ASSESSMENT OF ASSOCIATION BETWEEN PERCEIVED STIGMA, SOCIAL SUPPORT AND SUBSTANCE ABUSE AMONG CLIENTS AT THE COMPREHENSIVE CARE CENTRE AT THE COAST PROVINCE GENERAL HOSPITAL.

THESIS SUBMITTED IN PARTIAL FULFILMENT OF REQUIREMENTS FOR THE DEGREE OF MASTERS OF SCIENCE IN NURSING (MEDICAL-SURGICAL) OF THE UNIVERSITY OF NAIROBI

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DECLARATION

I declare that this dissertation is my original work and has not been submitted either wholly or in part to any other university for an award of any degree or diploma.

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DEDICATION

This dissertation is dedicated to my loving parents, Anthony and Theresa who have always believed in my ability and my dear husband, Anthony for the immense support.

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ABSTRACT

Clients in Comprehensive Care Centres (CCC) usually face stigma and have poor social support which results in poor coping mechanisms including substance (alcohol and illicit drugs) abuse. The prevalence of substance abuse among patients infected with the Human Immunodeficiency Virus (HIV) is higher than that in the general population. HIV infected patients abusing substances are not easily contracted into treatment which delays initiation of Highly Active Antiretroviral Therapy (HAART). Substance abuse also poses a great challenge in adherence to management and prevention of Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome contributing to high morbidity and mortality. The aim of this descriptive cross-sectional study was to explore the association between perceived stigma, social support and substance abuse among Comprehensive Care Centre clients at the Coast Province General Hospital – Mombasa. The CAGE – AID (acronym for cut down, annoyed, guilty, eye opener – adapted to include drug use) tool was used to screen patients for substance abuse and a score of ≥2 was considered significant. A sample of 235 patients was selected by convenience sampling method. Patients with a CAGE-AID score of ≥2 who consented were subjected to a socio-demographic questionnaire, the multidimensional scale of perceived social support and the HIV stigma instrument for People Living With HIV/AIDS (PLWHA). Data analysis was done using Statistical Package for Social Sciences version 21.0. Descriptive statistics were used to examine demographic characteristics while the Pearson's Chi square test was used to test the significance of association between perceived stigma, social support and substance abuse in HIV. Multivariate analysis was further done to test for association between the variables. The confidence interval was set at 95%, p value at ≤0.05.The findings of the study demonstrate a significant statistical association between lack of social support, stigma and substance abuse among people infected with HIV/AIDS. In conclusion, an assessment of perceived stigma and social support is instrumental in identifying HIV infected patients at risk of substance abuse. A reduction in perceived stigma among PLWHA and adequate social support would come in handy in dealing with substance abuse in HIV/AIDS which would see a reduction in HIV related morbidity and mortality. HIV/AIDS patients with substance abuse disorders should be linked with further counselling and probably psychiatric follow up. HIV/AIDS support groups should be established and membership encouraged.

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LIST OF ABBREVIATIONS

AIDS – Acquired Immune Deficiency Syndrome

ART – Antiretroviral Therapy

ARVs – Antiretrovirals

CCC – Comprehensive Care Centre

CD4 – Cluster of Differentiation 4

CPGH – Coast Province General Hospital

DSM IV – Diagnostic and Statistical Manual of Mental Disorders – Fourth edition.

DSM IV-TR - Diagnostic and Statistical Manual of Mental Disorders – Fourth edition - Text Revision

DSM 5 - Diagnostic and Statistical Manual of Mental Disorders – Fifth edition

ERC – Ethical and Research Committee

GIP - Global Initiative on Psychiatry

HAART –Highly Active Antiretroviral Therapy

HIV –Human Immunodeficiency Virus

KAIS – Kenya AIDS Indicator Survey

MSPSS – Multidimensional Scale of Perceived Social Support

PEPFAR – President's Emergency Plan For AIDS Relief

PLWHA – People Living With HIV/AIDS

UNAIDS – United Nations Programme for HIV/AIDS

US – United States

WHO – World Health Organisation

OPERATIONAL DEFINITIONS

Comprehensive Care Centre refers to a centre/unit in the hospital that gives comprehensive outpatient services to patients confirmed to have HIV infection. It will be the study area. **Comprehensive Care Centre (CCC) Clients** refers to individuals confirmed to be HIV infected and enrolled at the centre.

Family refers to people related to each other. In this study, a spouse or a sexual partner is excluded from this group**.**

Friend refers to a person whom one knows and with whom one has a bond of mutual affection, typically exclusive of sexual or family relations.

Perceived social support refers to beliefs or evaluations that participants have about family, friends and significant other(s) in their life.

Perceived stigma refers to real or imagined fear of societal negative attitudes regarding HIV/AIDS and a concern by the participants that this could result in acts of discrimination directed to them because of their HIV/AIDS status.

Significant other refers to a person with whom someone has an established romantic or sexual relationship.

Social support refers to any physical, financial or psychological assistance that participants receive from family, friends and significant other.

Substance refers to both alcohol and illicit drugs.

Substance abuse refers to any use of alcohol and/or illicit drugs that interferes with HIV management and prevention strategies. It will be diagnosed on the basis of a CAGE – AID score ≥2.

Substance use is any intake of alcohol and/or illicit drugs.

Substance dependence will refer to continued use of the substance(s) despite the negative effect on HIV/AIDS management and prevention.

CHAPTER ONE: INTRODUCTION

1.1 Background

People infected with the Human Immunodeficiency Virus (HIV) and engage in substance abuse have varied reasons or factors which may explain the link between their diagnosis (HIV infection) and substance use. Stigma and poor social support are common problems faced by HIV infected patients. Poor coping mechanisms among these patients may drive them into substance use as a means of coping. As the Global Initiative on Psychiatry (2006) points out, factors such as declining health, pain, fear, anxiety and grief which are familiar with HIV diagnosis may increase individual risk of resuming or escalating drug use. Reactions to a positive HIV test, illness progression, or other stressful events can include increased alcohol and drug use (Galvan, Davies, Banks and Bing, 2008). Stigma and lack of social support often go hand in hand such that stigmatization of persons begets failed social support. Stigma is common in a variety of health related conditions especially disabilities and chronic diseases, for example loss of (a) body part(s) and a diagnosis of HIV infection.

Stigma being socially construed varies in different settings and individuals react differently to the stigmatizing process (Stuenkel and Wong, 2009). HIV is particularly stigmatizing and is associated with promiscuous sexual behaviour and marginalized groups such as homosexuals, commercial sex workers and injecting drug use (Sayles, Wong, Kinsler, Martin and Cunningham, 2009). Social support on the other hand enables HIV infected patients face the psychological and physical demands of coping with medication side effects and comorbid illnesses (Gore-Felton and Koopman, 2008). Poor social support coupled with poor coping mechanisms may have a role to play in the prevalence of substance use among the HIV infected patients.

The physical and psychological demands of coping with Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome can be overwhelming and can influence behaviour such as medication adherence, substance use, sexual risk behaviour, and exercise that, in turn, affect health outcomes (Gore-Felton and Koopman, 2008). Substance use (substance abuse and substance dependence) is common among the HIV patients (Lucas, 2011; Korthuis, Fiellin, McGinnis, et al., 2012). Substance abuse refers to the harmful or hazardous use of psychoactive substances which include alcohol and illicit drugs. DSM-IV-

TR, (2000) defines it as a "maladaptive pattern of substance use manifested by recurrent and significant adverse consequences related to the repeated use of substances".

DSM-5 (2013) does not define substance abuse but notes that psychoactive substance use can lead to dependence syndrome which is a cluster of behavioural, cognitive, and physiological phenomena that develop after repeated substance use and that typically include a strong desire to take the drug, difficulties in controlling its use, persisting in its use despite harmful consequences, a higher priority given to drug use than to other activities and obligations, increased tolerance, and sometimes a physical withdrawal state.

Alcohol, tobacco and illicit drugs use remains a global problem with differences among populations arising only with respect to extent, patterns and consequences of use. There is a paucity of literature on the prevalence of substance use among HIV infected patients. For example in Kenya, the prevalence of substance abuse has only been studied among outpatients and in limited samples of inpatients in Kenya. Ndetei, Khasakhala, Ongecha – Owuor and Mutiso, (2009) in a study on prevalence of substance abuse among patients in general medical facilities in Kenya using the Alcohol Use Disorders Identification Test (AUDIT) and the Alcohol, Smoking and Substance Involvement Screening Test (ASSIST) found an overall alcohol user rate as 25.1% and 25.5% using the two instruments, respectively. However, Korthuis et al., (2012) found out that substance abuse was prevalent among the HIV infected individuals, with 25.8% reporting unhealthy alcohol use, 29.1% reporting illicit drug use, and 11.5% reporting both unhealthy alcohol and illicit drug use in past year. This shows that substance abuse is a problem not only in the general population but also among the sick. Substance abuse remains a big challenge in the fight against HIV/AIDS despite the effort and resources directed towards curbing the pandemic.

HIV/AIDS has become one of the most devastating diseases worldwide. The outcome of HIV/AIDS is even more severe and devastating where substance abuse is involved. Efforts put in place have not yielded a lot of success as expected. For example, In 2003, WHO and UNAIDS initiated the "3 by 5" programme i.e. treating 3 million people living in poor countries with ART by the end of 2005 and the US government embarked on the President's Emergency Plan for AIDS Relief (PEPFAR), claiming to treat 2 million with ART in the "most afflicted countries in Africa and the Caribbean". Meanwhile, the establishment of Global Fund for HIV/AIDS, Tuberculosis and Malaria helps devote much needed resource to

treat AIDS (Global Fund – http://www.theglobalfund.org/en/). Despite these efforts, HIV incidence continues to remain at a high level throughout many parts of the world, with 2.5 million people being newly infected with HIV in 2011 only (WHO,2011).

The advance of HAART (Highly Active Antiretroviral Therapy) has seen a reduction in HIV related mortality but challenges such as substance abuse still exist and have a negative impact on the gains realised in this fight. Substance abuse being a common comorbidity in HIV-infected individuals (Lucas 2011 and Korthuis et al. 2012) complicates both prevention and treatment of HIV/AIDS. This is through influencing access and adherence to treatment (Samet, Horton, Meli, Freedberg, et al, 2004; Samet, Walley and Bridden , 2007; Othieno, Obondo and Mathai, 2012) and engagement in high risk behaviours (Mhalu, Leyna, and Mmbaga, 2013). A diagnosis of substance abuse is associated with high mortality among HIV infected patients even where access to services and ability to pay are not significant factors (Braithwaite, Conigliaro, Roberts, Shecter et al., 2007 and DeLorenze, Weisner, Tsai, Satre et al., 2011). This is because substance abuse is often accompanied by non-adherence to HAART and other management of HIV/AIDS including prevention of further spread and infection with other strains of the virus.

Alcohol and drugs use is a major concern in Kenya particularly the Coast province. The HIV prevalence in Coast province stands at 4.3% coming only a third after Nyanza and Nairobi respectively among the eight regions (provinces) in Kenya (KAIS, 2012). The Comprehensive Care Centre at the Coast Province General Hospital has approximately 5,000 patients enrolled for follow up and an average of 300 patients attend the CCC monthly. The problem of substance use among HIV infected patients is rampant and has been found to negatively affect adherence.

This study hypothesizes that HIV infected patients with poor social support and stigma develop poor coping mechanisms leading to comorbid conditions of which substance abuse is common.
The findings of this study will expand the existing body of knowledge on the prevalence of alcohol and drugs abuse among HIV infected patients. The study is intended to fill the knowledge gap on the association between perceived stigma, social support and substance abuse which has effects on HIV/AIDS management. An assessment of stigma and lack of social support early into the HIV diagnosis would enable care givers to design interventions

to curb substance abuse in patients infected with HIV and thus positively impact on adherence.

1.2 Problem Statement

Substance abuse is a common phenomenon among HIV infected patients despite the adverse consequences of accelerated disease progression, further transmission of the virus and development of drug- resistant strains. Most importantly, substance abuse among HIV infected patient affects adherence to care which results in a rise in HIV related morbidity and mortality. Patients diagnosed with HIV face a lot of psychosocial challenges e.g stigma and poor social support which may predispose them to substance abuse. Dealing with substance abuse among this population and thus improvement on adherence to care requires an understanding of the associated factors.

The focus of this study was perceived stigma and social support which have not been adequately explored as factors associated with substance abuse among the HIV infected patients. Interventions targeting stigma and poor social support would be instrumental in curbing substance abuse among people infected with HIV/AIDS.

1.3 Significance of the study

Many studies (Gálvez-Buccollini, DeLea, Herrera, Gilman et al. 2009;Marshall, Ker, Qi, Montaner et al., 2010; El-Bassel, Gilbert, Terlikbayeva, Beyrer et al. 2013) have been conducted on alcohol and drugs use as risk factors for HIV infection. However, prevalence of alcohol and drugs use in HIV infected patients and the role of stigma and social support have not been adequately explored. The findings of this study are expected to expand the existing body of knowledge on the prevalence of alcohol and drugs abuse among HIV infected patients. The study is intended to fill the knowledge gap on the association between psychosocial factors (perceived stigma and social support) and behavioural factors, in this case substance abuse which has effects on HIV/AIDS management.

The contribution of perceived stigma and social support in alcohol and drugs abuse in this population was explored. This will be handy in addressing the problem of alcohol and substance abuse as regards HIV/AIDS prevention and treatment through addressing these risk factors in the planning for interventions. Identification of stigma and lack of social support early into the HIV diagnosis would enable care givers to design interventions which would curb substance abuse among these patients and thus positively impact on adherence. The outcome of such interventions will be critical in promoting better health outcomes by

reducing morbidity and mortality in HIV/AIDS. Such interventions will also mean that HIV patients get to be attended to in a multidisciplinary approach to ensure that the many issues affecting them are addressed.

1.4 Research Question

What is the association between perceived stigma, social support and substance abuse among CCC clients at the Coast Province General Hospital?

1.5 Hypothesis

There is no significant statistical association between perceived stigma, social support and substance abuse among CCC clients at the Coast Province General Hospital.

1.6 Objectives

1.6.1 Broad Objective

This study was carried out to explore the associations between perceived stigma, social support and substance abuse among CCC clients.

1.6.2 Specific Objectives/Aims

1. To determine the prevalence of substance abuse among clients at the CCC.
2. To establish the extent of perceived stigma and social support among CCC clients abusing substances.
3. To ascertain the association between perceived stigma, social support and substance abuse among clients at the CCC.

1.7 Theoretical Framework

1.7.1 The Roy Adaptation Model

The Roy Adaptation Model (Sister Callista Roy) was used to inform this study. According to this Adaptation theory, human beings are adaptive systems with inputs of stimuli and output as behaviour responses that serve as feedback. The systems have control processes known as coping mechanisms.

According to this model, there are three classes of stimuli; focal stimuli which are stimuli most immediately confronting the human system. In this study, HIV diagnosis / infection was the focal stimuli. All the participants in the study were patients infected with HIV. Perceived stigma and poor social support represent contextual stimuli which refer to all other stimuli of the human system's internal and external worlds that can be identified as having a negative or positive effect on the situation. This is because perceived stigma and perceived poor or lack of social support are conceptualized as having a negative effect on HIV/AIDS management especially concerning prevention and management. The third stimuli are the residual stimuli which are those internal and external factors whose current effects are unclear. In this study, the confounding factors e.g. age, gender, marital status, occupation, education level and management status will be the residual stimuli. The residual stimuli are thought to have an influence on HIV/AIDS diagnosis, perceived stigma and perceived social support.

Substance abuse is a maladaptation while perceived stigma and social support represents stimuli that determine the level of adaptation. Individuals who are overwhelmed by perceived stigma and the lack/poor social support end up engaging in substance abuse. Individuals adapt to a situation differently and this adaptation is reflected in the four modes; physiological (biological indicators e.g. the signs of infection), self-concept (self-esteem, hopelessness, powerlessness), role function (work, social, recreational activities) and interdependence mode (intrapsychic function, family relations, social support) {George J., 2002}. Perceived stigma is an indication of maladaptation in the self-concept mode while lack of social support is a maladaptation in the interdependence mode.

 The output of the human adaptive system is behavioural responses which can be both external and internal. The behavioural responses become the feedback to the system and the environment. The output can be adaptive responses (positive adaptation) or ineffective responses (negative adaptation). In this study, substance abuse represents ineffective response

to the stimuli (a maladaptation) which in this case is an increase in substance abuse after HIV/AIDS diagnosis. A positive adaptation would be said to be present when despite the presence of the stimuli (HIV stigma and poor social support), the individual develops coping mechanisms such that he/she does not engage in substance use. Substance use is therefore taken to be an ineffective response (negative adaptation).

An assessment of the input (contextual stimuli –perceived stigma and perceived social support) and thus forming a basis for intervention is instrumental in enhancing adaptive responses (positive adaptation) as feedback to stimuli in individuals.
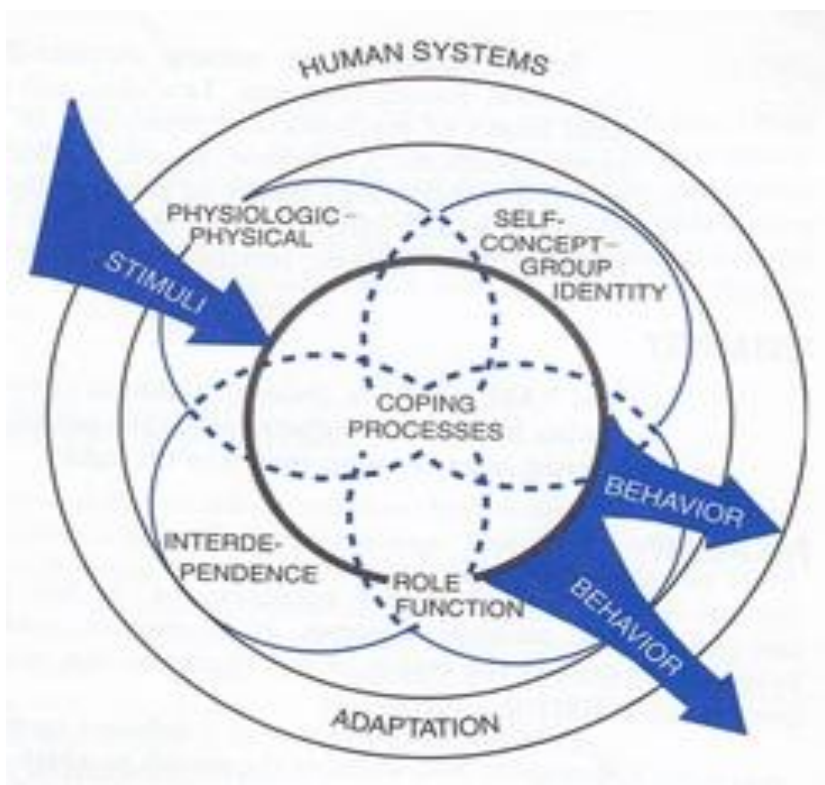
Figure 1: The person as an adaptive system

Adopted from Julia B. George, (2002)

1.8 Conceptual Framework

INDEPENDENT VARIABLES   **DEPENDENT VARIABLES**

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┌────────────────────────┐                    ┌────────────────────────┐
│ Perceived Stigma        │                   │ Substance abuse (Alcohol │
│                         │───────────────────▶│ and drugs use in HIV/AIDS)│
│ Perceived social support│                   │                          │
└────────────────────────┘                    └────────────────────────┘
              ▲                                            ▲
              │                                            │
              │          ┌────────────────────────────────┐│
              └──────────│ CONFOUNDERS                     ││
                         │ Age                             ││
                         │ Gender                          │┘
                         │ Occupation/Social-economic status│
                         │ Education level                 │
                         │ Marital status                  │
                         │ Management status (on/not on ARVs)│
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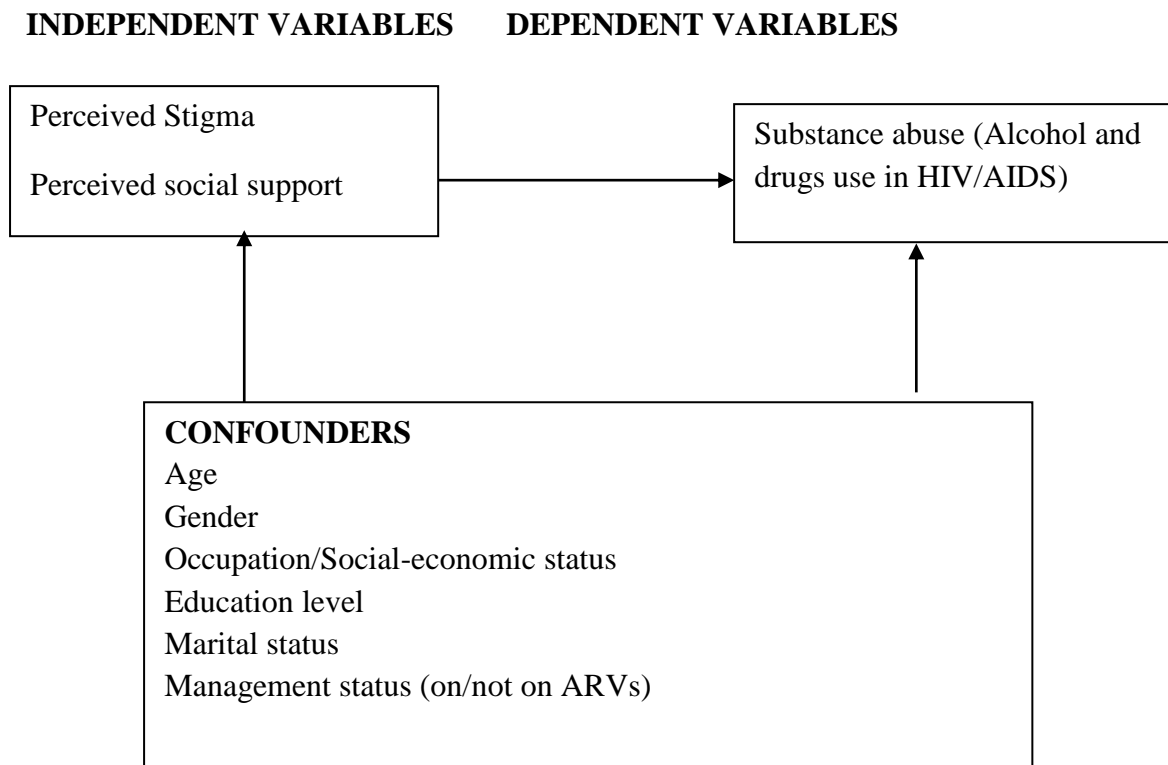
Figure 2: Conceptual Framework

Substance abuse in HIV was the dependent variable while stigma and social/family support were the independent variables. The researcher in this study conceptualizes that stigma and poor social support have a contribution towards substance abuse in HIV. The presence or absence of stigma and social support will determine whether participants engage in substance abuse or not. Engaging in substance abuse among the HIV infected will lead to non-adherence to treatment and prevention strategies as well as a high HIV related morbidity and mortality.

Age, gender, marital status, education level, occupation/socio-economic status and the management status (on/not on ARVs) will have an influence on the level of stigma and social support as well as on substance abuse in HIV. For example, the level of stigma and social support will be different in males and females as will the prevalence of substance abuse in HIV infection. These therefore are confounding factors.

CHAPTER TWO: LITERATURE REVIEW

2.1 Reaction to HIV/AIDS Diagnosis/Status

A HIV/AIDS diagnosis is often characterized by stigma, discrimination, and social isolation (Sowell & Phillips, 2010). This may be related to the outcome of a positive HIV test, illness progression (sickness and death) and association with contagion, promiscuous sexual behaviour and marginalized groups such as homosexuals and injecting drug users (Capitanio and Herek, 1999, Herek, 2002, Sayles et el., 2009). As Galvan et al., (2008) puts it, each stage of HIV/AIDS, including diagnosis of infection, adaptation to the disease, treatment regimen, and facing a chronic and potentially terminal illness, increases psychological distress, depression, and feelings of hopelessness. Such experiences are compounded by stigma and poor social support which are common problems faced by HIV infected patients. Poor coping mechanism in the face of stigma and poor social support predisposes this population to substance abuse.

2.2 Substance Abuse

The Diagnostic and Statistical Manual of mental disorders, fifth edition (DSM – 5) refers to a substance as a drug of abuse, a medication, or a toxin. The substance-related disorders are divided into two groups: substance use disorders and substance-induced disorders (DSM-5, 2013).

DSM-5 classifies the following conditions as substance-induced; intoxication, withdrawal, and other substance/medication-induced mental disorders (psychotic disorders, bipolar and related disorders, depressive disorders, anxiety disorders, obsessive-compulsive and related disorders, sleep disorders, sexual dysfunctions, delirium, and neurocognitive disorders).Substance use disorders consists of substance dependence and substance abuse. The essential feature of a substance use disorder is substance dependence which is a cluster of cognitive, behavioural, and physiological symptoms indicating that the individual continues using the substance despite significant substance-related problems (DSM-5, 2013).

Substance abuse refers to the harmful or hazardous use of psychoactive substances, including alcohol and illicit drugs. DSM-5 specifies that the essential feature of substance abuse is a maladaptive pattern of substance use manifested by recurrent and significant adverse consequences related to the repeated use of substances. There may be repeated failure to fulfil major role obligations, repeated use in situations in which it is physically hazardous, multiple

legal problems, and recurrent social and interpersonal problems. These problems must occur recurrently during the same 12-month period (DSM-5, 2013).

2.3 Prevalence of Substance Abuse in HIV

Several studies (Galvan, Bing, Fleishman, London et al., 2002 ; Conigliaro, Justice, Gordon and Bryant, 2006; Lucas 2011and Korthuis et al., 2012) have revealed that the abuse of alcohol and illicit drugs is a common phenomenon among HIV infected patients. Research also shows that people who are dependent on alcohol are much more likely than the general population to abuse drugs, and people with drug dependence are much more likely to drink alcohol (Falk,Yi and Hiller-Sturmhöfel, 2008 ; Korthuis et al., 2012). For example, Korthuis et al., (2012) found out that substance abuse was prevalent among the HIV infected individuals, with 25.8% reporting unhealthy alcohol use, 29.1% illicit drug use, and 11.5% both unhealthy alcohol and illicit drug use in past year. This observation could be related to the fact that similar factors drive individuals to abuse whatever substance they may and also that different substances may be available at the same time and location. This therefore means that the different psychoactive agents cannot be studied or assessed in isolation when effort is being made to rid a population of substance abuse. In spite of this, most studies have concentrated on alcohol abuse only.

In Kenya and generally in Africa, the prevalence of substance abuse in HIV infected individuals has not been explored. Most of the studies have explored alcohol abuse in other populations e.g. a Kenyan study on prevalence of substance abuse among patients in general medical facilities in Kenya using the Alcohol Use Disorders Identification Test (AUDIT) and the Alcohol, Smoking and Substance Involvement Screening Test (ASSIST) which found the overall alcohol user rate as 25.1% and 25.5% using the two instruments, respectively (Ndetei et al., 2009). This does not however mean that the problem is non – existent in the region but rather that more needs to be done. Most of the studies (Gálvez-Buccollini et al. 2009, Marshall et al. 2010,El-Bassel et al. 2013) conducted on substance abuse concentrated on alcohol and drugs use as risk factors for HIV infection. In Africa and particularly in Kenya, there is very minimal literature on substance abuse among HIV infected patients and its effect on HIV/AIDS management.

2.4 Substance Abuse and HIV Management

Substantial efforts aimed at reducing the spread of HIV have been made but the effects of substance abuse on the management and prevention of HIV/AIDS cannot be underestimated. HIV incidence continues to remain at a high level throughout many parts of the world, with 2.5 million people being newly infected with HIV in 2011 only (WHO, 2011).

Substance abuse has been associated with suboptimal health outcomes in HIV (DeLorenze et al., 2011,Braithwaite et al. 2007). DeLorenze et al., (2011) in their study concluded that excess mortality does occur in HIV-infected patients diagnosed with substance use dependence or abuse even when access to medical services and ability to pay for care are not significant factors. The reasons for such suboptimal outcomes among substance users could be non-adherence to HAART (Naidoo, Peltzer, Louw, Matseke et al., 2013, Othieno et al., 2012,Hendershot et al. 2009,Samet J.H. 2004 and 2007) and to other management services offered (Korthuis et al. 2012),and engagement in risky sexual behaviour (Mhalu et al., 2013;Gerbi, Habtemariam, Tameru, Nganwa et al., 2009;Chersich & Rees, 2010).

Risky sexual behaviours among substance abusers may be related to a state of disinhibition leading them to engage in harmful sexual practices e.g engaging in unprotected sexual intercourse that they would otherwise not engage in (Shuper, Joharchi, Irving and Rehm, 2009; Fisher, Bang and Kapiga, 2007). In addition, risk reduction intervention strategies have been found to be moderated by heavy substance abuse as in a study done in South Africa (Kalichman, Simbayi, Vermaak, Cain et al., 2008). Health workers caring for HIV infected patients impart a lot of knowledge to the patients on risky behaviours that may influence their management and wellness. Gerbi et al., (2011) however notes that PLWHA continue with substance abuse and alcohol consumption before sex after establishing their HIV status despite clear evidence of such risky behaviours that could lead to an increase in exposure to HIV.

Gore-Felton and Koopman , (2008) conceptualizes that the psychological and physical demands of coping with medications and comorbid illnesses can be overwhelming and may influence behaviour such as medication adherence, substance use and risky sexual behaviour that in turn, affect health outcomes. The consequences of such behaviour are HIV disease progression, CD4 cell decline, AIDS diagnosis, AIDS defining illness and AIDS related deaths (Gore-Felton and Koopman, 2008). The advent of HAART has been associated with

longevity due to a reduction in HIV related morbidity and mortality. Non adherence is a predictor of virological failure manifested in a high viral load and development of resistant strains. The resistant forms of the virus may then be spread through unprotected intercourse when individuals are under influence of alcohol and drugs.

2.5 Stigma and Social Support in HIV

People with higher HIV related stigma have been observed to engage in harmful alcohol use which has also been correlated with inadequate social support (Holtz, Sowell and Velasquez, 2012). Stressful life events have been associated with nonadherence to HAART which may be correlated with substance abuse (Leserman, Ironson, O'Cleirig, Fordiani et al.,2008). On the other hand, social support is associated with slow AIDS progression as Leserman et al., (2008) found out. The role of social support and the fight against HIV stigmatization can therefore not be underestimated.

Stigma can be defined as a mark of disgrace associated with a particular circumstance, quality, or person e.g. the stigma of mental disorder (Oxford Dictionaries – Oxford University Press). The National Cancer Institute (www.cancer.gov/dictionary) defines social support as "a network of family, friends, neighbours and community members that is available in times of needs to give psychological, physical, and financial help". Berger, Ferrans and Lashley (2001) notes that stigma can be viewed both as a trait (attribute/characteristic) and an outcome of possessing that trait. Stigma as a trait is an attribute viewed negatively by the society while as an outcome, stigma occurs when the negative social meanings attached to the discrediting attribute become linked to the individual. With that linkage the person's social identity changes, resulting in less than full acceptance of the person in social interaction, identity engulfment (in which the trait becomes the defining aspect of the person, colouring all other information about him or her), and limitation of the opportunities that would otherwise be available (Berger et al.,2001).

Stigma can take two forms: perceived (felt, imagined) and enacted (actual) stigma. Perceived (or felt) stigma occurs when there is a real or imagined fear of societal attitudes regarding a particular condition and a concern that this could result in acts of discrimination directed to individuals with that condition. Enacted (or actual) stigma, in turn, refers to experiences of discrimination directed to individuals because of specific attributes or conditions that characterize them (Galvan et al., 2008). Holzemer, Uys, Chirwa, Greeff et al., (2007) classifies stigma into internal (emic/perceived), external (received/actual/etic) and associated

stigma. Enacted /actual/received stigma refers to all types of stigmatizing behaviour towards a person living with HIV/AIDS as experienced or described by themselves or others. Such stigmatizing behaviour includes; neglecting, fearing contagion, avoiding, rejecting, labelling, pestering, negating, abusing and gossiping. Holzemer et al, (2007) describes internal stigma (emic view) as thoughts and behaviours stemming from the person's own negative perceptions about him/herself based on their HIV status. These include; perception of self (negative evaluation of self based on HIV-positive status), social withdrawal (withdraws from sexual and or loving relationships to protect self from discrimination), self exclusion (the person decides not to use the services due to being HIV-positive and fear of discrimination) and fear of disclosure (all behaviours related to revealing HIV status). Associated stigma is described as incidents that describe stigma against people who work or associate with HIV/AIDS affected people e.g. family /spouse – incidents directed at family members of a person living with HIV/AIDS and healthcare workers – incidents directed at healthcare worker who cares for people living with HIV/AIDS. Stigmatization can thus be said to reflect an attitude while discrimination is an act or behaviour that results from stigma.

Pryor, (2007) defining it slightly different from how Holzemer et al, (2007) does note that while perceived stigma is self- stigma (how one reacts to the possession of a stigmatizing situation), enacted (received) stigma may take the form of public stigma (people's social and psychological reactions to someone with a perceived stigma),stigma by association (social and psychological reactions to people somehow associated with a stigmatized person e.g. family members) and institutional stigma (the legitimatization and perpetuation of a stigmatized status by society's institutions and ideological systems). Whatever the type of stigma, it is important to note that stigma affects the quality of life of a HIV infected patient significantly and thus cannot be ignored.

An understanding of the daily struggles of living with HIV by those surrounding a patient is of critical importance in maintaining health and survival among people living with HIV(Sayles, Ryan, Silver, Sarkisian et al., 2007). Salyes et al., (2007); Sayles et al., (2009) and De, Bhandari, Roy, Bhowmik et al., (2013) in their studies note that experiences of stigma can hinder patients from accessing medical services and medications, and from disclosing their HIV status to family and friends. This would have a negative impact on the fight against HIV/AIDS.

Kelly, Bimbi, Izienicki and Parsons, (2009) in the study, *Stress and Coping among HIV-Positive Barebackers* observe that before coming to terms with an illness a person may experience negative feelings accompanied by stress and experience of stigma. In this study, the high levels of stress and stigma coupled with greater adverse coping methods were found to fuel both drug use and barebacking. This observation is consistent with what often happens with a HIV diagnosis where perceived stigma may fuel substance abuse and risky sexual behaviour. The same study notes that drug use may not only be limited to the times when individuals engage in such risky behaviour but also after such behaviour due to feelings of discomfort. In order to cope with the stress associated with these feelings of discomfort, they may tend toward increased engagement in substance use. In other words, drug use may function as a response to managing guilt related to seeking unsafe sex driven by stress and stigma (Kelly et al., 2009) which creates a vicious cycle. Stress related to a HIV diagnosis in addition to risky sexual behaviours that could have culminated to the infection may be a source of perceived and enacted stigma that may drive these patients to substance abuse. On the other hand, individuals under influence of substances may engage in risky sexual behaviour that may be a source of ridicule and stigma from the society in addition to fuelling the spread of HIV/AIDS.

Galvan et al., (2008) and Ying-Xia, Golin, Jin, Emrik et al., (2014) notes that how HIV-positive people manage HIV stigma and the strategies that they use can be influenced by the extent of social resources {family, friends, significant other(s)} that they have available in their lives. This may have an influence on the impact of the HIV stigma on the individual e.g the individual may describe/view self more positively enabling him/her to cope and may also face stressors more confidently knowing that there is someone available to help. Social support therefore enables individuals to cope with stigma and consequently risky behaviour such as substance abuse.

Even though many studies have provided information on the link between substance abuse and HIV, little has been done to find out the likely factors that drive HIV infected patients into substance abuse. Social support has been found to be an important pillar among the HIV infected patients while stigma and discrimination continue to tear families apart. The theme of the World AIDS Day, 2013 - "Getting to zero: Zero new infections, Zero discrimination and Zero AIDS-related deaths" is a wakeup call on all to participate in the fight against HIV/AIDS. Assessment of stigma and its reduction may be instrumental in tackling substance

abuse and hence prevention of further spread of HIV. A study on risky behaviours among young people living with HIV recommended integration of specific intervention measures to address alcohol consumption, risky sexual behaviour, and STI transmission and prevention in the routine HIV/AIDS care and treatment (Mhalu et al., 2013). Identifying the various factors associated with substance use in patients infected with HIV/AIDS would be an important step towards eradication of the problem and management of HIV/AIDS. In designing interventions to address alcohol and drugs use among the HIV infected patients, the risk factors should be taken into account.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Study Design

This was a descriptive cross-sectional study. Using this study design, the patients who met the inclusion criteria were assessed for perceived stigma and social support system at one point in time during the study period. This is because the information required was as perceived by the participants themselves at that point without any external manipulation/interventions or need for follow up.

3.2 Study Variables

The independent variables in this study were perceived stigma and social support while the dependent variable was substance abuse in HIV infection. A number of confounding factors were identified. These included age, gender, occupation, level of education, marital status and the management status (whether on or not on ARVs). The outcome variables were non adherence to treatment and prevention strategies and an increase in HIV related morbidity and mortality.

3.3 The Study Area

The sample population was obtained from the Comprehensive Care Centre (CCC) of the Coast Province General Hospital, Mombasa, Kenya. The Coast Province General Hospital is a public (Government of Kenya) facility that serves as a referral centre in the province and its environs. It therefore has a wide catchment area. It is located in the coastal city of Mombasa, Kenya, in the Coast province, Mombasa county, Mombasa district, Island division, Tononoka location, Tononoka sub-location in Mvita constituency.

3.4 Study Population

The CCC at the Coast General Hospital has approximately 5,000 enrolled patients on follow up. An average of 300 patients is seen in a month at the clinic.

The study population was patients infected with HIV enrolled for follow up at the CCC at the Coast Province General Hospital and fulfil the inclusion criteria.

3.4.1 Inclusion Criteria

1. All patients infected with HIV (both male and female) with substance use (CAGE – AID score ≥2) aged 18 years and above and enrolled at the CCC.
2. Those who gave informed consent to participate in the study.

3.4.2 Exclusion Criteria

1. Patients infected with HIV who are below 18 years of age and those without substance use problems.
2. Those who declined to give consent.

3.5 Sample Size Determination

A sample was obtained from the study population. Sample size determination ensures that the sample taken is adequate for power analysis.

The CCC at the Coast Province General Hospital attends to an average of 300 new patients in a month. Data collection was done in a span of two months and therefore the population was estimated at 600 patients. The following formula by Fisher, et al. as cited by Mugenda and Mugenda (2005) was used (a confidence interval of 95% and the prevalence rate of substance use assumed at 50%) to determine the sample size.

$$n = \frac{Z^2pq}{d}$$

Where,

n= desired sample size (if the target population is greater than 10,000).

Z is the standard normal deviate at the required confidence level, set at 1.96 which corresponds to 95% confidence interval.

P is the proportion in the target population estimated to have the characteristics being measured.

Having not found an estimate of the proportion of the HIV infected patients who are substance users from the literature, 50% was therefore used as recommended by Fisher et al.,(1998) cited by Mugenda and Mugenda(2005).

q = 1-p which is the proportion of the target population estimated not to have the characteristics being measured.

d is the level of statistical significance set at $\pm$ 0.05 (0.5%)

Substituting the letters in the formula with the numbers;

$n = \underline{Z^2 p(1-p)}$ $= \underline{1.96^2(0.5)(1-0.5)}$ $= \underline{3.8416 \times 0.5(0.5)}$

  d^2 0.05^2 0.0025

$n = \underline{3.8416 \times 0.25}$ $= 384.16$

     0.0025

$n = 384.16$

Since the target population was less than 10,000, the required sample would be smaller and was thus adjusted using the formula;

$nf = n/(1+n/N)$

   Where: nf is the desired sample size (when the population is less than 10,000)

         n is the desired sample size (when the population is more than 10,000)

         N is the estimate of the population size.

Hence nf = 384/ (1+384/600)   = 384/1+0.64) =384/1.64 =234.15

       = approximately 235 respondents.

Adjusted up by 10% to cater for attrition = 10% of 235 which is = 23.5

The total was 235+24=259 respondents.

3.6. Sampling

Sampling was done to enable the researcher test the hypothesis about the population from which the sample had been drawn.

3.6.1 Sampling Frame

The sampling frame included all the patients with HIV infection enrolled at the CCC who met the inclusion criteria.

3.6.2 Sampling Procedure

Convenience sampling method was used to obtain the study sample. With the data on the number of patients abusing substances not available, patients who met the inclusion criteria

and gave consent to participate were given the questionnaires to fill until a sample size of 235 was achieved.

3.6.3 Consenting Process

After determining their substance use status using the CAGE – AID tool, eligible respondents were informed about the study and consent to participate requested. After consent explanation, eligible respondents having understood were requested to sign the consent form. Further explanation was offered to those who did not understand until they understood enough to sign the consent form.

3.7 Study Instruments

The CAGE substance abuse screening tool which consists of four questions was used to assess the patients for substance abuse. Informed consent was sought from patients who met the inclusion criteria. After obtaining written consent, the entire eligible respondents were subjected to the same set of questions in the study instruments. The instruments constituted a socio-demographic questionnaire (12 items), a multidimensional scale of perceived social support (12 items) and the HIV/AIDS stigma instrument for people living with HIV/AIDS (33 items) to assess the exposure variables. To fill in all the study tools, a respondent required an average of 45 minutes. To ensure the respondents were not unduly exhausted, the researcher observed the respondents as they filled in the tools and also informed them that they would be free to stop and continue at a mutually agreed time later.

3.7.1 CAGE Questions Adapted to Include Drug Use (CAGE-AID) Tool

This tool is derived from Ewing J.A., (1984). The acronym CAGE is derived from the four questions of the tool: Cut down, Annoyed, Guilty, and Eye-opener. Item responses on the CAGE questions are scored 0 for "no" and 1 for "yes" answers, with a higher score being an indication of alcohol/drugs problems. A total score of ≥ 2 is considered clinically significant. The normal cut off for the CAGE is two positive answers. However, some authorities recommend lowering of the threshold to one positive answer to cast a wider net and identify more patients who may have substance abuse disorders (Ewing et al., 1984). This tool was administered to all patients coming to the CCC during their visits as a baseline assessment tool. It formed a basis of including patients in the study such that patients who scored 2 and above were considered to be abusing substances and therefore were included in the study if they consented.

3.7.2 Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988)

This tool was developed and tested by Zimet, Dahlem, Zimet & Farley in 1988. It is a 12 items self-report measure of subjectively assessing social support. It consists of three subscales, each addressing a different source of support, (a) Family, (b) Friends, and (c) Significant Other (Zimet et al., 1988). Each of the subscales has 4 items. Participants completing the MSPSS are asked to indicate their agreement with items on a 7-point Likert-type scale, ranging from *very strongly disagree* to *very strongly agree*.

The scale can be analysed by looking at the scores for each of the three subscales in order to ascertain the perceived social support from each (family, friends and significant other). Each subscale has a possible range of scores from 4 to 28, with a higher score reflecting a higher level of perceived social support.

The testing of this tool yielded good internal and test-retest reliability as well as moderate construct validity (Zimet et al., 1988, 1990). This tool has been used in other studies and has been tested in people of different age groups and cultural backgrounds e.g by Galvan et al., (2008) and Ege et al., (2008) to assess perceived social support.

3.7.3 The HIV/AIDS Stigma Instrument – PLWA (HASI-P) (Holzemer et al., 2007)

This tool was developed and tested by Holzemer et al., in 2007 with data collected from five African countries: Lesotho, Malawi, South Africa, Swaziland and Tanzania (Holzemer et al., 2007). It is a 33-item instrument that measures experiences of stigma among people living with HIV as perceived by them, and can be used to collect data on six dimensions of HIV related stigma thus;

Verbal abuse – 8 items,

Negative self-perception (self stigma) - 5 items,

Health care neglect – 7 items,

Social isolation – 5 items,

Fear of contagion – 6 items,

Workplace stigma – 2 items.

On a scale of 0–3, participants rate how often various stigmatizing events have happened to them in the past few months, because of their HIV status. The instrument is scored by summing the scores (0-3) for each item and then dividing by the number of items within each factor/dimension; thus each scale score range from 0-3 so that stigma frequency could be

compared across the factors. Higher scores are interpreted as reflecting greater perceived stigma. This tool is also useful in tracking changes in stigma over time (Holzemer et al., 2007). This tool has been tested in five African countries with good results on validity and reliability.

3.8 Pretesting of the Study Instruments

This enables the researcher to test the applicability of the study instruments and the methodology. Corrections can then be done where/when need be.

Pretesting of the study instrument was done by the researcher at the Tudor District Hospital CCC. This hospital had been chosen because it has a well established CCC similar in many aspects to the one at the Coast Province General Hospital. Tudor District Hospital is also located in Mombasa county and therefore clients attending the CCC were expected to have similar characteristics as those attending the CCC at the Coast Province General Hospital.

3.9 Data Collection procedure

Data collection was by use of the designed study instruments. The researcher collected data by administering the questionnaires to the eligible respondents. The researcher oversaw the administration of the questionnaires.

3.10 The Recruitment Process

After getting clearance from KNH/UON ethics committee and the hospital administration, the researcher explained the study protocol to the healthcare workers on site. The researcher used the clerks and the triage nurses to identify potential respondents. The researcher explained to the potential respondents about the study and obtained informed consent. Respondents completed the questionnaires during their clinic visits. Those who were unable to complete the questionnaire at first contact during the clinic visit were informed about the follow up to revisit the clinic so that they could complete the questionnaire. The ones who declined to give consent were excluded from the study.

3.12 Data Analysis and Presentation

Descriptive statistics (means, standard deviations, frequencies, and percentages) were used to describe demographic characteristics of the sample, perceived stigma and social support using the statistical package for social sciences (SPSS) version 21.0. Chi squared tests were used to determine the statistical significant differences between the independent, confounders and dependent variables. Further significant differences between perceived stigma, social

support and substance abuse were determined through multivariate analysis. The P value to determine the significant differences was set at $p \leq 0.05$ (confidence interval at 95%).

The results were presented in form of narratives, tables and charts.

3.13 Ethical Considerations

Ethics approval was sought from the Kenyatta National Hospital /University of Nairobi Ethics and Research Committee. Authority to carry out the study was obtained from the management of the Coast Province General Hospital and the Comprehensive Care Centre at the hospital.

Questionnaires were only administered to patients after a written consent had been voluntarily obtained. Participation in the study was voluntary and the participants had an option to withdraw at will at any stage without loss of benefits. Participants were informed that information obtained from them would be treated with utmost confidentiality. Anonymity was observed.

No invasive procedures were used. However, some questions caused the participants psychological discomfort in which case the participant were linked to counselling services. During the study, participants identified to have alcohol and drug use disorders as well as those identified to require counselling for any other reason were referred to a qualified counsellor and psychiatrist in order to link them with support and for management of the identified disorders.

Participants were informed that there would be no direct individual benefits expected from participating in the study but rather that the findings from the study would be instrumental in policy and interventions formulation in relation to substance use among HIV infected patients.

3.14 Study Limitations

The study relied on subjective information from the respondents.

The study population excluded patients below 18 years of age and therefore those below 18 years but with substance abuse disorders would not benefit from the study outcomes. In addition, convenience sampling method was used. This would affect generalizability of the study.

This was a cross sectional study and therefore the variables were assessed at one point in time. There was no follow up done on the findings which would have included establishment of support groups and their impact on substance abuse.

CHAPTER FOUR: RESULTS

4.1 SOCIO-DEMOGRAPHIC CHARACTERISTICS.

4.1.1 Gender

Majority of the respondents 67.2% (158) were male while 32.8% (77) were female.

4.1.2 Age

Figure 3 below illustrates the ages of the respondents with the majority being ages 30-39 years, 37.9% (89) and 40-49 years, 23.8% (56).

Figure 3: Age of Respondents
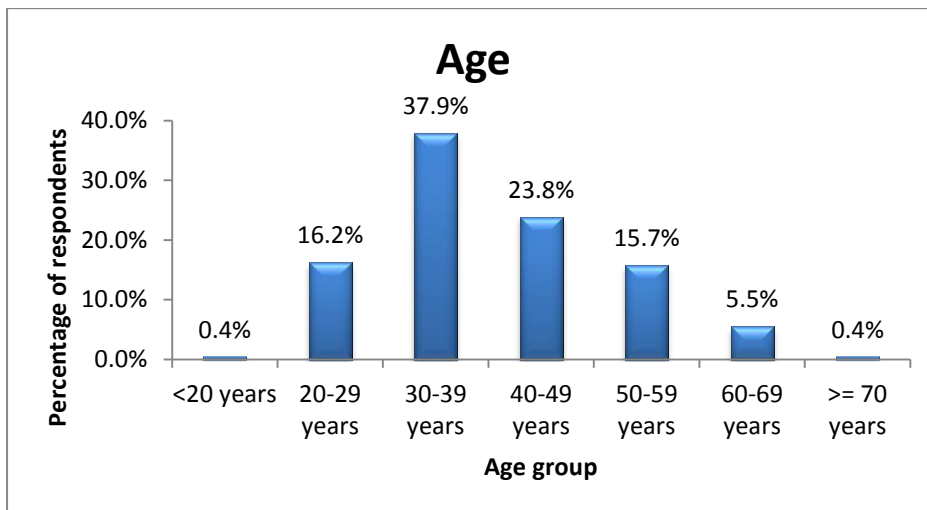
4.1.3 Education Level

Slightly above half, 55.6% (133) of the respondents had secondary level as the highest level of education with only 15.7% (37) having tertiary education as shown in figure 4 below.

Figure 4: Education Level

Education Levels

15.7% (Tertiary)
28.5% (Primary)
55.3% (Secondary)

Legend:
- Primary
- Secondary
- Tertiary
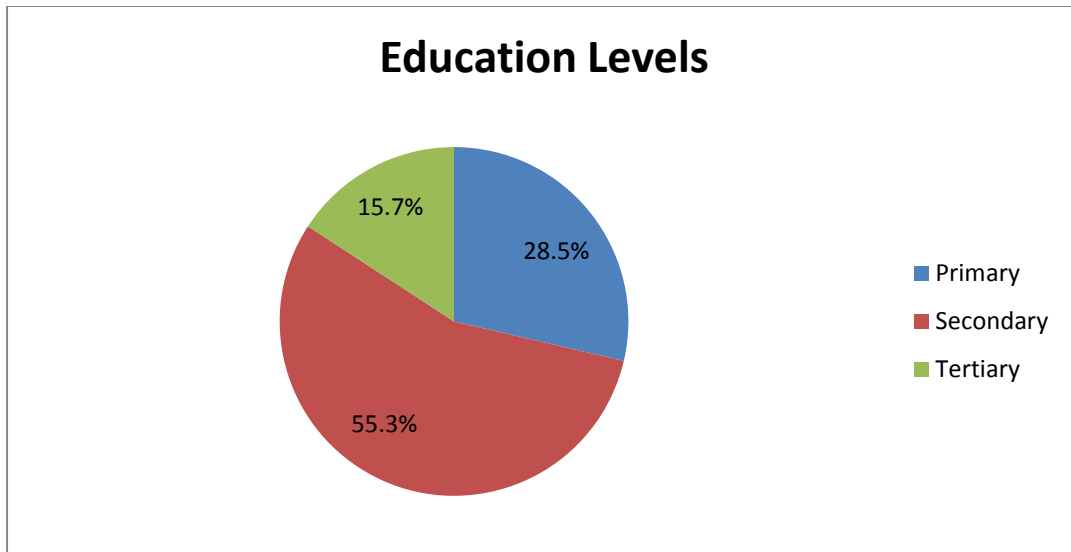
4.1.4 Marital Status

More respondents were married 44.7% (105), 15.3% (36) were single, 21.3% (50) were separated while 18.7% (44) were widowed.

Figure 5: Marital Status

Marital status

	percentage of respondents
Single	15.32%
Married	44.68%
Separated	21.28%
Widowed	18.72%
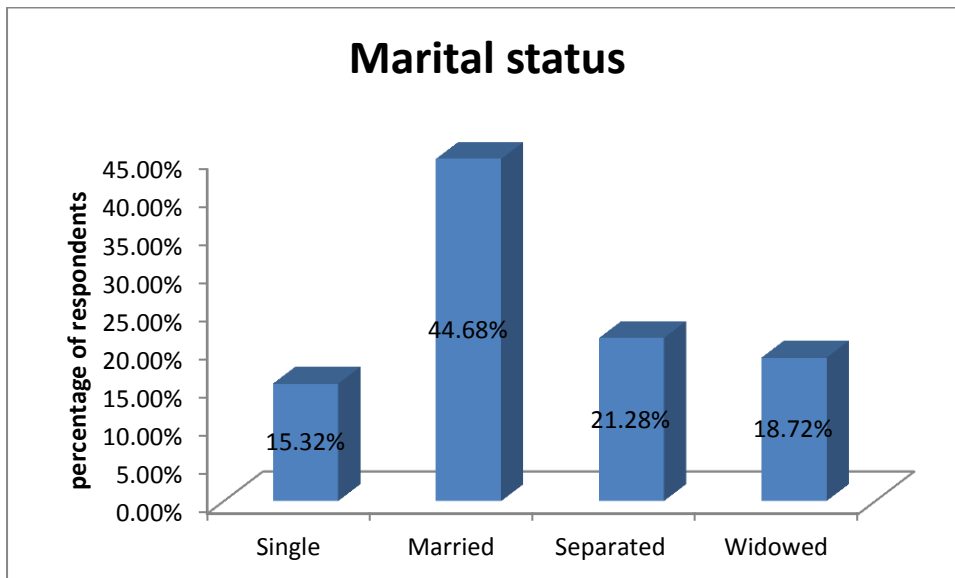
4.1.5 Religion

Majority of the respondents were Christians (83% (195) while the rest (17% (40) were Muslims as illustrated in figure 6 below.

Figure 6: Religion
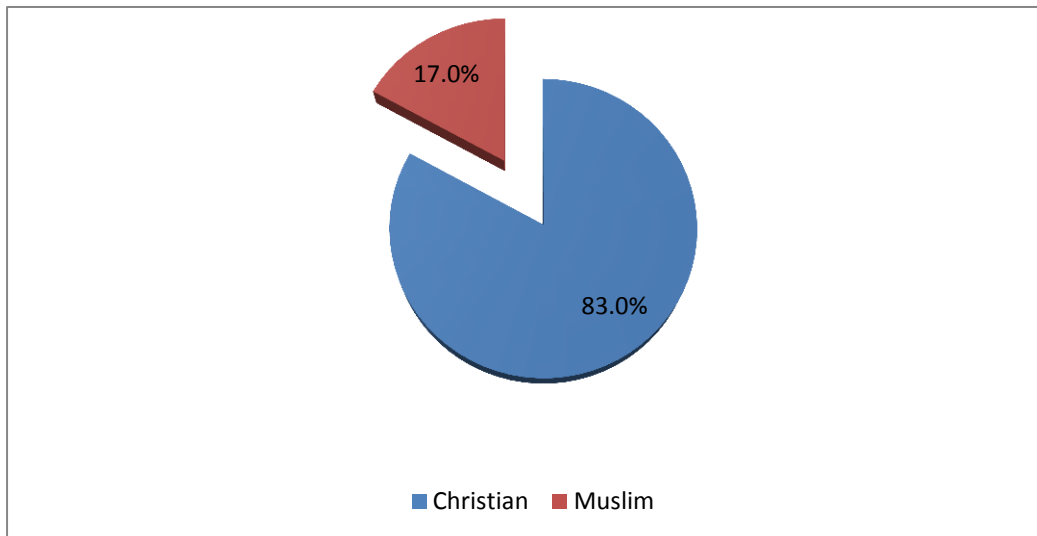
4.1.6 Occupation

Majority of the respondents were self-employed 46.4% (109) while 13.2% (31) were formally employed and 13.2% (85) were casual labourers. There was no student among the respondents while 4.26% (10) were unemployed. This is illustrated in figure 7 below.

Figure 7: Occupation
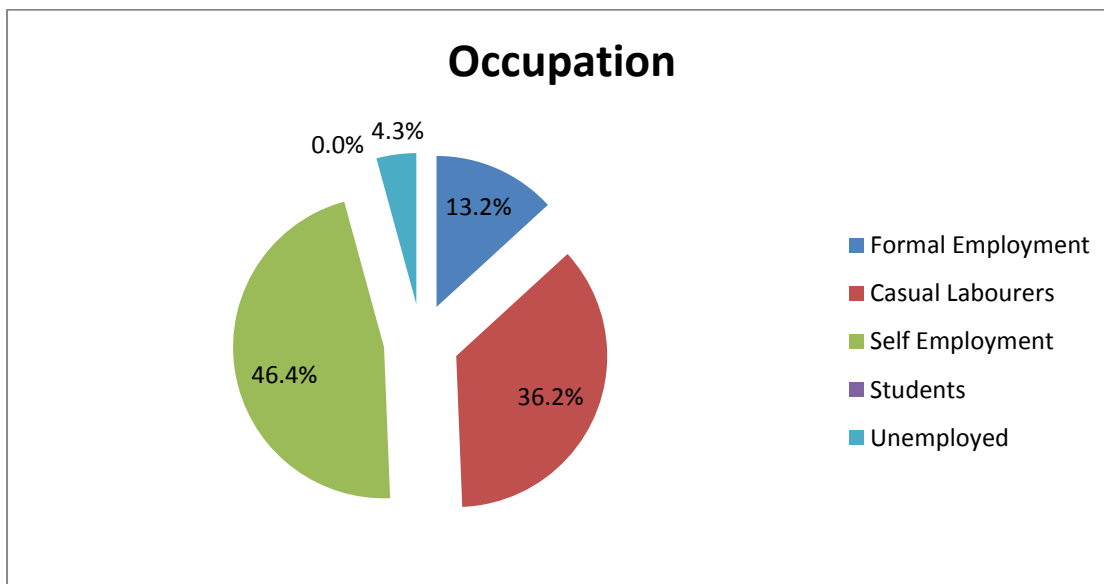
4.2 HIV/AIDS STATUS

4.2.1 Duration in years since diagnosis

Table 1 illustrates that the maximum duration in years since diagnosis among the respondents was 19 years while the maximum duration on ARVs treatment was 18 years. The minimum duration for both was less than one year meaning that the respondents had been diagnosed/ started on ARVs within the year (2014). The mean duration for both since diagnosis and on ARVs was 6 years.

Table 1: Duration in years since Diagnosis

	Mean	Median	Minimum	Maximum	Percentile 25	Percentile 75	Standard Deviation
Duration in years since diagnosis	6	6	<1	19	2	9	4
Duration in years on ARVs	6	6	<1	18	3	8	4

4.2.2 Treatment and social support

Majority of the respondents 90.6% (212) were on Antiretroviral (ARVs) treatment. However, only 7.7% (18) of the respondents had joined support groups as illustrated in figure 8 below.

Figure 8: Treatment and Social Support
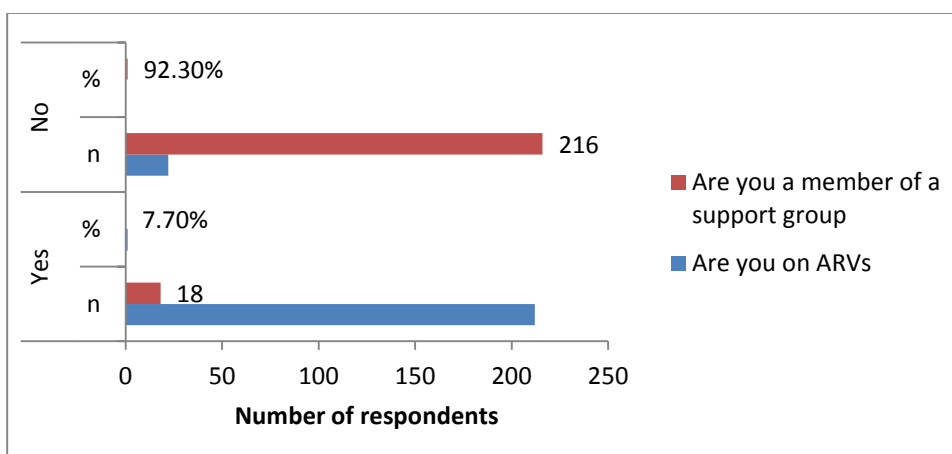
4.3 PREVALENCE OF SUBSTANCE ABUSE

During the study period, a total of 1,252 patients were seen at the Comprehensive Care Centre. Among these, 239 were found to abuse substances (CAGE score ≥2). This translates to a prevalence of 19.1%.

4.3.1 Variety of Substances of Abuse

Several substances of abuse were in use by the respondents as shown in table 2 below. Majority of the respondents were abusing alcohol, 91.9% (216) while only 0.9% (2) were abusing heroin. However, some respondents were found to be abusing more than one substance.

Table 2: Variety of substances of abuse in use

Substance	Number of Respondents	%
Alcohol	216	91.9%
Miraa/Khat	38	16.2%
Bhang/Marijuana	24	10.2%
Tobacco	23	9.8%
Heroin	2	0.9%

4.3.2 Duration (in years) of Substance Abuse

The mean duration of substance abuse was as illustrated in table 3 below. Abuse of tobacco had the highest mean duration (20 years) with alcohol having the lowest mean duration (15 years) among the substances abused. However, alcohol had the highest maximum number of years of abuse (54 years) compared to the rest which had a maximum of 46 years each. Only two respondents were found to be abusing heroin with one having abused it for 22 years and the other for 25 years.

Table 3: Mean Duration (in years) on Substances

	Mean	Median	Minimum	Maximum	Percentile 25	Percentile 75	Standard Deviation
Duration on Alcohol	15	14	1	54	8	20	9
Duration on Bhang	18	16	5	46	11	22	11
Duration on Miraa	17	14	1	46	9	22	11
Duration on Tobacco	20	20	3	46	14	25	9
Duration on heroin	24	24	22	25	22	25	2

4.3.3 Change in Substance Use after HIV/AIDS Diagnosis

Table 4 below illustrates that a number of respondents 40.9% (96) reported no change in their use of substances, 39.1% (92) had a decreased use while 20.0% (47) reported an increase in the use of substances after HIV/AIDS diagnosis.

Table 4: Change in Substance Abuse after HIV Diagnosis

		n	%
Change in Substance Abuse after HIV Diagnosis	Increased	47	20.0%
	Decreased	92	39.1%
	No change	96	40.9%

4.3.4 Reasons for Increase in Substance Intake

An increased abuse of substances after HIV/AIDS diagnosis was reported by 20% (47) respondents. The bar graph below (figure 9) shows the reasons given by the respondents for the increase in substance abuse with slightly above half (55.3% (26) giving stress as the reason. Influence from friends was reported by 7 respondents, loneliness by 6, panic by 3,working in bars and feeling an outcast by 2 each while 1 gave no reason.

Figure 9: Reasons for Increase in Substance Intake
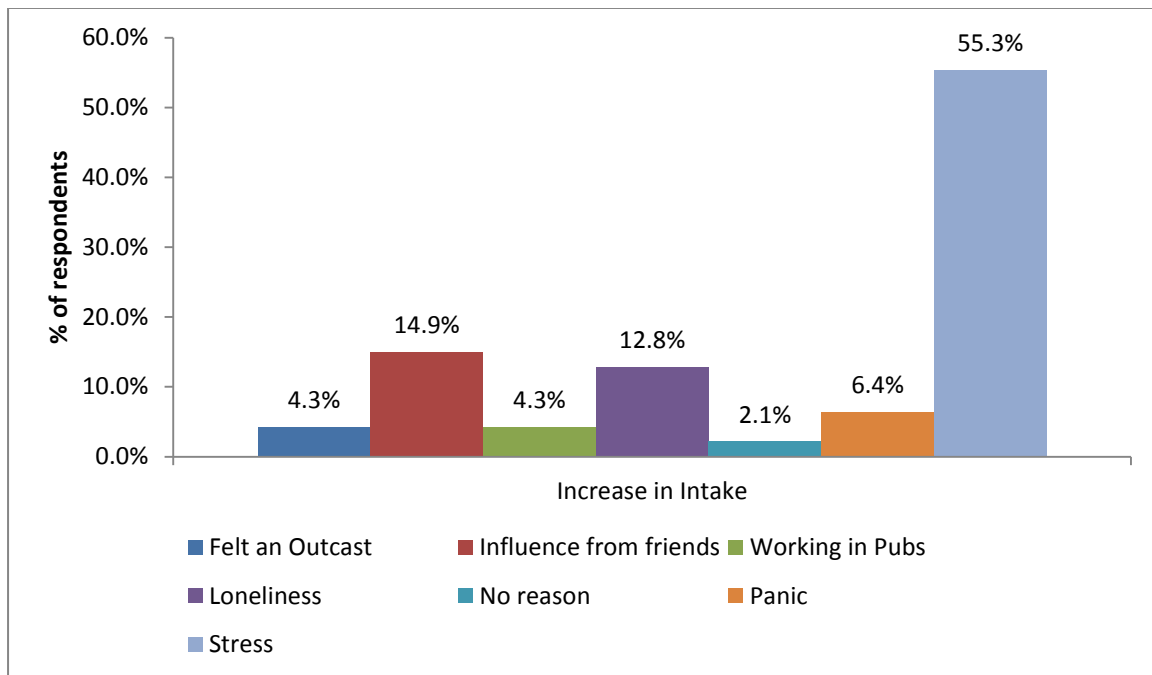
4.3.5 Reasons for Decrease in Substance Intake

A decreased abuse of substances after HIV/AIDS diagnosis was reported by 39.1% (92) of the respondents. Figure 10 below shows the reasons given by the respondents for the decrease in substance abuse after HIV/AIDS diagnosis with advise from the health facilities,78.3% (72) being the common reason reported. Effect of the substances on health was reported by 10.9% (10), lack of finances by 5.4% (5), side effects from drugs by4.3% (4) and 1.1% (1) gave no reason.

Figure 10: Reasons for Decrease in Substance Abuse
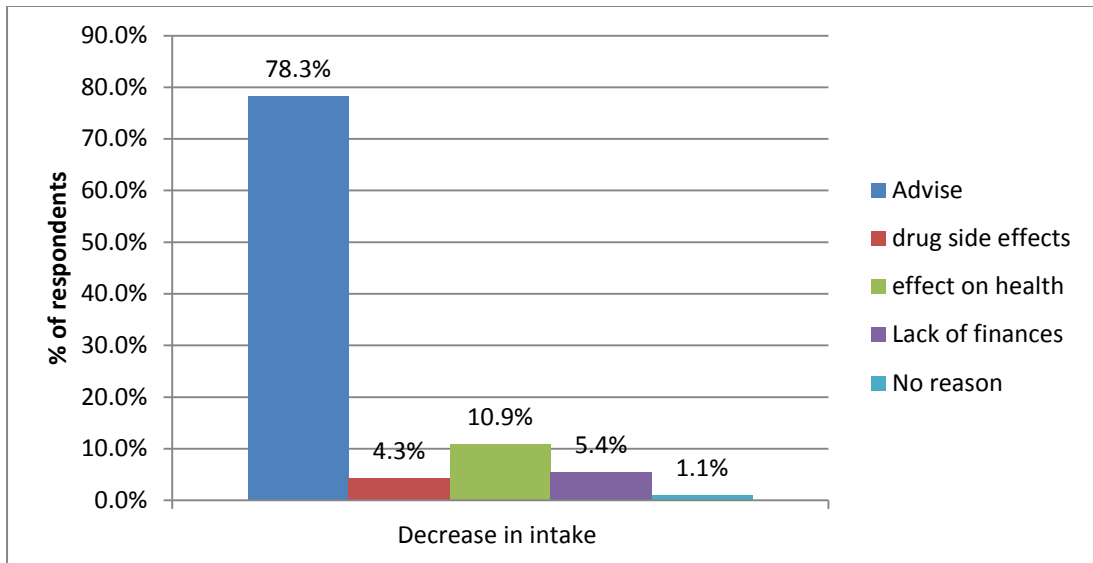
4.4 PERCEIVED SOCIAL SUPPORT

Three dimensions of social support (support from significant others, family and from friends) as perceived by the respondents were assessed. The responses were as illustrated in the tables below.

4.4.1 Social Support from Significant Others

Table 5 below illustrates that majority of respondents very strongly disagreed with having support from significant others as in the responses to the four statements, 46.2% (108), 46.2% (108), 46.6% (109) and 46.2% (108) respectively. The rest of the respondents, 14.5% (34), 15.4% (36), 12.8% (30) and 17.1% (40) very strongly agreed with the four statements respectively thus had social support from a significant other.

Table 5: Social Support from a Significant Other

	Very strongly disagree		Strongly disagree		Mildly disagree		Neutral		Mildly agree		Strongly agree		Very strongly agree	
	N	%	n	%	N	%	n	%	n	%	n	%	N	%
There is a special person who is around when I am in need	108	46.2%	7	3.0%	4	1.7%	6	2.6%	27	11.5%	48	20.5%	34	14.5%
There is a special person with whom I can share my joys and sorrows	108	46.2%	7	3.0%	9	3.8%	10	4.3%	25	10.7%	39	16.7%	36	15.4%
I have a special person who is a real source of comfort to me.	109	46.6%	7	3.0%	9	3.8%	10	4.3%	19	8.1%	50	21.4%	30	12.8%
There is a special person in my life who cares about my feelings.	108	46.2%	9	3.8%	10	4.3%	4	1.7%	21	9.0%	42	17.9%	40	17.1%

4.4.2 Social Support from Family

Table 6 illustrates the distribution of the responses to the four statements related to social support from the family with most respondents very strongly disagreeing 25.2% (59), 24.8% (58), 25.6% (60), 27.4% (64) to having social support from the family. The responses are however distributed throughout the 7 points likert scale with 'very strongly agree' having the least number of responses (9, 15, 6, and 6) for the four statements.

Table 6: Social Support from Family

	Very strongly disagree		Strongly disagree		Mildly disagree		Neutral		Mildly agree		Strongly agree		Very strongly agree	
	n	%	N	%	n	%	n	%	n	%	n	%	N	%
My family really tries to help me	59	25.2%	27	11.5%	40	17.1%	38	16.2%	32	13.7%	29	12.4%	9	3.8%
I get the emotional help and support I need from my family	58	24.8%	28	12.0%	38	16.2%	32	13.7%	38	16.2%	25	10.7%	15	6.4%
I can talk about my problems with my family.	60	25.6%	25	10.7%	24	10.3%	49	20.9%	42	17.9%	28	12.0%	6	2.6%
My family is willing to help me make decisions.	64	27.4%	37	15.8%	28	12.0%	48	20.5%	31	13.2%	20	8.5%	6	2.6%

4.4.3 Social Support from Friends

More than half of the respondents 76.1% (178), 76.9% (180), 73.1% (171), and 74.4% (174) respectively for the four statements very strongly disagreed indicating that they did not perceive social support from friends. Only a few respondents 5, 5, 0 and 3 for the four statements respectively very strongly agreed to perceiving social support from friends as illustrated in table 7 below.

Table 7: Social Support from Friends

	Very strongly disagree		Strongly disagree		Mildly disagree		Neutral		Mildly agree		Strongly agree		Very strongly agree	
	n	%	N	%	n	%	n	%	n	%	n	%	N	%
My friends really try to help me.	178	76.1%	11	4.7%	5	2.1%	10	4.3%	16	6.8%	9	3.8%	5	2.1%
I can count on my friends when things go wrong.	180	76.9%	10	4.3%	8	3.4%	14	6.0%	8	3.4%	9	3.8%	5	2.1%
I have friends with whom I can share my joys and sorrows.	171	73.1%	19	8.1%	6	2.6%	7	3.0%	17	7.3%	14	6.0%	0	0.0%
I can talk about my problems with my friends.	174	74.4%	21	9.0%	4	1.7%	8	3.4%	14	6.0%	10	4.3%	3	1.3%

4.5 PERCEIVED HIV/AIDS STIGMA

Six dimensions of perceived HIV/AIDS stigma among the PLWHA were assessed. These included verbal abuse, fear of contagion, social isolation, workplace stigma, healthcare neglect and negative self-perception (self stigma).

4.5.1 Verbal Abuse

Table 8 illustrates the responses given to the statements assessing verbal abuse related to HIV status. The mean responses for each score are indicated. Majority of the respondents, a mean of 69.6% (164) had never suffered verbal abuse related to their HIV status, 24.4% (57) had suffered once or twice, 4.6% (11) had often suffered while only 1.4% (3) had always suffered.

Table 8: Verbal Abuse

	Never		Once or twice		Often		Always	
	N	%	N	%	n	%	n	%
Someone mocked me when I passed by	202	86.3%	19	8.1%	11	4.7%	2	0.9%
I was called bad names	162	69.2%	57	24.4%	10	4.3%	5	2.1%
People sang offensive songs when I passed by	216	92.3%	7	3.0%	8	3.4%	3	1.3%
I was told that I have no future	167	71.4%	52	22.2%	9	3.8%	6	2.6%
Someone scolded me	150	64.1%	68	29.1%	13	5.6%	3	1.3%
I was told that God is punishing me	193	82.5%	35	15.0%	3	1.3%	3	1.3%
Someone insulted me	99	42.3%	122	52.1%	10	4.3%	3	1.3%
I was blamed for my HIV status	113	48.3%	97	41.5%	22	9.4%	2	0.9%
Mean		**69.63%**		**24.36%**		**4.57%**		**1.44%**

4.5.2 Fear of Contagion

Majority of the respondents a mean of 94.8% (223) had never suffered stigma related to fear of contagion as illustrated in table 9 below.

Table 9: Fear of contagion

	Never		Once or twice		Often		Always	
	N	%	N	%	n	%	n	%
I was told to use my own eating utensils	224	95.7%	2	0.9%	0	0.0%	8	3.4%
I was asked not to touch someone's child	225	96.6%	1	0.4%	4	1.7%	3	1.3%
I was made to drink last from the cup	230	98.3%	3	1.3%	1	0.4%	0	0.0%
I stopped eating with other people	213	91.0%	18	7.7%	3	1.3%	0	0.0%
I was asked to leave because I was coughing	225	96.2%	7	3.0%	2	0.9%	0	0.0%
I was made to eat alone	212	90.6%	18	7.7%	1	0.4%	3	1.3%
Mean		**94.8%**		**3.5%**		**0.8%**		**0.9%**

4.5.3 Social isolation

Table 10 illustrates that 33.8% (79) of the respondents had never been socially isolated due to HIV/AIDS status. 59.6% (140) had been socially isolated once or twice, 5.9% (14) had been isolated often while 0.7% (2) had always faced social isolation because of their HIV status.

Table 10 : Social isolation

	Never		Once or twice		Often		Always	
	N	%	N	%	n	%	n	%
Someone stopped being my friend	102	43.6%	121	51.7%	8	3.4%	3	1.3%
A friend would not chat with me	100	42.7%	118	50.4%	15	6.4%	1	0.4%
People avoided me	54	23.1%	163	69.7%	14	6.0%	3	1.3%
People cut down visiting me	58	24.8%	159	67.9%	14	6.0%	3	1.3%
People ended their relationships with me	61	26.1%	155	66.2%	18	7.7%	0	0.0%
Mean		**33.8%**		**59.6%**		**5.9%**		**0.7%**

4.5.4 Workplace stigma

Majority of the respondents -97.2% (228) had never suffered workplace stigma (table11).

Table 11: Workplace stigma

	Never		Once or twice		Often		Always	
	N	%	N	%	n	%	n	%
Someone tried to get me fired from my job	227	97.0%	5	2.1%	2	0.9%	0	0.0%
My employer denied me opportunities	229	97.9%	1	0.4%	4	1.7%	0	0.0%
Mean		**97.2%**		**1.5%**		**1.3%**		**0.0%**

4.5.5 Health care neglect

Healthcare neglect was not a common form of HIV/AIDS related stigma among the respondents with 97.9% (230) having never faced healthcare neglect as in table 12 below.

Table 12: Health care neglect

	Never		Once or twice		Often		Always	
	N	%	N	%	n	%	n	%
I was denied health care	234	100.0%	0	0.0%	0	0.0%	0	0.0%
I was refused treatment because I was told I was going to die anyway	233	99.6%	1	0.4%	0	0.0%	0	0.0%
I was discharged from the hospital while still needing care	233	99.6%	1	0.4%	0	0.0%	0	0.0%
I was shuttled around instead of being helped by a nurse	232	99.1%	2	0.9%	0	0.0%	0	0.0%
At the hospital/clinic, I was made to wait until last	230	98.3%	4	1.7%	0	0.0%	0	0.0%
At the hospital, I was left in a soiled bed	233	99.6%	1	0.4%	0	0.0%	0	0.0%
In the hospital or clinic, my pain was ignored	208	88.9%	21	9.0%	5	2.1%	0	0.0%
Mean		**97.9%**		**1.8%**		**0.3%**		**0.0%**

4.5.6 Negative self-perception (self stigma)

Negative self- perception was distributed throughout the scores as illustrated in table 13 below. Although 41.5% (97) of the respondents had never suffered negative self -perception, 35.6% (84) admitted to have had a negative self- perception once or twice, 11.8% (28) had it often while 11.2% (26) always had it.

Table 13: Negative self-perception (self stigma)

	Never		Once or twice		Often		Always	
	N	%	N	%	n	%	n	%
I felt that I did not deserve to live	106	45.3%	107	45.7%	14	6.0%	7	3.0%
I felt ashamed of having this disease	17	7.3%	104	44.4%	54	23.1%	59	25.2%
I felt completely worthless	155	66.2%	61	26.1%	14	6.0%	4	1.7%
I felt that I brought a lot of trouble to my family	26	11.1%	105	44.9%	47	20.1%	56	23.9%
I felt that I am no longer a person	181	77.4%	39	16.7%	9	3.8%	5	2.1%
Mean		**41.5%**		**35.6%**		**11.8%**		**11.2%**

4.6 RELATIONSHIPS BETWEEN THE VARIABLES

4.6.1 Relationship between Socio-Demographic Characteristics and Changes in Substance Abuse after HIV/AIDS Diagnosis

Table 14 illustrates the relationship between socio-demographic characteristics of the respondents and changes in substance abuse after HIV/AIDS diagnosis. There was a significant statistical association (p=0.034) between level of education and increase in substance abuse after HIV/AIDS diagnosis. Respondents who had attained tertiary education had the highest increase (27.0%) whereas the highest decrease was observed among those with secondary education (46.9%). However, a high number of respondents with primary level of education did not change their abuse of substances after HIV diagnosis. No significant statistical association was observed between gender, age, marital status, religion, occupation and changes in substance abuse after diagnosis.

Table 14: Relationship between Socio-Demographic Characteristics and Changes in Substance Abuse after HIV/AIDS Diagnosis

Socio-demographic characteristics		Covariates						Chi square test
		Changes in Substance Abuse after HIV/AIDS Diagnosis						
		Increased		Decreased		No change		
		n	%	n	%	n	%	P value
Gender	Male	35	22.2%	59	37.3%	64	40.5%	0.465
	Female	12	15.6%	33	42.9%	32	41.6%	
Age group	<20 years	0	0.0%	1	100.0%	0	0.0%	0.063
	20-29 years	5	13.2%	17	44.7%	16	42.1%	
	30-39 years	24	27.0%	25	28.1%	40	44.9%	
	40-49 years	10	17.9%	21	37.5%	25	44.6%	
	50-59 years	8	21.6%	18	48.6%	11	29.7%	
	60-69 years	0	0.0%	10	76.9%	3	23.1%	
	>= 70 years	0	0.0%	0	0.0%	1	100.0%	
Education Level	Primary	13	19.4%	18	26.9%	36	53.7%	**0.034***
	Secondary	24	18.5%	61	46.9%	45	34.6%	
	Tertiary	10	27.0%	13	35.1%	14	38.0%	

What is your marital status?	Single	7	19.4%	15	41.7%	14	38.9%	0.334
	Married	18	17.1%	43	41.0%	44	41.9%	
	Cohabiting	0	0.0%	0	0.0%	0	0.0%	
	Separated	8	16.0%	17	34.0%	25	50.0%	
	Widowed	14	31.8%	17	38.6%	13	29.5%	
What is your religion?	Christian	39	20.0%	78	40.0%	78	40.0%	0.813
	Muslim	8	20.0%	14	35.0%	18	45.0%	
	Hindu	0	0.0%	0	0.0%	0	0.0%	
	Others	0	0.0%	0	0.0%	0	0.0%	
What do you do for a living	Formal employment	10	32.3%	9	29.0%	12	38.7%	0.128
	Casual labourer	11	12.9%	38	44.7%	36	42.4%	
	Self-employment	26	23.9%	41	37.6%	42	38.5%	
	Still a student	0	0.0%	0	0.0%	0	0.0%	
	Unemployed	0	0.0%	4	40.0%	6	60.0%	
Are you on ARVs?	Yes	46	21.7%	75	35.4%	91	42.9%	**0.002***
	No	1	4.5%	16	72.7%	5	22.7%	
Are you a member of a support group?	Yes	0	0.0%	8	44.4%	10	55.6%	0.079
	No	47	21.8%	83	38.4%	86	39.8%	

There was a significant statistical association between changes in substance abuse after HIV diagnosis and ARVs treatment status (p=0.002). Among the respondents on ARVs,21.7%, (46) showed an increase in substance abuse after HIV diagnosis compared to those not on ARVs 4.5%, (1). Majority of the respondents who were not on ARVs had a decreased intake -72.7% (16).

There was no significant statistical association between membership to a support group and changes in substance abuse after HIV diagnosis (p=0.079).

4.6.2 Relationship between Social Support from Significant Other and Substance Abuse

Table15 illustrates the association between social support from the significant other and changes in substance abuse after HIV/AIDS diagnosis. There is a significant statistical association between not having a special person around when in need and increase in substance abuse after HIV diagnosis (25% versus 5.9%, p=0.017). A similar observation was made with respect to not having a special person to share joys and sorrows (25% versus 5%, p=0.03).

Table 15: Relationship between Social Support from a Significant Other and Substance Abuse.

Support from significant other		Covariates						Chi square test
		Did your use of the above substance change after HIV diagnosis						P value
		Increased		Decreased		No change		
		N	%	N	%	n	%	
There is a special person who is around when I am in need	Very strongly disagree	27	25.0%	39	36.1%	42	38.9%	**0.017***
	Strongly disagree	1	14.3%	6	85.7%	0	0.0%	
	Mildly disagree	0	0.0%	1	25.0%	3	75.0%	
	Neutral	1	16.7%	4	66.7%	1	16.7%	
	Mildly agree	4	14.8%	6	22.2%	17	63.0%	
	Strongly agree	12	25.0%	21	43.8%	15	31.2%	
	Very strongly agree	2	5.9%	15	44.1%	17	50.0%	
There is a special person with whom I can share my joys and sorrows	Very strongly disagree	27	25.0%	39	36.1%	42	38.9%	**0.03***
	Strongly disagree	1	14.3%	6	85.7%	0	0.0%	
	Mildly disagree	1	11.1%	3	33.3%	5	55.6%	
	Neutral	2	20.0%	4	40.0%	4	40.0%	
	Mildly agree	3	12.0%	6	24.0%	16	64.0%	
	Strongly agree	11	28.2%	17	43.6%	11	28.2%	
	Very strongly agree	2	5.6%	17	47.2%	17	47.2%	
I have a special person who is a real source of comfort to me.	Very strongly disagree	28	25.7%	39	35.8%	42	38.5%	0.154
	Strongly disagree	0	0.0%	4	57.1%	3	42.9%	
	Mildly disagree	2	22.2%	4	44.4%	3	33.3%	
	Neutral	2	20.0%	7	70.0%	1	10.0%	

		n	%	n	%	n	%	P value
	Mildly agree	3	15.8%	4	21.1%	12	63.2%	
	Strongly agree	10	20.0%	19	38.0%	21	42.0%	
	Very strongly agree	2	6.7%	15	50.0%	13	43.3%	
There is a special person in my life who cares about my feelings.	Very strongly disagree	27	25.0%	41	38.0%	40	37.0%	0.059
	Strongly disagree	0	0.0%	5	55.6%	4	44.4%	
	Mildly disagree	2	20.0%	3	30.0%	5	50.0%	
	Neutral	2	50.0%	2	50.0%	0	0.0%	
	Mildly agree	8	38.1%	8	38.1%	5	23.8%	
	Strongly agree	6	14.3%	15	35.7%	21	50.0%	
	Very strongly agree	2	5.0%	18	45.0%	20	50.0%	

4.6.3 Relationship between Social Support from Family and Substance Abuse

From the four items assessing social support from the family, there is a significant statistical association between lack of family social support and increase in substance abuse after HIV diagnosis (p=0.001, p=0.008, p=0.012, p=0.003).This is as shown in table 16 below.

Table 16: Relationship between Social Support from Family and Substance Abuse

Family support		**Covariates**						**Chi square test**
		Did your use of the above substance change after HIV diagnosis						
		Increased		Decreased		No change		P value
		n	%	n	%	n	%	
My family really tries to help me	Very strongly disagree	11	18.6%	16	27.1%	32	54.2%	**0.001***
	Strongly disagree	0	0.0%	13	48.1%	14	51.9%	
	Mildly disagree	7	17.5%	20	50.0%	13	32.5%	
	Neutral	10	26.3%	14	36.8%	14	36.8%	
	Mildly agree	15	46.9%	8	25.0%	9	28.1%	
	Strongly agree	4	13.8%	15	51.7%	10	34.5%	
	Very strongly agree	0	0.0%	6	66.7%	3	33.3%	
I get the emotional	Very strongly disagree	10	17.2%	17	29.3%	31	53.4%	**0.008***

help and support I need from my family	Strongly disagree	0	0.0%	14	50.0%	14	50.0%	
	Mildly disagree	9	23.7%	17	44.7%	12	31.6%	
	Neutral	8	25.0%	12	37.5%	12	37.5%	
	Mildly agree	15	39.5%	10	26.3%	13	34.2%	
	Strongly agree	4	16.0%	14	56.0%	7	28.0%	
	Very strongly agree	1	6.7%	8	53.3%	6	40.0%	
I can talk about my problems with my family.	Very strongly disagree	10	16.7%	16	26.7%	34	56.7%	0.012*
	Strongly disagree	2	8.0%	17	68.0%	6	24.0%	
	Mildly disagree	6	25.0%	11	45.8%	7	29.2%	
	Neutral	11	22.4%	17	34.7%	21	42.9%	
	Mildly agree	14	33.3%	15	35.7%	13	31.0%	
	Strongly agree	4	14.3%	14	50.0%	10	35.7%	
	Very strongly agree	0	0.0%	2	33.3%	4	66.7%	
My family is willing to help me make decisions.	Very strongly disagree	11	17.2%	18	28.1%	35	54.7%	0.003*
	Strongly disagree	3	8.1%	21	56.8%	13	35.1%	
	Mildly disagree	10	35.7%	11	39.3%	7	25.0%	
	Neutral	5	10.4%	23	47.9%	20	41.7%	
	Mildly agree	12	38.7%	8	25.8%	11	35.5%	
	Strongly agree	6	30.0%	8	40.0%	6	30.0%	
	Very strongly agree	0	0.0%	3	50.0%	3	50.0%	

4.6.4 Relationship between Social Support from Friends and Substance Abuse

Table 17 below illustrates the relationship between social support from friends and changes in substance abuse after HIV diagnosis. There is a significant statistical association between lack of social support from friends and increase in substance abuse after HIV diagnosis (p=0.004, p=0.005, p=0.001 and p=<0.0001).

Table 17: Relationship between Social Support from Friends and Substance Abuse

Friends support		Covariates						Chi square test
		Did your use of the above substance change after HIV diagnosis						
		Increased		Decreased		No change		P value
		n	%	n	%	N	%	
My friends really try to help me.	Very strongly disagree	32	18.0%	70	39.3%	76	42.7%	**0.004***
	Strongly disagree	0	0.0%	8	72.7%	3	27.3%	
	Mildly disagree	3	60.0%	0	0.0%	2	40.0%	
	Neutral	5	50.0%	3	30.0%	2	20.0%	
	Mildly agree	5	31.2%	8	50.0%	3	18.8%	
	Strongly agree	2	22.2%	3	33.3%	4	44.4%	
	Very strongly agree	0	0.0%	0	0.0%	5	100.0%	
I can count on my friends when things go wrong.	Very strongly disagree	32	17.8%	71	39.4%	77	42.8%	**0.005***
	Strongly disagree	0	0.0%	7	70.0%	3	30.0%	
	Mildly disagree	3	37.5%	2	25.0%	3	37.5%	
	Neutral	5	35.7%	7	50.0%	2	14.3%	
	Mildly agree	5	62.5%	2	25.0%	1	12.5%	
	Strongly agree	2	22.2%	3	33.3%	4	44.4%	
	Very strongly agree	0	0.0%	0	0.0%	5	100.0%	
I have friends with whom I can share my joys and sorrows.	Very strongly disagree	33	19.3%	64	37.4%	74	43.3%	**0.001***
	Strongly disagree	0	0.0%	13	68.4%	6	31.6%	
	Mildly disagree	2	33.3%	3	50.0%	1	16.7%	
	Neutral	5	71.4%	0	0.0%	2	28.6%	
	Mildly agree	5	29.4%	9	52.9%	3	17.6%	
	Strongly agree	2	14.3%	3	21.4%	9	64.3%	
	Very strongly agree	0	0.0%	0	0.0%	0	0.0%	

	Very strongly disagree	33	19.0%	68	39.1%	73	42.0%	**<0.0001***
I can talk about my problems with my friends.	Strongly disagree	0	0.0%	14	66.7%	7	33.3%	
	Mildly disagree	0	0.0%	2	50.0%	2	50.0%	
	Neutral	8	100.0%	0	0.0%	0	0.0%	
	Mildly agree	3	21.4%	7	50.0%	4	28.6%	
	Strongly agree	3	30.0%	1	10.0%	6	60.0%	
	Very strongly agree	0	0.0%	0	0.0%	3	100.0%	

4.6.5 Relationship between Verbal Abuse related to HIV/AIDS Stigma and Substance Abuse

On assessment of verbal abuse related to HIV status, majority of the respondents who had often and always been mocked had an increased abuse of substances after HIV diagnosis while majority of those who had never been mocked had a decreased abuse or no change after diagnosis. There was thus a significant statistical association between being mocked and increase in substance abuse after diagnosis (p=0.049). There however was no significant statistical association between the responses given to the other items and changes in substance abuse after diagnosis as illustrated in table 18.

Table 18: Relationship between Verbal Abuse related to HIV/AIDS Stigma and Substance Abuse

Verbal abuse		Covariates						Chi square test
		Did your use of the above substance change after HIV diagnosis						
		Increased		Decreased		No change		
		n	%	N	%	n	%	P value
Someone mocked me when I passed by	Never	41	20.3%	74	36.6%	87	43.1%	**0.049***
	Once or twice	2	10.5%	14	73.7%	3	15.8%	
	Often	3	27.3%	3	27.3%	5	45.5%	
	Always	1	50.0%	1	50.0%	0	0.0%	
I was called bad names	Never	35	21.6%	64	39.5%	63	38.9%	0.498
	Once or twice	10	17.5%	25	43.9%	22	38.6%	
	Often	1	10.0%	2	20.0%	7	70.0%	
	Always	1	20.0%	1	20.0%	3	60.0%	
People sang offensive songs when I passed by	Never	45	20.8%	85	39.4%	86	39.8%	0.443
	Once or twice	1	14.3%	4	57.1%	2	28.6%	
	Often	1	12.5%	3	37.5%	4	50.0%	
	Always	0	0.0%	0	0.0%	3	100.0%	
I was told that I have no future	Never	35	21.0%	61	36.5%	71	42.5%	0.454
	Once or twice	8	15.4%	27	51.9%	17	32.7%	
	Often	3	33.3%	2	22.2%	4	44.4%	
	Always	1	16.7%	2	33.3%	3	50.0%	
Someone scolded me	Never	33	22.0%	58	38.7%	59	39.3%	0.222
	Once or twice	14	20.6%	28	41.2%	26	38.2%	
	Often	0	0.0%	6	46.2%	7	53.8%	

	Always	0	0.0%	0	0.0%	3	100.0%	
I was told that God is punishing me	Never	38	19.7%	78	40.4%	77	39.9%	0.544
	Once or twice	8	22.9%	13	37.1%	14	40.0%	
	Often	1	33.3%	1	33.3%	1	33.3%	
	Always	0	0.0%	0	0.0%	3	100.0%	
Someone insulted me	Never	22	22.2%	40	40.4%	37	37.4%	0.539
	Once or twice	23	18.9%	48	39.3%	51	41.8%	
	Often	2	20.0%	4	40.0%	4	40.0%	
	Always	0	0.0%	0	0.0%	3	100.0%	
I was blamed for my HIV status	Never	22	19.5%	43	38.1%	48	42.5%	0.712
	Once or twice	20	20.6%	41	42.3%	36	37.1%	
	Often	5	22.7%	8	36.4%	9	40.9%	
	Always	0	0.0%	0	0.0%	2	100.0%	

4.6.6 Relationship between Fear of Contagion related to HIV/AIDS Stigma and Substance Abuse

There was no significant statistical association between fear of contagion related to HIV/AIDS stigma and change in substance abuse after HIV/AIDS diagnosis as illustrated in table 19 below.

Table 19: Relationship between Fear of Contagion related to HIV/AIDS Stigma and Substance Abuse

		Covariates						Chi square test
		Did your use of the above substance change after HIV diagnosis						
Fear of contagion		Increased		Decreased		No change		
		n	%	N	%	n	%	P value
I was told to use my own eating utensils	Never	46	20.5%	88	39.3%	90	40.2%	0.318
	Once or twice	0	0.0%	2	100.0%	0	0.0%	
	Often	0	0.0%	0	0.0%	0	0.0%	
	Always	1	12.5%	2	25.0%	5	62.5%	
I was asked not to touch someone's child	Never	46	20.4%	90	40.0%	89	39.6%	0.384
	Once or twice	0	0.0%	0	0.0%	1	100.0%	
	Often	1	25.0%	2	50.0%	1	25.0%	
	Always	0	0.0%	0	0.0%	3	100.0%	
I was made to drink last from the cup	Never	46	20.0%	90	39.1%	94	40.9%	0.758
	Once or twice	1	33.3%	1	33.3%	1	33.3%	
	Often	0	0.0%	1	100.0%	0	0.0%	
	Always	0	0.0%	0	0.0%	0	0.0%	
I stopped eating with other people	Never	43	20.2%	80	37.6%	90	42.3%	0.352
	Once or twice	3	16.7%	11	61.1%	4	22.2%	
	Often	1	33.3%	1	33.3%	1	33.3%	
	Always	0	0.0%	0	0.0%	0	0.0%	
I was asked to leave because I was	Never	46	20.4%	87	38.7%	92	40.9%	0.436
	Once or twice	0	0.0%	4	57.1%	3	42.9%	
	Often	1	50.0%	1	50.0%	0	0.0%	

coughing	Always	0	0.0%	0	0.0%	0	0.0%	
I was made to eat alone	Never	44	20.8%	86	40.6%	82	38.7%	0.336
	Once or twice	3	16.7%	6	33.3%	9	50.0%	
	Often	0	0.0%	0	0.0%	1	100.0%	
	Always	0	0.0%	0	0.0%	3	100.0%	

4.6.7 Relationship between Social isolation related to HIV/AIDS Stigma and Substance Abuse

Only one item assessing social isolation had a significant statistical association (p=0.022) predicting changes in substance abuse after HIV/AIDS diagnosis. Most respondents, 49% (50) who reported to have never had someone stopping being a friend due to their status had a decreased abuse of substances after HIV diagnosis compared to those who increased their intake 17.6% (18). This is illustrated in table 20 below.

Table 20: **Relationship between Social isolation related to HIV/AIDS Stigma and Substance Abuse**

Social isolation		Covariates						Chi square test
		Did your use of the above substance change after HIV diagnosis						
		Increased		Decreased		No change		
		n	%	N	%	n	%	P value
Someone stopped being my friend	Never	18	17.6%	50	49.0%	34	33.3%	**0.022***
	Once or twice	26	21.5%	42	34.7%	53	43.8%	
	Often	3	37.5%	0	0.0%	5	62.5%	
	Always	0	0.0%	0	0.0%	3	100.0%	
A friend would not chat with me	Never	19	19.0%	43	43.0%	38	38.0%	0.605
	Once or twice	24	20.3%	45	38.1%	49	41.5%	
	Often	4	26.7%	3	20.0%	8	53.3%	
	Always	0	0.0%	1	100.0%	0	0.0%	
People avoided me	Never	9	16.7%	25	46.3%	20	37.0%	0.109
	Once or twice	32	19.6%	64	39.3%	67	41.1%	
	Often	6	42.9%	3	21.4%	5	35.7%	
	Always	0	0.0%	0	0.0%	3	100.0%	
People cut down visiting me	Never	9	15.5%	23	39.7%	26	44.8%	0.263
	Once or twice	33	20.8%	64	40.3%	62	39.0%	
	Often	5	35.7%	5	35.7%	4	28.6%	
	Always	0	0.0%	0	0.0%	3	100.0%	
People ended their relationships with me	Never	11	18.0%	22	36.1%	28	45.9%	0.267
	Once or twice	29	18.7%	65	41.9%	61	39.4%	
	Often	7	38.9%	5	27.8%	6	33.3%	
	Always	0	0.0%	0	0.0%	0	0.0%	

4.6.8 Relationship between Workplace Stigma related to HIV/AIDS and Substance Abuse

There was no significant statistical association between workplace stigma and changes in substance abuse after HIV/AIDS diagnosis as shown in table 21.

Table 21: Relationship between Workplace Stigma related to HIV/AIDS and Substance Abuse

Workplace stigma		Covariates						Chi square test
		Did your use of the above substance change after HIV diagnosis						
		Increased		Decreased		No change		
		n	%	N	%	N	%	P value
Someone tried to get me fired from my job	Never	47	20.7%	90	39.6%	90	39.6%	0.343
	Once or twice	0	0.0%	2	40.0%	3	60.0%	
	Often	0	0.0%	0	0.0%	2	100.0%	
	Always	0	0.0%	0	0.0%	0	0.0%	
My employer denied me opportunities	Never	46	20.1%	90	39.3%	93	40.6%	0.289
	Once or twice	1	100.0%	0	0.0%	0	0.0%	
	Often	0	0.0%	2	50.0%	2	50.0%	
	Always	0	0.0%	0	0.0%	0	0.0%	

4.6.9 Relationship between Health Care Neglect related to HIV/AIDS and Substance Abuse

In assessment of health care neglect, only being made to wait until last at the hospital/clinic had a significant statistical association with change in substance abuse after HIV/AIDS diagnosis (p=0.043). In this case, 100% (4) of the respondents who had been made to wait till last reported a decrease in substance abuse after HIV diagnosis. None of the respondents had ever been denied healthcare. Table 22 illustrates this.

Table 22: Relationship between Health Care Neglect related to HIV/AIDS and Substance Abuse

Healthcare neglect		Covariates						Chi square test
		Did your use of the above substance change after HIV diagnosis						
		Increased		Decreased		No change		
		N	%	N	%	n	%	P value
I was denied health care	Never	47	20.1%	92	39.3%	95	40.6%	-
	Once or twice	0	0.0%	0	0.0%	0	0.0%	
	Often	0	0.0%	0	0.0%	0	0.0%	
	Always	0	0.0%	0	0.0%	0	0.0%	
I was refused treatment because I was told I was going to die anyway	Never	47	20.2%	92	39.5%	94	40.3%	0.480
	Once or twice	0	0.0%	0	0.0%	1	100.0%	
	Often	0	0.0%	0	0.0%	0	0.0%	
	Always	0	0.0%	0	0.0%	0	0.0%	
I was discharged from the hospital while still needing care	Never	47	20.2%	91	39.1%	95	40.8%	0.461
	Once or twice	0	0.0%	1	100.0%	0	0.0%	
	Often	0	0.0%	0	0.0%	0	0.0%	
	Always	0	0.0%	0	0.0%	0	0.0%	
I was shuttled around instead of being helped	Never	47	20.3%	90	38.8%	95	40.9%	0.211
	Once or twice	0	0.0%	2	100.0%	0	0.0%	

by a nurse	Often	0	0.0%	0	0.0%	0	0.0%	
	Always	0	0.0%	0	0.0%	0	0.0%	
At the hospital/clinic, I was made to wait until last	Never	47	20.4%	88	38.3%	95	41.3%	**0.043***
	Once or twice	0	0.0%	4	100.0%	0	0.0%	
	Often	0	0.0%	0	0.0%	0	0.0%	
	Always	0	0.0%	0	0.0%	0	0.0%	
At the hospital, I was left in a soiled bed	Never	47	20.2%	91	39.1%	95	40.8%	0.461
	Once or twice	0	0.0%	1	100.0%	0	0.0%	
	Often	0	0.0%	0	0.0%	0	0.0%	
	Always	0	0.0%	0	0.0%	0	0.0%	
In the hospital or clinic, my pain was ignored	Never	39	18.8%	79	38.0%	90	43.3%	0.087
	Once or twice	7	33.3%	9	42.9%	5	23.8%	
	Often	1	20.0%	4	80.0%	0	0.0%	
	Always	0	0.0%	0	0.0%	0	0.0%	

4.6.10 Relationship between Negative self-perception (self stigma) related to HIV/AIDS and Substance Abuse

Feeling that one was no longer a person because of his/her HIV status had a significant statistical association with changes in substance abuse after HIV/AIDS diagnosis (p=0.033). 41.4% (75) of the respondents who had never felt they were no longer a person reported a decrease in substance abuse after HIV/AIDS diagnosis compared to 28.2% (11) who had felt they were no longer a person once or twice. Table 23 below gives the illustration.

Table 23: Relationship between Negative self-perception (self stigma) related to HIV/AIDS and Substance Abuse

Negative self perception		Covariates						Chi square test
		Did your use of the above substance change after HIV diagnosis						
		Increased		Decreased		No change		
		n	%	N	%	n	%	P value
I felt that I did not deserve to live	Never	22	20.8%	49	46.2%	35	33.0%	0.146
	Once or twice	24	22.4%	35	32.7%	48	44.9%	
	Often	1	7.1%	6	42.9%	7	50.0%	
	Always	0	0.0%	2	28.6%	5	71.4%	
I felt ashamed of having this disease	Never	4	23.5%	5	29.4%	8	47.1%	0.658
	Once or twice	18	17.3%	40	38.5%	46	44.2%	
	Often	13	24.1%	19	35.2%	22	40.7%	
	Always	12	20.3%	28	47.5%	19	32.2%	
I felt completely worthless	Never	35	22.6%	61	39.4%	59	38.1%	0.083
	Once or twice	11	18.0%	22	36.1%	28	45.9%	
	Often	1	7.1%	9	64.3%	4	28.6%	
	Always	0	0.0%	0	0.0%	4	100.0%	
I felt that I brought a lot of trouble to my family	Never	5	19.2%	11	42.3%	10	38.5%	0.798
	Once or twice	19	18.1%	42	40.0%	44	41.9%	
	Often	11	23.4%	21	44.7%	15	31.9%	
	Always	12	21.4%	18	32.1%	26	46.4%	
I felt that I am no longer a person	Never	38	21.0%	75	41.4%	68	37.6%	**0.033***
	Once or twice	9	23.1%	11	28.2%	19	48.7%	
	Often	0	0.0%	6	66.7%	3	33.3%	
	Always	0	0.0%	0	0.0%	5	100.0%	

4.6.11 Multivariate Analysis of Variables

A multivariate analysis was done to determine the association between the independent variables and increase in substance abuse after HIV/AIDS diagnosis. An increase in substance abuse was associated with lack of a special person around when one is in need (p=0.044), lack of family support (p=0.020) and self- pity (p=0.008). This is illustrated in table 24 below.

Table 24: Multivariate Analysis of Variables

Variables	Coefficients	95.0% Confidence Interval for coefficients		P value
		Lower Bound	Upper Bound	
There is a special person who is around when I am in need	0.040	0.001	0.079	0.044
My family really tries to help me	0.061	0.112	0.010	0.020
I felt that I am no longer a person	0.205	0.054	0.356	0.008

Dependent Variable: Did your use of the above substance change after HIV diagnosis?

CHAPTER FIVE: DISCUSSION

5.1 Prevalence of Substance Abuse among PLWHA

From this study, the prevalence of substance abuse in HIV/AIDS among clients attending the CCC at the Coast Province General Hospital was found to be 19.1%. This is consistent with findings from several studies (Galvan, Bing, Fleishman, London et al., 2002; Conigliaro, Justice, Gordon and Bryant, 2006; Lucas 2011 and Korthuis et al.,2012) where the abuse of alcohol and illicit drugs has been found to be a common phenomenon among HIV infected patients. Among the respondents, 67.2% (158) were male while 32.8% (77) were female. This can be compared with findings from a study on correlates of substance abuse among patients carried out by Ward C.,Mertens J., Flisher A., et al., (2008) which also found that more males than females abused substances.

Majority of the respondents were involved in abuse of more than one substance consistent with findings that people who are dependent on alcohol are much more likely than the general population to abuse drugs, and people with drug dependence are much more likely to drink alcohol (Falk,Yi and Hiller-Sturmhöfel, 2008 and Korthuis et al., 2012).The abuse of multiple substances could be related to the fact that most substances of abuse are found in similar environments both in terms of location and reasons for engaging in their abuse. Among the substances abused were alcohol, miraa (khat), cannabis (bhang/marijuana), tobacco and heroin. Alcohol, tobacco and miraa were abused by a higher number of respondents 99.1% (233). Heroin was abused by only 0.9% (2) respondents. This could be a biased result since most respondents would not easily admit to abusing an illegal drug. The same case applied to bhang since its use is considered illegal in Kenya. On the duration the substances had been in use, alcohol had the least mean duration (15 years) compared to the rest. This could be attributed to the fact that alcohol use in HIV is associated with a faster progression of HIV infection thus resulting in high mortalities. People with HIV/AIDS poorly tolerate alcohol (Braithwaite et al, 2007) and alcohol increases the risk for HIV and antiretroviral-associated comorbidities (Justice A., Sullivan L. and Fiellin D., 2010).

Among the respondents, 39.1% reported having decreased their abuse of substances after HIV/AIDS diagnosis while others either increased (20%) their abuse or had no change (40.9%). The decrease observed could be attributed to the fact that health workers taking care of HIV/AIDS patients impart knowledge on the risks associated with substance abuse among

this population. This can be supported by the fact that the majority of the respondents attributed their decision to decrease the abuse of substances to advice from the health workers. A good number of respondents, 40.9% (96) reported no change in their abuse. The increase or lack of change was as a result of stress related to the diagnosis as expressed by the respondents. This as conceptualized by Gore-Felton and Koopman, (2008) could be related to the fact that the psychological and physical demands of coping with diagnosis, medications and comorbid illnesses can be overwhelming and may influence behaviour such as substance use and risky sexual behaviour that in turn, affect health outcomes. In addition, the abuse of substances is an impulsive disorder which requires considerable follow up of the individual in order to realise change. Advice alone therefore was not enough to realise a decrease in substance abuse among all the respondents

The respondents were of varying characteristics with the maximum duration since diagnosis and on ARVs being 19 years and 18 years respectively. The mean duration for both was 6 years reflecting a prompt initiation of ARVs upon diagnosis and on meeting the eligibility criteria. This prompt management positively supports the fight against HIV/AIDS which unfortunately is affected negatively by substance abuse leading to suboptimal health outcomes (DeLorenze et al., 2011,Braithwaite et al. 2007).

5.2 Perceived Social Support

In this study, only 7.7% (18) of the respondents were members of a HIV/AIDS support group. This is despite the fact that the majority of the respondents 90.6% (212) were on ARVs. Inadequate social support has been correlated with substance abuse (Holtz, Sowell and Velasquez, 2012). Majority of the respondents reported lack of social support from a significant other. Most of these were separated, single or widowed and made the bulk of the respondents - 55.3% (130). The ones who had social support from a significant other were mainly married and thus their spouses were the source of support. Very few respondents perceived social support from the family and even fewer perceived support from friends. This could however be correlated with disclosure of HIV status such that people may perceive more support from family before disclosure or vice versa. Respondents who perceived support from friends were likely to have disclosed their HIV status to the friends. Most significant is the fact that some respondents perceiving support from their friends disclosed that the said friends had encouraged them to seek health care at the clinic and were also HIV positive and on follow up at the clinic.

5.3 Perceived HIV/AIDS Stigma

Majority of the respondents had not suffered verbal abuse because of their HIV status. The same case applied to fear of contagion related to HIV status. The confounder in this case could be disclosure status of the respondents where stigma related from fear of contagion would not be expected where the respondent has not disclosed. A good number of the respondents had been socially isolated once or twice and this was consistent with the inadequate social support from friends observed among many respondents. Majority of the respondents 97.2% (228) had not suffered workplace stigma. This finding could be due to the fact that majority of the respondents were self- employed and therefore had not been in a position to be fired or denied opportunities at the workplace due to their HIV status. In addition disclosure of HIV status is not common in the workplace. Healthcare neglect was not a common form of HIV/AIDS related stigma among the respondents with 97.9% (230) having never faced healthcare neglect. This point to a reduction in stigma directed to HIV positive individuals by healthcare workers. This contrasts with findings from a study by Dlamini P., Kohi T., Uys L. et al, (2007) in five African countries (Lesotho, Malawi, South Africa, Swaziland, and Tanzania) where health care workers were found to neglect and verbally abuse HIV positive patients notwithstanding their professed professional ethics. However in the quoted study, the patients were attended to in an inpatient setting which gave more time for patient-caregiver interaction unlike in this study carried out in outpatient (CCC).

Although on average 41.5% (96) of the respondents had never suffered self stigma (negative self- perception), the rest had suffered once or twice (85), often (28) or always (26). This therefore indicates that there was self stigma among the respondents. This was particularly observed with regards to feeling ashamed of having the disease and feeling that they had brought a lot of trouble to their families. This aspect of self stigma would have contributed significantly to the abuse of substances. This is especially true for respondents who had always or often suffered the stigma and would therefore require intensive counselling and follow up compared to those who had not suffered or had suffered only once or twice.

5.4 Relationship between the Variables.

There was a significant statistical association between changes in substance abuse after HIV diagnosis and ARVs treatment status (p=0.002). Respondents on ARVs showed an increase in substance abuse after HIV diagnosis compared to those not on ARVs while majority of

those not on ARVs reported a decreased intake. This could be attributed to the fact that being initiated on ARVs is seen as an indication of severity of illness which would in itself increase the level of stigma. Being initiated on ARVs requires the patients to have a CD4 test and also measurement of viral load. A high viral load and a low CD4 count is an indication for ARVs. Taking ARV medication should however imply that the individual is participating in appropriate health monitoring and seeking treatment to retard illness progression .These findings reflect findings from other studies done elsewhere. For example a study on the impact of taking or not taking ARVs on HIV stigma as reported by persons living with HIV infection in five African countries by Makoae L., Portillo C., Uys L. et al,(2013) found out that being on ARVs increased HIV related stigma. Many respondents with a higher level of education (secondary and tertiary) reported a decrease in substance abuse after HIV diagnosis possibly because it probably could have been easier for them to understand and take in the advice given by the healthcare workers than those with primary level of education.

The findings in this study show a significant statistical association between lack of social support and substance abuse. Majority of the respondents who lacked social support from a significant other reported an increase in substance abuse after HIV diagnosis. The same case applies to those who lacked support from both families and friends. In addition, majority of the respondents were not members of any HIV support group. Inadequate social support has been correlated with substance abuse and a higher HIV related stigma(Holtz, Sowell and Velasquez, 2012). Stressful life events have been correlated with substance abuse and nonadherence to ARVs while on the other hand social support is associated with slow AIDS progression as Leserman et al., (2008) found out.

Assessment of stigma among the respondents revealed a low level of stigma experienced by the respondents with only a few items showing a significant statistical association. For example respondents who were often and always mocked when passing by reported an increase in substance abuse as well as those who had lost friends due to their HIV status. The few significant items could have played a role in the increase in substance abuse among the respondents. This therefore implies that stigma plays a role in substance abuse especially when coupled with inadequate social support as alluded to in other studies. Galvan et al., (2008) and Ying-Xia, Golin, Jin, Emrik et al., (2014) notes that how HIV positive people manage HIV stigma and the strategies that they use can be influenced by the extent of social resources {family, friends, significant other(s)} that they have available in their lives.

The findings indicate that there was an increase in substance abuse after HIV/AIDS diagnosis and this is predicted by lack of a special person around when one is in need (p=0.044), lack of family support (p=0.020) and self- pity(p=0.008). Sowell & Phillips,(2010) in their study point out that a HIV diagnosis is often characterized by stigma, discrimination, and social isolation. In addition, each stage of HIV/AIDS, including diagnosis, adaptation to the disease and treatment regimen, and facing a chronic and potentially terminal illness, increases psychological distress, depression, and feelings of hopelessness(Galvan et al., 2008). This may explain the reason why HIV/AIDS patients already abusing substances and who lack social support end up increasing their abuse of the substances after diagnosis in an effort to seek solace for their hopelessness. The hypothesis that there is no association between perceived stigma, social support and substance among CCC clients at the Coast Province General Hospital was therefore rejected.

5.5 Conclusions

The study assessed prevalence of substance abuse among PLWHA and found it at 19.1%. This is a high prevalence considering the fact that substance abuse has been found to be a leading cause of nonadherence to HIV/AIDS management and prevention. More than advice from healthcare workers is required to curb substance abuse in this population. Advice should be coupled with referral for further management and follow up since substance abuse is an impulsive disorder.

External stigma was found to be no longer as significant as internal stigma (self stigma) in HIV/AIDS. Patients suffered self stigma especially on initiation of antiretroviral medications as this was perceived as a measure of disease severity. High levels of stigma and reduction in social support led to an increased abuse of substances. Stress after HIV diagnosis was the main reason given for increasing substance abuse while advice from healthcare workers was the main reason given for decreasing abuse of substances.

Social support is expected to be derived from significant others and family. The high proportion of unmarried/ patients without partners led to a lack of support from significant other. The high prevalence of substance abuse among this population can be attributed to the inadequate social support and stigma for those who faced the stigma. Perceived lack of social support and perceived HIV related stigma demotivates the PLWHA leading them to engage in risky behaviours such as substance abuse. Most significant is the lack of support from significant others and from the family as well as self -pity.

5.6 Recommendations

The following recommendations have been made;

To the Healthcare givers at the CCC

- All patients should be assessed for substance abuse during both enrolment at the clinic and before initiation on antiretroviral medications.
- A social needs assessment should be carried out by the medical social workers especially for patients without significant others or family support.
- The family and significant other(s) should be counselled so as to encourage support for the patient.
- Formation and membership to HIV/AIDS support groups should be encouraged. This can be achieved in liason with the community health workers and Non-Governmental Organisations (NGOs).
- Advice provided to the patients abusing substances should be coupled with appropriate referral for further counselling and psychiatric management. This is because substance abuse is an impulsive disorder and therefore requires follow up.

To the Policy Makers

- Agencies dealing with substance abuse should incorporate HIV testing and counselling. This would ensure early referral and management of patients with substance abuse disorders which complicates HIV/AIDS management and prevention.

Further Research

The study was limited to patients aged 18 years and above and excluded those below 18 years of age. Further studies should be carried out to include those below 18 years of age but with substance abuse disorders. This is because this group of patients may have different reasons for abuse of substances other than those reported by respondents in this study. In addition, further studies would reveal other problems faced by PLWHA that would explain abuse of substances.

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APPENDICES

APPENDIX A: WORK PLAN

MONTH / ACTIVITY	OCT 2013	NOV 2013	DEC 2013	JAN 2014	FEB 2014	MAR 2014	APRIL 2014	MAY 2014	JUN 2014
Proposal development	■	■							
Approval by the school			■						
Ethical clearance			■	■					
Data collection					■	■			
Data analysis							■		
Report writing								■	
Presentation									■

APPENDIX B: BUDGET

ITEM	QUANTITY	UNIT PRICE	TOTAL(KSHS)	TOTAL(USD)
STATIONERY				
Biro pens	3pcs	20	60	0.70
Pencils	2pcs	20	40	0.47
Eraser	2pcs	15	30	0.35
Pencil sharpener	1pc	10	10	0.12
Folder	1pc	50	50	0.59
Box file	1pc	150	150	1.76
Paper punch	1pc	600	600	7.06
Stapler	1 pc	500	500	5.89
Staples	1pkt	150	150	1.76
Stapler remover	1pc	250	250	2.94
Note book	2pcs	100	200	2.35
Flash disc	1pc	1200	1200	14.12
Ruler	1pc	20	20	0.24
White out	1pc	120	120	1.41
Subtotals			**3380**	**39.76**
Others				
Draft proposal printing	3 copies	500	1500	17.65
Draft proposal photocopy	4 copies	150	600	7.06

Photocopy final report	13 copies	300	3,900	45.88
Printing final report	4 copies	1000	4,000	47.06
Final report binding	10 copies	250	2,500	29.41
Training of research assistants	3	1000	3,000	35.29
3 Research assistants' fee	@500x40 days	20000	60,000	705.88
Statistician	1	10000	10,000	117.64
Ethics committee fee	1	500	500	5.88
Ethics book	1	3000	3,000	35.29
Subsistence	40 days	500	20,000	235.29
Transport	40 days	200	8,000	94.12
Communication(mobile)	40 days	100	4,000	47.06
Accommodation	40 days	1500	60,000	705.88
Internet charges	8 weeks	2000	16,000	188.26
Sub totals			**197,000**	**2317.64**
Total			**200,380**	**2357.41**
10% contingency			20,038	235.74
GRAND TOTAL			**220,418**	**2593.15**

APPENDIX C: CONSENT EXPLANATION AND PARTICIPANT'S CONSENT

Title of the study: "Assessment of Association between Perceived Stigma, Social Support and Substance Abuse among Clients at the Comprehensive Care Centre at the Coast Province General Hospital".

Introduction

Hello and welcome. My name is Elizabeth W. Maina, a university student pursuing a masters degree in Nursing (Medical-Surgical Nursing) at the University of Nairobi. In partial fulfilment of the requirements of this course I am required to carry out a study.

The Objective of the Study

The objective of this study is to determine the associations between stigma, poor social support and the use of alcohol and drugs of abuse among patients infected with HIV.

Study Benefits

There will be no direct individual benefits from participating in this study. However, the findings of this study will assist in understanding any contribution of HIV related stigma and social support in alcohol and drugs use among CCC clients. This will enable the care givers design comprehensive interventions targeting alcohol and drugs use in this population which negatively affects management and prevention of HIV/AIDS. Ill health and deaths related to alcohol and drugs use in HIV will be addressed with such interventions.

Study Risks and Minimization of the Risks

This study does not include use of any invasive procedures. Minimal harm may result due to the nature of the questions asked leading to psychological disturbance. The researcher will ensure that participants are linked with qualified counsellors. You may also get tired during the filling in of the study tool. You will be allowed to fill the tools at your convenience and if need be another meeting can be arranged at your convenience to complete the process.

Confidentiality

To enable collection of information around this topic, I have designed a questionnaire and I am requesting you to participate by filling in the questionnaire. The information provided will be treated with utmost confidentiality as required by law and will not be used in any other way except for the purpose of research. You will not be required to write your name or anything that can identify you on the questionnaire. The information provided will never be published or availed to the public in a manner that identifies you.

Voluntarism

Participation in the study will be on a voluntary basis. You will be free to withdraw from the study at any stage without fear of victimization and you are under no obligation to answer any questions you do not want to answer.

Investigator's Contacts

In case of any queries relating to your participation in the study or anything requiring clarification, please feel free to contact me using the contact below.

Elizabeth Maina,

Mobile number – 0722657760

Email: elizaw013@gmail.com.

Supervisors - Mrs Miriam Wagoro – 0722737356

                Mrs Angeline Kirui – 0720440665

                Dr. Lincoln Khasakhala - 0722860485

Or contact the KNH/UON Ethics and Research Committee secretary on the contacts below;

Prof. M.L. Chindia

Tel. 2726300 Ext. 44102

Participant's Consent

I……………………………………………………………………. have read and understood the details concerning this research and voluntarily agree to participate.

Participant's signature……………………… Date…………………………………

Serial number………………………………

Witness's signature ………………………… Date……………………………….

Researcher's signature……………………….. Date……………………………….

APPENDIX D: MAELEZO YA RIDHAA NA RIDHAA YA MHUSIKA

Kielelezo

Hujambo na karibu. Kwa majina ni Elizabeth Maina kutoka chuo kikuu cha Nairobi. Kama mojawapo ya mahitaji ya shahada hii ya udhamini katika masomo ya uuguzi, inanihitaji kufanya utafiti. Utafiti huu utakuwa ni uchunguzi wa uhusiano ulioko kati ya unyanyapaa, msaada wa kijamii na utumiaji wa pombe na madawa ya kulevya kwa wagonjwa wanaohudumiwa katika kliniki hii ya CCC.

Lengo la Utafiti

Madhumuni ya utafiti huu ni kuelewa uhusiano ulioko kati ya unyanyapaa, ukosefu wa msaada wa kijamii na utumiaji wa pombe na madawa ya kulevya kwa watu walio na maambukizi ya virusi vya ukimwi.

Manufaa ya Utafiti

Habari tutakazopata katika utafiti huu hazitakuwa na manufaa ya kibinafsi. Zitakuwa na manufaa katika uboreshaji wa huduma kwa wagonjwa kwa jumla kwani zitachangia kuelewa jinsi unyanyapaa na msaada wa kijamii zinapohusika katika utumiaji wa pombe na madawa ya kulevya kwa waadhiriwa wa ugonjwa wa ukimwi. Huduma zitakapoboreshwa tutakuwa tumepiga hatua kupigana na magonjwa na vifo vinavyotokana na ugonjwa wa ukimwi.

Madhara ya Utafiti

Kuhusika kwako katika utafiti huu hakutakuletea madhara ila tu pengine kuhisi kulemewa au kusumbuka kimawazo juu ya maswali mengine ambayo tutakuuliza. Hata hivyo tutahakikisha kwamba tumekuelekeza kwa mshauri nasaha hapa hospitalini. Waweza pia kuchoka kabla hujamaliza kuyajibu maswali yote. Tutakuomba wewe mwenyewe kwa hiari yako utupatie nafasi nyingine ili uendelee kuyajibu.

Usiri

Hautahitajika kuandika majina yako mahali popote kwenye daftari hizi au kuandika chochote ambacho chaweza kukutambulisha wewe binafsi. Maelezo utakayotoa hayatatolewa kwa njia ambayo inaweza kukutambua wewe binafsi na yatatumika kwa manufaa ya utafiti pekee.

Kujitolea kwa Hiari

Ningependa uelewe kuwa kuhusika kwako katika utafiti huu ni kwa hiari yako na wala hushurutishwi kufanya hivyo. La muhimu pia ni kwamba unaweza kusitiza kushiriki kwako katika utafiti huu wakati wowote ule bila kuogopa dhuluma ya aina yoyote au kuadhiri huduma unzohitajika kupokea katika kliniki hii. Unapoyajibu maswali, ningependa uelewe

kwamba hushurutishwi kuyajibu yale usiyotaka kujibu. Hata hivyo, ningekuomba kujibu maswali utakayojibu vyema na kwa ukweli kulingana na ufahamu wako wa jambo hili.

Anwani ya Mtafiti

Endapo utakuwa hujaelewa chochote kuhusu utafiti huu au uwe na maswali yoyote, kuwa huru kuwasiliana nami kwa nambari za simu zilizoko hapo chini au barua pepe.

Elizabeth Maina,

Mobile number – 0722657760

Email: elizaw013@gmail.com

Wasimamizi - Mrs Miriam Wagoro – 0722737356

Mrs Angeline Kirui – 0720440665

Dr. Lincoln Khasakhala - 0722860485

Pia waweza wasiliana na katibu wa kamati ya maadili na utafiti katika chuo kikuu cha Nairobi na hospitali kuu ya Kenyatta kwa nambari ifuatayo;

Prof. M.L. Chindia

Tel. 2726300 Ext. 44102

Fomu Ya Ridhaa

Mimi …………………………………………….. nimesoma na kuelewa maelezo yote kuhusu utafiti huu na ninanuia kushiriki bila kushurutishwa kufanya hivyo.

Sahihi ya mhusika…………………………….. Tarehe……………………………..

Nambari ya utafiti…………………………………

Sahihi ya shahidi…………………………………Tarehe………………………………

Sahihi ya mtafiti……………………………..Tarehe………………………………

APPENDIX E: QUESTIONNAIRE

ASSESSMENT OF ASSOCIATION BETWEEN PERCEIVED STIGMA, SOCIAL SUPPORT AND SUBSTANCE ABUSE AMONG CLIENTS AT THE COMPREHENSIVE CARE CENTRE AT THE COAST PROVINCE GENERAL HOSPITAL.

Serial number………………………   Research assistant's initials………………

Instructions: Tick in the boxes or write in the spaces provided. DO NOT write your name on the questionnaire. Try and answer as many questions as you can. Thank you.

Section 1.0 Sociodemographic data

1.1 What is your gender?

Male ☐   Female ☐

1.2 What is your age on your last birthday?......................................

1.3 What is the highest level of education you have attained?

(specify)……………………………………………………………………………

   1.4 What is your marital status?...

    If single qualify (by choice, circumstances)...

1.5 What is your religion?

   Roman Catholic   ☐

   Protestants   ☐

   Muslim   ☐

   Hindu   ☐

   Others   ☐

(specify)……………………………………………………………………………………

1.6 What is your means of livelihood?

....

Section 2.0 HIV/AIDS status

2.1 When were you tested for HIV/AIDS and found to be positive? ……………......................

2.2 Have you been put on ARVs?

Yes ☐   No   ☐

2.2.1   If yes, when did you start taking ARVs? ………………………..

2.3 Do you attend HIV/AIDS support groups?

Yes   ☐   No   ☐

Section 3.0 Substance Use History

3.1 Have you ever used any of the following?

(Tick all that applies)

Alcohol   ☐

Bhang (marijuana)   ☐

Miraa(khat)   ☐

Cigarettes/ tobacco   ☐

Others? (specify substance)...

3.2. If yes when did you start using?

Alcohol?..

Bhang (marijuana)…………………………………

Miraa(khat)?..

Cigarettes/ tobacco……………………………...

Others? (specify

substance)..

3.2.1. Has your use of the above substances changed after HIV diagnosis?

If yes, specify

Increased   ☐   Decreased   ☐

3.2.2 Give reasons for the change

…………………………………………………………………………………………………

…………………………………………………………………………………………………..

APPENDIX F: CAGE QUESTIONS ADAPTED TO INCLUDE DRUG USE (CAGE-AID)

1. Have you ever felt you ought to cut down on your drinking or drug use?

   Yes ☐   No ☐

2. Do you get annoyed when people criticize your drinking or drug use?

   Yes ☐   No ☐

3. Do you feel bad or guilty about your drinking or drug use?

   Yes ☐   No ☐

4. Have you ever had a drink or used drugs first thing in the morning to steady your nerves or to get rid of a hangover (eye-opener)?

   Yes ☐   No ☐

APPENDIX G: MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT (Zimet, Dahlem, Zimet & Farley, 1988)

Instructions

I am interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Rate how you feel on a scale of 1 to 7.

Circle the "1" if you **Very Strongly Disagree**

Circle the "2" if you **Strongly Disagree**

Circle the "3" if you **Mildly Disagree**

Circle the "4" if you are **Neutral**

Circle the "5" if you **Mildly Agree**

Circle the "6" if you **Strongly Agree**

Circle the "7" if you **Very Strongly Agree**

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7	SO
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	SO
3.	My family really tries to help me.	1	2	3	4	5	6	7	Fam

4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7	Fam
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7	SO
6.	My friends really try to help me.	1	2	3	4	5	6	7	Fri
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7	Fri
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7	Fam

9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	Fri
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7	SO
11.	My family is willing to help me make a decision	1	2	3	4	5	6	7	Fam
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7	Fri

KEY

Source of social support

Fam – family

Fri – friends

SO – significant other

APPENDIX H: HIV/AIDS STIGMA INSTRUMENT – PLWHA (HASI – P)

I'm going to read a list of events that may have happened to you during the past three months. After I read each item, please tell me how often it happened to you because of your HIV status. Rate your experience on a scale of 0 – 3.

In the past 3 months, how often did the following events happen because of your HIV status?

	Scores	0	1	2	3
		Never,	Once or twice,	Often,	Always
1. I was told to use my own eating utensils.		☐	☐	☐	☐
2. I was asked not to touch someone's child.		☐	☐	☐	☐
3. I was made to drink last from the cup.		☐	☐	☐	☐
4. Someone mocked me when I passed by.		☐	☐	☐	☐
5. I stopped eating with other people.		☐	☐	☐	☐
6. I was asked to leave because I was coughing.		☐	☐	☐	☐
7. Someone stopped being my friend.		☐	☐	☐	☐
8. A friend would not chat with me.		☐	☐	☐	☐
9. I was called bad names.		☐	☐	☐	☐
10. People sang offensive songs when I passed by.		☐	☐	☐	☐
11. I was told that I have no future.		☐	☐	☐	☐
12. Someone scolded me.		☐	☐	☐	☐
13. I was told that God is punishing me.		☐	☐	☐	☐
14. I was made to eat alone.		☐	☐	☐	☐
15. Someone insulted me.		☐	☐	☐	☐
16. People avoided me.		☐	☐	☐	☐
17. People cut down visiting me.		☐	☐	☐	☐
18. People ended their relationships with me.		☐	☐	☐	☐
19. I was blamed for my HIV status.		☐	☐	☐	☐
20. Someone tried to get me fired from my job.		☐	☐	☐	☐
21. My employer denied me opportunities.		☐	☐	☐	☐

The next set of questions is about your experiences in the hospital or clinic.

In the past 3 months, how often did the following events happen because of your HIV status?

	0	1	2	3
	Never,	once or twice,	Often,	Always
22. I was denied health care.	☐	☐	☐	☐
23. I was refused treatment because I was told I was going to die anyway.	☐	☐	☐	☐
24. I was discharged from the hospital while still needing care.	☐	☐	☐	☐
25. I was shuttled around instead of being helped by a nurse.	☐	☐	☐	☐
26. At the hospital/clinic, I was made to wait until last.	☐	☐	☐	☐
27. At the hospital, I was left in a soiled bed.	☐	☐	☐	☐
28. In the hospital or clinic, my pain was ignored.	☐	☐	☐	☐

These questions are about some of your thoughts or feelings.

How often have you thought or felt this way during the past 3 months because of your HIV status?

	0	1	2	3
	Never,	Once or twice,	Often,	Always
29. I felt that I did not deserve to live.	☐	☐	☐	☐
30. I felt ashamed of having this disease.	☐	☐	☐	☐
31. I felt completely worthless.	☐	☐	☐	☐
32. I felt that I brought a lot of trouble to my family.	☐	☐	☐	☐
33. I felt that I am no longer a person.	☐	☐	☐	☐

Source: W. L. Holzemer et al., 2007

APPENDIX I: QUESTIONNAIRE TO EVALUATE PARTICIPANT'S UNDERSTANDING OF INFORMATION GIVEN FOR INFORMED CONSENT.

STUDYTITLE: *ASSESSMENT OF ASSOCIATION BETWEEN PERCEIVED STIGMA, SOCIAL SUPPORT AND SUBSTANCE ABUSE AMONG CLIENTS AT THE COMPREHENSIVE CARE CENTRE AT THE COAST PROVINCE GENERAL HOSPITAL.*

Questionnaire to be completed by the prospective participant to evaluate if s/he understood information as explained for informed consent

Instructions: Below you will find seven (7) questions on the information given to you about the study you are to participate in. Please circle the most appropriate response according to how well you understood the item (information).

1=you did not understand at all

5= you understood very well

	I did not understand at all				I understood this very well
The fact that I am participating in research	1	2	3	4	5
The purpose of the study	1	2	3	4	5
That participation is voluntary	1	2	3	4	5
The possible risks and discomforts of the study	1	2	3	4	5
The possible benefits of the study	1	2	3	4	5
The ways by which my privacy will be maintained	1	2	3	4	5
Overall I understood all aspects of the study	1	2	3	4	5

Adapted with slight modification and contains main themes in informed consent used by **Jof**fe et al (2001), Oduro et al (2008) and Minnies et al (2008).

APPENDIX J: LETTER OF APPROVAL FROM CPGH

MINISTRY OF HEALTH

Telegrams: "MEDICAL", Mombasa
Phone: Mombasa 2314202/5, 2222148, 2225845
Fax: 2220161 E-mail: chiefadmin@cpgh.co.ke
Address all correspondence to the Chief Admin.
When replying, please quote Ref. No. & date.

COAST PROVINCE GENERAL HOSPITAL
P.O. BOX 90231
MOMBASA

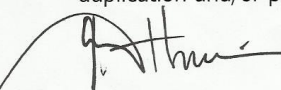**Ref. No. MED.4/II/VOL.I/49**   **Date: 30TH APRIL, 2014**

Maina Elizabeth Wanjiru
School of Nursing Sciences

**RE: RESEARCH PROPOSAL: ASSESSMENT OF ASSOCIATION BETWEEN
PERCEIVED STIGMA,SOCIAL SUPPORT AND SUBSTANCE ABUSE AMONG
CLIENTS AT THE CCC AT COAST PROVINCE GENERAL HOSPITAL**

This is to inform you that the CPGH Ethics & Research Committee has reviewed and approved your above proposal. The approval period are 30th April,2014 to 9th April,2015.

This approval is subject to compliance with the following requirements:

a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b) All changes (amendments, deviations, violations etc) are submitted for review and approval by CPGH-ERC before implementation.
c) Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the CPGH-ERC within 72 hours of notification
d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to CPGH-ERC within 72 hours
e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period (attach a comprehensive progress report to support the renewal)
f) Clearance for export of biological specimens must be obtained from CPGH-ERC for each batch of shipment.
g) Submission of an executive summary report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

DR. B. ATHMAN
SECRETARY, CPGH-ERC

C.C
Chairman – ERC
Chief Administrator – CPGH
Director of Nursing
Nurse in charge – CCC

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APPENDIX K: LETTER OF APPROVAL FROM KNH/UoN- ERC
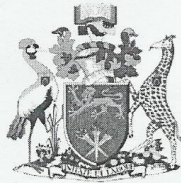
UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
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(254-020) 2726300 Ext 44355

KNH/UON-ERC
Email: uonknh_erc@uonbi.ac.ke
Website: www.uonbi.ac.ke

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/106   Link:www.uonbi.ac.ke/activities/KNHUoN   10th April 2014

Maina Elizabeth Wanjiru
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Elizabeth

RESEARCH PROPOSAL: ASSESSMENT OF ASSOCIATION BETWEEN PERCEIVED STIGMA, SOCIAL SUPPORT AND SUBSTANCE ABUSE AMONG CLIENTS AT THE COMPREHENSIVE CARE CENTRE AT THE COAST PROVINCE GENERAL HOSPITAL (P19/01/2014)

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and **approved** your above proposal. The approval periods are 10th April 2014 to 9th April 2015.

This approval is subject to compliance with the following requirements:

a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.
c) Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH/UoN ERC within 72 hours of notification.
d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH/UoN ERC within 72 hours.
e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
f) Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
g) Submission of an *executive summary* report within 90 days upon completion of the study
   This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

For more details consult the KNH/UoN ERC website **www.uonbi.ac.ke/activities/KNHUoN.**

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Yours sincerely

PROF. M. L. CHINDIA
SECRETARY,   KNH/UON-ERC

c.c.   The Chairperson, KNH/UoN-ERC
          The Deputy Director CS, KNH
          The Principal, College of Health Sciences, UoN
          The Director, School of Nursing Sciences, UoN
          The Assistant Director, Health Information, KNH
          Supervisors: Mrs. Miriam C.A.Wagoro, Mrs. Angeline C. Kirui, Dr.L. Khasakhala

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