UNIVERSITY OF CAPE COAST

SOCIAL DEATH: THE CASE OF HIV/AIDS STIGMATISATION IN THE CENTRAL REGIONAL HOSPITAL OF GHANA

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2009

DECLARATION

Candidate’s Declaration

I hereby declare that this thesis is a result of my own original research and that no part of it has been presented for another degree in this university or elsewhere.

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Supervisors’ Declaration:

We hereby declare that the preparation and presentation of the thesis were supervised in accordance with the guidelines on supervision of thesis laid down by the University of Cape Coast.

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ABSTRACT

The purpose of this study was to identify the causes and effects of stigmatisation on HIV and AIDS patients in the Central Region of Ghana. Some theoretical perspectives have been used to explain stigmatisation. They were the attribution theory and the exchange theory. These theories were found to be suitable for the explanation of stigmatisation in HIV and AIDS.

In conducting the study, a sample size of 120 was used in addition to 5 case studies. Two non-probability sampling techniques were used. Purposive and convenient/accidental sampling techniques were used. Both primary data and secondary information were used. Interview guides and case studies were used for the study.

The findings of the study included the fact that most people stigmatised people living with HIV and AIDS because of the correct and incorrect knowledge they have about HIV and its mode of transmission. Again, people stigmatised HIV and AIDS patients because of the myths surrounding AIDS and also, based on their socio-cultural background and orientation about its mode of transmission. These stigmatising and discriminatory behaviours from people towards People Living withHIV and AIDS have serious health, social and psychological effects on patients in particular and the society at large.

Based on the results of the study it was recommended that to reduce stigmatisation there should be an intensification of education of people about AIDS through the media to reduce the rate of misconception and fear among people.

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DEDICATION

This thesis is dedicated to the joy of my beloved parents, Albert K. Abima and Vincentia A. Owusu and also to my siblings, Samuel, Jonas, Richard, Erica and Rueben.

TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION

CHAPTER TWO: LITERATURE REVIEW

CHAPTER THREE: METHODOLOGY

CHAPTER FOUR: DEMOGRAPHIC AND SOCIO-ECONOMIC PROFILE OF RESPONDENTS

CHAPTER FIVE: HIV/AIDS STIGMATISATION AND DISCRIMINATION

CHAPTER SIX: CASE STUDIES

CHAPTER SEVEN: SUMMARY, CONCLUSIONS ANDRECOMMENDATIONS

LIST OF TABLES

LIST OF ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ARV	Anti-Retroviral
CDC	Centers for Disease Control and Prevention
CMV	Cytomegalovirus
DA	District Assemblies
DALY	Disability-Adjusted Life Years
DRI	District Response Initiative
GAC	Ghana AIDS Commission
GDHS	Ghana Demographic and Health Survey
GNACP	Ghana National AIDS Control Programme
GOG	Government of Ghana
GSS	Ghana Statistical Services
HIV	Human Immunodeficiency Virus
HIPC	Heavily Indebted Poor Countries
ICRW	International Center for Research and Women
JHS	Junior High School
MAC	Mycobacterium Avium Complex
MDAs	Ministries, Departments and Agencies
MTCT	Mother to Child Transmission
MSLC	Middle School Leaving Certificate
MOH	Ministry of Health
NGOs	Non-Governmental Organisations

OPD	Out Patient Department
PCP	Pneumocystis Carinii Pneumonia
PLWHA (PLHA)	People Living With HIV/AIDS
PSIs	Private Sector Institutions
SHS	Senior High School
STDs	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections
STV	Sexually Transmitted Virus
TB	Tuberculosis
UNAIDS	United Nations Programme on HIV and AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

CHAPTER ONE

INTRODUCTION

Background

In 1979, a few doctors in New York, San Francisco and Los Angeles had noticed a small outbreak of a deadly form of caposis Sarcoma, a rare cancer that normally produces only mild symptoms and that primarily affects elderly, hetero-sexual men who are Italian or Jewish. Subsequently doctors discovered five men who had pneumocystis carinii pneumonia (PCP) (Weitz, 2004).

The centers for Disease Control and Prevention (CDC) in the USA published the first report on the PCP cases in mid 1981, followed shortly by a report on Kaposis Sarcoma. At this point, no one knew what had caused these strange diseases. Obviously, however, something had destroyed the immune systems of these men leaving them susceptible to fatal infections by virtually any microorganism in their environment. The next year, the CDC officially coined the term Acquired Immunodeficiency Syndrome (AIDS) to describe what we now know is the last deadly stage of infection with Human Immunodeficiency Virus (HIV) (Weitz, 2004). Since then, the epidemic has generated a lot of fear in every part of the world.

A few behavioural changes could have virtually halted its spread: testing the blood supply for infection, using latex condoms and spermicidal with sexual partners and using clean needles when injecting drugs. Unfortunately, throughout the early years of the epidemic when intervention would have been most effective, most governments treated HIV disease as a distasteful moral issue rather than as a medical emergency (Barnett et al., 2002).

Sub-Saharan Africa is the region most affected by HIV/AIDS. Most, if not all of the 25 million people in Sub-Saharan Africa who are living with HIV/AIDS would have died by the year 2020, in addition to the 13.7 million Africans already claimed by the epidemic (Barnett et al., 2002).

The first AIDS cases were reported in Ghana in 1986. By the end of 2003, a cumulative total of 72,541 AIDS cases had been reported (GSSS, 2003). A major feature of the epidemic in Ghana was that at the beginning, nearly 80% of those diagnosed had either travelled or had lived outside the country. This trend has since changed with almost all the new cases being reported occurring among people without a history of previous travel (National HIV/AIDS and STI Policy, Ghana AIDS Commission 2004). Increasingly, there are reports of people suspected of having AIDS being ostracised by their neighbours, friends or work mates. Because of its association with sex outside marriage, AIDS is also seen as something for which the patients themselves are to blame. It is believed to be a “shame” disease and a cause of moral judgment and condemnation. In view of this, many people diagnosed as HIV-positive are understandably reluctant to tell their friends, work mates or neighbours about their condition for fear of condemnation and ostracism (Health and Human Rights, *Journal on HIV/AIDS and Human Rights*, Vol. 3 No. 1 (1998).

HIV and AIDS defined

Human Immunodeficiency Virus (HIV) is a fatal, sexually transmitted virus (STV). HIV is caused by two strains of the human immunodeficiency virus, HIV-1 and HIV-2. Within HIV-1 are at least nine slightly different subtypes, each predominating in different parts of the world, although researchers have found increased dispersion in recent years HIV-2, which is less infectious and progresses more slowly, are found primarily in West Africa, although, it is spreading to other regions. HIV-1 is the most common form of HIV and is hereafter referred to simply as HIV (World Bank, 1997).

Once introduced into the human body, HIV attacks mainly a subset of immune system cells, which bear a molecule called CD4. Specifically, the virus binds to two types of CD4-bearing cells: CD4+ T-cells and, to a lesser extent, macrophages. These cells perform various tasks critical to the normal functioning of the immune system. Macrophages engulf foreign invaders and prime the immune system to recognise these invaders in the future, and CD4+ T-cells organise the overall immune response by secreting chemicals to help other immune cells work properly. The mechanism-or mechanisms-by which HIV actually kills CD4+ T-cells is not well understood, but scientists did know that the immune system was able to check the onslaught of HIV to some extent, at least in the early stages of infection(World Bank, 1997).

Like other viral infections, HIV infection involves a battle between the immune system and the invading virus. What makes HIV unusual is that it is a relatively even match for the human immune system, resulting in a long struggle of, on average, eight to ten years, during which HIV advances slowly but inexorably. HIV finally "wins" the battle when the infected person develops serious opportunistic illnesses. Some of the illnesses are communicable, such as TB; others, like HIV-related cancers. Some are common infections that become unusually severe in people with AIDS, like sinusitis or pneumonia, while others are normally rare diseases that would not have taken hold at all had the person been HIV-negative. Some AIDS-associated infections can be treated with conventional antibiotics, particularly at the early stages of clinical AIDS. However, as the immune system continues to deteriorate, however, treatment becomes increasingly difficult and the number and variety of illnesses increases, leading to death. The Table 1 shows the lists of the main AIDS-associated illnesses diagnosed in developing countries.

Note: Co-infection with TB and one or more other opportunistic infections may be common in the developing world. Other important opportunistic infections, such as cytomegalovirus (CMV) and *mycobacterium avium* complex (MAC), do occur in developing countries, but are rarely diagnosed because of lack of resources (Morrow, Colebunders& Chin, 1989; Perriëns, 1996).

Table 1: Opportunistic illnesses often diagnosed in HIV-infected people in developing countries

Name	*Notes*
Tuberculosis	Because latent TB is common among HIV-negative people in developing countries, it is the most common opportunistic infection there, occurring in 40 to 60 percent of the HIV-infected. As in people without HIV, TB usually occurs as a lung infection, although the likelihood of TB infecting other parts of the body is higher in the HIV-infected.
Pneumococcal disease	This bacterial infection is the most common cause of pneumonia in people without HIV and causes bacterium, sinusitis, and meningitis among the HIV-infected.
Pneumocystics carinii pneumonia	Although almost unknown among people with normal immune systems, this small parasite is the most common cause of pneumonia among HIV-infected people outside Africa.
Toxoplasmosis	Previously known as a cause of an occasional birth defect when it infects pregnant women, in people with AIDS it is a common cause of encephalitis, or infection of the interior of the brain, which causes seizures, coma, and death.
Candidiasis	Commonly known as oral or esophageal thrush, this fungus infection occurs in almost every person with HIV and makes swallowing painful. Cryptococcosis: Although almost unknown in people without AIDS, this fungus infection occurs in about 5 percent of AIDS patients worldwide, usually as meningitis, an inflammation of the surface of the brain, which causes severe headache, fever, coma, and death.
AIDS-associated cancers	Common among upper-income people in developing countries (who have access to treatment for more common opportunistic illnesses).

Source: Morrow, Colebunders & Chin 1989; Perriëns, 1996.

The battle between HIV and the immune system is fought in three general stages. The first, known as primary (or acute) HIV infection, begins at the time of infection and lasts until the body's initial immune response gains some measure of control over viral replication, usually within a few weeks of infection. During this period, the CD4+ T-cell count drops dramatically, and between 30 and 70 percent of people experience flu like symptoms. These usually disappear within three weeks, as the CD4+ T-cell count rebounds.

The disease then enters its second stage, which is generally asymptomatic and accounts for about 80 percent of the time from infection to death. Only at the beginning of the second stage do antibodies to HIV become detectable in the bloodstream. Since most HIV tests work by detecting these antibodies, it is usually not possible prior to this stage to determine if a person is infected (World Bank, 1997).

Most HIV-infected people remain clinically healthy during this stage, while the immune system wages an invisible but intense struggle against the virus. Each day, HIV destroys huge numbers of CD4+ T-cells. The bone marrow compensates by speeding up production of new cells, but the rate of replacement cannot quite keep up with the rate of loss. The CD4+ T-cell count, which is about 800 to 1,000 per cubic millimeter of blood in an uninfected individual, gradually declines by about 50 to 70 cells each year. When the total CD4+ T-cell count diminishes to around 200 per cubic millimeter of blood, the rate of decline accelerates and the individual becomes susceptible to opportunistic infections and other illnesses. This marks the beginning of the final stage of HIV infection - Acquired Immune Deficiency Syndrome (AIDS).

Acquired Immune Deficiency Syndrome (AIDS) is not a single, distinct disease, but a complex illness that results from an immune deficiency. A complicating feature of the epidemic is the long period of latency between the initial HIV infection and the onset of the serious illness. In the United States and among middle-income and upper-incomes Africans, the average interval between infection (HIV-positive) and the illness (AIDS cases) for adults is about ten years (Myers & Henn, 1988). However, limited data suggest that the asymptomatic period might be as short as five years among the poorest people in the poorest countries (Mulder, 1996). During this latent period, infected individuals appear healthy, but they can and do infect others. The epidemic spreads unobserved and undetected. Some uninfected individuals are identified through routine blood screening and through special surveys in which blood tests for the presence of antibodies are conducted. AIDS cases are confirmed through blood tests once individuals develop illnesses that are associated with previously confirmed AIDS cases.

The length of survival after infection depends on many factors, including the strain and subtype of the virus, the general state of the person's health, and access to medical treatment for opportunistic illnesses. Most research on this question has focused on the industrial world. Prior to the use of triple-drug therapies, the median time from HIV-1 infection to death in industrial countries was around twelve years: the first two stages comprising eight to ten years and the final-stage, clinical AIDS comprising about fourteen to 25 months (Kitahata et al.,1996).

Much less is known about the survival rates of HIV-infected people in developing countries, but both the time from infection to AIDS and the time from AIDS to death are believed to be much shorter, with a total survival time from infection to death of perhaps around seven years. Aside from the generally poorer health and nutritional status of many in the developing world, lack of treatment for opportunistic infections that appear early in the course of AIDS is one factor in the shorter survival times. For example, people with HIV in developing countries are more likely than their counterparts in rich countries to succumb to TB, which is more prevalent and less likely to be treated in poor countries. In addition, TB has been associated with the faster evolution of HIV disease (De Cock, 1993).

Modes of transmission

The HIV/AIDS epidemic typically advances in waves of infection, starting with those engaging in the highest risk behaviour, then spreading to the general population (Myers & Ashakul, 1991). Like other STDs, HIV is difficult to transmit except by sex or other direct contact with the bodily fluids of an infected person. The major modes of transmission are sexual intercourse, reuse of contaminated syringes by injecting drug users, infection via birth or nursing from mother to child, reuse of needles in medical settings, and transfusions of contaminated blood or blood products. HIV cannot be transmitted by a sneeze, a handshake, or other casual contact (GNACP).

About three-quarters of HIV transmission worldwide is through sex; of these sexual transmissions, about three-quarters involve heterosexual intercourse and one-quarter involve sexual relations between men. In developing countries, sex accounts for an even greater proportion of cases. In Sub-Saharan Africa, Asia, and the Caribbean, sexual transmission is overwhelmingly between men and women; less than 1 percent involves homosexual acts. In Latin America and Eastern Europe, however, sex between men still accounted for most sexual transmission as recently as the early 1990s (Mann, Tarantola& Netter, 1992).

The next most important means of transmission after sexual intercourse is the sharing of unsterilised needles among injecting drug users. Transmission through injecting drug use has been the primary mode of transmission in China and Southeast Asia, except in Thailand, where heterosexual transmission has outpaced transmission by needle sharing. Injecting drug use is also thought to account for about one-quarter to one-third of transmissions in Brazil and Argentina. HIV can spread through a population of injecting drug users extremely rapidly, in some locales infecting the majority within a few months.

The mother-to-child transmission varies widely across countries. The major mode of infection among infants can occur in the uterus, through contact with the mother’s blood at birth or later through breastfeeding. About one-half to two-thirds of mother-to-infant transmission is believed to occur at the time of birth (Reggy, Simonds& Rogers, 1997). Since mother-to-child transmission can occur only if the mother is herself infected, it is most common in widespread heterosexual epidemics, such as in Sub-Saharan Africa. By one estimate, 15 to 20 percent of all HIV infections in Africa occur in infants infected by their mothers. Worldwide mother-to-child transmission accounts for about 5 to 10 percent of infections (Quinn, Ruff & Halsey, 1994). The risk of HIV transmission from mother to newborns can be reduced by two-thirds, from 25 percent to about 8 percent, by administering zidovudine (AZT) to the mother before and during birth, and to the nonbreastfed newborn for six weeks after birth (Connor et al., 1994).

HIV may also be spread through medical injections. In some of the poorest countries, injections are the preferred delivery system for a variety of medications, and the same syringe may be used on many people in one day without sterilisation between injections. However, even in these countries, medical injections with dirty needles are thought to account for less than 5 percent of all HIV infections.

Transmission through transfused blood and other blood products greatly increases the risk of medical care and can rapidly spread HIV among specific populations-for example, among hemophiliacs in industrial countries in the 1980s-HIV transmission through transfusions has never accounted for more than about 10 percent of total HIV infections, even in developing countries. Transmission through blood transfusions, a cause for concern in many countries, is gradually being eliminated, in many high- and middle-income and even in developing countries by routine screening of blood for transfusions.

Global HIV/AIDS update

HIV/AIDS continues to have a staggering impact on people’s health and on the social and economic stability of nations. AIDS, the leading infectious cause of young adult death globally, is rooted in racism, victim-blaming, disciplinary blindness, negative cultural and traditional beliefs and practices, poverty and shoddy research (UNAIDS, 2003). The AIDS epidemic claimed approximately 3 million lives in 2003, and an estimated 5 million people acquired the human immunodeficiency virus (HIV) in 2003, bringing to 40 million the number of people globally living with the virus at the end of 2003 (UNAIDS, 2003).

As the world enters the third decade of the AIDS epidemic, the evidence of its impact is undeniable. Wherever the epidemic has spread unchecked, it is robbing countries of the resources and capacities on which human security and development depend. The world stood by as HIV/AIDS swept through many countries. It cannot be allowed to turn a blind eye to an epidemic that continues to expand in some of most populous regions and countries of the world (UNAIDS, 2003).

Table 2: Global Estimates of the HIV/AIDS epidemic

		Estimate	Range
People newly infected with HIV in 2003:	Total	5 Million	(4.2 – 5.8 Million)
	Adults	4.2 Million	(3.6 – 4.8 Million)
	Children <15 years	700, 000	(590, 000 - 810, 000)
Number of people living with HIV/AIDS in 2003:	Total	40 Million	(34 – 46 Million)
	Adults	37 Million	(3.6 – 4.8 Million)
	Children <15 years	2.5 Million	(2.1 – 2.9 Million)
AIDS deaths in 2003:	Total	3 Million	(2.5 – 3.5 Million)
	Adults	2.5 Million	(2.1 – 2.9 Million)
	Children <15 years	500, 000	(420, 000 - 580, 000)
Total no. of AIDS deaths since the beginning of the epidemic until the end of 2001:	Total	21.8 Million	
	Adults	17.5 Million	
	Children <15 years	4.3 Million	
Total no. of AIDS orphans since the beginning of the epidemic until the end of 2001 (0-14 Years who've lost 1 or both parents to AIDS)	Total	14 Million	

Source: UNAIDS, (2003)

Large variations exist between regions and HIV prevalence rates greatly across the globe with Sub-Saharan Africa being the most affected region. This is visible in Table 3 below.

Table 3: Regional HIV/AIDS statistics

REGION	Epidemic started	Adults & children living with HIV/AIDS	Adult prevalence rate	Adults & children living infected with HIV/AIDS in 2003
Sub Saharan Africa	Late '70's - Early 80's	25-28.2 million	7.5-8.5%	2.2-2.4 million
North Africa & the Middle east	Late '80's	470, 00-730, 000	0.2-0.4%	35, 000-50, 000
South &South East Asia	Late '80's	4.6 – 8.2 million	0.4-0.8%	330, 000-590, 000
East Asia & Pacific	Late '80's	700, 000 - 1.3 million	0.1-0.1%	32, 000-58, 000
Latin America	Late ‘70's early 80's	1.3 – 1.9 million	0.5-0.7 %	49, 000 – 70, 000
Caribbean	Late '70's - Early 80's	350, 000- 590, 000	1.9-3.1 %	30, 000 – 50, 000
Eastern Europe &Central Asia	Early '90's	1.2 – 1.8 million	05-0.9%	23, 000 – 37, 000
Western Europe	Late '70's - Early '80's	520, 000 - 680, 000	0.3-0.3%	2, 600 - 3, 400
North America	Late 70's - Early 80's	790, 000 - 1.2 million	0.5-0.7%	12, 000 – 18, 000
Australia & New Zealand	Late '70's – Early '80's	12, 000 - 18, 000	0.1-0.1%	<100
Total		40 million (34-46 million)	1.1% (0.9-1.3%)	3 million (2.5-3.5 million)

Source: UNAIDS, (2003)

Notes: The ranges around the estimates in Table 1 and 2 define the boundaries within which the actual numbers lie, based on the best available information.

Adults in this report are defined as men and women aged 15-49. This age range captures those in their most sexually active years. While the risk of HIV infection continues beyond the age of 50, the vast majority of people with substantial risk behaviour are likely to have become infected by this age. Since population structures differ greatly from one country to another, especially for children and the upper adult ages, the restriction of 'adults' to 15-49 has the advantage of making different populations more comparable. The latest UNAIDS and WHO estimates published in 2003 are lower than those published in 2002. But the number of people living with HIV/AIDS is not actually lower, nor is there a decline in the epidemic. Better data and understanding has enabled the UNAIDS Secretariat and WHO to arrive at more accurate estimates (UNAIDS, 2003).

HIV/AIDS in Sub-Saharan Africa

HIV transmission in sub-Saharan Africa is a complex and regionally specific phenomenon rooted in local economies, deepening poverty, migration, gender, war, global economies, and cultural politics. Sub-Saharan Africa is the region of the world that is most affected by HIV/AIDS. An estimated 26.6 million people are living with HIV/AIDS and approximately 3.2 million new infections occurred in Sub-Saharan Africa in

2003(UNAIDS,2003). In just the past years the epidemic has claimed the lives of an estimated 2.3 million Africans. Ten million young people (aged 15-24) and almost 3 million children under 15 are living with HIV. An estimated eleven million children have been orphaned by AIDS in Sub-Saharan Africa (UNAIDS, 2003).

Large variations exist between individual countries. In some African countries, the epidemic is still growing despite its severity. Others face a growing danger of explosive growth. The sharp rise in HIV prevalence among pregnant women in Cameroon (more than doubling to over 11% among those aged 20-24 between 1998 and 2000) shows how suddenly the epidemic can surge. National HIV prevalence rates vary greatly between countries. In Somalia and Gambia the prevalence is under 2% of the adult population, whereas in South Africa and Zambia around 20% of the adult population is infected. In four southern African countries, the national adult HIV prevalence rate has risen higher than was thought possible and now exceeds 30%. These countries are Botswana (37.5%), Lesotho (31.5%), Swaziland (38.6%) and Zimbabwe (33.7%). West Africa is relatively less affected by HIV infection, but the prevalence rates in some countries are creeping up. In West and Central Africa HIV prevalence is estimated to exceed 5% in eight countries. These countries include Cameroon (11.8%), Central African Republic (12.9%), Côte d'Ivoire (9.7%) and Nigeria (5.8%). HIV infection in Eastern Africa varies between adult prevalence rates of 1% in Somalia to 15% in neighbouring Kenya (UNAIDS, 2002).

The extent of the epidemic is only now becoming clear in many African countries, as increasing numbers of people with HIV are now becoming ill. In the absence of massively expanded prevention, treatment and care efforts, the AIDS death toll on the continent is expected to continue rising before peaking around the end of the decade. This means that the worst of the epidemic's impact on these societies will be felt in the course of the next ten years and beyond. Its social and economic consequences are already being felt widely not only in health but in education, industry, agriculture, transport, human resources and the economy in general(UNAIDS, 2003).

Over and above the personal suffering that accompanies HIV infection wherever it strikes, HIV in sub-Saharan Africa threatens to devastate whole communities, rolling back decades of progress towards a healthier and more prosperous future. In many countries of Sub-Saharan Africa, AIDS is erasing decades of progress made in extending life expectancy. Millions of adults are dying young or in early middle age. Average life expectancy in Sub-Saharan Africa is now 47 years, when it could have been 62 without AIDS(UNAIDS, 2003). The toll of HIV/AIDS on households can be very severe. Many families are losing their income earners and the families of those that die have to find money to pay for their funerals. Many of those dying of AIDS have surviving partners who are themselves infected and in need of care. They leave behind children grieving and struggling to survive without a parent's care. HIV/AIDS strips the family assets further impoverishing the poor. In many cases, the presence of AIDS means that the household eventually dissolves, as the parents die and children are sent to relatives for care and upbringing (UNAIDS, 2003).

In all affected countries, the HIV/AIDS epidemic is bringing additional pressure to bear on the health sector. As the epidemic matures, the demand for care for those living with HIV/AIDS rises, as does the toll amongst health workers. Health-care services face different levels of strain, depending on the number of people who seek services, the nature of their need, and the capacity to deliver that care. How schools and other educational institutions are able to cope is a major factor in how well societies will eventually recover from the HIV/AIDS epidemic. A decline in school enrolment is one of the most visible effects of the HIV/AIDS epidemic on education in Africa (UNAIDS, 2002).

HIV/AIDS dramatically affects labour, setting back economic activity and social progress. The vast majority of people living with HIV/AIDS in Africa are between the ages of 15 and 49 - in the prime of their working lives. Employers, schools, factories and hospitals have to train other staff to replace those at the workplace that become too ill to work. Through its impacts on the labour force, households and enterprises, HIV/AIDS can act as a significant brake on economic growth and development. HIV/AIDS is already having a major effect on Africa's economic development, and in turn, this affects Africa's ability to cope with the epidemic.

It is not too late to introduce and augment measures that can reduce that impact, especially strategies to reduce the rate of stigmatisation and discrimination so as to pave way for voluntary counseling and testing (VCT), wider access to anti-retroviral drugs and socio-economic policies that genuinely shield the poor against the worst of the epidemic's effects. The vast majority of Africans – more than 90% have not acquired HIV. Enabling them to remain HIV – free is a massive challenge, with the protection of peoples' rights especially the young people as a priority (UNAIDS, 2003).

HIV/AIDS situation in Ghana

HIV /AIDS in Ghana was first recorded in 1986, mainly among women who had travelled outside the country. The HIV/AIDS epidemic in Ghana has since then been growing steadily. In the light of experience elsewhere in Africa, it is necessary to understand the potential effects of an HIV/AIDS epidemic (Ghana health service, National AIDS /STI Control Programme, 2003).

Transmissions of HIV infections in the country are due to heterosexual contact, mother to child transmission, transmission through contaminated blood (blood transfusion) or through sharing of needles or blades that have been in contact with the blood of an HIV infected person. The majority of the infections (80%) are transmitted through heterosexual contact and Mother-to child transmission accounts for approximately 15% of all HIV transmission (Ghana health service, National AIDS /STI Control Programme, 2003).

Burden of HIV / AIDS in Ghana: sex workers 22,000, prisoners 10,879, children living on the street 150,000 *(coverage of essential HIV/ AIDS services in Ghana, national questionnaire, July 2003; prepared by Dr. Agnes*

Dzokoto, National AIDS Control Programme). Cumulative total reported cases as at December 2002 was 64,361, and by end of June 2003 it had risen to 72,010 (estimated level of reporting 30%) Male: female ratio 1:2 (2002) and Adult HIV prevalence: median is 3.4% (2002). HIV 1 is the predominant type of HIV virus (92.2% HIV 1 only and 7.4% dual infection with HIV types 1 and 2). Peak age group is 30-34 yrs (general) and for Females: 25-29 and males: 30-34. Children between the ages of 5 and 14 may be special window of Hope. If these children can be taught to protect themselves from HIV infection before they become sexually active, they can remain free of HIV for their entire lives (National AIDS/STI Control Programme in Ghana, 2003).

According to Ghana Demographic Health Survey 1998, HIV /AIDS awareness is universal. Most women (97%) and men (99%) have heard of AIDS. However personal risk perception is low as 54% of women and 58% of men believe that they have no chance of contracting HIV /AIDS. Respondents who believe that they have no risk of contracting HIV /AIDS are less likely to change behaviour than those who believe they have a moderate or greater risk of contracting HIV /AIDS (GSS, 1998).

The National Response

Nearly all developing countries have responded in some way to the challenge of HIV/AIDS, often with the active assistance of donor countries and multilateral institutions. Ghana initially responded to HIV/AIDS as a health rather than a developmental issue. Consequently, the government directed the Ministry of Health (MOH) to handle the issue. However, in 1987, the National AIDS Control Programme (NACP) was established under the MOH to implement and coordinate the country's HIV/AIDS programme. In addition, a National HIV/AIDS and STI policy was developed to guide the national response. The MOH through the NACP has spearheaded various strategies to contain and limit the spread of HIV infection. These strategies include maintaining a safe blood supply, ensuring safe use of needles, and disseminating information through public campaigns to change social attitudes and behaviour (USAID/Ghana,2003).

When it became clear that HIV/AIDS prevalence rates were steadily increasing, in September 2000, the government established the Ghana AIDS Commission (GAC) for effective resource mobilisation, management, and coordination of HIV/AIDS activities and targeted prevention measures expected to successfully raise awareness and promote behavioural change among the population. In collaboration with the MOH and the National Population Council, the GAC published a National Strategic Framework on HIV/AIDS for the period 2001 to 2005. The Strategic Framework sets targets for HIV/AIDS infection reduction, addresses service delivery needs and individual and societal vulnerability, and promotes the establishment of a multi-Sectoral, multidisciplinary framework for coordinated implementation of HIV/AIDS programmes. The Framework also sets out goals, objectives and specific activities for all sectors, including the Government and various

Government Ministries, the private sector, non – governmental organisations and civil societies. Five key intervention areas identified are as follows:

i. Prevention of new transmission
ii. Care and support for people living with HIV/AIDS (PLWHA)
iii. Creating an Enabling Environment for National Response
iv. Decentralised Implementation and Institutional arrangements
v. Research , Monitoring and Evaluation

Each area is supported by set of broad strategies that are to guide the development of action plans by all Ministries, Departments and Agencies (MDAs), Non-Governmental Organisations(NGOs) and other Private Sector Institutions (PSIs). Sectoral plans – including those for the Ministry of Education, the Ministry of Health and the Local Government - have been developed.

The Ministry of Education is tasked to provide adequate information on HIV/AIDS to enrolled students. Several intervention strategies have been put in place. Key among them is the School HIV-Alert Model, an initiative that seeks to give momentum to school-based control efforts through nationwide campaigns. The specific objectives of the school alert programme are:

- to anchor and strengthen school based HIV/AIDS control programmes
- to provide a framework for harmonising school based HIV/AIDS control programmes in schools

- to provide a tool to support a focused , expanded and sustained HIV/AIDS control programmes in school
- to provide a framework for assessing the state and depth of implementation of school based programmes.

The Ministry of Health concentrates on the provision of clinical services for STI management and the treatment of PLWHA. The MOH through the NACP has spearheaded various strategies to contain and limit the spread of HIV infection. These strategies include maintaining a safe blood supply, ensuring safe use of needles, and disseminating information through public campaigns to change social attitudes and behaviour (USAID/GHANA, 2003).

In addition, the Ministry of Local Government is responsible for putting in place decentralised response structures for HIV/AIDS activities at the District levels. One of the structures put in place is the District Response Initiative (DRI) which was launched in 2000 at the urging of UNAIDS. Under the DRI, District Assemblies (DA) are to develop specific strategies for HIV/AIDS activities with their own funding and incorporated into their poverty alleviation programmes. In addition, the GAC embarks on programmes that support hundreds of NGOs at the community level. The GOG has successfully applied for a first round of Global Fund that largely supports the treatment of HIV/AIDS related conditions in the public sector. A second round of the applications for community mobilisation are being prepared, including care and support through NGOs, and Anti – Retroviral

(ARV) treatment and workplace prevention through the private sector (USAID/Ghana, 2003).

Until recently, the involvement of the religious bodies was limited to initiatives coordinated through the health institutions of the Christian Health Association of Ghana. These efforts have largely been in the area of care and support. Over the past years, however, there has been rapid growth and positive involvement of Christian and Muslims in the fight against the epidemic.

Other key thrusts of Ghana‘s response outlined in its framework include blood screening for HIV and increased access of PLWHA to care and support services within a human rights framework. The framework also supports the promotion of safe sex behaviour among most at-risk groups (out-of-school youth, uniformed services, vulnerable women, commercial sex workers, mobile population including teachers). It also outlines efforts to develop an enabling political, social, legal, and economic environment; expands of MTCT and VCT services, supports ARV procurement /treatment, strengthens the national HIV and STI surveillance system; and supports orphans and PLWHA.

Prevention of MTCT was introduced on a pilot basis in 2002. Through the Ghana Poverty Reduction Strategy/HIPC funding, Global Funds limited USAID support, ART was expected to be available for 4000 persons by mid-2003 on a pilot basis through Public Health System (USAID/Ghana, 2003)

Statement of the problem

AIDS infection has created the fear of stigmatisation, isolation and panic among infected persons.Evidence from AIDS research in the last decade has reinforced the view that the state ofhealth of any group of people is related to its living conditions, the socio-cultural context in which people are socialised and operate, and the respect for basic rights of the individual. In most parts of the world, the vulnerable in society have been the hardest hit by the AIDS epidemic (Mann 1992; Mann et al., 1994).

With the initial misconceptions and negative reactions to the disease, AIDS patientsthroughout the world have been blamed, stigmatised, marginalised and isolated (Sabatier, 1988). In developing countries, the conditions of HIV/AIDS patients have been furtherexacerbated by poverty, poor infrastructure and inadequate medical services. There is also a big gap in African countries between public statements about the disease and the reality of programmes in place and the living conditions of infected persons. For many of these countries, intervention programmes are basically concerned with education and information and the targeting of 'high-risk groups'. As the disease diffuses into the general population, the categories of infected people become more diverse and the effect of the disease become more complex (WHO 1992, 1994).

While there have been various attempts to measure the economic costs (Ainsworth & Over, 1992, 1994), and the social implications of the epidemic (Brokensha,1988, Schoepf, 1988), National Research Council 1993; Preston-

Whyte, 1994), the emotional and other costs of the disease can only be guessed (Shilts, 1987, Panos, 1992). Quantifying emotional stress from stigma, isolation, blame and self-pity in the individual and the family is difficult since AIDS infection involves some of the most intimate of personal relations. The World Bank in its World Development Report of 1993 introduced the concept of 'Disability-Adjusted Life Years (DALY)' as a measure of the burden of ill-health. Although an interesting concept, it will be difficult to apply to aspects of some diseases. As pointed out by Klauda (1994) '...how many'Disability-Adjusted Life Years(DALYs) would be allocated to a person who is stigmatised ...because (s) he has AIDS' (p. 104). And as the disease enters its third decade and more people get infected, there is the need to understand the psycho-social coping mechanisms adopted by HIV seropositive patients. This is important in Ghana where counselling is not well developed or incorporated into the modern health care system (Ego & Moran, 1993).

Fear of discrimination often prevents people from seeking treatment for AIDS or from admitting their HIV status publicly. People with (or suspected of having) HIV may be turned away from healthcare services, employment, refused entry to foreign country. In some cases, they may be evicted from home by their families and rejected by their friends and colleagues. The stigma attached to HIV/AIDS can extend into the next generation, placing an emotional burden on those left behind.

It is therefore obvious that, stigma has great effects on the individual and the society at large. There is therefore the need for studies to look at the effects of stigmatisation on HIV infected persons and the society at large so that measures can be put in place to control the epidemic.

The study examined the extent to which people came to stigmatise people living with HIV/AIDS. The examination was done by considering factors as misconceptions, knowledge of HIV/AIDS, fear of HIV/AIDS, and bias (discrimination) in health care delivery.

Objectives of the study

The general objective of this study was to determine the differential opinions and beliefs that individuals have toward people living with HIV/AIDS and the reason underlying the stigmatisation against People Living with HIV/AIDS.

The specific objectives were to:

- assess why there are differential reactions to people living with HIV/AIDS.
- determine the causes of stigma from HIV/AIDS patients’ perspective
- examine responses to a wide range of HIV/AIDS stigmatisation so as to better understand the reasons for differential reactions to these conditions.
- determine the effect of stigmatisation on HIV/AIDS patients.

- determine whether the modes of health care delivery to HIV/AIDS patients by health practitioners contribute to the stigmatising condition.

Research questions

- How do people stigmatise people living with HIV/AIDS?
- Why do people have different reactions towards people living with HIV/AIDS?
- How do HIV/AIDS patients' react to the stigmatising behaviours from people?
- Do perceived costs of engaging in social interaction with an HIV/AIDS patient increase stigmatisation and discrimination?
- Does the mode of health care delivery to HIV/AIDS patients by health practitioners lead to stigmatisation?

Significance of the study

This study clarified issues relating to HIV /AIDS stigmatisation in Ghana with particular emphasis on misconceptions, mode of health care delivery, bias, and fear. Again, the study contributed to existing knowledge on exchange, and attribution theories.

Scope of the study

The study was limited to the Central Region (i.e. the regional hospital). The study included health care practitioners, HIV/AIDS patients, family members, relatives and friends of HIV/AIDS patients and peoples' opinions regarding social stigmatisation and knowledge of HIV/AIDS.

Organisation of the study

The research work is divided into seven chapters with each chapter detailing the work.Chapter One consists of the general background of the study. This captures the introduction of the study, statement of the problem, the objectives of the study, research questions, the significance as well as the scope of the study.

Chapter Two of the work discussed the literature review and theoretical perspectives. The literature review discussed background issues to HIV/AIDS, stigmatisation and its causes and effects on the HIV/AIDS patients. Theoretically, the attribution theory and the exchange theory were discussed in relation to HIV/AIDS and stigmatisation.Chapter Three explains the research design, sampling procedure and the methods and techniques used in data collection. Interviews, questionnairesurveys and case studies formed the bulk of the work. Chapter Four examined data gathered from the field. The chapter analysed demographic and socio-economic profile of the respondents.

Chapter Five continued with the analyses of data. Factors as knowledge and misconceptions of HIV/AIDS, reactions towards people living with HIV/AIDS, and mode of health care delivery to HIV/AIDS patients were examined. Finally, the chapter analysed the effects of HIV/AIDS discrimination and stigmatisation on the people living with

HIV/AIDS.Chapter Six discussed the 5 case studies on case by case basis. Issues discussed in the cases bordered on discrimination of PLHA, and disclosure of HIV status by patients. Chapter Seven looked at the summary, conclusion, recommendation as well as the areas for further research.

CHAPTER TWO

LITERATURE REVIEW

Background to issues of HIV/AIDS

In a number of societies, the outbreak of a disease with no known cure or origin may be attributed to the commission of an offence against one’s spirits, the ancestors or the gods, or an omission of duty on the part of an infected person. It could also be attributed to a curse from a jealous neighbour, co-wife and even a family member or somebody who has been wronged (Twumasi, 1975, Appiah-Kubi, 1981). At different times in Ghana, the outbreak of diseases such as tuberculosis, measles and guinea worm has been attributed to supernatural sources (Dickson, 1969). According to Castle (1994), in Mali child mortality could be attributed to the owl or the wind, thus allowing for psychological adaptation to the high infant and child mortality.

There is a belief in Ghana that Western medicine can provide neither an explanation nor a cure for certain diseases (Appiah-Kubi, 1981). Therefore, people suffering from a disease whose origin has been attributed to supernatural causes and their families, may seek explanation and possible cure for the disease at fetish shrines, diviners or spiritualists. The first stage was to find the cause of the disease and this may be done by asking a person suspected of being the cause of the illness to ‘confess’ to misdeeds which might have brought about the disease or a suspected person may be accused on oath of being responsible for the disease. Some of these procedures for identifying the cause of a disease have been adopted by the Ghanaian-based Christian churches in their healing process (Appiah-Kubi, 1981).

An event is attributed to ‘divine intervention’ in the affairs of people when they are not able to deal with a new or unusual circumstance within the context of existing knowledge and practice (Kirby, 1994). Although African Societies have undergone dramatic socio-cultural changes this century in such areas as formal education, conversion to Christianity and Islam as well as changes in patterns of socialisation, the old and new ways of life co-exist and people continue to give supernatural explanations to events. Kirby (1994) observed that among the Anafo (Ghana), converts to Christianity, when confronted with problems, employed: (1) traditional solutions; (2) syncretic solutions that were orthodox in appearance but traditional in aim; and (3) orthodox solutions (West African Orthodoxy). He then concluded that ‘one could become Christian without ever confronting or redirecting one’s religious problem solving nexus’ (Kirby, 1994).

The outbreak of HIV/AIDS in Ghana has been given a similar supernatural explanation. The general view is that infected persons have defiled themselves or the ancestors or broken the moral code of behaviour. The view has been reinforced by the fact that most of the persons initially diagnosed to be HIV-Seropositive were females who had been involved in commercial sex. This explains some of the reported reactions to HIV infection as ‘they deserve it,’ or ‘they are immoral’ (Anarfi, 1992, Safo, 1993). Shilts (1987) and Sabatier (1988) described similar attitudes towards homosexuals and intravenous drug users in Europe and America.

HIV/AIDS has occurred at a time when sub-Saharan African countries were undergoing severe economic hardships: the World Bank (1981), described the 1980s as Africa’s lost decade. In the 1970s and 1980s, sub-Saharan African countries experienced low and, in cases negative, growth rates in gross domestic product. The decline in the economy led to the neglect and deterioration of social services and to shortages of basic goods.

In Ghana, as in a number of African countries, the decline in socio-economic conditions created individual and collective vulnerability to HIV infection. During the peak of Ghana’s economic decline in the 1970s and 1980s, a number of Ghanaians migrated to other African countries and to Europe and America as economic refugees (Bentsi-Enchill, 1983, Adomako, 1991). Within the overall socio-economic decline women were affected the most, owing to their already low socio-economic status relative to men. To some people, AIDS represents what has really gone wrong in the political economy of sub-Saharan Africa in the last three decades.

Ghana acknowledged the public health threat of AIDS and started to inform people about it long before the first case was diagnosed in the country in March 1986. The major reason for initiating educational campaigns was that people ‘should not be allowed to die of ignorance’ (Addo-Yobo & Lovel, 1992). Various evaluations of the campaigns indicate that the majority of

Ghanaians have heard about AIDS (Addo-Yobo & Lovel, 1992; McCombie & Anarfi, 1992). From the beginning, the HIV/AIDS epidemic has been accompanied by an epidemic of fear, ignorance and denial, leading to stigmatisation of and discrimination against people with HIV/AIDS and their family members (Herek & Glunt, 1988, Mann, 1987). In addition, many more who do not know their serostatus live in fear of facing stigma and discrimination should they contract the disease. HIV-related stigma is increasingly recognised as the single greatest challenge to slowing the spread of the disease (Gupta, 2001). In spite of increasing awareness that the impact of stigma must be addressed in policies and programmes aimed at reducing HIV/AIDS, efforts are impeded by the dearth of information on stigma and HIV/AIDS.

HIV/AIDS-related stigma and resulting discriminating acts create circumstances that fuel the spread of HIV (UNAIDS, 1998). Fear of being identified with HIV prevents people from learning their serostatus, changing unsafe behaviour and caring for people living with HIV/AIDS. An international center for Research and Women (ICRW) study in Botswana and Zambia found that stigma against HIV-positive people and fear of mistreatment prevented people from participating in voluntary counseling and testing (VCT) and programmes to prevent mother-to-child transmission (MTCT) (Nyblade & Field, 2000). Whether it is these programmes, home-based care or other support services, stigma prevents individuals and communities from using HIV/AIDS services.

Stigmatisation-conceptual definition and forms

Stigmatisation is generally defined as “attribute that is deeply discrediting” and it reduces the bearer “from a whole and usual person to a tainted discounted one” (Goffman, 1963). Link and Phelan (2001) describe stigma as occurring when four interrelated components-distinguishing and labeling differences; associating human differences with negative attributes; separating ‘us’ from ‘them’; and status loss and discrimination – converge in the context of social, economic and political power.

Stigmatisation often leads to discrimination, which refers to any form of distinction, exclusion, or restriction affecting a person by virtue of personal characteristics (Gilmore & Somerville, 1994).

Stigma is not unique to HIV/AIDS. It has been documented with other infectious diseases like tuberculosis, syphilis, and leprosy (Herek et al., 1998, Goldin, 1994). Stigma is most frequently associated with diseases that have severe, disfiguring, incurable and progressive outcomes, especially when modes of transmission are perceived to be under the control of individual behaviour. It is also common in diseases that are perceived to result from the transgression of social norms, such as socially unsanctioned sexual activity (Crandall & Moriarty, 1995). These criteria fit HIV/AIDS.

Erving Goffman is widely credited for conceptualising and creating a framework for the study of stigma. His explanation of stigma focuses on the public’s attitude toward a person who possesses an attribute that falls short of societal expectations. Goffman further explained that stigma falls into three categories:

- Abominations of the body: This includes various physical deformities.
- Blemishes of individual character: This entails weak will, domineering or unnatural passions, treacherous and rigid beliefs or dishonesty. Blemishes of character are inferred from, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts or radical political behaviour.
- Tribal stigma of race, nation and religion:

These are beliefs that are transmitted through lineages and equally contaminated by all members of a family (Goffman, 1963).

According to Goffman, diseases associated with the highest degree of stigma share common attributes:

- The person with the disease is seen as responsible for having the illness.
- The disease is progressive and incurable.
- The disease is not well understood among the public.
- The symptoms cannot be concealed.

HIV infection fits the profile of a condition that carries a high level of stigmatisation (Goffman, 1963; Herek, 1999, Jones et al., 1988). First, people infected with HIV are often blamed for their condition and many people believe HIV could be avoided if individuals made better moral decisions.

Second, although HIV is treatable, it is however a progressive, incurable disease (Herek, 1999, Stoddard, 1994). Third, HIV transmission is poorly understood by some people in the general population, causing them to feel threatened by the mere presence of the disease. Finally, although asymptomatic HIV infection can often be concealed, the symptoms of HIV-related illness cannot. HIV-related symptoms may be considered repulsive, ugly, and disruptive to social interaction (Herek, 1999).

The discrimination and devaluation of self identify associated with HIV-related stigma do not occur naturally (Herek, 1999). Rather, they are created by individuals and communities who, for the most part, generate the stigma as a response to their own fears.

HIV-positive individuals, their loved ones and even their caregivers are often subjected to rejection by their social circles and communities when they need support the most.

HIV-related stigma has been further divided into the following categories:

- Instrumental HIV-related stigma – a reflection of the fear and apprehension that are likely to be associated with any deadly and transmissible illness (Herek, 1999).
- Symbolic HIV-related stigma – the use of HIV/AIDS to express attitudes toward the social groups or “lifestyles” perceived to be associated with the disease (Herek, 1999).

- Courtesy HIV-related stigma – stigmatisation of people connected to the issue of HIV/AIDS or HIV- positive people (Snyder, 1999).

From the foregoing definitions, it has been realised that stigmatisation is a process. The qualities to which stigma adheres (e.g. the color of the skin, the way someone talks, the things that they do) can be quite arbitrary. Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy. Stigmatisation therefore describes a process of devaluation rather than a thing. Much HIV/AIDS-related stigma builds upon and reinforces negative thoughts. People with HIV/AIDS are often believed to have deserved what has happened by doing something wrong. Often these “wrong doings” are linked to sex or to illegal and socially – frowned – upon activities, such as injecting drug use. Men who become infected may be seen as homosexual, bisexual or having had sex with prostitutes. Women with HIV/AIDS are viewed as having been ‘promiscuous’ or as having been sex workers. The family and community often perpetuate stigma and discrimination, partly because it is convenient to blame those who have been affected first.

It is also necessary, when analysing the concept stigma and its forms, to demonstrate how different groups experience stigma and, most particularly how men and women are differentially affected by it. Images of HIV/AIDS in the media and television, which suggest that it is a ‘women’s disease; a ‘junkies’ diseases, a ‘Black disease’, an ‘American’ disease or a ‘gay plague’ also create HIV/AIDS-related stigma and discrimination and reinforce those stereotypes and beliefs. Although images associated with HIV/AIDS vary, they are patterned so as to ensure that HIV/AIDS-related stigma plays into and reinforces, existing social inequalities. These include gender inequalities; inequalities that deny sex workers their dignity and rights; inequalities based on race and ethnicity; and inequalities linked to sexuality in general, and homosexuality and transgendered status, in particular.

Like many other sexually transmitted infections, HIV/AIDS was first perceived as a disease of ‘outsiders’ (Gilman, 1988). In the early 1980s, for example, and among gay and other homosexually active men in Europe and Australia, it was seen as being closely linked with the United States of America (Gilman, 1988). In the eyes of some African and Asian leaders, HIV/AIDS has been viewed as a disease of the West, linked to the weakness of family structures, liberal social values and moral decline. With the passage of time, and for diverse reasons, in most countries of the world, AIDS has come to be associated with sub-Saharan Africa. Racism and Xenophobia are evident, not only with respect to the presumed ‘origins’ of HIV/AIDS, but also with respect to the stigmatisation and discrimination that have followed and still are pervasive in the wake of the epidemic. The racist assumptions of many early AIDS-related discourses were clear in startling statements about ‘African Sexuality’ that were typical during the early years of the epidemic.

These often evoked images of sex between humans and animals, or of exotic cultural practices such as the eating of raw or inadequately cooked green monkey flesh (Gilman, 1988). However xenophobia and racism have not only shaped dominant images and cultural constructions of the epidemic, they have also been reproduced within it. Thus, people with HIV/AIDS from racial and ethnic minorities are often seen not as individuals living in contexts of marginalisation and inequality, but as the causes of their own misfortune. This kind of approach can be seen in responses to HIV/AIDS all over the world. Undoubtedly, this underpins indifference to the plight of some of the most heavily affected regions.

Self-stigmatisation, or the shame that people living with HIV/AIDS experience when they internalise the negative responses and reactions of others, is also evident. Self-stigmatisation can lead to depression, withdrawal and feelings of worthlessness. It silences and saps the strengths of already-weakened individuals and communities and causes people to blame themselves for their predicament. It has connections with what some writers have called ‘felt’, as opposed to ‘enacted’, stigma, in that it affects primarily an individual’s or community’s feelings and sense of pride.

Stigmatisation is linked to power and domination throughout society as a whole. It plays a key role in producing and reproducing relations of power. Ultimately, stigma creates, and is reinforced by, social inequality. It has its origins deep within the structure of society as a whole, and in the norms and values that govern much of everyday life. It causes some groups to be devalued and ashamed, and others to feel that they are superior. For example, long-standing ideologies of gender have resulted in women being blamed for the transmission of sexually transmitted infections including HIV. This has influenced the ways in which families and communities react to the seropositivity of women. Many women are blamed for the illnesses from which they and their husbands suffer. Stigmatisation and its resulting discrimination also intensify the pain and suffering of both people living with HIV/AIDS and their families. So, if you have AIDS you die twice because the first thing that kills you is being lonely when everyone discriminates against you, (including your family members). The second one is the biological death, hence the title of the study, 'Social Death'.

Evaluating the conceptual definition of stigma

Definitions are important because they structure how we think about a phenomenon. If we compare disease stigma definitions, the first thing we notice is the lack of common ground; the definitions show wide variation (Link & Phelan, 2001) and reveal considerable polarisation between individualistic psychological explanations, 'social control' explanations in the sociological tradition and 'blaming' models of stigma. In addition, many authors do not clearly separate ideology and discriminatory practice in defining disease stigma. Herek (2002), perhaps comes closest to doing so when he distinguishes between stigma, prejudice (an individual's negative attitude towards a social group, which can only be termed stigma when it matches the negative evaluations of society towards the attributes held by that group), and discrimination (behaviour or actions that are differentiated according to membership of a specific group, which only becomes a manifestation of stigma when society defends or encourages it).

As stated earlier, the modern understanding of stigma owes much to Goffman (1963), who suggested that people who possess a characteristic defined as socially undesirable (HIV/AIDS in this case) acquire a ‘spoiled identity’ which then leads to social devaluation and discrimination. Following this interpretation, Herek (2002), defines HIV/AIDS stigma as an enduring attribute of an individual infected with HIV that is negatively valued by society and thus disadvantages people living with AIDS. Various authors have challenged the tendency in much psychological work to see HIV/AIDS stigma (or, indeed, any diseases stigma) in individual psychological terms (Link & Phelan, 2001, Parker & Aggleton, 2003). Alonzo and Reynolds (1995), for example, provide a more complex reading of Goffman, suggesting that stigma is not merely an attribute, but represents a language of relationships, as labelling one person as deviant reaffirms the normalcy of the person doing the labelling (Goffman 1963, citedin Alonzo & Reynolds, 1995).

In other areas of HIV/AIDS work, and in work on racism, much early work also conceptualised prejudice as a problem of individual ignorance. Campbell (2001, 2002) argues that individualistic biomedical and behavioural theories have dominated in the field of HIV/AIDS prevention research. There is the need to understand stigma as a social process which constantly changes and often resisted rather than as an individual attribute. However, in an attempt to recognise the social and political aspects of stigma, it has been defined primarily with reference to its discriminatory effects. Alonzo and Reynolds (1995), for example, define stigmatised people in terms of discrimination:

> ‘[They] are a category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanising benefit of free and unfettered social intercourse’(1995, p. 304).

Many researchers in sociology adopt the view that stigma is defined by its discriminatory results (Link& Phelan, 2001), and believe that stigma is a social process that functions to constantly reinforce existing social inequality (Parker & Aggleton, 2003), thus acting as an agent of social control. This approach avoids the problem of individualism (that is, explaining stigma solely as an individual attribute) but may fall into the domain of functionalism) if the outcome of some stigmatising processes is used to explain why all stigmatisation happens. The assumption underlying many traditional definitions of stigma and discrimination were traits of dysfunctional and ignorant individuals-‘rotten apples’- and could be ‘weeded out’ through education, leaving the rest of society intact. The systematic reproduction of stigma in large numbers of people, and the difficulty of addressing the problem through education, has challenged this assumption. Drawing from sociological theory, which often has to explain why people act against their own interests, some researchers have suggested that stigma persists, in spite of education programmes because it helps to maintain social control

(Link&Phelan, 2001, Parker & Aggleton, 2003). Parker and Aggleton suggest that stigma and discrimination should be understood as “part of the political economy of social exclusion present in the contemporary world” (2003,). HIV/AIDS stigma exacerbates social divisions by stereotyping marginalised or disempowered groups (such as poor, Africans, women and commercial sex workers) as responsible for the illness and its spread. From the foregoing discussion, it would be said that because stigma which leads to discrimination has the effect of reproducing relations of social inequality that are advantageous to the dominant class, these forms of stigmatisation are functional in the sense that they help to maintain the socio-political status quo and dysfunctional in the sense that they perpetuate the existing social inequality.

Causes of stigmatisation

The fight against HIV/AIDS is also a fight against the stigmatisation of HIV/AIDS. The HIV/AIDS related stigma is highly complex, dynamic and deeply ingrained. Data available shows that, the causes of stigma, its intensity, forms and consequences differ by the stage of the disease, the setting (household, health services, neighbourhood, places of worship, or workplace) and the individual’s identities in a particular setting overtime.

According to the InternationalCenter for Research and Women (ICRW) (2002), six themes have been found to be the root causes of HIV/AIDS related stigma:

- People are largely unaware that their attitudes and actions are stigmatising.
- Language is central to how stigma is expressed.
- Knowledge and fear interact in unexpected ways that allow stigma and discrimination to persist.
- Sex, morality, shame and blame are closely related to HIV –related stigma.
- Disclosure of positive HIV status is advocated, but acknowledged as difficult and unusual.
- Widespread care and support for people living with HIV/AIDS co-exists with stigma and discrimination.

People's attitudes and actions towards HIV/AIDS patients lead to stigmatisation:

Data suggests that people often do not recognise that a word, action, or belief is stigmatising or discriminatory towards People Living with HIV/AIDS (PLHA) and are not aware of the consequences for the individual as well as the larger community. People describe people who get HIV as promiscuous or as indulge in other immoral behaviours or deserve what they get or as people being punished by the gods for their own sins.For instance respondents in a research carried out by InternationalCenterfor Research and Women, 2002 in Ethiopia said they knew that HIV is not transmitted casually, but that they would not buy food from a vendor with HIV or would separate utensils, linens and other household items used by the PLHA from those used by other household members. For example, one respondent in Ethiopia who intended not to stigmatise PLHA talked about caring for PLHA:

> ‘‘I will not discriminate against him/her because he/she has the disease. I will console and be close to him/her…I would put his/her things, clothing and those utensils he/she uses separate. I will ask him/her what help he/she needs and buy him/her things he/she needs, but make sure that members of the family, including children, do not use things he/she uses.’’

This is a clear demonstration of discrimination but the individual seemed not to be aware of the consequences of his/her action. Stigmatisation is therefore inherent in our daily actions or inactions but we seem not to be mindful or aware that we are stigmatising people living with HIV/AIDS.

People express stigma through the languages they use towards HIV/AIDS patients

The use of words is a powerful means to stigmatise. Often, however, speakers are not aware that they are stigmatising with their words or of the damaging impact of what they are saying (ICRW, 2002).This is the case whether these are words used by individuals, the media, or educational materials.

One way that language can be stigmatising is in the use of derogatory references to those with HIV/AIDS. Discussing or naming HIV/AIDS openly, even in the abstract, is uncommon. In interviews, for example, HIV/AIDS is often referred to as ‘‘that disease we learned about.’’ Words with negative connotations to describe PLHA are part of daily conversation and used in rumours, gossip and even in the media. For example, PLHA in Tanzania are referred to as ‘‘maiti inayotembea’’ (walking corpse) and ‘‘marehemu mtarajiwa’’ (expected to die) (ICRW, 2002).

An analysis of the terms for HIV/AIDS in Tanzania and Zambia reveals that they vary depending on the history of the disease in the community and by the group (youth, men, women) using them, and that they are influenced by popular culture and HIV education messages. The Zambian terms to describe PLHA reflects the stigma associated with HIV/AIDS and can be grouped into seven main categories: individual deviant behaviour; death euphemism; physical appearance (especially frailty –metaphors of light or slight); public disclosure (no longer able to hide disease); acceptance of the existence of the disease; other diseases (related to HIV, e.g., diarrhea); and the burden of having a PLHA in the household (International Center for Research and Women, 2002). In Tanzania, terms changed with visible progression of the disease. For example, healthy-looking PLHA are called ‘‘nyambizi’’ (submarine), but PLHA exhibiting signs of AIDS are called ‘‘utakufa kilo mbili’’ (you will die weighing two kilos) (ICRW, 2002).

Knowledge and fear interact in unexpected ways that allow stigma and discrimination to persist:

Ignorance or lack of knowledge of HIV is considered to be a contributing factor to stigma and resulting discrimination. Thus, knowledge is one of the key factors the research is focusing on. Data available suggest that people maintain both correct and incorrect knowledge. However, even when people know how HIV is transmitted or prevented, fear of casual transmission persists in part because people feel compelled to adopt extraordinary risk-averse behaviour due to their fear of certain death if infected with HIV; and also because casual transmission would help explain the high prevalence of the disease. Moral judgments about sexual behaviour often associated with HIV further compound the problem of stigma and discrimination. There is a high level of correct knowledge about HIV transmission and prevention that is mixed with incorrect knowledge (ICRW, 2002).

Available information shows that while people may ‘know’ about HIV and about some means of transmission and prevention, they generally lack a greater depth of knowledge about HIV and AIDS. For example, it is not well understood that there is a difference between HIV and AIDS, how the disease progresses, what the longevity of a person with HIV/AIDS is, and that opportunistic infections in PLHA (such as tuberculosis) are treatable and curable. An HIV –positive test result is often equated with imminent death. Hence in the absence of greater depth of knowledge about HIV, the co-existence of some correct knowledge about HIV transmission and prevention and little knowledge about other aspects of HIV means that concerns about casual modes of transmission endure (ICRW, 2002).In most places, there is a genuine fear that HIV is transmitted casually despite knowing it is not. People fear getting HIV through food, linens, handshaking, and contact with dead bodies and caring for someone with HIV/AIDS. Data show that even highly knowledgeable people have genuine fears and concern about casual transmission and a belief that death is imminent once infected with HIV. Thus, even those who have a relatively accurate knowledge about HIV transmission might be prone to avoiding PLHA, isolating their belongings, or stigmatising them in other ways.

In Tanzania and Ethiopia, the persistence of concerns about casual transmission despite knowledge is linked to strong fears of death and the severity of suffering that accompanies HIV/AIDS. ‘‘When you hear the word HIV you immediately think of death’’, an urban respondent explained” (ICRW, 2002). The fear of death is so strong that people keep distance from those suspected to have HIV, even when they know that HIV is not transmitted through casual contact.

In Zambia, fear about casual transmission emanates less from a lack of information and more from people seeking explanations for how prevalent HIV/AIDS is and etiology around other diseases. There appears to be some disbelief that a disease that is so prevalent can have so few means of transmission (ICRW, 2002).

Another explanation for persistent stigma and discrimination when knowledge of transmission and prevention is moderately high might be that people hold strong attitudes and moral judgments about sexuality (ICRW, 2002).

Sex, morality, shame, and blame are closely related to HIV-related stigma

In most communities in Africa, much of the stigmatising language and description of stigmatising and discriminatory behaviour centers on the sexual transmission of HIV (ICRW, 2002). Many people think those with HIV get it through their own bad behaviour, namely sexual activity that is not socially sanctioned or goes against religious teachings. Behaviours like pre-marital sex, extra-marital sex and multiple partners are described as immoral and leading to HIV. Those who get HIV are said to be ‘‘promiscuous,’ ‘careless,’ or ‘unable to control themselves’ and have brought HIV upon themselves and they are blamed for bringing it into their community. In Ethiopia the belief that HIV is a punishment from god for sins committed is particularly strong (ICRW, 2002).

Several groups are singled out as spreading HIV. In Tanzania and Ethiopia, people believe that the young are getting HIV because their sexual behaviour is irresponsible, they do not listen to their elders, and they do not uphold traditions. In Tanzania, there is special concern about young girls who are seen as increasingly sexually active and vulnerable to infection from older partners. In Zambia and Ethiopia, merchants, truck drivers and other people whose work include travelling are seen as high-risk groups that are promiscuous and spread the disease from place to place.Sex workers and bar ladies are seen in Ethiopia to be at high risk, but are regarded sympathetically as people believe they are involved in this work because of poverty and lack of other available work. In Zambia, however, sex workers are more likely to be stigmatised (ICRW, 2002).

The concept of shame is another integral component of HIV-related stigma. This shaming extends to close family members, other relatives and children of PLHA.Fear of secondary stigma (stigma attached to those associated with PLHA) is frequently expressed in Tanzania, while stigma experienced by children of PLHA is discussed in Zambia (International Center for Research and Women, 2002).

Disclosure of positive HIV status is advocated, but acknowledged as difficult and unusual

According to the research carried out by the InternationalCenter for Research and Women in Ethiopia and Tanzania in 2002, it is found that people fear disclosing their HIV-positive status because of how they would be treated and viewed by others. People feel that family and community need to be more open and supportive to make disclosure easier. More than 80 percent of those surveyed in Ethiopia think that PLHA should disclose their status to the community, but very few apparently do so. Respondents state that people rarely find out about someone’s HIV-positive status through a PLHA’s own disclosure and usually infer status through change in behaviour, symptoms, or loss of weight. In view of the stigma and discrimination associated with HIV, few people disclose their status to their trusted persons and not necessarily relatives or family members.

Widespread care and support for PLHA co-exists with stigma and discrimination

A study undertaken at the Central Regional Hospital and the State Insurance Company in Cape Coast in 2004 on the topic; 'The Perceptions of Insurance Companies on HIV/AIDS Patients'(Koka,2004), showed that families care compassionately for their own family members living with HIV/AIDS. Care from those outside of families, friends, neighbours or the community at large- is not expected. Although loving care and support is given, it can be accompanied by stigmatising and discriminatory attitudes and behaviours from caregivers (like blaming and scolding), even though they may not recognise it as such.

In a survey undertaken by International Center for Research andWomen in Ethiopia and Zambia in 2002, over 70 percent of the respondents in Ethiopia said that PLHA are at fault, deserve what they got ,or should feel guilty; yet at the same time they feel that PLHA deserve sympathy or support. In Zambia, stigma is reported as being most intense in the home and the clinic, where the most intensive care takes place.Neighbours and the community stigmatise through voyeurism, where visitors come to 'see' how the patient is progressing (or the body of the deceased) and then feed this information into gossip and rumours.

Some of this stigmatising behaviour is caused by limited resources and fatigue. Although caregivers in the family and community provide care, they often regard PLHA as a burden. The feeling of burden is fueled by the knowledge that there is no cure and the belief that those with HIV/AIDS will soon die.

In sum, it can be said that an overarching theme which emerges from the literature on the causes of stigma is that, people who believe it is important not to stigmatise PLHA in fact do. Individuals maintain correct and incorrect knowledge about transmission of HIV simultaneously, but even those who know that HIV is not transmitted through casual contact continue to have doubts and behave as if it is transmitted through casual contact. The literature suggests that people express both sympathetic and stigmatising attitudes about PLHA.It also shows that families provide genuine care and compassion for PLHA and concurrently stigmatise and discriminate against them. People are also ambivalent about disclosure, which is described as positive and necessary but also uncommon and difficult due to stigmatisation and discrimination. These contradictions are an indication of the elusive and pervasive nature of stigmatisation and its effects on the society.

Effects of stigmatisation on HIV/AIDS patients

The consequences of HIV/AIDS related stigma and discrimination are serious and wide ranging. Stigma and discrimination affect individual behaviour, employment and delivery of services and treatment and prevention strategies. The effect of stigma on the HIV/AIDS patient can be experienced in two distinct ways, ‘felt’ and ‘enacted’.

‘Felt’ stigma is the effect on individual feelings such as shame, guilt, withdrawal, and self-stigmatisation. ‘Enacted’ stigma relates to experiences HIV/AIDS patients go through in the society. Individuals can be denied access to information, health services, company and the support they need. They can also face loss of job, compulsory testing, even violence and quarantine.

All over the world, the shame and stigma associated with the epidemic have silenced open discussion, both of its causes and of appropriate responses (UNAIDS, 2000). This has caused those infected with HIV and affected by the disease to feel guilty and ashamed. The effect again is that the HIV/AIDS patients are unable to express their views with the fear that they would not be taken seriously. The stigma and discrimination associated with HIV/AIDS have many other effects. They have powerful psychological consequences for how people with HIV/AIDS come to see themselves. This leads in some cases to depression, lack of self-worth and despair. They also undermine prevention by making people afraid to find out whether or not they are infected and seek treatment, for fear of the reactions of others(UNAIDS, 2000). In effect, they cause those at risk of infection and some of those affected to continue practicing unsafe sex in the belief that behaving differently would raise suspicion about their HIV-positive status.

In countries all over the world, there are well-documented cases of people with HIV/AIDS being stigmatised, discriminated against and denied access to services on the grounds of their serostatus (UNAIDS, 2000). At work, in education, in health care and in the community, people may lack the education to understand that HIV/AIDS cannot be transmitted through everyday contact. Moreover, they may not know that infection can be avoided by the adoption of relatively simple precautions. This lack of awareness can lead people to stigmatise and discriminate against those infected, or presumed to be infected with HIV/AIDS.

The effects of HIV/AIDS –related stigma and discrimination do not end with the patients. It also affects the capacity of societies to respond constructively to the devastation caused by the epidemic (UNAIDS, 2000). Despite the catastrophe, silence still prevails and action is slowed because of stigma and denial and ultimately, because of people's fears about being open. In 1999, for example, an estimated 860,000 children lost their teachers to AIDS in sub-Saharan Africa (UNAIDS, 2001). In Zambia, teacher deaths caused by AIDS are equivalent to about half the total number of new teachers the country manages to train annually (UNAIDS, 2001). A similar situation prevails among many other groups of government workers. The cause of these deaths among workers is partly due to the widespread stigma and discrimination.

The effects of HIV/AIDS on self-esteem

Stigma is not a singular concept expressed and experienced in a common way. Rather, it is a complex phenomenon expressed both subtly and overtly. Moreover, it is subjectively experienced in multiple ways that are partially dependent upon the nature of the stigmatising condition and the social circumstances of the individual.Stigmatised persons lose social status (Cumming & Cumming, 1965), they are discounted and discredited-reduced in the minds of others from being whole and acceptable individuals to those whose identities are spoiled or tainted (Goffman, 1963).

Furthermore, due to the reactions of others as well as to the internalised self-feelings (Crocker et al., 1991), stigmatised persons' life chances and opportunities are lessened, they are set apart from others and they are considered to be inferior and to represent a danger to society, all of which lead to social rejection and social isolation (Goffman, 1963, Jones et al., 1984 &Link et al., 1989).Stigma has been demonstrated to have a negative impact on social interaction, employment opportunities, emotional well-being and self-perception (Link et al., 1997, Miles et al., 1997). In other words, stigma has a negative impact on both the individuals' self-concept and on the social responses of others.

Based on the work of Mead (1934), it is assumed that the self arises through the process of interaction with others as the individual becomes an object to him and takes the attitude of others toward himself. Cooley’s (1964), notion of the ‘‘looking glass self’’ which is based on an individual’s perception of how others evaluate him/her, is consistent with HIV/AIDS stigmatisation. The concept of self then becomes the central point of the individual’s perceptual field and it provides the frame of reference from which all other perceptions acquire their meaning (Markus & Wurf, 1987). It is from these uniquely organised, socially acquired perceptions, which are integrated to form the self, that behaviour is generated in response to interaction. Therefore, life becomes organised around a stigma as the stigma becomes the focal of self-perception (Jones et al., 1984).

Furthermore, because persons who are stigmatised are likely to receive negative effective responses from others, they are also apt to construct a negative self –concept and engage in self-deprecation and withdrawal from social interaction (Crandall & Coleman, 1992).

The specific nature of the stigma associated with a serious illness as HIV/AIDS may be dependent on whether the individual can be blamed or held responsible for its occurrence, whether the illness has potentially serious consequences for others, whether there are outward manifestations of the illness and/or whether it results in a decreased level of competence (Jones et al., 1984, Conrad, 1986: Weitz, 1991). Once a stigma becomes evident to others, persons become labelled as outsiders and expectations and assumptions are associated with the individual from which patterns of response from others emerge during interaction (Berker, 1963). As the individual internalises this label, it becomes a part of his/her identity and thereby a part of the self that generates behaviour (Scheff, 1966; Link et al., 1989; Wright, Gronfein, & Owens, 1998). This acceptance of a negative designation, and subsequently a ‘‘spoiled identity’’ often results in self-deprecation and shame, as well as withdrawal behaviour (Link et al., 1987).

Individuals with HIV/AIDS are likely to accept and internalise the spread stereotypes associated with their illness through the process of socialisation prior to contracting it themselves. When they later develop the illness it takes on new meaning that put them at particular risk for low self-esteem (Rosenberg, 1979; Jones et al., 1984; Link, 1982). According to Goffman (1963), when individuals become stigmatised later in life they have been socialised regarding what it means to be normal and what it means to be stigmatised long before seeing themselves as deficient. Hence individuals diagnosed as having HIV/AIDS may condemn themselves because they see their illness as just punishment for behaviour labelled immoral (Weitz, 1989; Kayal, 1992).

Moreover, a stigmatised identity presents a greater threat to one’s self-concept if it is a central identity within the self –network. This is consistent with the hierarchical conceptualisation of self-concept (Epstein, 1973; Crocker & Major, 1989). This perspective is further supported by the work of Markus (1977), and her notion of self-schema. Schema are cognitive generalisations about the self that are derived from specific social experiences and events; they subsequently become integral and functional dimensions within the self-network which then serves as a guide for behaviour. Further, this also confirms Stryker's identity theory (1980), based on symbolic interaction, in which the self is comprised of a set of discrete identities or definitions of the self within specific social positions. These identities are organised within a hierarchical structure that is defined by the probability of each identity being enacted across a variety of situations; this probability is designated as the salience of each identity. Given these theoretical bases and the fact that stigma is a socially constructed phenomenon, it can be contended that the designation ''HIV/AIDS patient'' is more likely to be a highly salient identity as these individuals are held accountable for their illness by society.

Theoretical framework

Introduction

The thrust of the research is to look at the reactions that people give to People Living with HIV/AIDS and from the perspective of the HIV/AIDS patients how they are stigmatised.The research will therefore make use of the following theoretical perspectives- Attribution theory and exchange theory. Two theories will be used because stigmatisation and discrimination of PLWHA are complex phenomena which emanate from a multiplicity of factors.

Attribution theory

The theory postulates how people explain or attribute others' behaviour to some perceived causes. Again it further explains/demonstrates how those who are being perceived as such also explain the behaviour of others. This theory is significant to this research because HIV patients are being perceived by other people in many ways since this disease is usually argued through ways that are given human judgment or deemed morally unchaste. However, the HIV patients also perceive or judge the behaviour of people since they are assumed to be "sick human beings". Therefore, this theory will help explain how attributions are made on HIV patients and the reactions HIV patients also give to such perceived stigmatisation.

Attribution theory and stigma in HIV/AIDS

Attribution theory is basically about the study of how we infer the causes of other people's behaviour towards others and themselves. Fritz Heider (1958), is frequently referred to as the father of attribution theory. One of Heider's (1958), most valuable contributions in social psychology which is relevant to the understanding of stigmatisation in HIV/AIDS is a simple distinction in social perception. According to Heider (1958), when trying to decide why people behave or act as they do-for example why an individual distants him/herself from an HIV/AIDS patient-we can make one of two attributions. These are internal and external attributions. Internal attribution is the inference that, a person is behaving in a certain way because of something about him or her, such as the person's attitudes, character, or personality (Heider, 1958).

Drawing from Heider's definition of internal attribution, it follows therefore that the primary cause of stigmatisation or social distance in the area of HIV/AIDS is due to an individual's background, knowledge and personal disposition about HIV/AIDS disease. This culminates in the development of negative attitudes towards such people who have HIV/AIDS.

External attribution on the other hand is the inference that a person is behaving a certain way because of something about the situation he /she is in; the assumption here is that, most people would respond the same way in that situation (Heider, 1958).

Conversely, one can therefore make an external attribution based on Heider's explanation of the concept; thus concluding that people stigmatise HIV/AIDS patients because of the perceived circumstances under which ‘‘they' got infected-such as the fact that some in immoral sexual activities, commercial sex work, intravenous drug use, sexual promiscuity etc. This explanation therefore assigns the causality of people's behaviour towards HIV/AIDS patients externally. Hence many people are of the view that HIV/AIDS patients are the cause of their own plight and so should not be treated with compassion but rather be ostracised, discriminated against and be stigmatised. Again external attribution reveals the fact that people's past actions trigger reactions from other people. This therefore explains the fact that HIV/AIDS patients perceived past life and experiences result in negative reactions from people towards them after being diagnosed of HIV/AIDS and not something distinctive about non-HIV people's personality, attitudes or character.

It is however important to note that, drawing from these two explanations of attribution, it has been realised that people's impression about attributes especially HIV/AIDS stigmatisation will be very different depending on the type of attribution one makes. For instance if one sees HIV/AIDS stigmatisation as being caused by internal attribution, people will tend to have a negative impression of those who discriminate and stigmatise HIV/AIDS patients and sympathise with the patient. On the other hand, if external attribution is made with regards to HIV/AIDS stigmatisation, people would conclude that the HIV/AIDS patients deserve what they may be going through because they cause their own problem.

Correspondent inference theory

Heider (1958), observed that internal attributions are particularly attractive to perceivers in the sense that we tend to see the causes of a person's behaviour as residing in that person. Heider's observation was the starting point for one of the basic theories of how people make attributions-correspondent inference (Jones & Davis, 1965).

Edward Jones and Keith Davis developed correspondent inference theory to describe the process by which we arrive at an internal attribution: how we infer dispositions or internal personality characteristics from corresponding behaviours or actions (Jones, 1990; Jones & Davis, 1965; Jones & McGillis, 1976). Suppose, for example, we learn that the Vice Chancellor has withdrawn students diagnosed of HIV/AIDS from the university. The questions that many people may ask (especially human right activists) are; why should the Vice Chancellor do that? Did the Vice Chancellor withdraw the students because he/she does not like them? Because he/she wants to protect other students from being infected? Because the students were spreading the disease? Because he/she is punishing them for being HIV positive? Correspondent inference theory is concerned with how we narrow down these possibilities to a specific conclusion about why the Vice Chancellor did what he/she did. The main way we make internal attributions, according to the theory, is by comparing what people could accomplish by the behaviour they chose to perform with what they could have accomplished with alternative actions (comparing the effects of the different choices, in the words of the theory). HIV/AIDS is one of the sexually transmitted disease and a terminal one for that matter. Aside this, there are other modes through which it can be transmitted in the society. Being aware of the deadly nature of the disease and its modes of transmission naturally makes people panic if they come into contact with an HIV/AIDS patient. It becomes more dangerous if many people are identified or not identified as HIV/AIDS patients in an institution, a community or a social setting.

For example to determine why the Vice Chancellor withdraws the HIV/AIDS patients, one would have to consider what the Vice Chancellor might have accomplished or prevented by withdrawing the students compared to what he could have accomplished by not withdrawing them. Following the analogy outlined based on correspondent inference theory in arriving at internal attribution, one will say that people stigmatise, discriminate and ostracise HIV/AIDS patients due to the fact that the effects by these acts against them will be far lesser than the effects produce if one gets closer to them.

According to the correspondent inference theory, two different types of expectations come into play when people make internal attributions: category-based expectancies and target-based expectancies (Jones & McGillis, 1976; Weisz & Jones, 1993).

Category-based expectancies refer to expectations about people based on groups to which they belong (Jones & McGillis, 1976; Weisz & Jones, 1993). For example, despite the fact that sexual intercourse is not the only mode of HIV transmission, people would not be surprise if a commercial sex worker or a sexually promiscuous person is infected but they would be shock and disgusted if a ‘morally upright’ person is HIV-positive. This is simply because the society expects some people in a certain category to be far from being called HIV/AIDS patients. This can also be the reason why people living with HIV/AIDS are stigmatised.

For target-based expectancies, they are ways in which some particular persons are expected to behave based on their past actions (Jones & McGillis, 1976; Weisz & Jones, 1993).If they are seen by the society as moving or behaving contrary to expectation, they are labelled, discriminated against and stigmatised. Such people are seen as ‘disappointment’ in their families or communities. This theory corroborates HIV/AIDS stigmatisation. Drawing from this proposition, it implies that some people distant themselves from some HIV/AIDS patients not because of the fear of getting infected but because the patients are seen as disgrace to their families and communities.

The co-variation model: Internal versus External Attributions.

The co variation model was propounded by Kelley (1967). The covariation model is a theory which states that in order to form an attribution about what caused a persons behaviour, we systematically note the pattern between the presence (or absence) of possible causal factors and whether or not the behaviour occurs (Kelley, 1967). Kelley (1967), took a different approach when he developed the theory of attribution. Whereas Jones and Davis (1965) focused on the information people use to make a dispositional (internal) attribution, Kelley (1967), focused on the first step in the process of social perception i.e., how people decide whether to make an internal or an external attribution.

Another difference between the two theories of correspondent inference and covariation model is that, correspondent inference theory applies to a single observation of a behaviour (e.g. a friend or family member refuses to drink from the cup used by an HIV/AIDS patient), whereas Kelley’s (1967), covariation model applies to multiple instances of behaviour, occurring across time and across different situations (Did a friend refuse to drink from the cup in the past?, Does he/she drink from the cups of other people who are not HIV/AIDS positive?, Does he/she dislike drinking from people's cup? Kelley assumes that when we are in the process of forming attributions, we gather information or data that will help us reach a judgment. The data we use according to Kelley, are how a person's behaviourcovaries across time, place different actors and different targets of the behaviour. By discovering covariation in people's behaviour (e.g. a friend refuses to drink from a cup used by an HIV/AIDS patient; he/she accepts to drink water from a cup of non- HIV/AIDS people), one will be able to reach a judgment about what caused his/her behaviour. This theory best explains the processes of attribution in relation to HIV/AIDS discrimination and stigmatisation in the sense that there should be repeated acts of discrimination and stigmatisation before one reaches a judgment.

According to Kelley (1967), when we are forming an attribution, we need to examine some information for covariation; these are consensus, distinctiveness and consistency.These will be described with an example: An employer dismissed an employee because he/she was found out to be HIV positive and so was not coming to work regularly. Without any conscious effort on some people's part, they posed an attribution question: why should the employer do that to the employee-is it something about the employer or is it something about the situation that surrounded and affected him/her? These questions could be answered by Kelley's (1967), model of covariation.

Consensus information refers to how other people behave towards the same stimulus-in this case, the employee: Do other employers also dismiss workers who are HIV patients? Distinctiveness information refers to how the actor (the employer whose behaviour I am trying to explain) responds to other stimuli. Does the employer dismiss other people who have terminal diseases as HIV/AIDS? Consistency information refers to the frequency with which the observed behaviour between the same actor and the same stimulus occurs across time and circumstances. Do the employer and other employers dismiss workers who are HIV positive regularly and frequently?

According to Kelley’s theory, when these three sources of information combine into one of two distinct patterns, a clear attribution can be made. People are most likely to make an internal attribution (deciding the behaviour was due to something about the employer(s) when the consensus and distinctiveness of the act are low but its consistency is high. One would be confident to say that the employer is wicked by dismissing his/her employee because he/she is HIV positive if we knew that no employer does what he/she did.People are likely to make an external attribution (in this case about the HIV positive employee) if consensus, distinctiveness and consistency are all high. This is the stage where discrimination and stigmatisation of people living with HIV/AIDS become very high. People or employers would now overlook their personal dispositions and rather focus on the social and economic benefits of dismissing such people or distancing themselves from HIV/AIDS patients.

Appraisal of attribution theory

Drawing from the propositions of Heider, Jones, Davis and Kelley, it has been observed that both correspondent inference theory and covariation model assume that people make causal attributions in a rational, logical fashion. People observe the clues, such as the distinctiveness of the act, and then draw a logical inference about why the person did what he/she did. Several studies have confirmed that people often do make attributions the way that Jones, Davis's (1965) and Kelley's (1967) models say they should (Fosterling, 1989;Gilbert, 1998; Hazelwood & Olson, 1986; Hewstone &Jaspers, 1987; Major, 1980; Ruble & Feldman, 1976; Zuckerman, 1978)-with one exception.

Research studies, do not use consensus information as much as Kelley's theory predicted; they rely more on consistency and distinctiveness information when forming attributions (McArthur, 1972; Wright, Luus & Christie, 1990). This contention holds for HIV/AIDS stigmatisation and discrimination. Individuals discriminate and stigmatise people living with HIV/AIDS against the will of some other individuals. There is no consensus information in discrimination and stigmatisation of people with HIV/AIDS.

However, there is discrimination and stigmatisation of people with HIV/AIDS when the act is distinctive (targeting HIV/AIDS patients) and consistent (discriminating against HIV/AIDS patients regularly).

Again, the argument that people make causal attributions in a rational, logical fashion does hold in some situations especially with terminal diseases as HIV/AIDS. However, people sometimes are not that accurate or rational when forming judgments about others with infectious and life threatening diseases as HIV/AIDS. At times people become ignorant of information about HIV/AIDS and its modes of transmission. They therefore either act ignorantly or distort information to satisfy their need for high self-esteem leading to the devaluation of the self-esteem of others who are HIV/AIDS patients.

Exchange theory

Stigmatisation is social-psychological behaviour. This behaviour takes place between two or more actors. The interaction between the actors has to do with cost and rewards. People distant themselves or stigmatise HIV/AIDS patients based on the perceived costs they would incurred if they get close or have compassion for them over the perceived rewards they would derive. Exchange theory is therefore relevant for the study of stigmatisation in HIV/AIDS because it would contribute significantly to the understanding of the reasons why people distant themselves from certain people perceived as bringing cost rather than rewards in social interaction.

Exchange theory and stigmatisation in HIV/AIDS

The most important spokesperson for exchange theory is George Homans.He sought to explain social behaviour in terms of psychological principles-that is, behaviourism.Homans believed that psychological principles can be used to explain not only individual behaviour but also social structures and social change.

The heart of Homan's theory lies in the following basic propositions: the success proposition, the stimulus proposition, the value proposition, the deprivation-satiation proposition, the aggression-approval propositions, and the rationality proposition.

The aggression-approval proposition will be relevant in understanding the cost or reward of engaging in social distance in HIV/AIDS. This proposition shall therefore be adopted to analyse whether HIV/AIDS patients will engage in aggressive behaviour by spreading the disease if social distance and stigmatisation increase.

The aggression-approval propositions

Proposition A

> When a person's action does not receive the reward he/she expected, or receives punishment he/she did not expect, he/she will be angry; he/she becomes more likely to perform aggressive behaviour and the results of such behaviour becomes more valuable to him/her (Homans, 1974:37).

Putting this proposition in the context of HIV/AIDS stigmatisation, it implies that an HIV/AIDS patient who does not receive the compassion he/she expects from people but stigmatised can be angry and frustrated. Such patients may engage in aggressive behaviour by intentionally spreading the HIV. The result of such an act may become more valuable to the stigmatised HIV/AIDS patients.

Proposition B

> When a person's action receives the reward he/she expected, especially a greater reward than he/she expected, or does not receive punishment he/she expected, he/she will be pleased; he/she becomes more likely to perform approving behaviour and the results of such behaviour become more valuable to him/her (Homans, 1974:39).

For instance, if an HIV/AIDS patient is treated with compassion by his/her friends, family members and the community, he/she may become pleased and comfortable among people. He/she may be very careful with the people so that he/she may not infect other people. This therefore will be more valuable to the HIV/AIDS patients and showing compassion becomes more valuable to the people too.

Appraisal of exchange theory

Ekeh (1974) criticised Homans for ignoring the norms and values that symbolically shape exchange relations. I agree with Ekeh's criticism because in every society there are values and norms that guide the interactions of people. The cultural elements and symbols also influence the exchange relations of a particular society, be it social or economic exchange.

In the case of HIV/AIDS stigmatisation, the beliefs, norms and values that a particular society holds on to may also influence the degree of social distance in HIV/AIDS. Again, the extent to which people have been socialised to react to negative actions like discrimination, stigmatisation and labelling would show whether the aggrieved would engage in aggressive behaviour by way of revenge.

However, since Homan’s propositions have more relevance in social psychology than in sociology, it can be that even if people are socialised to hold on to values which discourage aggressive behaviour or revenge, there may still be some people who would derive their reward from such aggressive behaviour. Much as people engage in deviant behaviour by stigmatising and discriminating against people living with HIV/AIDS, so will some HIV/AIDS patients also engage in deviant behaviour by infecting people with HIV even if there are well specified values, norms and beliefs. This argument therefore holds for people who are stigmatised and discriminated against because they are HIV/AIDS patients. The understanding of exchange theory in relation to stigmatisation will contribute to the existing knowledge on social interaction and exchange.

Evaluation of theories with reference to the research

The theories of attribution and exchange as discussed above have much relevance to stigmatisation in HIV/AIDS. They threw light on the reasons or causes of stigmatisation and the actions and reactions of those who stigmatise and the ‘stigmatised’.

Attribution theory addresses how inferences are made by people about a particular group of people whiles exchange theory explains the cost and rewards people anticipate in social interaction.

Drawing from the two theories, it has been observed that they use rationality as the baseline in their propositions. Attribution theory assumes that people make causal attributions in a rational, logical fashion. Exchange theory also postulates that people make rational decisions by weighing the costs and rewards of their interaction, both social and economical. Based on the review of these, I agree to a large extent that people make rational decisions in their interaction with others. However, as Ekeh (1974), argued, there are norms and values that influence exchange relations. These norms and values differ from society to society. Hence rationality may not hold in some circumstances in exchange relations and attributions with regards to HIV/AIDS stigmatisation. Again since HIV/AIDS is a life-threatening disease, people may make irrational attributions and social exchanges based on ignorance and the norms and values that prevail in such societies. That is why it is difficult to measure and give accurate assessment of HIV/AIDS stigmatisation because of the differences in norms, values and even the information about the disease from society to society. It should however be noted that these two theories of attribution and exchange are guiding principles in the understanding of stigmatisation in HIV/AIDS and the reactions of the “stigmatised”

CHAPTER THREE

METHODOLOGY

Introduction

This chapter discusses the research methodology including the study area, research design, sampling procedure, methods of data collection, problems encountered and data analysis.

Study Area

Central region has an estimated population of 1.6 million and growth rate of about 2.1% per annum. The region is made up of 12 districts covering a coastal part and an interior forest zone. A larger proportion of the populations are fishermen and crop farmers. From an estimated figure of 205 identified HIV/AIDS cases in 1996, the number of reported cases in the region rose to 3290 in 2001 resulting in an infection rate of 2.7% of population. (Annual performance review report 2001, progress of work March 2002, Central Region Health Administration). The CentralRegionalHospital was chosen to gather data from HIV/AIDS patients because it is the only hospital in the region with a special clinic (fevers clinic) for HIV/AIDS.

Patients come to the clinic every two weeks for checkup and counselling. In this light getting access to them for data collection was easy, costless and less burdensome, hence the selection for the study.

Research design

The study was basically a descriptive research. A descriptive study was chosen because it is designed to gain more information about characteristics within a particular field of study with the purpose of providing a picture of situations as they naturally occur (Burn & Grove, 1995). The research problem as stated in this work does not lend itself to an experimental or quasi-experimental design. This is because human characteristics and behaviours are inherently not subjected to experimental manipulation; it will also not be ethical to manipulate the respondents' knowledge (Pilot & Hungler, 1995). Data on knowledge of HIV/AIDS, misconceptions, reactions from caretakers, friends, people as well as HIV patients and mode of healthcare delivery by health workers to people living with HIV was collected. The study made use of primary date from the field and secondary data from books, journals, published and unpublished literature and internet sources. Case studies were also used in order to get a vivid picture of how people living with HIV/AIDS are stigmatised and discriminated against.

According to Kumekpor (2002), a case study aims at enabling the investigator to grasp and understand an individual, a group a community, a social group situation or an issue in order to take decisions that take into consideration the special and peculiar circumstances surrounding the case investigated, or practical solutions relating to the case in question. It is a method of careful and critical inquiry or investigation and examination seeking the facts of a case, a problem, an issue, a community and following events or occurrences from the beginning through to the end. This method of data collection was relevant to the study because the individuality or peculiarity of factors and circumstances surrounding each case is paramount to the understanding of how people stigmatise and the effect it has on the individual in particular and society in general. It istherefore pertinent to describe each of the cases collected for the purposes of the uniqueness and peculiarity of how some people got infected with AIDS, how they were stigmatised and the effect it has on their health and psychological disposition.

A total of five (5) HIV and AIDS patients voluntarily accepted to be recorded on tape. There were narrations on how each of them contracted the disease, where and whom they got it from and how they were stigmatised and its effect on their health and lives. Such life histories as discussed in chapter six of this thesis give a vivid picture of how people living with HIV and AIDS were stigmatised.

Sampling Procedure

Two non-probability sampling techniques were employed.

First, purposive sampling technique was employed to gather information from caretakers and the nurses in charge of HIV and AIDS patients. Purposive sampling means selecting units of analysis that have vital information with the population (Kumekpor, 2002). Thirty (30) caretakers (relatives, friends, loved ones) were identified through the HIV and AIDS patients who came to the hospital for treatment.

Purposive sampling was also used to gather information from nurses who attend to HIVand AIDS patients in the Central Regional Hospital. The nurses who attend to HIV and AIDS patients at fevers clinic in the Central Regional Hospital were ten (10).

Through the senior nurse in charge of the fevers clinic, questionnaires were given to the nurses to fill at their convenience and returned them at a later date. The second non probability technique employed was convenient or accidental sampling technique. In this case the researcher places himself in a strategic place (fevers clinic) where he can easily have access to the units of analysis (HIV and AIDS patients) in this study.

The OPD of the fevers clinic at the CentralRegionalHospital, CapeCoast was used as the strategic place and as the HIV and AIDS patients came for care and treatment, they were interviewed. This technique was appropriate because of its convenience to the researcher and the respondents (HIV and AIDS patients).

The convenient sampling technique was also used to gather data from visitors or people who came to the hospital. These people were categorised as those who are assumed to be non-HIV positive persons and also non caretakers, relatives or friends of HIV and AIDS patients. The sample size for the study was 120.The breakdown is shown in the Table 4 below:

Table 4: Sample size for the study

Sample unit	Number
Nurses who attend to HIV/AIDS patients	10
HIV/AIDS patients	30
Caretakers	30
Non HIV visitors to the hospital	50
Total	120

Source: Fieldwork, 2008.

The thirty (30) HIV/AIDS patients were chosen because at the time of research, they were willing to be interviewed. Therefore their corresponding care takers were also interviewed. The ten (10) health workers at the fevers clinic at the Central Regional Hospital were purposively selected for data collection since they could provide the information needed. Since the population of visitors to the hospital could not be defined, a convenient sample of fifty (50) was taken.

Methods of Data Collection

Primary data was collected using the following data collection techniques: in-depth interview and questionnaire surveys as described below;

In-depth Interview

In-depth interview is a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, programme, or situation (Kumekpor, 2002). In-depth interviews are useful when you want detailed information about a person's thoughts and behaviours or want to explore new issues in depth. It is an effective qualitative method for getting people to talk about their personal feelings, opinions, and experiences (Kumekpor, 2002). It was used in this study to solicit information from People Living with HIV and AIDS and their caretakers on their knowledge, actions, and reactions and how they were stigmatised and how they stigmatised People Living with HIV and AIDS.

Locating patients was a further consideration since it was not easy identifying and approaching individuals for interview. Through consultations with the regional AIDS counsellors and medical officers of the hospital it became clear that some patients were willing to discuss their conditions with other people, provided confidentiality could be assured. Thus, appointments for interviews were made through the counsellors and those who accepted the request to be interviewed were interviewed when they came to the hospital. Since AIDS is a disease whose sufferers have been stigmatised and blamed for the outbreak and spread of the disease (Sabatier, 1988; Safo, 1993), patients who agreed to be interviewed could be considered as those motivated enough to share their experiences with others.

People Living with HIV and AIDS who came for treatment and medication at the hospital and accepted to be interviewed were invited for the interview about how they were being treated by their significant and generalised others who were aware of their HIV positive status. Some of the issues discussed with the patients bordered on demography of HIV/AIDS respondents, how they got to know of their HIV status, how they were treated by people and how the treatment affected their state of health and psychological disposition. Because the literacy level of the respondents was low, the interview was conducted in the local language and the responses recorded in English.

The caretakers were interviewed after each HIV/AIDS patient had been interviewed. The in-depth interview was conducted on the caretakers to solicit information on their demography, first reaction when they got to know of the HIV status of their relatives, how they catered for them and how their care affected the patients. However, some patients came to the hospital alone, so such patients had to be followed to their homes for their caretakers to be interviewed. Such instances were however few. This interview process for both patients and caretakers was carried out for four weeks until a total sample of sixty (30 patients and 30 caretakers) was met.

Questionnaire Survey

A survey implies a careful scrutiny or investigation of a demarcated geographical area in order to have a comprehensive view of the nature, conditions and composition of the social groups, institutions or premises within such a defined area (Kumekpor, 2002). A questionnaire is a form or document containing a number of questions on a particular theme, problem, issue or opinion to be investigated. The questions are intended to be answered by a particular or a specified group or individual, deemed to have, or to be knowledgeable about or concerned with the answers to questions in the questionnaire (Kumekpor, 2002). Since the study was limited to the Central Regional Hospital, questionnaire survey was convenient for the collection of data.

Questionnaire survey was administered to the non-HIV positive people who visited relatives and friends at the hospital. Such people were identified by going to other wards apart from the fevers clinic. Self –administered questionnaires were given to those who could read and write whiles personal interviews were given to those who could not read and write. The questionnaire consisted of both open and closed-ended questions. The open-ended questions solicited the respondents own views on the subjects whiles the closed-ended questions gave respondents options to choose from.

The nurses who take care of the HIV/AIDS patients at the fevers clinic were also given questionnaires to complete at their own convenience and returned later. All ten answered questionnaires were retrieved.

The objective of the questionnaire was to gather data about the mode of care and treatment given to HIV/AIDS patients to determine whether it could lead to stigmatisation. The rationale for the self-administered questionnaire was that, the literacy level of the nurses was high. Again due to their busy schedule at work this method gave them ample time to think through the questions before answering them.

Problems encountered

Problems were encountered with regards to anonymity. Almost all the patients did not want to take part because they thought their identities would be disclosed. They had to be convinced that their names would not be requested. This was done with the help of the nurses. Despite this shortcoming, an average of 30 minutes was spent on each interviewee.

Data Analysis

The data collected were edited coded and analysed for common themes. All the data excluding the case studies were generated and analysed using the Statistical Product for Service Solution (SPSS) computer software package (Version 16.0 for Microsoft windows). Some qualitative responses were presented and analysed whiles the few quantitative findings were presented in frequency tables and cross tabulations.

CHAPTER FOUR

DEMOGRAPHIC AND SOCIO-ECONOMIC PROFILE OF RESPONDENTS

Introduction

This chapter presents the demographic and socio-economic profile of the respondents. This analysis looks at the sex, age, marital status, educational level and occupation of respondents which in the study include People Living with HIV/AIDS, Caretakers, non-HIV Persons and health workers. These demographic variables will among others provide an insight of the coping mechanisms adopted by the HIV/AIDS patients in the face of stigmatisation.

Sex and Age of HIV/AIDS patients

The data gathered clearly show that more women than men were infected with HIV/AIDS. Out of the thirty (30) HIV/AIDS patients interviewed, 20 representing 66.7 percent were females whiles 10 representing 33.3 percent were males.

This finding therefore corroborates the literature review where Anarfi (1992) and Safo (1993) found that more females than males were infected with HIV/AIDS.

Table 5: Age of PLWHA by Sex

	Sex		
Age	Male	Female	Total
20 – 29	0	33	
30 – 393	1114		
40 – 497310			
50+ 0	3	3	
Total10	20	30	

Source: Fieldwork, 2008

Table 6: Descriptive Statistics

N	30	
Mean	0.6667 * 30	20.001
Median	1.0000 * 30	30
Standard deviation	0.47946	

Source: Fieldwork, 2008

Table5 shows the sex of the PLWHA and their age group. The Table shows that the majority of females belong to ages 30 to 39.On the other hand the total sample of males (10) fall within two age categories of 30 to 39 and 40 to 49.Therefore one can say that the average age of males falls within ages

30to 49. This is further explained by Table 6 which shows the descriptive statistical distribution of the sample. The mean distribution of the sample from Table 6 shows the mean age for both sexes to be 20.001.This implies the average age of both sexes falls within age 20. Table 5 which indicates the age and sex distributions of HIV/AIDS patients further confirmed that the average ages of the respondents fall within the active groups as it shown by 20-29 age category for females and between 30-to 39 and 40-49 for males. This active age categories further explains that bothsexes are or likely to be infected with HIV.

Sex of caretakers of HIV/AIDS patients

Sixteen (16) out of the 30 caretakers interviewed, representing 53.3 percent, were females whiles the remaining 14 representing 46.7 percent were males. This shows that more females than males take care of HIV/AIDS patients.

Cross-tabulation of Sex of Caretakers and Sex of AIDS patients

Table 7 on the next page (page 85) looks at the sex of the caretakers against the sex of HIV/AIDS patients.

Table 7:Sex of caretakers against sex of patients taken care of

		sex of HIV/AIDS patients		
		Male	Female	Total
Sexof caretakers	Male	4	10	14
	Female	6	10	16
Total		10	20	30

Source: Fieldwork, 2008

Given a sample of 14 respondents for both males and females made up of the sex of HIV/AIDS patients and sex of caretakers,' majority of females were caretakers. This is shown by 10 female caretakers and 4 male caretakers. Again given a sample of 16 respondents it is also shown that the majority of caretakerswere females as shown by 10 females and 6 males. On the other hand, out of a total of 10 respondents representing both sex of HIV/AIDS patients and sex of caretakers', majority of the female respondents were HIV/AIDS patients. This is shown by 6 female HIV/AIDS patients and 4 male HIV/AIDS patients. The result implies that more females than males were infected with HIV/AIDS and further implies that more females than males were caretakers.

Sex of Non HIV/AIDS people

The sex distribution of the non-HIV/AIDS people shows that out of 50 respondents, 27 representing 54.0 percent were males whiles 23 representing 46.0 percent were females.

Frequency Distribution of age of caretakers

Table 8 below shows the age distribution of caretakers of AIDS patients.

Table 8: Age distribution of caretakers

Age	Frequency	Percentage
20 – 293	10.0	
30 – 391343.3		
40 – 49620.0		
50 +	826.7	
Total	30 100.0	

Source: Fieldwork, 2008

From Table 8, Most of the caretakers of HIV/AIDS patients fell within 30-39age groups. This is shown (Table 8) as thirteen (13) of the caretakers, representing 43.3 percent fell within the age groups 30to 39. This finding shows that more younger people than older ones take care of their sick relatives, family members and friends.

Table 9: Age category of non-HIV People

Age	Frequency	Percentage
Less than 2014	28.0	
20 – 24 24	48.0	
25 – 29	9	18.0
30 and above	3	6.0
Total	50 100.0	

Source: Fieldwork, 2008

From table 9, about 94% of non-HIV/AIDS respondents were aged below 30 years with the majority (48%) of them aged between 20 and 24 years (Table 9).

Table 10: Educational Background of HIV/AIDS patients

Level of education	Frequency	Percentage
No education	6	20.0
Primary education	5	16.7
JHS/MSLC	12	40.0
SHS	2	6.7
Vocational/Technical	2	6.7
Tertiary education	3	10.0
Total	30	100.0

Source: Fieldwork, 2008

From Table 10, the educational levels of the HIV/AIDS patients show that their literacy level was relatively low. Twelve (12) out of the 30 patients ended their education at the then Middle School and now Junior High School. This represents 40 percent of the patients. Six (6) out of the 30 respondents representing 20.0 percent had no education at all whiles 5 patients representing 16.7 percent ended at the primary school. These figures show that a cumulative percent of 76.7 of the HIV/AIDS patients interviewed ended their education at the basic level.

Table 11: Educational level of caretakers

Level of education	Frequency	Percentage
No education	2	6.7
Primary education	2	6.7
JHS/MSLC	10	33.3
SHS	7	23.3
Vocational/Technical	4	13.3
Pre-tertiary	1	3.3
Tertiary education	4	13.3
Total	30	100.0

Source: Fieldwork, 2008

Caretakers’ educational level was also low. Comparatively however, caretakers were more educated than the HIV/AIDS patients, whiles about 76.7% of HIV/AIDS patients were educated only up to the basic level, and about 53.3% of their caretakers were educated beyond the basic level.

Table 12: Educational level of non-HIV People

Educational level	Frequency	Percentage
No education	1	2.0
Senior high school	5	10.0
Tertiary	44	88.0
Total	50	100.0

Source: Fieldwork, 2008

` The same fact that the majority of the respondents were students accounts for the high level of literacy rate among them, as illustrated in Table 12. Out of the 50 respondents, 44 representing 88 percent were at the tertiary level of education.

Table 13: Occupation of HIV/AIDS respondents

Occupation	Frequency	Percentage
Unemployed	4 13.3	
Trader	11	36.7
Artisan	12	40.0
White color jobs	3	10.0
Total	30	100.0

Source: Fieldwork, 2008.

The data on the occupation of the respondents reveals that the low literacy level of the patients influenced the type of occupation they engaged in. The Majority of them were traders and artisans while very few engaged in white colour jobs. It is important to note that, almost all the interviewees were no longer engaged in their occupations as effective and efficient as they used to do due to their state of health.

Table 14: Occupation of caretakers

Occupation	Frequency	Percentage
Learning a trade	1	3.3
Trader	8	26.7
Artisan	14	46.7
White color jobs 7 23.3		
Total	30	100.0

Source: Fieldwork, 2008

Data gathered shows that the caretakers could take care of their HIV/AIDS patients relatively because over 70% of them were self employed and therefore could vary their working hours appropriately. Also over 90% of the caretakers were engaged in economic ventures that enabled them to earn some income which is very vital in caring for the patients.

Table 15: Occupation of non-HIV people

Occupation	Frequency	Percentage
Trader	1	2.0
White color jobs	5	10.0
Other	2	4.0
Student	42	84.0
Total	50	100.0

Source: Fieldwork, 2008.

From the data gathered on the occupation of non-HIV/AIDS people, Table15 shows that a significant number of the respondents were students. Out of 50 respondents, 42 representing 84.0 percent were students, 5 representing 10.0 percent engaged in white colour jobs, 2 representing 4 percent engaged in other jobs and 1 was a trader. It is important to note that the data was gathered at the time that all schools including the tertiary institutions in the region were in session. Most of the students visit the hospital for one reason or another.

This fact accounts for the low age range of 18 to 28 of the respondents in this category.

Table 16: Marital status of the HIV/AIDS patients

Marital status	Frequency	Percentage
Single	1	3.3
Married	19	63.3
Separated	3	10.0
Divorced	5	16.7
Other	2	6.7
Total	30	100.0

Source: Fieldwork, 2008.

Most of the HIV/AIDS patients were married, as illustrated in Table 16, Nineteen (19) out of the 30 respondents were married. This represents 63.3 percent of the sample size .It is worth noting that most of the female married AIDS patients belonged to polygynous families and also had histories of travelling to neighbouring countries before settling home with their spouses. Again, most of the female married AIDS patients had earlier on divorced and remarried hence they found it difficult to trace the source of their infection. Ten percent of the patients were separated and 16.7 percent divorcees. Almost all of the separated and the divorcees were abandoned by their spouses after they had been diagnosed of being HIV positive. Some of the women were abandoned by their husbands' whiles most of the women however resolved to cater for their sick husbands despite their condition. This finding therefore brings to the fore the issue of gender discrimination and stigmatisation in HIV/AIDS cases.

Table 17: Relation of caretakers to HIV/AIDS patient

Caretakers	Frequency	Percentage
Father	2	6.7
Mother	4	13.3
Wife	5	16.7
Husband	7	23.3
Sibling	5	16.7
Friend	4	13.3
Other	3	10.0
Total	30	100.0

Source: Fieldwork, 2008.

The data on the relationship of the caretakers to the HIV/AIDS patients show that 7 of the caretakers representing 23.3 percent of the total sample size of 30 said the HIV/AIDS patients were their husbands. However, 5 caretakers representing 16.7 percent also said their patients were their wives.Again, 5(16.7%) caretakers also said their patients were their siblings whiles 4 (13.3%), and another 4 (13.3%) caretakers said their patients were their mothers and friends respectively.The data reveals that women are more likely to care for their spouse than men.

Table: 18: Length of period of work at the department (Health workers)

Length of work at department	Frequency	Percentage
1 year	2	20.0
1.5 months	3	30.0
3 years	3	30.0
6 months	2	20.0
Total	10	100.0

Source: Fieldwork, 2008.

The number of year of service showsthat 80% of health workers have been working at the fevers clinic of the Central Regional Hospital between a year and three (3) years. This suggests that the nurses were familiar with the HIV/AIDS patients and so might know their health needs. This has positive effects on health and service delivery of the workers to the HIV/AIDS patients. The number of years the nurses spend at the hospital may also influence the rate of discrimination and stigmatisation with regards to health delivery to patients' case

CHAPTER FIVE

HIV/AIDS STIGMATISATION AND DISCRIMINATION

Introduction

This chapter continues with the analysis of data gathered from the field. Factors such as knowledge, misconception, and mode of health care delivery to HIV/AIDS patients and reactions of people towards HIV/AIDS patients will be discussed. Analysis will be made on how the above factors affect HIV/AIDS patients' state of health. This analysis will be done in relation to the research questions, objectives as well as the literature reviewed in this thesis.

Knowledge and misconception of HIV/AIDS

This analysis is focused on knowledge and misconception of HIV/AIDS by the patients themselves, as well as other people who are assumed to be non-HIV/AIDS people. Knowledge is said to be an important factor in the fight against discrimination and stigmatisation in HIV/AIDS. Incorrect knowledge is also said to be a contributory factor for the existence of misconceptions about HIV/AIDS and its mode of transmission(ICRW,2002).

The literature reviewed in this thesis has shown that knowledge is one key contributory factor in the stigmatisation of People Living with HIV and

AIDS. The statement of the problem of the study also captured misconceptions as the other major factor that has to be considered in the examination of the issues of stigmatisation towards HIV and AIDS patients. Again, the theoretical literature reviewed in attribution postulated that knowledge plays a pivotal role in making attribution in stigmatisation. This will therefore help to examine the causes of discrimination and stigmatisation with regards to the HIV and AIDS patients in this study.

HIV/AIDS patients' awareness of HIV positive status

Table 19: Knowledge of HIV status

	Frequency	Percent
Voluntary testing	1	3.3
Frequent coughing	5	16.7
Frequent diarrhea	2	6.7
Skin rashes	2	6.7
Fever (Malaria)	20	66.7
Total	30	100.0

Source: Fieldwork,2008.

It is worthy of note that all the 30 HIV/AIDS patients interviewed said that they were informed of their HIV positive status when they went to the hospital for diagnosis other than HIV. As Table 19 shows, 20 respondents representing 66.7% went to the hospital as a result of frequent fever. To the question,’ how did you know your HIV status?’ the following responses were gathered:

> *I had some rashes and fever and went to the hospital for test and scan. It was noted there that I had HIV.*
>
> *I was in Accra and started coughing seriously so I went for tests and found nothing. After a lab test at Apam, I was diagnosed of HIV/AIDS.*
>
> *It all started when I returned from Nigeria in the 80's. I started falling ill frequently with severe cough. I went to hospitals for treatment until recently when a test conducted declared I had HIV,*
>
> *I used to cough and had blood in my coughing so I went to the hospital and was diagnosed of HIV.*

It is important to note that the most common opportunistic illness often diagnosed in HIV-infected persons in Ghana in general and Central region in particular is tuberculosis which goes with severe cough. Almost all the respondents admitted having suffered from severe cough and rashes before being diagnosed of HIV.

It is worth noting that only one out of the thirty respondents went to the hospital for voluntary counseling and testing for HIV, an indication that voluntary testing is very low in the Central region. Various reasons may account for this low level of voluntary testing in the Central region, however it has been argued that the fear of stigmatisation prevent people from going for voluntary counselling and testing in HIV.

Table 20: Source of general information about HIV/AIDS by Non-HIV Persons

	Frequency	Percent
School	7	14.0
Print and electronic media	37	74.0
Friends	4	8.0
Books	1	2.0
Parents	1	2.0
Total	50	100.0

Source: Fieldwork, 2008

The question how and where Non-HIV respondents heard of HIV/AIDS gives interesting information.Findings presented in Table 20 show that all (100%) respondents were aware of HIV/AIDS. Most of the respondents became aware of HIV/AIDS through the mass media table 20. This shows the important role of the mass media as a means of education and information dissemination in Ghana

Reaction of people towards HIV/AIDS patients

The thrust of this discussion is to look at some of the reactions towards HIV/AIDS patients by their caretakers, family members and friends and also from other people who are not close to the patients. The literature reviewed has shown that caretakers, family members, friends of HIV/AIDS patients and other people not related to them discriminate and stigmatise HIV/AIDS patients through their interactions with them. These are said to be expressed in either negative or positive reactions. Data on HIV/AIDS patients' perspectives and experience of discrimination and stigmatisation will be examined to confirm or disconfirm findings from other studies on the issues of discrimination and stigmatisation towards HIV/AIDS patients.

Table 21: Caretakers' and friends reaction to news of HIV/AIDS for the first time

	Care takers (%)	Friends (%)
Positive reaction	6 (20.0)	13 (43.3)
Negative reaction	23 (76.7)	12 (40.0)
Indifference	1 (3.3)	5 (16.7)
Total	30 (100)	30 (100.0)

Source: Fieldwork 2008

Caretakers and friends are considered in this study as significant others of HIV/AIDS patients upon their diagnosis. Responses from the significant as shown by Table 21 indicates that most caretakers, family members, relatives and friends reacted negatively for the first time they heard of a member being HIV positive. However, based on the proportional comparison in table 21, Out of the 30 caretakers interviewed, 23 (76.7%) show negative reactions towards people diagnosed as HIV positive whiles 12 (40.0%) out of 30 friends reacted negatively too. It implies that based on the findings, more caretakers than friends showed negative reactions towards HIV/AIDS patients. The data also show that more friends 13(43.3%) than caretakers 6(20.0%) reacted positively towards people living with HIV/AIDS. This negative attitude may be due to their misconceptions about HIV/AIDS, which could lead to discrimination and stigmatisation of people living with HIV/AIDS.

Reasons for the reaction by the caretakers

The qualitative data collected about the reasons why caretakers reacted either positively or negatively shows that their reactions emanated from genuine concerns, psychological disposition and outright misconceptions. Some of the genuine concerns as stated by the caretakers could be found in responses such as;

Because AIDS is a deadly disease

Because he is my husband

Because I have no money

Because of the cost involved in the treatment and its burden

On misconceptions about HIV/AIDS, a number of caretakers gave responses such as;

I fear of being infected

Fear of patient dying

I thought she will die.

A caretaker also gave a psychological justification for his/her reaction as, *because I became nervous and could not imagine how she got it.*

These findings mean that people may act rationally in their interactions with people living with HIV/AIDS and others may have misconceptions about HIV/AIDS. The misconceptions can lead to discrimination and stigmatisation of people living with HIV/AIDS.

Responses from Caretakers of PLWHA about differences between reactions of the close relatives and patient's ordinary friends

Qualitative responses by caretakers show that more relatives showedconcern and compassion to HIV/AIDS patients as compared to friends. Thus, some of the responses to this effect are;

Apart from my uncle who visits her more often, other relatives and friends have stopped visiting.

Family members still relate to her nicely but friends don't come.

Friends have absolutely abandoned him but relatives partially distance themselves from him.

Most friends have abandoned him while some relatives visit him with care occasionally.

Neighbors and friends point fingers at her whenever she is passing. Relatives get closer with caution.

Some friends even would not drink or eat from our house.

An important revelation from the data gathered was that many HIV/AIDS patients did not disclose their status to their relatives and friends. As one caretaker put it;

There is no reaction because I am the only person who knows.

Another caretaker said,

Since they are not aware, there is no reaction.

Yet another caretaker said,

Since nobody knows, I cannot tell.

Yet another stated,

Relatives and friends are not aware yet.

These statements point to the fact that many HIV/AIDS patients may disclose their status to only their close relatives and friends they trust. Fear of discrimination and stigmatisation might be the reason why HIV/AIDS patients do not disclose their status to people. This finding also corroborated the research carried out by the International Center for Research on Women (ICRW) in Ethiopia and Tanzania in 2002.The research found that people fear disclosing their HIV-positive status because of how they would be treated and viewed by others.

Non HIV/AIDS Persons

A question was put whether people would shake hands with HIV/AIDS patients. Out of 50 people interviewed, 44 representing 88% said they would shake hands with HIV/AIDS patients. This implies that majority of people may not discriminate against people living with HIVAIDS.

Table 22: Drinking or not drinking with a cup used by an AIDS patient

	Frequency	Valid Percent
Yes	18	36.7
No	31	63.3
Total	49	100.0

Source: Fieldwork,2008.

Following from the fact that the majority of respondents would like to shake hands with AIDS patients; the question was asked whether they would drink from a cup used by an AIDS patient. Out of the 50 people interviewed, 18 representing 36.7% said they would drink from a cup used by an AIDS patient while 31 representing 63.3.0% said they would not drink from a cup used by an AIDS patient. This finding contradicts the earlier finding that the majority of respondents would shake hands with AIDS patients. This finding shows that many people may not be willing to share food items and utensils with AIDS patients even when they know how HIV is transmitted or prevented for fear of casual transmission.The fact is even though people might know of the modes of HIV transmission, due to fear of the disease, they might adopt behaviours such as not eating or drinking from the same bowl or cup used by AIDS patients.

Reasons for drinking/ not drinking with the same cup

Following from the fact that the majority of people might not want to drink from the same cup use by people living with HIV/AIDS; the question was asked why they would drink or not drink from the same cup with HIV/AIDS patients. In contrast to the previous finding, majority of the respondents, 21(42%) said they would drink from the same cup with HIV/AIDS patients because they could not be infected through the use of cups. Ten (10) of the respondents, representing 20% said they would not drink from the same cup used by HIV/AIDS patients because of the fear of being infected. 18% (9) of the respondents also said they would not drink from the same cup so as to be prevented from being infected. This is confirmed by representative qualitative responses presented below;

> *The person might have a cut in the mouth and might transfer the virus from the mouth to the cup and I might get infected.*
>
> *Prevention is better than cure. Anything can happen by using items like cup with them*
>
> *It is dangerous to drink from a patient's cup because there can be exchange of body fluids.*
>
> *Because I am afraid of getting infected*

Because of fear

These findings imply that, some people may discriminate against people living with HIV/AIDS but others may show compassion.These responses also help to understand the explanations of exchange theory as discussed in chapter two of this thesis. Thus, people discriminate orstigmatise HIV/AIDS patients based on the perceived costs they would incur if they get close or have compassion for them over the perceived rewards they would derive. In this case, people may discriminate or not discriminate against HIV/AIDS patients because the perceived cost they will incur may outweigh the reward or otherwise.

People Living with HIV/AIDS (PLWHA)

Many PLWHA did not disclose their status to some friends. Out of the30 patients, 20 representing 66.7% said their friends did not know of their HIV status while 10, representing 33.3% said some friends were aware. This implies that many PLWHA fear to disclose their status.

Table 23: Reactions of friends when they got to know a person was HIV positive

	Frequency	Percentage
Negative reaction	3	17.65
Positive reaction	7	41.18
Neutral/Indifferent	1	5.88
Not aware	4	23.53
Mixed reaction	2	11.76
Total	17	100.0

Source: Fieldwork, 2008

Most reactions of close friends of PLWHA when they heard of their HIV status were positive rather than negative.Most of the responses show friends were sympathetic and showed care and compassion. This implies that whiles some PLWHA would not disclose their status to friends, others did and were not stigmatised but comforted. This is evident in some of the responses from the HIV/AIDS patients thus:

> *My closest friend got to know that I had HIV, from others and came to ask me but she did not distant herself from me.*
>
> *A close friend of mine decided to have compassion on me and attends to me.*

> *A close friend of mine decided to take care of me.*
>
> *My friend rather was closer to me.*
>
> *My friends too did not react in any negative way.*

Drawing from these responses, it means that some friends show care and compassion to HIV/AIDS patients and so will not discriminate against them. This finding helps to understand the proposition B of George Homan's aggression-approval perspective. Thus,

> *when a person's action receives the reward he/she expected, especially a greater reward than he/she expected, or does not receive punishment he/she expected, he/she will be pleased; he/she becomes more likely to perform approving behaviour and the results of such behaviour become more valuable to him/her (Homans, 1974:39).*

This finding gives a clearer insight into the stated proposition as reviewed in chapter two of this thesis. Hence if an HIV/AIDS patient is treated with compassion by his/her friends, family members and the community, he/she may become pleased and comfortable among people. He/she may be very careful with the people so that he/she may not infect other people.

On the other hand, some of the responses from the HIV/AIDS patients showed that some of their close friends discriminate against and stigmatise them. Some of the responses which show elements of discrimination and stigmatisation are as follows;

> *My friends stopped visiting me and neighbours pointed fingers at me when I am passing.*

My friends initially became scared of me in terms of eating together.

I heard people talked about me but nobody was able to confront me directly.

The responses of HIV/AIDS patients as quoted above might be a factor that deters people to disclose their status and even prevent them from going for voluntary testing.

Table 24: Behaviour of family or close friends upon realising a person was HIV/AIDS positive

	Frequency	Percentage
Care and compassion	4	36.36
Discrimination/Stigma	4	36.36
Mixed reactions	3	27.28
Total	11	100.0

Source: Fieldwork, 2008

When asked to explain the behaviour of their family members and friends, the patients observed that some family members initially discriminated against them but changed with time. 36.36% (4) of the respondents said they were shown care and compassion and another 36.36% (4) also said they were discriminated against and stigmatised.

This is evident in the responses given by the HIV/AIDS patients about how they were treated by their family members. Some of the responses which attest to this finding are;

> *They would not use the cup nor eat with me but there has been an improvement about their behaviour towards me.*
>
> *My wife left the marital home when she heard the news and my siblings discriminated against me but it was more serious with my friends.*
>
> *My mum's behaviour was negative but my friend's behaviour was positive.*
>
> *Family members rejected me and a friend rather came for me.*

It also shows that families provide genuine care and compassion for PLHA and concurrently stigmatised and discriminated against them.

Mode of health care delivery to HIV/AIDS patients

Available research and literature reviewed showed that the mode of health care delivery to HIV/AIDS patients also leads to stigmatisation and discrimination. In view of this, mode of health care delivery is one of the factors stated in the statement of problem to be examined in this thesis.

Table 25: Type of care given to PLWHA by health workers (Fevers Clinic, Central Regional Hospital)

	Frequency	Percent
Medical care	5	50.0
Counseling	3	30.0
Medical care and counseling	2	20.0
Total	10	100.0

Source: Fieldwork,2008

Responses of health workers about the type of care and treatment they gave to HIV/AIDS patients show that they provided almost the same kind of medical care to HIV/AIDS patients and other patients but with a slight variation. In addition to the normal treatment given to them, some take the PLWHA through education and counselling. The data also show that some of the health workers feared beinginfected with HIV and so treat patients with caution. This finding suggests elements of discrimination against PLWHA by health workers who indeed must be at the fore front of creating a positive awareness and attitude to PLWHA. Some of the responses which attest to this are:

> *I render quality healthcare to them with great caution to avoid infection myself with the HIV. Just as any patient but with care.*

These responses show that the mode of health care delivery to HIV/AIDS patients by some health practitioners may lead to stigmatisation because of the fear of being infected.

Reasons for handling or treating PLWHA with care by health workers

Responses to the question why some health workers were careful when treating patients show that most of the health workers fear of being infected with HIV hence the caution in handling patients. However, the reasons stated were genuine concerns.This position is captured in the following qualitative responses;

> *I don't want to be infected .Prevention of spread. You have to make sure you do not infect yourself. To prevent infecting oneself*

These responses also help us to understand the theory of social exchange as explained in the literature review in chapter two of this thesis. Thus people weigh the rewards and costs of engaging in social or economic exchange. This finding therefore fits into the explanation of exchange theory. Health workers, being rational weigh the rewards and costs of engaging in the treatment and care of HIV/AIDS patients. The data show that most of them perceived the costs of caring and treating HIV/AIDS patients as outweighing the rewards, hence the care and caution adopted in dealing with them.

Effects of stigmatisation on People Living with HIV/AIDS

Available data show that discrimination and stigmatisation of People Living with HIV/AIDS are the major causes of ‘social’ death and the spread of HIV. It was argued that, due to the reactions of others as well as the internalized self-feelings (Crocker et al.,1991), stigmatised persons life chances and opportunities are lessened, they are set apart from others and they are considered to be inferior and represent a danger to society, all of which lead to social rejection and social isolation (Goffman, 1963; Jones et al.,1984; Link et al., 1989).

People Living with HIV/AIDS on stigmatisation

To the question, ‘*do you know that some people do not like you because of your HIV/AIDS status?,*’ Out of the 30 HIV/AIDS patients interviewed, 20 representing 66.7% said no to the question whiles 10 representing 33.3% said they knew some people did not like them because of their HIV/AIDS status. The patients who said yes to the question might be the ones who have disclosed their status or whose status was known to people. However, those who said ‘no’ to the question might fall into two categories of HIV/AIDS patients: Patients who have disclosed their HIV/AIDS status and patients whose status were not known to people. This is because earlier findings in this thesis have it that many patients feared to disclose their HIV/AIDS status because of discrimination and stigmatisation. Hence such patients might not know whether they are liked or disliked as a result of their HIV/AIDS status since most people might not know of their status.

Following from the previous question, responses of HIV/AIDS patients about how they knew they were liked or disliked by people who knew of their HIV/AIDS status gave interesting revelations. The responses given by the HIV/AIDS patients showed that some patients who disclosed their status were treated well whiles some were not treated well. Again, there were some who did not disclose their HIV/AIDS status and so did not know whether they were liked or not. Some of the responses which showed that some of the HIV/AIDS patients were disliked or discriminated against or stigmatised are quoted as follows;

> *Because they rejected me*
>
> *My nieces and nephews did not even want to use my things like utensils and cups.*
>
> *Some people who know my status refuse to interact with me*
>
> *Through negative attitude when we were quarreling.*

This finding therefore falls into the category of enacted stigmatisation which is a situation where people reject HIV/AIDS patients, and refuse to interact with them and also prevent them from getting employment and access to health.

Table 26: The effect ofdislikeness or likeness onhealth, psychological disposition and self-esteem of the patient

	Frequency	Percentage
Normal	7	33.3
Psychological trauma	4	19.04
Low self esteem	2	9.52
Negatively affecting health	1	4.76
Mixed effects	7	33.33
Total	21	100.0

Source: Fieldwork, 2008

Responses of HIV/AIDS patients about how discrimination and stigmatisation was affecting them show that HIV/AIDS patients who were treated well said the care and compassion they were receiving had positively affected their health. Some representative qualitative responses are;

I am rather fine because my wife treats me well.

Since people are nice to me, I am fine.

The love and care and concern they show rather make me healthy and strong.

Their deeds help me to be healthy.

Those respondents who felt rejected, stigmatised and discriminated against went through a lot of psychological trauma and this affected their state of health negatively, as stated by them:

I get worried when I go through this discrimination from friends.

Infact these actions make me have sleepless nights and I am very lean and pale. Initially, I was thinking and always crying so it really affected me but I do not bother now.

It is affecting me seriously, psychologically and health-wise.

"As you can see, I have lost my self esteem and identity".

It was affecting me when my mum was avoiding me.

These responses confirm the view thatstigmatised persons lose social status (Cumming & Cumming, 1965); they are discounted and discredited-reduced in the minds of others from being whole and acceptable individuals.

So, if you have AIDS you 'die' twice because the first thing that kills you is being lonely when everyone discriminates against you. The seconddeath is the biological one.

Following the question on how discrimination and stigmatisation affects the HIV/AIDS patients, the question was asked as to how they feel when they are among non-HIV/AIDS patients. The responses show that some of them do not feel comfortable when they are in the company of non-HIV/AIDS people whiles some feel comfortable. Out of 30 HIV/AIDS patients interviewed, 15 representing 50% said they either felt ashamed or shy when they were in the company of non-HIV/AIDS people. This finding confirms the explanation of stigma in chapter two where two effects (felt and enacted) were examined. The revelation is consistent with felt stigma that afflicts HIV/AIDS patients. ‘Felt’ stigma is the effect on individual feelings such as shame, guilt, withdrawal, and self-stigmatisation.

CHAPTER SIX

CASE STUDIES

Introduction

This chapter presents the analysis of the five case studies on case by case basis. It focuses on each of the cases, how they got infected, how they were being treated by other people and health workers and its effect on their health. These case studies further throw more light on the effects of stigmatisation and discrimination to complement findings discussed in the previous chapters of this thesis.

Discrimination of People Living with HIV and AIDS

Case 1: A young man aged 36 years was infected with HIV after returning from Nigeria. He narrated his experiences thus;

I did not know how I got infected. I have been abandoned by my parents and other family members when they got to know of my HIV positive status. I am being cared for by my girl friend at home. I live in a small room and have my own household items such as plates and drinking cups which I used alone. My girl friend is responsible for my upkeep and hygiene.

This case study confirms the fact that some family members discriminate or isolate their HIV/AIDS patients whiles the friends rather care for them. The case study also confirmed the fact that there are misconceptions about the mode of transmission of HIV. Again, this might be due to the fear people have about HIV and AIDS. This case study as described above is a clear manifestation of the acts of discrimination against People Living with HIV and AIDS. This case study therefore corroborates earlier findings in this thesis about the misconceptions people have about HIV and how it is translated into acts of stigmatisation and subsequent discrimination of People Living with HIV and AIDS.

Case 2:A 34 year old AIDS patient (lady) was shunned by few friends who got to know of her status. She said;

I got infected through my late husband who was an AIDS patient. My family members also stopped visiting me. In fact these attitudes from friends and family members made me to think and worry a lot. This has affected my state of health seriously and at times I feel like poisoning myself or dying. In a sobbing mood she said, *I feel like drinking poison because I think it is not worth living in a society where people do not accept you because you have a particular disease.*

The case study above shows that both friends and family members discriminate against People Living with HIV/AIDS. The case study reveals that the discrimination by friends and family members affect some of the patients' state of health negatively as reported by a patient in (Case 2). The revelation by a patient from the case study implies that some People Living with HIV/AIDS who might have gone through the acts of discrimination will be more likely to commit suicide than those who are given the care and compassion. The discrimination also may affect the health and psychological disposition of the patients as reported by the respondent (Case 2). As stated earlier in this thesis, the acts of discrimination might be borne out of misconceptions or genuine fears of getting infected with HIV. These reasons notwithstanding, it is evident from the case study that (Case 2), discriminations of all forms against People living with HIV/AIDS affect their health, psychological disposition and life span negatively.

Disclosure of HIV positive status by PLHA

Case 3: A 39 year old woman suffering from AIDS said;

I would not disclose my status to anybody apart from my husband because my family members and friends would isolate and abandon me. Asked how she felt about the treatment at the hospital, she said, *I do not have problem with the nurses but creating a separate unit for AIDS patients is a form of discrimination because some people intentionally come to the unit to see those suffering from AIDS.A friend of mine who was suffering from AIDS drank poison and died recently because she was stigmatised and isolated.*

The case study (Case 3) above also confirmed earlier findings in this thesis about the refusal or reluctance of people diagnosed to be HIV positive to disclose their status to others due to the fear of discrimination and stigmatisation. Thus, disclosure of positive HIV status is advocated, but acknowledged as difficult and unusual (ICRW, 2002). This has negative ramifications on the society at large since many people are likely to be infected by those who would be reluctant to disclose their HIV positive status. Again, the assertion by the respondent in this case study (Case 3) that a friend drank poison and died as a result of discrimination against him confirmed the previous discussions in (Case 2) about the likelihood of People Living with AIDS committing suicide due to discrimination.

The issue of the mode of health care delivery to People Living with AIDS as stated in the statement of problem and previous discussions in this thesis as a factor in stigmatisation and discrimination has been confirmed in this case study (Case 3). Thus, some people do not like the special unit created for HIV/AIDS patients in the hospital. As reported in the case study (Case 3), it is a form of discrimination against People Living with HIV/AIDS. This revelation from the case study (Case 3) on mode of health care to AIDS patients supports earlier findings in this thesis that the mode of care given to AIDS patients might be another cause of stigmatisation and discrimination towards them.

Case 4: A 42 year old woman suffering from AIDS said;

I was ejected from my house by the landlord when he got to know that I have HIV. I am going through a lot of psychological trauma. I will never disclose my status to anyone again, if I die, I die with it. I think stigmatisation is one of the main causes of early death among HIV/AIDS patients. My health is deteriorating because I don't have peace of mind.

The case study (Case 4) suggests that some of the patients may refuse to disclose their HIV/AIDS status to people because of social isolation and discrimination. Thus some people may not disclose their status to others due to their earlier experiences with their significant others or people close to them (Case 4). The case study also underscores the effect of discrimination and stigmatisation on the state of health of HIV/AIDS patients. These revelations from the case studies about refusal by people to disclose their HIV positive status implies that disclosure is an important factor in the spread and reduction of discrimination and stigmatisation against People Living with AIDS.

Case 5: A young lady who was diagnosed of HIV said;

I have been advised by a nurse not tell my mother and other relatives. When I asked the nurse why I should not tell them, the nurse said they would isolate and discriminate against me if they get to know. In view of that, I have decided not to even inform my husband who lives abroad.

This case study (Case 5) once again illustrates some of the problems HIV patients were going through. For some, their HIV status had to be kept secret from the rest of the family members because they were afraid of being stigmatised and isolated. It has been observed through these case studies and the previous data analysis in this thesis that the social ‘safety net’ which was once offered by the corporate clan to its members appears to be undergoing changes; it does not seem to provide the individual with the protection and support it once gave. This may be because AIDS, as a disease with no known cure, is interpreted as a curse or punishment for disobedience. Such a situation brought shame not only to the individual, but also to the corporate clan (Bleek, 1981).

CHAPTER SEVEN

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Introduction

This chapter provides a summary of the major findings made, relevant conclusions drawn and recommendations of the study. The general objective of the study was to determine the differential opinions and beliefs that individuals have toward people living with HIV and AIDS and the reasons they give for stigmatising and discriminating against them.

Summary

The study investigated the case of People Living with HIV and AIDS in the Central Regional Hospital of Ghana.Two non-probability sampling techniques were employed. These were purposive sampling and the convenient sampling technique. A sample size of 120 was used for the research. Interviews, case studies and survey questionnaires were used for the data collection. Two main theories namely; attribution and exchange guided the study.

The major findings of the study focus on the knowledge and misconception of HIV and AIDS, reactions of people towards People Living with HIV and AIDS, mode of health care delivery to People Living with HIV and AIDS and the effects of stigmatisation and discrimination on People Living with HIV and AIDS.

It was found that knowledge and fear interact in unexpected ways to allow stigmatisation and discrimination to persist. The data showed that while people knew about HIV and about some means of transmission and prevention, they generally did not have anin-depth knowledge about HIV and AIDS. Although the awareness level is high among the people interviewed about HIV/AIDS, there is incorrect knowledge about the mode of transmission; hence the persistent discrimination and stigmatisation of people living with HIV/AIDS in the Central Region.

The study also found that, some family members, relatives, caretakers and friends reacted negatively for the first time they heard of a member being diagnosed HIV positive. Many people said they reacted negatively towards HIV and AIDS patients because they saw HIV and AIDS as a deadly disease and feared contracting it. It has been identified that due to the negative reactions people show to HIV and AIDS patients, most people diagnosed of HIV did not want to disclose their status to their relatives and friends. These negative reactions were demonstrated in several ways like isolation, derogatory statements, refusal to use household utensils with patients and pointing of fingers at them when they were passing.

The mode of health care delivery to People Living with HIV and AIDS by some health practitioners also lead to stigmatisation because the fear of being infected makes health workers treat patients with caution. Although theintention of most health workers was not to discriminate and stigmatise HIV/AIDS patients, the fact that they indirectly engaged in acts of discrimination and stigmatisation could be interpreted as an attitude associated with the fear of being infected.

It was found that those patients who experienced good care and compassion lived healthier and longer. Patients who felt rejected, stigmatised and discriminated against went through a lot of psychological trauma and it affected their state of health. The study discovered that the shame and stigma associated with the epidemic have silenced open discussion both of its causes and of appropriate responses among those diagnosed of HIV. It has therefore caused those infected with HIV/AIDS to feel guilty and ashamed.

Conclusions

Stigmatisation and discrimination of People Living with HIV and AIDS as seen in the study are complex and interrelated phenomena caused by a multiplicity of factors which could be broadly categorised asmisconceptions, lack of knowledge of HIV and AIDS, fear of HIV and AIDS (reactions) andmode of health care delivery to People Living with HIV and AIDS.

These factors are the sources or causes of stigmatisation and discrimination.An important revelation from the data gathered was that many People Living with HIV and AIDS did not disclose their status to their relatives and friends because they feared of being stigmatised and discriminated against. The study foundthat, stigmatisation and discrimination undermine efforts at AIDS prevention because fear of the reactions of others prevents people from finding out whether or not they are infected.In effect, many peopleget infected with HIV and still continue to engage in risky sexual and other behaviours with those who are ‘not infected’.

The issues raised above as factors responsible for stigmatisation and their effects on patients in the study contribute to understand attribution theorists’ view about how people explain or attribute others behaviour to some perceived causes. The theory argues that people make causal attributions in a rational, logical fashion. However, considering the factors of misconceptions and lack of knowledge about HIV and AIDS in this study, the proposition is not obvious in some situations especially with terminal diseases as HIV and AIDS. In this study somepeople were not that accurate or rational when forming judgments about others with infectious and life threatening diseases as HIV and AIDS. Some respondents became ignorant of information about HIV and AIDS and its modes of transmission. They therefore either acted ignorantly or distorted information to satisfy their need for high self-esteem leading to the devaluation of the self-esteem of others who were People Living with HIV and AIDS.

Again, the relevance of some of the factors as fear of HIV and AIDS and mode of health care delivery to People Living with HIV and AIDS were also found in the exchange theorists’ explanation of cost and rewards in social interaction. Exchange theory explains the cost and rewards people anticipate in social interaction. Thus, some of the family members, friends and caretakers in this study engaged in stigmatising and discriminatory behaviour in their interactions with People Living with HIV and AIDS because they claimed they might be infected. In this case, the respondents thought the cost of engaging in interaction with PLWHA might outweigh the reward, hence the stigmatisation and discrimination of People Living with HIV and AIDS.

Moreover, majority of the health care providers interviewed in this study admitted that they treated the People Living with HIV and AIDS with caution. Asked why they handled PLWHA with caution, some of the respondents claimed they might be infected if they were not careful in treating the patients. Thus, in their interaction with PLWHA, some health workers weighed the costs and rewards hence the precautions so that the cost (in this case of being infected with HIV) might not outweigh the rewards (in this case of not being infected with HIV).

The theories of attribution and exchange have contributed to enhancing discussions of the causes and effects of stigmatisation and discrimination of People Living with HIV and AIDS in the Central Regional Hospital of Ghana.

Recommendations

On the basis of the major findings the following are recommended:

1. Data gathered from the study showed that media coverage has helped to sensitise the public to the issues of AIDS. However, its educational impact has been minimal. There is therefore the need to increase the

education of people on AIDS by the various organisations and Ghana AIDS Commission through the media so as to reduce the rate of misconception and fear of AIDS.

2. There is the need to establish voluntary counselling and testing services in all the districts of the region by the Ghana health service and, if possible, it should be hospital based. Integration of voluntary counselling and testing services into health and social services would improve access and effectiveness of the services, reduce costs and ensure maximum patronage in the midst of the stigma as people would go under the pretext of normal hospital visit. This would help minimise the rate of infection in the region.

3. Stigmatisation can also be reduced by demystifying HIV and AIDS through targeting health care workers first and making several formal and informal interactions with them. In addition, regular discussions should be held on HIV and AIDS stigmatisation and its related issues at meetings, and sharing of experiences so as to make stigmatisation and discrimination an integral part of health care workers' capacity building efforts.

4. There is need to put in place organisations to provide emotional and practical support to People Living with HIV and AIDS. This can be carried out by NGOs and Ghana AIDS Commission. Such organisations should provide a kind of lifeline, to serve as a means for

a person to establish the ability to live fully within the limitations of the illness.

5. Family members and friends of PLWHA should be trained in the basic understanding of how HIV is transmitted or prevented by the community health personnel in the various districts. They should also be trained to access basic home nursing AIDS –care skills. This can play a key role in reducing stigmatisation and discrimination in the homes.

6. The use of linguists approach can be tried in the communities in the region, i.e. a linguist will act as a spokes person to the community by simplifying the technical vocabularies to the understanding of the community members to dispel myths and rumours surrounding AIDS. This can be done during community fora on HIV and AIDS in the various communities in the region. This would help reduce stigmatisation and discrimination in the region.

7. There should be emphasis on the quality of care provided to PLWHA. Care takers especially should be educated on how to provide a balanced diet, better hygienic practices which are very important for the health of the PLWHA. This could be done by NGOs and the health personnel and the media

Suggestions for Further Research

The following areas are identified for further research.

1. A gender focus research is needed to establish gender discrimination in HIV and AIDS and stigmatisation. This is because the study found that majority of the HIV and AIDS respondents were females but it did not go further to ascertain the factors which accounted for this.
2. This study has been silent on the abuse of Human Rights of People Living with HIV/AIDS. It is therefore suggested that a further study be conducted on the Human Rights implications for stigmatisationof People Living with HIV/AIDS.
3. Thorough investigation should be conducted to establish the relationship between poverty and stigmatisation of People Living with HIV and AIDS.This is because the study found that people who are infected with HIV and were also stigmatised were poor.It is therefore suggested that a further study be conducted on the relationship between poverty and stigmatisation in HIV and AIDS.

The information presented in this work is mainly based on the responses given by People Living with HIV and AIDS, their friends, caretakers, health workers and people assumed not to be infected with HIV in the Central Regional Hospital. Though, their responses have helped to explain the issues of stigmatisation in HIV and AIDS, gaps still exist in the field for further research.It is in the light of this that the above areas of study are suggested to help complement the understanding of the issues of stigmatisation and HIV and AIDS in the Central Region in particular and Ghana in general.

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APPENDICES

INTERVIEW GUIDE FOR HIV/AIDS PATIENTS

DEMOGRAPHIC DATA

1. Sex ……… Male { } Female { }
2. Age……………..
3. Educational level……..
4. Occupation, if any……….
5. Marital status, if any………..

Knowledge of HIV/AIDS status

6. How did you know your HIV/AIDS status?
7. How long have you been HIV/AIDS positive?
8. Do your friends know about your HIV/AIDS status?

Reactions of people from the perspective of HIV/AIDS patients

9. Can you briefly describe the reactions of your immediate family members (father, mother, siblings) when they were informed about your HIV/AIDS status?
10. Can you explain the reaction of your closest friend when he/she got to know you were HIV positive?
11. From Q8&Q9, can you explain the behavior of your family or close

friends upon realising that you were HIV/AIDS positive.

12. Can you explain in details the kind of behavior exhibited by any family member or friend?

Caretakers and stigmatisation

13. Who takes care of you?
14. Why do you think the person is taking care of you?
15. Who would you have preferred and why?

Effects of stigmatisation from the point of view of HIV/AIDS patients

16. Do you know that some people do not like you because of your HIV/AIDS status?
17. How do you know?
18. What are the things they do that show they do not like you?
19. How do you think these dislikeness is affecting your; (a) health, (b) psychological disposition, (c) self-esteem
20. How often do people visit you either in the hospital or at home?
21. How do you feel when people visit you in your sick bed?
22. How do you feel when you are among people who are not HIV positive or AIDS patients?

Mode of health care delivery to HIV/AIDS patients

23. What kind of treatment are you going through or receiving?
24. How long do nurses take to attend to you?
25. Explain into details the behavior of nurses whenever you go for treatment?

26. How do you feel when you are being treated?

GUIDE FOR CARETAKERS (family members/friends)

Demographic data

1. Sex…… Male { } Female { }
2. Age…….
3. Educational level……
4. Occupation….
5. How are you related to the HIV/AIDS patients?

Reactions and care by close relatives and friends

6. When you first heard about his/her HIV positive status, what was your first reaction?
7. Why did you react this way?
8. Where was the patient living before he/she became HIV positive?
9. What occupation was the patient engaged in before he/she became HIV positive?
10. How long have you been taking care of the patient?
11. Does the patient stay with you at home or in the hospital?
12. How often do you visit the patient if he/she is in the hospital?
13. Do other close relatives/friends visit the patient and if so how often?
14. What kind of services do you render to the AIDS patient?

15. How do friends and relatives react to the condition of the patient you are taking care of?
16. Can you explain how different the reactions of the close relatives are as compared to the patient’s ordinary friends?
17. How are you able to differentiate the reactions of friends and relatives?
18. Can you identify a close friend of the HIV/AIDS patient?
19. How would you explain the relationship of this friend after the patient was diagnosed HIV positive?
20. How is the relationship of the patient’s relatives after he/she was diagnosed HIV positive?

Mode of care for HIV/AIDS patients by health workers from the perspective of relative caregivers

21. Are there any differential treatments by nurses whenever you send the AIDS patient to the hospital?
22. Do the health workers treat AIDS patients differently from non-AIDS patients?
23. If yes, how different is their treatment of AIDS patients from other patients?

QUESTIONNAIRE FOR HEALTH WORKERS

Demographic data

1. Sex…… Male { } Female { }

2. Age…….
3. Educational level……
4. Occupation……….

Mode of health care delivery to HIV/AIDS patients by health workers

5. What is/are your duty schedule?

6. How long have you been working in this department?

7. What type of patients do you take care of?

8. Describe the type of care you give to HIV/AIDS patients.

9. Are units/departments created for different kinds of diseases?

10. Why do you create a special unit for HIV/AIDS patients?

11. How often do you come into contact with HIV/AIDS patients?

12. How do you disclose their HIV/AIDS positive status to them?

13. How careful are you when treating/caring for an HIV/AIDS patient?

14. Why are you careful when handling or treating an AIDS patient?

15. How many HIV/AIDS patients have you treated so far?

16. For how long have you been caring for HIV/AIDS patients?

Reactions of patients to care/treatment by health workers

17. How does the patient react to the way you handle/treat/care for him/her?

18. What are some of the supposed reasons given by patients as to the way you treat/care for them?

19. How different is your interaction with HIV/AIDS patients from other patients?

20. Does the status of the patient influence the way you treat him/her? How?

QUESTIONNAIRE FOR NON-HIV/AIDS PEOPLE

Demographic data

1. Sex …… Male { } Female { }

2. Age………

3. Occupation…….

4. Educational level……

Knowledge of people about HIV/AIDS

5. Have you ever heard of the disease HIV/AIDS?

6. Where/how did you hear of the disease?

7. Do you know anybody who has been affected by the disease?

8. Have you ever visited an HIV/AIDS patient in the hospital or home?

9. How was your interaction with the patient?

10. Why do you have this sort of interaction with an AIDS patient?

Social distance

10. Can you explain what you can do to avoid contracting HIV/AIDS when you come into contact with the patient?

11. How would you relate with a relative of yours who has AIDS?

12. How would you relate with a friend of yours who has AIDS?

13. Would you shake hands with a cup used by an AIDS patient?

14. Would you drink with a cup used by an AIDS patient?
15. From the questions above why would you do or would you not do the above?
16. Do you think AIDS patients should live with their families or not?
17. Should AIDS patients be isolated and why?