT) for testing to ascertain their
HIV status, it is this same positive bold step that eventually leads them to form internalized stigma if they are tested HIV positive. Also the initiative of getting tested at a VCT clinic has its associated form of perceived stigma because community members are already wondering what their family, friends, and other community member would think of them if they were tested HIV positive or even spotted at the clinic. For this community, the fear of death has been identified as the most powerful key trigger of the stigmatization processes. For example, one participant, unaware of his own status and was preparing to travel for studies in Europe was very adamant to follow through with the application processes which required that he takes an HIV test. This gentleman did not want to know his HIV status and also did not want to visit the VCT clinic not only for fear of being branded as a person receiving counselling or living with the virus but also for the fear of death he said. Clearly his vividly negative perception of being associated with the disease or even living with the virus triggers both perceived and internalized stigma.

Fear of infection and its associated fear of death hinders HIV positive disclosure, discourages testing, and also triggers significant levels of stigmatization. This fear is commonly associated with the physical signs of full-blown AIDS such as general weakness, noticeable rashes and sores, and being bedridden reinforces the fear of death and triggers either three of the stigmas associated with the disease (perceived, internalized, and experienced) which comes in the form of thoughts of the infected, avoidance and isolation on the part of family and community members. The fear of death of loved ones is also a common source of stigma because it is accompanied by the uncertainty of what to do with orphaned children of those loved ones (if they are also HIV positive, the chain of stigma does continue to live on).
Cultural and Traditional Beliefs

Culture and traditional beliefs of this community is a trigger to HIV and AIDS related stigma and it manifest itself by way of shame and blame and also the belief that contracting HIV is a curse, a form of punishment, or even a sin give it a lot of weight and meaning. For example, this community achieves conformity by contrasting those who are ‘normal’ as not PLWHA with those who are ‘different’ as PLWHA and in some cases uses this as a social stratification tool. Blame and shame typically comes from non-infected family members and triggers an extreme personalized stigma because in a closely-knit society, family members are the first line of support for a PLWHA. In some cases, PLWHA are held personally responsible for contracting the disease by way of a punishment or a sin hence are perceived as a disgrace to the nuclear and extended family or even the community. Shame is a common trigger most associated with the nuclear or immediate family members of PLWHA especially when the community perceives that the person living with the disease is cursed. A person living with the disease becomes an outcast and is excluded by general consent from the family’s social activities, conversation, or privileges; they are perceived to no longer be worthy of belonging. Close associates such as spouses, close friends, and family members in the community who share the same culture and traditional beliefs execute this personalized shame trigger in such a way as to clearly alienate a PLWHA to indicate they don’t belong to the family.

Cultural and traditional beliefs defines what makes a community member’s actions moral or immoral. In this community (as in most closely-knit communities) the principles of right and wrong behaviour and the goodness or badness of a person’s character is a personalized trigger that ties into traditions and cultural beliefs. A person’s morality is questioned upon learning of their infection with the HIV virus and is are usually associated with unacceptable culturally or
traditionally identified immoral behaviours such as prostitution, infidelity, or having sexual relations with a multiple partners on a casual basis. This question of morality riggers a set of notions that it is ok to alienate, abuse, or even disown the infected person because they have a lived a life that is contrary to the accepted way of life of the community and this can greatly personalized and thoroughly damage an individual’s self-esteem and change the perception of their situation.

Community members of Wa belief that getting infected with the HIV virus is a punishment for a person’s sins committed, usually an immoral sin or a taboo that is not supposed to be broken. Traditional believers in this community belief that the taboo is one that smears the entire family hence family members would want to get rid a person living with the HIV virus just so that they continue to belong in the community. In a closely-knit and culturally sensitive society such as this community, community members’ perception of the disease being a sin or taboo together with the fact that they want to continue to belong in the community triggers internalized and perceived stigma associated with the disease. And PLWHA also experience perceived, internalized, and experienced stigma in situations like this one.

*Education, Misinformation, and Stereotypes*

Education, misinformation, and stereotypes also triggers either perceived, internalized, or experienced stigma in this community and these three triggers (Education, Misinformation, and Stereotypes) are closely linked with the community’s cultural and traditional beliefs. Triggers of stigmatization are more active and effective when there is a lack of detailed and accurate information and knowledge regarding facts of transmission of the HIV virus.
Cultural and traditional beliefs of this community also influences, defines, and triggers their assumed perception of the mode of contraction of the HIV virus. For example, a community member’s assumed reason or mode of transmission of the HIV virus such as contraction as sin, contraction as a punishment of the ‘gods’, contraction as a curse to the individual and his family with the associated shame and blame of the disease triggers a negative perception that increases the levels of perceived and internalized stigma. These triggers of the community’s perception clouds the judgement of community members, especially the elderly and or less educated ones, to the extent that they do not consider other potential modes of contraction and consequently leads to perceived and internalized stigma.

Community’s perception of the mode of transmission of the HIV virus which triggers perceived and internalized stigma also leads to experienced stigma. Association with PLWHA may result in the assumption that because ‘birds of the same feathers flock together’ hence eating, playing, and being close to an infected person makes one very likely to also be infected and this may triggers experienced stigma on the part of PLWHA. Because, family and community members know what it means in this community to associate with PLWHA would disassociate with them. A lack of fact based knowledge sharing through the entire community’s involvement by way of training activities, radio coverage, counselling sessions and casual conversations lead to misinformation, stereotypes, myths and the dissemination of false information among the members of the community. For example, one participant maintained that one of the best ways to reduce stigma and new HIV infections is to quarantine PLWHA, clearly this community member does not know the modes of transmission of the disease or was misinformed. As such, the lack of knowledge with its associated misinformation and stereotypes are triggers for the process of stigmatization.
### 6.2 Stigma Outcomes

Targets of HIV and AIDS related stigma are often those living with the disease. They are at the receiving end of the stigmatization process and therefore, deeply affected by the outcomes of stigma. Their families and loved ones are also targeted, and in some cases their co-workers, neighbours, and people who associate with them are targeted. Advocates and employees who work (GHS and RCC) for PLWHA are also targets of stigmatization. The three main categories of stigma outcomes identified to be discussed in this research study are social isolation, reduced health and quality of life, and denial of rights.

**Social Isolation**

Social isolation as a stigma outcome occurs as abandonment, avoidance, or neglect and it is triggered by fear of death, cultural and traditional beliefs, and education, misinformation, and stereotypes. Social isolation as a stigma outcome is the lack of interaction, contact, or communication with members of the community. Those who are socially isolated have an absence of relationships with family and friends, or other forms of social networks that gives them the feeling of belonging. Social isolation of PLWHA begins with the disclosure of an HIV positive status or even the mere suspicion of an HIV positive status. Family and community members do not verify or confirm the status of an infected person before initiating triggers that usually results in social isolation. In this community, specific stigma outcomes may include a woman being driven from her polygamous matrimonial home because she is HIV positive without even investigating her mode of transmission; another women expelled from her family home because she tested HIV positive; a man not allowed to play soccer with his friends because he is HIV positive.
Reduced Health & Quality of Life

Reduced health and quality of life as stigma outcomes are very common after community members disclose their HIV positive statuses or even when they are suspected of living with the HIV virus. PLWHA suffer verbal and emotional abuses when they disclose their statuses and these abuses, in the long run reduces the general wellbeing and their quality of life which often leads to the feelings of shame, feeling of unworthiness, and social withdrawal. Abandoned PLWHA experience emotional abuse and verbal abuses occurs when family and friends make utterances such as you are a “walking corpse”.

The lack of access to treatment and care and an increased number of infections are the outcomes included in the reduced health category. This stigmatization outcome is as a result of a chain reaction following previously experienced outcomes. For example, an infected individual who has given up hope of prolonging their life would more likely give up efforts of visiting or reaching out to a healthcare faculty for either treatment or counselling. The more likely scenario is that the infected individual believes strongly in their culture or traditions and has accepted the myths of the mode of contagion of the virus to be a punishment or curse hence there is reason for soliciting treatment they believe wouldn’t work. An increased number of infections, can also be understood as an outcome with the surrounding chain of chain of events. For example, an HIV infected and stigmatized individual may choose to want to punish their stigmatizers by seeking vengeance or revenge and knowingly engaging in risky behaviours to infect community members.

Negative self-image is the stigma outcome that comprised of thoughts, feelings, and behaviours that are directly connected to PLWHA. This stigma outcome is triggered by an individual’s strong traditional and cultural beliefs, fear of abandonment and isolation, and the
belief of an imminent danger such as death, it is dependent entirely on the frame of mind of the targeted individual. It can also be as be triggered by either three of the main types of stigma - perceived, internalized, and experienced causing a person living with HIV/AIDS to feel worthless. Negative self-image as noted in this community leads to social withdrawal and isolation of the affected individual from participating in any social activities; there was one participant of this study who lived alone with her dog and declined to come out to be interviewed, she wanted me to rather join her inside her room. As in the case of this participant, strong negative self-image is most triggered by stigmatization outcomes of shame and feelings of worthlessness often associated with morality and cultural beliefs in a very culturally sensitive community. It is also reinforced by enormous physical, verbal, emotional abuses from community members.

The most powerful component of the negative self-image outcome is triggered by fear generally. Fear is associated with all the aspects of the stigmatization process and can include a fear of death and dying, fear of being tested HIV positive, fear of losing loved ones and isolation, and more importantly fear of being stigmatized. Fear prevents a person from disclosing their HIV status and leads to potentially more HIV infections. Fear also prevents a person from disclosing their HIV positive status and leads to declining health. Fear as an outcome, can reinforce triggers of denial and can perpetuate the verbal and emotional abuses of others who are known to be living with HIV and AIDS and is therefore, a major component of the stigmatization cycle.
Denial of Rights

Denial of rights has been identified as a stigma outcome in terms of employment discrimination and denial of equal opportunities. Missing out on a potential employment opportunities, losing a current employment position, evictions from homes, unable to attend school because of isolation and finger pointing, and forgoing religious participation due to exclusion and unwelcomed reception from members of the religious congregation due to one’s HIV positive status are outcomes resulting from the triggers of fear of the disease, lack of knowledge, and the community’s perception the HIV/AIDS sickness.

Missed opportunities leads to other outcomes such as a negative self-image and social isolation because whiles targeting PLWHA there are chances when someone other than the targeted individual experiences the outcome. For example, a participant of this research study was verbally abused at school because her mother is a person living with HIV and this consequently led to her dropping out of school because she couldn’t concentrate on her studies.

Denial of rights is an issue encountered in this community, although Ghana’s constitution protects all citizens from discrimination in employment, housing, education, and also ensures their right to privacy, there are gaps and ambiguities in the way these provisions apply to people living with HIV/AIDS and to key affected populations. For example, the constitution protects people living with HIV and AIDS from discrimination within the healthcare system, but these protection are difficult to enforce outside of public health facilities due to culturally sensitive nature of the community. Also, consensual sex between adult males and commercial sex workers (prostitution) is criminalized, deterring sex workers and MSM from seeking effective and adequate healthcare services.
6.3 Stigma Reduction Strategies

HIV/AIDS related stigma reduction approaches as suggested by participants through interviews are healthcare and support, education, and community involvement. The pie charts below (Figure 6.1) illustrates these approaches in terms of how often each was mentioned in the interviews conducted.

Figure 6.1: Stigma reduction approaches as identified by participants

Program participants identified healthcare and support as the most important and effective strategy in the reduction of HIV and AIDS related stigma, receiving about (47%) of the total recommendations. Education ranked second with about (29%) of the recommendations (23%), followed by community involvement, receiving about (24%) of the total recommendations.

Education

According to participants, education should run through the other two approaches (healthcare & support and community involvement) and used to deliver factual, and rational information to all members of the community. Participant emphasized that HIV and AIDS
related stigma education should not be limited to only community members but also PLWHA to help them with coping mechanisms. Providing HIV and AIDS related awareness and education to members of the community and PLWHA would offer opportunities for stigma reduction that targets several of the outputs of stigma as identified in this study. According to participants, workshops, seminars, and counselling would provide the necessary knowledge to empower PLWHA and also teach educate them on proper eating habits, properly adherence to drugs, and how to have positive outlooks in the community.

Participants agreed that educating PLWHA would make them feel happy, actively involved, and have a sense of belonging to the community. Education would also demonstrate a sense of belonging and prove that PLWHA can have partners, uninfected children, and have productive lives. Education and awareness campaigns of HIV transmission facts and prevention strategies are effective de-stigmatizing strategies, knowing the facts of general HIV and AIDS issues are important for both self-protection and general knowledge of the disease. Dissemination of accurate and facts about the disease can help to eliminate stigma triggers such as lack of information, inaccurate knowledge, and stigma outcomes of social isolation and negative self-image.

The use of radio programs are already in use in this community but participants reiterated the inclusion of community radio programs, billboard advertisements, television shows, and t-shirt messages to educate the community about the importance of getting an HIV test, disclosing the results to partners, supporting those infected, and more importantly knowing how to protect oneself from getting infected with the HIV virus.

Even though already a strategy used by stakeholders in the community, participants urged the inclusion of religious leaders in forums to offer additional outlet for education of HIV/AIDS
awareness generally and also specifically target issues of stigma. Since cultural and traditional beliefs are triggers of the stigmatization process, involving traditional and religious leaders would effectively and efficiently combat the trigger of believing that HIV/AIDS is a curse, the result of sinful behaviour, or the breaking of a taboo.

**Community Involvement**

Closely related education is community involvement. According to participants, the interaction with and involvement of PLWHA and the community is a very important and effective way of the stigma reduction approaches. When infected individuals are actively involved in the facilitation of training events and workshops, a sense of self-worth and belonging is nurtured in addition to the knowledge gained from participating in those events. Participation would also provide an opportunity for revealing to the community that PLWHA are not different after all. The inclusion of PLWHA in these community events would further emphasize the fact that infected individuals are normal and interested in contributing to the betterment of the community.

The involvement of uninfected community members in the lives of PLWHA would create an opportunity for interaction and consequently reduce such triggers as fear to associate with infected individuals. The involvement of uninfected community members in HIV and AIDS related stigma reduction strategies and approaches would ease tensions and create a sense that both the infected and uninfected have the wellbeing of the community at heart. The most important reason of the community’s involvement would be to reduce triggers such as the fear of contagion and foster care and love for PLWHA. The community’s perception of PLWHA would be a favourable one and outcomes such as social isolation and abuses would be drastically reduced.
Healthcare and Support

Effective healthcare and adequate support for PLWHA and their families are essential for an effective HIV and AIDS related stigma reduction campaign, according to members of this community. There is no doubt that seeking proper healthcare and maintaining general good health is the most important coping strategy for reducing stigma. Eating nutritious foods that support a healthy immune system and adhering to strict antiretroviral HIV medication is very essential for living life to the fullest as a person living with HIV. The reason is simple, infected individuals can escape from the potential issues of physical deterioration that has advert effects on their psych. Opportunistic infections are drastically reduced, the infected individual would look healthy and confident, thereby reducing many such stigma outcomes such as denial of rights, evictions, negative self-image or even self-isolation.

Participants also suggested home-based care to be an effective stigma reduction approaches. The reason is that bedridden PLWHA would have the care needed without having to deal with issues of leaving their places of abode and they would also have the company of their care-givers to ease the issue of isolation when their family members are unavailable to support. Emphasizing on the benefits of home-based care, some participants argued that bedridden PLWHA could benefit from donations of nutritious foods and essential household items if caring community members wanted to help. Home-based care would facilitate visits to curb trigger of fear of contagion because of frequent visits from community members and well-wishers.

Support for PLWHA was found to be a most valuable and effective means of stigma reduction strategies if implemented in both formal and informal settings. Group meetings and informal networking with either community members or fellow PLWHA to discuss issues of the HIV/AIDS disease or any topic of their interest would create a form of socializing to eradicate
stigmatization outcomes of isolation. Support group meetings for fellow PLWHA could gather to exchange stories, offer ideas and receive advice from the most experienced individuals amongst them; especially coping mechanism or discuss issues pertaining to their blight. This would allow others to empathize with given situation release unwanted and shameful feelings that may be the result of stigmatizing triggers and outcomes in the community. Group counselling sessions, according to this community should be used in conjunction with home-based support to offer opportunities to share thoughts or feelings that may be appropriate for group settings. Networks and support systems, including any form of income generating activity (IGA) opportunities should be used to encourage self-sufficiency or financial independence in the community.

During a World AIDS Day community radio discussion on issues of HIV/AIDS related stigma in this community, stakeholders mentioned that the RCC in conjunction with the district administration office would be initiating support opportunities in the area of micro-financing. The micro-financing initiative would be intended to help PLWHA engage in income generating ventures to help them be self-sufficient, engage in substituent farming activities. Self-sufficiency according to stakeholders is extremely effective in reducing stigma and fosters positive self-image of participants.

6.4 Summary

This chapter discusses the findings of the research exercise through a process of interpretation, analysis, and description of the attitudes of community members and the impact of the process of stigmatization as it relates to HIV and AIDS. The chapter also identifies and describes stigmatizing triggers, outcomes, and reduction strategies that are relevant to the
stigmatization process and addresses the impact of stigma on both the infected and affected individuals in the community. In addition, the chapter describes HIV and AIDS related stigma reducing strategies as suggested by community members.
CHAPTER SEVEN

SUMMARY, CONCLUSIONS, and RECOMMENDATIONS

7.0 Introduction

This chapter provides a key summary of the findings of the research study, its conclusions, and recommendation as it relates to HIV and AIDS related stigma in a rural Ghanaian community. The chapter starts with a very brief description of conceptual framework and academic literature review used, mentions the methodological approach adapted, and matches the objectives of the study to findings of the research. Salient points and findings of the research are then summarized in the conclusions section followed by the recommendations of the study and further research.

7.1 Final Summary

The aim of this research study was to describe attitudes of a rural Ghanaian community members about HIV and AIDS related stigma and how this stigma is being addressed by the GAC generally and relevant bodies in the community of Wa. The objectives of this research was achieved through a variety of qualitative research techniques to explore and describe the perceptions and experiences of HIV and AIDS related stigma among PLWHA, community members, and relevant bodies working in the community.

The conceptual framework used in this research study was based broadly on the work of Parker & Aggleton (2003) who suggested the use of frameworks that incorporates the interaction of pre-existing stigma like sexuality, gender, or differences within a broader cultural settings and
the fear of contagion of the disease. The work of Deacon et al. (2005), Nyblade (2006), and Yang et al. (2007) who argued that HIV and AIDS related stigma is partly a problem of individual ignorance and part of a complex cultural and social mechanism of exclusion and dominance in any particular social setting. And also, the work of Deacon (2006) who argued that stigma should be viewed across a full range of domains like knowledge, attitudes, and discriminatory behaviours and finally the work of Bos et al. (2008) who argued that stigma starts with certain triggers and usually results in stigmatization behaviours with outcomes.

The methodological approach adopted and used in this research study is based on the social constructivism theory, one through which the behaviours and social settings shaped and formed the perceptions of members of the rural community of Wa was explored and described in relation to stigma associated with HIV and AIDS. This qualitative study was facilitated mainly through interviews, participant observation, and secondary data collected.

The first objective is to describe attitudes of research participants about HIV and AIDS related stigma in the community; types of stigma, sources of stigma, and also ways through which participants felt HIV and AIDS related stigma can be reduced in their community. Participants indicated that the main types of stigma in the community are perceived, internalized, and experienced and the perpetrators of stigma included their co-workers, family members, and community members. Participants also indicated that the most common trigger of stigma is the fear of contagion of the HIV virus which is geared by the fear of death, social avoidance, misinformation, and stereotypes. The most common outcome of stigma (perceived, internalized, or experienced) in this community is isolation, social avoidance, and social withdrawal. Participants identified the availability of healthcare and support, education and involvement of
community members, and financial independence of PLWHA as the most effective stigma reducing strategies needed.

The goal of the second objective of this research study is to describe de-stigmatization approaches and strategies used by relevant bodies in the community to reduce HIV and AIDS related stigma. The most effective strategy for reducing stigma used by the two main relevant bodies (GHS and RCC) in this community were that of education, awareness, and protecting the rights of PLWHA (criminalizing common forms of stigma). The GHS and RCC implemented de-stigmatization strategies under the strict supervision of the GAC, which is the highest policy making body on HIV and AIDS in the country and provides effective and efficient leadership in coordination of all programmes and activities of all stakeholders. The main de-stigmatization strategies includes the provision of HIV testing and counselling clinics, general HIV and AIDS education, enlightening PLWHA of their constitutional rights and protecting them, and educating community members on HIV and AIDS related stigma issues. These activities are fulfilled through local radio station broadcast, posters, role modelling, involvement of community leaders and CHRAJ, and campaigns in second cycle institutions. Community members indicated that education and community awareness of the modes of transmission of HIV with its associated issues of stigma can reduce the misconceptions, misinformation, and stereotypes of HIV/AIDS in the community.

The third research objective of this study is to examine in a preliminary manner, the effectiveness of GHS and RCC’s strategies in reducing stigma in the community. The problem with measuring stigma in this community though is that there are very few tested and validated measures from which indicators can be developed. This study did not find any documented statistics from relevant bodies in the community to either augment or disprove the effectiveness
of stigma reduction strategies in this community therefore, these preliminary findings are based solely on the interviews conducted. Due to the culturally sensitive and closely-knit nature of this community, participants indicated that the most effective way that stigma is being addressed in their community is through the involvement of community leaders such as traditional spiritual leaders, pastors, and imams in campaigns and educational initiatives. Participants also agreed that criminalizing stigma and discrimination and the involvement CHRAJ has caused the fear of prosecution in community members thereby very infective because people don’t want to face the law. Strengthening the rights of people living with HIV and AIDS and the anonymous reporting of stigmatization behaviours and discrimination through a web-based reporting mechanism launched in 2013 are also very effective in reducing stigma and discrimination in the community. Knowledge dissemination is by far the most efficient and effective strategy in addressing issues of stigma and discrimination in this community, according to participants.

This study suggests that the severity of HIV/AIDS related stigma vary within the social context in which it exist; it is severe in rural Ghana due to rural social interaction and the implications of rural economics, urban households are able to cope with stigma better than rural communities. There is a strong sense that urban households, even in poverty would more likely be able to cope with HIV/AIDS related stigma, rural households are more deprived and less able to cope partly due to less in depth knowledge of the disease (HIV/AIDS) and information on coping mechanism. Compared to urban Ghana, rural communities have less economic opportunities and hence PLWHA are unable to financially support the required healthy lifestyles of the disease. Also, urban dwellers spend most of their time trying to make ends meet instead of engaging in stigmatization behaviours; PLWHA use financial independence as a coping mechanism to take control of their respective situation.
7.2 Conclusions

This research study concluded and re-enforced the notion that reducing HIV and AIDS related stigma can reduce the number of new infections. This conclusion is based on the responses of participants of this research. In rural and culturally sensitive communities, stigma is the main factor in the spread of the disease because infected individuals would not disclose their statuses for fear of being isolated, abandoned, abused, and discriminated against. Rural and culturally sensitive communities have a very strong sense of belonging due to the extended family system hence almost the entire community have some kind of relation or know each other.

This inter-connectedness makes stigma something community members would do everything possible to avoid by hiding their statuses and we know that not disclosing HIV statuses leads to new infections. Logically, by reducing HIV and AIDS related stigma and the impact it has, the number of new infections can potentially be reduced and consequently slow down the spread of the disease. By reducing stigma through increased awareness and knowledge, decrease negative self-image, and role modelling for example would reduce the triggers of fear of contagion generally and triggers of a community’s wrong perception and that would alter the community’s perceived immorality of the disease, give them better understanding of transmission modes, and also increase the number of people willing to visit a VCT clinic for HIV diagnosis and counselling. The end result would be fewer new infections; these are just a few examples of how reducing HIV and AIDS related stigma can slow down new infections and improve the quality of life for those already infected in the long run.

The findings identified in this research study indicates that HIV and AIDS related stigma is present in the Wa community; the process of stigmatization is multidirectional, it extends and
operates in several directions at the same time. HIV and AIDS related stigma triggers occur at multiple levels and directions to produce outcomes and these outcomes provide an understanding of the areas that need to be targeted by stigma reducing strategies in order to eliminate potential stigma triggers.

The effectiveness and efficiency of HIV and AIDS related stigma reduction strategies should be addressed at all levels with support from various levels of government, community organizations, NGO’s, and especially the most marginalized and vulnerable groups in the community. National, regional, and district level interventions need to work together to implement effective programs targeted at the reduction of stigma. National leaders, especially in sub-Saharan Africa and local organizations require collaboration with international organizations in order to obtain adequate funding and support, share best practices, and gain valuable insight from various knowledge sharing avenues to deal with issues of HIV and AIDS related stigma. Also, stigma reduction strategies should be shared and modified to suit the needs of specific local communities.

The initial point of fighting HIV and AIDS related stigma is from the individual; the fear of contagion of the disease starts with the individual, an individual’s perceptions of the disease becomes reality in the community. In other words, internalized stigma, which starts with the individual drives the other two main types of stigma (perceived and experienced) hence it is internalized stigma that remains the key factor to significantly reducing the impact of HIV and AIDS related stigma on both the infected and affected. This research study concludes that empowering the infected individual with confidence and self-esteem, together with the ability to be self-sufficient by way of subsistence living (could be subsistence farming, petty trading, or any form of income generating venture) could reduce many of the outcomes of stigma triggers or
have very minimal impact on that person. Social isolation or exclusion may be entirely eliminated from the list of potential stigma outcomes for a person living with the HIV virus especially in rural communities.

It is clear from participants of this research through interviews that HIV and AIDS related stigma is gradually decreasing but this is mainly realized through the educated and well-informed community members (those who know the modes of transmission of the virus) and those whose family members are directly affected or infected. Religious institutions and traditional spiritual leaders are receiving and sharing facts about the disease in this community, yet HIV and AIDS related stigma still remains an issue, and it continues to present incredible obstacles when it comes to improving the quality of life of infected and affected individuals and reducing new infections. One important conclusion of this study is that community members would say one thing, that which is believed to be a proper or ‘accepted’ response of someone who has been enlightened about the disease yet behaves in a manner that directly contradicts what was just verbally recorded in the interview. Community members whose loved ones or very close family members are living with the HIV virus spoke favourably or showed signs of accepting them.

Even though the involvement of CHRAJ, RCC, and the GHS in educating community members is changing the perceptions of the mode of transmission of the virus, some members of this community still believe that infections are as a result of punishment and sin (this is true of the very spiritual members of the community). Their explanation is simple, if one is clean and pure in the eyes of God or the gods, they cannot be infected with the virus (they would definitely be protected from a ‘supernatural power’). Factual knowledge is therefore not the same as behavioural change in this community. Knowledge is simply not enough. Knowledge is critical
in understanding the issues and consequences of HIV and AIDS related stigma but that alone is not enough, behavioural change needs to be linked to people’s emotions to get them to not only sympathize but also empathize with the plight of PLWHA and can be effective by targeting one person at a time.

### 7.3 Recommendations

Because of HIV and AIDS related stigma many people are afraid to get tested for the disease, to take up HIV/AIDS prevention and treatment, to disclose their HIV status, and in some countries and rural communities have little chance of getting legal redress for HIV or AIDS related harms (Parker & Aggleton, 2003; Deacon et al., 2005; Deacon, 2006; Nyblade, 2006; Yang et al., 2007). Stigma associated with the disease still remains high in some countries especially rural communities and access to justice in the context of the disease is very low.

GAC and collaborating institutions like the RCC and GHS should intensify their strategies, approaches, and programs (healthcare and support, education, community involvement, and empowering PLWHA) in an effort to reduce stigma. Some of these strategies, approaches, and programs however are more effective in reduction stigma than others hence the highly effective stigma reducing strategies currently in place should be strengthened and expanded. The GAC which is a ministerial and multi sectoral body, established under the Chairmanship of The President of the Republic of Ghana with its mandate to provide support, guidance and leadership for the national response to the HIV and AIDS epidemic, should lobby to create a better enabling legal environment in the country generally to give stigma and discrimination reduction efforts greater resonance and impact.
Legal rights of PLWHA against stigma and discrimination should be reinforced with a greater voice, visibility, and leadership for people living with HIV/AIDS to help challenge stigma and foster hope, action, and new believes about rights. This community of Wa particularly should continue to encourage the involvement of CHRAJ and PLWHA associations to pressure traditional and religious leaders for a change of attitude towards PLWHA. Capacities of organizations for PLWHA should be built and encouraged to help shape and implement research activities in the community and these organizations should be actively involved in litigation for achieving the rights of PLWHA. For a culturally sensitive community such as this one, the active involvement of PLWHA is crucial for developing and implementing effective anti-stigma campaigns. When persons affected by stigma are empowered to become agents of change, acting collectively to challenge stigma can be very effective.

HIV and AIDS related stigma are particularly harsh for populations that are already socially excluded or have unequal status in the community particularly women and drug users. Women and children for example are more prone than men to abandonment and violence as a result of their HIV status or association with the disease. Relevant bodies in this community should prioritize stigma involving women and children. The national HIV and AIDS strategic plan of the GAC and the activities of the RCC identified and targets most vulnerable groups and most at risk populations (MARPs) to new HIV infections to reduce stigma but missing from the MARPs is the GLBT (gay, lesbian, bisexual, and trans-gender) communities. To reduce HIV and AIDS related stigma, GLBT should also be classified as marginalized groups and targeted. Throughout this research exercise participants did not mention GLBT as a community, participants identified MSM as a target group but only refers to gay men and did not include lesbians, bisexuals, and trans-gender members of the community. It appears the GLBT are
ignored and deemed invisible by this community. A cultural shift of the community’s perceptions of PLWHA should also include GLBT, no matter how small their population is in this community.

This study recommends that stakeholders in this community find ways of improving family cohesion because, in a culturally sensitive community such as this one, family cohesion, the sense of unity, and belonging bridges gaps of differences. Improving family cohesion would influence and decrease internalized and experienced stigma. The overall impact of HIV and AIDS related stigma begins with internalized stigma because the individual’s perception of how they are perceived in the community can potentially positively influence their wellbeing and instill self-respect in the way they conduct themselves.

Currently, organizations in this community disproportionately focus on healthcare and education as the main means of reducing stigma and discrimination. The bulk of the educational campaigns are focused on reducing the number of new infections of the HIV virus rather than taking into account the social, economic, and cultural environments in which young people and PLWHA exist. HIV and AIDS related stigma reduction activities should massively empower PLWHA to engage in activities of financial emancipation, income generating activities, and financial help in subsistence farming. Further funding needs to be allocated to the reduction of internalized stigma through supporting income generating activities for infected individuals to be independent. Since households bear the heaviest impact of HIV/AIDS and its associated stigma, increased support should be provided for community initiatives for example care for orphans and sustain educational financial support may be relevant in particular cases where the person providing for the family succumb to AIDS.
This research study confirms that whiles stigma associated with the disease will in no way disappear in the future, it is absolutely crucial that the process of stigmatization be addressed as a significant barrier to fighting HIV and AIDS through the collaboration of individuals, organizations, building the capacity of marginalized groups like MARP’s, and improving the quality of life the infected and affected.

7.4 Research

Stigma is an intangible element of the HIV and AIDS epidemic and offers a challenge in the fields of both qualitative and quantitative researches globally. Given the significant impact of the process of stigmatization of infected individuals, their families, and the communities in which they live, this area of research that needs further attention. Stigma associated with the disease occur within a wide range of settings and there has been progress in the efforts to either reduce and eradicate traces of stigmatization behaviours but what needs further attention is how to measure the effectiveness of strategies, approaches, and also programs geared toward the eradication of stigma. What is needed is an effective and efficient monitoring and evaluation tool of stigma and discrimination reduction efforts, as an integral part of HIV and AIDS programs because evaluation data are limited.

Monitoring and evaluation of HIV and AIDS related stigma should be an integral part of any intervention, whether the programs are focused solely on stigma reduction or incorporate stigma and discrimination reduction strategies into ongoing activities. Ongoing monitoring and evaluation programs with reliable, quantitative measures will determine if the stigma intervention is effective, what aspects of stigma and discrimination are most responsive to the
intervention, and if there is any need for modifications. Measurement of stigma and
discrimination can also show if the program is exacerbating stigma and discrimination and what
aspects needs to be amended or changed.
REFERENCES


Smallholder farmer in East Africa. Photo: Neil Palmer/CIAT. Association for International Agriculture and Rural Development (AIARD).


UNAIDS. (2012), Sub-Saharan African Regional Fact Sheet on HIV/AIDS.


APPENDIX

Appendix A: GAC HIV/AIDS M&E system linked with M&E data flows
Appendix B: Photographs of the GAC Office (posters, charts, etc.)
STOP
THE BLAME GAME
There is life after HIV Testing

DISCORDANT COUPLES
can live healthier sexual & reproductive lives

GHANA AIDS COMMISSION
Be Bold Get Tested
There is life after HIV testing

Knowing your status (+Positive or -Negative) will help you live.

BE BOLD, GET TESTED
There is life after HIV Testing

Knowing your status (+Positive or -Negative) will help you live an informed life

GHANA AIDS COMMISSION
DON’T STIGMATIZE HIV POSITIVE PREGNANT WOMEN

PROVIDE SUPPORT
GHANA AIDS COMMISSION

DON’T STIGMATIZE HIV POSITIVE WOMEN

SHOW LOVE AND CARE
GHANA AIDS COMMISSION
Appendix C: Photographs of the RCC Office HIV and AIDS Educational Campaigns
Appendix D: Sample Participant Consent Form

SCHOOL OF ENVIRONMENTAL DESIGN AND RURAL DEVELOPMENT
Landscape Architecture  Capacity Development and Extension  Rural Planning and Development

If you volunteer to participate in this study, we would ask you to participate in interview conducted by Farouq Ayiworoh, a student from the Capacity Development & Extension Program at the University of Guelph. The results of this research will be used in my thesis. If you have any questions or concerns about the research, please feel free to contact Dr. Helen Hambly Odame at hambly@uoguelph.ca or on telephone number +1 (519) 824-4120 ex. 53408.

PURPOSE OF THE STUDY
The purpose of this study is to better understand how you view HIV/AIDS-related stigma and how this stigma impacts your community. If you volunteer to participate in this study, we would ask you to do the following things:

Participate in interview. The interview will include questions asking for your thoughts and personal experiences surrounding HIV/AIDS as well as the issue of stigma as it related to HIV/AIDS. What can you expect in the interview?

- Your identity will remain private and confidential to the extent allowed by law
- You have the right to refuse to answer any question asked or end the interview at any time
- Participation is completely voluntary and the interview will include you and the interviewer
- The interview will be no more than 45 minutes long
- The interview will take place at the GAC office, your CBO office, or a place of your choice
- The interviewer will take notes on paper and also digitally record your responses
- Recorded responses would be encrypted and saved with a password on a password protected computer
- Research results will be available to participants at the HIV/AIDS Coordinating Council in the Upper West if needed

POTENTIAL RISKS AND DISCOMFORTS
During the study you may experience feelings of discomfort, such as embarrassment, loneliness or sadness. If you do, you may talk about these feelings with us. There is the potential for social risks such as privacy and reputation concerns. In order to keep this risk as low as possible, we will make every effort
to keep your personally identifying information confidential by saving and encrypting your responses with a password. No one except the researcher has access to the information and all materials will be kept in a locked cabinet in a locked room. Some quotes from your responses may be used in Farouq Ayiworoh’s thesis, conference presentations, or published papers. If you are quoted, your name will never be used and there will be no way of identifying you from the quotation.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY
There is no direct benefit to you as a participant but you may experience feelings of relief for having had the opportunity to talk about some of your concerns regarding stigma and discrimination. Potential benefits to the community include less stigma and discrimination and a better understanding of how to overcome stigma associated with HIV/AIDS.

PARTICIPATION AND WITHDRAWAL
You may exercise the option of removing your data from the study. The investigator may withdraw you from this research if circumstances arise that warrant doing so. The level of service from GAC or any Community Based Organizations (CBO) that you affiliate with will not be affected by your decision to participate, or not participate in this research. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant, please contact:

Director, Research Ethics
University of Guelph, 437UC
50 Stone Road West
Guelph, Ontario
Canada, N1G 2W1
Telephone: +1 (519) 824-4120, ext. 56606

SIGNATURE OF RESEARCH PARTICIPANT
I have read the information provided for the study “HIV-AIDS Related Stigma - Wa, Ghana” as described herein and I agree to participate in this study. I have been given a copy of this form.

___________________    ____________________    ____________________
Name of Participant         Signature of Participant           Date
Appendix E: Sample Interview Guides

SCHOOL OF ENVIRONMENTAL DESIGN AND RURAL DEVELOPMENT
Landscape Architecture  Capacity Development and Extension  Rural Planning and Development

Key Informant Guiding Interview Questions

1) Can you share with me some of the negative thoughts that the community has regarding HIV/AIDS?
2) How do people react when they learn that you work for an organization about HIV/AIDS?
   a. Friends
   b. Family
   c. Neighbours
3) Are there some examples of stigma that you have seen or heard occurring in the community?
   a. Are there stories you can share?
   b. Experiences you have had?
4) Why do you think some people don’t want to associate with somebody who is HIV positive?
5) Can you describe any times when you have felt stigmatized because of where you work?
6) What can we do to help people feel more comfortable being around someone who is HIV positive?
7) Do you think stigmatization causes more infections?
8) Why do you think it is so difficult to reduce stigma?
9) What is your organization doing to help reduce stigma?
   a. Is there more the organization could be doing?
   b. Is there a particular area missing from your organization’s programming?
10) Is there anything else you would like to share with me; stories, comments?
Community Members Guiding Questions

1) Could you share with me your thoughts about HIV/AIDS?
2) Do you know how HIV is contracted?
   a. If Yes - Can you tell me how HIV is contracted?
   b. If No – Would you be willing to learn about how HIV is contracted?
3) Is there stigma attached to HIV/AIDS?
   a. Can you tell me your experiences about HIV/AIDS related stigma?
   b. Don’t mention names but do you know anyone who is HIV positive - family members, neighbours, or friends
   c. Do you feel sad for people living with HIV/AIDS?
4) Are you HIV positive?
5) If yes, have you disclosed your status to your friend and family members? Have people changed their behaviour towards you?
6) If HIV positive – Is support from organizations like GAC and CBOs helping you in any way?
7) How do you think you or this community can do to get people to be more comfortable around someone living with HIV/AIDS?
8) Do you think stigma causes more infections to happen?
9) What do you think you or members of the Wa community can do to reduce HIV/AIDS related stigma?
10) How can organizations like GAC, CBOs, and the Wa community do to help reduce HIV/AIDS related stigma?
11) Do you have any other thoughts that you would like to share with me; stories, comments?