

## **ABSTRACT**

Zambia, like many other countries is experiencing the crisis of the Human Immune Deficiency Virus/ Acquired Immune Deficiency Syndrome (HIV/AIDS) epidemic with a prevalence rate of 14.7%. Community home based care (CHBC) is one of the ways of responding to the crisis. No known study in Zambia to ascertain factors that attract or repel PLWHA to utilizing CHBC is available. This study focused on bringing out clients' and CHBC workers' concerns, experiences and suggestions regarding utilization of CHBC by PLWHA.

The objective of the study was to establish factors affecting utilisation of CHBC services by PLWHA.

A total number of 161 PLWHA attending ART in Chongwe district were selected using systematic random sampling. Purposive sampling for CHBC providers was used to select CHBC groups. There were two FGDs conducted in each ART static study site one with a faith-based organization and one with an NGO CHBC group.

The level of clients who at least had an encounter with a CHBC was 57.7% though at the time of the study, the number of clients who were actually being attended to had gone down to 54.7%. PLWHA were very satisfied only with psychosocial support. Generally, there was a highly significant association ( $P < 0.001$ ) between type of care received, in particular psychosocial counselling and satisfaction. The results showed that PLWHA were dissatisfied with the staff attitudes as well as quantity and quality of supplies.

Our empirical investigation has identified and demonstrated important associations between utilisation and satisfaction in CHBC. Exploratory and descriptive case studies using local survey data could be used to gain information about CHBC services. Noting that utilisation and knowledge of CHBC is unsatisfactory, there is a need to educate the public through various media on what CHBC provide and what types of CHBC organizations may be present in an area. There is also need to strengthen CHBC groups in order to adequately meet the needs of PLWHA.

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## **DEDICATION**

To my husband Charles who endured my absence from home, encouraged and supported me throughout my study and to my five children; Alice, Gracious, Michael, Mishael and Hope for their support throughout my studies.

**DECLARATION**

I Kaluba Dainess do hereby declare that the work presented in this dissertation is the product of my own work, and that it has not been previously submitted for a degree, diploma or other qualification at this or another University.

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I/We \_\_\_\_\_ have supervised and read this dissertation and am/are satisfied that this is the original work of the author under whose name it is being presented. I/We confirm that this work is completely satisfactory and is ready for the presentation to the examiners.

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## **LIST OF ABBREVIATIONS/ACRONYM**

AIDS	-	Acquired Immune Deficiency Syndrome
ART	-	Anti-Retroviral Treatment
ARV	-	Anti-retroviral
CHAZ	-	Churches Health Association of Zambia
CHBC	-	Community Home Based Care
CSO	-	Central Statistics Office
DCT	-	Diagnostic Counselling and Testing
DHMT	-	District Health Management Team
FBO	-	Faith Based Organizations
FGD	-	Focus Group Discussion
HBC	-	Home Based Care
HC	-	Health Centre
HIV	-	Human Immunodeficiency Virus
HMIS	-	Health Management Information System
MoH	-	Ministry of Health
NAC	-	National AIDS Council
NGO	-	Non-Governmental Organization
PLWHA	-	People Living with HIV/AIDS
PMTCT	-	Prevention of Mother to-Child Transmission
SAP	-	Structural Adjustment Programme
SD	-	Standard Deviation
SPSS	-	Statistical Package for Social Sciences
TASO	-	The AIDS Support Organization
UNAIDS	-	Joint United Nations Programme on HIV and AIDS
UNZA	-	University of Zambia
VCT	-	Voluntary Counselling and Testing
WHO	-	World Health Organization
ZAMBART	-	Zambia AIDS-Related Tuberculosis Project

## CHAPTER ONE- INTRODUCTION

### 1.0 BACKGROUND INFORMATION

The Human Immune Deficiency Virus/ Acquired Immune Deficiency Syndrome (HIV/AIDS) epidemic has created a crisis of unprecedented proportion that greatly impacts society as a whole (UNAIDS 2004). Communities everywhere are struggling to respond in various ways. In Zambia, people have faced calamities brought about by disease, famine, drought, civil strife and the like for generations. But somehow the strong extended family and kinship networks that are the backbone of the African social structure have been able to cope with these catastrophes. The extended family and kinship networks have been the backbone in the sense that when afflictions come, members have been there for one another and it has been easy to cope. While this has been so, HIV and AIDS is different from all these other calamities in the sense that it has weakened the kinship networks by affecting adults more than children and yet these adults happen to be bread winners (Russell and Schneider 2000). *“Home-based care is taking us back to the root of human coexistence. It reminds us that we all have the responsibility to one another. If we hold hands through this tragedy, we will be able to retain our humanity and will come out of this epidemic as a stronger community” (WHO 2003).* This quotation sets the theme of this study which is linked to Community Home- Based Care (CHBC) service utilization

Zambia with an HIV prevalence of 14.3% (CSO 2007) is among the countries in sub-Saharan Africa most seriously affected by the HIV/AIDS epidemic and the health system has faced constraints in responding to its immensity (NAC 2006). An estimated 40,000-90,000 AIDS-related deaths would have occurred by the end of 2000 (Stringer et al 2006). The epidemic is now not only affecting the adult population in the age group 20- 45 years but is afflicting the very young and those who are old arising from caring for their loved ones. In just 10 years, the AIDS epidemic has affected the lives of more than 40 million people in Africa (WHO 2003) with significant loss of family income and creating so much strain caused by prohibitive medical and funeral costs, or the stigma

sometimes attached to families affected by AIDS (Serpell, 2006). In some cases, surviving family members have been abandoned, abused or attacked while struggling to cope with their own HIV-related illness. As these members weaken or die, the remaining family members and friends remain with no alternative form of mitigation. With almost every family having experienced the impacts of HIV and AIDS, the potential psychosocial and economic devastation faced by People Living with HIV/AIDS (PLWHA) and family members in Zambia is enormous. The situation worsened by the fact that the epidemic has struck at a time of economic down turn when people are living in abject poverty. The nation at the same time is struggling to mitigate poverty as she faces the task of implementing Structural Adjustment Programmes (SAP) whose serious measures reduce rather than support the nation's ability to provide health care and social services (Bengtsson and Bengtsson 2005). Noting that the epidemic has overburdened the government, continued community care to PLWHA and family members is vital. Escalating case loads of clients or patients who seek medical care and continued budget reductions, many organizations and governments have consistently and in recent past recommended CHBC approaches to care for PLWHA and family members as the first line strategy of mitigating the disease and its impacts on PLWHA and family members (van Rensburg 2004).

It is a well-known fact that the HIV/AIDS epidemic had moved beyond public health crisis to a personal, community, and national development catastrophe. Because the epidemic acts at all these levels, efforts to contain it must also act at individual, community, and national levels. One important way of addressing the epidemic at these points is by developing systems, strategies, and capacities to provide care for PLWHA within their own homes and communities. The answer and viable option to the growing number of AIDS clients in need of quality care has been government led and supported introduction of CHBC as a strategy that transfers some of the responsibilities of care from the health facility to the community and ultimately to the family (Stengling 2004; Cataldo et al. 2008).

In sub Sahara Africa, the high prevalence of HIV/AIDS continues to exert pressure on already weak health care delivery system leaving them severely constrained and grossly under sourced (Gathumbi 2007). Poor and run down facilities, lack of medication, overcrowding and a shortage of health care providers are some of the challenges that characterize public health institutions. The increasing number of people getting infected and requiring care can only weaken the system further. There is no doubt that by caring for the sick at home, those who offer support get to learn more about HIV and ways of prevention. The benefits of HBC therefore far outweigh the much more costly hospital system (Russell and Scheneider 2000, Mcnelrney 2005 and Gathumbi 2007). To reinforce the point, in 2002, the World Health Organization (WHO 2002) estimated that between 70% and 90% of HIV and AIDS care took place within the home.

The implementation process of the CHBC programme in Zambia began in 2001. Initially only Non Governmental Organisations (NGOs) like the Catholic Church, World Vision, Family Health Trust and Africare took an upper hand in training CHBC givers. To date NGOs have trained a total of 205 care givers while government under Ministry of Health (MoH) has trained about 84 caregivers in selected health centers under Chongwe District (Chongwe DHMT 2009). The entry points for CHBC services are Voluntary Counselling Testing (VCT), Prevention of Mother to Child Transmission (PMTCT) services, Diagnostic Counselling and Testing (DCT) as well as ART clinic.

While we expect PLWHA to access care in their communities, we need to bear in mind that there are some who may utilize these services and others may not for various belief - based reasons. For those who utilize these services, we need to know whether they are satisfied with the services and what factors influenced utilization of CHBC. In recent years, there has been increasing emphasis by policy makers and managers on issues concerning client satisfaction in the evaluation of health care. This in turn has led to a growing realization of the importance of eliciting consumers' views and opinions, *vis-à-vis* those of the health care professions and health service managers, concerning both the quality of care received and the quality of life experienced because of health care. Recent Government policies concerning the quality care both reflect and reinforce this commitment but studies in this area in Zambia are limiting.

In recent years, there has been an increasing demand of accountability and productivity by consumers globally. It is now a global trend in healthcare development toward integrating subjective user satisfaction into the evaluation of health care service quality (Hudak and Wright, 2000; Urden, 2000). There is evidence that client satisfaction is associated with better care outcomes (Holcomb et al., 1998) though the cause–effect relationship is not clear. It is possible that illness behaviour plays a role in the mechanism through which satisfaction affects clinical outcomes. Ferris and the Health Services Research Group (Ferris, 1992) reported that satisfied clients are more likely than their dissatisfied counterparts to show positive illness behaviours, e.g. complying with their care regimens and disclosing important information to their carers (Aharony and Strasser, 1992). Therefore, knowledge of users’ satisfaction with the service can serve as a performance indicator of better care of services.

## **1.2 STATEMENT OF THE PROBLEM**

It is a widely acknowledged fact that HBC offers a more viable alternative for providing care to persons living with HIV/AIDS as opposed to hospital based care. In sub Sahara Africa, the high prevalence of HIV/AIDS continues to exert pressure on already weak health care delivery system leaving them severely constrained and grossly under sourced (Gathumbi 2007).

HBC is the provision of services in support of the HIV/AIDS care process that take place in the home of an HIV infected person (WHO 1992). This formed continuum of care connects the hospital with the community based on care of people who are infected. In the case of a person infected with HIV, this continuum should start at the time the person is diagnosed with carrying the virus, followed by post test counselling and advised on positive living, including emotional support and be carried through to the point when client actually falls ill with AIDS (UNAIDS 2005). Communities need to be supported in their response to the crisis in form of tangible help and basic information on HIV/AIDS to keep themselves safe and to help those in their care stay healthy and emotionally positive

for as long as possible through HBC (van Dyk 2001).

In Chongwe district, both faith-based and non faith-based organizations provide HBC for HIV/AIDS. In 2006, there were 12 CHBC groups with 126 caregivers (Chongwe DHMT 2006). Currently there are 30 registered CHBC groups and 289 caregivers (Chongwe DHMT 2009). Despite HBC having been widely institutionalized, utilization of CHBC in Chongwe has taken a downward trend over the last few years. In 2005, among 962 people who tested HIV positive, 597 were enrolled on HBC for psychosocial and palliative care, representing 62% and between 2006 and 2009, 2041 patients were enrolled on ART and only 672 were on HBC representing 33%. Hence, this forms the basis for this study.

### **1.3 STUDY JUSTIFICATION**

A continual cohesion commitment between community, governments, organizations and development agencies can achieve an effective programme for PLWHA that can yield major health and social benefits starting from the patients and their families, and consequently to the entire community (Mohammad & Gikonyo 2005).

There is no known study in Zambia to ascertain factors that attract or repel PLWHA to utilizing CHBC. This is also true for sub-Saharan Africa in general. Most literature contains simple descriptions of services and identifies problems with such services without either numbering the problems or identifying and measuring influencing factors. However, the studies acknowledge the important role that CHBC plays in the care and support of PLWHA (Kaleeba et al 1997).

NAC (2009) indicates that one of the strategic objectives in their plan is to strengthen home/community based care and support including access to comprehensive palliative care and pain management.

The investigator conducted a study among clients attending ART clinic and CHBC groups to identify factors that affect the utilization of CHBC services in Chongwe district. The information obtained from this study will bring out clients' and CHBC workers' concerns, experiences and suggestions regarding improvement of service

utilization. Policy makers can use the information to formulate and strengthen already existing strategies needed to support PLWHA as well as CHBC workers.

There has never been an investigation of this nature at national level and this is the first attempt. The research design should act as a blue print for those who may wish to undertake a similar study. The study outcomes have varying impacts in that the findings have included the voice of PLWHA adding value to acceptability and sustainability as well as act as a stimulant to many organizations that run VCT centres and yet have neglected continued care into the community to consider providing CHBC. The findings also act as a stimulant to the government, parliamentarians, NGOs and other stakeholders to join hands in improving CHBC services

## **1.4 PROBLEM ANALYSIS**

The factors that may be affecting utilization of CHBC by PLWHA and determining some elements that may attract or repel users of the service include these outlined below. Details are in the problem analysis diagram (see appendix v).

### **1.4.1 Factors Affecting Utilization of Services**

CHBC is an important strategy in the care and support for PLWHA. Its benefits far outweigh the much costly hospital system (Gathumbi, 2007). However, some known factors that affect utilization of CHBC services could be categorised into three namely; socio-cultural economic factors, service related factors and disease related factors.

#### **1.4.1.1 Socio Cultural Economic Factors**

Many authors suggest that major determining factor in the use of medical care is the economics of access while income is linked to use of services usually in an inverse relationship (Anderson 1994). In the case of CHBC, PLWHA are more likely to seek CHBC services if they are unable to meet the basic needs of their households and meet their perceived services by utilizing CHBC.

### **(a) Age**

Older people are more likely than younger people to be at least temporarily disabled by sickness and therefore in need of care. In other words, actual need for care is the most important reason for increased care as people age (Cockerham 1997). Hospitalization occurs more often for client or patients over the age of 65. Many writers have shown a relationship between age and utilization of health services (Longino et al. 2000). Need modulated by age is not the only factor in the utilization decision. In the case of CHBC, there have been no studies to elucidate this fact.

### **(b) Stigma and discrimination**

ZCC (2003) indicates that isolation and secrecy in dealing with HIV is detrimental to client's health and emotional well-being. The partner, spouse, family and friends enhance care and support. Most PLWHA do not know any other person in the same situation. Lacking a community in which to share their fears and grief, PLWHA remain isolated, secretive and fearful. Marger (1993) stated that clients should be encouraged to attend at least one support group and to utilize community structures such as CHBC, which is possible if the family members are aware about the HIV sero status.

### **(c) Sex**

In general, research has shown that there are inequalities in the manner people respond when they are ill. The effects of inequalities for women accessing both preventive and therapeutic measures services were lower in comparison to men. Some other studies have shown an increased number of male client or patients attending medical services than women in areas where disease rates are practically the same for both sexes (Mckinlay 1992). Whether this can be true for CHBC services, it is yet for approval. There is evidence to prove that women when compared to men have limited access to cash money for coping with illness costs. Bonilla and Rodriguez (1993) once pointed out that women are mainly engaged in the private sphere while men work in the public sphere and that decisions which economically affect the household lie with the male breadwinner. The duo once argued that this situation made women dependent on men for accessing health

services because they depend on the men who control funds (Mwenesi 1993).

#### **1.4.1.2 Disease Related Factors**

The phase at which the disease is may have an influence on how the person would treat the HIV status. Those who would have reached a phase where significant damage to their immunity system has taken place may be more likely to disclose their status and be able to seek care, treatment and support (Marger 1993).

#### **1.4.1.3 Service Related Factors**

This approach focuses on the proximity of services as the determinant of health care utilization (McKinlay 1992). It assumes that the greater the distance the client or patient must travel to receive care, the less likely he or she is to do so. In the case of CHBC, the longer the distance, the less frequent the visits of CHBC groups to PLWHA especially during economic downturns. For example, Oath (1994) showed that distance of travel to clinics in Peru was a determinative variable in utilization. Distance and place are examples of the social context that affect morbidity and mortality as well as behaviour during illness (LeClere et al. 1997, 1998).

##### **(a) Type of Counselling**

Everywhere HIV is prevalent, health services have faced major increase in client or patient numbers and counselling developed often for the first time (ZCC 2003). Counselling people is noble understanding and can exert psychological pressures on the counsellor. Witnessing people suffer and die from HIV/AIDS related illnesses could evoke worry in the counsellor to the extent that the counsellor fails to function competently and professionally. This may result in poor counselling outcome.

##### **(b) Attitude of Caregivers**

There have been reports on the behaviour of staff plus negative attitude and other deficiencies in relation to utilization of health services. Vlassoff (1995) once described how women often are treated in an inferior way by the health system and therefore

hesitate to seek care. This may be true for caregivers of CHBC. Interaction between caregivers and PLWHA appears to be of great importance for the trust and confidence in CHBC system. Consequences of poor attitudes and behaviour of staff has also been described by Greeneich et al (2003) from his experience in Nepal, where health workers frequently responded aggressively to people who finally presented for treatment in terminal stages of tuberculosis. Greeneich concluded that such attitudes may make the client or patients feel threatened, uncomfortable, unwelcome and unwilling to return.

## **CHAPTER TWO - LITERATURE REVIEW**

### **2.0 INTRODUCTION**

This chapter discusses the literature reviewed for this study. This literature review has mainly been on the primary empirical sources contained in scientific journals, books, dissertations both published and unpublished. The commissioning of any research according to Babbie and Mouton (2001) should be in the context of the general body of knowledge. This literature is in three categories and these are global, regional and local perspective.

### **2.1 GLOBAL PERSPECTIVE**

UNAIDS (2008) reports states that 63 million people around the world are living with HIV/AIDS and this is further described as the most severe crises in the world (UNAIDS/WHO 2007). The epidemic has struck especially hard in developing countries which in many other ways are vulnerable and almost two thirds of the infected people live in sub Sahara Africa (UNAIDS/WHO 2007). Globally therefore not many studies have been done in the context of HBC and HIV/AIDS outside the continent of Africa.

WHO Regional Office for South-East Asia developed a unique model for comprehensive CHBC to provide information to countries on how best they can strengthen their community health services to meet the changing health needs and for better utilization of resources. This model place patients/clients at the centre of care and acknowledges the contributions that individuals, groups and communities make in achieving and maintaining their health, and managing illness throughout the lifespan. It provides an overall framework, and includes systems and processes that can be adapted to meet the needs and priorities of local communities. It, however, builds on the existing health system that is available in the community, and aims to make essential care for priority health problems more accessible to the needy, such as Directly Observed Treatment Short-course (DOTS) for the treatment of tuberculosis (TB) and

home-based AIDS care (WHO 2005) that was developed with active involvement of member states.

A study conducted in Mumbai (India) and Bangalore, looked at perception of HIV and AIDS related stigmatization and discrimination across societies of the country. The study revealed that there were responses of ostracism and rejection. The pre dominant effect at the individual level was fear and withdrawal leading to secrecy about HIV status and self imposed social isolation and this led to difficulties in accessing community care and support services such as HBC (UNAIDS 2004).

## **2.2 REGIONAL PERSPECTIVE**

In Uganda's Kaborole and Budingyo communities, primary caregivers for PLWHA are mainly families in a home care programme and offer their services within a district health care system (Anderson 1994, Adebayo et al. 2004). According to the summary of conclusions of a WHO Technical Report based on a study done in developing countries, primary health care systems in developing countries can form the basis for sustainable, cost-effective and long-term care (Campbell and Foulis 2004). The summary further states that it is important to avoid over medicalization of long-term care, to recognize the need for caregiver support, and mostly to avoid the danger of home care being used to justify abdication of public or government responsibility. Developing countries should not adopt the strategies that have evolved in industrialized countries, which often segregate age groups and provide separate health and social services for acute and long term care. HBC should be tailored in a culturally appropriate care and be structured according to the culture and needs of the community (UNAIDS 2005).

Hansen et al. (1998) conducted a study in Zimbabwe on cost-effectiveness of a CHBC project with 60 PLWHA and their caregivers in four HBC programmes. The investigators concluded that the programme costs were high and the schemes did not generally assess effectiveness or cost-effectiveness. The high cost of home visits led to less frequent visits, leaving a larger proportion of both the burden and the cost of care to the families and the client or patients. However, given the lack of a control group, this

study fails to show what would happen if the CHBC services were not available to make a difference. In addition, this study makes an important contribution through its recommendations to CHBC within the context of primary health care model to recognize basic needs. There is also need for higher levels of community involvement and greater use of existing community resources, as it offers effective support to families providing care (Uys and Hensher 2002).

The AIDS Support Organisation (TASO) in Uganda conducted an action research study through its CHBC programme, and evaluated its outcomes (Kaleeba et al. 1997). The results showed that individuals and their families were able to live positively with HIV/AIDS, through counselling, medical care, and material support to clients and their families, TASO has effected a change in people's attitudes, knowledge, and lifestyles. In particular, TASO has shown a strong capacity to overcome four problems that haunt AIDS care in most places and these include revealing one's HIV status to relevant others, accepting the PLWHA in family and community, seeking early treatment, and combining prevention and care. In general, TASO has shown that there is need for specialized services to meet needs of AIDS care to existing health services at district levels.

Results of a study conducted in Zimbabwe among the rural communities to examine their readiness for HIV testing showed that knowledge of HIV status acquired voluntarily in a psychologically and socially supportive environment would be a significant motivator for individuals and their partners to initiate and maintain safer sexual behaviour. It observed the need for a closer link with other services that offer primary prevention, pilot treatment, and support activities such as home-based care. This study showed some preparedness to test for HIV among adults from two rural communities because of such linkages (WHO 2001a). There is a need to build on positive perceptions about testing and embrace a strategy that reduces fear, particularly among women. The initiative must go beyond the individual as the primary target and be promoted within the broader context of the community with the assistance of credible opinion leaders and CHBC groups.

In a collaborative project coordinated by WHO (2001b) on community tuberculosis care in Africa, it was recommended that further research is necessary to determine how to harness the contribution, specifically of HIV/AIDS groups, and how to overcome stigma. Furthermore, the report highlights the importance of further research on extension of treatment for HIV-related diseases (tuberculosis, pneumonia, diarrhoea, etc.) beyond the wards and clinics. The report also stresses the importance of the abolition of the mystery surrounding HIV/AIDS disease in the eyes of those who are hesitant to seek advice, thereby leading diagnosis and treatment of persons. HBC programmes can play a major role in de-stigmatisation of HIV/AIDS in communities served. The preparation has been the major obstacle to the success of any CHBC programme. In essence, the study recognizes the importance of CHBC but the obstacle to utilization of CHBC seems to be stigma associated with HIV/AIDS within communities. UNAIDS (2005) reported that generally there is still poor accessibility and utilization of palliative care services such as CHBC due to stigma.

A study conducted in Botswana (Seloilwe 2000) reported that the quality of CHBC was poor, with an alarmingly high rate of readmission to hospitals of PLWHA with numerous complications. There was also anecdotal evidence of elderly caregivers being HIV-positive, which suggests that they might have become infected during the process of giving care. This then raises a question about caregivers' knowledge of prevention of HIV. The lack of knowledge among home-based caregivers was partly responsible for the quality of care. This finding was in agreement with the study conducted in Blantyre (Malawi), which also showed that lack of prior preparation for HBC was a major factor contributing to poor service (Zimba and McInerney 2001).

WHO (2003) reported that CHBC in Kenya had been sporadic and needs based without any organizational structure or system of delivery in place until the late 1990s. NGO/Faith Based Organisations (FBO) have been initiating most programmes. The Kenyan government's plan was to integrate most CHBC programmes into existing health care and support services by complementing these services. However, the main problem encountered was funding.

In Botswana, the government initiated a comprehensive CHBC programme and in some communities; HIV clients or patients were cared at home with the assistance of CHBC and family caregivers (Lindsey et al. 2003). The problems highlighted were the impact of care giving on older women and young girls, poverty, isolation, stigma, lack of knowledge, and the need for psychosocial support.

Similarly, studies of home-based care from Nigeria (Adebayo et al. 2004) and Swaziland (McCreary et al. 2004) have also highlighted the problem of poor funding of home-based care programmes and the fact that it is mainly left to the NGOs to run, and NGOs often lack infrastructure and sometimes capacity. This continues to happen even though these programmes have shown effectiveness and appreciation by the families and communities served.

### **2.3 LOCAL PERSPECTIVE**

Chaava (2005) in a qualitative descriptive case study explored perspectives regarding skills, supervision and support mechanisms at Chikankata. According to the above study, support to caregivers was not a factor as the HIV/AIDS caregivers were highly motivated (personally and collectively) with very limited support from local health workers. They managed to mobilize resources collectively to meet CHBC clientele delivery needs. This included the local arrangements for training, skills and support of carers aligned to national guidelines regarding process, content and duration of programmes. The carers acquired skills in CHBC through formal and informal training processes as they were facing challenges related to inadequate skills, poor infrastructure and extreme poverty in households caring for PLWHA.

Nsutebu et al. (2001) investigating low coverage of HBC programmes in Africa using two HBC projects in Zambia as case studies found that the very limited involvement of governments in the provision of HBC services appeared to be one of the main reasons behind the low coverage of HBC in Africa. Governments therefore should provide some form of basic HBC services and/or strengthen support to other institutions providing HBC. In order to facilitate governments' involvement in HBC activities, an analysis of

tasks performed by community care providers and volunteers to identify tasks that government, missionary or NGO employed care providers may be able to provide without, or with very limited, donor assistance. However, there is need to conduct further research and to develop affordable, feasible and sustainable HBC programmes that can be implemented by staff working in government, NGO and missionary health facilities. In addition, innovative strategies are required to establish effective partnerships between the NGOs, missionary and government health facilities.

Chela and Siankanga (1991) in a paper discussing Zambia's experience with HBC of PLWHA stated that HBC in Zambia is acceptable to most clients or patients and families, although some clients or patients prefer to visit the out client or patient clinic rather than to have home visits. The dual explained that experience from Chikankata and Katete suggested that stigmatization by the community of the sick individual cared for at home and his/her carers was rarely a problem for the individuals involved. Most care programmes are able to supply foods or other materials for client or patient use in the home, but it is important to achieve a balance between what the client or patient needs and what the client or patient wants. The role of volunteers cannot be overstated; transport has been a problem for all programmes. Furthermore, the spiritual aspect of home care should be emphasised because majority of client or patients are religious.

Mundia (2008) stated that up to 90% of care for clients or patients in developing countries takes place in homes. However, the increased and widespread accessibility of antiretroviral therapy (ART) to PLWHA in Zambia through the public health system is changing the type of demands by the PLWHA on the HBC services. Many formerly bedridden clients or patients are now fit and what they need most is support to restart their livelihoods. They also need support and monitoring of their adherence to ART. Some HBC Programmes have started changing to meet these new and evolving demands, although at a slow pace. The consequence of the delayed response to these changing needs is that PLWHA life status are likely to slide back to PLWHA care and support status due to low adherence and the absence of persistent support and improved nutrition.

## 2.4 CONCLUSION

In summary, the above studies have highlighted the following as some of the challenges facing CHBC:

- Sustainability, cost-effectiveness and long-term care, hence the need to integrate CHBC in primary health care model and recognize basic needs.
- High cost of home visits leading to less frequent visits, leaving a larger proportion of both the burden and the cost of care to the families and the patients.
- Recognition on the importance of home based care in relation to utilization of CHBC, which seems to be associated with HIV/AIDS stigmatization within communities.
- Lack of funding to CHBC groups

In addition to this, literature shows that CHBC is an area of HIV/AIDS care relatively under researched in sub-Saharan Africa. Most literature contains simple descriptions of services and identifies problems with such services without either numbering the problems or identifying and measuring influencing factors. There has been no research to establish cost-effectiveness of using volunteers including patient and family outcomes. There has been no systematic exploration of factors influencing professional supervision and availability of transport for community workers. This is equally applicable to measurement of the actual service and as a result, this affects planning process. There is no documentation of an average medication needs for pain control in different stages of care. The cost of the programme has not been measured, compared, or evaluated. In Africa, the contribution to community/home-based HIV/AIDS care is enormous. However, this has remained mainly in the form of setting up such programmes, often at great personal cost; training and supervising volunteers; and assisting family caregivers directly. Public health researchers have not made an equal contribution by describing and evaluating this practice.

## **CHAPTER THREE - RESEARCH METHODOLOGY**

### **3.0 INTRODUCTION**

This chapter describes the study question, research objectives and research methodology. It comprises the study variables, study design, study population, sample selection, data collection techniques and ethical considerations.

#### **3.1 RESEARCH QUESTION**

What are the factors that attract or repel PLWHA to utilizing CHBC services?

#### **3.2 STUDY OBJECTIVES**

##### **3.2.1 General Objective**

To establish factors affecting utilization of CHBC services for PLWHA in Chongwe district.

##### **3.2.2 Specific Objectives**

- a) To assess the levels of knowledge of PLWHA on CHBC services
- b) To determine whether PLWHA were aware of the roles of CHBC services
- c) To determine the levels of satisfaction with CHBC service delivery by PLWHA

### **3.3 HYPOTHESES**

Linked to the question, the study wishes to test the following hypothesis:

*HO<sub>1</sub>*: Demographic characteristics like sex, educational level, age group are not related to dissatisfaction with service delivery by a CHBC organization.

*HA<sub>1</sub>*: Demographic characteristics like sex, educational level, age group are related to dissatisfaction with service delivery by a CHBC organization.

*HO<sub>2</sub>*: Illness stage is not related dissatisfaction with service delivery by a CHBC.

*HA<sub>2</sub>*: Illness stage is related to dissatisfaction with service delivery by a CHBC.

*HO<sub>3</sub>*: Client satisfaction is not related to the type of help a CHBC renders.

*HA<sub>3</sub>*: Client satisfaction is related to the type of help a CHBC renders.

### **3.4 OPERATIONAL DEFINITIONS**

**Utilization:** means the ability and willingness to use or consume available CHBC services by PLWHA.

**Community Home-Based Care:** means the care given to an individual in his/her own environment by the family and supported by skilled officers and communities to meet not only the physical and health needs but also the spiritual, material and psychosocial needs.

**Counselling:** means a helping relationship, which often involves clients revealing information about their current and past situations, their opinions and innermost feelings.

**HIV status:** means a state of being either sero positive or negative to HIV.

**Stigma:** means labelling, name-calling and distinguishing a person as a disgrace due to one's HIV status.

**Discrimination:** means any form of exclusion, restriction or prejudice due to one's HIV status.

**Disclosure:** means revelation of one's HIV status to others who were not aware.

**HIV:** means the virus that causes HIV infection and AIDS

**AIDS:** a group of illnesses caused by HIV that weakens the immune system

**Satisfaction:** the extent to which the patients feel that their needs and expectations are met by the services provided.

**Access:** availability of CHBC services to PLWHA

### **3.5 VARIABLES**

In this study, the dependable variable was the utilization of community home based care (CHBC) services while the independent variables were level of education, level of knowledge on CHBC services by caregivers, awareness on roles of CHBC by PLWHA, age, distance, accessibility, income, counselling, degree of disease and quality of service.

### **3.6 STUDY DESIGN**

This is a cross-sectional study conducted in Chongwe based on a combination of both quantitative and qualitative methods, with each complementing the other.

### **3.7 RESEARCH SETTING**

The study site for this research was in Chongwe district within Lusaka province. Chongwe district covers an area of around 10,500 square kilometres, with a population of approximately 205, 996 people with an HIV prevalence rate of 16% (Chongwe DHMT 2009). Chongwe district is one of the four districts in Lusaka Province that have implemented CHBC. The district has 23 health centres, 10 health posts and 1 hospital. The Great East Road forms the cornerstone of Chongwe life. On it are bars and shops. The district consists of traditionally built buildings of single storey, with a sprawling market area. Houses in the district are brick built with metal sheet roofs and a few have electricity and running water. The houses in surrounding villages are small and usually built from burnt bricks with thatched roofs. Most of the population is scattered over vast geographical area. People of Chongwe are involved in subsistence farming, cattle-rearing, traditional crafts, including pottery and basket making. These activities provide the local economy with a small diversity of products, such as milk, meat, charcoal and cash crops. The majority of inhabitants live far below the current national poverty line.

Due to the vast geographical area, the scattered population and the lack of transport in communities, adequate access to health services is not available. Furthermore, there is a critical shortage of trained staff of all cadres in all health institutions. Infectious diseases, such as malaria, respiratory tract infections, diarrhoea, and sexually transmitted diseases, including HIV/AIDS, are responsible for high morbidity and mortality among children and adults (Stekelenburg et al., 2002). Similar to the rest of the country and even many parts of sub-Saharan Africa, there is low utilization of health services and poor quality of care in the health institutions.

### **3.8 STUDY POPULATION AND SAMPLE SELECTION**

The study population were PLWHA attending ART clinic and CHBC groups. The sampling strategies used to draw the study population included; randomised systematic sampling, maximum variation sampling (for clients on ART) and purposive sampling (for CHBC providers).

#### **3.8.1 Randomised systematic sampling**

In order to present the sought reality and from which explanations on utilization may refer, this study drew clients as respondents using systematic random sampling based on a sampling frame of ART attendees. The sampling frame had a reliability of over 95%. The sampling decision to include these study elements was for the explicit purpose of obtaining the richest possible source of information to render reality on the service, disease and social cultural factors.

### **3.9 DETERMINATION OF SAMPLE SIZE FOR PLWHA**

Sample size for quantitative data was calculated using Epi info version 3.3.2 stat calc. The total number of PLWHAs on ART for a period of one month at the two study sites was approximately 300. This was taken as the study population.

#### Sample size for quantitative data

- Population size = 300
- Expected frequency = 50%
- Worst acceptable = 55%
- Confidence interval = 95%
- n = 168
- Increased by 10% = 17
- n = 185

The study therefore set to recruit 185 participants.

The inclusion criteria in this study were PLWHA 18 years and above residing in Chongwe who were attending ART clinic and willing to consent to participate in the study. The exclusion criteria were PLWHA below 18 years and residing outside Chongwe district. The exclusion criteria for assessing client satisfaction were on those clients not linked to CHBC.

#### **3.9.1 Purposive Maximum Variation Sampling**

The reasons for using Purposive Maximum Variation Sampling were:

1. The in-depth interview sampling was on purposive or theoretical sampling criteria.
2. Sample selection driven by an evolving theory derived inductively from the data as the research proceeds.
3. The researcher is not interested in adequate representation, generalising findings since the research focuses on getting personal experiences, and the researcher wanted thick descriptions of what was happening.

4. This type of sampling may be appropriate when selecting a sample of clients that needed to represent a wide range of experience related to the phenomenon of interest.

The principle of recruiting clients by maximum variation sampling allowed the researcher to get the most ideal information across the key parameters of CHBC where a random sample cannot provide personal lived experiences. The researcher drew a sample of 27 respondents (13 males and 14 females) purposively from a preliminary descriptive analysis of 93 respondents who were surveyed. From the descriptive analysis, the researcher tried to identify extremes and regularities by looking for respondents with the following characteristics:

- Educational variables
- Age ranges
- Stage of illness
- The type of CHBC provider
- The scores for levels of satisfaction

### **3.9.2 Purposive sampling CHBC providers for FGDs**

The recruitment of caregivers in this study used purposive sampling in order to increase transferability of the study and maximise the range of information by including the views of caregivers. The caregivers were few and there was no sampling frame. In some of such circumstances, researchers opt to use purposive sampling to include presumably typical persons and groups (Kerlinger, 1986; Babbie and Mouton, 2001). Since the researcher was not going to be interested in making inferences about the population with a measurable degree of precision (Lilienfeld and Lilienfeld, 1980), probability sampling for FGDs was therefore not necessary.

### **3.10 DATA COLLECTION**

Data in this study was collected using a researcher administered standard structured questionnaire, one to one in-depth interviews with clients and focus group discussions guide (FGD) with care providers over a period of one month (Appendix ii and iii).

#### **3.10.1 Validity**

Validity is the degree to which an instrument measures what it is intended to measure (Hofstee 2007). There was an extensive literature review to measure validity of the tool before designing the tools and some questions in the tool were adapted from similar studies. Experts in the CHBC programme also checked the questions. The researcher conducted a pre-test of instruments to determine whether they were bringing out the required responses from respondents.

#### **3.10.2 Reliability**

Reliability refers to the degree of consistency or accuracy with which an instrument measures designed attributes intended to measure (Hofstee 2007). In this study to ensure reliability, the researcher used qualitative data reliability process using the Delphi approach. The researcher further consulted various experts to review the instrument before administering it. There were minor alterations during the Delphi meetings. A pilot test was at Kasisi Health Centre with similar demographic characteristics as the actual research sites. The respondents for pre-test were 19, which is 10% of the study sample size. This helped to correct and validate a newly developed instrument to identify flaws or assess time requirements (Polit and Hungler 2001). The purpose of the pre test was also to elicit flaws in the data collection tools, such as ambiguity and illogically sequenced questions and make revisions to strengthen the methodology.

### **3.10.3 In-depth Interviews**

The interview for all eligible clients was in privacy using the structured questions in (Appendix ii) and a tape recorder. The researcher transcribed the results immediately after each interview.

### **3.10.4 Focus group discussions (FGD) guide with care providers**

Participants for the FGD were those who were directly involved in the care and those with extensive organisational ability. The criterion for selection to participate was extensive experience in organisational consulting, as well as being a care provider. Thus, each of the Focus groups had less than 12 participants and held within ninety minutes period. There was prior arrangement for the venue before the session at a location accessible to participants.

There were two FGDs for CHBC caregivers within each ART static study site of which one was with a faith-based organization and another with an NGO CHBC. The study sites included St Luke Mission Hospital and Chongwe Rural Health Centre. Interviews were on tape recorder and transcription of the results was soon after the interview. The tape recorder was set up prior to the participants' arrival. Focus groups used a checklist guide based on open-ended interviews (Appendix iii).

## **3.11 ETHICAL CONSIDERATION**

The University of Zambia attaches great importance to research and ethics and it does not want researchers to take respondents for granted and generally, this is one of the requirements of doing research on human subjects (Bernard, 2000; Hannigan and Allen, 2003; Lothen-Kline et al., 2000). Clients, health centre in charges, the District Medical Office, proprietors of CHBC gave consent while the Biomedical Research Ethics of the University of Zambia gave clearance to conduct the study. The researcher adhered to anonymity and confidentiality of respondents during the whole study process.

## **3.12 DATA PROCESSING AND ANALYSIS**

This is under two sections as follows:

### **3.12.1 Analysis of Interview and FGD Data**

Every evening after data collection recordings, the researcher listened to the recordings over and over. The researcher transcribed main points from the recording. After the transcription was completed, the researcher together with the research assistants transcribed all audiotapes. The researcher acting as a moderator reviewed and analysed the final transcripts for accuracy as compared with written notes taken during each session. If the moderator discovered a discrepancy between written notes and transcript, audiotape was the final alternative for clarity. Next, the researcher coded the transcripts into categories based on regularities of phenomena that were emerging from the data. In the coding process, the unit of analysis included all word groups or sentences that related to CHBC utilization and client satisfaction. The codes were assigned to each category, then entered and analyzed using N Vivo version 6 2.1 software.

Quantitative data was analysed using SPSS-PC to allow production of descriptive statistics. The confidence interval was set at 95%. This means being 95% confident that the sample mean represents the population mean, 5% level of significance has been set, only *P* values of 0.05 or less are considered statistically significant thereby rejecting the null hypothesis.

### **3.12.2 Analysis of Survey Data**

In order to understand data and determine further statistical tests, univariate data analyses were used. The four types of univariate analysis were; socio demographic, utilization of CHBC, satisfaction levels, calculation of composite satisfaction scores and other characteristics of the sample. The calculation of component mean score of satisfaction for each respondent was by summing the values of all valid responses to the items in the component and dividing by the number of valid responses. Thus because there was no rationale for ascribing different weights to items, they were weighed

equally. Then recoded each individual component score to produce an overall satisfaction category for that component

## **CHAPTER FOUR – DATA ANALYSIS AND PRESENTATION OF FINDINGS**

### **4.0 INTRODUCTION**

This study integrates qualitative and quantitative data while looking at them in combination in order to get a deeper insight of the problem under study and possibly inspire a deeper and more rewarding analysis. For easy presentation of the findings, the study is described using the themes in the research questions to help the reader follow the findings of the research. Between the months of December, 2010 and January, 2011, a total of 161 survey questionnaires were administered to PLWHA in addition to four FGDs which were conducted with service providers.

### **4.1 QUANTITATIVE DATA ANALYSIS**

Under quantitative data, as there was no sampling frame for PLWHA that were accessing CHBC, the researcher used a sampling frame of people on the ART register and who were attending reviews to enlist potential respondents of those who were accessing or who had at one time accessed CHBC. A preliminary analysis revealed that the respondents in this study were all residents of Chongwe and out of 161 ART recipients; only 57.7% (93) of the respondents were accessing and had accessed CHBC leaving out 42.3% (68) as not being eligible for further study in terms of eliciting satisfaction with CHBC. Based on the utilization indicator, which was set at the time of the study, utilization can be said to be high (> 50%).

Given that, the analysis needed to be restricted to persons who had a CHBC experience, this study presents first the general profile of the 161 respondents who were on ART and thereafter concentrates on the 93 PLWHA who had an experience with CHBC. In this way, it was possible to study all variables related to this sub sample. The presentations of findings of this research are in the form of tables, graphs and pie charts to give vivid illustrations of findings under the following areas:

- Demographic characteristics
- Awareness of PLWHA on CHBC services
- Quality of service
- Disease progression
- Counselling sessions

#### 4.1.1 Demographic characteristics in line with inclusion criteria

**Table 1: Demographic characteristics of ART respondents n = 161**

<b>Parameter</b>	<b>Sex distribution</b>		
<b>Age Group</b>	<b>Male</b>	<b>Female</b>	<b>Total Percentage</b>
18 – 27 years	37 (23)	27 (16.8)	64 (39.7)
28 – 36 years	34 (21.0)	51 (31.7)	85 (52.7)
Above 37 years	5 (3.1)	7 (4.3)	12 (7.5)
<b>Total</b>	<b>76 (47.2)</b>	<b>85 (52.8)</b>	<b>161 (100.0)</b>
<b>Marital Status</b>	<b>Frequency</b>		<b>Total Percentage</b>
Single	50 (31.1)	51 (31.7)	101 (62.7)
Married	19 (11.8)	11 (6.8)	30 (18.6)
Divorced	7 (4.3)	23 (14.5)	25 (18.6)
<b>Total</b>	<b>76 (47.2)</b>	<b>85 (52.8)</b>	<b>161 (100.0)</b>
<b>Religion</b>	<b>Frequency</b>		<b>Total Percentage</b>
Christian	75 (46.6)	83 (51.6)	158 (98.1)
Other	1 (0.6)	2 (1.2)	3 (1.9)
<b>Total</b>	<b>76 (42.7)</b>	<b>85 (52.8)</b>	<b>161 (100.0)</b>
<b>Educational Status</b>	<b>Frequency</b>		<b>Total Percentage</b>
Primary	49 (30.4)	78 (48.5)	127 (78.9)
Secondary	22 (13.7)	3 (1.9)	25 (15.5)
Tertiary	5 (3.1)	4 (2.5)	9 (5.5)
<b>Total</b>	<b>76 (42.7)</b>	<b>85 (52.8)</b>	<b>161 (100.0)</b>
<b>Occupation</b>	<b>Frequency</b>		<b>Total Percentage</b>
Formal employment	20 (12.4)	10 (6.2)	30 (18.6)
Self employed	40 (25.6)	44 (27.3)	90 (52.2)
Unemployed	16 (10)	31 (19.2)	47 (29.2)
<b>Total</b>	<b>76 (42.7)</b>	<b>85 (52.8)</b>	<b>161 (100.0)</b>
<b>Income</b>	<b>Frequency</b>		<b>Total Percentage</b>
K1, 000,000 and above	11 (6.8)	6 (3.7)	17 (10.6)
K500, 000- K1, 000,000	14 (8.7)	2 (1.2)	16 (9.9)
Below K500, 000	51 (31.7)	77 (37.9)	128 (79.5)
<b>Total</b>	<b>76 (47.2)</b>	<b>85 (52.8)</b>	<b>161 (100.0)</b>

Table 1 illustrates the demographic profile of the sample population under study. It

shows that majority 85 52.7% (85) of the respondents were in the age group 28 to 36 years. Within the same age group, female were a majority 31.7% (51), while males were 21.0% (34). However, in the age group 18 to 27 years, majority were males 23% (37), while 16.7% (27) were females. This therefore may indicate that 28-36 years age range is the most affected by HIV/AIDS.

The table also shows that majority 62.7% (101) of the respondents were single and the number of single women almost equalled that of men 31.7% (51). This shows the extent of support that PLWHA need in terms of care.

Nearly 98.1% (158) of the respondents were Christians and only 1.9% (3) was from other denominations.

The educational status of respondents was low. Majority 78.9% (129) had only attained primary education and out of these 48.5% (78) of them were females.

Within this sample, more than half of the respondents 52.2% (90) were not in formal employment but were rather self-employed and 19.2% (31) of the unemployed respondents were females. It was generally, expected in this rural place that most of the respondents would be unemployed because of limited employment options in formal organizations.

The incomes in this sample were very low. More than 79.5% (128) of the respondents had incomes below K500 000 from their income generating activities while only 10.6% (17) of the respondents earned above one million kwacha. This clearly meant that majority of the respondents were in need of financial support.

**Table 2: Measurement of age n= 161**

<b>Measure</b>	<b>Age last birthday</b>
Mean	28.7
Median	29.00
Mode	29.00
Std. Deviation	5.75
Variance	33.11
Minimum	18.00
Maximum	46.00

Table 2 shows that the sample population was relatively young. The youngest among the respondents was 18 years and the oldest was 46 years of age. The mean sample age group was 28 with SD  $\pm$  5.7.

#### **4.1.2. Awareness on CHBC**

##### **Knowledge Levels of PLWHA on CHBC services**

The establishment of linkages between knowledge on the existence of CHBC services and utilization was through an assessment of knowledge gaps among PLWHA.

**Table 3: Awareness of CHBC = 161**

<b>Awareness of local CHBC</b>	<b>Frequency</b>	<b>Percentage</b>
Aware	115	71.4
Not aware	46	28.6
<b>Total</b>	<b>161</b>	<b>100</b>

Table 3 above shows that within the study sample, majority (71.4%) of the respondents knew of the existence of CHBC in their area whereas 28.6% did not. Thus when probed further, one respondent stated that they came to know about CHBC after a feeling of self-stigma and blaming one-self of having been careless. He said, *“I remember how I felt. I did not want to live. I was struggling to take my life I felt I had brought mischief upon my family. However, as things work out sometimes, my wife brought me in the church and that was how I was connected to a CHBC.”*

**Table 4: Access to CHBC n = 161**

<b>Access to CHBC</b>	<b>Frequency</b>	<b>Percentage</b>
Present	52	37.3
Absent	109	62.7
<b>Total</b>	<b>161</b>	<b>100</b>

Table 4 above shows an attempt to try to find out how many PLWHA had access to CHBC during the critical phase of their therapy. This study has revealed that majority (62.7%) of the respondents did not have access to CHBC while only 37.3% had access. This therefore means that as PLWHA get critically ill, they stop accessing the service.

**Table 5: Provision of service by CHBC to PLWHA n = 161**

<b>PLWHA receiving care</b>	<b>Frequency</b>	<b>Percentage</b>
Receiving care	88	54.7
Not receiving care	73	45.3
<b>Total</b>	<b>161</b>	<b>100.0</b>

Table 5 shows that majority (54.7%) of the respondents had been receiving help from CHBC as compared to 45.3%. However, even though a greater number did not access CHBC (table 4) when they best needed it during the critical phase, they still felt that whenever it was made available they felt satisfied.

**Figure 1 Knowledge on CHBC activities n = 161**

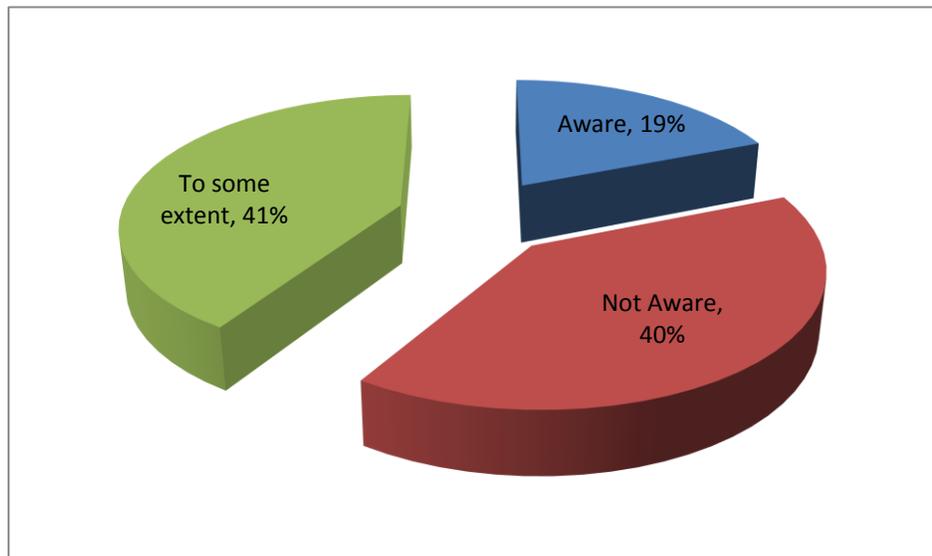


Figure 1 above shows that 81% (130) of the respondents knew about CHBC although some (19%) appeared not to be sure to extent of their existence. This information corresponds with information obtained from qualitative data where a mother of two and widowed said, *“I did not know what the organization offered prior to entry into a treatment programme”*. This shows that there was little publicity about the organizations providing CHBC even though their services were of value to the PLWHA.

**Table 6: Contact with local CHBC n = 93**

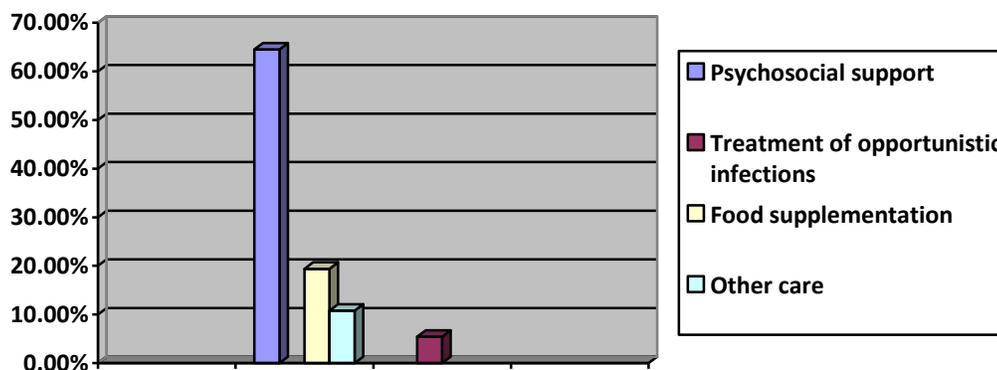
Organisation	Frequency	Percentage
Faith-based organization	79	85
Nongovernmental organization	13	14
Government	1	1
<b>Total</b>	<b>93</b>	<b>100</b>

Table 6 shows that majority (85%) of the respondent’s contacted FBOs while 14% had contact with NGOs. This point is more illustrated by one respondent who said, *“I did not know what to expect, or how one CHBC might be different from another. He felt that the church was better than NGO. When asked how they learnt of organisations, most of the respondents said through friends and some members of a charismatic church who visited*

them. What this means is that some PLWHA had no idea about what CHBC do although they had high regard for faith-based CHBC and this could have been through previous encounters with the church in different circumstances compared to the NGO-based CHBC. This may also be due to that faith-based CHBC groups were closer to the communities than other service providers were.

#### 4.1.3. Quality of service

**Figure 2: Types of services provided by CHBC n = 93**



When respondents were asked about types of services they received from CHBC organizations, they indicated a range of services and these included psychosocial support, treatment of opportunistic infections and food supplementation. Figure 2 above shows that the most frequently cited task performed by CHBC was psychosocial counselling (64.5%) while other services like; treatment of opportunistic infections, food supplementation and other services were not among the top most activities performed by the organisations.

**Table 7: Relationship between provision of care and level of satisfaction**

Type of care	Level of satisfaction		Total	P- value
	Satisfactory	Unsatisfactory		
Psychosocial support	60 (64.5%)	0	60 (64.5)	< 0.001
Food supplementation	18 (19.4%)	0	18 (19.4)	
Treatment of opportunistic infections	5 (5.4%)	0	5 (5.4)	
Visitation	4 (4.3)	6 (6.4)	10 (10.8)	
<b>Total</b>	<b>87 (93.5%)</b>	<b>6 (6.4)</b>	<b>93 (100)</b>	

$$X^2 = 2.131$$

In this section, the four critical ranges of services reported were, psychosocial support, food supplementation, treatment of opportunistic infections and visitation. When PLWHA, were asked about how satisfied they were with the services they were receiving, it was evident that out of the four service areas, PLWHA were satisfied with psychosocial support only. Generally, we can say that there was a significant association between kind of care received in particular psychosocial counselling and satisfaction to service provision ( $P < 0.001$ ).

**Table 8: Satisfaction of non-critical care components n = 93**

Satisfaction parameter	Level of satisfaction		Total
	High	Low	
Counselling sessions	71 (76.3)	22 (23.7)	93 (100)
Visitation	81 (87.1)	12 (12.9)	93 (100)
Care giver attitude	37 (39.8)	56 (60.2)	93 (100)
quantity and quality of the supplies	38 (40.9)	55 (59.1)	93 (100)

When asked on non-critical care components for satisfaction, the results showed that PLWHA were satisfied with counselling services and visitations but were dissatisfied with the staff attitudes that were exhibited as well as the quantity and quality of the supplies.

#### 4.1.4. Disease progression

**Table 9: The severity of illness n = 161**

<b>Illness Stage while on ART</b>	<b>Frequency</b>	<b>Percent</b>
Chronically ill but able to perform daily living activities with assistance	66	41.0
Recovered	62	38.5
Chronically ill, bedridden and unable to perform daily living activities	33	20.5
<b>Total</b>	<b>161</b>	<b>100.0</b>

Table 9 above shows that within the sample more than half (61.5%) of the respondents were chronically ill. Thus, those who were visited and were chronically ill but in critical phase (Bedridden and unable to perform daily living activities) were 20.5% (33) and those who were chronically ill but with minor symptoms (able to perform daily living activities with assistance) were 41.0% (66). About a third 38.5% (62) had recovered while receiving ART.

**Figure 3: Period on Antiretroviral Treatment n = 161**

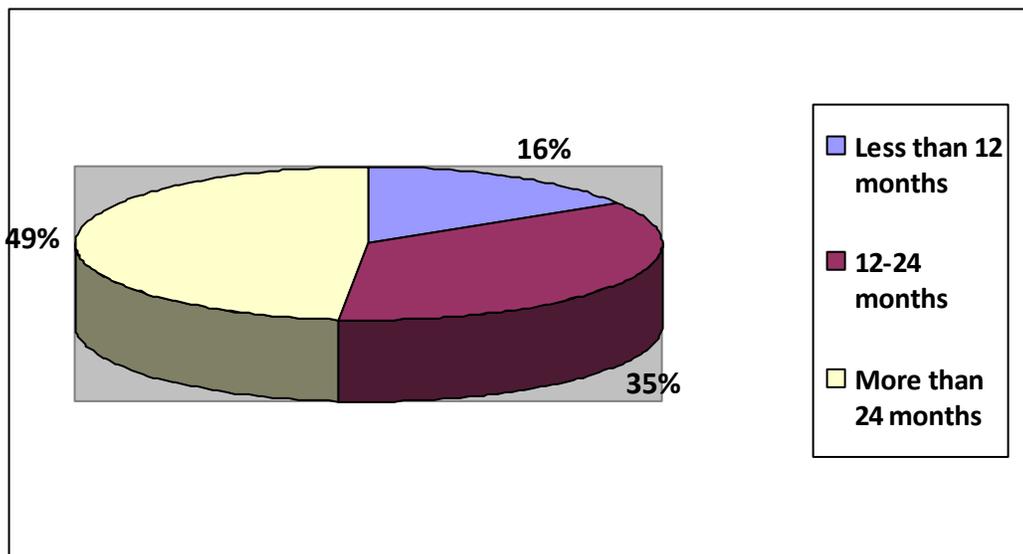


Figure 3 above shows that majority (83.8%) of the respondents had been on ART for more than 12 months with only 16.1% on ART for less than 12 months.

#### 4.1.5. Counselling sessions

**Table 10: Counseling sessions during early visitations at the health centre n = 161**

<b>Encountered counselling Sessions</b>	<b>Frequency</b>	<b>Percentage</b>
1-2 sessions	32	19.9
3-4 sessions	106	65.8
5 and above sessions	23	14.3
<b>Total</b>	<b>161</b>	<b>100</b>

Noting the importance of onward counselling, PLWHA were asked the number of times they were counselled. In this study, most of the respondents revealed that they have had more than one session majority being 3-4 sessions according to table 10.

**Table 11: Average duration for counseling sessions n = 161**

<b>Duration of counselling in minutes</b>	<b>Frequency</b>	<b>Percentage</b>
Less than 10	30	18.6
10-20	103	64.0
21-30	28	17.4
<b>Total</b>	<b>161</b>	<b>100.0</b>

Table 11 reveals that while majority of respondents had more than two sessions, the mean estimate time for counselling was 18 (SD  $\pm$  1: 5.46) minutes. The shortest session lasted less than 10 minutes and the longest lasted 30 minutes. This therefore means that counselling sessions for majority of PLWHA was for less than 18 minutes. This is far below the recommended national average of 25 minutes.

**Table 12: PLWHA referred to a Local CHBC in relation to seriousness of illness n = 161**

Stage of illness	Referral of PLWHA to CHBC		Total	P- value
	Referred	Not referred		
Chronically ill and able to perform daily living activities	31 (19.3)	35 (21.7)	66 (41)	0.113
Chronically ill, bedridden and unable to perform daily living activities	13 (8.1)	20 (12.4)	33 (20.5)	
Recovered	18 (11.2)	44 (27.3)	62 (38.5)	
<b>Total</b>	<b>62 (38.5)</b>	<b>99 (61.5)</b>	<b>161 (100)</b>	

$X^2 = 4.358$

Table 12 reveals that among people on ART, majority (61.5%) of the respondents were not referred to a CHBC group in spite of the fact that some of these were at one time critically ill. This means that most health care workers in the health centres did not consider illness stage as a factor for referring a person to a local CHBC. This study has further revealed that there was no significant association between referral and seriousness of illness ( $P = 0.113$ ).

**Table 13: Explanation of benefits for CHBC during Counselling n = 161**

Benefits for CHBC	Frequency	Percentage
Not explained	93	57.8
Explained	68	42.2
<b>Total</b>	<b>161</b>	<b>100.0</b>

Table 13 above shows that majority (57.8%) of the respondents were not informed on the benefits of receiving CHBC services during counselling sessions. This therefore means that issues related to CHBC were poorly included as topical issues.

The low rate of addressing benefits of CHBC among counsellors includes many factors such as amount of time spent with clients. For example, most PLWHA came to know about CHBC through friends, members of the church or when catastrophe was imminent and word went round and a CHBC giver came in.

## **4.2. QUALITATIVE DATA ANALYSIS**

Qualitative data were collected using focus group discussions. A comprehensive FGD guide was developed in order to ensure that appropriate quality data was collected..

The FGD elicited information pertaining to various aspects of the role of caregivers in the community and problems associated with the provision of HBC to PLWHA. It captured the following information:

- Community home-based care profile focusing on existence of the organisation and services offered by CHBC
- Knowledge on HIV/AIDS and CHBC
- Quality of service covering areas of training of caregivers and the common challenges faced in the field.

### **4.2.1. CHBC profiling**

Information obtained from the hospital and the district health office revealed that there are about 43 CHBC groups falling under the FBO (Catholic Church and Churches Health Association of Zambia (CHAZ)), World Vision and Ministry of Health. Majority of these HBCs are inactive due to certain challenges such as inadequate supervision and lack of material and financial resources. When HBCs were initiated both men and women were encouraged to belong to the groups but in due process, mostly men find jobs in the newly opened farms and drop out and hence majority of the caregivers in the HBCs are women.

Most CHBC groups reported to have been in existence since 2004. The earliest was the Catholic Church HBC, which started operating as early as 2002. Its structure seemed well established than government led groups under Ministry of Health. Furthermore, government-led groups had been in operation since 2002 but not in comparison to those under faith-based organizations (FBOs). This is partly due to lack of support from the government health facilities, while the faith-based groups receive support from the

respective churches. The client ratio for the FBOs is one caregiver to four clients, (1:4) while for the government it is not clearly stated. Biblical teaching of caring for the sick and under-privileged people motivated the faith-based home based caregivers. For example, one caregiver stated that, *“The Bible teaches to love your neighbour as you love yourself”*. Yet another caregiver said, *“I feel good visiting sick people and helping them out in their difficulties although I do not have enough to share with them”*. Therefore, HBC perceived as a way of showing the love of God to those who are weak and are in need of help.

#### **4.2.2. Services offered**

The main services that FBO community home based groups offer are psychosocial support, spiritual support, food supplementation though quite erratic supplies. When FBOs had just started, they were treating some minor opportunistic infections. This was the time they were being given some community home based care kits which contained some ORS, a tablet of soap, a bottle of vaseline, some iron tablets and a roll of bandage. This acted like another motivating factor to the caregivers. The government-led CHBC groups also used to receive some kits but could not go round all the caregivers, as they were inadequate.

Nowadays even if they visit their clients, they have nothing in material form to offer apart from spiritual support, assisting with household chores such as fetching water and firewood, cleaning the surrounding of those who are unable to perform daily living activities and washing.

#### **4.2.3. Knowledge about HIV/AIDS**

When asked to state what type of care they should give to PLWHA, they were able to state such things like; counsel and test some family members when they had test-kits, give spiritual and psychosocial support, give food supplementation and help with homes chores.

Regarding HIV/AIDS on causes and transmission, almost all caregivers were knowledgeable about the modes of transmission and protection when giving care but complained of not having such things like gloves to use. They also had inadequate knowledge on detection of early manifestation of some opportunistic infections and remedies that could help their clients. Apart from one training manual that a district facilitator had, the caregivers did not have written guidelines they could refer to when in need.

#### **4.2.4. Quality of service**

The FGDs revealed that most of the caregivers received basic training on HIV/AIDS for an average period of five days. The trainings period varied (3-5 days) from those who recently trained to those who had their trainings more than 3 years ago. Most of the caregivers barely went to school. Only a few had attained grade nine and grade 12 educational levels. The common areas covered during training included; knowledge about HIV/AIDS, nutrition for PLWHA, management of minor opportunistic infections and general hygiene. Emphasis is mainly on psychosocial counselling, as this is an area, which almost all the PLWHA must have competence. The caregivers complained of lack of refresher courses. For example, those who trained before the introduction of ART lack knowledge about ART. In terms of follow up and supervision after training there was little or nothing done and this usually leads to demotivation of the volunteers especially those falling under NGOs and the church. The training manuals were also not standardized and this was evident by varying durations of training.

#### **4.2.5. Operational Challenges**

##### **4.2.5.1. Distance**

Most caregivers do not have means of transport to help move between clients. This demotivates them, leading to inactivity of most CBHC groups. The average walking distance between the caregivers and the client is 1-2 hours but it can be as short as less than 30 minutes in certain instances.

#### **4.2.5.2. Lack of supplies to give to clients**

Most CBHC groups complained of not having things like food supplements, remedies and drugs for simple opportunistic infections. They said some PLWHA had accused them of hiding food supplements and fertilizers meant for them from well-wishers but in fact, most of the caregivers do not receive any such materials. Where there are income-generating ventures managed by caregivers, the PLWHA accuse caregivers of using both the income and inputs on themselves. This is one reason of repulsion by PLWHA towards caregivers.

#### **4.2.5.3. Lack of support from health facilities**

One of the major challenges is the lack of support from health facilities. For example, in the days when CBHC began, there was close relationship between caregivers and health staff shown through visitations to clients by both caregivers and health workers. Nowadays this relationship is non-existent and it makes the work of caregivers difficult.

#### **4.2.5.4. Lack of recognition by the health care system**

The caregivers complained of not receiving recognition of their work by the health system shown through lack of meetings between them and the health facilities. It seems as though no one really cares about the contribution of CBHC to the general management of PLWHA.

#### **4.2.5.5. No formal system of referring patients to health facilities**

Caregivers complained of not having a formal system of referring their clients and reporting their activities. This was in spite of them living within the community and close to PLWHA. Thus according to them, this disadvantaged the PLWHA because of delayed in the delivery of care.

#### **4.2.5.6. Case finding vs. transportation of clients to health facilities**

Lack of transport to take patients to health facilities from their homes is another challenge. Even when they request health facilities to assist them, the answer given to

them is that the policy of MoH is not to pick patients from their homes but from health facility-to-health facility.

#### **4.2.5.7. Lack of refresher training**

Almost all caregivers complained that they neglected after training because no one bothers to follow them up. No refresher courses are organised for them to update them on their knowledge and skills in line with changes taking place in care and support for PLWHA.

### **4.3. ATTRACTION AND REPULSION SCORES FOR PLWHA TO CHBC SERVICES**

#### **4.3.1. Attraction scores**

This study has revealed that there were no significant association between demographic factors and service utilization. When asked PLWHA on the service areas, they seemed to agree that they were only able to report about what was available and not what they expected to be done. However, there were certain qualities of attraction for CHBC that needed highlighting and these are as follows:

- Interpersonal relationships of service providers
- Empathy from service providers
- Confidentiality (PLWHA regard confidentiality important on human issues)

Some PLWHA expressed satisfaction with CHBC programming regarding individual and group therapy. They described how both group and individual sessions with their therapist were helpful in their recovery. For example, the strength of group therapy session allows them to see that we are not alone, as there are others in the same situation. It is comforting for clients to discover that “it’s not just me.” They need to know that there are other people like them and they are not the only ones.

### 4.3.2 Repulsion scores

Some of those who were dissatisfied referred to care giver factors such as not wanting any “uncertified” person treating them. In addition, confrontational, harsh attitude and reminding clients of what they did wrong in life was not helpful by PLWHA.

#### 4.3.2.1 Social barriers to uptake of CHBC

There are some PLWHA who could not continue with CHBC because of personal apprehension, service constraints and fear of inadvertent disclosure or false rumours by caregivers. The same sentiments was equally echoed during focus group discussions with caregivers some of whom stated that, certain clients were not comfortable with caregivers visiting them wearing t-shirts labelled “caregiver” because they became subjects of rumours. This eventually led to drop out soon after they pick up form their ill health.

**Table 15: Repulsion and Attraction Scores**

Deviation from $\mu$	Satisfaction Score	Frequency	Percentage
-2SD	6.00	15	16.1
	7.00	12	12.9
-1SD	8.00	3	3.2
	9.00	2	2.2
	10.00	2	2.2
	11.00	7	7.5
<i>Sample <math>\mu</math></i>	12.00	5	5.4
+1SD	13.00	6	6.5
	14.00	9	9.7
	15.00	6	6.5
	16.00	2	2.2
	17.00	6	6.5
+2SD	18.00	7	7.5
	19.00	3	3.2
	20.00	3	3.2
	21.00	2	2.2
	22.00	1	1.1
+3SD	24.00	1	1.1
	28.00	1	1.1
Total		93	100.0

Table 15 shows 11-point Likert-type scale score for each of the six items. This summed up the values of each respondent to determine which repulsion and attraction scores were above or below the mean. Although PLWHA have shown that they were satisfied with psychosocial counselling and visitations, they were dissatisfied with the exhibited attitudes and the quantity and quality of the supplies. What we can generally say, by looking at attractions and repulsion scores in the domain of technical quality of care, is that most respondents  $n = 47$  got higher attraction scores to access CHBC. Their scores were above the mean personal attraction and repulsion score of 12.47 (SD  $\pm 5.14$ ) as compared to those respondents  $n = 41$  who got lower repulsion scores not to access CHBC.

#### **4.4 SUMMARY ON THE UTILIZATION AND SATISFACTION OF SERVICES**

In summary the factors that determine service utilization and satisfaction from the quantitative and qualitative analysis appear in table below:

This study has revealed that there was significant association between income with level of education ( $P < 0.001$ ), type of income generating activity and sex ( $P < 0.001$ ). Further, it has also been established that if one was more educated and was a man by sex and had an income generating activity, the chance of having a better income were higher than for woman. In this sample, majority of the respondents had bare education that accounted for 64.6% (104), followed by those that had attended primary school of which 44 and 60 were men and women respectively. However, in spite the fact that at face value it appeared that more respondents were women than men who had been to school, the school attendance sample was higher for men (84.2%) than the women (64.7%). It was not expected that the school attendance rates could be this high in a rural area of Chongwe.

This study has proved all hypotheses correct with  $P = 0.05$  level and Chi square tests proved significance result. The decision was that if the obtained  $\rho$  value was less than or equal to 0.05, then there was a significant association and where  $\rho$  value was greater

than to 0.05, then there was no significant association. Tests of significance showed that all the demographic characteristics, illness stage and distance were not key factors to CHBC access or utilization.

## **CHAPTER FIVE – DISCUSSION OF FINDINGS**

### **5.0 INTRODUCTION**

The first element in this section relates to the summary of the findings that have arisen from the overall research question and the objectives that directed this inquiry. The researcher then makes an analysis and inferences from previous research findings in order to illuminate the research problem, elaborate and corroborate facts with previous research in the area of CHBC.

Community Home Based Care (CHBC) in a community setting is essential in delivering health services that are supportive of the public health system and when integrated into the general health care. Identification of patient requests, needs, and judgment on health care received is the starting point of a patient centred approach (Baker, 1991; Joos et al., 1993). Therefore, patient satisfaction is considered as an important measure to evaluate the quality of health services and a measure to predict compliance and utilization (Roghmann et al., 1979) associated with the continuity of care (Williams and Calnan, 1991), the health workers' communication skills (Weiss and Ramsey, 1989) and confidence in the health care system (Weiss,1988).

This study assessed the overall utilization and satisfaction for home based care services in Chongwe provided by CHBC organisations; and it showed the following:

### **5.1 DEMOGRAPHIC CHARACTERISTICS**

Demographic factors like age, sex, level of education and illness stage played no significant role in accessing CHBC and that these factors played no role in receiving satisfactory services. From the perspective of gender, though previous research links it well, our study has shown no association at all. This may of course relate to the non-differential utilization patterns and experiences of health care by gender and it may

reflect the non-differing needs and expectations of men and women. In general, this study seems to support the point made by Weiss (1988) that factor other than socio-demographic characteristics influence level of satisfaction invariably in different social settings. What we can now say is that patient background characteristics are among the most difficult to relate to the level of satisfaction. Therefore, satisfaction and dissatisfaction are just products of service delivery and provider characteristics and especially attitude and skill. Thus concerning issues of age, gender and educational levels, it is clear that although they appear not to influence satisfaction, further research that is required in order to try to unravel other possible explanatory factors.

Regarding educational level, there are different findings with the present work. Babic-Banaszak et al. (2001) for instance reported that less educated patients were generally more satisfied, since they are less demanding. Ayatollahi (1999) also found that level of education correlated with satisfaction. The finding in our study may in our view, reflect real similarities in the experience of health care between generations of patients who may have similar levels of education.

## **5.2 UTILIZATION LEVELS**

The level of CHBC utilization was just over 50%. The level of those who at least had an encounter with a CHBC was 57.7% though at the time of the study, the numbers of those who were actually being attended to had gone down to 54.66%. A greater number within the population in Chongwe of PLWHA did not access CHBC when they were in the critical phase which time they best needed help.

## **5.3 KNOWLEDGE LEVELS**

Only a small number of PLWHA who were on ART 41.1% (66) were aware of what CHBC were doing whereas 39.8% (64) doubted and 19.3% (31) knew nothing. This could be attributed to the fact that during counselling not much time is allocated to discuss what CHBC is all about.

## 5.4 SATISFACTION SCORE

PLWHA were satisfied with only psychosocial support. Generally, we can say that there was a significant association ( $P < 0.001$ ) between type of care received and in particular psychosocial counselling. When assessment of other non-critical care components for satisfaction was done, the results showed that PLWHA were satisfied with counselling services and visitations but were dissatisfied with the attitudes that staff exhibited as well as quantity and quality of the supplies.

Generally PLWHA were more attracted than repulsed at attending CHBC because attraction scores to access CHBC were above the mean score of 12.47 (SD  $\pm 5.14$ ). This study shows that, client or patient satisfaction is an important component in palliative care in addition to multiple reasons. First, client or patient satisfaction in this study has shown that it is an indicator of the good quality of psychosocial counselling and not the overall general care in CHBC.

This study has revealed that though clients were satisfied with psychosocial counselling and the technical quality of its provision, satisfaction scores could be high for such organisations that operate on voluntary basis than public organisations. It could be said that these PLWHA who were satisfied, had indeed a positive perception of CHBC even when they were not provided with other forms of care like; treatment of opportunistic infections, provision of supplementation food and financial assistance. When clients or patients leave the CHBC satisfied with the care provided which they would not get from public institutions, they often show this appreciation through their attitudes and expressions as evidenced during the interview.

In line with previous findings, this suggests that whilst general levels of satisfaction are high and utilization is somewhat moderate, questions of a more detailed analysis of interviews reveal a satisfied sample punctuated with greater levels of expressed dissatisfaction.

PLWHA seemed to be satisfied with psychosocial counselling and visitations. However, they were dissatisfied with treatment of opportunistic infections, food supplementation and financial assistance, which appear to be of greater importance to PLWHA than psychosocial counselling because there are tangible. Relationship between basic socio-demographic variables and client satisfaction with primary care services did not reveal age, educational status and sex as important factors to service utilization and satisfaction. This is in agreement with Gadallah et al. (2003) who found that there was no association between overall patient satisfaction and age, gender, or education level. However, findings of this study are contrary to what other studies have found in the recent and too distant past (Al- Doghaither, 2004; and Kuzuya et al. 2008) although none of these relationships is particularly strong.

Furthermore, previous studies have shown that there is an association between patients' satisfaction and age distribution. The oldest group of respondents seems to be less satisfied with issues surrounding the primary care of services than younger patients. Those over 65 years of age are not easily satisfied with care because they generally expect less care from their providers (Saeed et al., 2001; Al-Faris et al., 1996; Al-Doghaither, 2004).

## **CHAPTER SIX – CONCLUSION AND RECOMMENDATIONS**

### **6.1 CONCLUSION**

Empirical investigation demonstrates that it is possible to identify important associations between utilization and satisfaction in CHBC. Exploratory and descriptive case studies like this one using local survey data could provide clue for CHBC services in settings similar to Chongwe. Thus noting that utilization and knowledge of CHBC is not very satisfactory, there is a need to educate the public through various media on what CHBC do and what types of CHBC organizations may be in an area. There is need to consider providing care beyond the current psychosocial support.

### **6.2 RECOMMENDATIONS**

In order to improve home based care in Chongwe, the following are recommendations directed to the National AIDS Council, Ministry of Health and Faith based organizations:

1. There is need for the National AIDS Council to develop CHBC models for all Home Based Care groups.
2. At the district level, there is need to earmark funding, preferably with incentives for volunteers. There is need to write proposals for such funding because budgetary allocations from the Ministry of health do not cover such undertakings.
3. It is necessary to train a sufficient number of care providers. To do this, faith-based organisations, which seem to be in the forefront may have to pool resources for this undertaking and should be in partnership with Chongwe District Health Management Team.
4. We recommend that Faith Based Organisations consider introducing new services. These should include developing a package for treatment of

opportunistic infections, food supplementation, financial assistance and transport provision among others.

5. There it is necessary to integrate and harmonise Chongwe home based care into a variety of other structures especially the health centre. This may reduce the risk that well-organized small-scale services fail to scale up and achieve wider impact. This requires engagement with the institutionalized health care system, as well as systems of family and community support. This includes village headmen, lay counsellors and other significant people in the community. There is also need to engage cultural, spiritual and socioeconomic support systems together with the efforts of both governmental and nongovernmental agencies. Therefore, there is need to integrate general health care with the mainstream of health care practice and social care.

### **6.3 LIMITATIONS OF THE STUDY**

In spite of the care taken at every stage of this research, there are several limitations to our study, but also potentially fruitful areas for further research. The following are some of the notable limitations:

1. The results should be accepted because they are generalizable across Chongwe. However, as usual in such survey research, the broad generalizability of these results to other districts cannot automatically be assumed.
2. This study involved a cross-sectional survey. This means, data was gathered at one point in time. As such, it offers a static view. An interesting area of research could be the use of the measure to track utilization and satisfaction over time to investigate how utilization and satisfaction changes over time. Research that measures utilization and satisfaction over several time periods could also assess how the relative importance of variable dimensions change over longer time periods. Therefore, the research should be replicated not only in diverse environments, but also over time to increase confidence.

3. It should be noted that we collected data in retrospect. Retrospective capture of views about the quality of services and satisfaction runs the risk of recall bias, but time delays in eliciting experience can be useful because satisfaction immediately after an episode of service utilization tends to reflect the quality of communication between patient or client and health care providers.

## **6.4 IMPLICATIONS OF THE STUDY**

### **6.4.1 Methodological and Theoretical Implications**

This study does not relate to any recent attempts in Zambia to empirically test factors that could link utilization and satisfaction. We recognize that our study is not comprehensive, and we echo the need for further research in this important and emerging research stream. Our study provides further evidence of the questionable quality of the so much talked about CHBC by showing that CHBC organisations do not provide similar services. Against this background, multi-informant research of organizational and service delivery issues should be employed than the current study.

Noting that this study was based on the use of key concepts from previous research and narrative accounts of care givers and PLWHA, there was no attempt to use theory to test the hypotheses. There is need for future research to consider testing older theories or to develop new ones in order to explain factors of utilization and satisfaction. Considering that PLWHA raised issues of motivation and demotivation in seeking CHBC, there is need to test older theories which have been put forth to explain patient satisfaction and utilization. Most of the theories which seem appropriate come from motivation theories which have been developed and mainly used in the workplace.

We suggest using the two-factor theory presented by Herzberg et al. (1959). This theory could give a possible interpretation to the factors which lead patients to satisfaction or dissatisfaction (Altschul 1983; Bond and Thomas 1992).

## **6.4.2 Managerial implications**

Increasing patient or client satisfaction is an important goal in health care service delivery today, and measurement of satisfaction is becoming increasingly common. Against this background, our research has several implications for health service managers. First, the survey tool that was developed could be used as guidance for health service managers. The study provides increasing insight for health policy makers and health care managers into how PLWHA in Chongwe choose where to go for treatment. Most probably, the findings can be valuable for health care policy-makers in similar rural districts, with comparable health problems and socio-demographic features.

We contend that improving CHBC in Chongwe requires attention to service features that are not provided. These features include treatment of opportunistic infections, food supplementation, financial assistance and transport provision among others, CHBC should be incorporated into the national continuum of care package so that CHBC services become more widely available and PLWHA should be informed about CHBC programs within their communities.

The study has shown that PLWHA were either attracted or repelled to CHBC. Some of the explanatory variables that attracted PLWHA included: Learning about oneself, getting help, in a better position to handle relationships, finances, children, jobs, etc, understanding staff, staffs' positive attitude and ability by staff to address sexuality issues. In addition, some of the explanatory variables that repulsed PLWHA included strict supervision of DOTS therapy, being rebuked, forcing people, negative attitude and uncertified persons treating members of staff.

These attractions and repulsions could be readily acted on and incorporated in a CHBC organization's strategic stance. For example, the findings of this study suggest that PLWHA accord great importance to the demeanor of the staff. However, instilling the qualities of demeanor among the service providers and gaining their commitment to these qualities can be challenging. Although the attained score is reasonable, there is room for improvement. If CHBC management wants to ensure client or patient

satisfaction, they could periodically track staff performance on the negative. Where consistently low scores of satisfaction are obtained, management can quickly direct the concerned staff and take necessary action to instill the appropriate demeanor. Training programs can play an important role here. These programs must emphasize the fact that the role of the care providers is vital to satisfaction. As the measures and results suggest, care providers must (to the extent possible) be helpful, friendly, and make the patient feel at home during each encounter.

Conveying an image of competence to customers is perhaps a more challenging task. To develop and maintain this image, CHBC staff must rely on the experience properties attributable to competence. Clients or patients will generally form an impression of the level of competence of the staff as they experience various services during their visit. Efforts must, therefore, be devoted to making every user experience a positive one to build and reinforce the belief among them that the staff is competent. One way of achieving this is through training programs that must be designed to reinforce the need to incorporate this mode of thinking among all the CHBC staff.

The explanatory power of the independent variables that are being discussed above underscores that CHBC nurses for instance should be cognizant of the importance of the selected variables. Strategy formulation should focus on these variables if competitive advantage is to be gained through delivering customer satisfaction.

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## APPENDICES

### APPENDIX I - INFORMATION SHEET AND INFORMED CONSENT

**Title of Study:           Factors affecting utilization of CHBC services by PLWHA in  
Chongwe District**

My name is ....., I am a research assistant

We are carrying out a study to find out what influences PLWHA to utilize CHBC services. The overall aim of the study is to improve the utilization of CHBC services by PLWHA. **This interview will take approximately 10-15 minutes.**

There are no known or anticipated risks for you to participate in the study. There may not be direct benefits to you by participating in this study and it will not cost you anything either.

The information that we will get from this study will be used to improve the health service delivery. Please seek clarification where you do not understand. The participation in this study is voluntary. If you are not interested to participate you are free to do so. Even after you have joined the study, you are free to withdraw as you wish, and that will not affect your health services at this centre.

Whatever information you provide will be kept strictly confidential and will not be shown to other people. If you feel uncomfortable to answer any questions, you may not answer.

**a) Informed consent form**

The purpose of this study has been explained to me and I understand the purpose, the benefits, risks and discomforts and confidentiality of the study. I further understand that:

If I agree to take part in this study, I can withdraw at any time without having to give an explanation and that taking part in this study is purely voluntary.

I \_\_\_\_\_ (Names)  
agree to take part in this study.

Signed: \_\_\_\_\_ Date: \_\_\_\_\_ (Participant)  
Participant's signature or thumb print

Signed: \_\_\_\_\_ Date: \_\_\_\_\_ (Witness)

Signed: \_\_\_\_\_ Date: \_\_\_\_\_ (Researcher)

**b) Persons to contact for problems or questions**

1. Kaluba Dainess, University of Zambia, Department of Community Medicine, P.O. Box 50110, Lusaka. Cell: 0977697513.
2. Dr Ndonyo Likwa, University of Zambia, Department of Community Medicine, P.O. Box 50110, Lusaka.
3. Mr. Allan Mbewe, University of Zambia, Department of Environmental Health, P.O. Box 50110, Lusaka.
4. The Chairman, Research Ethics Committee, University of Zambia. P.O. Box 50110, Lusaka.

## **APPENDIX II: QUESTIONNAIRE FOR PEOPLE LIVING WITH HIV/AIDS**

**THE UNIVERSITY OF ZAMBIA**

**SCHOOL OF MEDICINE**

**DEPARTMENT OF COMMUNITY MEDICINE**

### **STRUCTURED INTERVIEW SCHEDULE**

**TOPIC: FACTORS AFFECTING UTILIZATION OF COMMUNITY HOME  
BASED CARE SERVICES FOR PEOPLE LIVING WITH AIDS IN  
CHONGWE**

**DATE OF INTERVIEW** : \_\_\_\_\_  
**PLACE OF INTERVIEW** : \_\_\_\_\_  
**NAME OF INTERVIEWER:** \_\_\_\_\_  
**SERIAL NUMBER** : \_\_\_\_\_

### **INSTRUCTIONS FOR THE INTERVIEWER**

- Introduce yourself to the respondent.
- Explain the reason for the interview.
- Assure the respondent of confidentiality and anonymity
- Do not write the name of the respondent on the interview schedule.
- Fill in the most appropriate response to the question on the space provided.
- Provide time for the respondent to ask questions at the end of the interview.
- Refer the respondents to a person who can answer the questions you are not sure of.

**SECTION A: DEMOGRAPHIC DATA**

For official use only

1. Sex of respondent

(a) Male

(b) Female


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2. Age at last birthday

(a) 18 – 22 years

(b) 23 – 27 years

(c) 38 – 32 years

(d) 33 – 37 years

(e) Above 37 years


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3. What is your marital status?

(a) Single

(b) Married

(c) Divorced

(d) Separated

(e) Widowed


--

4. What is your religion?

(a) Christian

(b) Moslem

(c) Hindu

(d) Buddhist

(e) Other specify \_\_\_\_\_


--

5. What is your educational Level?

- (a) None
- (b) Primary
- (c) Secondary
- (d) College
- (e) University


For official use only

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6. What is your occupation?

- (a) Housewife
- (b) Student
- (c) Farmer
- (d) Formal employment
- (e) Self employed
- (f) Unemployed


--

7. What is your income per month?

- (a) Above K1, 000,000
- (b) Between K500, 000- K1, 000,000
- (c) Below K500, 000
- (d) Others, specify\_\_\_\_\_


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**SECTION B: AWARENESS ON CHBC**

8. Have you ever heard about CHBC in relation to HIV/AIDS?

- (a) Yes
- (b) No


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9. Do you know any CHBC organization in your area?

- (a) Yes
- (b) No


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10. In your own opinion, do you think CHBC is relevant to your situation?

(a) Yes

(b) No


For official use only

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11. If the answer is no to question 10, state reasons why.

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12. Do you receive care from any CHBC group?

(a) Yes

(b) No


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13. If yes, which CHBC organization provides you with care?

(a) Faith-based organization

(b) Nongovernmental organization

(c) Government

(d) Others specify \_\_\_\_\_


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***(Go to section C)***

14. If the answer is no to question 12, has the non-availability of CHBC affected your way of living with HIV/AIDS?

(a) Yes

(b) No


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15. If yes to question 14, explain to me how it has affected your way of living with HIV/AIDS

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**SECTIOB C: QUALITY OF SERVICE**

For official use only

*Note: (This section only applies to people receiving CHBC service).*

16. What type of care do you receive prominently?

(a) Psychosocial support

(b) Treatment of opportunistic infections

(c) Food supplementation

(d) Transportation to referral units

(e) Others, specify \_\_\_\_\_

17. Are you satisfied with the care that is provided?

(a) Yes

(b) No

18. If no to question 17, what are the reasons for lack of satisfaction?  
(Tick all applicable).

(a) Irregular visits

(b) Inadequate supplies

(c) Poor attitude

(d) Irrelevant follow ups

(e) Others, specify \_\_\_\_\_

19. If you are in need of a service, is it possible for you to get it  
in the shortest possible time?

(a) Yes

(b) No

20. If yes to question 19, the last time you asked for help, how long did it take you to receive help from the CHBC group?

For official use only

- (a) Less than a day
- (b) 1 – 2 days
- (c) 3-4 days
- (d) More than 4 days


21. How much time does the nearest CHBC giver take to reach you?

- (a) Less than 30 minutes
- (b) 30 minutes – 1 hour
- (c) 1 – 2 hours
- (d) More than 2 hours


22. What suggestions can you make to improve the quality of service?

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**SECTIOB D: PHASE OF DISEASE**

23. How long have you been on antiretroviral treatment?

- (a) Less than one month
- (b) 1month to 3 months
- (c) 4 months to 7 months
- (d) 8 months to 12 months


24. Did you receive any CHBC in the critical phase of your situation?

- (a) Yes
- (b) No


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25. If yes to question 24, are you still receiving CHBC services?

- (a) Yes
- (b) No


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26. If no to question 25, give reasons why you are not receiving any CHBC services.

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**SECTION E: FAMILY SUPPORT**

27. Are some of your family members aware of your HIV status?

- (a) Yes
- (b) No


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28. If yes to question 27, do you receive any support from your family members?

- (a) Yes
- (b) No


--

29. If yes to question 28, state the support that you are given.

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30. If no to question 27, state reasons why you haven't disclosed your HIV status to some of your family members.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

31. If no to question 27, explain to me what you think would be the reaction of your family members if you disclosed your status.

- (a) Supportive
- (b) Not supportive
- (c) Not sure
- (d) Any other, specify \_\_\_\_\_

**SECTION F: TYPE OF COUNSELLING**

32. How many counselling sessions did you have regarding HIV testing?

- (a) One
- (b) Two
- (c) Three
- (d) Four
- (e) Five

33. How long was the counselling session?

- (a) 10 minutes
- (b) 15 minutes
- (c) 20 minutes
- (d) 25 minutes
- (e) 30 minutes

		For official use only	
35.	During counselling was the importance of HBC discussed?		
	(a) Yes	<input type="checkbox"/>	<input type="checkbox"/>
	(b) No		
36.	If yes to question 35, did the counsellor explain to you the benefits of HBC in the context of HIV infection and AIDS?		
	(a) Yes	<input type="checkbox"/>	<input type="checkbox"/>
	(b) No		
37.	Did the counsellor refer you to any CHBC group in your area?		
	(a)Yes	<input type="checkbox"/>	<input type="checkbox"/>
	(b)No		
38.	Mention any other two issues that were discussed concerning CHBC.		
	_____		
	_____		
	_____		
	_____		<input type="checkbox"/>
39.	Did the counsellors provide ongoing counselling from the initial counselling session?		
	(a) yes	<input type="checkbox"/>	<input type="checkbox"/>
	(b) No		

***We have come to the end of the interview and I thank you for your Co-operation.***

## **APPENDIX III - FOCUS GROUP DISCUSSION FOR HOME BASED CARE PROVIDERS**

I would like to find out a few things about your role in the community and the possible problems associated with the provision of HBC to PLWHA.

### **A. Community home-based care profile**

1. Existence of the organization
  - Period the organizations have been in the area of operation
  - Care givers and client ratio
  - Walking distance between care givers and clients (hours or kilometres)
  - How many CHBC groups are active and functional
2. Services offered by CHBC
  - Food Supplementation: Source, Types, Frequency and Quantity
  - Medical supplies: HBC kits, Frequency and Quantity
  - House work: Fetching domestic water supply, Firewood, Cleaning of the house and surroundings, Washing clothes, give bath and Preparation of food

### **B. Knowledge on HIV/AIDS and CHBC**

3. Do you have any guidelines on the operation of your CHBC?
  - What do the guidelines stipulate on the care for PLWHA
  - Availability of the documents (guidelines)
4. Common infections for PLWHA
  - What are the common infections for PLWHA
  - How do you manage them at household level?
  - How do you protect yourself from infection?

### **C. Quality of service**

5. Training for care givers
  - Formal training for care givers before providing the service
  - Level of academic qualification for care givers
  - Period of training; adequate, standard
6. Areas of training in HBC:
  - Infection prevention
  - Counselling
  - Treatment of infections and referral
  - Nutrition and HIV/AIDS
7. Common challenges in the field?
  - What are the common challenges faced in the field?
  - Possible solution to address them
  - Remuneration

### **D. Summary**

Let us summarize some of the key points from our discussion. Is there anything else? Do you have any questions?

*“Thank you for taking your precious time to talk to us”*

**APPENDIX IV - VARIABLES, SCALE OF MEASUREMENT, INDICATORS**

<b>VARIABLES</b>	<b>SCALE OF MEASUREMENT</b>	<b>INDICATORS</b>
<b>DEPENDENT VARIABLE</b>		
Utilization of Community Home-Based Care	Low Average High	0 – 25% of PLWHA on ART utilizing CHBC service 26%-50% of PLWHA on ART utilizing CHBC services 51%-75% of PLWHA on ART utilizing CHBC services
<b>INDEPENDENT VARIABLE</b>		
Awareness on roles of CHBC	Poor Fair Good	Gives positive responses to 0 -1 questions on awareness Gives positive responses to 2 -3 questions on awareness Gives positive responses to 4-5 questions on awareness
Age	Teenager Youth Early Adulthood Late Adulthood	18-20 Years 21- 35 Years 36-49 Years 50 years and above
Income	Low Medium High	Monthly income of below K500 000 Monthly income of between K500 000 – K1,000 000 Monthly income of above K1,000 000
Education	Uneducated Low education Average education High education	None Primary Secondary College and university
Distance	Short Fairly Short Long Very long	Less than 30 minutes walking distance 30 minutes – 1 hour walking distance 1 hour – 2 hours walking distance More than 2 hours walking distance

<b>Accessibility</b>	<b>Inaccessible</b>	<b>Takes more than 4 day to reach the client</b>
	Fairly accessible	Takes 3-4 days to reach the client
	Accessible	Takes 1-2 days to reach the client
	Easily accessible	Takes less than 1 day to reach the client
Phase of Disease	Chronically ill in critical phase	Bedridden and unable to perform daily living activities
	Chronically ill with minor symptoms	Able to perform daily living activities with assistance
	Recovered	Able to perform daily living activities without assistance
Type of counselling	Adequate	Able to answer correctly 5 and above questions on the type of counselling received
	Inadequate	Able to answer correctly 4 and below questions on the type of counselling received

**APPENDIX V - PROBLEM ANALYSIS DIAGRAM**

**Service Delivery Factors**

**Disease Related Factors**

**Socio Cultural Economic**

