BENEFITS OF HOME BASED CARE UTILISATION AND CLIENT SATISFACTION:
A CASE STUDY OF PLWHAS IN RURAL CHOMA

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A Dissertation submitted to the University of Zambia in partial fulfilment of the Masters Degree in Public Health.

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ABSTRACT

The AIDS epidemic has affected the lives of more than 40 million people in Africa since the mid-1980s. Zambia is not an exception of this epidemic. This has lead to significant losses of family income and has created so much strain. It has been caused by prohibitive medical and funeral costs. The health resources are depleted because of the growing number of patients that seek medical care. In recent times non-governmental organizations and governments have consistently been recommending HBC approach for HIV/AIDS patients as one way to mitigate the problem of HIV and AIDS. The main question was: "are clients satisfied with the type of home-based care they receive?" The general objective was "to establish the level of satisfaction by PLWHA benefiting from the Home-based care programs in Choma rural district of Zambia.

A non-interventional, cross-sectional and descriptive study design was applied. Using a precision level at 95 percent confidence based on Yamane's guidelines, a sample size of 79 PLWHA and 6 care givers to provide a total sample of 85 were randomly sampled from a population of 123 as enlisted by CRAIDS and CHAZ. Six care givers were selected conveniently to complement validation of information. Data was collected using a survey questionnaire and a checklist, analyzed using the SPSS version 12 computer software.

The findings show a general satisfaction with the care among clients. 58.2 percent of the clients were very satisfied against 2.5 percent that were very unsatisfied with the manner care givers communicated to clients. In the spiritual support area, 68.4 percent of the clients were not satisfied with the Holy Communion being brought to them compared to 31.6 percent that were satisfied. In the clinical care area, the element "care givers bring drugs for clients" showed that 87.3 percent were not satisfied compared to 12.7 percent that were satisfied. In the social support area, most satisfaction levels for each component were lower than the dissatisfaction levels. In the financial support element, 96.2 percent expressed their dissatisfaction while only 3.8 percent were satisfied. The majority of care providers in HBC were nurses. There was less participation by other clinical professionals in HBC programs. Most supplies required in the execution of home-based care activities were either in short supply or unavailable.

The findings direct their recommendations to the government authorities to consider rendering support to Home-Based Care activities. This could be in form of formulation of a specific policy that is home-based care directed. This will afford the program a budget line. This will, in turn, supplement the efforts of the few care providers. Furthermore, active participation of other clinical care professionals would boost the program and lead to quality care for the clients.

COPY RIGHT DECLARATION

This dissertation has not been submitted for a degree in another University or similar Institution. The contents of this dissertation are of my original work.

Signed :_____(Candidate)
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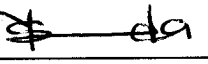
This is to certify that the dissertation by Gracious Adams Simwanza, in partial fulfillment of the requirement for the degree of the Master in Public Health is ready for examination.

Signed: 

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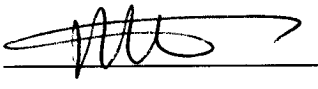
Signed: 

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DEDICATION

This dissertation is dedicated, with deep, heartfelt feelings, to my wife Annette as a helper towards my achievement; my sons: Andrew, Barnabas, Emmanuel, Jotham and Nathan; my daughters: Bridget and Susan; and Chinyama for their great comfort and encouragement.

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I would also like to thank the following: Southern Province Health Office; Choma District Health Office; Pemba Health Clinic administration and staff for allowing me to carry out my study in Pemba. I specifically need to thank Mrs. Mary N. Phiri, Susan and Albertina for their guidance and support in trying to locate the study subjects in various widely spaced villages. Finally, though not the least, I wish to thank Ms. P. A. Lungu for typing the first manuscript and Chinyama for the moral support.

May the good Lord richly bless you all as you now take time to read about the Benefits of home-based care utilization and client satisfaction: a case study of HIV/AIDS in rural Choma.

TABLE OF CONTENTS

ABSTRACT.....i
COPYRIGHT DECLARATION.....ii
SUPERVISORS' CERTIFICATE.....iii
CERTIFICATE OF APPROVAL FORM.....iv
DEDICATION.....v
ACKNOWLEDGMENTS.....vi
TABLE OF CONTENTS.....vii
LIST OF TABLES.....ix
LIST OF FIGURES.....x
LIST OF APPENDICES.....xi
LIST OF ABBREVIATIONS.....xii

CHAPTER ONE-----INTRODUCTION.....1

1.0 Introduction.....1
1.1 Background.....2
1.1.1 Key Players and their Roles in HBC.....3
1.1.2 Components of Home-Based Care.....4
1.1.3 The Home-Based Care Team.....5
1.1.4 Community Mobilization.....6
1.2 The Problem.....7
1.3 Justification (Advantages and Disadvantages of HBC).....8
1.4 Research Questions.....8
1.5 Research Objectives.....9
1.6 Hypotheses.....9
1.7 Conceptual Model.....10

CHAPTER TWO-----LITERATURE REVIEW.....11

2.0 Introduction.....11
2.1 Definition of Key Terms.....11
2.1.1 Home-Based Care.....11
2.1.2 Benefits.....12
2.1.3 Satisfaction.....12
2.1.4 Utilization.....12
2.2 The Magnitude of the Problem.....13
2.2.1 Global.....13
2.2.2 Regional.....13
2.2.3 Zambia.....14
2.2.4 Choma.....15
2.3 Home-Based Care.....15
2.4 Policies on Home-Based Care.....16
2.5 Consumer Model and Approach.....17
2.6 Satisfaction.....17

2.6.1 Purpose of Satisfaction Measurement....18
2.6.2 Determinants of Satisfaction....19
2.6.3 Components of Satisfaction....20
2.7 Previous Studies... 21

CHAPTER THREE-----METHODOLOGY....22

3.0 Study Design....22
3.1 Conceptual Framework....22
3.2 Study Site....26
3.3 Target Population....26
3.4 Sampling and Sample Size....27
3.4.1 Sampling Employees of CHAZ and CRAIDS or Directors....27
3.4.2 Clients Sample....27
3.5 Data Collection Techniques....28
3.6 Pre-Test....29
3.7 Limitations of the Study 29

CHAPTER FOUR-----FINDINGS....30

4.0 Introduction....30
4.1 Sample Description....30
4.1.1 Demographic Data....31
4.2 Provision of Home-Based Care....35
4.3 Levels of Satisfaction with Home-Based Care....38
4.4 Care Givers' Collaboration with Clinical Professionals; Drugs and Material Supplies; and Monitoring....48

CHAPTER FIVE-----DISCUSSION....53

5.0 Discussion....53

CHAPTER SIX-----RECOMMENDATIONS AND CONCLUSION....60

6.1 Conclusions 60
6.2 Recommendations 61

REFERENCES....63
APPENDICES....69

LIST OF TABLES

Table 3.1 Conceptual Framework.....22
Table 3.2 Profile of Data Collection Methods and related questions.....28
Table 4.1.1 (a-g) Demographic Data.....31
Table 4.2.1 Manner of Communication.....35
Table 4.2.2 Spiritual Care ... .36
Table 4.2.3 Clinical Care.....37
Table 4.2.4 Social Support.....38
Table 4.3.1 (a-e) Manner of Communication and Satisfaction.....39
Table 4.3.2 (a-d) Spiritual Care and Satisfaction 41
Table 4.3.3 (a-e) Clinical Care and Satisfaction.....43
Table 4.3.4 (a-d) Social Support and Satisfaction.....46
Table 4.4.1 (a-d) Care Givers' Collaboration with Clinical Professionals; Drugs and Material Supplies; and Monitoring.....48
Table 4.4.2 Clinical Care Management Responses by Care Givers.....50
Table 4.4.3 Psycho-social and Spiritual Care Responses by Care Givers.....51
Table 4.4.4 Support Tools and Documents Responses by Care Givers.....52

LIST OF FIGURES

Figure 1.1 Conceptual Model of Care Givers' Package and Clients' Expectations.....10
Figure 4.1 Age Distribution.....31

LIST OF APPENDICES

Appendix A—Ethical Issues.....69
Appendix B— Yamane's Sample Determination Tables 70
Appendix C— Authority Letter (Provincial Health Office).....72
Appendix D— Authority Letter (District Director of Health).....73
Appendix E— Authority Letter (Pemba Health Centre).....74
Appendix F— Authority Letter (KARA).....75
Appendix G— Client's Introductory Letter/Information Sheet 76
Appendix H— Client's Consent Form 78
Appendix I— Questionnaire (Clients & Caregivers).....79
Appendix J— Checklist/Inventory Sheet (Caregivers).....82

LIST OF ABBREVIATIONS

ACC: -	AIDS Control Committee
ACU: -	AIDS Control Unit
AIDS: -	Acquired Immune Deficiency Syndrome
CACC: -	Constituency AIDS Control Committee
CBO: -	Community Based Organization
CHAZ: -	Churches Health Association of Zambia
CHBC: -	Community Home-Based Care
CHW	Community Health Worker
CRAIDS: -	Community Response to HIV/AIDS
CSO: -	Central Statistical Office
DACC	District AIDS Control Committee
DDH: -	District Director of Health
DHMT	District Health Management Team
HBC: -	Home Based Care
HIV: -	Human Immunodeficiency Virus
ILO: -	International Labour Organization
JHPIEGO: -	John Hopkins for International Education in Gynaecology and Obstetrics.
M & E	Monitoring and Evaluation
NAC	National AIDS Council
NACC	National AIDS Control Committee
NASCOP	National AIDS/STD Control Programme
NGO: -	Non-Government Organization
PCIZ: -	Project Concern International Zambia
PHD: -	Provincial Health Director
PLWHAs: -	People Living With HIV/AIDS
SAfAIDS: -	Southern Africa Information Dissemination Services
STI: -	Sexually Transmitted Infections
TB: -	Tuberculosis
UNAIDS: -	United Nations AIDS Agency
USAID	United States Agency for International Development
WHO: -	World Health Organization
ZANARA: -	Zambia National Response to HIV/AIDS
ZDHA: -	Zambia Demographic and Health Survey

CHAPTER ONE

INTRODUCTION

1.0 INTRODUCTION

Home-based care of PLWHA is an approach to care provision that combines clinical services, nursing care, counselling and psycho-spiritual care, and social support. It represents a continuum of care, from the health facility to the community and the family of the individual infected with HIV/AIDS and vise versa. It is a critical area for the PLWHA. Home-based care ensures a high standard of humane, holistic care that meets the physical and social needs of persons living with HIV/AIDS.

The study sought to establish the proportion of HBC beneficiaries and their levels of satisfaction from utilization of the services. It was carried out in Pemba, part of Choma rural with a population of 10, 000 people. The study is explained in six chapters. Chapter one discusses the research problem. It presents the scenario of HIV and AIDS and shows the need for home-based care. Chapter two is literature review. It discusses the magnitude of the HIV and AIDS problem. The literature focuses on what is being done in Sub-Saharan Africa using examples from Kenya, Botswana, South Africa and Malawi as models. It also covers previous work done in Home-based care, the consumer model and satisfaction. Chapter three gives a description of the research design and the description of the research setting. Chapter four shows the results. Results in this chapter follow the framework suggested by Yin (1998). The significance of this study and limitations form part of this chapter. Chapter six is composed of the conclusion and recommendations.

1.1 Background

The AIDS epidemic has affected the lives of more than 40 million people in Africa since the mid-1980s (WHO, 2003). This has lead to significant losses of family income and creating so much strain. It has been caused by prohibitive medical and funeral costs; or the stigma sometimes attached to families affected by AIDS. In some cases, surviving family members have been abandoned, abused or attacked, often while struggling to cope with their own HIV-related illness. As these members weaken or die, remaining family members and friends are further traumatized (Dazinger, 1994) and are left with no alternative mitigation. As the number of individuals and households affected by HIV multiplies, the social impact of the epidemic both widens and deepens. Rising morbidity, mortality and absenteeism threaten productivity in a number of economic sectors. Health facilities are stretched to their limits by increased demand for supplies and services. Social support systems and traditional coping mechanisms face unprecedented challenges.

It has been shown that health care institutions are overflowing with infected patients (WHO, 2003). Health resources are depleted because of the growing number of patients who seek medical care. Organizations and governments have consistently, in recent times, been recommending HBC approach for HIV/ AIDS patients (van Rensburg, 2004). The alternative solution to a great many of these impacts has been Home-Based Care programmes. Choma district in southern Zambia is not an exception. Choma District is located in the Southern Province of Zambia. It is over 300 kilometres away from Lusaka and about 190 kilometres away from Livingstone. It acts as a shopping centre for other districts such as Namwala, Kalomo, Monze and Sinazongwe. Choma has an area of 7,296 square kilometres (CSO, 2003).

Economic Activities in Choma:

Before 1991, maize was the main crop produced by farmers. Frequent droughts have led to a fall in production of crops. There are substantial dairy and game ranching and a number of agro-processing operations in Choma (CSO, 2003). These are done both on large and small scales.

Health Profile of Choma :

Choma district has a total number of 33 health institutions. The government runs twenty-four of these; missions run five and four of them are privately owned (CSO, 2003). There is one government-run hospital and one mission-run hospital. These two hospitals are about 70 kilometres apart. The rest of health institutions are at health centre level. Of these about 90 percent are in the rural areas of Choma district. The total bed capacity of the district is 716 beds and 47 cots (CSO, 2003). Choma district has a population of 204,898 (CSO, 2003). This represents 16.9 percent of Southern Province's population. About 48.7 percent are aged 15 to 64 years; 2.5 percent are aged above 65 years and 48.8 percent are 0 to 14 years (CSO, 2003). About 80.3 percent of Choma's population lives in the rural areas.

The HIV/AIDS prevalence rate of Choma district is about 18 percent (in urban areas) and 16.5 percent (in rural areas) among adults aged 15-49 years (CSO, 2003).

1.1.1 Key Players and their Roles in HBC

Home-based care is a collaborative venture by the nation, the health care system, the community, the family, and the PLWHA to meet the crisis of HIV/AIDS. At every level it will be necessary to define specific programme objectives, roles, and responsibilities. Where necessary, the effective implementation of home-based care programmes will be supported by appropriate legislation.

1.1.2 Components of Home-Based Care

Home-based care is a holistic, integrated system of care that incorporates the following components:

- Clinical care
- Nursing care
- Counselling/psycho-spiritual care
- Social support

All home-based care programmes must contain some combination of these four components, with the proportion of each component to be determined by local realities and needs.

Clinical Care Component

The goal is to ensure the continuity of the care and treatment the PLWHA was receiving from the health facility. Clinical care intends to:

- Ensure early detection and treatment of opportunistic infections and other complications that occur as a result of HIV/AIDS.
- Reduce the suffering from conditions associated with the HIV/AIDS infection.
- Protect the patient against further infections especially during a long hospital stay.
- Prevent transmission of HIV or other opportunistic infections from PLWHA to health workers, relatives, and friends.
- Ensure that drugs prescribed by the clinician are administered at home according to the regimen of intake.

Nursing Care Component

The objectives of the nursing care component are to:

- Alleviate physical and psychological symptoms.
- Maximize the level of function of the affected person.
- Systematically assess the needs of the sick.

Counselling/Psycho-Spiritual Care Component

The objectives of this component are to:

- Control the spread of HIV/AIDS through information dissemination, promotion of safer sex, advocacy for behaviour change, and encouragement of better health seeking behaviour. Help the PLWHA to come to terms with the infection and to adopt a positive living attitude.
- Help the PLWHA make well informed decisions about sex and sexuality.
- Offer psychological/spiritual support to PLWHA and their families.
- Help PLWHA accept the need to talk to family members about their condition and future plans.
- Strengthen the spiritual, physical, mental, and social well-being of the PLWHA and the family.
- Help the community to avoid condemnation of the infected and affected and hence be challenged to help when needs arise.

Social Support Component

The objectives of this component are to:

- Contribute to the social and material well-being of the PLWHA.
- Involve the community in the care of the PLWHA and support for the affected family.
- Provide relief for family caregivers from the burden of care.
- Raise awareness among community members of issues related to the transmission of HIV.
- Develop social safety nets for affected children.

1.1.3 The Home-Based Care Team

The home-based care team should be multi-disciplinary in order to handle the physical, social, psychological, and spiritual needs of care recipients. Responsibilities of the team

members will include records management and monitoring and evaluation functions as well as professional services. The team leader should be a care professional – a doctor, nurse, counsellor, or social worker. Ideally, core team members should include a clinician or nurse, a counsellor, community health worker, and spiritual leader, with a home care supervisor on each team appointed by the relevant health facility or responsible non-government or community-based organization. Other members of the team may be volunteers on full or part time basis, drawn from the community and trained by the core team to handle various responsibilities.

1.1.4 Community Mobilization

Because the HIV/AIDS epidemic is both a health and a development emergency, the Government of Kenya is fighting it on both the health front and the community mobilization front. These two systems consist, on the one hand, of established Ministry of Health programmes and practices and, on the other hand, of the relatively new structure of AIDS control units and committees. NASCOP stresses the importance of public—private coordination and collaboration on programme frameworks and common issues, for example, determining incentives for volunteer members of home care teams (Crouch, et al.2002)

Income-generating activity

A number of measures can be taken to promote the sustainability of services to PLWHA and their families. To ensure this happens, home based care programmes should make provisions for:

- Encouraging a multi-disciplinary involvement of all government ministries to improve land use and increase food production.
- Participating in and collaborating with the local CACC to ensure the full benefit of community support to PLWHA and their families.
- Empowering the family and the community to use locally available resources.
- Empowering communities to establish income-generating activities to support the provision and replenishment of home care kits for needy PLWHA/families.

Networking

The quality of care for people living with HIV/AIDS can be greatly improved through cooperation and sharing of experiences between organizations. A good network facilitates a link between homes and resources. If organisations work cooperatively, the weakness of one in a specific area can be complemented by the strength of another. Organisations can improve their services through learning from the expertise and experience of others (USAID • August 2002).

1.2 The Problem

The health care infrastructure is constrained by the immensity of the HIV/AIDS crisis. It has become apparent that home-based care efforts of HIV/AIDS prevention and care of those affected are the first line of mitigating the disease and its impacts on PLWHA and family members. Home-based care programmes have been in existence in Choma for the past four to six years. Research to assess what the programmes were to provide, and what was actually provided has not been done. Home-based care programmes are said to be failing to meet the aspirations of the people; leading to dissatisfaction. This, however, is not supported with data. In the absence of empirical data, it is not possible to agree or disagree with the claims that the home-based care programmes have or have not lived to their ideals. In addition, we cannot improve service delivery in the absence of user assessment of health care delivery. If we are to continue to provide meaningful and effective home-based care programmes, there is need to have information driven by research.

Home-based care is a holistic, integrated system of care that incorporates all services. If one of the services lacks, as is the case usually, then HBC activities will not be effective. Lack of some or all of the services affects the utilization of HBC services and hence, satisfaction levels of HBC users.

1.3 Justification-Advantages and Disadvantages of Home-Based care

Few studies showed that there are advantages and disadvantages of home based care, in that there is holistic care for the patients but it is not cheap to offer home-based care (Hansen et al, 1998). Care givers need to be skilled in rendering home based care (Hollander, 1999). A study by Uys (2003) showed that there is a significant relationship between a good death and dying at home. Patients preferred to die at home, cared for by their relatives and loved ones.

Caring for patients in their homes is a means of breaking the cycle of fear surrounding terminal illness. It increases the visibility of people with HIV/AIDS in the community, thereby encouraging the normalisation of the virus. Educating family members about identifying and caring for people living with HIV/AIDS can benefit both the family and community, but it can also lead to the perception, that hospice is an 'AIDS organisation' and may result in people who are not comfortable with their status being known, to be identified as HIV positive. In some instances, patients have requested that caregivers meet them outside their homes or to leave their medicine at a shop nearby. Sometimes educating family members is not enough to make them understand and acknowledge the virus.

Main Factors:

Demographic data (These will have an effect on the attitude of HBC service beneficiaries)

Provision of HBC and Accruing Benefits (The type of services and benefits received by clients will determine their satisfaction levels)

HBC Management (Service providers need special logistics and training for the job)

1.4 Research Questions

The main question was: "are clients satisfied with the type of home based care they receive?" Drawing from the main question we had subsidiary ones and these were:

1. What have the care givers said that they would provide?
2. What do caregivers actually provide?
3. What type of care does the clientele expect from the caregivers?

4. To what extent are clients satisfied with HBC provided?
5. Based on the consumer model, why do clients show a particular level of satisfaction?

1.5 Research Objectives

The general objective was "to establish the level of satisfaction by PLWHA depending on the Home-based care package rendered by CHAZ and CRAIDS".

The study's specific objectives were:

1. To determine the proportion of PLWHA benefiting from the utilization of home-based care services provided by care givers in the study site.
2. To determine the levels of satisfaction of PLWHA with manner of communication; spiritual support; clinical care; and social support services rendered in the study site by CRAIDS and CHAZ.
3. To explain[1] home-based care services that might be associated with the type of satisfaction based on the consumer model.

1.6 Hypotheses

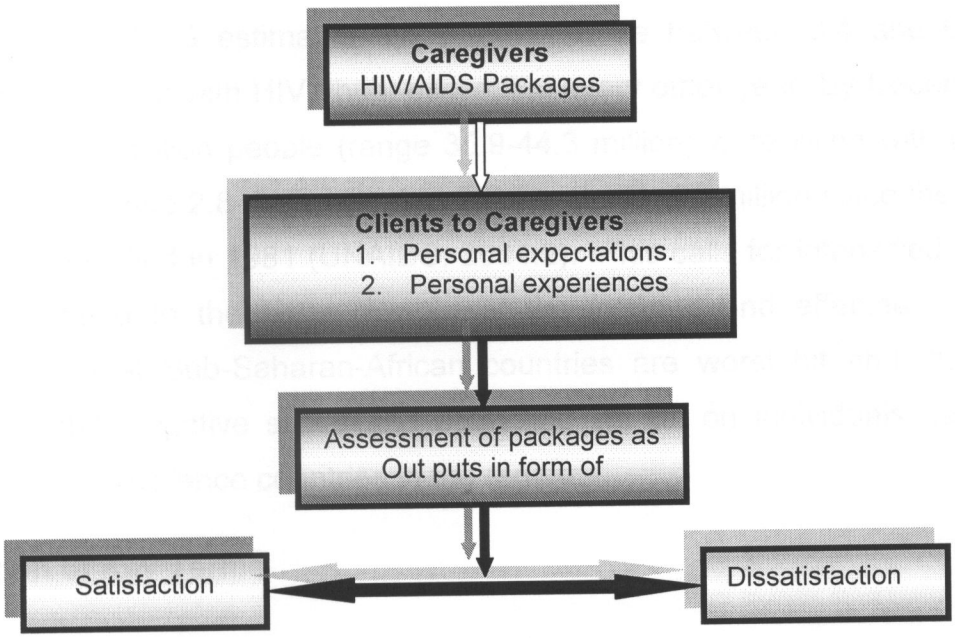
The null hypothesis for the study was "There is no relationship between the benefits accruing to utilizing home based care and the type of satisfaction clients demonstrate". The independent variable is "benefits accruing to utilizing home based care "and the dependent variable is "the level of satisfaction clients demonstrate"
The alternate hypothesis was "There is a relationship between the benefits accruing to utilizing home-based care and the type of satisfaction clients demonstrate".

[1] Explaining in research is linked to the answering the "Why" question which is rooted in a model or theory. The why question is used to test the main hypothesis which is "There is no relationship between the benefits accruing to utilizing home-based care and the type of satisfaction clients demonstrate.

1.7 Conceptual Model

This study was based on the consumer model as shown in figure 1.1 below.

Figure 1.1 Conceptual Model of Caregivers' Packages and Clients' expectations



The assumptions of the consumer model are that users of a facility have points- of-view in form of satisfaction about the care they receive or the service they use. These points-of-view in form of satisfaction are determined by personal experiences and personal expectations (Locker *etal* 1978; and Bond *etal.* 1992)

CHAPTER TWO

LITERATURE REVIEW

2.0 INTRODUCTION

Current statistical information, shows that at the global level, in 2004 an estimated 4.9 million people (UNAIDS estimates this number to be between 3.4 and 6.4 million) became newly infected with HIV, thus, exceeding every other year. By December 2004, an estimated 39.4 million people (range 35.9-44.3 million) were living with HIV, which killed 3.1 million (range 2.8–3.5 million) in 2004 and over 20 million since the first cases of AIDS were identified in 1981 (UNAIDS, 2004:2). This calls for intensified community response to attend to the large number of the infected and affected. The same document says that Sub-Saharan-African countries are worst hit and that this has brought invariable negative social and economic impact on individuals, families and societies in high-prevalence countries in the region.

2.1 Definition of Key Terms

Below are definitions of key concepts that have been used in this study.

2.1.1 Home-Based Care[2]

The World Health Organization defines home-based care as "the provision of health services by formal and informal caregivers in the home." Such care includes physical, palliative and spiritual activities. (Foundation for Hospices in Sub-Saharan Africa).

The Kenya National HIV/AIDS Strategic Plan 2000–2005 defines home based care in the following way: "Home-based care includes the care given to the sick and affected in their own homes and care extended from the hospital or health facility to their homes through family participation and community involvement (Crouch et al, 2002).

[2] The Operationalisation of home based care in this study appears in section 3.5 of the methodology section

2.1.2 *Benefits*

A benefit is an advantage that something gives you; a helpful and useful effect that something has (Hornby, 2000). The Ministry of Health in Kenya has enumerated a number of benefits of home-based care (National Home-Based Care Policy Guidelines, 2002). They include:

- The provision of medication
- Physical and emotional care, or will the care and support
- Counselling
- The provision of food or food supplements
- The provision of material items such as bedding and soap
- The cost of transport for the ill person
- Help with housework and other instrumental activities of daily living
- Giving families cash allowances so that they can access CHBC services as they see fit.

2.1.3 Satisfaction

This is the good feeling that you have when you have achieved something or when something you wanted to happen does happen (Hornby, 2000). Interest in patients' opinions developed alongside the sociological interest in interpersonal relationships, giving rise to studies of patient-practitioner relationships, which demonstrated the importance of understanding the patient's point of view (Cartwright, 1964, 1967; Locker and Dunt, 1978).

2.1.4 Utilisation

'Utility' is an economic term indicating the welfare gained by individuals through consumption. The assumption is that individuals 'maximize utility', so that in general, more consumption is better than less, other things being equal. Utilization is the use of the existing capacity, often measured as an average over a period of time (Witter et al, 2000).

2.2 The magnitude of the problem

2.2.1 Global

Kloos et al (2005) mention that various CBOs can be partners in HIV/AIDS prevention, patient care/support and control programmes. These programs may facilitate efforts to curb the spread of HIV through the expansion of awareness creation and prevention initiative. They say among new strategies, integrated home-based care programmes involving people living with HIV/AIDS (PLWHA), families and neighbours, and poverty alleviation with an integrated HIV/AIDS component promise to create an enabling environment and promote project ownership by communities. In addition to the recognition that the traditional top-down public health approach to community participation cannot satisfactorily "manage" the complex behavioural and social-economic environment of the HIV/AIDS epidemic or generate strong community commitment, there is also increasing evidence that deep-rooted stigma cannot be reduced through the usual awareness creation campaigns but through community-based and community-trained support groups, which promote open discussion of the HIV/AIDS problem. Due to the high acceptability of, and respect toward community-based organizations (because of their cultural and social compatibility), they may be appropriate, effective, and necessary advocates and vehicles in HIV prevention and patient care/support programmes (Kloos et al 2005:5).

2.2.2 Regional

In Africa, there has been a gradual shift from hospital-based care of people living with HIV/AIDS to home-based care. People living with HIV/AIDS often constitute a large proportion of people seeking medical treatment at hospitals. Many hospitals do not have adequate resources to care for HIV patients. In response, hospitals and departments of health have implemented policies to promote home-based care of patients. However, in South Africa, the effectiveness of home-based care programmes is questionable (Akintola, 2004). The consequence in many cases is that patients are discharged to

households whose family members have not received any form of training on how to care for people living with HIV.

2.2.3 Zambia

The picture in Zambia is similar to that of her neighbouring countries, Tanzania and Zimbabwe. A 1994 Zambian study estimated a coverage rate of 1-2 percent (Chela et al, 1994 in Sichinga, 2002:8). Since 1994, there has been an alarming increase in the number of AIDS patients needing home care in both the rural and urban areas of Zambia (Sichinga, 2002:8). Community involvement is not an option-it is a necessity based on the promise it offers for sustainability, increasing levels of self esteem and self reliance. Improving the accessibility of health services and organizing health action at the community level requires enhanced performance of peripheral clinics and community health agents in terms of training, supervision, support and continuing education programmes (MoH, 1991:62, 63). The MoH recognized the importance of training, supervision, support and continuing education. These are factors that are very cardinal for the success of any given community-based care programme. More participants need to be trained and supervision needs to be strengthened. A critical aspect of the community-oriented Home-Based Care Service is the preparation and involvement of the community for its voluntary participation, support and commitment in the activity (JHPIEGO & PCIZ, 2004:7, 8).

The AIDS Care and Prevention Programme, implemented by the Churches Health Association of Zambia (CHAZ), provides an example of a cross-sectoral and multidisciplinary HIV/AIDS prevention and control programme. The CHAZ AIDS Care and Prevention Programme has been developed gradually over the period 1991-2004, and currently comprise a wide range of complementary HIV/AIDS prevention and control components (Staugard, 2005:6). These efforts need to be upheld and monitored with great supervision.

Due in large part to limitations in the health sector, there has been a significant growth in Home-Based Care Programmes to support chronically ill people. These programmes are still predominately in urban areas and close to District Hospitals. To function effectively, they need support from both the health sector and other sectors (e.g. Welfare support or assistance to establish income generation activities). In the long term, it is not clear how much of the burden of care can continue to be passed on to communities without this support (MoH, 2002). HBC Programmes should involve social and behavioural scientists as well as public health researchers with the objective of examining the origin, functions, leadership structure and motivation and capacity for participation in HIV/AIDS prevention and care/support activities.

2.2.4 Choma

The HIV/AIDS prevalence rate of Choma district is about 18 percent (in urban areas) and 16.5 percent (in rural areas) among adults aged 15-49 years (CSO, 2003). Like in any other districts, in Choma, CRAIDS activities are in existence, though mostly in the urban setting. At the same time, CHAZ HBC activities have been running for almost five years now (in some parts of Choma Rural). However, not much information is in place to determine the levels of accessibility to quality HIV/AIDS-HBC services being undertaken by CHAZ and CRAIDS.

2.3 Home-Based Care

Modern home-based care began in England in 1859 when William Rathbon, with the help of Florence Nightingale, started a school to train visiting nurses. The main purpose was to care for poor, sick people in their homes. In the United States during the 1800s, the waves of poor immigrants induced philanthropists to help establish visiting nurse agencies in Boston, Buffalo, New York and Philadelphia (Stackhouse, 1998:304).

2.4 Policies on Home-Based Care

In South Africa, Kenya, Zimbabwe and Uganda, it is National Government Policy to promote home-based care. In these countries, there are different organizations, mostly NGOs, offering different models of home-based care, ranging from home visiting to home-based palliative care, to comprehensive treatment, care and support programmes. In South Africa, most of these care programmes rely on volunteers from the affected communities to carry out basic nursing and other care giving activities in patients' homes. The volunteers are usually not paid or, in few cases, paid small stipends for transport. In contrast, a striking feature of HBC programmes in Uganda is the professionalisation of care. The general pattern is for patients at home to be provided with specialized medical care as well as support home-visit services by teams that consist of medical doctors, nurses, other paramedics, and clerics for spiritual care. The HBC programmes use volunteers who identify sick people and in some cases provide basic care, but are themselves supported by the mobile teams of professionals. There are care organizations that operate different models of care, but there is substantive co-ordination and networking between hospitals, NGOs, religious sects and communities to override the limitations of individual organizations (Akintola, 2004). This emphasizes the importance of skills, professionalism and strong collaboration with other stakeholders who will enhance the accessibility to and effectiveness of the HBC. In most cases, this has lacked.

In Zambia, International and National Non-Governmental Organizations are conducting HBC Programmes, but their coverage is low and largely limited to urban areas (CARE, International-Zambia, 2002). Similarly, local community-based organization and faith-based organizations are absorbing some of the care requirement. However, the number of people developing AIDS is growing more rapidly than the increase in services-leading to what is termed the "Home Care Gap" (CARE, International-Zambia, 2002). In spite the fact that the HIV/AIDS policy exists in Zambia the area on Home-Based Care has not been made clear.

2.5 Consumer Model and Approach

The assumptions of the consumer model are that users of a facility have points- of-view in form of satisfaction about the care they receive or the service they use. These points-of-view are determined by personal experiences and personal expectations (Locker and Dunt, 1978; Bond and Thomas, 1992; Cochrane, 1992). Consumer organisations also influenced the consumerist approach to health care, with publications such as Patient's Rights produced by the National Consumer Council, and the Consumers' Association's "A Patient's Guide" to the National Health Service, both published in 1983, examining all aspects of the NHS system (Jones et al., 1987). Fitzpatrick (1984), however, refuted the suggestion that patient satisfaction work is part of a wider social movement towards consumerism.

Blaxter (1995) points out that the term "consumer" may be alienating as a result of its connections with the commercial world, and there has been strong criticism of the use of the term in the health care field in the U.K. (Leavy et al., 1989; Normand, 1991). On the other hand, it could be argued that the term "consumer" dignifies the professional/patient relationship in a way that the traditional term "patient", (with its associations of powerlessness visa vis against the medical establishment), does not do. In parallel areas, social services and community health services commonly refer to "clients" or "service users" in order to move away from the idea that users of their services are passive and dependent.

2.6 Satisfaction

A factor common to many patient satisfaction surveys is that very few patients express dissatisfaction or are critical of their care (Abramowitz et al, 1987; Hopton, et al, 1993). Greater response variability is found with regard to specific aspects of care, and there is much evidence to show that patients do in fact distinguish among the dimensions of care when they judge its quality (Fitzpatrick, 1984; Rubin, 1990). It has become increasingly accepted that substantial dissatisfaction exists with specific components of care, notably waiting times and communication in primary care, and "rigid hospital routines" (Cartwright, 1964; Ley, 1972; Jones *et al.*, 1987; Williams and Calnan, 1991a).

2.6.2 Determinants of Satisfaction

The determinants of satisfaction include the following:

Patient Expectations:

Expectations emerge repeatedly as having a fundamental role in expressions of satisfaction. Stimson and Webb (1975) were among the first to suggest that satisfaction is related to the perception of the benefits of care and the extent to which these meet the patient's expectations. Expectations make more complex the concept of satisfaction as an evaluative tool. As patient satisfaction is a recognised component of Quality Assurance (Devitt, 1992). It is tempting to equate "high" levels of reported satisfaction with "high" levels of quality of care. Different levels of satisfaction may indicate different perspectives on care quality rather than different levels of satisfaction with the same experience.

Patient Characteristics:

It is commonly believed that satisfaction with health care may be dependent upon variables such as social class, marital status, gender, and, in particular, age. A meta-analysis of work reported before 1989, however, concluded that socio-demographic characteristics are at best a minor predictor of satisfaction (Hall and Dornan, 1990). Other characteristics include educational attainment and ethnic origin. Perhaps the most consistent determinant characteristic is patient age, with a body of evidence from various countries to suggest that older people tend to be more satisfied with health care than do younger people (Houts et al., 1986; Blanchard, et al., 1990; Zahr et al., 1991).

Psychosocial determinants:

A number of "social-psychological artefacts" may affect expressions of patient satisfaction (LeVois et al., 1981). "Social desirability response bias" argues that patients may report greater satisfaction than they actually feel because they believe positive comments are more acceptable to survey administrators. Similarly, "ingratiating response bias" occurs when patients use the satisfaction survey to ingratiate themselves with researchers or medical staff, especially if there are any reservations

over the anonymity of respondents. A number of observers have suggested that patients may be reluctant to complain for fear of unfavourable treatment in the future (Raphael, 1967; Ley, 1972).

2.6.3 Components of Satisfaction

A factor common to many patient satisfaction surveys is that very few patients express dissatisfaction, or are critical of their care (Abramowitz et al, 1987; Hopton, *et al,* 1993). Greater response variability is found with regard to specific aspects of care, and there is much evidence to show that patients do in fact distinguish among the dimensions of care when they judge its quality (Fitzpatrick, 1984; Rubin, 1990). Several classifications of components have been proposed, some appropriate only for specific health care contexts, others aiming at broad applicability. A more definitive taxonomy with nine contexts (Ware et al., 1983):

- Interpersonal manner; features of the way in which providers interact personally with patients.
- Technical quality of care; competence of providers and adherence to high standards of diagnosis and treatment.
- Accessibility/convenience; factors involved in arranging to receive medical care.
- Finances; factors involved in paying for medical services.
- Continuity of care; constancy in provider or location of care.
- Physical environment; features of setting in which care is delivered.
- Availability; presence of medical care resource.
- Social support; types of social support rendered.
- Physical support; nature of physical support given

2.7 Previous Studies

There has not been any notable study done on the utilization of Home-Based Care in Zambia. However, a number of studies that have been done have been focused on various issues as follows:

Chela et al, (1989) did a study in Chikankata which focused on the common opportunistic infection in Home-Based Care patients. It was a cross sectional comparative study. The study was biased on treatment of opportunistic infections. However, no theoretical basis of the study was clearly indicated. Chela and Siankanga, (1991) did a study in Chikankata area. This study had a focus on the experiences of Zambia in HBC of people with AIDS and the various difficulties faced. The methodology was not indicated; no solutions were given; and no theory or model was indicated to have been used. Chela et al. (1994) did a study with focus on the cost implications of hospital-based HIV patients versus Home-based HIV patients. It was indicated that home-based care services are cheaper to run. This is in agreement with other studies. However, the theory or model used was not specified. Banda (quoted by the CARE, International-Zambia) also did a study which focused on the coverage of the PLWHA needing HBC. This study does not indicate the methodology used; issues covered; solutions arrived at; and theories or models used. Sichinga (2002) did a thesis (not published) on the Scaling up HIV/AIDS HBC for PLWHA in rural Zambia: a case for Churches Association of Zambia (CHAZ). This was an In-depth Programme review study. It was based on the review of other researchers, studies. The methodology of the study; the various issues of concern; recommendations; and the models and approaches to HIV/AIDS care were discussed.

All this work and other works point to the fact that there is need to understand the benefits in the utilization of HBC services in Zambia. In spite of this, no specific study has been done to look at the satisfaction levels among PLWHA with the HBC services.

CHAPTER THREE

METHODOLOGY

3.0 STUDY DESIGN

The research was non-interventional, cross-sectional and descriptive in nature. (Baltes *et al.*, 1988; Creswell, 1994). This design was adopted due to the fact that only observations and explanations were to be made. The time factor and economic reasons also contributed to this decision.

3.1 Conceptual Framework

In order to measure the variables and develop the research instrument, the key variables were operationalised and measured as follows:

Home based care in this study is operationalised as that care in the home of any person knowing as having HIV/AIDS or any family member caring for such a one through the provision of all or some of the following: clinical care, nursing care, counselling and psycho-spiritual, spiritual and social support.

Table 3.1 Conceptual Framework

	VARIABLES	**INDICATORS**	**SCALES**
DEPENDENT:	Satisfaction with HBC Services	Levels of Client Satisfaction	Numbers, percentages and ratings-Lirket's Scale
INDEPENDENT: (Demographic)	Age	Age as stated for 15 and above	15-19=1 , 35-39=5 20-24=2, 40-44=6 (number, %) 25-29=3, 45-49=7 30-34=4, 50+=8
	Sex	Female or Male	F = 1 (Number, %) M = 2
	Marital status	Singleness, Married, Separation, Widowhood, Divorce, Co-habiting	Single =1, Married =2, Separated=3 Widowed=4,,Divorced=5, Co-habiting 6 (number, %)
		None, Christianity, Islam, Hinduism,	None=1, Christianity=2, Islam=3, Hinduism=4,

	Religious Inclination	Buddhism, Others	Buddhism=5, Others=6 (Number, %)
	Education levels	Never been to school, Primary, Secondary, College, University	Never been to school=1,Primary = 2 Secondary=3, College=4 University=5 (Number,%)
	Employment	Nature of occupation Or employment	Unemployed=1, Self-employed=2 Employed=3 (number, %)
	Family Income	Amount of money each family earns per month	Below K1,000, 000=1 K1,000,000-K2,000,000=2 Over K2,000,000=3 Number & %
	Number of Children per client	Number of children per client	None=1, 1-2=2, 3-4=3, 5-6=4, 7-8=5, 9-10=6, 11-12=7 Number & %
Provision of Home-based Care (Accruing Benefits)	Manner of Communication	-The care givers offer respect to client -The care givers have concern for clients -The care givers are friendly -The care givers are polite. -The care givers are confidential about what they do	Number, %
	Spiritual care	-Strengthen me that God is with me -Receive encouragement for the state in which I am that I have been forgiven -Receiving the Holy Communion -Praying with me and for me	Number, %
	Clinical care	-Care givers bring the drugs -Care givers assess my health status. - Care givers examine me - Care givers relieve me of signs and	Number, %

		symptoms -Care givers advise and arrange for referral depending on what they find.	
	Social support	-Care givers provide financial support when necessary. - Care givers arrange for additional support from the local community for me. -Care givers provide relief for my family members to reduce the burden of care. - Care givers provide information to family members on creating awareness of issues related to the transmission of HIV.	Number, %
HBC Management	Drugs and other material supplies availability	-Medication accessibility -Material items -Referral arrangement -Bedding materials -Cash allowances for clients -Additional help for Clients	Numbers, %
	Collaboration between HBC providers and other Clinical Professionals.	Involvement of : -Medical Doctors -Trained Nurses -Clinical Officers -Physiotherapists -Lab. Technologists -Trained Social workers -Priests -Trained HBC givers	Numbers, %
	Support tools and documents	-HBC Guidelines manual -ART and OIs Guideline manual -DOTs Guidelines manual -ITG for frontline health workers -Other written notes	Numbers, %

The independent variable "benefits accruing to utilizing home based care "is the direct care rendered to clients using four variables as:

1. Manner of communication being interpersonal manner-features of the way in which caregivers interact personally with their clientele. This will be measured on a Likert scale using the labels:

a. The care givers offer respect to me
b. The care givers have concern for me
c. The care givers are friendly
d. The care givers are polite.
e. The care givers are confidential about what they do

2. Spiritual care being a subjective form of assistance which is rendered will be measured on a Likert scale using the labels:
   a. Strengthen me that God is with me
   b. Receive encouragement for the state in which I am that I have been forgiven
   c. Receiving the Holy Communion
   d. Praying with me and for me

3. Clinical care being help to alleviate suffering from signs and symptoms of HIV/AIDS will be measured on a Likert scale using the labels:
   a. Care givers bring the drugs
   b. Care givers assess my health status.
   c. Care givers examine me
   d. Care givers relieve me of signs and symptoms that they find
   e. Care givers advise and arrange for referral depending on what they find.
4. Social support being assistance from outside the family circle to benefit the client and family members be measured on a Likert scale using the labels:
   a. Care givers provide financial support when necessary.
   b. Care givers arrange for additional support from the local community for me.

c. Care givers provide relief for my family members to reduce the burden of care.
d. Care givers provide information to family members on creating awareness of issues related to the transmission of HIV.

The dependent variable "the type of satisfaction clients demonstrate" is the assessment of benefits accruing to utilizing home based care which constitute care rendered based on the four domains above. These will be measured on a Likert Scale as a level of happiness shown in form of a type of satisfaction.

3.2 Study Site:

The research was undertaken in Pemba rural in Choma District in Southern Province of Zambia. Selection of the study site was influenced by the fact that home based care organisations have been firmly established in this area than any other in Southern Province.

Pemba rural is serviced by a clinic that has a catchment population of about 10, 000 people living in the 16 broadly spread villages. Pemba has three basic schools and one high school. The majority of the population in Pemba are subsistence farmers.

3.3 Target Population

The research targeted individuals that were HIV/AIDS positive and had been enrolled as beneficiaries of home based care in rural Choma. The clientele were those who were served either by CHAZ or/and CRAIDS. The inclusion criteria were that respondents needed to be:

1. 15 years and older
2. Had been recruited and their names appeared on the register of beneficiaries under CHAZ or/and CRAIDS dwelling in rural Choma
3. Their state of health warranted them to participate in the study. Those who were acutely ill or mentally unable were not included in this study.

The exclusion criteria were that respondents who would not meet the above criteria and were acutely ill and the mentally ill were not included in the study.

3.4 Sampling and sample size

This study was focused on two samples and these were: care givers (employees of CHAZ or/and CRAIDS or directors as the case might be) and clientele being serviced by CHAZ or/and CRAIDS. In accordance with the governing regulations on research involving human subjects, before sampling was done, the researcher obtained clearance from the University of Zambia Research Ethics Committee (UNZAREC). In addition, permission was obtained from each participant on the study.

3.4.1 Sampling Employees of CHAZ or/and CRAIDS or Directors

In order to obtain documentary evidence the researcher interviewed a panel of six individuals being care providers or experts in home based care. There was one reason that made us consider expert sampling. Use of experts was the best way to elicit the views of persons who had specific expertise on the policy issues and care packages. In the end, 2 HIV/AIDS Psychosocial Counsellors who are also Nurses and 4 community based health care givers were available at the time of the study to give information on the checklist/inventory that was developed. Respondents were selected conveniently due to their being very few.

3.4.2 Clients Sample

Simple random sampling was employed because there was a sampling frame for the clientele. In this type of sampling, each sample element in the population was given an equal chance of being selected. From the population sample, an ideal sample at Precision Level of ±7 percent and Confidence Level of .95 using Yamane's (1967) table was determined (See Yamane's Table-Appendix B).

A table of random numbers was assigned to each client in order to draw out potential respondents as study elements. The ideal sample given the population of PLWHA being 123 having been enlisted was 78, though 79 subjects were selected. Each sample

element that was drawn had an address tagged with a random number and in this way it was easy to reach out to them. The home care givers were at hand to lead the researcher to the specific addresses. On average the researcher made two visitations in the event that the respondent was not available at home.

3.5 Data Collection Techniques

In order to answer the research questions, this study employed the following data collection methods:

Table 3.2 Profile of data collection methods and related questions

Research Question	Data collection methods
1. What have the care givers said that they will provide?	Documentary review and Interviews
2. What do care givers actually provide?	Documentary review , Interviews and Survey questionnaire (checklist)
3. What type of care does the clientele expect from the caregivers?	Documentary review and Interviews
4. Based on the clientele's experiences of what is provided, what is the level of satisfaction with home based care?	Survey questionnaire
5. Based on the consumer model, why do clients show a particular level of satisfaction?	Survey questionnaire

As can be seen in table 3.2, this study triangulated the data collection methods. This was done with a view to give a holistic picture because a single research tool would limit, distort, or even obscure reality of relationships between systems, people, organizations, and society according to Landry and Banville's (1992:77-79).

3.6 Pre-Test

Following the operationalisation of the variables, the survey questionnaire were validated using the guidelines of developing a new research instrument by relying on Guillemin et al., (1993) and Burns and Grove (1997) approaches. The development was based on theoretical knowledge in the domains of satisfaction and home-based care. After reviewing relevant theories on consumer model and home-based care, the researcher derived applied meaning to the terms so as to cast the items for the questionnaire. Some of the questions were constructed on an ordinal scale, in order to eliminate social desirability biases. Social desirability according to Smith (1981:300-302) are tendencies by most respondents to give answers that present a favourable self concept to make them appear "well adjusted, or unprejudiced or democratic or open minded or rational." In this study, social desirability was controlled by providing in some questions by giving examples as enhancement in order to provide extra contextual information to respondents so as to make it easy for them to give honest answers (Neuman, 2000:258). Pilot testing was done in Lusaka for four weeks at Jon Hospice HBC unit (KARA). This pilot testing served two purposes. The first purpose was to let the researcher have an experience of how to go about interviewing respondents. The second one was to test the data collection tools with a view to perfecting them.

3.7 Limitations of the Study

The study was mainly deductive and did not explore the expectations of the HBC beneficiaries. It also did not provide for responses in terms of their feelings and views about HBC services. Another limitation is that no program manager was interviewed to give their view as pertaining to the HBC programs. The study site was limited and did not provide adequate sample for this type of a study. We are proposing that a qualitative or mixed study be employed in future to provide meaning and elicit the motives for the behaviour of social actors if we needed to have a holistic picture. It is also better to conduct such a study in more than one site. This will provide for more and unbiased data to make general inferences.

CHAPTER FOUR

FINDINGS

4.0 INTRODUCTION

The findings in this chapter are organized according to the framework suggested by Yin (1998). Yin advises researchers to present their research findings according to the research questions. Since there are four research questions we present them one after another. Before presenting the results, it is research prudent to present a description of the respondents.

4.1 Sample Description

This study is about a sample of 79 clients living in Choma rural (Pemba). A sample of Six (6) Home-Based Care Providers was also conveniently and randomly selected to supplement the information obtained from the clients. The sample description is presented in Tables 4.1.1a to 4.1.1h.

4.1.1 Demographic Data

Figure 4.1 Age distribution

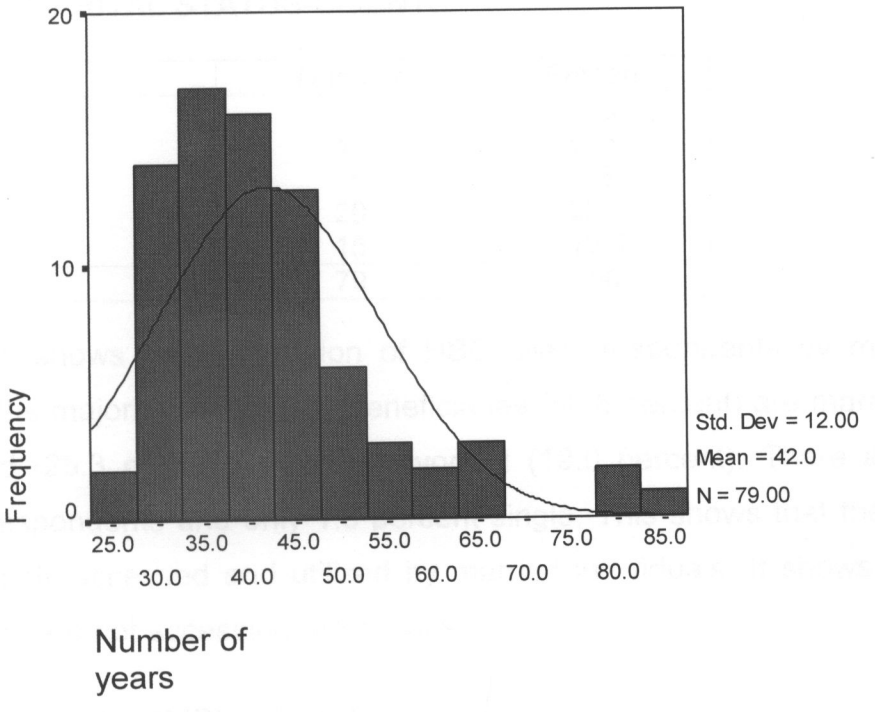


Figure 4.1 shows the age distribution of the HBC beneficiary respondents. It shows that a wide range of age of PLWHA access and utilize HBC services. It also shows that HIV/AIDS has afflicted a wide age range of 61 with the youngest age being 23 and the oldest 84 in this study population. The mean sample age was 42 with a wide variation of 143 and SD 11.99. The sample under study demonstrated a positive skew (fig.4.1).

Table 4.1.1a. GENDER-HBC BENEFICIARIES (CLIENTS)

Category	Number	Percent	*P. value*
Female	55	69.6	0.696
Male	24	30.4	0.304
Total	79	100	1.000

Table 4.1.1a shows the distribution of respondents as HBC beneficiaries by gender. There is a high proportion of 69.6 percent of females compared to 30.4 percent of males. It shows that there are more woman clients accessing and utilizing HBC services than males in this study. There is no significance in the findings.

Table 4.1.1b. MARITAL STATUS-CLIENTS

Category	Number	Percent
Single	1	1.3
Married	40	50.6
Separated	3	3.8
Widowed	20	25.3
Divorced	15	19.0
Total	79	100

Table 4.1.1b shows the distribution of HBC client respondents by marital status. It shows that the majority of the HBC beneficiaries (50.6 percent) are married followed by the widowed (25.3 percent) and the divorced (19.0 percent). There are 3.8 percent separated respondents and only 1.3 percent single. This shows that the HBC services are almost only accessed and utilized by married individuals. It shows that the single and the youth are not accessing the services.

Table 4.1.1c. EMPLOYMENT STATUS

Category	Number	Percent
Unemployed	71	89.8
Self-employed	4	5.1
Formerly Employed	4	5.1
Total	79	100

Table 4.1.1c shows the distribution of respondents as HBC beneficiaries by employment status. There is a very high proportion of 89.8 percent of the unemployed compared to 5.1 percent of those that are self-employed and formerly employed each. There are more PLWHA that are not employed than those that are employed. This shows that accessibility to finances is affected and hence high levels of poverty leading to failure to meet most requirements pertaining to HBC management.

Table 4.1.1d. FAMILY INCOME LEVELS

Category	Number	Percent
Below K1,000,000.00	78	98.7
K1,000,000-K2,000,000	1	1.3
Above K2,000,000	0	0
Total	79	100

Table 4.1.1d shows the distribution of HBC beneficiaries by family income levels per month. It shows a very high proportion of 98.7 percent of those that earn below K1, 000, 000.00 per month compared to only 1.3 percent earning between K1,000,000.00 and K2, 000, 000.00 per month. It shows that most HBC beneficiaries are not able to raise enough funds to supplement on what they receive from the care givers. This means that they solely depend on what they are given by the care givers. It also shows that poverty levels are high. This has a negative effect on the management of HBC.

Table 4.1.1e. NUMBER OF CHILDREN

Category	Number	Percent
None	1	1.3
1-4	36	45.6
5-8	34	43.0
9-12	8	10.1
Total	79	100

Table 4.1.1e shows the distribution of HBC beneficiary respondents by number of children they have. The majority of them (45.6 percent) have 1 to 4 children; 43.0 percent have 5 to 8 children; 10.1 percent have 9 to 12 children; and 1.3 percent has no child. It shows that almost all of the respondents have family members to look after. It also shows that even those that are widowed; divorced; and separated have family members to take care of. This increases the burden of care that clients have to carry despite the prevailing levels of poverty.

Table 4.1.1f. RELIGIOUS INCLINATION

Category	Number	Percent
None	1	1.3
Christianity	78	98.7
Islam	0	0
Hinduism	0	0
Buddhism	0	0
Others	0	0
Total	79	100

Table 4.1.1f shows the distribution of HBC beneficiary respondents by religious inclination. It shows that most of them (98.7 percent) have faith in Christianity compared to only 1.3 percent that has no faith in any of the religions. It shows that they have belief in God through Jesus Christ. Their faith has a bearing on the type of service they appreciate, thus, spiritual-oriented support. This also shows that HIV/AIDS has affected even the religious individuals and hence the need to approach HBC with wide collaboration. It also shows that HIV has affected a cross section of the society without discrimination.

Table 4.1.1g. EDUCATION STATUS

Category	Number	Percent
Never been to School	1	1.3
Primary	48	60.8
Secondary	28	35.4
College	2	2.5
University	0	0
Total	79	100

Table 4.1.1g shows the distribution of HBC beneficiary respondents by their education status. It shows that more (60.8 percent) of the PLWHA respondents have been to primary school compared to 35.4 percent that have been to secondary school; 2.5 percent that have been to college; and 1.3 percent that has never been to school. It shows that the majority of the PLWHA have not been to higher institutions of learning. This also shows that levels of education have an effect on the understanding of the HIV/AIDS effects and management.

4.2 Provision of Home-Based Care[3].

Provision of home based care addressed four domains bordering on: manner of communication, spiritual care, clinical care and social support.

Table 4.2.1 Manner of communication responses by clients

Characteristics	Response type Yes		No		Total		
	N	%	N	%	N	%	*P.value*
Care givers offer respect	75	94.9	4	5.1	79	100	*.949*
Care givers have concern	68	86.1	11	13.9	79	100	*.861*
Care givers are friendly	71	89.9	8	10.1	79	100	*.899*
Care givers are polite	74	93.7	5	6.3	79	100	*.937*
Care givers are confidential	71	89.9	8	10.1	79	100	*.899*

Table 4.2.1 shows the distribution of responses given by HBC beneficiaries in regard to the manner in which care givers communicated to them. It shows that 94.9 percent said they were treated with respect; 86.1 percent said they were shown concern; 89.9 percent said care givers were friendly; 93.7 percent said they were polite; and 89.9 percent said care givers showed confidentiality in the manner they attended to their client. This shows that care givers, generally, won the trust of their clients.

[3] This heading is related to answering the second research question which is: What do care givers render to patients in home based care?

Table 4.2.2 Spiritual care responses by clients

Characteristics	Response type Yes		No		Total		
	N	%	N	%	N	%	*P.value*
Care givers strengthen me that God is with me	65	82.3	14	17.7	79	100	*.823*
Care givers encourage me that I have been forgiven by God	57	72.2	22	27.8	79	100	*.722*
Care givers make me receive the holy communion	22	27.8	57	72.2	79	100	*.278*
Care givers pray with and for me	56	70.9	23	29.1	79	100	*.709*

Table 4.2.2 shows the distribution of responses given by HBC beneficiaries in regard to the type of spiritual care they received from care givers.

It shows that 82.3 percent said they were strengthened with the message of the presence of God with them; 72.2 percent said they had been encouraged that they have been forgiven by God; 70.9 percent said they prayed with the care givers at each visit; only 27.8 percent said they received Holy Communion. It shows that Holy Communion is not adequately administered among these clients though a greater number of respondents asserted that care givers gave most of each element of spiritual care.

Table 4.2.3 Clinical care responses by clients

Characteristics	Response type						
	Yes		No		Total		
	N	%	N	%	N	%	*P. value*
Care givers bring drugs	16	20.3	63	79.7	79	100	*.203*
Care givers assess my health status through inquiries	66	83.5	13	16.5	79	100	*.835*
Care givers examine me	47	59.5	32	40.5	79	100	*.595*
Care givers relieve me of signs and symptoms that they find	54	68.4	25	31.6	79	100	*.684*
Referral and Counselling	55	69.6	24	30.4	79	100	*.696*

Table 4.2.3 shows the distribution of responses given by HBC beneficiaries in regard to the type of clinical care they received from care givers. It shows that 83.5 percent agreed that care givers assessed their health status; 69.6 percent said they received counselling and referral when necessary; 68.4 percent said they received relief or personal support; 59.5 percent said they were physically examined by care givers during their visits; and only 20.3 percent said they were given drugs by care givers during their visits. It shows that a greater proportion of respondents asserted that care givers rendered most of each element of the clinical care domain apart from the provision of drugs.

Table 4.2.4 Social Support responses by clients

Characteristics	Response type						
	Yes		No		Total		
	N	%	N	%	N	%	*P. value*
Provision of financial support	3	3.8	76	96.2	79	100	*.038*
Arranging for additional support	29	36.7	50	63.3	79	100	.367
Provision of relief for family Members	32	40.5	47	59.5	79	100	.405
Provision of awareness information to family members	50	63.3	29	36.7	79	100	.633

Table 4.2.4 shows the distribution of responses given by HBC beneficiaries in regard to the type of social support they received from care givers. It shows that only 3.8 percent said they received financial support; 36.7 percent said they received additional support; 40.5 percent said they had their families provided with relief; and 63. 3 percent said their families received awareness information about HIV. It shows that the social support services were not as adequately administered as the other services in this study population. It is significant that the HBC beneficiaries were not happy with the type of financial support they received from the care givers {*P.value .038*}. There was a strong relationship between care and client satisfaction.

4.3 Levels of Satisfaction with Home-Based Care[4]

Satisfaction with home based care addressed four domains bordering on: satisfaction with the manner of communication, spiritual care, clinical care and social support. The detailed profile of levels of satisfaction is presented below. Generally, it was observed that satisfaction with home-based care is high for each domain; more than 50 percent of

[4] This heading is related to the research question: Based on the clientele's experiences of what is provided, what is the level of satisfaction with home based care?

the respondents said they were either very satisfied or satisfied with care than being dissatisfied or very dissatisfied except for social support which had the lowest satisfaction level (tables 4.3.1a to 4.3.1e)

4.3.1 Manner of Communication and Satisfaction

Table 4.3.1a. Care givers offer you respect

Category	Number	Percent
Very Satisfied	41	51.9
Satisfied	24	30.4
Fairly Satisfied	9	11.4
Not Satisfied	3	3.8
Very Unsatisfied	2	2.5
Total	79	100

Table 4.3.1a shows the satisfaction levels expressed by HBC beneficiary respondents about the respect they received from care givers. It shows that the majority (93.7 percent) were satisfied and 6.3 percent were not satisfied with the HBC services rendered to them. This shows that generally, care givers treated the clients with respect. It shows that care providers have regard for the HBC beneficiaries.

Table 4.3.1b. Care givers have shown concern for clients' needs

Category	Number	Percent
Very Satisfied	35	44.3
Satisfied	26	32.9
Fairly Satisfied	7	8.9
Not Satisfied	7	8.9
Very Unsatisfied	4	5.0
Total	79	100

Table 4.3.1b shows how satisfied HBC beneficiary respondents were with the concern shown to them by care providers. The majority of them (86.1 percent) were generally satisfied compared to 13.9 percent that were not satisfied with the HBC services they received from the care providers in the study site. It shows that care givers took time to be

with and listen to their clients. However, it also shows that there are some clients that felt they were not receiving appropriate concern from the care givers.

Table 4.3.1c. Care givers have shown friendliness

Category	Number	Percent
Very Satisfied	39	49.4
Satisfied	29	36.7
Fairly Satisfied	2	2.5
Not Satisfied	6	7.6
Very Unsatisfied	3	3.8
Total	79	100

Table 4.3.1c shows the satisfaction levels expressed by HBC beneficiary respondents about the friendliness with which they were treated by the care providers. Most clients (88.6 percent) were satisfied with the way care givers showed their friendliness to them while 11.4 percent were not satisfied with the services in this area. It shows that the majority of them felt the care givers did not neglect them based on their condition. This could be due to the religious background of the care givers.

Table 4.3.1d. Care givers have shown politeness

Category	Number	Percent
Very Satisfied	44	55.7
Satisfied	26	32.9
Fairly Satisfied	3	3.8
Not Satisfied	4	5.1
Very Unsatisfied	2	2.5
Total	79	100

Table 4.3.1d shows how HBC beneficiary respondents appreciated the politeness with which they were treated by care providers. Most of them (92.4 percent) were satisfied compared to 7.6 percent that were not satisfied. It shows that care givers attended to clients with courtesy. This also shows that care givers treated their clients with a positive attitude. This can also be attributed to Christian beliefs held by care givers in this study site as shown in table 4.1.1f.

Table 4.3.1e. Care givers have been confidential

Category	Number	Percent
Very Satisfied	46	58.2
Satisfied	21	26.5
Fairly Satisfied	4	5.1
Not Satisfied	4	5.1
Very Unsatisfied	4	5.1
Total	79	100

Table 4.3.1e shows levels of satisfaction expressed by HBC beneficiary respondents towards the confidentiality that was exhibited by care givers. Most clients (89.8 percent) were satisfied compared to 10.2 percent that were not satisfied. This shows that most clients trusted the care givers. It shows that clients are able to rely on the care givers and discuss with them issues concerning their health in details with hope to receive the necessary assistance. It also implies that care providers worked according to the norms and guidelines of counselling.

4.3.2 Spiritual Care and Satisfaction

Table 4.3.2a. Care givers strengthen that God is there

Category	Number	Percent
Very Satisfied	35	44.3
Satisfied	26	32.9
Fairly Satisfied	3	3.8
Not Satisfied	13	16.5
Very Unsatisfied	2	2.5
Total	79	100

Table 4.3.2a shows the satisfaction levels the HBC beneficiary respondents expressed about the encouragement they received from care givers concerning the presence of God.

It shows that the majority (81.0 percent) as compared to 19.0 percent that were not satisfied. It shows that the majority accept and believe in the existence of God. It shows that care givers take time to talk about religious issues. Apparently, 16.5 percent, quite

a big group were not satisfied with the way they received the strengthening. This shows that they were not happy with the way this service was provided.

Table 4.3.2b. Care givers encourage that God has forgiven you

Category	Number	Percent
Very Satisfied	25	31.6
Satisfied	25	31.6
Fairly Satisfied	6	7.6
Not Satisfied	19	24.1
Very Unsatisfied	4	5.1
Total	79	100

Table 4.3.2b shows satisfaction levels expressed by HBC beneficiary respondents concerning the spiritual encouragement they received from care givers about God's forgiveness for their sins. Most clients (70.8 percent) were satisfied compared to 29.2 percent that were not satisfied. It shows that most of the clients accepted the forgiveness of their sins by God. It shows that the forgiveness encouragement was not happily received by 29.2 percent of the clients.

Table 4.3.2c. Care givers bring Holy Communion

Category	Number	Percent
Very Satisfied	12	15.2
Satisfied	11	13.9
Fairly Satisfied	2	2.5
Not Satisfied	45	57.0
Very Unsatisfied	9	11.4
Total	79	100

Table 4.3.2c shows responses given by HBC beneficiaries on their satisfaction levels concerning their receipt of Holy Communion from care givers. The majority {68.4 percent} were not satisfied compared to 31.6 percent that were satisfied with the HBC services. It shows that though religious, most clients were not receiving Holy Communion. It also shows that these clients belong to different denominations and not all denominations administer Holy Communion. The other reason could be that Holy Communion is supposed to be given by the Clergy only and so there might not have

been much participation of the clergy in HBC in this site of study to administer Holy Communion to the clients as shown in table 4.4.1a.

Table 4.3.2d. Care givers pray with and for you

Category	Number	Percent
Very Satisfied	22	27.8
Satisfied	27	34.2
Fairly Satisfied	8	10.1
Not Satisfied	14	17.8
Very Unsatisfied	8	10.1
Total	79	100

Table 4.3.2d shows the satisfaction levels expressed by HBC beneficiary respondents about prayers they had with care givers during visits. Most of them (72.1 percent) were satisfied compared to 27.9 percent that were not satisfied. It shows that the majority were happy with the prayers they had with care givers and a few of them were not happy with the service. This can be attributed to the religious beliefs of both the care givers and clients themselves.

4.3.3 Clinical Care and Satisfaction

Clinical care in the context of home-based care is the continuation of medical care in the home.

Table 4.3.3a. Care givers provide drugs

Category	Number	Percent
Very Satisfied	3	3.8
Satisfied	4	5.1
Fairly Satisfied	3	3.8
Not Satisfied	51	64.6
Very Unsatisfied	18	22.8
Total	79	100

Table 4.3.3a shows the satisfaction levels that HBC beneficiary respondents expressed about the provision of drugs by care givers. It shows that the majority {87.3 percent} of the clients were not satisfied with the services compared to 12.7 percent that were

satisfied. It shows that drug supplies were not adequately provided and that most clients were not happy about the service in this area.

Table 4.3.3b. Care givers assess your health status

Category	Number	Percent
Very Satisfied	17	21.5
Satisfied	41	51.9
Fairly Satisfied	5	6.3
Not Satisfied	13	16.5
Very Unsatisfied	3	3.8
Total	79	100

Table 4.3.3b shows the satisfaction levels that HBC beneficiary respondents expressed about the way care givers assessed their health status at each visit. The majority (79.7 percent) were satisfied compared to 20.3 percent that were not satisfied. It shows that care givers took time to ask about how the clients were feeling each time they visited. It shows that most clients were happy with the service. However a few of them (16.5 percent and 3.8 percent) were not happy and very unhappy with the service respectively.

Table 4.3.3c. Care givers examine you

Category	Number	Percent
Very Satisfied	16	20.3
Satisfied	30	38.0
Fairly Satisfied	1	1.3
Not Satisfied	28	35.4
Very Unsatisfied	4	5.0
Total	79	100

Table 4.3.3c shows the satisfaction levels that HBC beneficiary respondents expressed about the way care givers examined them at each visit. Most of them (50.6 percent) were satisfied compared to a large proportion of 40.4 percent that were not satisfied with the HBC services. It shows that though the majority of the clients were happy with the service, though quite a good proportion of them were not happy and a minimal

proportion was very unhappy with the service. This could be due to the different perceptions and expectations that the clients had.

Table 4.3.3d. Care givers offer personal support to clients

Category	Number	Percent
Very Satisfied	23	29.1
Satisfied	32	40.5
Fairly Satisfied	1	1.3
Not Satisfied	17	21.5
Very Unsatisfied	6	7.6
Total	79	100

Table 4.3.3d shows the satisfaction levels that HBC beneficiary respondents expressed about the way care givers offered personal support to them whenever necessary. The majority (70.9 percent) were satisfied compared to 29.1 percent that were not satisfied with HBC services. It shows that though many of them were happy with personal support they received, quite a good proportion of the clients were not happy and a small proportion was very unhappy.

Table 4.3.3e Care givers counsel and arrange for referral

Category	Number	Percent
Very Satisfied	24	30.4
Satisfied	28	35.5
Fairly Satisfied	5	6.3
Not Satisfied	17	21.5
Very Unsatisfied	5	6.3
Total	79	100

Table 4.3.3e shows the satisfaction levels that HBC beneficiary respondents expressed about the provision of counsel and arrangement of referral for them by care givers. It shows that the majority (72.2 percent) were satisfied compared to 27.8 percent that were not satisfied with the HBC services. It shows that even if the majority of the clients were happy with this service, a good proportion of them were not happy. This could be due to a number of factors related to the cost of transport for referrals.

4.3.4 Social Support and Satisfaction

Social support, for HIV infected people, is the creation of an enabling environment for the PLWHA by all involved in providing care. It incorporates information dissemination and referral to support groups and welfare, economic, and legal services.

Table 4.3.4a. Care givers offering financial support

Category	Number	Percent	*P.value*
Very Satisfied	0	0	
Satisfied	1	1.3	
Fairly Satisfied	2	2.5	0.038
Not Satisfied	41	51.9	
Very Unsatisfied	35	25.3	0.962
Total	79	100	

Table 4.3.4a shows the satisfaction levels that HBC beneficiary respondents expressed about the provision of financial support to them by care givers. It shows 96.2 percent {*p.value .962*} of the clients were not satisfied compared to only 3.8 percent {*p.value .038*} that were satisfied. It shows that almost all the clients were not happy with the financial support service given to them.

Table 4.3.4b.Care givers offering additional support through community involvement

Category	Number	Percent	*P.value*
Very Satisfied	6	7.6	
Satisfied	17	21.5	
Fairly Satisfied	13	16.5	.456
Not Satisfied	23	29.1	
Very Unsatisfied	20	25.3	.544
Total	79	100	

Table 4.3.4b shows the satisfaction levels that HBC beneficiary respondents expressed about the provision of additional support to them by care givers.

It shows that the majority (54.4 percent) were not satisfied compared to 45.6 percent that were satisfied. It shows that most clients were not happy with this type of service. This may be attributed to the low numbers of care givers who were over-burdened by the amount of work they needed to do.

Table 4.3.4c. Care givers offering relief to family members

Category	Number	Percent
Very Satisfied	3	3.8
Satisfied	16	20.3
Fairly Satisfied	12	15.2
Not Satisfied	28	35.4
Very Unsatisfied	20	25.3
Total	79	100

Table 4.3.4c shows the satisfaction levels that HBC beneficiary respondents expressed about the provision of relief to family members of the PLWHA by care providers. It shows that the majority (60.7 percent) were not satisfied compared to 39.3 percent that were satisfied with the HBC services. It shows that even if some of the clients were happy with this service, most of them were not happy. This again could have been due to the load of work which was so high for few care givers to do.

Table 4.3.4d. Care givers creating awareness to family members.

Category	Number	Percent
Very Satisfied	21	26.6
Satisfied	26	32.9
Fairly Satisfied	5	6.3
Not Satisfied	15	19.0
Very Unsatisfied	12	15.2
Total	79	100

Table 4.3.4d shows the satisfaction levels that HBC beneficiary respondents expressed about the way care givers created awareness to family members on issues pertaining to HIV/AIDS. It shows that the majority (65.8 percent) were satisfied compared to 34.2 percent that were not satisfied with the HBC services rendered to them. It shows that even if most of the clients were happy with this activity, a reasonable proportion was not happy with the same.

4.4 Care Givers' Collaboration with Clinical Professionals; Drugs and Material Supplies; and Monitoring.

Six care givers were sampled by virtue of availability in their offices. They gave the following responses:

Table 4.4.1a Responses on Collaboration with Clinical Professionals-by Care Providers

Characteristics	Response type					
	Yes		No		Total	
	N	%	N	%	N	%
Trained Medical Doctors	0	0	6	100	6	100
Trained Nurses	6	100	0	0	6	100
Trained Clinical Officers	1	16.7	5	83.3	6	100
Trained Physiotherapists	0	0	6	100	6	100
Trained Lab. Technologists	3	50	3	50	6	100
Trained Social Workers	3	50	3	50	6	100
Trained Priests/Clergy	1	16.7	5	83.3	6	100
Trained CHW/HBC Givers	1	16.7	5	83.3	6	100

Table 4.4.1a shows the distribution of responses given by care givers when they were asked about the involvement of various cadres of clinical professionals in HBC activities. It shows that all (100 percent) declined the involvement of medical doctors and physiotherapists and only 16.7 percent said there was an involvement of clinical officers, priests, and trained home-based care givers each. It shows that 50 percent said trained laboratory personnel and social workers were involved in HBC activities and 100 percent said trained nurses were involved. It shows that there is little involvement of clinical professionals in HBC programs. It also shows that most participants in HBC programs are nurses.

Table 4.4.1b Responses on Drug supplies to Clients-by Care Providers

Characteristics	Response type					
	Yes		No		Total	
	N	%	N	%	N	%
Anti-fungals	2	33.3	4	66.7	6	100
Anti-Biotics	3	50.0	3	50.0	6	100
Anti-diarrhoeals	5	83.3	1	16.7	6	100
Analgesics	5	83.3	1	16.7	6	100
Anti-Tb drugs	2	33.3	4	66.7	6	100
Rehydration Salts	5	83.3	1	16.7	6	100
Herbs	0	00.0	6	100.0	6	100

Table 4.4.1b shows the responses given by care givers when they were asked about the availability of different types of drugs pertaining to HBC. It shows that 83.3 percent said that anti-diarrhoea drugs; analgesics; and rehydration salts were available; 50 percent said antibiotics were available; and 33.3 percent said anti-fungal and tuberculosis drugs were available. It also shows that though this is a rural place, where the use of herbs would be encouraged, no one reported the availability of herbs.

Table 4.4.1c Responses on other material supplies to Clients-by Care Providers

Characteristics	Response type					
	Yes		No		Total	
	N	%	N	%	N	%
Presence of Gloves	4	67.7	2	33.3	6	100
Presence of Water-proof Sheeting	0	00.0	6	100.0	6	100
Presence of Draw sheets	0	00.0	6	100.0	6	100
Presence of Bed sheets	0	00.0	6	100.0	6	100
Presence of Cotton wool	2	33.3	4	67.7	6	100
Presence of Gauze	1	16.7	5	83.3	6	100
Presence of Strapping	1	16.7	5	83.3	6	100
Presence of Cleansing lotions	3	50.0	3	50.3	6	100
Effective local remedies	1	16.7	5	83.3	6	100
Presence of Disinfectants	1	16.7	5	83.3	6	100

Table 4.4.1c shows the responses from HBC providers when they were asked about the availability of materials that are required in HBC programs. It shows that most of these materials were in short supply and some were completely out of stock at the time of the

study. This shows that it was difficult to carry out services that needed the use of the materials.

Table 4.4.1d Responses on monitoring of Clients-by Care Providers

Characteristics	Response type					
	Yes		No		Total	
	N	%	N	%	N	%
Clinical Monitoring of PLWHA	4	67.7	2	33.3	6	100
Laboratory Monitoring of PLWHA	1	16.7	4	67.7	6	100

Table 4.4.1d shows the responses given by HBC givers when they were asked about the monitoring of their clients. In this study Clinical Monitoring of PLWHA means the physical, daily check-ups conducted by a nurse, clinical officer or medical officer on the clients. Laboratory Monitoring of PLWHA is referred to the various laboratory tests done on clients" specimens to check their response to treatment. It shows that 67 percent said that clinical monitoring of their clients was done and only 16.7 percent said laboratory monitoring of their clients was done. It shows that laboratory services are lacking.

Clinical Care Management

Table 4.4.2 Clinical Care Management responses by Care givers

Characteristics	Response type					
	Yes		No		Total	
	No.	%	No.	%	No.	%
Supply of drugs to clients	5	83.3	1	16.7	6	100
Health status of clients assessment	6	100	0	0	6	100
Examining clients at each visit	5	83.3	1	16.7	6	100
Clients' personal support	6	100	0	0	6	100
Referral and counselling	6	100	0	0	6	100

Table 4.4.2 shows the distribution of responses that care givers gave when they were asked about the type of clinical care they gave to their HBC clients. It shows that the all (100 percent) agreed that they assessed the health status of their clients; they offered

personal support to clients during their visits; and they counselled and referred their clients when necessary. It also shows that most of them (83.3 percent) supplied drugs and examined their clients at each visit.

Table 4.4.3 Psycho social and Spiritual care responses by Care givers

Characteristics	Response type					
	Yes		No		Total	
	No.	%	No.	%	No.	%	p.*value.05*
Provision of Financial Support	0	0	6	100	6	100	.000
Additional support for clients	2	33.3	4	66.7	6	100	.333
Provision of relief for members to reduce the burden of care	5	83.3	1	16.7	6	100	.833
Awareness information to family members	5	83.3	1	16.7	6	100	.833
Strengthening clients that God is there	6	100	0	0	6	100	1.000
Encouraging spiritually	6	100	0	0	6	100	1.000
Giving the Holy Communion	0	0	6	100	6	100	.000
Praying for and with the clients	6	100	0	0	6	100	1.000

Table 4.4.3 shows the distribution of responses that care givers gave when they were asked about the type of counselling, social and spiritual support they gave to their HBC clients. It shows that no one gave any financial support and administered Holy Communion to clients. Only 33.3 percent gave additional support to their clients. However, it shows that 100 percent gave spiritual support in terms of talking about the existence of God, encouraging spiritually and praying with and for clients. It also shows that 83.3 percent assisted clients' family members and provided awareness information in regard to HIV infection. This shows that care givers never helped PLWHA financially but were able to arrange for spiritual support and counselling. It was strongly significant that there was a dissatisfaction with the provision of financial support from care givers to the HBC beneficiaries {p.value <.05}. Generally, there is no significance in the findings.

Table 4.4.4 Support Tools and documents responses by Care givers

Characteristics	Response type					
	Yes		No		Total	
	No.	%	N	%	No.	%	*P. value.05*
Home-Based Care Guidelines Manual	3	50	3	50	6	100	.500
Anti-Retroviral Treatment and Opportunistic Infections Management Guidelines Manual	1	16.7	5	83.3	6	100	.167
Directly-Observed Treatment short course (DOTs) for TB Guidelines Manual	4	66.7	2	33.3	6	100	.667
Integrated Technical Guidelines for Frontline Health Workers	1	16.7	5	83.3	6	100	.167
Others: Personal written notes	2	33.3	4	66.7	6	100	.333

Table 4.4.4 shows the distribution of responses that care givers gave when they were asked about the type of support tools in terms of manuals and written guidelines for reference during their work. It shows that 66.7 percent said they had the TB treatment guidelines manual; 50 percent said they had HBC guidelines manual; 16.7 percent said they had ART and ITG manuals; and 33.3 percent had personal written notes. It shows that the care givers did not have adequate information for reference as they were attending to their clients. (Table 4.4.4).

CHAPTER FIVE

DISCUSSIONS

5.0 DISCUSSION

The findings have demonstrated that HBC programs have a direct impact on the lives of the PLWHA. Satisfaction levels are based on the type and quality of care that HBC beneficiaries receive. The study sought to establish satisfaction levels of PLWHA-HBC beneficiaries with the type of home-based care they received.

Care providers said they provided the services in form of spiritual care; clinical care; and social support. These activities are enhanced with the availability of support tools, medical supplies and collaboration with clinical professionals.

Provision of Home-based care:

Based on the statement of the problem, this study sought to answer one main question which is: are PLWHA satisfied with the type of home based care they receive? The answer is that they are `indeed satisfied. However we drew four subsidiary questions from this main research question and the answers to each one are discussed below.

Regarding research question one[5] we found that care givers claimed that they provided spiritual care, clinical care and social support. This is in line with other HBC programs in countries such as Botswana (Seloilwe, 2000); Kenya (Republic of Kenya, 2002); and Malawi (Malawi Ministry of Health, 2003). Home-based care programs are supposed to be holistic in their approach. However, when we physically counter checked, we found that both material and human resources required to provide home-based care were extremely low as shown in tables 4.4.1a to 4.4.1d. According to the USAID August, 2002 report, the quality of care for PLWHA is dependent, to some extent on the availability of support materials and personnel. This is a critical area in service delivery.

[5] "What have care givers stated about provision of care?"

Provision of home based care addressed four domains bordering on: manner of communication, spiritual care, clinical care and social support.

Manner of Communication:

In the area of Manner of communication it was found that the satisfaction levels were between 86.1 and 94.9 percent. The clients were satisfied with the care given to them through proper communication (table 4.2.1). This was confirmed by their satisfaction levels as shown in tables 4.3.1a to 4.3.1e. This can be attributed to the fact that Zambians are naturally tender-hearted and God-fearing. So they respect other human beings regardless of their state of health. Faith values have an impact on one's attitude towards others.

Spiritual Care:

We can say that PLWHA do have relief from a wide range of experiences. This is borne out by their response to intense questions pertaining to spiritual and other related issues which may manifest as clinical suffering, and aggravate pain and psychosocial problems. These organizations attach recognition and management of spiritual issues as an important part of home-based care, which is addressed by involving spiritual leaders in the HBC programmes and in home visits at the patient's request.
Receiving of the Holy Communion was done by only 27.8 percent as compared to 70.9 percent of those that prayed with the care givers; 72.2 percent of those that were encouraged pertaining to God's forgiveness of their sins; and 82.3 percent of those that were strengthened as regards to God being with them (Table 4.2.2). This was confirmed by satisfaction levels in tables 4.3.2a to 4.3.2d. This is because the others are not Catholics and they do not receive Holy Communion. It can be said that HBC programmes in this site is spiritual-biased. Religion seems to have a big impact on the community members in this study site. Spiritual care, according to the quoted countries in the region (Botswana, Kenya, Malawi and Uganda) has a big impact on someone's

response to the state of their health. It produces belief that God is going to heal the sickness.

Clinical Care:

In the clinical care domain, apart from the provision of drugs, to which only 20.3 percent of the clients responded positively, the rest had between 59.5 and 83.5 percent positive responses (table 4.2.3). This was confirmed by satisfaction levels in tables 4.3.3a to 4.3.3e. This could be attributed to the low participation of other clinical professionals besides nurses in home-based care programmes as shown in table 4.4.1a. Home based care in this domain is intended to begin at diagnosis, providing counselling, nutrition and education, preventive therapies, amongst others. It extends to appropriate care and treatment of opportunistic infections, as well as effective management of pain and symptom control. Caregivers ought to also provide supervision of medication and are trained as DOTS workers to supervise TB treatment. They would also be ideally placed to supervise and support ARV treatment. Support tools and manuals are lacking. This, in many ways, will negatively affect the performance of HBC providers. Provision of such requirements by relevant organs should be encouraged.

In their National Home-Based care Policy Guidelines of 2002, the Ministry of Health in Kenya places clinical care component on top of their list in as far as HBC activities are concerned. This was also alluded to by Campbell, Chela and Siankanga in their studies done in Chikankata. Unfortunately due to constraints in the study site in terms of drugs and non-involvement of other clinical professionals, this area is not adequately attended to. There is need for the organizations and the government to adequately address the issue if HBC has to succeed.

Social Support:

In the social support domain provision of financial support was the lowest (3.8 percent). Arranging for additional support, provision of relief to family members and provision of awareness were 36.7; 40.5; and 63.3 percent respectively (table 4.2.4). This was confirmed in satisfaction levels in tables 4.3.4a to 4.3.4d. The low positive response in financial support could be as a result of low in comes in the study site as shown in the demographic data (table 4.1.1d). This could be due to the unemployment levels that are very high (89.8 percent) as shown in table 4.1.1c. This poses a very negative effect on the success of any given program, let alone HBC that needs moving from one area to another.

Regarding research question two,[6] it can be said that home based care providers rendered care optimally in the four critical domains except for clinical and social support where actual care was low. This is supported by the responses given by HBC beneficiaries in tables 4.2.3 and 4.2.4 which are confirmed by their satisfaction levels in tables 4.3.3a to 4.3.4d. This can be attributed to lack of finances and support tools for care givers to carry out various activities.

Regarding research question three[7], the level of satisfaction with home based care is high except for social support which had the lowest satisfaction levels and this was occasioned by failure by the care givers to provide financial support, arranging for additional support and providing relief for family members.

Financial assistance is one of the major policy items in the Kenyan National HBC Guidelines. This produces some form of empowerment to care givers as well as HBC beneficiaries. Crouch and friends attested to the same. The USAID also wrote that financial support was an integral part of HBC programs. This will lead to the formulation of Income-Generating activities that will further empower beneficiaries.

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[6] "What do caregivers actually provide?"

[7] Based on the clientele's experiences of what is provided, "what is the level of satisfaction with home based care?"

Determinants of Satisfaction:

Regarding research question four[8] PLWHA' points of view of high satisfaction levels were determined by personal experiences and this was occasioned by the good feeling that what they expected happened.

This type of care fits Russell and Schneider (2000) type where various home-based care team members visit their clients. With this type, care providers visit patients in their homes and spend time talking and educating them and their families about basic care needs. Home visiting also provides support with cooking and cleaning (Russell & Schneider, 2000).

Other Observations:

From what has been shown in the results section, a striking pattern found in this study are two contradictions and these are (i) a contradiction between what was said would be provided and what is actually provided and (ii) what is actually provided and appreciated by the beneficiaries.

Concerning the first contradiction, what we can say is that we have home-based care organisations that do not have resources for purposes of relief from signs and symptoms; and fail to provide basic needs of food, bedding and clothing, but they claim that they render such services. It is surprising that the most critical areas of home-based care like patient assessments and actual relief of signs and symptoms are not adequately done. This scenario shows that the care organisations are far from meeting the needs of PLWHA and fail to encourage traditional community life and create 'responsibilities'; a facet noted by the Department of Health (2001: 10). This finding is similar to that of Seloilwe (2000) in Botswana.

[8] Based on the consumer model, "why do clients show a particular level of satisfaction?"

On the basis of failing to meet the basic needs of PLWHA, we can suggest that poor quality home based care is related to:

a) High rates of opportunistic infections.
b) Low levels of drug compliance.
c) Higher levels of drug resistance particularly to anti TBs and ARVs
d) Persistent high levels of HIV poor knowledge, attitudes and practices to reduce the spread and recovery when infected and family caregivers being HIV-positive, which suggests that they might become infected during the process of giving care.
e) High rate of re-admission to hospitals of PLWHA with numerous complications and mortality.
f) High rates of hospital as well as home mortality.

Concerning the second contradiction, what we can say is that in spite of the fact that home-based care organisations did not have the resources to render comprehensive home based care in terms of PLWHA; the ratings could be explained on the basis of the assumptions of the consumer model. PLWHA had points of view determined by personal experiences and personal expectations (Locker and Dunt, 1978; Bond and Thomas, 1992; Cochrane, 1992). The regularity is that when PLWHA are in need, the hospital system and the nuclear or extended family system do offer assistance in a small way. The assistance is not measured against any official guidelines and so clients appreciate the little they receive. They count it better than nothing. It therefore follows that PLWHA gave high ratings and the null hypotheses were rejected on the basis of this principle.

Limitations of the Study

The study did not include accounts of the researched and as such we were unable to collect the subjective experiences and expectations of the respondents. Another limitation is that no sponsor of the program was interviewed to give their view as

pertaining to the HBC programs. The sample size was not adequate enough for this type of a study. It was more of an academic research

We are proposing that a qualitative or mixed study be employed in future to provide meaning and elicit the motives for the behaviour of social actors if we needed to have a holistic picture. The population targeted was mainly a religious group and confined in one part of Choma district. It is better to conduct such a study in more than one site. This will provide for more and unbiased data to make general inferences.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusions

What can be concluded from this study is that home based care in Choma rural- Pemba as provided by CRAIDS and CHAZ is predominantly non-clinical, but spiritual and focuses only on minimal areas of providing social support. This is appreciated by PLWHA, yet it fails to meet the foundational tenets of home based care explained by Spier and Edwards (1990), Kaleeba, et al. (1997), and countries like Kenya and Malawi. We may attribute this inadequate care to the lack of government policy on home-based care and insufficient capital resources. 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 programs and that it is mainly left to the NGOs to run them; and NGOs often lack infrastructure and sometimes capacity. Like all research, this study has notable significances and limitations. We begin by advancing the significant components. This is an attempt to investigate client satisfaction of home-based care services in this country. The results in this study provided a basic background of what is happening in home-based which cannot be generalized to other areas outside Pemba.

The study is also significant in the methodology it has adopted. With improved methodology, where the cost benefit analysis and program effectiveness are done, the study would provide more beneficial information.

Another significance of this study is adding perspectives towards resolving the vacuum in home-based care based on unknown issues of home-based care. The vacuum was in part due to the relative absence of a theoretical framework to determine satisfaction levels of home-based care. This study also contributes towards the scientific world knowledge on the need to have a policy on home-based care.

The consumer model was used as a basis to gauge satisfaction and models that have been used outside Zambia were used to determine the content of the home-based care domains in constructing our data collection tools. What this entails is that what has been theorized elsewhere about home based care must also hold in our country and this is a fallacy in knowledge. The deductive strategy does not include accounts of the researched and as such we were unable to collect the subjective experiences of the social actors. We are proposing that a qualitative or mixed study be employed in future to provide meaning and elicit the motives for the behaviour of social actors if we needed to have a holistic picture beyond the mundane realism of empirical research.

6.2 RECOMMENDATIONS

Based on the findings of the study, it seems clear that most of the activities undertaken are adequately carried out if they are not resource-based. The low involvement of other clinical professionals further limits the rate of activity. In other countries, for example, Botswana, Kenya, Malawi, and Uganda clinical professionals are said to be an integral part of HBC programmes. The non-existence of a national policy on Home-Based care has a negative bearing on the success of the programme.

It is recommended that:

- The government needs to formulate a specific policy that is tailored to home-based care in the community.
- A deliberate move to set up a small fund for home-based care activities should be put in place. This will supplement the efforts of the few care providers.
- Active participation of other trained clinical professionals would boost the program and lead to quality care for the clients.
- Those involved in HBC programmes should undertake special training so as to face the challenges in HBC with success.
- Zambia should learn from Kenya (Republic of Kenya, 2002), Botswana (Seloilwe, 2000) and Malawi (Malawi Ministry of Health, 2003) to come up with home-based care policies that would address fundamental tenets of home-based care.

- Zambia could modify and adopt one of the recommendations from the study conducted by Sapepa (1998) in the Eastern Cape of South Africa where home-based care for PLWHA was modified to incorporate CHBC programs into primary health care programs; it developed an inter-sectoral approach to management.

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APPENDICES

APPENDIX A- Ethical Matters

Since this study was going to involve human subjects, it was paramount to obtain consent to under-take this study (other than from the respondents) from the District board and the designated research and ethics committees.

It therefore followed that all relevant parties would require obtaining informed consent prior to data collection. In this vein, letters expressing purposes, benefits and risks were sent/given to all eligible respondents and the district board.

The critical ethical elements of concern in this study are set below and they appear in the drafted copies of the letters that appear in this study as appendices (Appendices C-G)

Usage of the respondents

Regarding the usage of the respondents being human subjects, all respondents were availed with information as to how they had been selected. This helped in reducing uncertainties and questions for example, "why have they selected me and not the other person".

What was to be done?

Regarding what would be done to the respondent and the data, all respondents would be availed with details of what steps would be followed and that nothing would be done to them that would be injurious.

Risk

The respondents were informed that they may have some discomfort or some anxiety and if they feel or they see this, they may not wish to participate in the study. They were availed with the necessary information so as to encourage their participation.

Benefits.

All respondents were availed with information regarding direct and indirect benefits.

Confidentiality

Assurances were given that all information that would be provided by the respondents would be treated with utmost confidentiality. In this way respondents would be satisfied with anonymity.

Rights

Respondents were availed with information regarding the authority they had to quit the study anytime and to submit their complaints to the authority and even to the researcher. A grievance process was availed to them.

APPENDIX B–Yamane's Sample Determination Tables

Table 1 and Table 2 present sample sizes that would be necessary for given combinations of precision, confidence levels, and variability. Please note two things. First, these sample sizes reflect the number of obtained responses, and not necessarily the number of surveys mailed or interviews planned (this number is often increased to compensate for non response). Second, the sample sizes in Table 2 presume that the attributes being measured are distributed normally or nearly so. If this assumption cannot be met, then the entire population may need to be surveyed.

Table 1. Sample size for ±5%, ±7% and ±10% Precision Levels Where Confidence Level is 95% and P=. 5.

Size of Population	Sample Size (n) for Precision (e) of:		
	±5%	±7%	±10%
100	81	67	51
125	96	78	56
150	110	86	61
175	122	94	64
200	134	101	67
225	144	107	70
250	154	112	72
275	163	117	74
300	172	121	76
325	180	125	77
350	187	129	78
375	194	132	80
400	201	135	81
425	207	138	82
450	212	140	82

Appendix B continued

Table 2. Sample size for ±3%, ±5%, ±7% and ±10% Precision Levels Where Confidence Level is 95% and P=. 5.				
Size of Population	Sample Size (n) for Precision (e) of:			
	±3%	±5%	±7%	±10%
500	A	222	145	83
600	A	240	152	86
700	A	255	158	88
800	A	267	163	89
900	A	277	166	90
1,000	A	286	169	91
2,000	714	333	185	95
3,000	811	353	191	97
4,000	870	364	194	98
5,000	909	370	196	98
6,000	938	375	197	98
7,000	959	378	198	99
8,000	976	381	199	99
9,000	989	383	200	99
10,000	1,000	385	200	99
15,000	1,034	390	201	99
20,000	1,053	392	204	100
25,000	1,064	394	204	100
50,000	1,087	397	204	100
100,000	1,099	398	204	100
>100,000	1,111	400	204	100
a = Assumption of normal population is poor (Yamane, 1967). The entire population should be sampled.				

APPENDIX C– Authority Letter (Provincial Health Office)

THE UNIVERSITY OF ZAMBIA,
SCHOOL OF MEDICINE,
DEPT. OF COMMUNITY MEDICINE,
P.O. BOX 50110,
LUSAKA. ZAMBIA.
25th January, 2007

U.f.s. The Head of Department of Community Medicine,
University of Zambia,
School of Medicine,

THE PRONVINCIAL HEALTH DIRECTOR,
P.O. BOX 60206,
LIVINGSTONE,
ZAMBIA.

Dear Sir,
RE; PERMISSION TO CONDUCT RESEARCH
My name is Gracious Adams Simwanza; a Master of Public Health student at the above named institution. In partial fulfillment for the award of the said degree, I am required to carry out a research study.

I am writing to you seeking permission to conduct my research for gain of a masters` degree. My research is centred on the benefits accrued from the utilisation of Home-Based Care services.

SUBJECT: Home-Based Care for People Living with HIV/AIDS

TOPIC BENEFITS OF HOME BASED CARE UTILISATION AND CLIENT SATISFACTION: A CASE STUDY OF PLWHAs IN RURAL CHOMA
SAMPLES:

1. Care providers
2. People Living with HIV/AIDS.

DATA COLLECTING TOOLS:
1. Documentary/check lists reviews and interviews.
2. Survey questionnaire

SAMPLING METHODS: Purposive sampling, Simple random sampling

STUDY DURATION: Two months.

Thanking you in advance for your cooperation.
Yours sincerely

Gracious Adams Simwanza

APPENDIX D– Authority Letter (District Director of Health)

THE UNIVERSITY OF ZAMBIA,
SCHOOL OF MEDICINE,
DEPT. OF COMMUNITY MEDICINE,
P.O. BOX 50110,
LUSAKA. ZAMBIA.
25th January, 2007

U.f.s. The Head of Department of Community Medicine,
University of Zambia,
School of Medicine,

THE DISTRICT DIRECTOR OF HEALTH,
P.O. BOX
CHOMA. ZAMBIA.
ZAMBIA.

Dear Sir,

RE; PERMISSION TO CONDUCT RESEARCH

My name is Gracious Adams Simwanza; a Master of Public Health student at the above named institution. In partial fulfillment for the award of the said degree, I am required to carry out a research study.

I am writing to you seeking permission to conduct my research for gain of a masters` degree. My research is centred on the benefits accrued from the utilisation of Home-Based Care services.

SUBJECT: Home-Based Care for People Living with HIV/AIDS

TOPIC BENEFITS OF HOME BASED CARE UTILISATION AND CLIENT SATISFACTION: A CASE STUDY OF PLWHAs IN RURAL CHOMA
SAMPLES:

1. Care providers
2. People Living with HIV/AIDS.

DATA COLLECTING TOOLS:

1. Documentary/check lists reviews and interviews.
2. Survey questionnaire

SAMPLING METHODS: Purposive sampling, Simple random sampling

STUDY DURATION: Two months.

Thanking you in advance for your cooperation.

Yours sincerely

Gracious Adams Simwanza

APPENDIX E– Authority Letter (Pemba Health Centre)

THE UNIVERSITY OF ZAMBIA,
SCHOOL OF MEDICINE,
DEPT. OF COMMUNITY MEDICINE,
P.O. BOX 50110,
LUSAKA. ZAMBIA.
25th January, 2007

U.f.s. The Head of Department of Community Medicine,
University of Zambia,
School of Medicine,

The Officer in-charge,
Pemba Health Centre
CHOMA. ZAMBIA.
ZAMBIA.

Dear Sir,

RE; PERMISSION TO CONDUCT RESEARCH

My name is Gracious Adams Simwanza; a Master of Public Health student at the above named institution. In partial fulfillment for the award of the said degree, I am required to carry out a research study.

I am writing to you seeking permission to conduct my research for gain of a masters` degree. My research is centred on the benefits accrued from the utilisation of Home-Based Care services.

SUBJECT: Home-Based Care for People Living with HIV/AIDS

TOPIC BENEFITS OF HOME BASED CARE UTILISATION AND CLIENT SATISFACTION: A CASE STUDY OF PLWHAs IN RURAL CHOMA
SAMPLES:

1. Care providers
2. People Living with HIV/AIDS.

DATA COLLECTING TOOLS:

1. Documentary/check lists reviews and interviews.
2. Survey questionnaire

SAMPLING METHODS: Purposive sampling, Simple random sampling

STUDY DURATION: Two months.

Thanking you in advance for your cooperation.

Yours sincerely

Gracious Adams Simwanza

APPENDIX F –Authority Letter (KARA)

THE UNIVERSITY OF ZAMBIA,
SCHOOL OF MEDICINE,
DEPT. OF COMMUNITY MEDICINE,
P.O. BOX 50110,
LUSAKA. ZAMBIA.
25th January, 2007

U.f.s. The Head of Department of Community Medicine,
University of Zambia,
School of Medicine,

KARA Counselling Unit (Jon Hospice)
Kamwala. Lusaka.
ZAMBIA.

Dear Sir,

RE; PERMISSION TO CONDUCT RESEARCH PRETEST

My name is Gracious Adams Simwanza; a Master of Public Health student at the above named institution. In partial fulfillment for the award of the said degree, I am required to carry out a research study.

I am writing to you seeking permission to conduct my research for gain of a masters` degree. My research is centred on the benefits accrued from the utilisation of Home-Based Care services.

SUBJECT: Home-Based Care for People Living with HIV/AIDS

TOPIC: BENEFITS OF HOME BASED CARE UTILISATION AND CLIENT SATISFACTION: A CASE STUDY OF PLWHAs IN RURAL CHOMA
SAMPLES:

1. Care providers
2. People Living with HIV/AIDS.

DATA COLLECTING TOOLS:

1. Documentary/check lists reviews and interviews.
2. Survey questionnaire

SAMPLING METHODS: Purposive sampling. Simple random sampling

STUDY DURATION: Two months.

Thanking you in advance for your cooperation.

Yours sincerely

Gracious Adams Simwanza

APPENDIX G – Client's Introductory Letter

THE UNIVERSITY OF ZAMBIA,
SCHOOL OF MEDICINE,
DEPT. OF COMMUNITY MEDICINE,
P.O. BOX 50110,
LUSAKA. ZAMBIA.
25th January, 2007

.Dear Sir / Madam,

Re: - INVITATION TO PARTICIPATE IN THE BENEFITS OF HOME BASED CARE UTILISATION CLIENT SATISFACTION: A CASE STUDY OF PLWHAs IN RURAL CHOMA

My name is Gracious Adams Simwanza and I am a student at the above mentioned school doing my Master of Public Health. I am required to carry out a study as part of my school requirements.

I am inviting you to take part in the study.

Back ground
As you may be aware, HIV/AIDS is a global problem and a very big disease burden in Zambia, in particular.

One of the Zambian Government's strategies in the mitigation of the effects and impacts of HIV/AIDS is to strengthen the Home – based care activities through the involvement of the local communities.

There are a number of organizations carrying out Home-based care activities in various communities. The aim of this study is to determine the utilization of Home-based care services.

Title of Study:

The project is titled "The benefits that arise from the utilization of Home-Based Care services for HIV/AIDS".

Main objective of the Study:

The main objective of the study is to explore Clients' Satisfaction which arises from the Utilization of Home-Based Care Services.

Description of the Study:

If you decide to take part in the project, you will be involved in an interview. Your part in the project will involve answering questions on the questionnaire. Beneficiaries of the home-based care services as well as some care providers will be interviewed. Your name will not appear on the questionnaire. A code number will be used for each respondent.

Duration of the Interview

The interview will last between twenty to forty-five minutes.

Benefits for participating on the Study:

There is no immediate personal benefit (e.g. monetary or material) arising from your participation in this research. However, it is hoped that this will help the planners, managers and implementers to make valuable changes aimed at improving the services required by the beneficiaries, and enhance the participation of the beneficiaries in the HIV/AIDS-HOME-BASED CARE activities.
Risks:

The possible risks in the project are not there at all. You may however, feel some discomfort with some questions, which is usual, in case you are anxious. If that will be the case, and if you feel to stop the interview, you shall do so voluntarily because the decision to be part of the study is entirely up to you and you may terminate the interview any time. What ever you decide, it will not be held against you. No traumatic procedure will be done on you.

Confidentiality:

All information you give will be dealt with in strict confidence. No document that bears your names will be part of the responses you are going to make. All your responses will be identified by a number. Your individual rights will be respected.

Decision to quit

The decision whether to take part or not is up to you. You do not have to be in the study. If you decide not to take part in the study, you can quit any time. What ever you decide is okay for you. You shall tell Gracious, the person who is responsible for the project that you are quitting or you cannot go further in the interview.

Rights and Complaints

Whatever decision you make about your participation in the research will not influence your current or future access to health care services. You will still receive whatever care is due to you. In the event that you need further clarification about this study you are free to ask the attending interviewer. If you are not satisfied with any given response you are at liberty to contact the Principal Investigator- Mr. Gracious Adams Simwanza, University of Zambia, School of Medicine, Department of Community Medicine, P.O. Box 50110, Lusaka. Cell no. 095/096/097 746 446. Email: gracious_simwanza@yahoo.co.uk.
OR The Secretary, Research Ethics Committee, University of Zambia, P.O. Box 50110, Ridgeway Campus, Lusaka, Zambia. Telephone (01) 256067.
E-mail: unzarec@zamnet.zm

You are, therefore, being requested to take part in this research.

Thank you.

APPENDIX H– Client's Consent Form

I,.....have read the purpose of the study / it has been explained to me. I do understand that the study aims at determining the "benefits that arise from the utilization of Home-Based Care services for HIV/AIDS".

There is no immediate personal benefit (e.g. monetary or material) arising from my participation in this research.

I do understand that the results of this study will help planners, managers and caregivers to make valuable programmes and that this will lead to improvement on the care rendered to the ultimate beneficiaries.

I have been assured that all the information I give will be treated with strict confidence.

I have also been informed that whether I take part in the research or not, I will still receive whatever care is due to me.

I have, therefore, accepted to participate in the research with the above understanding.

Participant's sign .....Date__ __/__ __/2007.

Thumb print..... Date__ __/__ __/2007.

Witness's Sign..... Date__ __/__ __/2007.

Research Assistant's sign.....Date__ __/__ __/2007.

APPENDIX I– Questionnaire (Client & Care giver)

CHAZ		CRAIDS	

Serial No._____

Date of Administration_____/_____/_____

Village/Compound_____

SECTION A- DEMOGRAPHIC DATA

1. Age _____ 2. Sex_____

3. Age Group (years)

a. 15-19	
b. 20-24	
c. 25-29	
d. 30-34	
e. 35-39	
f. 40-44	
g. 45-49	
h. 50 and above	

4. Marital Status

a. Single	
b. Married	
c. Separated	
d. Widowed	
e. Divorced	
f. Co-habiting	
g. Others:	

5. Employment

a. Unemployed	
b. Self employed	
c. Employed	

6. Family Income

a. Below K1 000 000	
b. K1 000 000-K2 000 000	
c. Over K 2 000 000	

7. Number of Children

a. None	
b.1-2	
c. 3-4	
d. 5-6	
e. 7-8	
f. 9-10	
g. 11-12	

8. Religious Inclination

a. None	
b. Christianity	
c. Islam	
d. Hinduism	
e. Buddhism	
f. Others:	

9. Education Status

a) Never been to school	
b) Primary	
c) Secondary	
d) College	
e) University	

SECTION B Benefits of Utilization

Manner of communication

10. What can you say about the way care is rendered to you by the care givers?

Label	Yes	No
1. The care givers offer respect to me		
2. The care givers have concern for me		
3. The care givers are friendly		
4. The care givers are polite.		
5. The care givers are confidential about what they do		

Spiritual care

11 What can you say about the spiritual support that care givers render to you?

Label	Yes	No
1. Strengthen you that God is with you		
2. Receive encouragement for the state in which you are that you have been forgiven		
3. Receiving the Holy Communion		
4. Praying with you and for you		

Clinical care

12 What can you say about Clinical care that care givers render to you?

Label	Yes	No
1. The care givers bring the drugs		
2. The care givers assess my health status.		
3. The care givers examine me		
4. The care givers relieve me of signs and symptoms that they find		
5. The care givers advise and arrange for referral depending on what they find.		

Social support

12 What can you say about Social support that care givers render to you?

Label	Yes	No
a. . Care givers provide financial support when necessary.		
b. . Care givers arrange for additional support from the local community for me.		
c. . Care givers provide relief for my family members to reduce the burden of care.		
d. . Care givers provide information to family members on creating awareness of issues related to the transmission of HIV.		

SECTION C: SATIFACTION LEVELS

Now that you have commented on the benefits of utilizing this type of care, please indicate the extent to which you are satisfied with each type of care. Please tick in the appropriate answer box.

Manner of communication

13 What can you say about the manner in which caregivers communicate personally with you?

Label	Very Satisfied	Satisfied	Somewhat Satisfied	Not Satisfied	Very Unsatisfied
a. The care givers offer respect to me					
b. The care givers have concern for me					
c. The care givers are friendly					
d. The care givers are polite.					
e. The care givers are confidential about what they do					

Spiritual care

14. What can you say about the spiritual support that care givers render to you?

Label	Very Satisfied	Satisfied	Somewhat Satisfied	Not Satisfied	Very Unsatisfied
a. Strengthen me that God is with me					
b. Receive encouragement for the state in which I am that I have been forgiven					
c. Receiving the Holy Communion					
d. Praying with me and for me					
e. Strengthen me that God is with me					

Clinical care

15 What can you say about clinical care that care givers render to you?

Label	Very Satisfied	Satisfied	Somewhat Satisfied	Not Satisfied	Very Unsatisfied
a. The care givers bring the drugs					
b. The care givers assess my health status.					
c. The care givers examine me					
d. The care givers relieve me of signs and symptoms that they find					
e. The care givers advise and arrange for referral depending on what they find.					

Social support

15. What can you say about social support that care givers render to you?

Label	Very Satisfied	Satisfied	Somewhat Satisfied	Not Satisfied	Very Unsatisfied
a. Care givers provide financial support when necessary.					
b. Care givers arrange for additional support from the local community for me.					
c. Care givers provide relief for my family members to reduce the burden of care.					
d. Care givers provide information to family members on creating awareness of issues related to the transmission of HIV.					

APPENDIX J–Checklist/Inventory Sheet (Care givers)

CRAIDS ☐ CHAZ ☐

SECTION A Requirements for Various Aspects of Home-Based Care[9]

The following are recognized as minimum requirements for effective home-based care services:

1. Clinical Management Requirements

☐Trained clinical personnel (TICK- √ to show presence & CROSS-× to show absence)

Doctors_____ Nurses____ Clinical officers___

Paramedical staff involved in patient management, e.g.,

Physiotherapists___ Laboratory technologists____ Social workers____,

Others (specify)_____

☐Drugs for opportunistic infections:

Anti-fungals___ Antibiotics___ Anti-diarrhoeals____ Analgesics_____

Anti TB drugs____ Rehydration solutions____ Herbs____

Effective local remedies_____ ☐Anti-retrovirals_____:

Close clinical monitoring of the PLWHA ____

Close Laboratory monitoring of the PLWHA____

☐Supplies of various types:

Gloves___, waterproof sheeting___ draw sheets___ bed sheets_____

Others (Specify)_____

Cotton wool____ gauze___ strapping___ cleansing lotions_____

2. Nursing Care Requirements

☐Nurses and health care workers trained in HBC_____

☐Community health workers trained to provide care_____

family members trained to provide care_____.

☐Home care kits containing gloves, cotton wool, disinfectants, and basic medicines_____.

☐Equipment and supplies for general nursing procedures_____.

☐Time and transport_____.

3. Counselling/Psycho-Spiritual Care Requirements

☐Professional ethics:

Observance of confidentiality____ backed by legislation as necessary____.

☐Training:

Integration of counselling into all training curricula for health workers____

Social workers___ teachers____ community health workers____

Trainers of trainers_____ PLWHAs_____

☐Monitoring and supervision:

Follow up of all those offering counselling services to provide technical support and to ensure quality control_____.

Hotline service and counselling support services for PLWHAs and their families_____.

Presence of voluntary counselling and HIV testing centres_____.

Political will and support_____

4. Support Literature materials.

Home-Based Care Guidelines Manual_____

Anti-Retroviral Treatment and Opportunistic Infections Management Guidelines Manual_____

Directly Observed Treatment short course (for Tuberculosis) Guidelines Manual_____

Integrated Technical Guidelines for Frontline Health workers_____

Others (specify)_____

[9]Inductively drawn and based on the Home-Based Care Policy Guidelines of South Africa and Kenya. The two countries have well developed policy and packages on home based care

SECTION B

Claims of Care provided on Paper

Label	Yes	No
1. Taking drugs to the clients		
2. Assessing the health status at each visit		
3. Examine the client at each visit		
4. Relieving of signs and symptoms that are found after each assessment and examination		
5. Advise and arranging for referral depending on what is found after the examination and assessment		
6. Providing financial support when necessary.		
7. Arranging for additional support from the local community		
8. providing relief for family members to reduce the burden of care.		
9. Providing information to family members on creating awareness of issues related to the transmission of HIV.		
10. Strengthening that God is there		
11. Encouraging spiritually		
12. Giving the Holy Communion		
13. Praying with clientele		
14. Providing supplies of various types in form of home based care kits: a. Gloves, b. waterproof sheeting c. draw sheets d. bed sheets e. Cotton wool f. Gauze g. Strapping h. cleansing lotions i. disinfectants, j. basic medicines		

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0275869

THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE

Tel: 252641

Assistant Dean (UG) Office
P.O. Box 50110
LUSAKA

21st February, 2007

Mr. Gracious Adams Simwanza
Dept of Community Medicine
LUSAKA

Dear Mr. Simwanza

RE: GRADUATES PRESENTATION

Following the graduate presentation of 21st December 2006, we are now happy that all the corrections to your research proposal have been done. The proposal meets the standard as laid down by the Board of Graduate Studies.

You can proceed and present to the Research Ethics.

Yours faithfully

Mr. K. Bowa
ASSISTANT DEAN POSTGRADUATE

CC: Research Ethics

THE UNIVERSITY OF ZAMBIA

RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@zamtel.zm

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

Assurance No. FWA00000338
IRB00001131 of IORG0000774

12 April, 2007
Ref.: 018-03-07

Mr Gracious Adams Simwanza
Department of Community Medicine
School of Medicine
University of Zambia
LUSAKA

Dear Mr Simwanza,

RE: RESEARCH PROPOSAL ENTITLED: **"BENEFITS OF HOME BASED CARE UTILISATION AND CLIENT SATISFACTION: A CASE STUDY OF HIV/AIDS IN RURAL CHOMA"**

The following research proposal was presented to the Research Ethics Committee Secretariat on 3 April, 2007 where changes were recommended. We would like to acknowledge receipt of the corrected version with clarifications. The proposal has now been approved. Congratulations!

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.

Yours sincerely,

for Prof. J. T. Karashani, MB, ChB, PhD
CHAIRMAN
RESEARCH ETHICS COMMITTEE

Date of approval: 12 April, 2007 **Date of expiry:** 11 April, 2008