

**KNOWLEDGE, ATTITUDES AND PRACTICES OF BWAFWANO HOME  
BASED CARE GIVERS TOWARDS PEOPLE LIVING WITH HIV (PLHIV)  
BUT ALSO SUFFERING FROM MENTAL ILLNESS IN LUSAKA AND  
CENTRAL PROVINCES, ZAMBIA.**

**BY**

**PATRICIA ZULU ULAYA**

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**THE UNIVERSITY OF ZAMBIA  
SCHOOL OF MEDICINE  
DEPARTMENT OF COMMUNITY MEDICINE  
LUSAKA**

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Signature:..... Date:.....

**Head of Department:**

Signature:..... Date:.....

Department of Community Medicine, Public Health. School of Medicine, University of Zambia.

**CERTIFICATE OF APPROVAL**

This dissertation submitted by **PATRICIA ZULU ULAYA**, is approved as fulfilling the requirements for the award of the Degree of **MASTER OF PUBLIC HEALTH** at the University of Zambia.

Dr S. Nzala	.....	.....
Supervisor	Signature	Date

	.....	.....
Examiner	Signature	Date

	.....	.....
Examiner	Signature	Date

	.....	.....
Examiner	Signature	Date

	.....	.....
Chairman (Board of Examiners)	Signature	Date

## ABSTRACT

Arising from the assumption that knowledge, attitudes and practices may be lacking or poor among home based care givers towards people living with HIV (PLHIV) but suffering from mental illness, a cross sectional mixed study design employing a survey of 111 questioners and 12 focus group discussions was undertaken with caregivers enlisted within four sites mainly; Chazanga peri urban compound and Ngwerere rural in Lusaka province and Chibombo and Mkushi rural in Central Province of the Bwafwano Home Based Care establishment to determine their knowledge, attitudes and practices. Using One Way ANOVA, there were statistically no significant differences ( $p = 0.587$ ) in the mean scores of the respondents in the four sites. The results indicated poor knowledge in the sample about mental health and the extent to which mental illness was a problem among PLHIV and mental illness as well as the care given. The study established that Males and females in the study sample showed significant differences in their perceptions on the knowledge variable ( $t=35.069$ ,  $df = 110$   $p = 0.00$ ). On the attitude variable it was observed that these were poor in the three domains: restriction, benevolence and stereotype. Practices did not differ significantly between the two levels of the independent variables: "town" ( $F= 2.040$ ,  $df, 3$ ,  $p = 0.113$ ). The results further showed that on the independent variable "sex", males and females did not show significant differences in their perceptions on the dependent variable "Practices Score" ( $F= 0.010$ ,  $df, 1$ ,  $p = 0.921$ ). The practice domain further shows that the care givers were unable to offer any treatment and mostly referred clients to religious leaders, private practitioners and nearest hospitals. More respondents  $n = 68$  (61.3%) felt that the PLHIV but suffering from mental illness were not receiving the attention they deserved from the home based care givers

This study has provided important indications of Community caregivers' perceptions of mental illness in people living with HIV and AIDS in Bwafwano Home Based Care, which had not been sought previously. These findings have implication on the quality of care that PLHIV but suffering from mental illness may be receiving under Home Based Care (HBC). The findings therefore highlight the need for strategies to improve the capacities of home based care givers to provide quality care to PLHIV and suffering from mental illness.

## DEDICATION

This work is dedicated to **my beloved husband William, my children Chimwemwe, Daliso and Nthokozo** for their patience, encouragement, emotional and spiritual support during the time of my study. Above all I thank **God Almighty**, for making all things possible.

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## ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
CBOH	Central Board of Health
CNS	Central Nervous system
CSO	Central Statistics
FGD	Focused Group Discussion
HAD	HIV/AIDS Dementia
HIV	Human Immune Virus
HBC	Home Based Care
KAP	Knowledge Attitude and Practice
LAMIC	Low and Medium Income Countries
MOH	Ministry of Health
NAC	National AIDS Council
NASF	National AIDS Strategic Framework 2011-2015
NGO	Non Governmental Organization
PLHIV	People Living with HIV
STI	Sexually Transmitted Infections
TB	Tuberculosis
UNAIDS	Joint United Nations Program on HIV/AIDS
UN	United Nations
WHO	World Health Organization

## **CHAPTER ONE**

### **INTRODUCTION**

The relationship between mental health and Human Immune Virus and Acquired immunodeficiency syndrome (HIV and AIDS) in developing countries, including Zambia, is complex and remains to be fully investigated. Studies have shown that there is a bi-directional relationship between mental illness and HIV and AIDS (Bodibe, 2010). Mental illnesses increase vulnerability to HIV infection (Calvert and Robert, 1995; Leserman *et al.*, 1999), on the converse, HIV and AIDS increases vulnerability to mental illnesses. Research has also shown higher rates of mental illness amongst people living with HIV, (PLHIV). However, the evidence-base was largely from the developed world (Baingana *et al.*, 2005), and research from developing countries remains limited (Collins *et al.*, 2006). From the general population in South Africa, 16.5% of people were reported to be suffering from some form of mental illness. However, when only people living with HIV were considered the figure went up to 43.7% (Bodibe, 2010).

Mental illnesses manifest in three different categories: those resulting from HIV brain infection; those manifesting primary psychiatric disorders prior to HIV infection; and the majority who have HIV and common illness, such as depression, anxiety and substance abuse disorders. This later group is largely due to psycho-social stress attributed to loss of

relationships, dealing with being HIV-positive and death that further cause strain on patients' mental well-being (Palitza, 2009). ARVs can also cause negative side effects on a patient's mental health. The drug Efaviranz is associated with central nervous system side effects such as drowsiness, insomnia abnormal dreams and impaired concentration (MOH, 2007).

Many countries including Zambia face serious challenges in providing basic quality health care and support to individuals and families affected with mental illnesses and are living with HIV and AIDS. The challenges include limited financial resources, staff shortage due to natural attrition such as brain drain, retirement and death of health care givers coupled with inadequate bed capacity in hospitals. In response to these health concerns, the Zambian Government created the Home Based Care (HBC) Programme which extended the care of such patients to community care givers who work through Home Based Care Non-Governmental Organizations (NGOs) which provide care and support services beyond clinic walls to meet the overall needs of people suffering from prolonged/chronic illnesses like HIV and AIDS with mental illness within the home environment (MOH, CBOH, 2005).

Among the many Non Governmental Organizations (NGO) that are involved in HBC for PLHIV in Zambia is Bwafwano Community Home-Based Care Organization. The NGO was established in 1996 with its headquarters situated in Chazanga compound in Lusaka Province. Bwafwano is currently operating in 4 sites mainly Chazanga peri urban compound and Ngwerere rural in Lusaka province and Chibombo and Mkushi rural in

Central Province. The organisation offers service to a total number of 7,421 PLHIV patients and works with support from a team of 386 care givers (Bwafwano Semi-annual Reports October 2009 – March 2010). Bwafwano works with community home based volunteers and family care givers in the provision of care. The role of the community care givers is to visit the sick, provide nursing care and provide basic medication and cook for the patient (Bwafwano Home Based Care, 2007).

Since PLHIV are likely to develop mental illness, home based care givers ought to have appropriate knowledge, attitudes, practices and skills to render meaningful and effective care service. It has been shown that almost all communities in Zambia feel the impact of nursing patients with a mental illness under HBC approach (Alciati *et al.*, 2001). In their Community study, Geoffrey, *et al.*, (1996) stated that severe psychotic symptoms among people living with mental illness contribute to the difficulties of medical care in the community. They observed that these people actually were not very well looked after; they required both immediate management and continued care. Research in the West and limited to nurses and doctors has shown that there is a relationship between nurses' and doctors' attitudes towards mental patients and the organisation of psychiatric care (Rössler *et al.*, 1995; Kingdon *et al.*, 2004; Lauber *et al.*, 2004; Jorm *et al.*, 1999; Kurihara *et al.*, 2000; Caldwell and Jorm, 2000).

Empirical research on this topic among community care givers in Zambia has not been conducted. This study aimed at highlighting areas within the home based care establishments that may need emphasis and review. The findings would be helpful in

fortifying community mental health packages for people living with HIV and AIDS. In addition, the study's findings would provide baseline data for extended research to other home based care giver organizations.

### **1.1.0 Statement of the problem**

Following the researcher's experience with a home care giver in Ngwerere who was able to provide care to a patient living with HIV and AIDS only for an opportunistic infections but could not attend to symptoms of mental illness, an assumption was generated that the care givers' knowledge, attitudes and practices about mental illness may have been lacking or poor and that appropriate care givers' training may not have taken place.

The Ministry of Health developed integrated guidelines for the treatment of mental illness and yet the extent to which these have been integrated into the HBC practice is not known. There is a wide gap of knowledge in this area in Zambia because of lack of systemic research on this subject compared to Europe and other parts of the world where the subject has been well researched (Rössler *et al.*, 1995; Kingdon *et al.*, 2004; Lauber *et al.*, 2004; Jorm *et al.*, 1999; Kurihara *et al.*, 2000; Caldwell and Jorm, 2000).

### **1.2.0 Research questions**

- 1) What is the understanding of mental illness among caregivers?
- 2) What knowledge, attitudes and care practices do caregivers have on mental illness on persons living with HIV/AIDS but suffering from mental illness?

- 3) Why do caregivers have particular perceptions on persons living with HIV/AIDS but suffering from mental illness?
- 4) Are there any differences within the four Bwafwano sites and between genders in terms of these perceptions?

### **1.3.0 Main objective**

To determine the knowledge, attitudes and practices among care givers involved in caring for people living with HIV but suffering from mental illness within Bwafwano home based care institutions in Zambia.

### **1.4.0 Specific objective**

- 1) Based on community caregivers accounts, to describe their own understanding of what mental illness is.
- 2) To determine the knowledge, attitudes and care practices community caregivers have on mental illness on persons living with HIV/AIDS but suffering from mental illness.
- 3) To determine the differences which exist in terms of perceptions within the four sites in Bwafwano and across gender.

### **1.5.0 Operational definition**

Attitude – A mind set about something or someone.

Practice – It is a way of doing things.

Knowledge – Awareness of the existence of mental illness and being able to recognise signs and symptoms.

Mental illness – Disease of the mind leading to disturbance in thinking, mood, perception and action.

Home Based Care – A system of providing prevention, care and services beyond clinic walls to meet the overall needs of people suffering from chronic illness within the patient's environment.

Home Based Care Giver – A Community volunteer who gives care to the client in a home set up.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1.0 The burden of HIV/AIDS and mental illness**

The literature review shows that there is a lot of literature on mental illness and on HIV and AIDS treated separately. However, there is little literature linking the two health phenomena. This has been acknowledged by Carey (1995) who says “people with mental illness have been overlooked in the AIDS epidemic”. In Zambia, the 2011 to 2015 National AIDS Strategic Framework (NASF) is completely silent about the relationship between the two either as one being a causal factor or an effect of the other. Mentally ill persons are not mentioned amongst the vulnerable groups or needing special attention from care givers. This highlights the gap that this study will attempt to fill.

#### **2.1.1 Global problem of HIV/AIDS**

Over thirty three million people were living with HIV and AIDS worldwide at the end of 2009 with the majority of these being in developing countries. The global prevalence (rate) stands at 0.8% among the 15 to 49 age group and an infection rate of more than 7, 000 cases each day with the majority being in sub-Saharan Africa of which Zambia is a part (UNAIDS, 2011).



### **2.1.2 Zambia's profile of HIV/AIDS**

Zambia's population stands at 13,046,508 and it is estimated that 14.3% are HIV positive (CSO, 2010; NASF, 2010). One in every six adults in Zambia is living with HIV and life expectancy at birth has fallen below 40 years. In 2002, the Government made anti retroviral drugs accessible to all those in need at a subsidized fee. In 2004, the drugs were provided free of charge in the public health sector. In the same year, HIV/AIDS was declared a national emergency by the Zambian Government and a targeted was made to provide ARVs to 10,000 people by the end of the year; having exceeded this target, another target was made to provide free treatment for 100,000 by the end of 2005. While there were these advances, little progress was being made to link up the management of mental illness among people living with HIV/AIDS.

### **2.1.3 The global profile of mental illness**

In the past two decades, research has shown a high level of psychological morbidity in the general population (Meltzer *et al.*, 1995) and in those with physical illness (Kissane *et al.*, 1994; Glasdam *et al.*, 1996; Duits *et al.*, 1998). According to Patel, (2007), the report on Global Burden of Disease and Risk Factors has become the benchmark to assess, and compare, the burden posed by various health conditions, in each region of the world. The major findings from this report indicated that neuropsychiatric disorders account for 9.8% of the total burden of disease in Low and Medium Income Countries (LAMIC); addition of self-inflicted injuries increases this proportion to 11.1%, unipolar depressive disorder

accounts for 3.1% of the total burden of disease attributable to non-communicable conditions in Low and medium income countries (LAMIC); this disorder is the leading neuropsychiatric cause of burden of disease. The report further indicates that self-inflicted injuries account for 1.5% of all deaths in LAMIC; with regional variations in this proportion, self-inflicted injuries account for 0.2% of total deaths in Europe and Central Asia, making them the fifth leading cause of mortality in these LAMIC and that unipolar depressive disorders is the single leading cause of Years Lived with Disability. Schizophrenia and alcohol use disorders appear in the leading 10 cause. In addition, given that most mental illnesses begin in childhood or young adulthood, the attributable burden of disease for adults in the age group of 15–44 is much higher.

According to the WHO Mental Health Survey Consortium, (2004), research findings have confirmed the high prevalence of mental illness and the large burden associated with them. The Health Survey, in the analyses of data from 15 countries found that the 12 month prevalence of mental illness varied between 4.3% in Shanghai, China to 26.4% in the United States of America. Milder disorders were more prevalent than severer ones. The prevalence of moderate and severe disorders was between 0.5 to 9.4% and 0.4 to 7.7%, respectively, compared to 1.8 to 9.7% for mild disorders. The report further estimates that the burden of neuropsychiatric conditions in disability Adjusted Life Years is 13% of the total burden of all health conditions and this is likely to increase, (WHO Mental Health Survey, 2004).

#### **2.1.4 Zambia's profile of mental illness**

Data on mental illness in Zambia is very scarce. This may be due to the shortage of experts in the field to conduct regular studies and surveys to produce the much needed information. In 2002, there were about 560 beds for psychiatric patients across the country. Common mental illnesses found in Zambia are acute psychotic episodes, schizophrenia, affective disorders, alcohol related problems and organic brain syndromes (Mayeya, *et al*, 2004). About between 70 to 80% of people with mental health problems consult traditional health practitioners prior to seeking treatment or care from conventional health practitioners. Over the years, the number of frontline mental health workers and professional staff has been declining owing to 'brain drain', retirement, death and low output from training institutions. In 2002, there was only one practicing psychiatrist available for the whole country while related mental health workers such as psychologists, social workers and occupational therapists were also in short supply (Mayeya, *et al*, 2004). This picture shows a critical shortage of mental health professionals in the country.

#### **2.2.0 Mental illness and HIV co morbidity**

Research has shown that mental health is often co morbid with many physical health problems such as cancer, HIV/AIDS, diabetes and tuberculosis, among others (Becker *et al.*, 2004; Gallego *et al.*, 2000). As HIV progresses, it has been shown that a greater risk of psychological morbidity occurs (Gallego *et al.*, 2000; Hutton and Treisman, 2008). According to Adle-Biassette, *et al.* (1995), HIV infection has been linked to: Dementia, psychosis, anxiety syndromes, mood disorders, suicidality and alcohol dependence. Similar

to other serious illnesses, HIV is associated with a wide range of mental health problems. Almeida, *et al.*, (2005), stated that Organic problems such as delirium are common. Specific HIV-related dementias have been described in detail elsewhere (Almeida and Lautenschlager, 2005). Older individuals are at greater risk of HIV-related cognitive impairment and dementia (Becker *et al.*, 2004) and experience more social isolation (Bruce *et al.*, 1991) with improved survival and ageing cohorts, these problems may increase. Gender and associated social consequences contribute to increased risk of mental health problems (Gallego *et al.*, 2000; Hutton and Treisman, 2008). Previous contact with psychiatric services, often because of substance misuse or personality problems, is associated with an increased risk of mental health problems in people with HIV (Gallego *et al.*, 2000). The increased risk of mental health problems can also occur when patients commence antiretroviral medication due to potential side effects; this time is associated with major health problems and chronic disabling symptoms (Gallego *et al.*, 2000; Hutton and Treisman, 2008).

In a study done in Zambia, Chipimo and Fylkesnes, (2009) found a 13% prevalence of mental distress within the general population with a 2.0 higher odds ratio among the HIV infected. Health workers have for a long time encountered neurologic and psychiatric complications in patients with human immunodeficiency virus (HIV) infection. While there are advances in the control of HIV/AIDS, there is little progress to link up the management of mental illness among PLHIV in Zambia.

The presence of substantial co morbidity has serious implications for the identification, treatment and rehabilitation of affected individuals. In addition, Adle-Biassette, *et al.* (1995) have observed that other HIV-associated neuropsychiatric complications include the following: Minor cognitive motor disorder, which differs from HIV and AIDS Dementia (HAD) in severity and degree of functional disability but may progress to HAD; Neurobehavioral impairments (e.g., apathy, depression, anxiety/agitation, sleep disturbance, hypomania); Myelopathy, which is functional disturbance and/or pathologic change to the spinal cord; and Aseptic meningitis. Despite the decreasing incidence of HAD in recent years, cognitive impairment is the most common Central Nervous System complication in people with HIV/AIDS. Delirium is the most common cognitive disorder in hospitalized patients with AIDS. The prompt diagnosis of cognitive impairment/dementia and delirium may significantly decrease morbidity and mortality. Most scholars attribute the high incidence of mental illness in developing countries to be related to HIV/AIDS. Other scholars have similarly underscored the strong causal link between HIV/AIDS and mental illness. According to Frank *et al.*, (2004), HIV infection increases the risk of developing psychiatric disorders, including depression, mania, psychosis, and substance abuse. For patients with pre-existing mental illness, a diagnosis of HIV can significantly impact their ability to cope with HIV disease, adhere to treatment regimens, and take advantage of support networks and care systems, and can result in deterioration in their quality of life. Individuals with previous histories of mood, cognitive, or anxiety disorders may exhibit a re-emergence or exacerbation of symptoms. In addition, studies have shown a significant prevalence of substance and alcohol use in people with mental problems. The

studies point to a higher problematic use of alcohol and drugs among those with mental illness than among the general population (Graham *et al*, 2004).

Studies have shown that, among sero-positive individuals, there is a higher rate of anxiety described by the DSM-IV as Generalized Anxiety Disorder. Studies have also shown that both sero-negative and seropositive homosexual men report episodes of clinical anxiety lasting from one to several months, with the majority of onsets being related to sero-conversions or commencing after the advent of the AIDS pandemic. In other words, it has been suggested that the very existence of HIV infection is responsible for a significant rise in prevalence rates for clinically diagnosable persistent anxiety (Schoub, 1994). Remarkably, a number of studies have shown that the rates of other major anxiety disorders (panic disorder, obsessive compulsive disorder) do not appear to be markedly above community standards in HIV seropositive individuals, even though HIV can be the manifest content of these conditions. In a study of 140 AIDS patients that received palliative care, over 33% exhibited severe anxiety (Butters, *et al*, 1992).

Delirium is the most common neuropsychiatric complication in hospitalized patients with AIDS. Delirium may be life-threatening and requires immediate medical attention. Occasionally, patients may present with early signs of delirium in the primary care setting. Thus, it is essential that health workers be able to recognize the signs and symptoms and refer patients to the hospital immediately. In these cases, the clinician should then contact the emergency department to follow-up with the disposition of the patient.

Categories of patients who are at risk for developing delirium includes those in advanced stages of immunosuppression, those with a history of opportunistic infections, substance use, head/brain injuries, or episodes of delirium and those with HAD or infections and malignancies of the CNS. Health workers should assess for delirium when there is a sudden change in a patient’s cognitive functioning, consciousness, or behaviour. The hallmarks of delirium are an impairment of consciousness, with a reduced ability to focus or sustain or shift attention, and changes in cognition or development of perceptual disturbances that are not explained by a pre existing dementia. These disturbances may develop over a short period of time, and the symptoms may fluctuate in severity. Delirium is generally a direct physiologic consequence of a medical condition. (MARP, 2009). Table 2.1 gives a summary of delirium in patients with HIV.

Table 2.1 Clinical manifestations of delirium in HIV-infected patients

Source: MHAPP (2009) Handbook of mental illness

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**Impairment of memory, orientation, prefrontal “executive” functions**

**Difficulty with abstraction**

**Difficulty with sequential thinking**

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**Impaired temporal memory**

**Impaired judgment**

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**Disturbances in thought and language**

**Decreased verbal fluency**

**Disturbances in perception**

**Hallucinations (primarily visual)**

**Illusions (misinterpretation of visual cues, e.g., mistaking shadows for people)**

**Disturbances in psychomotor function**

**Hypoactive**

**Hyperactive**

**Mixed hypo- and hyperactive**

**Disturbances in sleep-wake cycle**

**Daytime lethargy**

**Night time agitation**

**Delusions\***

**Affective lability**

**Neurologic abnormalities**

**Tremors**

**Ataxia**

**Myoclonus**

**Cranial nerve palsies**

**Asterixis**

**Cerebellar signs**

**Nystagmus**

---

\* Delusions are usually paranoid but more disorganized than those seen in psychoses.

Delirium is often difficult to diagnose. When patients appear hypoactive, depression is a frequent misdiagnosis for delirium. Possible causes of delirium are listed in Table 2.2.

Health workers should maintain a high index of suspicion for delirium related to CNS



infections and substance use in HIV-infected patients. The combination of HIV infection and methamphetamine use is associated with significant brain structure alterations and cognitive impairment.

Table 2.2 Possible causes of delirium

- 
- 
- Metabolic abnormalities
  - Almost all HIV-related and psychotropic medications
  - Sepsis
  - Opioids
  - Hypoxemia
  - Anaemia
  - Alcohol intoxication and withdrawal
  - CNS infections and malignancies
- 
- 

### **2.3.0 Knowledge about PLHIV but suffering from mental illness**

According to Stivilia *et al.*, (2008), mental health specialists have little knowledge about the problems specific to patients living with HIV. As noted above (Mayeya, 2004), states that mental health care in general, is a great need. It can be inferred from the information provided that the huge burden of care for AIDS patients and for those patients who also have mental illnesses is borne by the HBC. Empowerment is vital for family and volunteer “caregivers with training on personal care, psycho-social support and some medical care” (Webster *et al.*, 2007).

Several studies reveal poor knowledge and practices about mental illness in the general population toward people with mental illness (Jorm *et al.*, 1997; Caldwell and Jorm, 2000; Pinfold *et al.*, 2003). These have been noted to be shortcomings in mental healthcare, together with deficiencies in formal support and training for non-mental health specialists, such as primary care and hospital staff (Ford *et al.*, 1997). According to Brockington *et al.* (1993), people with advanced education and high occupational level seem to have more positive attitudes towards persons with mental illness. Furthermore, people with personal experience of mental illness often display positive attitudes. However, other proponents such Högberg *et al.* (2005) have argued that it is not obvious that individuals with considerable knowledge and experience about mental illness always have positive attitudes towards persons with a serious mental illness. Other studies indicate that educated people may not want to live in the same neighbourhood as people with mental illness. (Rudder-Baker, 1995; Oppenheim, 2000).

The marginalisation of the mentally ill in societies has largely been attributed to lack of sufficient and correct knowledge about the problem. In a census of knowledge of mental illness conducted in two areas prior to opening of long stay supported houses for the mentally ill, most respondents (80%) knew somebody who had mental illness while the rest had little knowledge about mental illness (Geoffrey *et al.*, 1996). In a similar study conducted in Lusaka Zambia, where 200 policemen were sampled on Epilepsy related knowledge, attitude and practices, a significant number lacked knowledge regarding epilepsy and self-reported detrimental actions toward people with seizures with 14.3%

indicated that people with epilepsy in police custody require quarantine (Mbewe, *et al.*, 2007).

#### **2.4.0 Attitudes towards PLHIV but suffering from mental illness**

The term ‘attitude’ is described as a tripartite concept, consisting of a cognitive, an affective, and a behavioural component. The cognitive component consists of beliefs, the affective component of emotions, and the behavioural component covers actions or the intention to act (Kruglanski and Higgins, 2003; Niven and Robinsin, 1994). Some behaviour such as social distance, are more responsive to emotional-based attitudes and some belief-based attitudes like political opinion (Röndal, 2005). Most of a person’s attitude originates in childhood. According to Niven and Robinsin’s (1994) theory, instrumental conditioning, models, and personal experience are the three main elements in the process of forming attitudes. In addition, attitudes formed by personal experience are stronger and more resistant against alteration than attitudes formed by indirect experience, perceptions, experience of symptoms, recognition and labelling. The conception, perceptions, experience of symptoms, recognition and labelling, as well as treatment course of mental illness differ from one culture to another, and even within cultures (Kleinman, 1977a; Kleinman, 1977b). Notwithstanding this, it is a well acknowledged fact that mental illness is universal across cultures (Lauber and Rossler, 2007). Further, Raguram *et al.*, (2004) acknowledged that negative attitudes are universal responses towards people with mental illness. Negative attitudes about mental illness often underlie stigma, which can cause affected persons to deny symptoms; delay treatment; be excluded from employment, housing, or relationships; and interfere with recovery (Weiss *et al.*, 2006). These adverse

attitudes and social responses, usually conceptualized as stigma, have become a concern not only for those affected and their families, but also for research, advocacy and policy across the world (Raguram *et al.*, 2004).

#### **2.5.0 Practice towards PLHIV but suffering from mental illness.**

Nichols (1995) found that patients' psychological and emotional needs were often neglected by professional staff. Nichols recommended that all health professionals should possess counselling and reflection skills to enable emotional and informational care. The Royal College of Physicians and British Paediatric Association (1995) suggested that whilst problems such as anxiety, depression, alcohol and substance abuse and self-harm were prevalent in generic settings, they remained largely undetected because staff lacked the appropriate skills. A concurrent theme emerging from more recent studies that have sought to investigate the role of primary care health professionals in mental health work has been the inadequacy of prior training and the urgent need for improved knowledge and skills to support mental health work (Ford *et al.*, 1997; Gray *et al.*, 1999).

Researchers have also identified a huge gap in the need for psychiatric care. The median treatment gap, as evident from review of 37 studies across regions of the world, was estimated to be 32.2% for schizophrenia and other non-affective psychotic disorders, 56.3% for major depression, 50.2% for bipolar disorder, 78.1% for alcohol abuse and dependence. (Kohn *et al.*, 2004). The WHO World Mental Health Survey Consortium (2004) revealed that treatment was received by 0.8% to 15.3% of those affected with a mental illness, the proportion of treatment was higher for severe cases (14.6% – 64.5%) compared to mild

cases (0.5% – 35.2%). The report further state that, the chances of getting treated for any type of disorder was more in developed countries than in less developed countries.

The worst kind of practice against PLHIV with mental illness is stigmatization. According to Stivilia *et al.*, (2008), the main reason for stigma and discrimination is the lack of skills working with PLHIV. Mental patients have generally received a very negative perception in society usually based on misconceptions, stereotypes, ignorance, fear and other factors (Hinshaw, 2007). The stigmatization of mental illness is a serious problem affecting patients and their relatives as well as institutions and health care personnel working with persons with mental illness (Link *et al.*, 2001). Mental illness, unlike other forms of illness carry a social stigma that further disadvantages those afflicted, embarrasses the relatives and others who want to help thereby leading to avoidance of the subject by the population at large (Richmond, 1983). Evidence from North America and parallel findings from research in Western Europe suggest that stigma and discrimination are major problems in the community with negative attitudes towards people with mental illness being wide spread (Gelder *at el.*, 2000).

There is not much literature on studies conducted in mental illness in Africa. However a study conducted to investigating knowledge and attitude of the general South Africa public towards mental illness, Hugo and colleagues found that knowledge was low and stigma was high. Such stigma was associated with the fact that mental illness was understood as a lack of will power and stress related rather than a medical condition (Hugo *et al.*, 2007). Evidence from Egypt widely believed that mental illness could be treated by gods. Many mentally ill individuals therefore were taken to these gods for healing (Johns, 1983). In the

developing countries many people still regard mental illness as caused by supernatural forces such as witchcraft, evil spirits, and failure to fulfil traditional rites as well as curses (WHO Report, 1976).

Abundant evidence from Western countries indicates that people with mental illness are stigmatized and discriminated against not only by the general public but by mental health professionals as well (Lauber, *et al.*, 2004a; Lauber, *et al.*, 2005b; Luaber, *et al.*, 2006; Nordt, *et al.*, 2006a; Brockington *et al.*, 1993; Crisp *et al.*, 2000). These studies are unanimous in their conclusion that negative attitudes and discriminatory behaviour towards people with mental illness are widespread and commonly held.

Among the stereotypes reportedly commonly held by the general population, are that people with mental illness are dangerous, violent and unpredictable (Lauber, *et al.*, 2006c). Furthermore, it has been found that the general population frequently favours measures that tend to restrict civil rights and freedoms of people with mental illness (Lauber, *et al.*, 2000). Moreover, treatment suggestions for people with mental illness include a wide range of proposals, some of which are far away from official guideline recommendations (Lauber, *et al.*, 2001; Lauber, *et al.*, 2003).

Adewuya and Makanjuola (2005), states that stigma and discrimination of mental illness is less severe in African countries. It is unclear however whether this finding indicates that Africa represents geographical region that does not promote stigma, or whether there is a dearth of research in these societies (Gureje *et al.*, 2005). Studies elucidating mental illness stigma and discrimination derive mainly from Western countries, with a paucity of

comprehensive studies having been conducted in Africa, particularly in Sub-Saharan Africa (Adewuya and Makanjuola, 2005; Lauber and Rössler, 2007). Although few studies have been conducted in Africa, the few that have, suggest that the experience of stigma by people with mental illness may be common, and thus contradict common assertions about stigma and mental health in Africa (Awaritefe and Ebie, 1975; Shibre et al, 2001). A study conducted in South Africa (Hugo *et al*, 2003) reported that, among the general public, knowledge of mental illness was low and stigma was high. In Nigeria, where the first large-scale community representative study of popular attitudes towards mentally ill was conducted, it was found that stigma was widespread, with most people indicating that they would not tolerate even basic social interactions with someone with a mental disorder (Gureje *et al.*, 2005).

In a recent study Kapungwe *et al.*, (2010), revealed that there is widespread stigma and discrimination toward mental illness in Zambia at various levels including among community members, family as well as among general and mental health care providers. This has been attributed to “misunderstandings of mental illness aetiology; fears of contagion and the perceived dangerousness of people with mental illness; “*and associations between HIV/AIDS and mental illness*”, further the report indicates that mental ill patients are feared, marginalized and labelled in exclusively negative terms. These preliminary findings thus confirm assertion by Corrigan and Gelb, B., (2006) that the lack of empirical data in African countries may explain the speculation that stigmatization and discrimination of mental illness may be less common in these societies. More studies on the continent are needed, in order to avoid ill-informed assumptions, and prevent uncritical transposition of findings from Western contexts to Africa, given cultural and structural regional differences.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.1.0 Study design**

This was mixed explorative and descriptive study (Brink and Wood, 1989). The main assumptions behind this mixed approach/design was to describe knowledge, attitudes and practices of community caregivers towards PLHIV but were suffering from mental illness under Bwafwano home based care. The volunteer care provider was seen from a holistic perspective, as a living human being with body, soul and spirit (Leininger, 1984). This study asked questions about events or experiences for which little was known. The realist component, which was related to the quantitative component, was aimed at bringing out independent phenomena (Burrell and Morgan, 1979; Brink, 1989). In following up realism in qualitative methods, there was close contact with the research object and a more profound understanding of the field of research was gained as well as discovery to insights and meanings about human health conditions and behaviour (Leininger, 1985). The qualitative approach provided deeper understanding of the meaning of the care-givers experiences of caring relationships with the patient suffering from dementia.

Exploratory studies serve many purposes and the notable ones include: (i) Getting into a research area with an adequate understanding of what is to be investigated (ii) determining the feasibility of expanding the research, (iii) formulating questions or hypotheses for future research and (iv) to generate foundational knowledge that could be used for making design decisions.



### 3.2.0 Sample size and sampling

The study population was 386 care givers who were enlisted on the Bwafwano home based care project within the four sites before the study. Using Yamane Taro's (1967) formula below for determining sample size when the population is known

$$n = \frac{N}{1 + N(e^2)}$$

Where:

$N$  is the population,  $n$  is the desired sample and  $e$  is the confidence level or precision.

Substituting the values in the formula, the sample size 196 was obtained.

$$n = \frac{386}{1 + 386(0.05^2)}$$

$$n = \frac{386}{1 + 386(0.05^2)}$$

$$n = \frac{386}{1.965}$$

$$n = \frac{386}{1.965}$$

Therefore,  $n = 196$  was the ideal sample size

This formula provided the number of responses that needed to be obtained and it included 10% to compensate for persons that were unable to be contacted.

### **3.3.0 Variables**

The identification and operationalisation of variables was based on Blaikie's (2000) taxonomy. From the statement of the problem one assumes that the training which home based care workers underwent gave them the knowledge, attitudes and practices to meet the needs of PLHIV but suffering of mental illness. In addition, for those who did not undergo any training, it is assumed that they would not be in position to meet the needs of Patients. In either of these two situations, what is demonstrated is that the community care givers have a way in which they construct mental illness among PLHIV and this is a result of their own perceptions and particular reasons (Figure 3.2.1).

The key variables to be studied were:

#### **3.3.1 Independent variable inherent of training received**

- Construction of mental illness among PLHIV
- Perceptions
- Reasons for particular perceptions

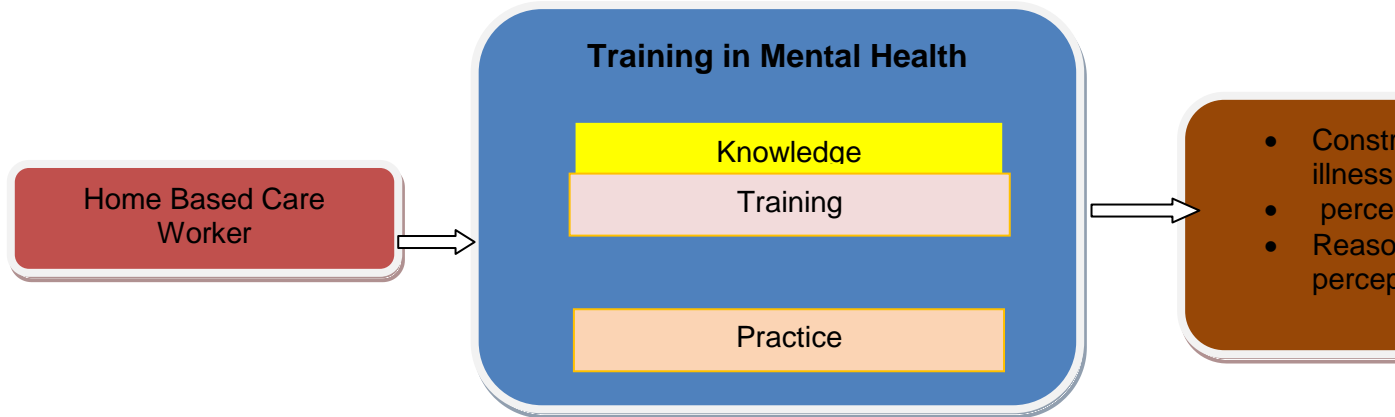
#### **3.3.2 Dependent variable**

Knowledge expressed on mental illness in a person with HIV.

Attitudes expressed on mental illness in a person with HIV.

Practices expressed on mental illness in a person with HIV.

**Figure 3.2.1 Conceptual model of community care givers**



### **3.4.0 Data collection tools**

Two data collection instruments were used in this study and these were the KAP inventory and focus group discussions (Appendix V and VI). The details of the developments and contents of the data collection methods appear below.

### **3.5.0 The process of developing the KAP inventory**

Initially, plausible items on mental health knowledge, attitudes, and practices were compiled using induction by searching for themes in literature. Two hundred and thirty six items were identified. These plausible items were not a finite set upon which sourcing information was to be based. Other people were engaged who formed the hermeneutic circle for consultancy, which ensured that ideas and information from literature were in agreement with what experts in the field of mental health knew and practiced. This circular character of working stressed the notion that, the experiences of the research team and those of practitioners must be understood, found and be woven within the medical cultural and historical context prevailing at the time.

An informal structured think-aloud workshop composed of selected heterogeneous mental health (Seven Clinical officers and eleven nurses) and social workers was organised to invent or discover a satisfactory course of action for the tool and eventually the intervention. Reliance was made on what proponents of the Delphi approach (Turoff, 1970, Delbecq *et al.*, 1975 and Ziglio, 1996) noted that using the tool could improve creativity in decision making where accurate information was unavailable. Many opinions (beyond what the researcher had conceived) were derived to maximize the chance of covering the most important opinions and issues on district mental health care.

While relying as much as possible on the guidelines advanced by Göransson *et al.*, (1998) and Beech (1999) to arrive at a consensus on all the variables that were discussed, out of the two hundred and thirty six items that were developed in this workshop, some were eliminated, others were collapsed while the rest were categorized into four thematic domains for the study, these included:

1. Demographic domain.
2. Knowledge domain.
3. Practices domain.
4. Attitudes domain (separatism, stereotypes, benevolence and restrictive domains).

These thematic domains were the basis for reviewing existing literature to find evidence which would support the ideas of the study. The thematic domains provided clues to search for facts (see the bibliography of the resources we used in appendix I). While working through the literature deductively and inductively, the four domains were refined as they appear in the inventory.

When the review was done, only variables based on theoretical knowledge in the domain of mental health knowledge, attitudes and practices (KAP) were selected. From the one hundred ninety nine items, only one hundred and eighty concepts were matched in the review with the four thematic domains. It was then possible to cast the concepts into variable items as questions relying on what literature-applied meaning to the terms. Eighty-nine items were constructed using collaborative interpreter agreement for construction of questions for the inventory. This inventory was pilot tested after ethical approval was granted.

### **3.6.0 Process of developing focus group themes**

Initially, plausible items on mental health knowledge, attitudes, and practices using induction by searching for themes in literature were compiled. The themes appear below:

**1. Theme I: Self description.**

Please tell me about yourself and what is going in Bwafwano?

**2. Theme II: Incidence of mental illness.**

Please tell me about the numbers of people living with HIV among those cared for in homes who have mental illness that you are aware of? What do you see as mental illness?

**3. Theme III: Knowledge about mental illness**

What do you know about the causes of mental illness?

**4. Theme IV: Practices**

What do you actually do for people who are living with mental illness?

**5. Theme V: Attitudes**

What are your feelings about these people-Please describe.

**6. Theme VI: Reasons for particular practices and attitudes**

Please explain the motive for what you do (Probe for the attitudes presented and practices)

### **3.7.0 Ethical considerations**

This protocol was reviewed by the University of Zambia Biomedical Research Ethics Committee. Since this study involved human participants, it was paramount to obtain consent from the respondents or social actors.

### **3.8.0 Informed consent**

Consent to participate in this study was guaranteed as a right so that the person involved should have legal capacity to give consent and exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion. To do so, all respondents were availed with sufficient knowledge and comprehension of the elements of the subject matter involved as to enable them to make an understanding and enlightened decision. This latter element required that before acceptance of an affirmative decision by the respondents, it was made known to them the nature, duration, and purpose of the research; the method and means by which the study was to be conducted and all possible inconveniences. Respondents were informed of their rights to withdraw from the study at any time without any sanctions (Kostrewski and Oppenheim, 1980; Breakwell *et al.*, 2006).

### **3.9.0 Risks**

It was explained to respondents that there would be no risks or harm with regards to their participation in the study except for the tolerable discomfort of getting into their private time while answering the questionnaire or being interviewed. The respondents were informed that the time to be spent answering the questionnaire or being interviewed would not disrupt their social life negatively. They were guaranteed that their names would not be on any paper and that the questionnaires would be destroyed after six months following the analysis.

### **3.10.0 Benefits**

Respondents were informed that they would be no guaranteed direct immediate personal benefits on account of the research. The benefits if any would be reimbursements of transport money and training in mental health care where possible.

### **3.11.0 Confidentiality**

The participation in this study conferred confidentiality. None of the information was used to identify all the respondents by name or in any manner. All information provided by the respondents was treated confidentially and stored only for six months after which it was to be destroyed.

### **3.12.0 Rights and complaints**

Any concerns raised by participants on any aspects of the study were to be referred to the Chair Person University of Zambia Biomedical Sciences Research Ethics.

### **3.13.0 Piloting**

The study was done in two phases; first a pilot study was done targeting 10 home based care providers in Chongwe. The experiences from the pilot study lead to the refining of the tool (Appendix V and VI). The second phase was the main study.

### **3.14.0 Conducting focus group discussions (FGDs)**

Three focus group discussions were conducted in each of the sites with members numbering between six and eight. Before the focus group discussions the researcher conducted a preliminary exploratory analysis of key variables to use in selecting volunteers for the focus group discussion. In order to get the experiences of volunteer care workers, purposive sampling was employed to include as wide a range of volunteer characteristics as possible (Based on age, sex, education and duration of service). Each volunteer care worker was recruited into only one of the focus groups.



Qualitative focus group discussions were planned to provide a systematic and ordered system of topics with related prompt questions. All topics were started with an open-question and example to encourage the group discussion and allow the views and experiences of caring for a person living with HIV and suffering from mental illness. A topic heading folder was used to help the group remain focused on the topic being discussed. The topics and questions were sourced from previous literature and the professional experience of the researcher

All focus group discussions were conducted with the help of home based care team leaders who acted as co-facilitators. After the initial introduction of all participants, research issues were presented thematically (Krueger and Casey, 2000; Mertens, 2000). Participants were encouraged to explore alternative arguments to those presented within the group, and if appropriate, challenged on their views. All proceedings were digitally recorded and on spot field notes too were taken. Recordings were later transcribed verbatim.

### **3.15.0 Administering the questionnaire**

Data was gathered using self-reported questionnaires and in-person interviews. Respondents answered the questionnaires as they came to get their daily tasks. Answering the questionnaire was facilitated by the district coordinators who had intimated to the volunteers a month prior to the study the presence of the researcher in the district.

### **3.16.0 Data analysis**

The KAP inventory items were coded in both numeric and ordinal (0-1-2-4-3-5) format originally and analyzed using SPSS software version 17. The descriptive statistics for the

demographic characteristics were processed and included frequency distributions for categorical demographic variables and activity variables. Means, modes medians and standard deviations for a participants' response regarding their preferences were computed.

To examine positive versus negative scores in the areas of knowledge attitudes, and practices, three attitude variables were dichotomized from a 5 –point Likert scale into a positive (represented by Agree (A) and Strongly Agree SA) or negative (represented by Disagree (DA) and Strongly Disagree SDA) attitudes. A median score was also determined and was represented by “the somewhat agree (SWA) value label). An additional, two sample tests and an analysis of variance (ANOVA) were used to test the differences on key parameters. Associations for selected variables were computed using Chi-square test. The significance level was set to be  $p < 0.05$ . Confidence intervals have been set at 95%. Cut off point for significance was set at 5%, statistical significance achieved if  $p$  value is  $< 0.05$ .

A grounded theory hermeneutic transformative process for analysis of data was used. Qualitative data was analysed using grounded theory. The use of meaning units and categories and core categories formed the core of the analysis. This was in line with authors on research regarding the current type of project (Strauss and Corbin, 1998). After each focus group discussion, the researcher listened to the recording to become familiar and more sensitive to the content via repeated listening. A so-called 'naive' reading (Ricoeur, 1976) of the whole narrative material was done whose purpose was to get a total picture of the Focus Group Discussions. This was repeated five times in order to gain a deep understanding of the text. The tapes were listened to again without interruption for typewriting. The recordings were then typed out in the language of the discussants. A research assistant was recruited to

also listen to the tapes to pick up any errors and agree with the typed translated transcription based on Jeon's (2004) process.

Constant comparative method was used to analyse the text and field notes. Through the comparison of data, categories and relationships, central core categories were identified. Open coding was used to label the transcribed data. The researcher initially analysed data line by line, theme by theme and labelled with descriptive codes for meanings. The same concepts were grouped in categories and conceptualised into more abstract levels of codes. Through this work, the core category (variable) was surmised. When the core category was discovered, selective coding was conducted. From that point on, the exploration of the issues and ideas occurred primarily around the core category (Strauss and Corbin, 1998). In presenting the qualitative data in the preceding chapter, a hermeneutic interpretation was made from the statements and from the authors' pre-understanding (Leininger, 1984; Leininger, 1985; Lindström, 1990). This allowed presentation of a personal analysis or contextualisation of the narration with what was already obtaining in the literature.

## **CHAPTER FOUR**

### **RESEARCH FINDINGS**

#### **4.1.0 Introduction**

Using the realist and social constructionist view, four research questions were formulated: What is the construction of mental illness among caregivers? What perceptions do caregivers have on mental illness on persons living with both mental illness and HIV/AIDS? Why do caregivers exhibit particular perceptions on persons living with both mental illness and HIV/AIDS? What differences exist within the four sites and whether gender plays apart in these perceptions? The results contained in this section were an integration of data from the analysis of qualitative data obtained from focus group discussions with caregivers and questionnaires that were administered to them. Their common and peculiar responses were captured under the themes that were directly related to the four research questions. However, before presenting the findings for each research question, the researcher presents in the first instance the demographic profile of the respondents.

#### **4.2.0 Demographic**

Prior to the approval of the study by the research ethics committee and authority by the Ministry of Health to conduct the study, there were 386 volunteer caregivers on the Bwafwano register. However, at the time of the study a number of care givers had dropped out leaving only 111 who were actively involved in voluntary care. The population was distributed as follows: Ngwerere, 24; Chazanga, 29; Mkushi, 43 and Chibombo, 15 (Table 4.1).

Table 4.1 Respondents by Area

<b>Number</b>			
<b>Area</b>	<b>Before the study</b>	<b>Caregiver drop out inclusive of refusals</b>	<b>Derived Sample</b>
Ngwerere	62	30 quit before the study, 2 declined and 6 not reachable	24
Mkushi	141	50 quit before the study, 12 declined and 36 not reachable	43
Chazanga	106	35 quit before the study, 18 declined and 24 were not reachable	29
Chibombo	71	38 quit before the study, 18 not reachable	15
<b>Total</b>	<b>386</b>	<b>275</b>	<b>111</b>

Therefore the profile of those studied is listed in table 4.1

Within the study sample, female volunteers accounted for n = 69 (62.2%) whereas males accounted for n = 42 (37.8%).

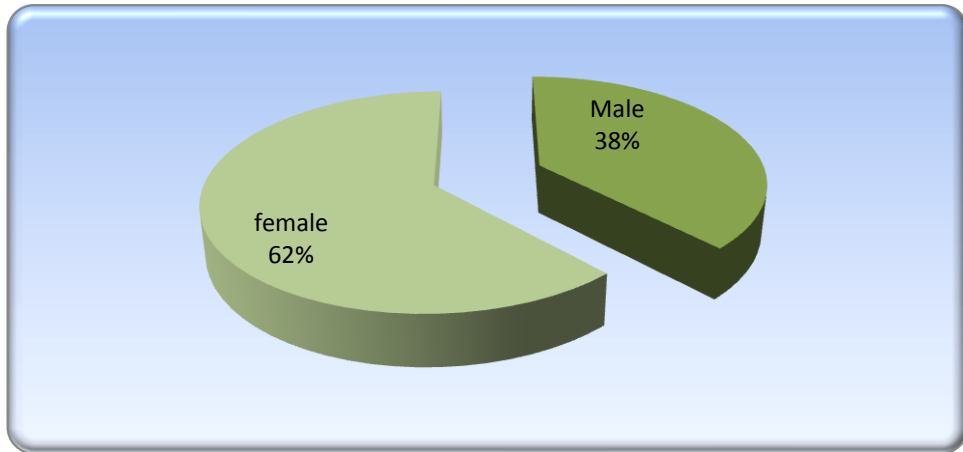


Figure 4.1. Profile of representation by sex

There were more volunteers 84.7%, 33(29.7%) being males and 61(55%) being females who were not trained in mental health as compared to 15.3 % who had been trained, 9(8.1%) being males and 8(7.2%) being females. Out of the 17 who were trained in HIV care, only 10 had an opportunity to be trained in mental health (Figure 4.2).

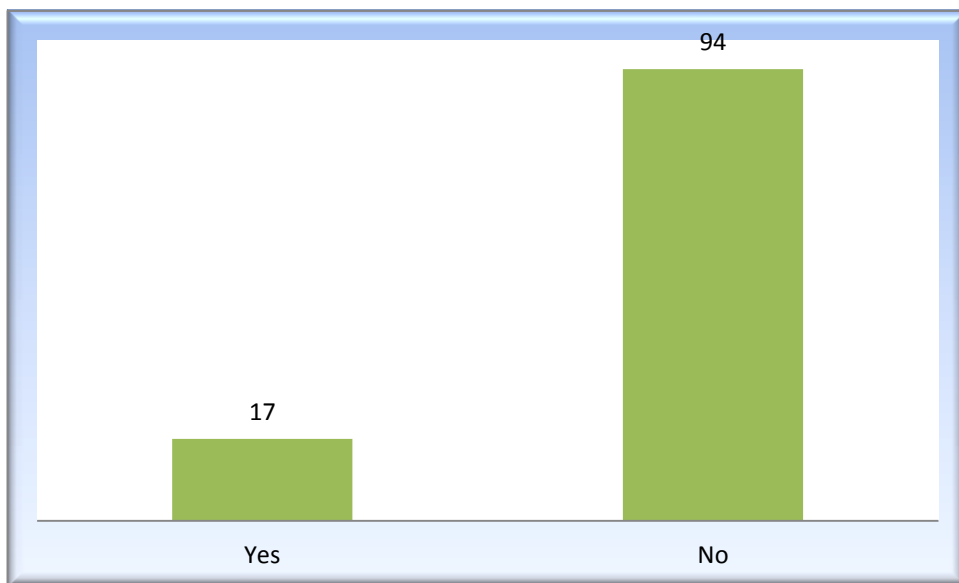


Figure 4.2 Profile of training

The sample was relatively composed of youthful volunteers, most of them (57%) being older than the median age of 36. Their ages ranged from 23 years to 57 years. The sample median was 36 ( $\pm$  SD 7.1), (figure 4.2) and table 4.2.

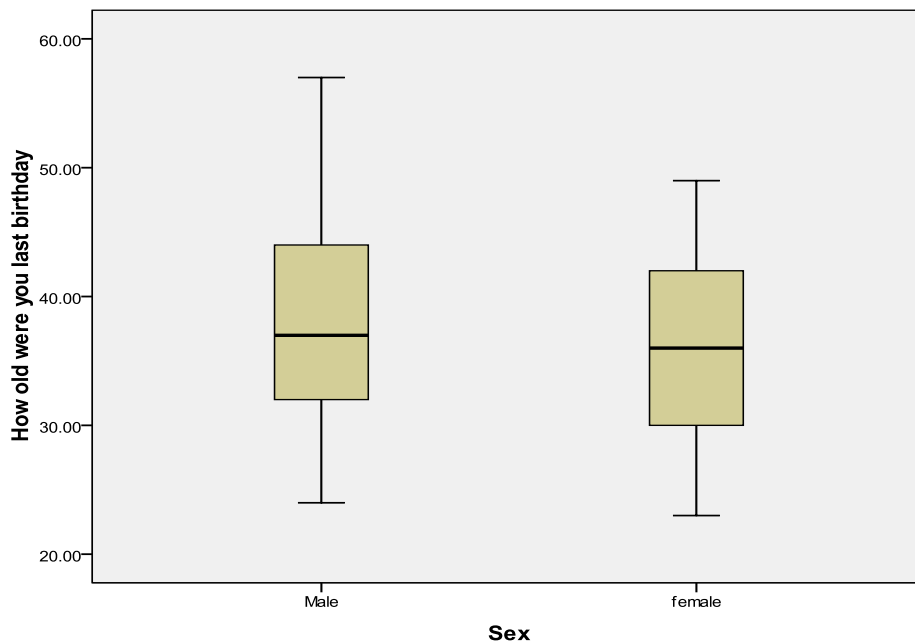


Figure 4.3 Mean box plot of age by sex

These volunteers were in service for at least 5 years with the least having been in service for 1 year. Majority of them had served either two or 3 years (table 4.2).

Table 4.2 Profile of Age and Service in Years

<b>Age</b>	<b>Mean</b>	<b>Median</b>	<b>Mode</b>	<b>SD</b>	<b>Minimum</b>	<b>Maximum</b>
Age	36.5	36.0	36	7.1	23	57
Years in service	4.1	5.0	5	1.4	1	5

### **4.3.0 Construction of mental illness among caregivers**

The study revealed that lay caregivers described themselves in various ways and indicated that they performed diverse functions related to healthcare delivery. They also presented moving events about mental illness. Further, they stated that they were not provided with home based training in HIV care and worse still in mental health care. Apart from the challenges they faced in dealing with physical health concerns of people, they strongly desired to have skill to manage people living with HIV and AIDs who have mental illness. The Mukushi care givers focus group stated that the inability to offer help to people who had mental illness was strongly associated with lack of training. Below are selected examples of subthemes focusing on description of self and events?

#### **4.3.1 Description of self (Home Based Care Givers)**

“They are sim card operators and some will call us (meaning carers of people with HIV and AIDs who also are positive)... We consider ourselves as frontline workers.

We are concerned with, orphans and vulnerable children, TB and ART adherence, counselling with patients, referrals of patients to Bwafwano and the nearest clinic...”

Chibombo focus group discussion

“Yes people may call us all sorts of names but that does not change our perception of being volunteers.”

Chazanga focus group discussion



“Our work stems from the call of our Lord Jesus to serve those who are sick. We are actually Jesus’ co workers. This is work where you do not get rewards on earth.... but you see there are rewards in the end and that is salvation.”

Nkumbi M’kushi focus group discussion

#### **4.3.2 The nature of the job**

“Our job is to provide, HIV sensitization, client identification, referrals, home visitations, care and support such as; providing food, blankets, bathing patients, washing clothes, counselling, direct observation therapy and adherence support for TB, ART Adherence support and health Education. For mental illness, there are no major activities going on, however pockets of care is given.”

“We do not have a mental health programs, we offer advice and referral when we get mental cases.”

Ngwerere focus group discussion

#### **4.3.3 Description of events surrounding mental illness**

“In our home based care group, not a lot of them show signs and symptoms of mental illness...I may be wrong but hmmm... For some, I think they develop mental illness in the late stages of HIV. This is the time there seems to be a breakdown of the brain system. They just become crazy and do funny things you know. Some symptoms are very worrying. But we try to do

something ... get them local medicine but the results are not encouraging.  
The authorities should just train us in most of the areas including mental.”

Chazanga focus group discussion

“I was assaulted as I went to deliver some drugs...

My client had missed ARVs and TB drugs for six days. I could not do anything to help calm her.

I feared getting injured and acquiring the illness. So I waited to see what the relatives could do. But we ended up tying him any way...What we did I came to learn was wrong but this is what happens when you are not trained.”

Nkumbi Mkushi focus group discussion

“One of our clients just came out of the house yelling and naked. He was in total confusion. We all just stood there helpless.....”

Ngwerere focus group discussion

“The challenge here is that we are able to recognize signs of mental illness but what can we do in our community? we just take to the nganga (traditional healer)”.

We need some skill and a few but not the powerful drugs and these can go a long way in this part of the world.”

Chibombo focus group discussion

Overall, these volunteers conceptualized lack of skill as critical. This deficiency and the many new strange things the volunteer caregivers encountered, point to failure by the mental health unit to actualize its policy promulgation of training community mental health workers.

### **3.3.4 The nature of mental illness**

Hughner *et al.* (2004) observed that lay people tend to describe the disease of mental illness and causes of mental illness using different symptoms and origins. According to the descriptions of volunteer care workers, there were different levels of mental illness: a patient who is incapable of taking care of him or herself; a patient who needs to be looked after every day, a patient who needs constant care and one who is violent. Volunteer care givers lamented about their shortfall in managing cases of mental illness. These seemed to be the most recurring themes and below are examples of the researcher's experiences about the construction of mental illness.

### **4.3.5 Signs and symptoms of mental illness**

“Usually they are talking and laughing to themselves ...

You will see some wearing torn dirty cloths picked from the street or you will see them the next day in unexpected manner wearing too many cloths at one time, such as coat, bombasa (a big short worn inside a trouser), and shirt even when it is hot.

I have seen some carrying heavy and different items, eating dirty food, insulting people. Some we are not sure if it is the stigma of HIV or the metal illness will be shy or violent or withdrawn.

Undressing in front of people has become very common you know.”

Chibombo focus group discussion

#### **4.3.6 Burdens of caring**

“Burdens faced in caring for these clients – Difficult to communicate with because they do not think properly and are sometimes stubborn, no adherence to treatment, care givers end up running away due to fear of being hurt from the violent behaviour and rape....”

When mental illness chips in, our clients do not have permanent homes therefore making follow up has been difficult.

Some become violent especially when they are too sick, they are difficult to counsel and even communicate to when they are depressed...They may try to speak to you in an own language or use symbols.”

Chazanga focus group discussion

In line with the outcomes of the Chazanga focus group discussions, Jansson (1993) emphasised that the main problem in some mental illnesses (dementia for instance) care is to interpret the patients' communicative signals and to understand their wishes. In this specific context, where patients with severe dementia reside, it is obvious that communication skills could be of importance to lay caregivers. Most difficulties in caring for these patients lie in interpretation of the patient's verbal and facial expressions ( Jansson, 1993).

“Some of our patients are just too difficult to look after. They seem to have a demon or demons.... If you do not take “nice food such as chicken, they will not welcome you.”

Ngwerere focus group discussion

It can be demanding for the care-giver to meet anxiety and screaming or silence. Hallberg, (1990), described how difficult and challenging the care of the dementia patient was. And Hallberg, (1993), suggested that the care of Dementia patients was like 'moving on the border line between human meeting and non-meeting, not so often physical as existential'.

#### **4.4.7 Aetiology and defining mental illness**

Perceptions of lay caregivers on the causes and social consequences of mental illness play an important role, influencing the experience of burden of care, the development of coping strategies and the decision to refer as well as to utilise local traditional remedies as well as mental health services (Magliano *et al.*, 2000; Jungbauer *et al.*, 2002). The focus group data showed that the perceptions of mental illness among PLHIV were not sharply distinguished conceptually from causal attributions or influenced by these, the linkage with their management was also important.

The volunteer caregivers have very strong beliefs in the local or traditional causes of mental illness in people with HIV and AIDs. They believe the following to be linked to the aetiology of mental illness.

“Cases of mental illness- They are many, with most going to witch doctors because they think that they have been bewitched, the numbers increasing with this HIV.”

Nkumbi Mkushi focus group discussion

“Well there are many explanations for people who are infected with HIV develop mental problems. Some its poverty in a home you do not expect anybody to function well, with hunger no food. You see ARVs increase the appetite and when there is no food, you become stressed and confused....

As for us as an NGO, we have challenges to help. We do not have enough food to go round.

We have many people o our register. At first we were able to cope and now, we have these challenges. You have seen for yourself.”

Chazanga focus group discussion

“Some people who have HIV are cursed. They may have been misbehaving with some one’s partner and just like that someone is cursed... like an omen or an abomination, so God punishes them through poor mental health.

Perhaps prayer can do. As for me, drugs cannot work. How?”

Chibombo focus group discussion

“Mental illness in HIV is an illness just like others. You see meningitis, it just comes. It is a normal sickness, ubulwele bwakufulungana umutwe, Kufunta, loss of memory, brain mixing with blood due to the virus... So to treat such a problem requires skill and knowledge...the things we see are tough.”

Ngwerere focus group discussion

#### **4.4.0 Perceptions caregivers have on mental illness on persons PLHIV**

Volunteer caregivers were asked what they perceived mental illness was like among people living with HIV and AIDs and what they actually did. Their perceptions were categorised based on six variables and these were: knowledge, attitudes, practices, benevolence, stereotypes and separatism. Below, were their perceptions variable by variable.

##### **4.4.1 Knowledge**

In order to assess the level of knowledge (what people know about mental illness and HIV and AIDs, how they feel, and how lay caregivers behave, two general questions were established from the outset which were related to (a) finding out whether or not mental illness was a problem among people living with HIV and AIDs and (ii) whether or not within Bwafwano Home Based Care, people living with HIV and AIDS who had mental illness were receiving attention they deserved within the home based care. Within the sample n= 111, 69 (62.2%) noted that mental illness was a problem among people living with HIV and AIDS whereas 42 (37.8%) stated that mental illness was not a problem among people living with HIV and AIDS (figure 4.4). Though few respondents stated that mental illness was not a problem (see table 4.3), it was surprising to see that more respondents 68 (61.3%) felt that the condition was not receiving the attention it deserved from the home based care as compared to 43 (38.7%) who felt that the condition was receiving the attention it deserved.

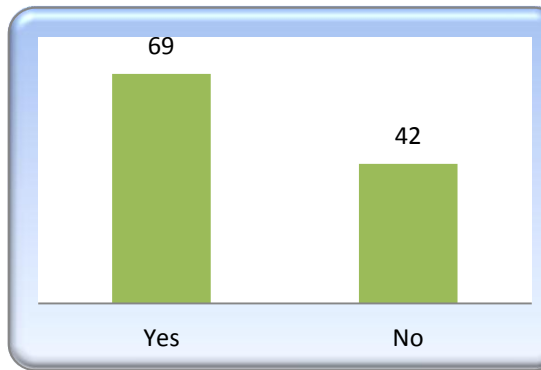


Figure 4.3 mental illness as problem among people living with HIV and AIDS

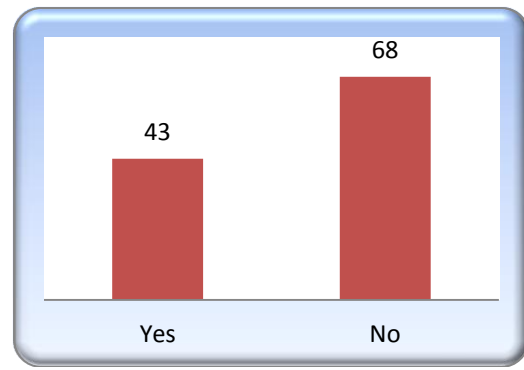


Figure 4.4 Mental illness receiving attention it deserves

A total of 8 Likert based questions were designed to evaluate the volunteer care givers knowledge on matters related to mental illness in people living with HIV and AIDS. A total knowledge score, out of a maximum of 8 items, was created and was set at 40 and the minimum was set at 8. respondents in the four sites. Knowledge content about mental illness was the same across the towns and within the volunteer workers (Table 4.3, figure 4.6).



Table 4.3 Differential knowledge score according to town

<b>Total Knowledge Score</b>		
Scheffe <sup>a,b</sup>		
Locality	N	Subset for alpha = 0.05
		1
Chazanga	29	25.1724
Mkushi	43	25.6047
Chibombo	15	26.4667
Ngwerere	24	26.5833
<b>Sig.</b>		<b>0.587</b>

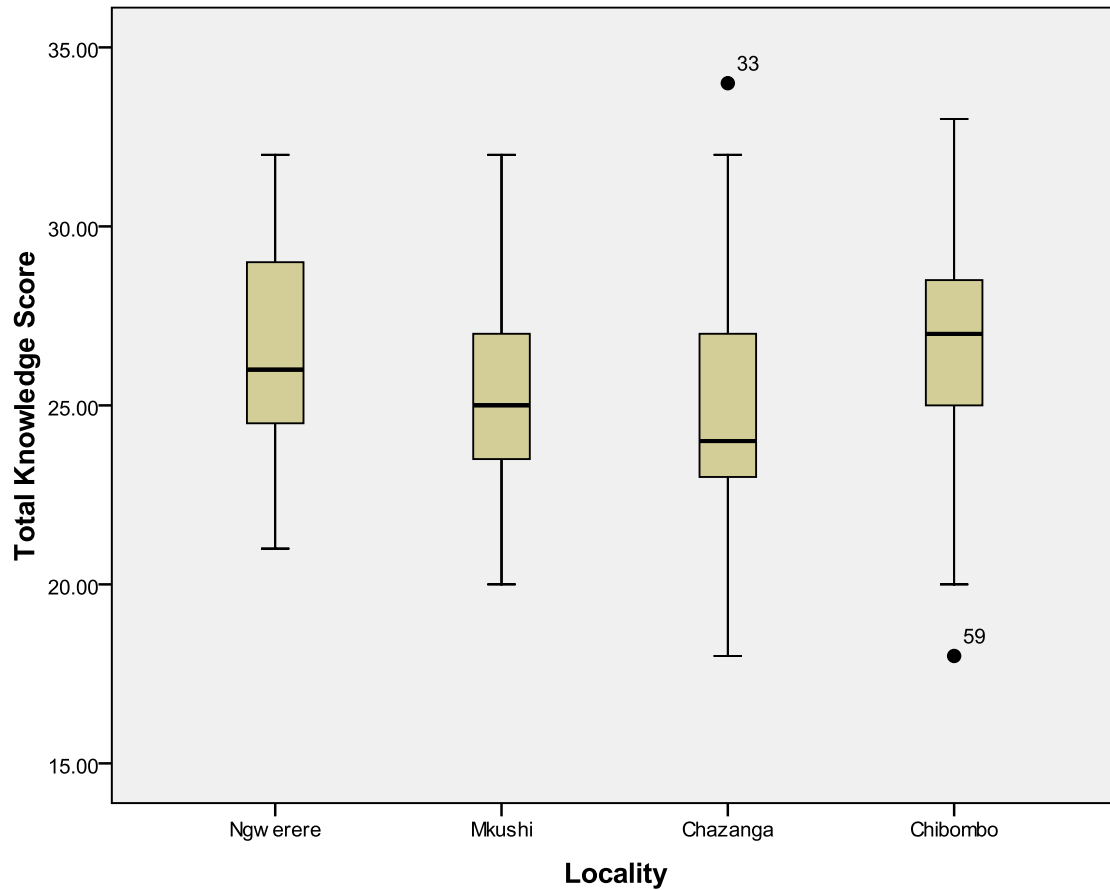


Figure 4.6 Knowledge means plots of four study places

Details of the knowledge variable domain are presented using Likert scales below shown in table 4.4. It was evident that poor knowledge about mental illness was widespread in the sample.

Table 4.4 Knowledge scores by variable

<b>Knowledge variable domains</b>	<b>SA</b>	<b>A</b>	<b>SWA</b>	<b>D</b>	<b>SDA</b>
	<b>(1)</b>	<b>(2)</b>	<b>(3)</b>	<b>(4)</b>	<b>(5)</b>
ARV drugs could cause mental illness among people living with HIV and AIDS	5	11	36	0	<b>59</b>
HIV causes mental illness	0	3	1	<b>53</b>	<b>54</b>
Stress in people living with HIV and AIDS could cause mental illness	4	7	<b>53</b>	47	0
Close contact of a person living with HIV and AIDS with a mentally ill person could cause mental illness	<b>65</b>	<b>26</b>	2	0	18
There are more people in the community with mental illness related to HIV	<b>24</b>	<b>67</b>	9	2	9
Poverty could complicate mental illness among people living with HIV	21	19	18	<b>31</b>	<b>22</b>
Most care givers in this home based care understand the problem of mental illness faced by people living with HIV and AIDS	11	36	0	<b>29</b>	<b>35</b>
There are more people with mental illness that is related to HIV and AIDS in the community than those that are seen at health facilities	<b>12</b>	<b>39</b>	28	20	12

In order to test the occurrence of a difference in the scores between male and female volunteers in the knowledge domain, the independent samples t-test was performed. The

results suggested that males and females differ significantly in their perceptions on the knowledge variable (table 4.4).

Table 4.5 Knowledge differential scores by sex

Test Value = 0						
					95% Confidence Interval of the Difference	
	t	df	Sig. (2-tailed)	Mean Difference	Lower	Upper
Sex	35.069	110	.000	1.622	1.53	1.71

The results are indicated in figure 4.6

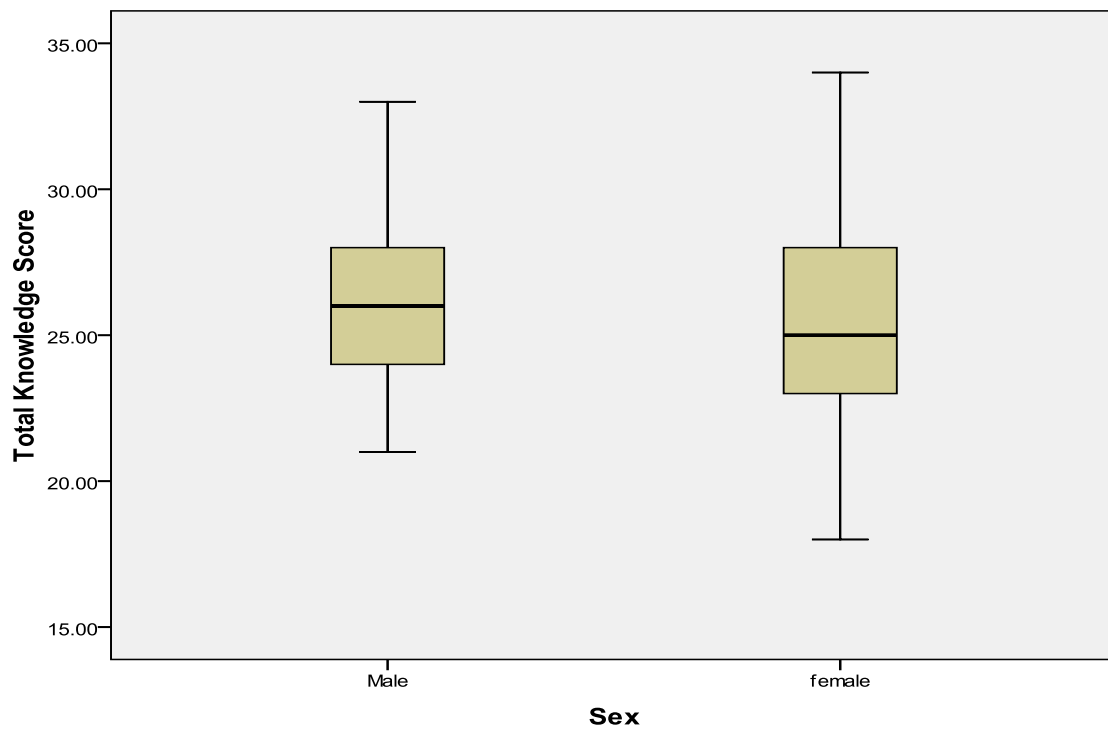


Figure 4.7 Mean differences across sex

#### **4.4.2 Attitudes**

Respondents were also asked to agree or disagree using a series of attitudinal statements about mental illness in people living with HIV and AIDS. These statements covered a wide range of sub attitude measures, including separatism, restriction, benevolence and stereotype. In spite of the apparent knowledge gap that many volunteer care givers have about mental illness among people living with HIV and AIDs, the study found that the lay caregivers generally have negative attitudes towards mental illness among people living with HIV and AIDs. Below is shown how the respondents faired on all attitude measures.

#### **4.4.3 Restrictiveness**

On restrictiveness, it was observed that lay caregivers had a negative position that of restricting people living with HIV and AIDs who had mental illness table (4.6).

Table 4.6 Attitude - Restrictive scores by variable

<b>Restrictive variable domains</b>	<b>SA</b>	<b>A</b>	<b>SWA</b>	<b>D</b>	<b>SDA</b>
	<b>(1)</b>	<b>(2)</b>	<b>(3)</b>	<b>(4)</b>	<b>(5)</b>
There is no future for people with mental illness who have HIV	<b>50</b> <b>(45%)</b>	<b>46</b> <b>(41.4%)</b>	<b>15</b> <b>(14%)</b>	<b>0</b> <b>(0%)</b>	<b>0</b> <b>(0%)</b>
Those who are HIV positive and have mentally ill should not have children	<b>44</b> <b>(40%)</b>	<b>51</b> <b>(46%)</b>	<b>16</b> <b>(14.4%)</b>	<b>0</b> <b>(0%)</b>	<b>0</b> <b>(0%)</b>
Violent and HIV positive mental patients should be handcuffed	<b>14</b> <b>(13%)</b>	<b>86</b> <b>(76%)</b>	<b>11</b> <b>(10%)</b>	<b>0</b> <b>(0%)</b>	<b>0</b> <b>(0%)</b>
Detentions in a solitary place should be considered for people who are HIV positive and have a mental illness	<b>7</b> <b>(6.3%)</b>	<b>84</b> <b>(76%)</b>	<b>20</b> <b>(18%)</b>	<b>0</b> <b>(0%)</b>	<b>0</b> <b>(0%)</b>

In order to test the occurrence of a difference in the scores between male and female volunteers and between the four localities on restrictiveness, the independent samples t-test was performed. The results suggest that the dependent variable “restrictiveness” do not differ significantly between the two levels of independent variable “sex” and the four independent variables “locality.”

Concerning the variable restrictiveness, the mean scores for males and females were 11.45 and 12.3 respectively (table 4.7). However, a critical examination of one sample tests of

males and females showed that the two did differ significantly in their attitudinal orientation to restrictiveness (p value = 0.00) table 4.8.

Table 4.7 Restrictiveness mean scores by sex

<i>Sex</i>	<i>Mean</i>	<i>N</i>	<i>Std. Deviation</i>
Male	11.4524	42	2.09765
Female	12.3623	69	2.24244
Total	12.0180	111	2.22376

Table 4.8 Significant tests of restrictiveness by sex

Test Value = 0						
					95% Confidence Interval of the Difference	
	t	df	Sig. (2-tailed)	Mean Difference	Lower	Upper
Sex	56.938	110	.000	12.01802	11.599	12.4363
					7	

The top 50% of the group who were able to practice, are represented above the median (the black line). Those in the top 25% of best practice are shown by the top "whisker" and "dots"

and these are respondents 38, 39, 68, 105, 23, 33 and 8. It is evident also from the whisker plot that the medians of two sexes are unequal though not statistically different.

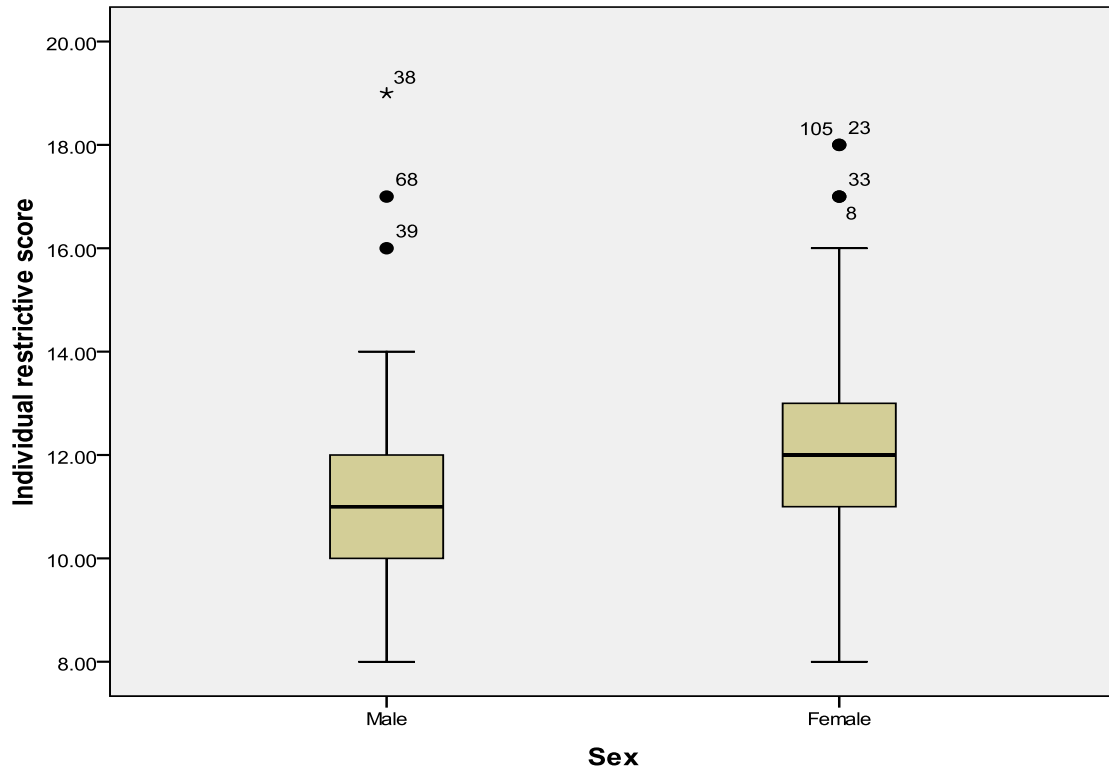


Figure 4.8 Attitude – differential restrictive scores by sex

Concerning the variable restrictiveness, the mean scores for the four localities were: Mkushi (11.511), Ngwerere (11.080) Chazanga (12.75) and Chibombo (13.53) in ascending order (table 4.9).



Table 4.9 Restrictiveness mean scores by locality

Locality	Mean	N	Std. Deviation
Ngwerere	11.0833	24	1.88626
Mkushi	11.5116	43	1.99251
Chazanga	12.7586	29	2.19830
Chibombo	13.5333	15	2.35635
Total	12.0180	111	2.22376

However, a critical examination of one sample tests of the four localities showed that the four differed significantly in their attitudinal orientation to restrictiveness ( $t = 56.938$ ,  $df = 110$   $p = 0.00$  and this  $p$  value is less than 0.05) table 4.10.

Table 4.10 Significant tests of restrictiveness by locality

Test Value = 0						
					95% Confidence Interval of the Difference	
	T	df	Sig. (2-tailed)	Mean Difference	Lower	Upper
Locality	25.336	110	.000	2.315	2.13	2.50

The top 50% of the group who were able to practice, are represented above the median (the black line). Those in the top 25% of best practice are shown by the top "whisker" and "dots"

and these are respondents 105, 68, 3 and 38. It is evident also from the whisker plot that the medians of two towns Ngwerere and Mkushi are equal but across the four towns, they are different.

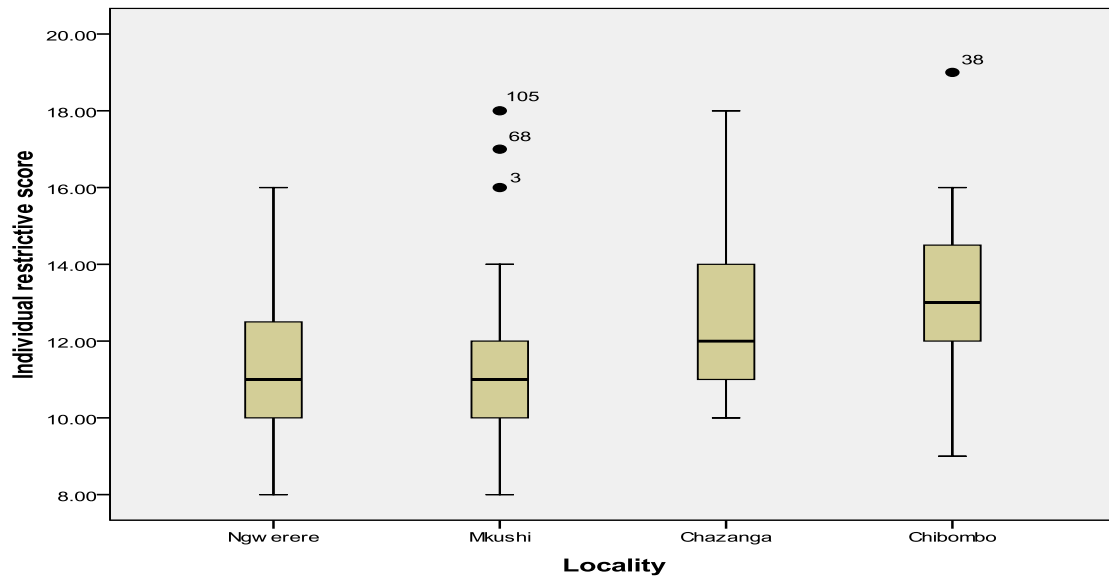


Figure 4.9 Attitude – Differential restrictive scores by locality

#### 4.4.4 Benevolence

A negative position towards people living with HIV and AIDS who had mental illness was observed. More than half of the respondents seemed to be unkind to people with mental illness that have HIV (table 4.11).

Table 4.11 Attitude - benevolence scores by variable

<b>Benevolence variable domains</b>	<b>SA</b>	<b>A</b>	<b>SWA</b>	<b>D</b>	<b>SDA</b>
	<b>(1)</b>	<b>(2)</b>	<b>(3)</b>	<b>(4)</b>	<b>(5)</b>
People with mental illness of HIV and AIDS should not be allowed to work (hold a job)	<b>32</b>	<b>60</b>	0	19	0
It is possible for anyone who has HIV to suffer from a mental illness	19	19	0	<b>44</b>	<b>29</b>
To effectively deal with mental illness of HIV and AIDS, it is important to involve the family and the community	26	26	4	55	0
The Ministry of Health wants to train people like you in mental illness. How important do you think this is?	<b>16</b>	<b>32</b>	23	40	0

In order to test the occurrence of a difference in the scores between male and female volunteers and between the four localities on benevolence, the independent samples t-test was performed. The results suggest that the dependent variable "benevolence" do not differ significantly between the two levels of the independent variable "sex" and the four independent variables "locality." The mean scores for males and females in relation to the variable benevolence were 11.45 and 10.78 respectively (table 4.12).

Table 4.12 Benevolence mean scores by sex

<i>Sex</i>	<i>Mean</i>	<i>N</i>	<i>Std. Deviation</i>
Male	11.4524	42	2.21086
Female	10.7826	69	2.22201
Total	11.0360	111	2.23171

However, a critical examination of one sample tests of males and females showed that the two did differ significantly in their attitudinal orientation to benevolence ( $p = 0.00$ ) table 4.13 and figure 4.10.

Table 4.13 Significant tests of benevolence by sex

	Test Value = 0					
					95% Confidence Interval of the Difference	
	t	df	Sig. (2-tailed)	Mean Difference	Lower	Upper
Sex	35.069	110	.000	1.622	1.53	1.71

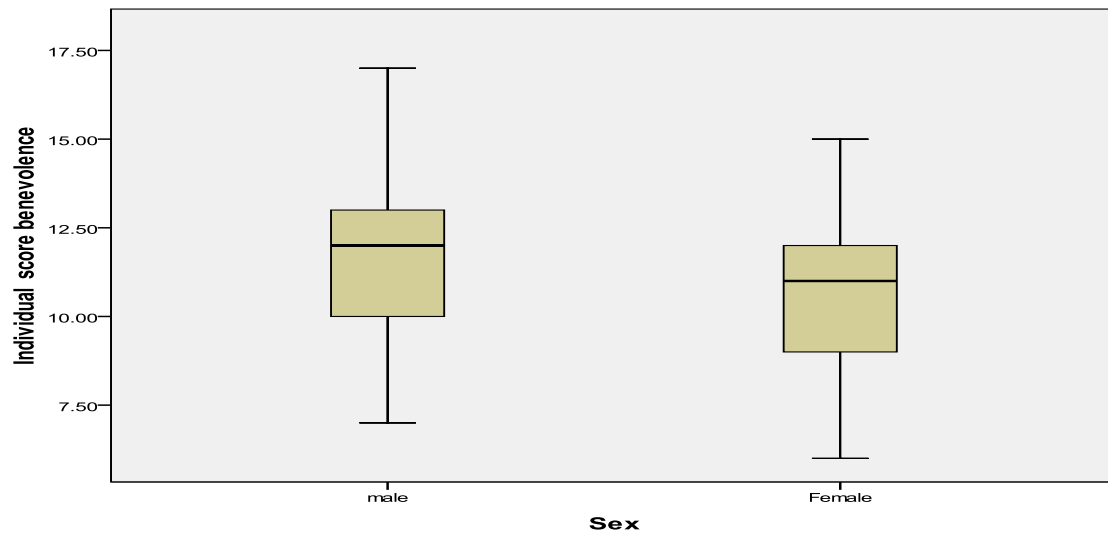


Figure 4.10 shows a detailed distribution of scores.

Concerning the variable benevolence, the mean scores for the four localities were: Ngwerere (9.54), Chibombo (10.26), Chazanga, (11.51.75) and Mkushi (11.81) in ascending order (table 4.14).

Table 4.14 Benevolence mean scores by locality

Locality	Mean	N	Std. Deviation
Ngwerere	9.5417	24	1.79320
Mkushi	11.8140	43	2.33254
Chazanga	11.5172	29	1.86357
Chibombo	10.2667	15	1.94447
Total	11.0360	111	2.23171

However, a critical examination of one sample tests of the localities showed that the four did differ significantly in their attitudinal orientation to benevolence ( $t= 25.36$ ,  $df = 110$   $p = 0.00$  and this  $p$  value is less than 0.05) table 4.15) and figure 4.11.

Table 4.15 Significant tests of benevolence by locality

	Test Value = 0					
					95% Confidence Interval of the Difference	
	t	df	Sig. (2-tailed)	Mean Difference	Lower	Upper
Locality	25.336	110	.000	2.315	2.13	2.50

Figure 4.11 shows a detailed distribution of scores. The top 50% of the group who were more kind, are represented above the median which is a black line. Those in the bottom are shown by the lower “whisker” and dots in form of numbers. Dots represent those who were extremely unkind (outliers).

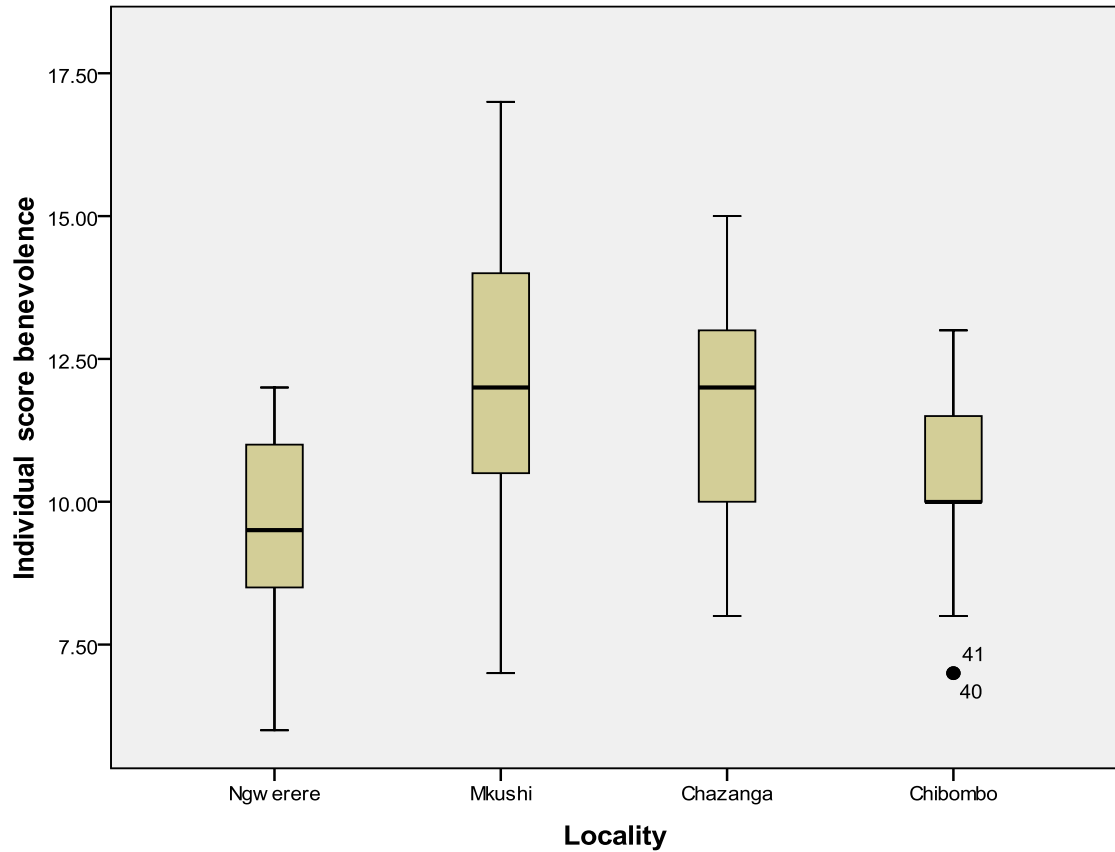


Figure 4.11 Mean plots of benevolence by locality

#### 4.4.5 Stereotype

On stereotype or rigidness or typecast, it was observed that lay caregivers had a rigid position that of unkindness to people living with HIV and AIDs who had mental illness. More than three quarters of the respondents were all agreement that if people living with HIV and AIDs became mentally ill once, they will easily become ill again. They also held a strong fixed position that; it is easy to tell among people living with HIV and AIDs who has a mental illness by the characteristics of their behavior. Most had a position also that all people living with HIV and AIDs who have a mental illness have some strange behavior (table 4.16).

Table 4.16 Attitude - stereotype scores by variable

<b>Stereotype variable domains</b>	<b>SA</b>	<b>A</b>	<b>SWA</b>	<b>D</b>	<b>SDA</b>
	<b>(1)</b>	<b>(2)</b>	<b>(3)</b>	<b>(4)</b>	<b>(5)</b>
If people living with HIV and AIDs become mentally ill once, they will easily become ill again	<b>4</b>	<b>101</b>	0	6	0
You can easily tell among people living with HIV and AIDs who has a mental illness by the characteristics of their behavior	<b>10</b>	<b>75</b>	0	26	0
All people living with HIV and AIDs who have a mental illness have some strange behavior	<b>17</b>	<b>79</b>	0	15	0

In order to test the occurrence of a difference in the scores between male and female volunteers and between the four localities on stereotype, the independent samples t-test was performed. The results suggest that the dependent variable “stereotype” do not differ significantly between the two levels of the independent variable "sex" and the four independent variables “locality.” Concerning the variable stereotype, the mean scores for males and females were 6.38 and 6.68 respectively (table 4.17).



Table 4.17 Stereotype mean scores by sex

<i>Sex</i>	<i>Mean</i>	<i>N</i>	<i>Std. Deviation</i>
Male	6.3810	42	1.52942
Female	6.6812	69	1.33387
Total	6.5676	111	1.41178

However, a critical examination of one sample tests of males and females showed that the two did differ significantly in their attitudinal orientation to stereotype ( $t = 35.06$ ,  $df = 110$   $p = 0.00$  and this  $p$  value is less than 0.05) table 4.18.

Table 4.18 Significant tests of stereotype by sex

Test Value = 0						
					95% Confidence Interval of the Difference	
	t	df	Sig. (2-tailed)	Mean Difference	Lower	Upper
Sex	35.069	110	.000	1.622	1.53	1.71

Figure 4.12 shows a detailed distribution of scores. Take the top 50% of the group who were more kind; they are represented by everything above the median which is a black line. Those in the bottom are shown by the lower “whisker” and dots in form of numbers. Dots represent those who were extremely unkind (outliers).

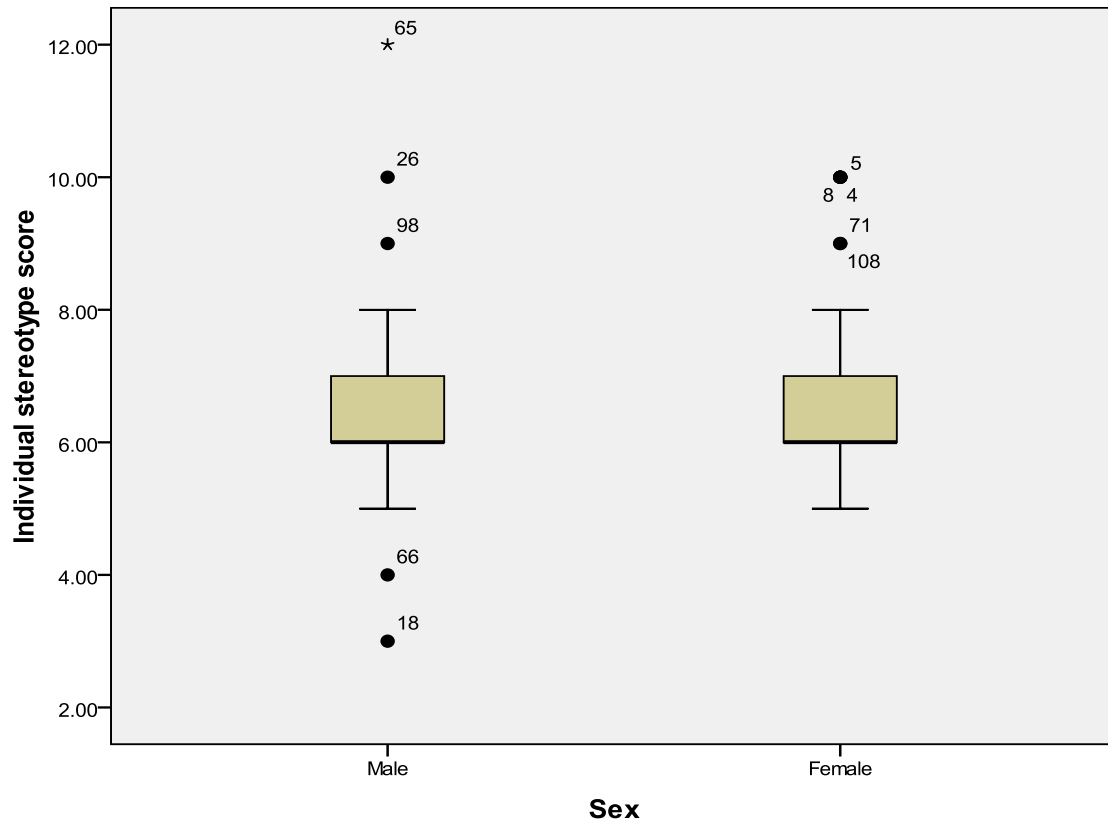


Figure 4.12 Mean plots of stereotype by locality

Concerning the variable stereotype, the mean scores for the four localities were: Chibombo (6.00) Mkushi (6.55), Ngwerere (6.62) Chazanga (6.82) and in ascending order (table 4.19).

Table 4.19 Stereotype mean scores by locality

Locality	Mean	N	Std. Deviation
Ngwerere	6.6250	24	1.24455
Mkushi	6.5581	43	1.48488
Chazanga	6.8276	29	1.44096
Chibombo	6.0000	15	1.36277
Total	6.5676	111	1.41178

However, a critical examination of one sample tests of the localities showed that the four differed significantly in their attitudinal orientation to stereotype ( $t= 25.33$ ,  $df = 110$   $p = 0.00$  and this  $p$  value is less than 0.05) table 4.20.

Table 4.20 Significant tests of stereotype by locality

Test Value = 0						
					95% Confidence Interval of the Difference	
	t	df	Sig. (2-tailed)	Mean Difference	Lower	Upper
Locality	25.336	110	.000	2.315	2.13	2.50

Figure 4.13 shows a detailed distribution of scores. Take the top 50% of the group who were more rigid; they are represented by everything above the median which is a black line. Those in the bottom are shown by the lower “whisker” and dots in form of numbers. Dots represent those who were extremely rigid (outliers).

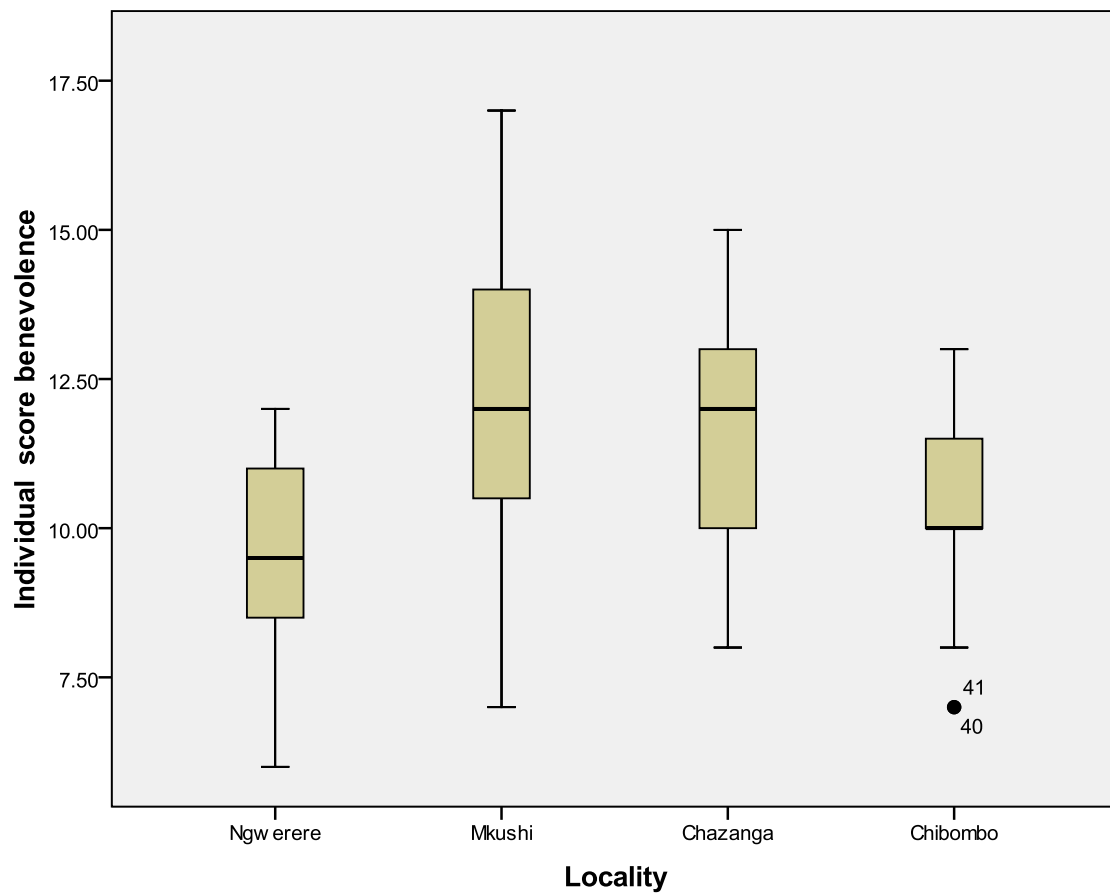


Figure 4.13 Mean plots of stereotype by locality

### 4.3.2 Practices

A total of 13 categorical coded questions were designed to evaluate the volunteer care giver practices on matters related to mental illness in people living with HIV and AIDS. In order to test the occurrence of a difference in the scores within and across the four towns in the practice domain, independent sample F-tests were performed. The results suggest that the dependent variable "Practices Score" did not differ significantly between the two levels of the independent variable "town." That is, the four towns did not differ significantly in their perceptions on practices test ( $p = 0.113$ ).

Table 4.21 One sample test practices differential scores by town

Test Value = 0						
		Sum of squares	df	Mean Square	F	Sig.
	Between groups	7.356	3	2.452	2.040	.113
Locality	Within groups	127.408	106	1.202	0	0
Practices Score	Total	134.764	109		23.3717	23.7919

The details of the critical differentiating values appear in table 4.22. Of the four towns, Ngwerere has the lowest score values.

Table 4.22 Differential practices score according to town

		Statistic	Std. Error	
Total Practice	Ngwerere	Mean	23.1250	.26452
		Minimum	21.00	
		Maximum	26.00	
		Median	23.00	
		Std. Deviation	1.29	
	Mkushi	Mean	23.6429	.16281
		Minimum	22.00	
		Maximum	26.00	
		Median	24.0000	
		Std. Deviation	1.055	
	Chazanga	Mean	23.6897	.20525
		Minimum	22.00	
		Maximum	26.00	
		Median	24.00	
		Std. Deviation	1.10529	
	Chibombo	Mean	23.9333	.20625
		Minimum	23.00	
		Maximum	26.00	
		Median	24.0000	
		Std. Deviation	.79881	

The top 50% of the group who were able to practice (phoning the police or social worker (see figure 4.14); are represented above the median (the black line). Those in the top 25% of best practice are shown by the top "whisker" and dots and these are respondents 20, 12 and 14 (figure 4.14). It is evident also from the whisker plot that the medians of three towns which are Mkushi, Chazanga and Chibombo are the same except for Ngwerere which is different.

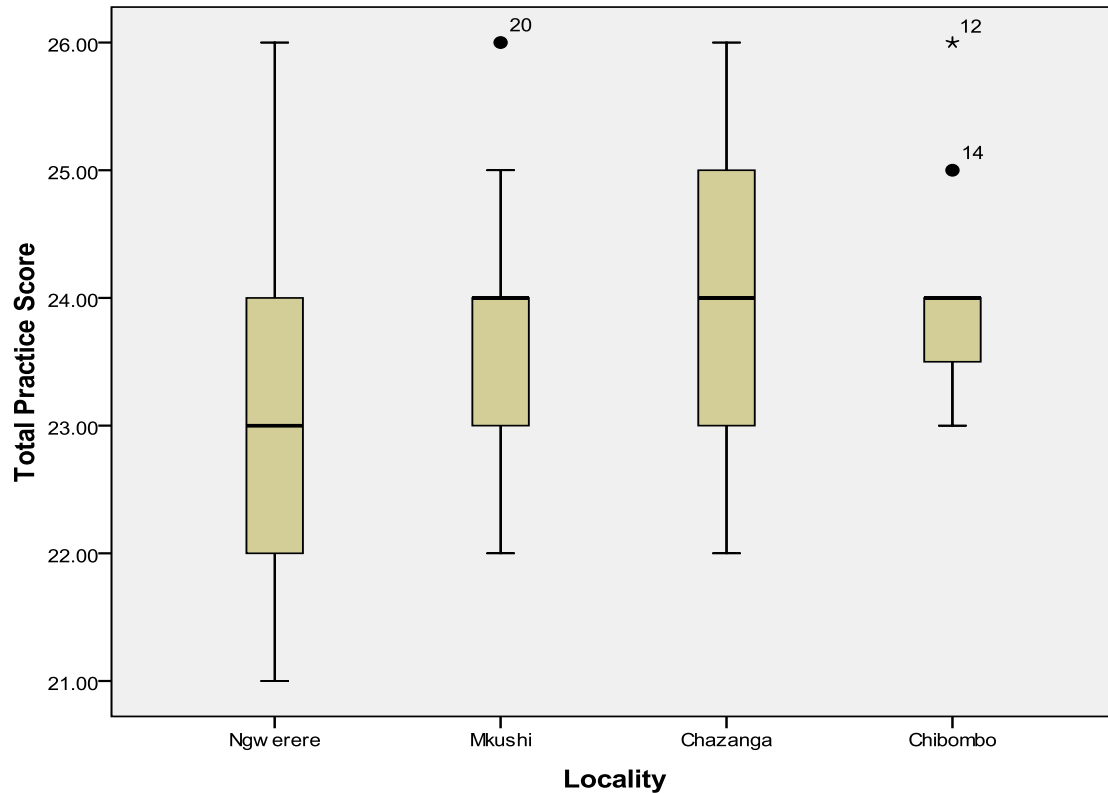


Figure 4.14 Practice median plots of four study slaces

Further, the details of the practice variable domain are presented using a nominal grading (see table 4.23). What the study shows is that of all the expected practices, the volunteer care givers are best able to phone the police or the social worker. This is because more volunteers seem to have hand phones. The volunteers are unable to offer any treatment refer and when they do, their clients end up in the hands of religious leaders, private practitioners, the nearest hospital or sparingly at Chainama. The results indicated poor practices in the sample.

Table 4.23 Practices scores by variable

<i>Practice variable domains</i>	<i>Yes</i>		<i>No</i>		<i>Not aware</i>	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>N</i>	<i>%</i>
1. At the moment are you able to treat a patient with HIV and AIDS suffering from mental illness?	0	0	<b>111</b>	<b>100</b>	0	0
2. Are you able to prescribe drugs for personality disorders?	0	0	<b>111</b>	<b>100</b>	0	0
3. Are you able to prescribe drugs for suicidal behaviours?	0	0	<b>111</b>	<b>100</b>	0	0
4. Are you able to prescribe drugs for serious disorders of children and adolescents	0	0	<b>111</b>	<b>100</b>	0	0
5. Are you able to phone the police?	<b>82</b>	<b>73.9</b>	29	26.1	0	0
6. Do you have a plan for locating available resources for help in a psychiatric emergency	0	0	<b>111</b>	<b>100</b>	0	0
7. Are you able to phone or contact a social worker?	2	1.8	<b>109</b>	<b>98.2</b>	0	0
8. Are you able to phone a health care worker at short notice?	<b>73</b>	<b>65.8</b>	38	34.2	0	0
9. Do you refer patients with mental illness to Traditional healers?	17	15.3	<b>94</b>	<b>84.7</b>	0	0
10. Do you refer patients with mental illness to Chainama?	3	2.7	<b>108</b>	<b>97.3</b>	0	0
11. Do you refer patients with mental illness to the nearest hospital?	20	18.0	<b>91</b>	<b>82.0</b>	0	0
12. Do you refer patients with mental illness to Private Practitioners?	21	18.9	<b>90</b>	<b>81.1</b>	0	0
13. Do you refer patients with mental illness to religious leaders?	50	45.0	<b>61</b>	<b>55.0</b>	0	0



In order to test the occurrence of a difference in the scores between male and female volunteers in the practices domain, the independent samples F-test was performed. The results suggest that the dependent variable “Practices Score” did not differ significantly between the two levels of the independent variable "sex." That is, males and females did not differ significantly in their perceptions on practices test ( $p = 0.921$ ).

Table 4.24 One sample test practices differential scores by sex

		Test Value = 0				
		Sum of squares	df	Mean Square	F	Sig.
	Between groups	0.012	1	0.012	.010	0.921
Sex	Within groups	134.751	108	1.248	0	0
Practices Score	Total	134.764	.000	23.58182	23.3717	23.7919

The top 50% of the group who were able to practice, are represented above the median (the black line). Those in the top 25% of best practice are shown by the top "whisker" and “dots” and these are respondents 20, 4, 9 and 12. In addition, those in the lower 25% of worst practice are shown by the low “whisker and dots and these are respondents 91, 32 and 58 (figure 4.15). It is evident also from the whisker plot that the medians of three towns which are Mkushi, Chazanga and Chibombo are the same except for Ngwerere which is different.

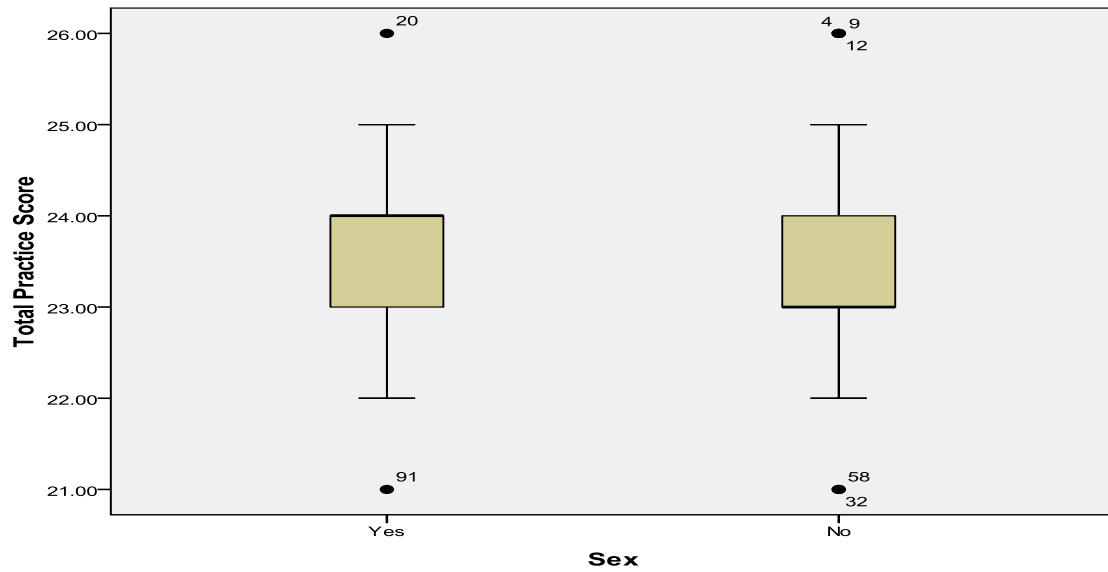


Figure 4.15 One sample test practices differential scores by sex

#### 4.6.0 Reasons care givers exhibit particular perceptions on persons living with both mental illness and HIV/AIDS

It was evident from the focus group discussions that culture and level of education play a vital role in shaping public and lay caregivers' attitudes, knowledge and practices toward mental illness. There was mention of supernatural powers such as demons (creatures that live among people and have the power to change things or hurt people who have violated norms or taboos but cannot be seen), devils, failure to follow rituals, or fate as considered causes of mental illnesses.

In addition, a plurality of care givers in the focus group discussions did not agree that mental health facilities should be kept out of residential neighborhoods. Furthermore, the vast majority of lay caregivers did not agree that the best way to handle the mentally ill is to keep them behind locked doors.

There appeared to be an apparent knowledge gap among lay caregivers concerning mental illness and HIV and AIDS. However, the focus groups discussions generated eight themes as reasons for the perceptions on persons living with both mental illness and HIV/AIDS and these were:

- a) Culture describes mental illness,
- b) Superstitions as causes of mental illness,
- c) Treatment by traditional means;
- d) Stigma is a factor for attitudes,
- e) Stereotypes and mental illness,
- f) Inability to treat because of poor knowledge and skill,
- g) Isolation versus community care.

The illustrations below based on the eight themes speak for themselves.

#### **4.6.1 Culture describes mental illness ( Home Based Care Givers)**

“As you know (referring to the researcher), our own culture plays a real role in describing what we see in people who are mad....We have varying descriptions of illnesses causes and approaches to treatment.”

Chibombo focus group discussion

#### **4.6.2 Superstitions as causes of mental illness**

“When someone is mad even when they have HIV, in our setting, we tend to think that one may have misbehaved with someone’s partner. It happens that you can get AIDS and are bewitched at the same time with mental

illness.....Supernatural powers such as demons, refusing to follow rituals like sexual cleansing or to be set free after the loss of a spouse (called *ku suzula in Nyanja*) or fate we believe cause mental illness among those who are infected.“

Chazanga focus group discussion

#### **4.6.3 Treatment by traditional means**

“We believe that patients with mental illness who are possessed by devils can be cured or treated by traditional treatments..... Oh yes not only in this way alone, some can be treated by healers or by visiting holy places and pastors. In Mkushi, we have sacred places in the hills. We exorcise demons and neutralize curses.”

Nkumbi M’kushi Focus Group Discussion

#### **4.6.4 Stigma is a factor for Attitudes**

“As you may know that mental illness can have a lot of stigma, in this area, many families try to hide and manage mental illness at home. Stigma may make families conceal the illness. These illnesses have many implications like marriage....., especially for female patients. You can see why we have these attitudes when one has a mental illness.”

Chazanga focus group discussion

#### **4.6.5 Stereotypes and mental illness**

“Here in Chibombo, we have this belief that mental illness affects only a certain group of people who have HIV. Not everyone can become mentally

ill...There are some whose HIV attacks the brain. Some just get depressed with fear or shame.... There is still a lot of stigma attached to mental illness.”

Ngwerere focus group discussion

“As far as I have seen, it is not possible to maintain a normal life in the community of a person with both HIV and mental illness ... I have not seen a person with a serious mental illness getting well and return to a productive life.... There is no way even with these drugs.....”

Chibombo focus group discussion

#### **4.5.6 Inability to treat because of poor knowledge and skill**

“We are seeing a lot of them developing mental illness. Some of us have seen that we cannot do much and we know very little. We are not trained to recognize and treat these illnesses. But, we should try as much as possible to send them to Chainama...we should keep them indoors.”

#### **4.5.7 Isolation versus community care**

“We should try as much as possible to be with them and not to send them away to places like Kabwe mental annex or Chainama.”

Chazanga focus group discussion

“I do not agree, the best way to handle the mentally ill is to keep them behind locked doors.”

Ngwerere focus group discussion

## CHAPTER FIVE

### DISCUSSION

This was the first in depth study on community care giver knowledge, attitude and practices towards PLHIV but suffering from HIV in Zambia. The study was able to demonstrate that HIV clients suffering from mental illness are mostly discriminated against due to poor knowledge, attitudes and practices by community home based care givers. This chapter discusses in summary the research findings by outlining specific outcomes according to the three research questions. This is followed by a contextual presentation of the findings to try to decipher what previous research has found.

The study sample was composed of relatively youthful volunteers (57%), most of who were older than the median age 36 years. The answers to the research questions were summarised thematically as follows to show the outcomes unambiguously as advised by de Vaus (1993).

#### ***Research Question 1: What is the construction of mental illness among caregivers?***

The community lay caregivers described themselves in various ways; as *sim card operators*”, frontline workers and Jesus’ co-workers. They described themselves by the nature of the job they were providing which includes; HIV sensitization, client identification, referrals, home visitations, care and support such as; providing food, blankets, bathing patients, washing clothes, counselling, direct observation therapy and adherence support for TB, ART adherence support and health Education.

The lay caregivers described varying events surrounding mental illness and these included particular signs and symptoms of mental illness such as taking cloths off, insulting, talking to oneself. They feared assaults, fear to get injured and acquiring the illness. They also state that they were burdened with caring for mentally ill patients. The perceptions of lay caregivers on the causes and social consequences of mental illness played an important role, influencing the experience of burden of care, the development of coping strategies, and the decision to refer as well as to utilise local traditional remedies as well as mental health services. These studies confirm the results of Adewiya and Makanguola (2005) which indicates that communities exhibited fear of contagion, transmission and fear of mental ill patients being violent when caring for mental ill patients.

**Research Question 2: What perceptions in terms of knowledge, attitudes and care practices do caregivers have on mental illness on PLHIV but have mental illness.**

The results of the study showed that more respondents in the four sites (62.2%) noted that mental illness was a problem among people living with HIV and AIDS. 61.3% felt that the condition was not receiving the attention it deserved from the home based care. It was evident from the study that poor knowledge about mental illness was widespread in the sample and that males and females showed significant differences in their perceptions on the knowledge variable. These findings are in agreement with the World Federation for Mental Health (WFMH), who identified the lack of adequately trained mental health providers as a major issue in the capacity of health care systems to respond to the impact of the HIV epidemic (Griffin 2008; Anderson 2005). Crowther, (2000) also stated that the ability to recognize mental illness is a central part of “mental health literacy” not only for lay care

givers but for all front line mental health care workers who may be dealing with HIV and AIDS because it is a prerequisite for appropriate health care.

The findings of the study suggest that the dependent variable "Practices Score" did not differ significantly between the two levels of the independent variable "town." This implies that perceptions on practices are similar in different communities. The results further suggest that there were similarities in perceptions on practices by males and females. In a focused group discussion conducted in Ngwerere by Kapungwe *et al*, (2010), one participant indicated that "I do not agree, the best way to handle the mentally ill is to keep them behind locked doors." This is a sign of negative practice towards patients with mental illness. The research findings confirm the results from other studies which have been conducted in Africa which have shown community stigma and discrimination surrounding mental illness to be overt and pernicious. (Adewiya and Makanguola 2005). In reference to attitudes, it was generally observed that these were poor in the three domains: restriction, benevolence and stereotype.

The study attempted to find out whether restrictiveness was existent in the four study site and among males and females. The results indicated that the four localities showed significant differences in their attitudinal orientation to restrictiveness. The results of one sample tests of males and females showed that the two did differ significantly in their attitudinal orientation to restrictiveness. This implied that restrictiveness was being practiced at different levels in the different sites and practiced more by females than males. The study has revealed that PLHIV but suffering from mental illness are often discriminated against by not only lay care givers but by the community at large. The findings of this study are in agreement with those of Chou *et al.*, 1996 and Angermeyer *et al.*, 2004 which showed that people with mental illness and are living with HIV and AIDS form another group facing much societal



discrimination. Other related studies also indicate that PLHIV face discrimination by the community (Blendon and Donelan, 1988; King, 1989; Lau and Tsui, 2003). Such discrimination toward PLHIV would compromise the effectiveness of HIV prevention and care programs (Cheney and Smith, 1999).

For benevolence or kindness, the results suggested that males and females showed significant difference in their attitudinal orientation to benevolence. And a critical examination of one sample tests of the four localities also showed that there was a significant difference in their attitudinal orientation to benevolence.

For stereotype or rigidity or typecast, the results suggest that males and females showed significant differences in their attitudinal orientation to stereotype with females showing more stereotyping orientation than males. This could have been because there were more female caregivers than men in all the study sites. Loutfy, (2012), also observed that female gender was consistently associated with higher total and subscale stigma scores. The results of one sample tests of the four localities showed that there was significant difference in their attitudinal orientation to stereotype. This implied that negative attitudinal orientation was not commonly spread in communities.

### **Research question 3: Reasons caregivers exhibit particular perceptions on persons living with both mental illness and HIV/AIDS**

The study revealed varied reasons by caregivers why they have particular attitudes, knowledge and practices towards people living with mental illness and have HIV or AIDS. There was mention of supernatural powers such as demons (creatures that live among people and have the power to change things or hurt people who have violated norms or taboos but cannot be

seen), devils, failure to follow rituals, or fate that were considered to be the causes of mental illnesses. These findings are similar to those of Yip, (2005), who observed that within traditional Chinese superstition, mental illness is perceived as something mythical like demon possession or by some evil spirit and that it may be perceived as punishment of misdeeds done by clients themselves or their family members. A plurality of care givers in the focus group discussions of this study did not agree that mental health facilities should be kept out of residential neighborhoods. Furthermore, the vast majority of lay caregivers did not agree, that the best way to handle the mentally ill is to keep them behind locked doors. There appeared to be an apparent knowledge gap among lay caregivers concerning mental illness and HIV and AIDS. However, the focus groups discussions generated eight themes as reasons for the perceptions on persons living with both mental illness and HIV/AIDS and these were:

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- e) Stereotypes and mental illness,
- f) Inability to treat because of poor knowledge and skill,
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The focus group discussions in this study showed that different categories of mental illnesses were associated with different levels of negative opinions; agreeing with Crisp *et al.*, (2000) who observed that despite the common occurrence of mental health problems, societies continue to hold deep-rooted, culturally sensitive, negative beliefs about mental illnesses. There is evidence to show that culture and training, play a vital role in shaping the attitudes of

the public, men and women caring for people living with mental illness especially toward mental illness (Foster *et al.* 2008). The findings of this study have alluded to supernatural powers as causes and determinants of care among persons with mental illness, an observation also alluded to by Sijuwola, (1995), who in his study of Culture, religion and mental illness in Nigeria observed that supernatural powers such as Jinn or demons (creatures that live among people and have the power to change things or hurt people but cannot be seen), devils, failure to follow rituals, or fate are also considered to be the causes of mental illnesses. The decisions to have some patients who have HIV and AIDS treated by traditional healers or religious leaders are not a novel finding for the setting studied. Research in Africa has shown that patients with mental illness who are believed to be possessed by devils or Jinn can be cured or treated by traditional treatments such as by traditional healers or by visiting holy places and religious people (Abdel-Latif, 1989).

#### **5.1.0 Limitations of this study**

The study had several limitations. Firstly, the results of the survey question were self-reported and reporting bias due to social desirability may have existed. The study was also not anonymous especially among those who would not read or write. However, influence was exerted on how the respondents would answer the questions. Further, if reporting bias had existed, the poor attitude, practice and knowledge scores would most likely have been sharper than what was reported. Secondly, was the content of the questionnaire? Questions did not include HIV and AIDS material and were concentrated more on mental illness co related to HIV. This however, was due to the limited time of field work and the advice given during protocol review by the graduate forum to shorten the toll.

The third one was related to the link between attitudes and behavior. There was a difference between held attitudes and enacted behavior. The questions of this study focused on practices, knowledge and attitudes independently rather than looking for causes and effects. Caution therefore should thus be taken when interpreting the results. Another factor is related to the questionnaire used in this study. It had not been previously tested except in a pilot study but the findings were valid because the tool was tested in the context of our Zambian culture. However, the process used to develop the tool was rigorous and the focus group discussions revealed extra information beyond the tool.

Despite these limitations, this dissertation does present new data on the knowledge levels, attitudes and practices of lay caregivers in Bwafwano and studies of such nature have been reported to be meaningful.

### **5.2.0 Strengths of this study**

This study provides useful information to mental health professionals and home based care proprietors in Zambia and elsewhere to understand the belief system of Zambian lay caregivers of people having co-morbidities of HIV and AIDS with mental illness. This knowledge can be applied to trans-cultural counselling and community based lay care training to help caregivers to adjust to their roles.

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## CHAPTER FIVE

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The study had the following limitations:

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## **CHAPTER SIX**

### **CONCLUSION**

In Zambia as in many other countries, little is devoted to addressing the Community care givers poor knowledge, negative attitudes and practices surrounding PLHIV but suffering from mental illness. This study aimed at establishing the level of knowledge, attitude and perceptions of Community caregivers' towards PLHIV but suffering from mental illness under HBC. Indications of Community caregivers' perceptions of mental illness in people living with HIV and AIDS in Bwafwano Home Based Care, which was previously lacking have been provided. The findings indicate more negative attitudes among community care givers which include separation, restriction benevolence and stereotype. The community care givers had less knowledge about the extent to which mental illness was a problem among PLHIV, their practices showed that they were unable to offer any treatment and mostly referred clients to religious leaders, private practitioners and nearest hospitals. These findings suggest that poor or lack of training and cultural factors were a contributing factor. Therefore the results of this study emphasize the need for empowering community care givers with appropriate knowledge and capacity to care for PLHIV but suffering from mental illness under HBC. In addition, the results underscore the need for greater commitment from Government as well as community care giver establishments to begin recognizing mental illness co morbid with HIV/AIDS as a major area needing attention.

## **CHAPTER SEVEN**

### **RECOMMENDATIONS**

1. There will be need for policy makers and home based care organizations to revise the home based care curriculum to include mental illness and HIV management at community level as well as conducting training workshops and short courses and sensitization programs for community caregivers.
2. Qualitative studies would be required to enhance understanding of the knowledge gaps, practices, and attitudes that community caregivers have and how these influence the quality of care in home care giver settings.
3. Effective anti-stigma campaigns to improve the community care givers attitudes towards patients with HIV and mental illness.
4. All health care workers working with community volunteers involved in the care and treatment of PLHIV should be trained in mental health care.
5. Mental health and AIDS community treatment facilities should ensure continuous training of personnel involved in the care and treatment of PLHIV in providing mental health care.

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## APPENDICES

### APPENDIX – I WORK PLAN

NO	ACTIVITY	TIME FRAME	RESPONSIBLE PERSON	
1.	Writing of the research proposal	1 <sup>st</sup> May 2009 to 10 <sup>th</sup> December 2009	Researcher	R
2.	Sending proposal to relevant authorities for proof reading.	11 <sup>th</sup> December to 11 <sup>th</sup> January 2010 (4 weeks)	Researcher	T
3.	Binding of research proposal	13 <sup>th</sup> – 14 <sup>th</sup> January 2010. (2 days)	Researcher	R
4.	Obtaining permission from the Permanent Secretary Ministry of Health, Director of Bwafwano Home Based Care.	15 <sup>th</sup> January – 5 <sup>th</sup> February 2010 (3 weeks)	Researcher	S
5.	Submission and approval of research proposal by the Ethics Committee of the University of Zambia	15 <sup>th</sup> January – 5 <sup>th</sup> February 2010 (3 weeks)	Researcher	S
6.	Printing of schedules, interview questionnaires	6 <sup>th</sup> February 2010 (1 day)	Researcher	S
7.	Pretesting of questionnaire in Chongwe and revision of the questionnaire	7 <sup>th</sup> February 2010 to 9 <sup>th</sup> 2010 (2 days)	Researcher, and Director of the chosen organization	P
8.	Collection of data	11 <sup>th</sup> February 2010 - 5 <sup>th</sup> March 2010 (3 weeks)	Researcher	P
9.	Data Analysis	9 <sup>th</sup> March 15 <sup>th</sup> March, 2010 (5 days)	Researcher and computer programmer	S
10.	Report writing	16 <sup>th</sup> March – 5 <sup>th</sup> April, 2010 (4 weeks)	Researcher	S
11.	Preliminary submission of draft proposal for correction	13 <sup>th</sup> April 2010 (1 week)	Researcher and the supervisor	D
12.	submitting the research report	20 <sup>th</sup> April, 2010 (2 weeks)	Researcher	T



## APPENDIX II- PROPOSED BUDGET

ACTIVITY	QUANTITY	UNIT COST (ZMK)
Reams of paper	5	30,000
Packets of pens	2	20,000
Packets of pencils with rubber	2	20,000
Photocopying questionnaires	350 x 8 pages each	300
Photocopying questionnaires Focused Group Discussions	12	300
Photocopying of informed consent forms	350 x 3 pages each	300
Photocopying introductory letters	386	300
Typing and printing proposals	5	25,000
Notepads	5	6,000
Binding of proposals	5	20,000
Typing and printing proposal summaries	25 x 4 pages each	300
Review of Proposal by out side Supervisor	3 meetings	500,000
Review of proposal by Ethics committee	1 meeting	250,000
Lunch allowance for principle researcher	1 x 21 days	50,000
Lunch allowances for research participants	386	20,000
Transport allowance for research participants	386	30,000
Fuel to transport researcher	125 litres	7,500
Accommodation for principle researcher	8	200,000
Data entry and analysis by Principle investigator and Computer Programmer	5 days	200,000
Typing of preliminary report	1 report	100,000
Typing final report	1 reports	100,000
Binding of reports	3	100,000
<b>Total</b>		

### **APPENDIX III - Introductory Letter to the Research Participants**

Dear participant,

#### **KNOWLEDGE, ATTITUDES AND PRACTICES OF BWAFWANO HOME BASED CARE GIVERS TOWARDS PEOPLE LIVING WITH HIV (PLHIV) BUT SUFFERING FROM MENTAL ILLNESS IN LUSAKA AND CENTRAL PROVINCES, ZAMBIA.**

The above named research will be conducted in selected and peri – urban and rural catchment areas of Bwafwano Home Based Care Organization in Chazanga, Ngwerere (Lusaka province), Chibombo and Mkushi (Central Province). The aim of the study is to determine the knowledge, attitudes towards PLHIV and practices of care givers of HIV/AIDS patients under HBC who develop mental illness.

The findings of this study will be vital and you are therefore requested to participate in this study by answering very honestly the questions in the questionnaire.

Your answers will be confidential and will only be used for the study and after the study, the questionnaires and any notes will be kept by the University of Zambia for only six months. Thereafter, questionnaires and any notes will be destroyed. Your identity will not be disclosed in the study. In case you decide to take part in the study, and you decide to withdrawal, you may do so voluntarily. There are no consequences of this withdrawal. If you are willing to participate in the study, kindly sign the consent form attached to this letter.

Should you need further clarification, you are free to contact the Chairperson Biomedical Research Ethics Committee, UNZA, Box, 50110, Lusaka land Phone, 260 1256067.

Yours Sincerely,

Patricia Zulu Ulaya

## APPENDIX IV – Information Form/Consent Form

UNIVERSITY OF ZAMBIA  
SCHOOL OF MEDICINE  
DEPARTMENT OF COMMUNITY MEDICINE  
TITLE OF THE RESEARCH PROJECT:

Title of the Research study

**KNOWLEDGE, ATTITUDES AND PRACTICES OF BWAFWANO HOME BASED CARE GIVERS TOWARDS PEOPLE LIVING WITH HIV (PLHIV) BUT SUFFERING FROM MENTAL ILLNESS LUSAKA AND CENTRAL PROVINCES, ZAMBIA.**

Investigator

Patricia Zulu Ulaya, Cell no. 0979569261.

Purpose and Background

This is a research relating to mental illness among people living with HIV and AIDS. People living with HIV are likely to develop mental illness therefore; this study is exploring this issue from your point of view. The researcher Patricia Zulu Ulaya is interested to know what you really know, your feelings and what you do for people who are living with HIV and AIDS and are actually suffering from mental illness.

Procedure

If you agree to participate, the following things will happen:

1. You will be asked questions on what you really know, your feelings and what you do for people who are living with HIV and AIDS and are actually suffering from mental illness.
2. Your names will not be written on the questionnaire.

Benefits

The results of the study will be beneficial to you and the clientele that you are serving in the following ways:

1. You will be given an opportunity to be retrained on a module in caring for people who are living with HIV and AIDS and are actually suffering from mental illness.
2. You will be given a community health worker's handbook to help you in recognizing signs and symptoms of mental illness and to follow up care after your training.

## Risks

There are no envisaged risks to you that may ensue from participating in the study. However, the study may intrude in your work or private time as you participate in the study. The time however will not be more than 30 minutes.

## Reimbursement

You will be paid a token sum of money as transport reimbursement and an expression of gratitude for availing time and information. For further information about this, you may contact the Chair Person, Biomedical Ethics Committee of the University of Zambia, School of Medicine, PO Box 50110, Ridgeway campus, Lusaka.

## Confidentiality

A private room shall be made available for you to answer the questionnaire and participate in the interviews where possible. An envelope will be provided where to put in the completed questionnaire. Your identity will be kept confidential and no one would know that it is you who has answered in a particular manner.

Your answers to the questions will be kept confidential and will only be used for research purposes. The answered questionnaire will be kept by the researcher in the strictest of confidence for only six months after which time all the responses will have been examined. There after it shall be destroyed.

## Right to refuse or withdraw

Your participation in the study is entirely voluntary and you are free to refuse to take part or to withdraw at any time without affecting or jeopardizing my future medical care.

## Consent

I have been given a copy of this form. The purpose of this research has been fully explained to me and I have understood it. I also understand that my rights and privacy will be respected. I agree to participate in this study.

Name of participant:

.....

Signature or thumb print of

participant..... Name and signature  
of interviewer.....



12. To what extent would you agree or disagree that witchcraft can cause mental illness?  
(Knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

13. To what extent would you agree or disagree that genetic disorders can cause mental illness? (Knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

14. To what extent would you agree or disagree that medical conditions can cause mental illness? (Knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

15. To what extent would you agree or disagree that a stressful life can cause mental illness?  
(Knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

16. To what extent would you agree or disagree that a deviance or lack of discipline can cause mental illness? (Knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

17. To what extent would you agree or disagree that brain damage can cause mental illness?  
(Knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

18. To what extent would you agree or disagree that close contact with a mentally ill person can cause mental illness? (Knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

19. There are more people with mental illness in the community than those that are seen at health facilities (Knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

20. Mental illness can lead to poverty (Knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

21. Poverty can bring about mental illness (Knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

22. In your view, is the problem of mental illness serious in Zambia?  
(Knowledge)

Yes	No
1	2

23. In your own assessment, is mental illness in Zambia currently receiving the attention it deserves? (Knowledge)

Yes	No
1	2

24. Most people in Zambia do not understand the problem of mental illness (knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

25. To effectively manage mental illness it is important to involve traditional healers (Knowledge)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

**Practice Scores**

	Yes	No
26. At the moment, are you able to treat a patient who is suffering from a mental illness (practice)	1	2
27. At the moment, are you able to treat in individuals suffering from substance abuse? (Practice)	1	2
28. At the moment, are you able to prescribe drugs for Personality disorders(practice)	1	2
29. At the moment, are you able to prescribe drugs for Suicidal behaviours(practice)	1	2
30. At the moment, are you able to prescribe drugs for Serious disorders of children and adolescents(practice)	1	2
31. Do you have a plan as Bwafwano for locating available sources for help in a psychiatric emergency? (practice)	1	2
32. You are able to phone the police? (practice)	1	2
33. You are able to phone a social worker (practice)	1	2
34. You are able to contact a clinical officer psychiatry or psychiatrist at short notice (practice)	1	2
35. Do you refer patients with mental illness to Traditional healers(Practice)	1	2
36. Do you refer patients with mental illness to Chainama Hospital(Practice)	1	2
37. Do you refer patients with mental illness to Both traditional healers and hospital(Practice)	1	2
38. Do you refer patients with mental illness to Private practitioners (Practice)	1	2
39. Do you refer patients with mental illness to Religious leaders(Practice)	1	2
40. Do you refer patients with mental illness to their families/communities(Practice)	1	2
41. Since you started work, have ever dealt with a mentally sick person? (Practice)	1	2

42. Do you have a referral protocol/form for mental illness? (Practice)

Yes	No	Not aware
1	2	0

44. If you refer any mental health patients, do you get any feedback? (Practice)

Yes	No	Not aware
1	2	0

45. Are you able to evacuate patients with mental illness to the nearest health unit for care? (Practice)

Yes	No	Not aware
1	2	0



*Attitudes*

44. People with mental illness have unpredictable behavior? (Separatism)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

45. I would find it hard to talk to someone with mental health problems(Separatism)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

46. If people become mentally ill once, they will easily become ill again (Stereotype)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

47. If a mental health screening room is set up, I will ask for an exemption to treat those with a mental illness(Separatism)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

48. Even after a person with mental illness is treated, I would still be doubtful to be around them(Separatism)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

49. Mental patients and other patients should not be treated in this same health centre (Separatism)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

50. People with mental illness are dangerous (Stereotype)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

51. You can easily tell who has a mental illness by the characteristics of their behaviour (Stereotype)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

52. All people with mental illness have some strange behavior (Stereotype)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

53. There is no future for people with mental illness (Restrictiveness)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

54. Those who are mentally ill should not have children (Restrictiveness)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

55. The care and support of family and friends can help people with mental illness to get rehabilitated (benevolence)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

56. The best way to help those with a mental illness to recover is to let them stay in the community and live a normal life (benevolence)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

57. People with mental illness should not be allowed to work (hold a job) (Separatism)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

58. It is possible for anyone to suffer from a mental illness (benevolence)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

59. Those who have a mental illness should not tell anyone about their illness (stigma)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

60. Those who have a mental illness are entitled to the same attention in the health centre as general patients(benevolence)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

61. Chainama is the only place where people with a mental illness should be treated (Separatism)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

62. Violent mental patients should be handcuffed (Restrictiveness)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

63. Detentions in a solitary place should be considered for people with a mental illness(Restrictiveness)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

64. Sedation of mental patients would guarantee safety of other people in all cases (Restrictiveness)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

65. Drugs and supplies for people with mental illness must be available in health centres (benevolence)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

66. It is hard to have good friends if you have a mental illness (Pessimistic prediction)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

67. After treatment it is be difficult for the mentally ill to return to the community (Pessimistic prediction)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

68. People are prejudiced towards those with mental illness(Pessimistic prediction)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

69. Political and individual rights of mentally ill persons should be suspended while on treatment to help them (Restrictiveness)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
4	3	0	2	1

70. To effectively deal with mental illness it is important to involve the family and the community (benevolence)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	2	0	3	4

71. Indicate the degree to which you are comfortable to attend to patients with mental illness (Separatism)

Extremely comfortable	Comfortable	Uncomfortable	Extremely uncomfortable
4	3	2	1

72. The Ministry of Health is soon to embark on training primary health care staff like you in identification and management of mental illness. How important do you think this is? (benevolence)

Extremely important	Important	Unimportant	Extremely Unimportant
4	3	2	1

73. The idea behind training of primary health care in mental illness is to integrate mental illness into the primary health care system. How important do you think this is? (Benevolence)

Extremely important	Important	Unimportant	Extremely Unimportant
4	3	2	1

74. In your view, what type of impact will the training of mental illness into primary health care going to have on the provision of primary health care in general? (benevolence)

Positive impact	Negative Impact	No impact at all	I do not know
4	3	2	1

75. There are other more important areas of primary health other than mental health in which primary health staff should be trained? (Separatism)

Strongly agree	Agree	Undecided	Disagree	Strongly disagree
1	2	0	3	4

## **Appendix VI- FGDs Guides**

**Theme I: Self description.** Please tell me about yourself and what is going in Bwafwano regarding HIV/AIDS and mental illness?

**Theme II:** Care givers' own perceptions of symptoms of mental illness and the burdens faced in caring for one who has mental illness and HIV/AIDS. Please tell me about the numbers of people living with HIV among those cared for in homes who have signs and symptoms of mental illness in Bwafwano that you are aware of? What do you see as mental illness?

**Theme III:** KAPs care givers have on mental illness on persons living with mental illness and HIV/AIDS. What do you know about the causes of mental illness?

Theme IV Practices: What do you actually do for people who are living with mental illness?

**Theme V: Attitudes:** What are your feelings about these people-Please describe.

**Theme VI:** The motives for exhibiting particular KAPs on persons living with mental illness and HIV/AIDS.