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FACULTY OF ARTS

DEPARTMENT OF SOCIOLOGY

INFLUENCE OF STIGMA ON TREATMENT FAILURE ON HIV PATIENTS UNDERGOING TREATMENT AT MBAGATHI DISTRICT HOSPITAL

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OCTOBER 2014

DECLARATION

This research project is the result of my original	al work and it has not been presented to
any other college, institution or university for ex	camination.
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DEDICATION

I dedicate this research project to my loving children Monicah, Samuel and Emmanuel who have been of great inspiration and encouragement. We have spent many hours together as they also did their homework.

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I feel greatly indebted to several personalities and institutions for the assistance offered to enable the researcher to successfully complete this research project report and produce final report. First and foremost, I would like to thank the Almighty living God for providing me with the opportunity to pursue this course to successfully end.

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I wish you all good health and God's grace.

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LIST OF ABBREVIATIONS

API- Asian and Pacific Islanders

ART- Standard antiretroviral therapy

CD4- is a glycoprotein found on the surface of immune cells such as T

helper cells, monocytes, macrophages, and dendritic cells

CSWs- Centre for the Study of Women in Society

H/A – HIV and AIDS

HRSA- Health Resources and Services Administration

ICRW- International Centre for Research on Women

MSM- Men who have sex with men

MTCT- Mother-to-child transmission

NACM- National AIDS Control Manual

NASTAD - National Alliance of State and Territorial AIDS Directors

NASW- National Association of Social Workers

RNA- Ribonucleic acid is a ubiquitous family of large biological

molecules that perform multiple vital roles in the coding,

decoding, regulation, and expression of genes

UNAIDS- United Nations Programme on HIV/AIDS

ABSTRACT

Though much study has been conducted on HIV/AIDS and its scope, the area that seems to have been relegated to the back of most studies is about stigma and how it affects the overall outcome of the existing measures to mitigate the effects of the pandemic to the infected, affected and the community at large. Despite all the efforts that have been put in place, there are still many cases of treatment failure. Treatment success is when the measures being employed help the infected live and leads a normal life even when testing HIV/AIDS positive while failure would imply where the condition of the patient deteriorates progressively inspite of being on treatment. Most studies are concentrated on these known factors, that is, non-adherence, drug toxicity and potency of the antiretroviral regimen but studies on the stigma and its contribution to treatment failure has been neglected. This is the gap that my study was aimed at exploring as a way of knowledge furtherance. The study sought to establish the level of treatment failure among HIV patients undergoing treatment, to identify the causes of stigma among HIV patients undergoing treatment, to determine how stigma contributes to the failure in treatment among HIV patients undergoing treatment and to find out strategies of stigma reduction among HIV patients undergoing treatment. This research problem was studied through the use of a descriptive survey research design. The target population of this study was 298 respondents comprising 23 staff members and 275 HIV patients undergoing treatment at Mbagathi District Hospital. The researcher used purposeful sampling to select 13 staff members dealing with HIV treatment and simple random sampling to select 155 HIV patients undergoing treatment using random number tables. Qualitative data was collected by use of interview guides while quantitative data was collected by use of semi-structured questionnaires. The quantitative data in this research was analyzed by descriptive statistics using statistical package for social sciences (SPSS V 21.0). The study concludes that people often avoid being associated with HIV, with devastating effects on prevention, care and treatment. Stigma can reduce the likelihood of people using condoms and accessing preventive services such as educational meetings and counselling. People who hold stigmatizing attitudes are also less likely to adopt preventive behaviours. The study also concludes that stigma often prevents disclosure of an HIV-positive status to partners, providers and family members, which in turn deter behaviours that can prevent further spread of HIV, such as condom use, or mitigate its impact, such as care seeking. The study further concludes that stigma deters use of health facilities and adversely affects quality of health services. The study recommends that there is need to understand the underlying factors producing stigma, integrate action on these into programs wherever possible including participatory reflection and action in and by the communities concerned. The study also recommends that there is need to involve people living with HIV and AIDS in program interventions at all levels- community, district and national level. Their involvement should also extend to policy development, research and evaluation. NACC should address stigma at levels where it arises or where it can be acted on in communities, including workplaces, Media, Recreational facilities, Schools, Churches and in Faith-based organizations. The government should promote complementary action on stigma at the level of individuals, families, social groups, organizations and at national level.

CHAPTER ONE: INTRODUCTION

1.1 Background Information

The National AIDS Control Manual (NACM) (2008) notes: "People who are stigmatised are marked out as being different, and stigma is often attached to things which are seen as embarrassing or a danger. Stigma can be used as a way of denying dignity, respect and rights to some members of society, and can result in people being isolated or abused. It can lead to discrimination, where people are treated less well because of a characteristic they have." HIV stigma is particularly complex, fuelled by racial, homophobic and drug related prejudice and discriminatory behaviour. It is also a way for people to cope with irrational fears of catching the condition (Kelly, 2006). HIV is also a self-stigmatising condition. People with the virus often report feelings of guilt and self-loathing, internalising society's views that they are at fault or deserving of retribution for risk taking and "immoral behaviours" (NACM, 2008).

HIV/AIDS-related stigma (H/A stigma) is invoked as a persistent and pernicious problem in any discussion about effective responses to the pandemic. In addition to devastating the familial, social and economic lives of individuals, H/A stigma is cited as a major barrier to accessing prevention, care and treatment services. Despite widespread recognition of the differential treatment of individuals living with HIV/AIDS (people living with HIV/AIDS) by society and its institutions, over the first 25 years of the pandemic, community, national, and global actors have only had limited success in alleviating the deleterious effects of H/A stigma (Herek, 1998). In describing a sustained response to the HIV/AIDS pandemic, Piot, Executive Director of the Joint United Nations Programme on HIV/AIDS, identified tackling stigma and discrimination as one of five key imperatives for success. At the same time, Piot noted that stigma reduction efforts are relegated to the bottom of AIDS programme priorities, often without funding to support such activities (Duffy, 1990).

Much of the rhetoric and literature has cited the complexity of H/A stigma and its diversity in different cultural settings as the primary reasons for the limited response to this pervasive phenomenon. The complexity of the phenomenon has led to difficulties

and disagreement about how to define H/A stigma and, sometimes, to an erroneous conflation of stigma with its related concept of discrimination (Janssen, 1980). The manifestation of H/A stigma not only varies by cultural/national setting, but also by whether one is considering intrapersonal versus societal levels of stigma. The variability in manifestations of stigma by setting and level has led to difficulty in measuring the extent of stigma, assessing the impact of stigma on the effectiveness of HIV prevention/treatment programmes and devising interventions to reduce stigma. These four challenges: defining, measuring, assessing the impact of and reducing stigma, among others have hampered local and global efforts to address H/A stigma (Centres, 2001).

Stigma is a complicated issue that has deep roots in the convoluted domains of gender, race, ethnicity, class, sexuality, and culture. Granted, it is not easily understood, nor is it readily addressed. But public health practitioners must not shy away from the subject of stigma, thinking that it is outside the scope of public health or beyond the reach of their capabilities. Cited among the 10 essential health services of every public health agency are the following activities: empower people about health issues, mobilize communities to solve health problems, develop policies and plans in support of individual and community health, and conduct research to find innovative solutions to health problems. To ensure these essential services in the context of HIV prevention and care, there is no question that every segment of the public health community confronts the impact of HIV/AIDS stigma (Stokes, 1998).

Certainly, stigma is not the only impediment faced in an attempt to create effective HIV prevention and care programs. Gaps in the scientific knowledge base, inadequate transfer of proven prevention technologies, skills deficits among providers and clients both, and resource constraints are among the many factors influencing the success or failure of our efforts. But undoubtedly, stigma needs to be recognized as a continuing impediment to HIV prevention and care programs. As public health practitioners, it is our responsibility to work toward minimizing the negative health consequences of HIV/AIDS stigma (Valdiserri, 1987).

In this study, the researcher systematically review the scientific literature on H/A stigma to document the current state of research with specific reference to how stigma contributes to the treatment failure in HIV patients undergoing treatment at Mbagathi District hospital, with an emphasis on identifying gaps in as well as summarizing existing knowledge on the four aforementioned challenges to effective intervention: defining, measuring, assessing the impact of and reducing stigma. In assessing impact, the researcher will critically examine the literature to elucidate the relationship of H/A stigma to the effectiveness of HIV prevention and treatment programmes. Finally, based on the available literature, the researcher will offer recommendations for each of the challenges that are believed to represent critical next steps in ameliorating the devastating effects of H/A stigma.

In this study, treatment experienced patients are those patients who have already had some treatment, though very little. The mostly used and recognized treatment of HIV is the use of antiretroviral therapy. Although success with antiretroviral therapy has greatly improved with the introduction of more potent and well tolerated medications, treatment failure remains an important challenge for clinicians. Failure of antiretroviral therapy is defined under the following circumstances; virologic failure (suboptimal viral suppression or loss of suppression>50 HIV-1 RNA copies/M1; immunologic failure to achieve or maintain in CD4 cell count recovery despite effective viral suppression and clinical disease progression (development of new opportunistic infections or neoplasm's despite apparent CD4 recovery).

Treatment failure is often due to multiple factors. The identification of potential contributing factors is important so that corrective measures can be instituted to improve the likelihood of success with new therapy. Common known factors to treatment failure include; non-adherence; drug toxicity and potency of the antiretroviral regimen. Though the above are some of the known factors, it would be prudent to establish how stigma also contributes to the treatment failure, and this forms the basis of my study. The study will focus on Mbagathi District Hospital.

1.2 Problem Statement

HIV/AIDS-related stigma is a complex concept that refers to prejudice, discounting, discrediting and discrimination directed at persons perceived to have AIDS or HIV, as well as their partners, friends, families and communities. HIV/AIDS stigma often reinforces existing social inequalities based on gender, race, ethnicity, class, sexuality and culture. Stigma against many populations disproportionately affected by HIV has been present for a long time in Kenya. HIV has compounded the stigma of homosexuality, drug use, poverty, sex work and racial minority status (Valdiserri, 1987).

HIV/AIDS stigma is a problem in Kenya and throughout the world. Stigma has been expressed in a variety of ways, including: 1) ostracism, rejection and avoidance of people living with AIDS; 2) discrimination against people living with AIDS by their families, health care professionals, communities and governments; 3) mandatory HIV testing of individuals without prior informed consent or confidentiality protections; 4) quarantine of persons who are HIV infected; and 5) violence against persons who are perceived to have AIDS, be infected with HIV or belong to "high risk groups" (Centres, 2001).

HIV/AIDS stigma adds to the stress experienced by HIV persons. In addition, it leads to challenges for HIV prevention efforts. Fear of negative social consequences of a positive HIV test result can deter some persons from getting tested. A study of men and women in seven cities in the US found that stigma was associated with a decreased likelihood of being tested for HIV. People who are HIV positive but haven't tested and don't know they are HIV positive are less likely to try to prevent transmitting HIV to others (Herek, 1998). Some HIV positive persons may fear that disclosing their HIV status or using condoms may bring partner rejection, limit sexual opportunities or increase risk for physical and sexual violence. A study of rural men who have sex with men (MSM), found that men who thought health care providers in their community were intolerant of HIV positive persons, also reported more high-risk sexual behaviours (Janssen, 2001).

Stigma surrounding HIV, homosexuality, commercial sex work and drug use make it difficult for HIV prevention services to be offered in a variety of settings. While it is widely accepted that HIV prevention should be integrated into a broader health and community context, many community venues such as churches, businesses, jails, prisons and schools have resisted incorporating frank discussions of HIV. HIV/AIDS stigma can also negatively affect the health and well being of HIV positive persons. HIV positive persons may not seek treatment or delay going to doctors due to real or perceived discrimination against them. A national study of HIV positive adults found that 36 percent reported experiencing discrimination by a health care provider, including 8 percent who had been refused medical service (Herek, 1998).

Some HIV positive persons don't have an adequate support network because they fear that friends or family will abandon them or suffer the same stigma they do. One study of Asian and Pacific Islanders (API) living with HIV found high levels of internalized stigma. Asian and Pacific Islanders avoided seeking support because they were afraid of disclosure and saw themselves as unworthy of getting support (Brandt, 1980). Experiences of social rejection, disapproval and discrimination related to HIV may decrease the motivation of HIV positive persons to stay healthy (Duffy, 1990). A study of HIV positive men and women found that those who had experienced stigma were also more likely to miss HIV clinic appointments and lapse in adherence to their medication. Although stigma is considered a major barrier to effective responses to the HIV/AIDS pandemic, stigma reduction efforts are relegated to the bottom of AIDS program priorities. The complexity of HIV/AIDS related stigma is often cited as a primary reason for the limited response to this pervasive phenomenon (Brandt, 1980). In government health institutions, stigma is manifested in laws and policies. In these institutions, you find the centres taking care of people living with HIV/AIDS are normally located away from other main hospital departments and they are labelled as comprehensive care centres (comprehensive care centres) whose main function is to exclusively attend to HIV patients alone. HIV being a stigmatizing disease should not be treated separately from other medical problems as separating it is a form of discrimination and stigmatizing these people. Integrated services where they are attended to with other patients would appear to reduce stigma.

At Mbagathi District Hospital for instance, the comprehensive care centres is located on one side of the hospital compound as one enters the gate which automatically would expose those people living with HIV as they would be seen walking towards the centre. The study therefore aimed at determining how stigma contributes to the treatment failure in HIV patients undergoing treatment at Mbagathi District Hospital.

1.3 Research Questions

- i. How significant are the levels of treatment failure among the HIV patients undergoing treatment?
- ii. What are the commonest causes of stigma among the HIV patients undergoing treatment?
- iii. Does stigma contribute to the treatment failure in HIV patients undergoing treatment?
- iv. What are the strategies of stigma reduction among HIV patients undergoing treatment?

1.4 Objectives of the Study

1.4.1 Main Objective

To determine how stigma contributes to the treatment failure in HIV patients undergoing treatment in Mbagathi District Hospital.

1.4.2 Specific Objectives

- i. To establish the level of treatment failure among HIV patients undergoing treatment.
- ii. To identify the commonest causes of stigma among HIV patients undergoing treatment.
- iii. To determine how stigma contributes to the failure in treatment among HIV patients undergoing treatment.
- iv. To find out some strategies of stigma reduction among HIV patients undergoing treatment.

1.5 Importance of the Study

The study results would be beneficial to the organisations that focus on stigma since it contributes to shame, fear and silence that shape negative perceptions of people living with HIV and of the behaviours thought to be associated with HIV transmission. Several literatures in the series refer to a conspiracy of silence surrounding the disease that is both entrenched and pervasive.

The study would also be beneficial to the health care providers in the country since the perceptions of HIV, and of people living with the virus, are partly fuelled by the inadequate health care infrastructure and services in many settings. This means that there are few incentives for HIV testing and for disclosure of HIV status. If there is no adequate health care provision in the country, HIV–related stigma discourages infected and affected people from seeking counseling and testing, as well as other related prevention, care and support services that are available hence the researcher sought to determine the treatment failure in treatment experienced HIV/ AIDS patients at Mbagathi District Hospital.

Finally, the study would be beneficial to other researchers since it will add to the literature in the library on effect of stigma among HIV patients. The study findings would help develop the knowledge of stigma and HIV. To the researcher, it is advancement on what was taught in classes during the course work cover period.

1.6 Scope and Limitations of the Study

The study collected data only from staff members and HIV patients undergoing treatment at Mbagathi District Hospital. Collected data was only on matters of stigma and its relations to failure in the treatment of HIV experienced persons. The researcher collected data from patients that had consented in writing to participate in the study and the staff in the hospital had to agree in writing to participate in the study.

The study was limited by the respondents' half hearted willingness to participate in it. Since the study concentrated on the stigmatized individuals, there was limited participation in the study. The study was also limited by the challenged participation of the staff at Mbagathi Hospital due to fear of intimidation on their responses due to the

fact that most of the HIV/ AIDs information was treated with a lot of confidentiality and secrecy.

The study was limited by its sample since Mbagathi Hospital alone couldn't be fully representative of all hospitals in the country. The study was also limited by the fact that it is not really possible to quantify the failure or measure it.

The other factor is that causes of the failure may not be exhaustive in my study due to the fact that they are diverse and complicated. Furthermore the remedies that the study may cover are not exhaustive too.

CHAPTER TWO: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.0 Introduction

Chapter two gives the literature of the study based on the following sub-thematic areas: Views on Stigma; Stigma at Individual/Societal Levels; Levels of AIDS Stigma Manifestation in the Society; Problems Associated with HIV Stigma; Empirical Review and Theoretical Review.

2.1 LITERATURE REVIEW

2.1.1 Views on Stigma

Stigma generally refers to a negatively perceived defining characteristic, either tangible or intangible. It is an attribute used to set the affected persons or groups apart from the normalized social order, and this separation implies devaluation (Gilmore and Somerville 1994). In regard to HIV/AIDS, the stigma may be the actual infection or it may be based on behaviours believed to lead to infection. As the global pandemic first received international recognition in populations of men who have sex with men (MSM), injection drug users (IDU), and sex workers (SW), these already socially marginalized groups began to face additional stigmatization. In such cases, "... the stigma attached to AIDS as an illness is layered upon pre-existing stigma" (Herek and Glunt 1988). The association with an incurable disease is then used as medical justification for established patterns of exclusion of groups already deemed morally questionable (McGrath 1992). Conversely, people living with HIV/AIDS (PHA) may become implicitly associated with stigmatized behaviours, regardless of how they actually became infected (Tan and Brown 1994).

Kegeles et al. (1989) indicated that pathways of stigma are difficult to disentangle, but mutually reinforce each other. Furthermore, stigma may be applied with varying degrees of force, depending on local moral judgments about means of acquisition. Following a report given by Bunting (1996), in Southeast Asia, a clear gradient of "guilt" and "innocence" has formed the discourse surrounding HIV/AIDS. Sex workers or IDUs who contract HIV are classified as most guilty, with clients of SW following.

At the other end of the spectrum, common wisdom posits monogamous wives infected by their IDU or SW-client husbands as "innocent" and "vulnerable," while their HIV positive children, infected during pregnancy, birth, or breastfeeding become the ultimate "defenceless victims." Varying degrees of stigma are applied to these PHA groups, and often to their family members or immediate communities.

According to Bunting (1996) discrimination is composed of "... the actions or treatment based on the stigma and directed toward the stigmatized...." The stigmatized find themselves ostracized, rejected, and shunned (Alonzo et al. 1995) and may experience sanctions, harassment, scapegoating, and even violence based on their infection or association with HIV/AIDS. McGrath (1992) indicate that discrimination may spring from social disapproval of the infection and its implied behaviours or from fears due to lack of knowledge about how HIV/AIDS can or cannot be transmitted. Because the HIV pandemic emerged so suddenly and progressed so quickly, in many countries discrimination could result from people's belief "... that not enough time remains to weigh carefully the strengths and weaknesses of various alternative solutions to an AIDS-related problem" (Herek and Glunt 1988) and the reaction is thus to err on the side of caution, even at the expense of individual rights.

2.1.2 Stigma at Individual/Societal Levels

According to HRSA (2009), HIV/AIDS doesn't discriminate; people do. AIDS stigma can be experienced at both the individual and societal level. At the individual level, AIDS stigma takes the form of behaviours, thoughts, and feelings that express prejudice against people living with HIV or AIDS, and can also be experienced by persons perceived to be living with HIV/AIDS. Further, concerns about stigma affect an individual's decision to get tested, access health care, and withhold information about their status from family members, friends, and care providers. Social isolation negatively affects the lives of people living with HIV.

At the societal level, Herek and Glunt (1988) indicated that AIDS stigma is manifested in laws, policies, popular discourse, and the social conditions of persons living with HIV/AIDS and those at risk of infection. NASW (2008) recognizes that people with

HIV/AIDS, and sometimes even those that have been tested for the virus, continue to face discrimination in employment, military service, housing, access to health services, social and community programs, and basic civil and human rights. NASTAD (2001) also indicate that societal stigma emerges in the form of laws, regulations, and policies that single out people with HIV. For example, local school boards' refusal to enrol HIV-positive children; the criminalization of HIV transmission and forcible segregation of HIV-positive prisoners; and reducing the protections afforded to HIV-positive individuals under the Americans with Disabilities Act (ADA). Additionally, Wilson, (2010) felt that social stigma is practiced through failure of public policy and practices as well as private groups; non-government organizations (NGO's), and faith based organizations that do not recognize or ensure equal rights for gay, lesbian, bisexual, and transgender persons.

Even though awareness of HIV and AIDS in Kenya is high, many people living with the virus still face stigma and discrimination. Studies have shown that although people are aware of the basic facts about HIV and AIDS, many do not have the more in-depth knowledge that addresses issues of stigma (Njue, 2009). With 16 percent of people living with HIV in Kenya reporting having felt suicidal, social stigma of HIV is an urgent issue.

One report revealed that only a third of healthcare facilities that have policies to protect people living with HIV against discrimination were actually implementing such policies (Cheluget, 2006). People are still afraid to disclose their status and will often avoid health centres that provide HIV services, from fear of being seen by neighbours or community members. Surveys among people living with HIV have shown that 30 percent have reported being excluded from family events and 79 percent have reported being gossiped about by members of their community (NACC, 2009).

2.1.3 Levels of AIDS Stigma Manifestation in the Society

Ankrah, (1993) indicates that HIV/AIDS-stigma manifests at various levels of the society, ranging from the family to such public places like health sector, employment places and at religious circles. In developing countries, families and communities are

generally supportive for illness management and treatment. However data from Bharat (1999) indicate that some African and Asian countries report both supportive and non-supportive household responses to HIV-positive people while negative responses are more evident in the case of HIV-positive women (Warwick et al 1998) and those whose lifestyles and sexual behaviour elicit popular disapproval (Warwick et al 1998). The harassing and scapegoating of individuals suspected of being infected or of belonging to a particular group has been widely reported. In extreme circumstances it can lead to acts of violence and murder (Nardi and Bolton, 1991). For instance, Peterson (1990) reported that CSWs and street children in Brazil have been singled out for violence and abuse while Panos (1990) reported HIV-related murders in diverse countries such as Ethiopia, South Africa, India, etc.

Family responses to infected individuals are heavily influenced by community perceptions of the disease. Those families with People living with HIV/AIDs may fear isolation and ostracism within the community (McGrath et al 1993). Consequently they may try to conceal an HIV diagnosis, which in turn may cause considerable stress and depression within the family (Bharat and Aggleton, 1999). Despite the fact that the family plays an important role in providing support and care for people living with HIV/AIDS, infected family members may still be stigmatized and discriminated against within the home. In this case women are reported to be more badly treated than children and men so management of stigmatization within the wider community by family members may affect health care utilization and even the quality of care (World Bank, 1997).

Lwihula et al (1993) reported that families might shield affected members from the community by keeping them within the house or by protecting them from questioning. Also fear of rejection and stigmatization within the home and local community may prevent people living with HIV/AIDS revealing their sero-status to family members (McGrath et al 1993). In Indonesia, Horizons (1999) reported that families in Bali have been found to separate the household items, clothing and personal belongings of people living with HIV/AIDS. Sometimes entire family has experienced rejection by the wider community (Sarjana et al 1999).

Reports also reveal the extent to which individuals are stigmatized and discriminated against by the health care system. There have been reports of withheld treatment (Panebianco et al 1994), non-attendance of hospital staff to patients left lying in their beds (Ogola 1990, Msini); HIV testing without consent, breaches of confidentiality, and denial of hospital facilities and medications (Panebianco et al 1994). Many health workers are reported to have expressed negative attitudes to people living with HIV/AIDS and would demonstrate a preference not to treat them. Contributing to the above responses are ignorance and lack of knowledge about HIV/AIDS transmission (Herek et al 1998) and the perceived incurability of the disease, these conspire to make it appear pointless to offer quality care (UNAIDS, 2000). The existence of AIDS-stigma in health care settings is a serious threat to HIV/AIDS prevention care and treatment efforts. AIDS-stigma has also been reported in the working places (UNAIDS, 2000).

According to Panos (1990), in Zambian workplaces, people with HIV/AIDS were ostracized, isolated and gossiped about. Affected individuals are subjected to mental abuse and dismissal from work on grounds of sero-status has been noted in some countries namely Thailand, Singapore, Malaysia and Indonesia. Hira et al (1998) reported that in India most businesses had no policy on AIDS and management has adopted the wait and see attitude – waiting to see how many workers became infected and whether this had an impact on productivity Ditto in Nigeria (Rosen et al 1998). Anecdotal evidence of employment related discrimination and stigmatization has begun to emerge. Individual cases of job loss, emotional isolation, and denial of employment on the basis of HIV status have been reported in the media but again these are cached in anonymity because of the need to protect the persons involved. The validity of these experiences becomes difficult to measure. In Nigeria, a high court judge refused to entertain a case brought to her by an HIV-positive woman for fear of 'spreading' the disease in her court. In another case, a young man who tested positive in Ibadan City of Nigeria committed suicide because 'he was not ready to bear the shame'.

According to UNAIDS (2000), the religious sector has also been reported to be instrumental to the perpetuation of AIDS-stigma. In Nigeria, the failings of religious

leaders (Christians and Moslems) to date centre around the ostracization and marginalization of people living with HIV/AIDS and the refusal of the leaders to turn inward and confront their own attitudes toward the epidemic and the social behaviours associated with the spread of HIV. Rosen et al (1998) also indicated that the leadership interprets the pandemic to be a punishment from God for the sin of the infected. The stigma attached to the AIDS virus obviously has many far-reaching effects. A person victimized by the disease is further victimized by society. Family, friends and neighbours often alienate HIV-positive people. He finally indicated that the surrounding community attacks or ostracizes them and the government balks at the prospect of enacting legislation; but even if enacted, implementation becomes difficult since the mass media unabashedly publishes incendiary lies about the disease, and the medical community does little to combat the lies with their actions.

According to UNAIDS (2000), all of these forms of discrimination create an environment extremely unfriendly to the victims of the epidemic. To avoid stigma, discrimination and possible losses, 'sero-positive individuals attempt to conceal their status, and this causes them to be cut off from social support and needed medical and social services. They may also delay in obtaining medical care or fail to adhere adequately to medical treatment regimens once they enter care. Herek et al (1998) also indicated that AIDS-stigma can also interfere with people living with HIV/AIDS's coping and adjustment. The psychological distress experienced may be exacerbated by self- imposed isolation and experiences with ostracism, hostility and discrimination'. There have been reports of People living with HIV/AIDs committing suicide in Nigeria. Individuals may blame themselves to the extent that they cease to exert their right to decent treatment and other social benefits.

The perpetrators of AIDS stigma are individuals who express negative attitudes or feelings toward people living with HIV/AIDS or who engage in discrimination or other stigmatizing behaviours (Herek et al 1998). There are two fundamental sources of negative reactions to AIDS victims. The perpetrators may fear certain outcomes directly related to HIV stigma; this results in what is called instrumental stigma. This arises as a result of the fact that AIDS is regarded as generative and fatal conditions; it

is transmissible, hence the affected person is seen as repellent, ugly or upsetting. Any disease that is degenerative, ugly and repellent and disfiguring is likely to be stigmatized. Rosen et al (1998) also indicated that symbolic AIDS stigma results from social meanings attached to AIDS. It also represents the use of disease to express attitudes toward the groups associated with it and the behaviours that transmit it. AIDS stigma is also affected by attitudes toward other stigmatized groups associated with HIV in public perceptions.

2.1.4 Problems Associated with HIV Stigma

Existing studies and commentaries have noted that stigma remains a major fact of life for persons living with HIV/AIDS in sub-Saharan Africa and the rest of the world. The issue of gender as well as poverty, lack of economic opportunities, limited access to education, information and services, traditional norms and practices exacerbates this (Kelly, 2003). Panos (2001) reported a study in Zambia, India, Ukraine and Burkina Faso, which found that pregnant women with HIV suffer multiple layers of stigma. They may be devalued because they are women, have HIV and because they are pregnant and have HIV. Moreover in settings where breast- feeding is the norm, the decision by an infected mother not to breast- feed could draw attention to her sero-status placing her at risk of abuse and ostracism (ICRW, 2002). Even the concept of MTCT invites negative reactions since it implies that the woman transfers the virus to the baby. The blame becomes more accentuated if the child is a male in cultures that place high value on male children (Panos 2001).

Four studies tested information-based approaches alone, one each in the United States, Jamaica, Tanzania, and Israel (Ashworth et al. 1994; Hue and Kauffman 1998; Mwambu 1998; Soskolne et al. 1993). Overall these studies found positive effects (i.e., increased tolerance of people living with HIV/AIDS) in comparison to control groups, if there was one. However, where more than one approach was tested there was no difference between intervention groups. For example, Ashworth et al. (1994) tested the provision of the same information in two different formats, a 15-minute videotape on AIDS and a standardized presentation of AIDS facts given by a black nurse educator, among poor black American women. This study found that compared to the control

group, both experimental groups had a higher tolerance toward people living with HIV/AIDS at both the immediate post-test and at the two-month follow-up, although no differential treatment effects were observed. In Jamaica and Israel, significant increases in positive attitudes toward people living with HIV/AIDS were achieved through the provision of information provided through peer education, lectures, pamphlets, or workshops.

Five studies combined information-based approaches with counselling (Kaleeba et al. 1997; Kerry and Margie 1996; Kikonyogo et al. 1996; Nansubuga, Aneko and Kirega 1996; Simpson et al. 1998), a strategy used to provide praise and social support for positive attitudes, behaviour change, or maintenance of safe behaviours. An example of this approach is a support group for people living with HIV/AIDS, in which individuals receive personal support for resolving issues or situations with spouses, families, communities, and so forth, in a safe environment. All five information and counselling studies targeted their interventions at people living with HIV/AIDS and those potentially at risk. Two studies focused on HIV testing, one to improve uptake of the HIV test among antenatal women in a Scottish hospital (Simpson et al. 1998) and the other to reduce emotional distress after having the HIV test (Perry et al. 1991). The latter used the counselling sessions for behavioural reinforcement and to teach coping skills acquisition. The interventions in both of these studies reduced anxiety and distress in the experimental groups as compared to controls, but there were no differential treatment effects across experimental groups. The interventions tested in the three remaining studies-two in Uganda and one in Zimbabwe-increased disclosure among people living with HIV/AIDS and improved community attitudes compared with a baseline measure, although there were no control groups.

According to Collymore (2003), interventions that attempted to teach potential perpetrators skills for diffusing conflicting situations were applied at the individual or small group level, because more instruction was required than a standard presentation of facts. The five studies conducted among small groups of psychology and other students tested these types of approaches. Perry et al. (1991) further indicated that master imagery and group desensitization are examples of coping skill acquisition

techniques. In master imagery an individual is presented with a hypothetical situation where they have contact with a people living with HIV/AIDS and is taught appropriate coping skills for resolving the situation. Group desensitization teaches relaxation training first and then progressively exposes the individual or group to a number of situations in which there is exposure to people living with HIV/AIDS, utilizing the newly learned relaxation techniques to decrease tension in a hypothetical situation.

Two studies used a combination of information and coping skill acquisition to increase positive attitudes toward people living with HIV/AIDS among members of the general community. A study among primary school children in Tanzania used role-play and small group discussions in addition to factual information, with the hope that improving their knowledge, attitudes, and practices would have beneficial effects on the surrounding communities (Klepp et al. 1997). Using a randomized community trial, local teachers and health workers implemented a two- to three-month program consisting of AIDS related information, small group discussions about risk reduction, and student-created posters depicting perceptions of HIV risk factors. Attitudes toward people living with HIV/AIDS among the school children at the 12-month follow-up significantly improved. The second study used information/coping skills acquisition strategy tested techniques to resolve negative feelings among physical therapy students in New York and increased their willingness to treat people living with HIV/AIDS (Held 1992). Contact with infected or affected groups was used alone or in combination with other approaches in seven studies (Batson et al. 1997; Bean 1989; Herek and Capitanio 1997; Mwandha and Were 1998; Venkataraman et al. 1996; Wyness, Goldstone, and Trussler 1996). Contact creates an environment in which the general population can interact with the stigmatized group, either directly or vicariously (e.g., through the media). The theory is that a more personal relationship with a people living with HIV/AIDS, either through face-to-face conversations or hearing a testimonial from infected or affected individuals, will demystify and dispel misinformation and generate empathy, which in turn reduces stigma and prejudice (Allport 1954; Brewer and Miller 1984).

The Herek and Capitanio (1997) study was a natural intervention that looked at the effects of Earvin "Magic" Johnson's disclosure of his HIV status to the public three weeks before the second wave of a national telephone survey took place. Among those respondents who reported being strongly influenced by Johnson's disclosure, avoidance of people living with HIV/AIDS scores was lower at wave II. However, these same individuals were also found to have had very high avoidance scores and strong support for coercive policies of people living with HIV/AIDS at wave I. This means that they originally had highly stigmatizing scores and subsequently had the most room for improvement. Individuals who had low avoidance scores at wave I did not reduce their avoidance scores at wave II. Support for coercive policies for people living with HIV/AIDS and attitudes of blame toward specific groups for spreading the disease remained unchanged at wave II.

According to ICRW (2002), the language that surrounds the epidemic helps reinforce these stereotypes and attitudes. Derogatory terms are used to describe those with the virus. The ICRW study in Tanzania and Zambia found that the choice of terms for HIV was influenced by popular culture and by HIV education messages. Myths and ignorance about the ways in which HIV is transmitted also trigger damaging attitudes. Various euphemisms are used to describe the disease and those affected by it. Its tendency to disfigure one's appearance and to impair one's ability for social interaction is one of the reasons why People living with HIV/AIDs are stigmatized. Thirdly it is a sexually transmitted disease (Hallman, 1989). This means that society looks down upon it for its connection with immoral behaviour (Berk, 1988). Another point is that in the early years of HIV/AIDS, it was associated with individuals on the unpopular fringe of society such as homosexuals, commercial sex workers, and drug addicts. Hence AIDS was and is regarded as God's punishment to these "evil doers". Added to these points are the facts that there is no cure, and it is fatal. These factors combined scared the public to create a stigma associated with the disease as much if not more popular than knowledge about the disease itself (Herek et al 1998; Omangi, 1997). In fact most of the points were mentioned in the Nigerian study. Although AIDS stigma is a product of the HIV epidemic, the association of stigma with the disease is not a new phenomenon.

History has shown that stigma associated with epidemic illnesses and the social groups linked to them have often hampered treatment and prevention (Herek et al 1996). Thus AIDS stigma displays continuity with many past epidemics. However in the case of AIDS, the nature and intensity of stigma are shaped by the social construction of the epidemic in different locales. It takes different forms in different societies while the specific groups targeted for AIDS stigma vary considerably across cultures and national borders. The factors affecting this variation include the local epidemiology of HIV, preexisting beliefs and values surrounding sexuality, disease, gender and prejudices toward specific cultural out groups. It is thus an expression of social and cultural norms shaping relationships among people according to some societal norms (Alonzo and Reynolds, 1995). The stigmatized are usually considered deviant or shameful and as a result are shunned, avoided, discredited, rejected, restrained or penalized.

2.1.4.1 HIV Stigma Tends to Heighten Existing Prejudices

According to UNAIDS (2000), vulnerable groups such as women and girls, sex workers, men who have sex with men, and injecting drug users, tend to experience the harshest forms of HIV stigma, including violence and the refusal of health and other services. Thus, stigma tends to be most debilitating for people who are already socially excluded, most vulnerable to HIV, often subject to discriminatory laws, and frequently neglected in national AIDS responses.

2.1.4.2 HIV Stigma Undermines Prevention

People often avoid being associated with HIV, with devastating effects on prevention, care and treatment. Stigma can reduce the likelihood of people using condoms and accessing preventive services such as educational meetings and counselling. People who hold stigmatizing attitudes are also less likely to adopt preventive behaviours. One study among Chinese migrants found those holding stigmatizing beliefs were more likely to have multiple sexual partners, a commercial sex partner, and a sexually transmitted infection. Those with stigmatizing beliefs were also less likely to use condoms (Panos 1990).

2.1.4.3 Stigma can deter or delay testing and disclosure.

According to McGrath et al (1993), in Botswana, a survey of HIV patients receiving antiretroviral therapy (ART) found that 40 percent had delayed getting tested for HIV, mostly due to stigma. Stigmatizing beliefs, which perpetuate the notion that HIV only happens to others, also can reduce testing, as people are less likely to believe they are at risk. Further, he indicated that a study of truckers in Brazil found that men with more stigmatizing attitudes were less likely to have had an HIV test. Finally, stigma often prevents disclosure of an HIV-positive status to partners, providers and family members, which in turn deter behaviours that can prevent further spread of HIV, such as condom use, or mitigate its impact, such as care seeking. A review of 17 studies on (Panos 1990) disclosure found the main barriers to disclosure for women are fear of infidelity accusations, abandonment, discrimination and partner violence. Of women who disclosed, 3.5 percent to 14.6 percent reported experiencing a violent reaction from a partner. Stigma also can delay disclosure. Only half of people living with HIV in a Tanzania study had disclosed their status to an intimate partner. Among those who had disclosed, the average time from knowing their status to disclosure was 2.5 years for men and 4 years for women.

2.1.4.4 Stigma reduces the quality of care

Stigma deters use of health facilities and adversely affects quality of health services. People with HIV have been refused services, denied medicine, passed from provider to provider, tested for HIV or have had their sero-status disclosed without consent, and isolated unnecessarily. Groups such as sex workers, men who have sex with men and injecting drug users face additional barriers in accessing care. These include avoidance of care seeking due to fear of being "found out," discrimination by health workers, and, in some instances, of incarceration and having their property taken away (McGrath et al 1993).

2.1.4.5 Stigma can delay treatment and reduce survival.

Delayed testing can lead to delayed diagnosis and treatment. People who begin ART in the earlier stages of HIV (e.g., stages two or three) have a longer life expectancy than people who wait until it is more advanced (e.g., stage four). One study found a 94

percent increase in the risk of death among patients who did not start ART until stage four (UNAIDS, 2000).

2.1.4.6 Stigma impedes adherence to medication

ART requires strict adherence for effectiveness, and adherence is the strongest determinant of patient survival. In South Africa, fear of stigma has led people to grind drugs into powder, which can result in inconsistent doses, and to avoid taking medicines in front of others. Stigma also adversely affects mental health, and depression interferes with consistent drug use (UNAIDS, 2000).

Similarly, the results from a 2009 study conducted by Otieno et al suggest that stigma accounts for 78 percent of women's reasoning as to why not to access HIV health care programs. Although accessing maternal health care at clinics does not automatically declare one's positive HIV status, healthy women perceived HIV inclusive care clinics to bear a higher social cost should anyone assume a positive diagnosis (Otieno et al, 2009).

2.2 THEORETICAL FRAMEWORK

2.2.1 Labelling Theory

Labeling theory is the theory of how the self-identity and behavior of individuals may be determined or influenced by the terms used to describe or classify them. It is associated with the concepts of self-fulfilling prophecy and stereotyping. Labeling theory holds that deviance is not inherent to an act, but instead focuses on the tendency of majorities to negatively label minorities or those seen as deviant from standard cultural norms (Becker, 1973). The theory was prominent during the 1960s and 1970s, and some modified versions of the theory have developed and are still currently popular.

Labeling theory concerns itself mostly not with the normal roles that define our lives, but with those very special roles that society provides for deviant behavior, called deviant roles, stigmatic roles, or social stigma. A social role is a set of expectations we have about a behavior. Social roles are necessary for the organization and functioning

of any society or group. We expect the postman, for example, to adhere to certain fixed rules about how he does his job.

In 1999, Link and colleagues tested modified labeling theory in a longitudinal study that compared the effects of stigma on the well-being of clients who had mental illness and a pattern of substance abuse to determine the strength of the long-term negative effects of stigma and whether the effects of treatment have counter-balancing positive effects Link et al., 1999). They found that perceived devaluation and discrimination, as well as actual reports of discrimination, continued to have negative effects on clients even though clients were improved and had responded well to treatment. They concluded that healthcare professionals attempting to improve quality of life for clients with mental illness must contend initially with the effects of stigma in its own right to be successful.

Modified Labeling theory has been described as a "sophisticated social-psychological model of 'why labels matter' ". In 2000 results from a prospective two-year study of patients discharged from a mental hospital (in the context of deinstitutionalization) showed that stigma was a powerful and persistent force in their lives, and that experiences of social rejection were a persistent source of social stress. Efforts to cope with labels, such as not telling anyone, educating people about mental distress/disorder, withdrawing from stigmatizing situations, could result in further social isolation and reinforce negative self-concepts. Sometimes an identity as a low self-esteem minority in society would be accepted. The stigma was associated with diminished motivation and ability to "make it in mainstream society" and with "a state of social and psychological vulnerability to prolonged and recurrent problems". There was an up and down pattern in self-esteem, however, and it was suggested that, rather than simply gradual erosion of self-worth and increasing self-deprecating tendencies, people were sometimes managing, but struggling, to maintain consistent feelings of self-worth. Ultimately, "a cadre of patients had developed an entrenched, negative view of themselves, and their experiences of rejection appear to be a key element in the construction of these self-related feelings" and "hostile neighbourhoods may not only

affect their self-concept but may also ultimately impact the patient's mental health status and how successful they are (Bruce et al, 2002).

2.2.1.1Applications of Labelling Theory

Fife and Wright (2000) studied stigma using modified labeling theory as a framework in individuals with HIV/AIDS and cancer. They found that stigma had a significant influence on the lives of persons with HIV/AIDS and with cancer. However, they also found that the nature of the illness had few direct effects on self-perception, whereas the effects on self appeared to relate directly to the perception of stigma. Their findings suggested that stigma has different dimensions, which have different effects on self. Rejection and social isolation lead to diminished self-esteem. Social isolation influences body image. A lack of sense of personal control stems from social isolation and financial insecurity. Social isolation appears to be the only dimension of stigma that affects each component of self.

Camp, Finlay, and Lyons (2002) questioned the inevitability of the effects of stigma on self based on the hypothesis that, in order for stigma to exert a negative influence on self-concept, the individuals must first be aware of and accept the negative selfperceptions, accept that the identity relates to them, and then apply the negative perceptions to themselves. A study of women with long-term mental health problems found that these women did not accept negative social perceptions as relevant to them. Rather, they attributed the negative perceptions to deficiencies among those who stigmatized them. These researchers found no evidence of the passive acceptance of labels and negative identities. These women appeared to avoid social interactions where they anticipated feeling different and excluded, and formed new social networks with groups in which they felt accepted and understood. Whereas they acknowledged the negative consequences of mental illness, there did not appear to be an automatic link between these consequences and negative self-evaluation. Factors that contributed to a positive self-evaluation included membership in a supportive in-group, finding themselves in a more favorable circumstance than others with the same problems, and sharing experiences with others who had knowledge and insight about mental illness.

The practical relevance of the sociological construct of 'labelling' has been acknowledged within medical practice since the 1960s. Labelling theory draws attention to the view that the experience of having an illness has both social as well as physical consequences for an individual. This approach, however, is much more concerned with societal reaction to the attachment of a chronic disease label than with the physical impact of that illness. Here the notion of the 'symbolic meanings' attached to an illness comes into play. Symbolic meanings are, for sociologists, the shared social connotations and imagery that are associated with particular events and objects and upon which our actions are largely based.

2.2.2 Social Identity Theory

In Erving Goffmans theory of social identity, a stigma is an attribute, behaviour, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in undesirable, rejected stereotype rather than in an accepted, normal one. Goffman, (1963) a noted sociologist, defined stigma as a special kind of gap between virtual social identity and actual social identity; society establishes the means of categorising persons and the compliment of attributes felt to be ordinary and natural for members of each of these categories. He added that when a stranger comes to our presence, then, first appearances are likely to enable us to anticipate his category and attributes, his "social identity" we lean on these anticipations that we have, transforming them into normative expectations, into righteously presented demands. He also indicated that it is when an active question arises as to whether these demands would be filled that we are likely to realise that all along we had been making certain assumptions as to what the individuals before us ought to be.

Goffman, (1963) also indicated that the assumed demands and character we impute to the individual would be called virtual social identity. The category and attributes he could in fact be proved to posses will be called his actual social identity. He added that while a stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to

a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effects are very extensive. Finally, he concluded that it constitutes a special discrepancy between virtual and actual social identity and should be known that there are other types of (such) discrepancy for example, the kind that causes us to reclassify an individual from one socially anticipated category to a different but equally well anticipated one, and the kind that causes us to alter our estimation of the individuals upward.

2.2.2.1 Goffman's Theory relationship to the subject of the study

Just the fact that stigma is regarded as above, it is proper to look at it in the manner by which HIV/AIDS patients are discriminated in most hospitals thereby enhancing stigma in them and the people around them. One form of this discrimination or rather stigmatization is the way most comprehensive care centres are constructed in most hospitals and their locations mostly separate from other hospital installations and departments. Most of these centres are alone and it is a known fact that the centres cater specifically for HIV/AIDS patients. This means that every time a HIV patient comes to the hospital, everyone will know that he/she is a HIV positive person because they will be seen turning and walking to the centre while other patients with other ailments will go to the main hospital. This alone is stigmatizing enough knowing that many of the victims would want to remain secret as to their ailment.

Setting of the centres separate from where other patients are attended to alone is an attribute that only HIV patients are treated there. This is the situation at Mbagathi District Hospital where the comprehensive care centre is on its own near the gate while the area for other ailments are put together meaning nobody will know what you came to the hospital to be treated for. Socially it is discrediting to find that you have been segregated and categorized and assigned a separate place for treatment more so if it is a stigmatizing disease like HIV/AIDS. Attributes that make HIV patients different from others are perceived infectiousness of the disease and thus the categorization. He /she are perceived as a less desirable kind of a person and a dangerous person who can infect others with the incurable disease. Therefore, this person is reduced in our minds

from a whole and usual person to a tainted, discounted one and such an attribute is a stigma.

2.2.3 Family Theory of Discrimination

Discrimination, in family theory postulated by Becker (1981), takes form as mental categorization of minorities and the use of stereotype. This theory describes difference as deviance from the norm, which results in internal devaluation and social stigma that may be seen as discrimination. It is started by describing a 'natural' social order. It is distinguished between the fundamental principle of fascism and social democracy. This theory emerged from General Systems Theory by scholars who found it had many applications to families and other social systems. Any system is defined as a bounded set of interrelated elements exhibiting coherent behavior as a trait (Constantine, 1986). Another definition is an assemblage of objects related to each other by some regular interaction or interdependence. Families are considered systems because they are made up of interrelated elements or objectives, they exhibit coherent behaviors, they have regular interactions, and they are interdependent on one another (Williams, 2001).

2.2.3.1Applications of Family Theory of Discrimination

According to this theory children and adults with experience of HIV are at high risk of internalizing stigma and suffering diminished self-esteem, feelings of confidence and mastery in their own abilities (Corrigan, 1998, Link, 1987). The low self-esteem that results from internalized stigma is often experienced as shame, and interferes with a person's life goals and quality of life (Corrigan, 2004). This low self-esteem and demoralization from constant reinforcement that one is shameful and devalued has been associated with failing to pursue work or independent living. In the view of one researcher, "It is undoubtedly threatening and personally disheartening to believe that one has developed an illness that others are afraid of" (Link et al, 2001). Internalized stigma is also related to willingness to engage in treatment.

The combined effects of societal stigma internalized by adults and children with AIDS can lead to substance abuse and suicide. According to Corrigan, (2004), almost half of people with the disease develop alcohol or other drug use problems at some point in

their lives. Substance use exacerbates symptoms, hospitalization, depression, suicide, incarceration, family friction and costs of treatment. It also exposes people to negative life outcomes and to health risks such as violence (Department of Health and Human Services, 1999). However, despite the high association of substance abuse and AIDS, substance abuse treatment for persons with HIV/AIDS is scarce.

Exacerbated by separate delivery systems that are both underfunded, majority of HIV/AIDS patients in the world need psychological treatment to move forward in recovery, but do not receive it (Little Hoover Commission, 2000). Family members and caregivers of persons with HIV are also frequently treated with stigma and discrimination. Known as "stigma by association," parents, partners and spouses, caregivers, siblings, and other relatives who care about a person with the illness often face obstacles and barriers that are associated with the problems of illness, and the struggle to navigate a disconnected and poorly funded health system.

Programs that support families, lighten financial burdens, support caregiver mental health and provide respite for stressed families and caregivers are practically non-existent in the underfunded health system. Programs that appropriately acknowledge the contribution of family members and caregivers are essential to reducing stigma, preventing discrimination and supporting the well-being of those with HIV/AIDS as well as their families and support systems In many countries and communities, the stigma associated with HIV and the resulting discrimination can be as devastating as the illness itself: abandonment by spouse and/or family, social ostracism, job and property loss, school expulsion, denial of medical services, lack of care and support, and violence. These consequences, or fear of them, mean that people are less likely to come in for HIV testing, disclose their HIV status to others, and adopt HIV preventive behaviour, or access treatment, care and support and if they do, they could lose everything.

Globally, stigma and discrimination are associated with lower uptake of HIV preventive services, including under or nonparticipation in HIV information meetings and counselling and reduced participation in programs to prevent mother-to-child

transmission (Tan and brown, 1994). Stigmatizing attitudes are associated with denial of risk and a lower likelihood of adopting preventive behaviours. According to Gilmore (1994) both the fear of stigma and stigmatizing beliefs which perpetuate the notion that HIV only happens to others keep people from testing in numerous contexts. Women tend to experience greater stigma and discrimination than men, are more likely to experience its harshest and most damaging forms, and have fewer resources for coping with it. Violence is a severe consequence of stigma faced principally by women. Both women and girls report increased violence at the hands of their partners for requesting condom use, accessing voluntary testing and counselling, refusing sex within or outside marriage or for testing HIV-positive (McGrath, 1992).

2.3 CONCEPTUAL FRAMEWORK

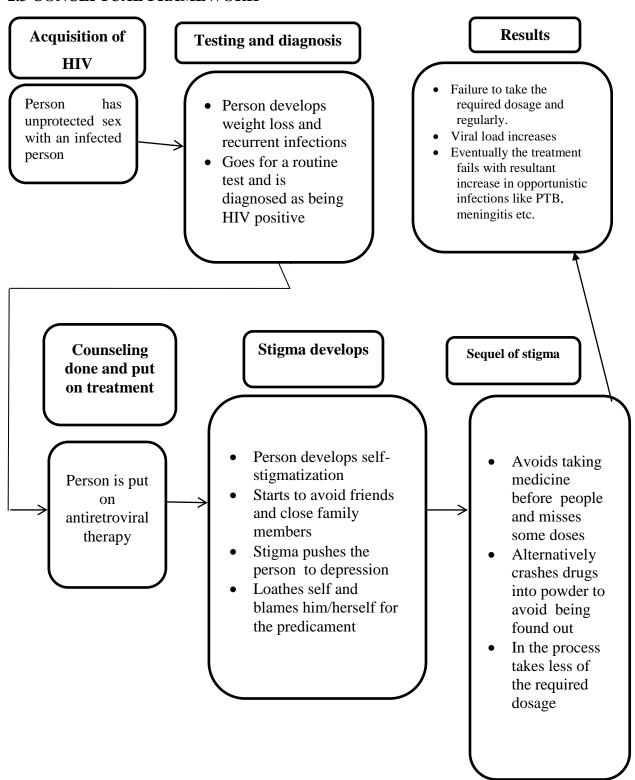


Figure 2.1: Conceptual Framework

2.4 CRITICAL REVIEW OF THE CHAPTER

The results by other scholars in the literature have indicated that AIDS stigma and discrimination exist worldwide, although they manifest themselves differently across countries, communities, religious groups and individuals. They occur alongside other forms of stigma and discrimination, such as racism, stigma based on physical appearance, homophobia or misogyny and can be directed towards those involved in what are considered socially unacceptable activities such as prostitution or drug use. The literature has clearly indicated that stigma not only makes it more difficult for people trying to come to terms with HIV and manage their illness on a personal level,

but it also interferes with attempts to fight the AIDS epidemic as a whole however, no study has indicated the effect of stigma on the government efforts towards HIV reduction yet it is indicated at the literature that on a national level, the stigma associated with HIV can deter governments from taking fast, effective action against the epidemic, whilst on a personal level it can make individuals reluctant to access HIV testing, treatment and care.

Various scholars have indicated that HIV/AIDS-related stigma is not a straightforward phenomenon as attitudes towards the epidemic and those affected vary massively. Even within one country reactions to HIV/AIDS will vary between individuals and groups of people. Religion, gender, sexuality, age and levels of AIDS education can all affect how somebody feels about HIV and AIDS since AIDS-related stigma is not static and it changes over time as infection levels, knowledge of the disease and treatment availability vary.

The findings in the literature have indicated that it is difficult to assess the accuracy of the study topic as levels of stigma are hard to measure and a number of small-scale studies have shown that the relationship between increased access to HIV treatment and a reduction in stigma is not always clear. From the literature, a study of 1,268 adults in Botswana found that stigmatizing attitudes had lessened three years after the national programme providing universal access to treatment was introduced. However, the study concluded that although improving access to antiretroviral treatment may be a factor in

reducing stigma, it does not eliminate stigma altogether and does not lessen the fear of stigma amongst HIV positive people.

However the study literature hints that as there are many types of stigma, it is possible that the availability of treatment may reduce some types of stigma and not others. For example, a study in Tanzania (from literature review) found that, on the one hand, stigma caused by the perception of people living with HIV as weak and therefore a 'burden' on the community had decreased with the uptake of treatment. The tendency of people living with HIV to 'self stigmatize' had also decreased, as contact with not only health professionals but also with other people living with HIV helped them see that they were not alone. On the other hand, 'fear based stigma' was found to have increased. Those studied were concerned that because it was now difficult to differentiate between people infected with HIV, and those who are not, HIV transmission would increase as they would no longer know to "avoid those who 'look ill".

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

This chapter will outline methodology in line with the research questions of the study. In this chapter the research methodology is presented in the following order, research design, target population, sample size and sampling technique, data collection method, validity, reliability, data analysis, presentation and ethical issues.

3.2 Research Design

Research design refers to the method used to carry out a research. This research problem was studied through the use of a descriptive survey research design. According to Cooper and Schindler (2003), a descriptive study is concerned with finding out the what, where and how of a phenomenon. Descriptive survey research design was chosen because it enables the researcher to generalise the findings to a larger population. Gill and Johnson (2006) also observed that descriptive surveys address specific characteristics of a selected population of subjects at a point in time, for the purpose of comparing the relationship between variables. Thus, this study addressed specific characteristics of the HIV patients undergoing treatment in a bid to establish the how stigma contributes to the treatment failure.

3.3 Study Area

Mbagathi District Hospital is located in Nairobi Dagoretti District in the capital city of Kenya. It borders KEMRI to the South, memorial hospital to the East, Mbagathi road and Kenyatta National hospital to the North and Kenyatta market, Ngumo estate and Kibera slums on the Western side. Much of the hospital's catchments area is from Kibera slums. Kibera is the largest slum in Kenya and in the region, that is, East and Central Africa.

The hospital was built to admit and treat infectious diseases such as measles, cholera, diarrhoea, epidemics, leprosy, meningitis, plague, tuberculosis (TB) and HIV/AIDS among others. The hospital was opened with 266 beds and at that time used to isolate infectious diseases such as tuberculosis. It was built in the early 1950s to offer healthcare services and was later opened on 17th May1956 by Sir Fredrick Crawford,

the then deputy governor of Kenya. It was then called South Hill Hospital for infectious diseases and was run as a component of the main Hospital, King George VI now Kenyatta National Hospital. People would refer to it as IDH, that is infectious diseases hospital. Upon independence in 1963 King George Hospital was renamed Kenyatta National Hospital, while infectious disease hospital (IDH) became the popular name of this part of Kenyatta National hospital complex. Kenyatta national hospital upon becoming a state corporation in 1987, the ministry of health decided to make infectious diseases hospital (IDH) an autonomous entity and renamed it as Mbagathi District Hospital run under the ministry. Today it's a level 4 District Hospital with a bed capacity of 200 beds in the 4 blocks of the wards, and a new maternity wing of 150 beds capacity. Daily the number of patients coming to the hospital as out patients in all the clinics including the comprehensive care centre (CCC) is about 800 to 1000 patients.

The move to deliberately separate it from Kenyatta National Hospital was to decongest Kenyatta National Hospital and it was officially commissioned on 1st July 1995. The challenge was then to convert it from a special tertiary infectious disease hospital with a stigma of dangerous infectious diseases to a simple community hospital. The stigma has not fully dissipated due to the fact that most TB patients and HIV/AIDS patients are admitted in the Hospital for intensive and comprehensive care. Today as a District Hospital, it is offering to the public most health care services as can be found in any other District Hospital in the country.

3.4 Target Population

A population is the group that the research focuses on in accordance to Cooper and Schindler (2003). Target population is the specific population from which information is obtained. The target population of this study was 298 respondents comprising 23 staff members and 275 HIV patients undergoing treatment at Mbagathi District Hospital.

3.5 Sample Size and Sampling Technique

A sample population of 168 was arrived at by calculating the target population of 298 using Krejcie and Morgan (1970) sampling table (Appendix V).

Table 3.1: Sampling Frame and Sampling Procedure

	Frequency	Ratio	Sample size
Staff members	23	0.56	13
HIV patients undergoing treatment	275	0.56	155
Total	298	0.56	168

The researcher then used purposeful sampling to select 13 staff members dealing with HIV treatment and simple random sampling to select 155 HIV patients undergoing treatment using random number tables as shown in the table above. According to Oso and Onen (2005), purposive sampling starts with a purpose in mind and the sample is thus selected to include people of interest and exclude those who do not suit the purpose. This method was therefore suitable in selecting the staff members dealing with HIV treatment and HIV patients undergoing treatment. Saunders and Thornhill (2003) also posited that purposeful sampling is useful when one want to access a particular subset of people.

3.6 Research Instrument

The researcher collected both qualitative and quantitative data. Qualitative data was collected by use of interview guides while quantitative data was collected by use of semi-structured questionnaires.

3.6.1 Questionnaire for the Patients

The questionnaire was structured to include both closed, open-ended and matrix questions to allow variety. The structured questions are normally close ended with alternatives from which the respondent is expected to choose the most appropriate answer (Mugenda & Mugenda, 2003). The main advantage of this type of questions is that they are easy to analyse and require a lower investment in terms of time and money. Unstructured questions are open-ended and present the respondent with the

opportunity to provide their own answers. These types of questions are easy to formulate and allow the respondent to present their feelings on the subject matter enabling a greater depth of response (Mugenda & Mugenda, 2003).

3.6.2 Interview Guide for the Staff

An interview guide with open-ended questions was used to collect in depth information from the hospital staff. Interviewing involves the collection of data through talking to respondents or interviewees and recording their responses. Face to face interview was used in this study to collected data from healthcare workers. Face-face interviews is a method which the investigation follows a rigid procedure and seeks answers to a set of pre-conceived questions through personal interviews. With unstructured questions, a respondent's response may give an insight to his feelings, background, hidden motivation, interests and decisions and give as much information as possible without holding back (Asika, 1991). Copper and Schindler (2003), emphasize the value of personal interview when they stated that it enables in depth and detailed information to be obtained.

3.7 Validity of the Research Instrument

Validity was assessed through content and construct validity. Content validity is a measure of the degree to which data collected using a particular instrument represents a specific domain or content of a particular concept. Content validity is established through the extensive process of item selection and refinement in the development of the instrument. The content validity was extensively pre-tested with the specialists in the field including the doctors, VCT counsellors and lecturers. Particular attention was given to wording, structure, sequence and overall presentation of the items in the questionnaire. The questionnaire was then be piloted with 15 patients randomly selected from the sample size. Interviews were conducted with these respondents to determine whether there was any problem with the questionnaire format. On the basis of their comments, changes were made to the questionnaire to clarify wordings and increase readability. The pre-testing procedure will be important to establish content validity (Chwelos et al., 2001).

Construct validity, on the other hand, testifies to how well the results obtained from the use of the measure fit the theories around which the test is designed. This will be assessed through convergent and discriminant validity (Sekaran, 2003). Convergent validity is established when the scores obtained with two different instruments measuring the same concept are highly correlated. Discriminant validity is established when, based on theory, two variables are predicted to be uncorrelated. Convergent validity will be evaluated using exploratory factor analysis (EFA) (Zikmund, 2003).

3.8 Reliability of the Research Instrument

Reliability is ensured by including many similar items on a measure, by testing a diverse sample of individuals and by using uniform testing procedures. The researcher intended to select a pilot group of 10 individuals from the target population to test the reliability of the research instruments. In order to test the reliability of the instruments, internal consistency techniques was applied using Cronbach's Alpha. The alpha value ranges between 0 and 1 with reliability increasing with the increase in value. Coefficient of 0.6-0.7 is a commonly accepted rule of thumb that indicates acceptable reliability and 0.8 or higher indicated good reliability (Mugenda, 2008). The pilot data was not included in the actual study.

3.9 Data Collection Procedure

This refers to the means the researcher used to gather the required data or information. The researcher administered the questionnaire individually to all sampled patients and wait for them to fill. The researcher exercised care and control to ensure all questionnaires issued to the respondents were received and to achieve this, the researcher maintained a register of questionnaires. The researcher also booked appointments with hospital staff for the face to face interviews.

3.10 Data Analysis Techniques

Data analysis is a process used to make sense of the data. The type of data analysis tool used is dependent on the type of data, that is; is the data qualitative or quantitative. The quantitative data in this research was analyzed by descriptive statistics using statistical package for social sciences (SPSS V 21.0). Descriptive statistics includes mean,

frequency, standard deviation and percentages to profile sample characteristics and major patterns emerging from the data. The data collected using interview guides which is qualitative in nature, was analyzed using conceptual content analysis which is the best suited method of analysis. Content analysis is a technique of making inferences by systematically and objectively identifying specific characteristics of messages and themes and using the same to relate to trends. Creswell (2003) defined qualitative data analysis as working with data, organizing it, breaking it into manageable units, synthesizing it, searching for patterns, discovering what is important and what is to be learned, and deciding what you will tell others. Data was then presented in frequency tables and in prose form.

3.11 Ethical Consideration

According to Kerridge, Lowe and McPhee (2005), ethics involves making a judgment about right and wrong behavior. Ethics as noted by Minja (2009) is referred to, as norms governing human conduct which have a significant impact on human welfare. In this study, confidentiality was of concern as the information relevant to the study was personal. In this regard, the names of the respondents were not disclosed. In addition, where a response could have been attributed to specific individuals the said information was maintained in strict confidence. The researcher collected data from patients that had consented in writing to participate in the study and the staff in the hospital had to agree in writing to participate in the study.

The researcher obtained permission from the University of Nairobi before conducting any study. The letter of authority given by the University allowed the researcher to conduct the study in the defined institution as well as proving that the researcher was a bona fide member of that institution. The researcher obtained a written permission from the patients and the staff members from Mbagathi hospital through signing of a prewritten sheet defining the level of agreement between the two parties on the intended research. Agreement letter had to be obtained by the researcher from the hospital and the overall permission to conduct the research was also obtained from the hospital management. A letter from the Kenyatta National Hospital and the University of Nairobi ethics and regulation committee was also obtained.

CHAPTER FOUR: DATA PRESENTATION AND ANALYSIS

4.1 Introduction

This chapter discusses the interpretation and presentation of the findings. This chapter presents analysis of the data on how stigma contributes to the treatment failure in HIV patients undergoing treatment at Mbagathi District Hospital. The chapter also provides the major findings and results of the study.

4.1.1 Response Rate

The study targeted a sample size of 168 respondents from which 99 filled in and returned the questionnaires making a response rate of 58.9%. This response rate was adequate, representative and conforms to Mugenda and Mugenda (1999) stipulation that a response rate of 50% is adequate for analysis and reporting; a rate of 60% is good and a response rate of 70% and over is excellent.

4.2 Demographic Characteristics

The study sought to establish the background information of the respondents including respondents' gender, level of education and age.

4.2.1 Gender Distribution

The study sought to establish the respondents' gender. Table 4.1 shows how males and females are distributed.

Table 4.1: Distribution by Gender

Gender	Frequency	Percent
Male	46	46.5
Female	53	53.5
Total	99	100.0

From the findings, the majority of the respondents (53.5%) were female and 46.5% were male. From this findings we can therefore infer that majority of the HIV/AIDS patients are female.

4.2.2 Level of Education

The study also sought to establish the respondents' highest level of education as shown in Table 4.2 below.

Table 4.2: Respondents' highest level of education

Level of Education	Frequency	Percent
Primary	28	28.3
Secondary	37	37.4
College/Diploma	30	30.3
University degree	4	4.0
Total	99	100.0

According to the findings, the majority of the respondents (37.4%) had a secondary certificate, 30.3% had a College/Diploma certificate, 28.3% had a primary certificate while 4% of the respondents had a university degree. We can therefore infer that education affects how somebody feels about HIV and AIDS since AIDS-related stigma is not static and it changes over time as infection levels, knowledge of the disease and treatment availability vary.

4.2.3 Age Distribution

The study also sought to establish the age of the respondents. Table 4.3 shows how the respondents are distributed in various age groups.

Table 4.3: Age group distribution of the respondents

Age group	Frequency	Percent
15-20 years	7	7.1
21-30 years	29	29.3
31-40 years	27	27.3
41-50 years	22	22.2
Above 50 years	14	14.1
Total	99	100.0

On the age of the respondents table 4.3 shows that 29.3% of the respondents were aged 21-30 years, 27.3% were aged 31-40 years, 22.2% were aged 41-50 years, 14.1% were aged above 50 years, while 17.% were aged 15 to 20 years. These findings imply that majority of the HIV/AIDS patients were aged 21-30 years. This age bracket is a representative of the productive stage.

4.3 Treatment failure among HIV Patients

The study sought to establish whether there are cases of treatment failure among HIV patients undergoing treatment at Mbagathi District Hospital.

4.3.1 Treatment failure among the HIV patients undergoing treatment

The study sought to establish the level of treatment failure among the HIV patients undergoing treatment.

Table 4.4: Response on the level of treatment failure among the HIV patients undergoing treatment

Response	Frequency	Percent
Very high	64	64.6
High	32	32.3
Moderate	3	3.0
Total	99	100.0

Regarding the level of treatment failure among the HIV patients undergoing treatment, majority of the respondents (64.6%) indicated that there were very high levels of treatment failure among the HIV patients undergoing treatment 32.3% said the levels were high while 3.0% of the respondents believed that there were moderate levels of treatment failure among the HIV patients undergoing treatment. We can therefore infer that although success with antiretroviral therapy has greatly improved with the introduction of more potent and well tolerated medications, treatment failure remains an important challenge for clinicians.

4.3.2 Stigma and Discrimination on HIV Patients

The study sought to establish whether there was stigma and discrimination on HIV patients. The findings are presented in Table 4. 6 below.

Table 4.5: Level of Stigma and discrimination on HIV patients

	Frequency	Percent
Very high	58	58.6
High	36	36.4
Moderate	4	4.0
Low	1	1.0
Total	99	100.0

According to the findings, 58.6% of the respondents indicated that there was a very high levels of stigma and discrimination on HIV patients, 36.4% said it was high, 4% said it was moderate while 1% of the respondents said that there was low level of stigma and discrimination on HIV patients. From these findings we can therefore deduce that discrimination springs from social disapproval of the infection and its implied behaviours or from fears due to lack of knowledge about how HIV/AIDS can or cannot be transmitted.

4.3.3 Forms of HIV Stigma Experienced

The study sought to find out the forms of HIV stigma experienced by HIV patients and the findings are shown in Table 4.7 below.

Table 4.6: Forms of HIV Stigma/mistreatment and whether the respondents have experienced them

Forms of HIV Stigma/mistreatments/other experiences	Frequ	ency	Percent		
	Yes	No	Yes	No	
Violence/harassment	48	51	48.5	51.5	
Isolation/abandonment	66	33	66.7	33.3	
Having Property Taken Away	31	68	31.3	68.7	
Infidelity Accusation	54	45	54.5	45.5	
Refusal of Health and Other Services/Withheld	12	87	12.1	87.9	
Treatment					
Scapegoating	31	68	31.3	68.7	
Job loss/ Denial of Employment on the Basis of HIV	57	42	57.6	42.4	
Status					
Ostracism, rejection and avoidance of people living with	60	39	60.6	39.4	
AIDS					
Mandatory HIV Testing Without Informed Consent or	23	76	23.2	76.8	
Confidentiality Protections					

According to the findings, 51.5% of the respondents indicated that they hadn't experienced violence/harassment while 48.5% of the respondents indicated that they had experienced violence/harassment as a form of stigma.

From the findings, 66.7% of the respondents indicated that they had experienced isolation/abandonment while 33.3% of the respondents indicated that they hadn't experienced isolation/abandonment as a form of stigma.

From the findings, 68.7% of the respondents indicated that they didn't have their property taken away from them while 31.3% of the respondents indicated that they had their property taken away.

From the findings, 54.5% of the respondents indicated that they were accused of infidelity while 45.5% of the respondents indicated that they weren't accused of infidelity.

According to the findings, majority of the respondents (87.9%) indicated that they didn't experience refusal of healthy and other services/withheld treatment while 12.1 % indicated that they had experience refusal of healthy and other services/withheld treatment.

From the findings, 68.7% of the respondents indicated that they didn't experience scapegoating while 31.3% of the respondents indicated that they experienced scapegoating.

From the findings, 576% of the respondents indicated that they experienced job loss/denial of employment on the basis of HIV status while 42.4% of the respondents indicated that they didn't experience job loss/denial of employment on the basis of HIV status.

From the findings, 60.6% of the respondents indicated that they experienced ostracism, rejection and avoidance while 39.4% of the respondents indicated that they didn't experience ostracism, rejection and avoidance.

From the findings, 76.8% of the respondents indicated that they didn't experience mandatory HIV testing without informed consent or confidentiality protections while 23.2% of the respondents indicated that they experienced mandatory HIV testing without informed consent or confidentiality protections.

From these findings we can therefore infer that families with people living with HIV/AIDs may fear isolation and ostracism within the community. The harassing and scapegoating of individuals suspected of being infected can lead to acts of violence and murder. Fear of rejection and stigmatization within the home and local community may prevent people living with HIV/AIDS revealing their status to family members.

4.3.4 Prevalence of Stigma on HIV Patients

The study also required the respondent to indicate the prevalence of stigma on HIV patients.

Table 4.7: Prevalence of Stigma on HIV Patients

	Very low	Low	Moderate	High	Very high	Mean	Stdev
Family members	8.0	24.0	28.0	17.0	23.0	3.2525	1.25636
Community	3.0	8.0	23.0	43.0	23.0	3.8061	0.92679
Health workers	13.0	30.0	46.0	8.0	3.0	2.5556	0.89468
Work place	1.0	16.0	40.0	30.0	13.0	3.3636	0.93082
Religious groups	10.0	20.0	38.0	23.0	9.0	3.0000	1.09731

All the figures add up to 100 per row before the mean score

According to the findings, the respondents indicated that the prevalence of stigma on HIV patients from the community was high as shown by a mean score of 3.8061, the respondents indicated that the prevalence of stigma on HIV patients from the work place, family members, religious groups and health workers was moderate as shown by a mean score of 3.3636, 3.2525, 3.0000 and 2.5556 respectively. From these findings we can therefore infer that family responses to infected individuals are heavily influenced by community perceptions of the disease.

4.4 Causes of Stigma

The study sought to identify the causes of stigma among HIV patients undergoing treatment.

4.4.1 Causes of Stigma

The study sought to find out how much the following factors caused stigma among the HIV patients undergoing treatment.

Table 4.8: Causes of Stigma

Causes of Stigma							
_	Strongly	Disagree	91 Neutral	Agree	Strongly		Stdev
Availability of treatment	10	15	16	38	21	2.6667	1.61624
Perception of people living	8	11	23	33	25	3.5859	1.18675
with HIV as weak and							
therefore a 'burden' on the							
community							
Derogatory terms are used to	9	5	17	33	36	4.3131	5.29082
describe those with the virus							
Myths and ignorance about	3	9	21	44	23	3.7778	0.97474
the ways in which HIV is							
transmitted trigger damaging							
attitudes.							
Fear of illness/ fear of	4	9	8	32	47	4.3838	4.15198
contagion (AIDS is regarded							
as generative and fatal							
conditions; it is transmissible,							
hence the affected person is							
seen as repellent, ugly or							
upsetting).							
HIV infection is associated	4	3	15	35	43	4.1212	1.0129
with behaviours (such as							
homosexuality, drug							
addiction, prostitution or							
promiscuity) that are already							
stigmatized in the society							
Most people become infected	8	6	11	42	33	3.9697	1.216
with HIV through sex, which							
often carries moral baggage.							
l			1	1		l	I.

There is a lot of inaccurate	13	10	29	33	15	3.8061	5.36245
information about how HIV is							
transmitted, creating irrational							
behaviour and misperceptions							
of personal risk.							
Religious or moral beliefs lead	7	4	14	23	52	4.1111	1.19428
some people to believe that							
being infected with HIV is the							
result of moral fault (such as							
promiscuity or 'deviant sex')							
that deserves to be punished.							
The effects of antiretroviral	9	13	16	36	26	3.5859	1.25365
therapy on people's physical							
appearance can result in							
forced disclosure and							
discrimination based on							
appearance.							
Stigma reduction efforts are	10	12	22	33	23	3.4848	1.24838
relegated to the bottom of							
AIDS programme priorities,							
often without funding to							
support such activities							

Every row adds up to 100 before the mean score

From the study findings, majority of the respondents agreed that fear of illness/ fear of contagion (AIDS is regarded as generative and fatal conditions; it is transmissible, hence the affected person is seen as repellent, ugly or upsetting), that derogatory terms were used to describe those with the virus, that HIV infection was associated with behaviours (such as homosexuality, drug addiction, prostitution or promiscuity) that were already stigmatized in the society and that religious or moral beliefs led some people to believe that being infected with HIV was the result of moral fault (such as

promiscuity or 'deviant sex') that deserved to be punished as shown by a mean score of 4.3838, 4.3131, 4.1212 and 4.1111 respectively.

The respondents also agreed that most people became infected with HIV through sex, which often carries moral baggage, that there was a lot of inaccurate information about how HIV is transmitted, creating irrational behaviour and misperceptions of personal risk and that myths and ignorance about the ways in which HIV was transmitted triggered damaging attitudes as shown by a mean score of 3.9697, 3.8061 and 3.7778 respectively.

The respondents further agreed that perception of people living with HIV as weak and therefore a 'burden' on the community and that the effects of antiretroviral therapy on people's physical appearance can result in forced disclosure and discrimination based on appearance as shown by a mean score of 3.5859 respectively.

The respondents remained agreed that stigma reduction efforts were relegated to the bottom of AIDS programme priorities, often without funding to support such activities and availability of treatment as shown by a mean score of 3.4848 and 2.6667 respectively.

From these findings we can therefore infer that AIDS stigma can be experienced at both the individual and societal level. At the individual level, AIDS stigma takes the form of behaviours, thoughts, and feelings that express prejudice against people living with HIV or AIDS, and can also be experienced by persons perceived to be living with HIV/AIDS. Further, concerns about stigma affect an individual's decision to get tested, access health care, and withhold information about their status from family members, friends, and care providers. Social isolation negatively affects the lives of people living with HIV.

4.5 Stigma Contributes to the Failure in Treatment

The study sought to determine whether and how stigma contributes to the failure in treatment among HIV patients undergoing treatment.

4.5.1 Stigma Contribute to the Treatment Failure

The study further sought to find out whether stigma contributed to the treatment failure in HIV patients undergoing treatment.

Table 4.9: Extent that Stigma Contribute to the Treatment Failure

	Frequency	Percent
Very great extent	61	61.6
Great extent	32	32.3
Moderate extent	6	6.1
Total	99	100.0

According to the findings, 61.6% of the respondents indicated that stigma contributed to the treatment failure in HIV patients undergoing treatment to a very great extent, 32.3% said to a great extent while 6.1% of the respondents indicated that stigma contribute to the treatment failure in HIV patients undergoing treatment to a moderate extent. From these findings we can therefore infer that stigma affect an individual's decision to get tested, access health care, and withhold information about their status from family members, friends, and care providers. Social isolation negatively affects the lives of people living with HIV.

4.5.2 Level of Agreement on how Stigma Contribute to the Treatment Failure

The study sought to find out the respondents level of agreement with the following statement on how stigma contributed to the treatment failure in HIV patients undergoing treatment.

 Table 4.10: Level of Agreement on how Stigma Contribute to Treatment Failure

How stigma contribute to						Mean	Std.
treatment failure	Strongly	Disagree	Neutral	Agree	Strongly		Deviation
HIV Stigma Tends to	4	3	19	31	43	4.0808	1.03684
Heighten Existing Prejudices							
HIV Stigma Undermines	5	9	15	34	37	4.4242	5.24908
Prevention							
Stigmatizing attitudes are associated with denial of risk and a lower likelihood of adopting preventive behaviours	5	10	13	32	40	3.8687	1.1033
Concerns about stigma affect an individual's decision to access health care	2	4	12	32	50	4.2727	0.90145
Social isolation negatively affects the lives of people living with HIV.	8	5	12	29	46	4.0303	1.1991
Stigma and discrimination are associated with under or nonparticipation in HIV information meetings and counselling and reduced participation in programs to prevent mother-to-child transmission	3	9	17	35	36	3.9495	1.04368
Stigma can reduce the likelihood of people using condoms and accessing preventive services	3	4	14	37	42	4.1414	0.94772

People who hold stigmatizing attitudes are also less likely to adopt preventive behaviours such as having multiple sexual partners or a commercial sex partner, and a sexually	5	6	14	32	43	3.9394	1.03823
transmitted infection							
Stigma can deter or delay testing	2	1	7	31	59	4.4747	0.76055
Concerns about stigma affect an individual's decision to withhold information about their status from family members, friends, and care providers.	4	2	10	27	57	4.3232	1.00842
Stigma reduces the quality of care due to discrimination by health workers	24	18	20	20	18	2.9192	1.4334
People with HIV have been refused services, denied medicine, passed from provider to provider	35	17	13	23	12	2.6162	1.46181
People with HIV have been isolated unnecessarily	9	11	12	32	36	3.7857	1.28633
Stigma leads to avoidance of care seeking due to fear of being "found out,"	4	2	15	28	51	4.2449	0.99547
Stigma can delay treatment and reduce survival (Delayed testing can lead to delayed diagnosis and treatment)	1	6	12	28	53	4.2929	0.90636

Stigma impedes adherence to	1	1	16	33	49	4.3131	0.77784
medication							
Fear of stigma has led people	5	3	14	40	38	4.0505	1.03385
to grind drugs into powder,							
which can result in							
inconsistent doses,							
Fear of stigma has led people	3	3	10	30	54	4.3232	0.92393
to avoid taking medicines in							
front of others.							
Stigma adversely affects	2	5	12	31	50	4.2525	0.9296
mental health, and							
depression interferes with							
consistent drug use							
Individuals with HIV may	3	2	16	36	43	4.1717	0.91518
blame themselves to the							
extent that they cease to							
exert their right to decent							
treatment and other social							
benefits							
Experiences of social	2	3	17	34	44	4.1717	0.92627
rejection, disapproval and							
discrimination related to HIV							
may decrease the motivation							
of HIV positive persons to							
stay healthy							

Each row adds up to 100 before the mean score

According to the findings, the respondents strongly agreed that stigma could deter or delay testing and that HIV stigma undermined prevention as shown by a mean score of 4.4747 and 4.4242 respectively. The respondents also strongly agreed that concerns about stigma affected an individual's decision to withhold information about their status from family members, friends, and care providers and that fear of stigma had led

people to avoid taking medicines in front of others as shown by a mean score of 4.3232 respectively. The respondents strongly agreed that stigma impedes adherence to medication, that stigma can delay treatment and reduce survival (Delayed testing can lead to delayed diagnosis and treatment), that concerns about stigma affected an individual's decision to access health care and that stigma adversely affected mental health, and depression interferes with consistent drug use, that stigma leads to avoidance of care seeking due to fear of being "found out," as shown by a mean score of 4.3131, 4.2929, 4.2727, 4.2525 and 4.2449 respectively.

The respondents further strongly agreed that individuals with HIV may blame themselves to the extent that they cease to exert their right to decent treatment and other social benefits and that experiences of social rejection, disapproval and discrimination related to HIV may decrease the motivation of HIV positive persons to stay healthy as shown by a mean score of 4.1717 respectively.

The respondents also strongly agreed that stigma can reduce the likelihood of people using condoms and accessing preventive services, that HIV stigma tends to heighten existing prejudices ,that fear of stigma has led people to grind drugs into powder, which can result in inconsistent doses, that social isolation negatively affects the lives of people living with HIV, that stigma and discrimination are associated with under or nonparticipation in HIV information meetings and counseling and reduced participation in programs to prevent mother-to-child transmission, that people who hold stigmatizing attitudes are also less likely to adopt preventive behaviors such as having multiple sexual partners or a commercial sex partner, and a sexually transmitted infection, that stigmatizing attitudes are associated with denial of risk and a lower likelihood of adopting preventive behaviors and that people with HIV have been isolated unnecessarily as shown by a mean score of 4.1414, 4.0808, 4.0505, 4.0303, 3.9495, 3.9394, 3.8687 and 3.7857 respectively.

The respondents strongly disagreed that stigma reduced the quality of care due to discrimination by health workers and that people with HIV have been refused services,

denied medicine, passed from provider to provider as shown by a mean score of 2.9192 and 2.6162 respectively.

We can therefore infer that AIDS stigma displays continuity with many past epidemics. However in the case of AIDS, the nature and intensity of stigma are shaped by the social construction of the epidemic in different locales. It takes different forms in different societies while the specific groups targeted for AIDS stigma vary considerably across cultures and national borders. The factors affecting this variation include the local epidemiology of HIV, pre-existing beliefs and values surrounding sexuality, disease, gender and prejudices toward specific cultural out groups.

4.6 Strategies in reducing HIV related stigma

The study sought to find out remedies of stigma among HIV patients undergoing treatment.

4.6.1 Strategies in reducing HIV related stigma

The study also inquired how effective the strategies were in reducing HIV related stigma.

Table 4.11: Strategies in reducing HIV related stigma

Very	Effective	Moderately	Slightly effective	Ineffective	Mean	Std. Deviation
1	5	18	26	50	4.2424	0.89318
1	6	17	17	59	4.303	0.96314
4	10	13	33	40	4.5204	5.26852
6	8	21	28	37	3.8776	1.13306
3	4	15	30	48	4.1919	0.97601
1	6	16	30	47	4.1919	0.92225
2	4	20	22	52	4.2121	0.97177
	1 1 4 6	1 6 4 10 6 8 1 6 1 6 1 6 1 6 1 6 1 6 1 6 1 6 1 6	1 5 18 1 6 17 4 10 13 6 8 21 3 4 15 1 6 16	1 5 18 26 1 6 17 17 4 10 13 33 6 8 21 28 3 4 15 30 1 6 16 30	1 5 18 26 50 1 6 17 17 59 4 10 13 33 40 6 8 21 28 37 3 4 15 30 48 1 6 16 30 47	1 5 18 26 50 4.2424 1 6 17 17 59 4.303 4 10 13 33 40 4.5204 6 8 21 28 37 3.8776 3 4 15 30 48 4.1919 1 6 16 30 47 4.1919

Support group for people	3	2	17	22	56	4.2828	0.99016
living with HIV/AIDS, in							
which individuals receive							
personal support for resolving							
issues or situations with							
spouses, families,							
communities, and so forth, in a							
safe environment							
Programs that support	4	4	18	18	56	4.2121	1.07164
families, lighten financial							
burdens, support caregiver							
mental health and provide							
respite for stressed families							
and caregivers							

Each row adds up to 100 before the mean score

From the findings, majority of the respondents rated direct contact with people living with HIV or AIDS as very effective in reducing HIV related stigma as shown by a mean score of 4.5204. The respondents also rated patient counseling and coping skills acquisition and support group for people living with HIV/AIDS, in which individuals receive personal support for resolving issues or situations with spouses, families, communities, and so forth, in a safe environment as very effective in reducing HIV related stigma as shown by a mean score of 4.3030, 4.2828 respectively.

The respondents further rated focused information dissemination as very effective in reducing HIV related stigma as shown by a mean score of 4.2424 respectively. The respondents also rated HIV negative people need to be educated in order to create an environment free of fear of HIV biased social attitudes and no stereotypes towards HIV and Programs that support families, lighten financial burdens, support caregiver mental health and provide respite for stressed families and caregivers as very effective in reducing HIV related stigma as shown by a mean score of 4.2121 respectively.

The respondents also rated people living with HIV/AIDS need to be educated on their basic human rights and institutions should implement their HIV/AIDS policies based on sound information and taking into account the rights of everybody as very effective in reducing HIV related stigma as shown by a mean score of 4.1919 respectively. Finally, the respondents rated integrated services (no isolation of their sections in hospitals) as very effective in reducing HIV related stigma as shown by a mean score of 3.8776.

From these findings we can therefore infer that programs that support families, lighten financial burdens, support caregiver mental health and provide respite for stressed families and caregivers are practically non-existent in the underfunded health system. Programs that appropriately acknowledge the contribution of family members and caregivers are essential to reducing stigma, preventing discrimination and supporting the well-being of those with HIV/AIDS as well as their families and support systems.

4.7 Findings from the Staff

The interviewee indicated that there are treatment failure among the HIV patients undergoing treatment which are very prevalent. The interviewed also intimated that there is stigma and discrimination on HIV patients which springs from social disapproval of the infection and its implied behaviours or from fears due to lack of knowledge about how HIV/AIDS can or cannot be transmitted. The form(s) of HIV stigma experienced by the patients include rejection and avoidance, Infidelity Accusation, abandonment, retrenchment/denial of Employment and Scapegoating.

The interviewees indicated that fear of being affected, low esteem and denial, lack of support from family members, ignorance, lack of information, poor social economic status, lack of social support, the mentality that the populations have about patients with HIV, that is, immorality, deterioration of the conduction, ignorance from the staff towards patients and lack of knowledge were some of the causes of stigma among HIV patients.

On how does stigma contribute to the treatment failure in HIV patients undergoing treatment, the interviewees were of the view that stigma affect an individual's decision

to get tested, access health care, and withhold information about their status from family members, friends, and care providers.

The interviewees also indicated that patients feared taking drugs in front of others (publicly), thus timings are never adhered to, fear to attend clinic, avoiding medication are some of the factors that contributed to treatment failure. They also added that stigma can reduce the likelihood of people using condoms and accessing preventive services, tends to heighten existing prejudices and has led people to grind drugs into powder, which can result in inconsistent doses.

The interviewees suggested that to reduce stigma among HIV patients undergoing treatment, there is need for community sensitization through training in seminars and workshop on the various aspects of HIV/AIDs including prevention and transmission, patient counseling and direct contact with people living with HIV or AIDS. They also indicated that all institutions both private and public should implement their HIV/AIDS policies based on sound information and taking into account the rights of everybody. Programs that appropriately acknowledge the contribution of family members and caregivers are essential to reducing stigma, preventing discrimination and supporting the well-being of those with HIV/AIDS as well as their families and support systems.

4.8 Discussion

This section sought to discuss how stigma contributes to the treatment failure in HIV patients undergoing treatment at Mbagathi District Hospital in the light of previous studies done.

4.8.1 Treatment failure among HIV Patients

The study deduced that stigma and discrimination, resource constraints, Non-adherence to drugs, inadequate transfer of proven prevention technologies, drug toxicity, potency of the antiretroviral regimen, Skills deficits among patients and gaps in the scientific knowledge base influenced the success or failure of treatment efforts among the HIV patients undergoing treatment. Reports also reveal the extent to which individuals are stigmatized and discriminated against by the health care system. There have been

reports of withheld treatment (Panebianco et al 1994), non-attendance of hospital staff to patients left lying in their beds (Ogola 1990, Msini); HIV testing without consent, breaches of confidentiality, and denial of hospital facilities and medications (Panebianco et al 1994). Many health workers are reported to have expressed negative attitudes to people living with HIV/AIDS and would demonstrate a preference not to treat them. Contributing to the above responses are ignorance and lack of knowledge about HIV/AIDS transmission (Herek et al 1998) and the perceived incurability of the disease, these conspire to make it appear pointless to offer quality care (UNAIDS, 2000).

The study further deduced that there was stigma and discrimination on HIV patients and that majority of HIV patients had experienced the different forms of stigma. They include: violence/harassment, isolation/ abandonment, having property taken away, infidelity accusations, refusal of health and other services/ withheld treatment, scapegoating, job loss/ denial of employment on the basis of HIV status, ostracism, rejection and avoidance of people living with AIDS and mandatory HIV testing without informed consent or confidentiality protections. According to Bunting (1996) discrimination is composed of "... the actions or treatment based on the stigma and directed toward the stigmatized...." The stigmatized find themselves ostracized, rejected, and shunned (Alonzo et al. 1995) and may experience sanctions, harassment, scapegoating, and even violence based on their infection or association with HIV/AIDS. McGrath (1992) indicate that discrimination may spring from social disapproval of the infection and its implied behaviours or from fears due to lack of knowledge about how HIV/AIDS can or cannot be transmitted.

4.8.2 Causes of Stigma

The study further established that fear of illness/ fear of contagion (AIDS is regarded as generative and fatal conditions; it is transmissible, hence the affected person is seen as repellent, ugly or upsetting), that derogatory terms were used to describe those with the virus, that HIV infection was associated with behaviours (such as homosexuality, drug addiction, prostitution or promiscuity) that were already stigmatized in the society and that religious or moral beliefs led some people to believe that being infected with HIV

was the result of moral fault (such as promiscuity or 'deviant sex') that deserved to be punished. At the societal level, Herek and Glunt (1988) indicated that AIDS stigma is manifested in laws, policies, popular discourse, and the social conditions of persons living with HIV/AIDS and those at risk of infection. NASW (2008) recognizes that people with HIV/AIDS, and sometimes even those that have been tested for the virus, continue to face discrimination in employment, military service, housing, access to health services, social and community programs, and basic civil and human rights. NASTAD (2001) also indicate that societal stigma emerges in the form of laws, regulations, and policies that single out people with HIV.

4.8.3 Stigma Contributes to the Failure in Treatment

This study also revealed stigma could deter or delay testing and that HIV stigma undermined prevention, that concerns about stigma affected an individual's decision to withhold information about their status from family members, friends, and care providers and that fear of stigma had led people to avoid taking medicines in front of others. According to McGrath et al (1993), in Botswana, a survey of HIV patients receiving antiretroviral therapy (ART) found that 40 percent had delayed getting tested for HIV, mostly due to stigma. Stigmatizing beliefs, which perpetuate the notion that HIV only happens to others, also can reduce testing, as people are less likely to believe they are at risk. Further, he indicated that a study of truckers in Brazil found that men with more stigmatizing attitudes were less likely to have had an HIV test. Finally, stigma often prevents disclosure of an HIV-positive status to partners, providers and family members, which in turn deter behaviours that can prevent further spread of HIV, such as condom use, or mitigate its impact, such as care seeking. Data from Bharat (1999) indicate that some African and Asian countries report both supportive and nonsupportive household responses to HIV-positive people while negative responses are more evident in the case of HIV-positive women (Warwick et al 1998) and those whose lifestyles and sexual behaviour elicit popular disapproval (Warwick et al 1998). The harassing and scapegoating of individuals suspected of being infected or of belonging to a particular group has been widely reported. In extreme circumstances it can lead to acts of violence and murder (Nardi and Bolton, 1991). For instance, Peterson (1990)

reported that CSWs and street children in Brazil have been singled out for violence and abuse while Panos (1990) reported HIV-related murders in diverse countries.

4.8.4 Strategies in Reducing HIV Related Stigma

The study revealed that direct contact with people living with HIV or AIDS, patient counseling and coping skills acquisition and support group for people living with HIV/AIDS, in which individuals receive personal support for resolving issues or situations with spouses, families, communities, and so forth, in a safe environment, negative people need to be educated in order to create an environment free of fear of HIV biased social attitudes and no stereotypes towards HIV.

Perry et al. (1991), indicated that master imagery and group desensitization are examples of coping skill acquisition techniques. In master imagery an individual is presented with a hypothetical situation where they have contact with a people living with HIV/AIDS and is taught appropriate coping skills for resolving the situation. Group desensitization teaches relaxation training first and then progressively exposes the individual or group to a number of situations in which there is exposure to people living with HIV/AIDS, utilizing the newly learned relaxation techniques to decrease tension in a hypothetical situation.

CHAPTER FIVE: SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter presented the discussion of key data findings, conclusion drawn from the findings highlighted and recommendation made there-to. The conclusions and recommendations drawn were focused on addressing the objective of the study.

5.2 Summary of Findings

The study sought to determine how stigma contributes to the treatment failure in HIV patients undergoing treatment in Mbagathi District Hospital.

5.2.1 Treatment failure among HIV Patients

The study deduced that there was treatment failure among the HIV patients undergoing treatment. The study also deduced that stigma and discrimination, resource constraints, Non-adherence to drugs, inadequate transfer of proven prevention technologies, drug toxicity, potency of the antiretroviral regimen, Skills deficits among patients and gaps in the scientific knowledge base influenced the success or failure of treatment efforts among the HIV patients undergoing treatment.

The study further deduced that there was stigma and discrimination on HIV patients and that majority of HIV patients had experienced the different forms of stigma. They include: violence/harassment, isolation/ abandonment, having property taken away, infidelity accusations, refusal of health and other services/ withheld treatment, scapegoating, job loss/ denial of employment on the basis of HIV status, ostracism, rejection and avoidance of people living with AIDS and mandatory HIV testing without informed consent or confidentiality protections.

The study also deduced that the prevalence of stigma on HIV patients from the community, work place, family members, religious groups and health workers was high.

5.2.2 Causes of Stigma

The study further established that fear of illness/ fear of contagion (AIDS is regarded as generative and fatal conditions; it is transmissible, hence the affected person is seen as repellent, ugly or upsetting), that derogatory terms were used to describe those with the virus, that HIV infection was associated with behaviours (such as homosexuality, drug addiction, prostitution or promiscuity) that were already stigmatized in the society and that religious or moral beliefs led some people to believe that being infected with HIV was the result of moral fault (such as promiscuity or 'deviant sex') that deserved to be punished.

The study established that most people became infected with HIV through sex, which often carries moral baggage, that there was a lot of inaccurate information about how HIV is transmitted, creating irrational behaviour and misperceptions of personal risk and that myths and ignorance about the ways in which HIV was transmitted triggered damaging attitudes.

The study also deduced that perception of people living with HIV as weak and therefore a 'burden' on the community and that the effects of antiretroviral therapy on people's physical appearance can result in forced disclosure and discrimination based on .

5.2.3 Stigma Contributes to the Failure in Treatment

This study also revealed stigma could deter or delay testing and that HIV stigma undermined prevention, that concerns about stigma affected an individual's decision to withhold information about their status from family members, friends, and care providers and that fear of stigma had led people to avoid taking medicines in front of others.

The study established that stigma impedes adherence to medication, that stigma can delay treatment and reduce survival (Delayed testing can lead to delayed diagnosis and treatment), that concerns about stigma affected an individual's decision to access health care and that stigma adversely affected mental health, and depression interferes with consistent drug use, that stigma leads to avoidance of care seeking due to fear of being "found out,".

The study also established that stigma can reduce the likelihood of people using condoms and accessing preventive services, that HIV stigma tends to heighten existing prejudices ,that fear of stigma has led people to grind drugs into powder, which can result in inconsistent doses, that social isolation negatively affects the lives of people living with HIV, that stigma and discrimination are associated with under or nonparticipation in HIV information meetings and counseling and reduced participation in programs to prevent mother-to-child transmission, that people who hold stigmatizing attitudes are also less likely to adopt preventive behaviors such as having multiple sexual partners or a commercial sex partner, and a sexually transmitted infection, that stigmatizing attitudes are associated with denial of risk and a lower likelihood of adopting preventive behaviors and that people with HIV have been isolated unnecessarily.

5.2.4 Strategies in Reducing HIV Related Stigma

The study revealed that direct contact with people living with HIV or AIDS, patient counseling and coping skills acquisition and support group for people living with HIV/AIDS, in which individuals receive personal support for resolving issues or situations with spouses, families, communities, and so forth, in a safe environment, negative people need to be educated in order to create an environment free of fear of HIV biased social attitudes and no stereotypes towards HIV and Programs that support families, lighten financial burdens, support caregiver mental health and provide respite for stressed families and caregivers as effective strategies in reducing HIV related stigma.

5.3 Conclusion

The study concludes that people often avoid being associated with HIV, with devastating effects on prevention, care and treatment. Stigma can reduce the likelihood of people using condoms and accessing preventive services such as educational meetings and counselling. People who hold stigmatizing attitudes are also less likely to adopt preventive behaviours.

The study also concludes that stigma often prevents disclosure of an HIV-positive status to partners, providers and family members, which in turn deter behaviours that

can prevent further spread of HIV, such as condom use, or mitigate its impact, such as care seeking.

The study further concludes that stigma deters use of health facilities and adversely affects quality of health services. People with HIV have been refused services, denied medicine, passed from provider to provider, tested for HIV or have had their sero-status disclosed without consent, and isolated unnecessarily.

5.4 Recommendations

From the study findings and conclusions, the study recommends that there is need to understand the underlying factors producing stigma, integrate action on these into programs wherever possible including participatory reflection and action in and by the communities concerned. In other words, before beginning an intervention it is a very valuable process to involve the communities in identifying the issues and problems and possible solutions. This is known as the participatory reflection and action (PRA) approach whereby researchers or development workers use various techniques to listen more closely to community voices and to address the need identified by the target population, rather than applying a predetermined notion of community needs. Various tools can be used for PRA processes as points of discussion.

The study also recommends that there is need to involve people living with HIV and AIDS in program interventions at all levels- community, district and national level. Their involvement should also extend to policy development, research and evaluation. Mainstream HIV prevention, care, treatment and support activities should also be included into existing programs and facilities where possible. The stakeholders should be aware of gender issues at all levels of interventions.

NACC should address stigma at levels where it arises or where it can be acted on in communities, including workplaces, Media, Recreational facilities, Schools, Churches and in Faith-based organizations. This is mainly through continuous education and sensitization trough seminars and workshops.

There is also need to ensure that people are not exposed to contradictory environments, and that where they are this is identified as a social problem and not an individual problem. For example, an individual who has disclosed their status to their family may find it difficult to do so at a Workplace where an organization has not mainstreamed HIV and AIDS into the organizational activities and policies.

The government should promote complementary action on stigma at the level of individuals, families, social groups, organizations and at national level. For example, awareness activities aimed at women as a social group may need to be complemented by activities that promote communication between couples, and by an organization of services and laws that reinforce these actions.

5.5 Recommendations for Future Research

In terms of gaps in our knowledge of how to reduce stigma, this review can begin to point in a few directions. First, relatively few interventions to reduce AIDS stigma have been conducted (or at least rigorously evaluated, documented, and published) in developing countries. Many more interventions need to be tried. If future research is to benefit and learn from past interventions, the results of these studies need to be widely disseminated. Moreover, studies on the effect of mass media campaign on stigma, but if the studies do exist, they have not been documented in the published literature.

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APPENDICES

Appendix I: Introduction Letter

RE: PARTICIPATION IN RESEARCH

I am a postgraduate student pursuing my master degree in advanced disaster

management at the University of Nairobi and conducting a research entitled "A Survey

of How Stigma Contributes To The Treatment Failure In HIV patients undergoing

treatment at Mbagathi District Hospital." as one of the major requirements. In this

regard, you have been selected to take part in this study as a respondent.

Kindly respond to all items to reflect your opinion and experience. Please answer all the

questions freely. You will not be identified from the information you provide and no

information about individuals will be given to any organization. The data collected will

be used for this academic research only.

Your participation is important for the success of this project and I greatly appreciate

your contribution.

Yours Sincerely,

GEOFFREY NGUGI MONICAH

Appendix II: Consent Form

My name islocation Kenya. I
have been informed about the research and the researcher has informed me on benefits
and the risks involved. The information given in this resource will assist in
understanding how stigma contributes to the treatment failure in HIV patients
undergoing treatment. I have been assured of confidentiality on the information that
will be given. Participation in this research is voluntary. I have willingly accepted to
participate in research.
Signature of intervieweeDateDate

Appendix III: Questionnaire for the Patients

Instructions: Kindly tick on the appropriate response

PART A: BIO DATA

Drug toxicity

regimen

base

Potency of the antiretroviral

Gaps in the scientific knowledge

Inadequate transfer of proven

prevention technologies

1. Gender	Male []	Female	[]			
2. Kindly indica	te your highes	at level of edu	cation			
Primary	[]	Sec	condary]]	
Collage/diploma	[]	Un	iversity d	legree []	
Postgraduate degree	[]					
3. Age bracket						
Below 15 yrs []	15 -20 yrs	[]]			
21 - 30 yrs	[] 31 -	40 yrs []			
41 - 50 yrs	[] Abov	ve 50 yrs []			
PART B: MAIN ISS						
In your view, what is	the level of t	reatment fail	ure amon	g the HIV p	atients u	ndergoing
treatment?						
Very high [High	[] Mo	oderate []		
Low []	Very	low[]				
4. To what exte	ent do the fol	llowing facto	ors influe	ence the suc	cess or	failure of
treatment effo	orts among the	HIV patient	s undergo	ing treatmen	ıt?	
Factors that influence or failure of treatmen		Very great extent	Great extent	Moderate extent	Low extent	Very low extent
Skills deficits among	g heath care					
providers and clients						
Resource constraints Stigma and discrimin	ation					
Non-adherence to dru						

5. What is	the level of st	igma and discr	imination on Hl	V patients?	
Very high	[]	High	[] Modera	nte []	
Low	[] Very lo	ow []			
6. Which	form(s) of HIV	stigma have y	ou experienced	?	
Violence/haras	sment	[]	Isolation	/ abandonment	t []
Having propert	ty taken away	[]	Infideli	ty accusations	[]
Refusal of heal	th and other se	ervices/ withhel	ld treatment []	Scapegoating	[]
Job loss/ denia	l of employme	nt on the basis	of HIV status	[]	
Ostracism, reje	ection and avoid	dance of people	e living with AI	DS []	
Mandatory HIV	V testing witho	ut informed co	nsent or confide	entiality protec	tions []
7. What is	the prevalence	e of stigma on	HIV patients fro	om the following	ng quotas?
Quotas	Very high	High	Moderate	Low	Very low
Family					
members					
Community					
Health					
workers					
Work place					
Religious					
groups					

8. HIV stigma has many causes. How much do the following cause stigma among the HIV patients undergoing treatment? use a scale of 1-5 where:

Strongly Disagree	[1]	Disagree [2]
Neither Agree nor Disagree	[3]	Agree [4]
Strongly agree	[5]	

Causes of stigma	1	2	3	4	5
Availability of treatment					
Perception of people living with HIV as weak and therefore a					
'burden' on the community					
Derogatory terms are used to describe those with the virus					
Myths and ignorance about the ways in which HIV is transmitted					
trigger damaging attitudes.					
Fear of illness/ fear of contagion (AIDS is regarded as generative					
and fatal conditions; it is transmissible, hence the affected person					
is seen as repellent, ugly or upsetting).					
HIV infection is associated with behaviours (such as					
homosexuality, drug addiction, prostitution or promiscuity) that					
are already stigmatized in the society					
Most people become infected with HIV through sex, which often					
carries moral baggage.					
There is a lot of inaccurate information about how HIV is					
transmitted, creating irrational behaviour and misperceptions of					
personal risk.					
Religious or moral beliefs lead some people to believe that being					
infected with HIV is the result of moral fault (such as					
promiscuity or 'deviant sex') that deserves to be punished.					
The effects of antiretroviral therapy on people's physical					
appearance can result in forced disclosure and discrimination					
based on appearance.					
Stigma reduction efforts are relegated to the bottom of AIDS					
programme priorities, often without funding to support such					
activities					

treatment?	v pa	mems	o um	uerge	nng
treatment:					
	•••••	••••••	•••••	•••••	•••••
	• • • • • • • •	••••••	•••••	•••••	•••••
	••••••				
10. To what extent does stigma contribute to the treatment	failu	re in	HIV	patie	ents
undergoing treatment?					
Very great extent [] Great extent []					
Moderate extent [] Low extent [] Very low extent	xtent		[]		
·					
11. What is your level of agreement with the following st	ateme	ent on	hov	v stig	gma
contribute to the treatment failure in HIV patients unde					
	igom	s irea	tilici	it. O	sc a
scale of 1-5 where:					
Strongly Disagree [1] Disagree [2]					
Neither Agree nor Disagree [3] Agree [4]					
Strongly agree [5]					
How stigma contributes to the treatment failure	1	2	3	4	5
HIV Stigma Tends to Heighten Existing Prejudices					
HIV Stigma Undermines Prevention					
Stigmatizing attitudes are associated with denial of risk and a					
lower likelihood of adopting preventive behaviours					
Concerns about stigma affect an individual's decision to					
access health care					
Social isolation negatively affects the lives of people living			l		

Stigma and discrimination are associated with under or nonparticipation in HIV information meetings and counselling and reduced participation in programs to prevent mother-to-

Stigma can reduce the likelihood of people using condoms

People who hold stigmatizing attitudes are also less likely to adopt preventive behaviours such as having multiple sexual partners or a commercial sex partner, and a sexually

with HIV.

child transmission

transmitted infection

and accessing preventive services

Stigma can deter or delay testing		
Concerns about stigma affect an individual's decision to		
withhold information about their status from family members,		
friends, and care providers.		
Stigma reduces the quality of care due to discrimination by		
health workers		
People with HIV have been refused services, denied medicine,		
passed from provider to provider		
People with HIV have been isolated unnecessarily		
Stigma leads to avoidance of care seeking due to fear of being		
"found out,"		
Stigma can delay treatment and reduce survival (Delayed		
testing can lead to delayed diagnosis and treatment)		
Stigma impedes adherence to medication		
Fear of stigma has led people to grind drugs into powder,		
which can result in inconsistent doses,		
Fear of stigma has led people to avoid taking medicines in		
front of others.		
Stigma adversely affects mental health, and depression		
interferes with consistent drug use		
Individuals with HIV may blame themselves to the extent that		
they cease to exert their right to decent treatment and other		
social benefits		
Experiences of social rejection, disapproval and		
discrimination related to HIV may decrease the motivation of		
HIV positive persons to stay healthy		

12. In your view, how effective are the following strategies in reducing HIV related stigma?

Strategies in reducing HIV	Very	Effective	Moderately		Ineffective
related stigma	effective		effective	effective	
Focussed information					
dissemination					
Patient counselling and					
coping skills acquisition					
Direct contact with people					
living with HIV or AIDS					
Integrated services (no					
isolation of their sections in					
hospitals)					
People living with					
HIV/AIDS need to be					
educated on their basic					
human rights;					
Institutions should					
implement their HIV/AIDS					
policies based on sound					
information and taking into					
account the rights of					
everybody					
HIV negative people need					
to be educated in order to					
create an environment free					
of fear of HIV biased social					
attitudes and no stereotypes					
towards HIV					

Support group for people living with HIV/AIDS, in which				
,				
individuals receive personal				
support for resolving issues or				
situations with spouses,				
families, communities, and so				
forth, in a safe environment				
Programs that support families,				
lighten financial burdens,				
support caregiver mental health				
and provide respite for stressed				
families and caregivers				
	•	•	•	

13. What other remedies of stigma among HIV patients undergoing treatment of you recommend?	an

Appendix IV: Interview Guide for the Staff

- 1. Is there treatment failure among the HIV patients undergoing treatment? How prevalent are the cases?
- 2. What are the common known factors to treatment failure among HIV patients?
- 3. Is there stigma and discrimination on HIV patients?
- 4. If yes, which form(s) of HIV stigma have you experienced?
- 5. What is the prevalence of stigma on HIV patients from the following quotas?
- 6. What are the causes of stigma among the HIV patients undergoing treatment?
- 7. How does stigma contribute to the treatment failure in HIV patients undergoing treatment?
- 8. What interventions can you suggest for reducing stigma among HIV patients undergoing treatment?
- 9. As a public health practitioner, what is our responsibility toward minimizing the negative health consequences of HIV/AIDS stigma?
- 10. What do you think are the reasons for the limited response to HIV/AIDS related stigma?

Appendix V: Sampling Table

N	S	N	S	N	S	N	S	N	S
10	10	100	80	280	162	800	260	2800	338
15	14	110	86	290	165	850	265	3000	341
20	19	120	92	300	169	900	269	3500	246
25	24	130	97	320	175	950	274	4000	351
30	28	140	103	340	181	1000	278	4500	351
35	32	150	108	360	186	1100	285	5000	357
40	36	160	113	380	181	1200	291	6000	361
45	40	180	118	400	196	1300	297	7000	364
50	44	190	123	420	201	1400	302	8000	367
55	48	200	127	440	205	1500	306	9000	368
60	52	210	132	460	210	1600	310	10000	373
65	56	220	136	480	214	1700	313	15000	375
70	59	230	140	500	217	1800	317	20000	377
75	63	240	144	550	225	1900	320	30000	379
80	66	250	148	600	234	2000	322	40000	380
85	70	260	152	650	242	2200	327	50000	381
90	73	270	155	700	248	2400	331	75000	382
95	76	270	159	750	256	2600	335	100000	384

Note: "N" is population size

"S" is sample size.