

## **DECLARATION**

I Ruth T. Mbukwa, declare that this Dissertation represents my own work and that all the sources I have quoted have been cited and acknowledged by means of complete references. I further declare that this Dissertation has not been previously submitted for a Degree, Diploma or other qualification at this or another University. It has been prepared in accordance with the guidelines for Masters of Science in Nursing Dissertations of the University of Zambia.

**Signed.....**

**Date.....**

**Candidate**

**Signed.....**

**Date.....**

**Supervisor**

## **CERTIFICATE OF APPROVAL**

The University of Zambia approves this Dissertation on Determinants of utilization of home based care services among PLWHA 18 years and above on antiretroviral therapy in Chadiza district in partial fulfillment for the award of Degree of Master of Science in Nursing.

**Examiner's Signature..... Date.....**

**Examiner's Signature..... Date.....**

**Examiner's Signature..... Date.....**

## **ABSTRACT**

HIV/AIDS is a major public health concern in Zambia. The HIV/AIDS epidemic has placed a large burden on public health facilities that are already functioning with limited resources. This has shifted the burden of care to families and communities, because public health services are often stretched beyond their capacities. Several community home-based care and services evolved in response to the identified need.

The reason for carrying out the research was to investigate determinants of utilization of Home-based care services by People above 18 years in Chadiza District Living with HIV/AIDS. The specific objectives were to identify who are the commonest types of home-based care preferred in the community, to determine PLWHA's level of knowledge about the Home-Based Care services, to determine the demographic characteristics that may influence utilization of HBC services by PLWHA and to establish whether socio-cultural factors influence utilization of Home-Based Care services by PLWHA.

The study used a mixed method design. A total of 223 participants took part in the study in Chadiza district at two static and two mobile ART sites for two months and two weeks. Quota sampling was needed to determine the sample of two antiretroviral sites, while convenient sampling was used at ART centres. Purposive type of sampling was used to select the participants for Focus Group Discussions. Quantitative data was analyzed using SPSS 16.0 for windows. Chi square tests were used to determine measures of associations between the independent and dependent variables. Qualitative data was recorded on audio tapes, later transcribed verbatim. The most useful quotations were selected from discussions to summarize main ideas.

The study revealed that Home Based Care services for the terminally ill were provided by family members (34.4%; n=223). Most 8 (7.3%; n=223) respondents reported had heard about Home Based Care and were able to correctly define Home Based Care (86.2%; n=223) and were also able to identify correctly the kind of people who are supposed to receive Home Based Care services (92.4%; n=223).

The findings showed a statistically significant relationship between knowledge of Home Based Care and client receiving Home Based Care services. Married respondents tended to receive Home Based Care services as compared to the unmarried people and the young. Educational level and occupation of respondents demonstrated a relationship with receiving HBC services. The more educated people were the less likely they are to receiving Home Based Care services. Those who were in formal employment were less likely to receive Home Based Care services than those in non formal and the unemployed such as housewives.

Some socio-cultural factors such as religion, sex and service related factors such as availability, accessibility, lack of funding for HBC organizations, general poor quality of service delivery were the major factors identified as very important in the effective utilization of home based services.

The study emphasizes that home based care should be spelled out clearly within the new national HIV and AIDS policy (2010-2015) and other relevant policies stressing the care for the terminally ill, caring for caregivers and possible funding by Government through the Ministry of Health.

In order to improve performance of HBC services utilization it is necessary to develop robust strategies enhance health education and promote use of HBC's especially among the highly educated, those who are in formal employment, traditional leaders and general community.

The study also identified that vigorous stigma reduction campaigns are a priority if the educated, employed, youth and unmarried PLWHA are to utilize HBC services because these are some of the group that have shown low uptake of his service..

Capacity and system strengthening of HBC organizations such as community based and Non-Governmental organizations should be prioritized by donors and other organizations operating in Chadiza District. Most of such Organizations have proved to be very weak in term of capacities hence limiting productivity.

## **Factors Influencing the Study and Literature Review**

The study was conducted in ART sites and there was need to go to the sites for data collection using a vehicle which were also engaged in other competing District activities. This affected duration for data collection. There was no full funding by the Ministry Health to buy items on the budget for use during the process and financial support to data collecting assistants and this may have influenced data collection in a way.

The location Chadiza District has problems in accessing internet to help in information searching. This affected my speed in completing the study and thus prolonged period of study.

## **DEDICATION**

I dedicate this study to God for giving me knowledge and strength throughout the study.

To my husband Victor Mwafulirwa and my children Tamara, Elizabeth, Kondwani and Geoffrey who have been a source of inspiration and encouragement throughout the study.

To my family members; sisters, brothers, nephews and nieces for their tireless encouragement and support, I say thank you so much.

Lastly but not the least to management (Chadiza District Health Management Team), my workmates, my classmates and school mates, church mates and friends, I say thank you so much for the support.

I managed because you were there for me socially, materially and spiritually.

## **ACKNOWLEDGEMENTS**

Many thanks go to Ministry of Health for granting me paid study leave to undertake the studies for Masters in Nursing at the University of Zambia and partially funding the research proposal.

Also many thanks go to Chadiza District Medical Office for approving the training plan and support throughout my study time.

Special thanks go to my supervisors; Dr Catherine M. Ngoma, Mrs. Patricia Ndele and all staff at the Department of Nursing Sciences who through their tireless efforts in guiding me throughout and whose knowledge made it possible for this dissertation to be a reality.

Many thanks also go to Mr Mwanei Simasiku, workmates and friends for the encouragement and help they rendered to me through their inputs in various ways to see this dissertation where it is. Many thanks go to the respondents, participants and data collectors for accepting the request to take part in the study.

Lastly but not the least, many more thanks go to my family, relatives and friends for the encouragement and support throughout my study period, thank you for your understanding.

## Table of Contents

<b>DECLARATION</b> .....	<b>i</b>
<b>CERTIFICATE OF APPROVAL</b> .....	<b>ii</b>
<b>ABSTRACT</b> .....	<b>iii</b>
<b>DEDICATION</b> .....	<b>v</b>
<b>ACKNOWLEDGEMENTS</b> .....	<b>vi</b>
<b>LIST OF FIGURES</b> .....	<b>x</b>
<b>LIST OF ABBREVIATIONS</b> .....	<b>xiii</b>
<b>CHAPTER ONE</b> .....	<b>1</b>
<b>1 INTRODUCTION</b> .....	<b>1</b>
<b>1.1 BACKGROUND</b> .....	<b>1</b>
1.1.1 TYPES OF HOME- BASED CARE SERVICES.....	4
1.1.2 GENERAL ROLE OF HOME BASED CARE PROGRAMMES .....	5
1.1.3 SPECIFIC ROLES OF HOME BASED CARE PROGRAMMES .....	5
<b>1.2 STATEMENT OF THE PROBLEM</b> .....	<b>8</b>
<b>1.3 CONCEPTUAL FRAMEWORK</b> .....	<b>10</b>
1.3.1 SERVICE RELATED FACTORS .....	10
1.3.2 SOCIO-CULTURAL AND ECONOMIC RELATED FACTORS .....	14
1.3.3 DISEASE RELATED FACTORS .....	16
<b>1.4 THEORETICAL FRAMEWORK</b> .....	<b>18</b>
<b>1.5 JUSTIFICATION</b> .....	<b>19</b>
<b>1.6 RESEARCH QUESTIONS</b> .....	<b>20</b>
<b>1.7 RESEARCH OBJECTIVES</b> .....	<b>21</b>
1.7.1 GENERAL OBJECTIVE .....	21
1.7.2 SPECIFIC OBJECTIVES .....	21
<b>1.8 HYPOTHESIS</b> .....	<b>21</b>
1.8.1 NULL HYPOTHESIS.....	21
1.8.2 ALTERNATIVE HYPOTHESIS .....	21
<b>1.9 VARIABLES AND CUT OFF POINTS</b> .....	<b>22</b>
<b>1.10 CONCEPTUAL DEFINITION OF TERMS</b> .....	<b>23</b>
<b>CHAPTER TWO</b> .....	<b>25</b>
<b>2.1 LITERATURE REVIEW</b> .....	<b>25</b>
<b>2.2 INTRODUCTION</b> .....	<b>25</b>

<b>2.3</b>	<b>GLOBAL PERSPECTIVE.....</b>	<b>25</b>
<b>2.4</b>	<b>REGIONAL PERSPECTIVE.....</b>	<b>26</b>
<b>2.5</b>	<b>NATIONAL PERSPECTIVE.....</b>	<b>27</b>
<b>2.6</b>	<b>CONCLUSION .....</b>	<b>29</b>
<b>CHAPTER THREE .....</b>		<b>30</b>
<b>3.1</b>	<b>RESEARCH METHODOLOGY .....</b>	<b>30</b>
<b>3.2</b>	<b>INTRODUCTION .....</b>	<b>30</b>
<b>3.3</b>	<b>RESEARCH DESIGN .....</b>	<b>30</b>
<b>3.4</b>	<b>RESEARCH SETTING.....</b>	<b>32</b>
<b>3.5</b>	<b>STUDY POPULATION .....</b>	<b>32</b>
<b>3.6</b>	<b>SOURCES OF DATA .....</b>	<b>33</b>
<b>3.7</b>	<b>SAMPLE SELECTION.....</b>	<b>33</b>
3.7.1	INCLUSION CRITERIA.....	33
3.7.2	EXCLUSION CRITERIA .....	34
<b>3.8</b>	<b>SAMPLE SIZE .....</b>	<b>34</b>
<b>3.9</b>	<b>DATA COLLECTION TOOLS .....</b>	<b>35</b>
3.9.1	SEMI STRUCTURED INTERVIEW SCHEDULE .....	35
3.9.2	FOCUS GROUP DISCUSSION GUIDE (APPENDIX 6).....	36
3.9.3	VALIDITY- .....	36
3.9.4	RELIABILITY .....	36
<b>3.10</b>	<b>DATA COLLECTION TECHNIQUE .....</b>	<b>37</b>
3.10.1	DATA COLLECTION TECHNIQUE FOR QUANTITATIVE DATA.....	37
3.10.2	DATA COLLECTION TECHNIQUE FOR QUALITATIVE DATA .....	38
3.10.3	PRE-TEST .....	38
3.10.4	ADJUSTMENTS MADE TO THE DATA COLLECTING TOOL .....	39
<b>3.11</b>	<b>ETHICAL CONSIDERATIONS.....</b>	<b>39</b>
<b>CHAPTER FOUR .....</b>		<b>41</b>
<b>4.1</b>	<b>DATA ANALYSIS AND PRESENTATION OF FINDINGS.....</b>	<b>41</b>
<b>4.2</b>	<b>INTRODUCTION .....</b>	<b>41</b>
<b>4.3</b>	<b>DATA PROCESSING AND ANALYSIS .....</b>	<b>41</b>
4.3.1	QUANTITATIVE DATA.....	41
<b>4.4</b>	<b>DATA PRESENTATION.....</b>	<b>42</b>
4.4.1	QUANTITATIVE FINDINGS .....	42
4.4.2	QUALITATIVE FINDINGS .....	73



CHAPTER FIVE .....	83
<b>5.1 DISCUSSION OF FINDINGS AND IMPLICATIONS .....</b>	<b>83</b>
<b>5.2 INTRODUCTION .....</b>	<b>83</b>
<b>5.3 SOCIO DEMOGRAPHIC CHARACTERISTICS OF SAMPLE .....</b>	<b>83</b>
<b>5.4 PLWHA’S LEVEL OF KNOWLEDGE ABOUT THE HBC .....</b>	<b>88</b>
<b>5.5 UTILIZATION OF HOME BASED CARE SERVICES.....</b>	<b>91</b>
<b>5.6 CONCLUSION .....</b>	<b>95</b>
<b>5.7 IMPLICATIONS TO NURSING .....</b>	<b>96</b>
5.7.1 NURSING PRACTICE .....	96
5.7.2 NURSING ADMINISTRATION .....	97
5.7.3 NURSING RESEARCH .....	97
<b>5.8 LIMITATIONS OF THE STUDY.....</b>	<b>97</b>
<b>5.9 RECOMMENDATIONS.....</b>	<b>98</b>
<b>REFERENCES.....</b>	<b>100</b>
APPENDIX 1: GHANT CHART .....	108
APPENDIX 2: BUDGET .....	109
APPENDIX 3: INFORMATION SHEET .....	111
APPENDIX 4: INFORMED CONSENT FORM .....	114
APPENDIX 5: STRUCTURED INTERVIEW SCHEDULE .....	116
APPENDIX 6: FOCUS GROUP DISCUSSION GUIDE.....	125
APPENDIX 7: FOCUS GROUP DISCUSSION .....	127
APPENTIX 8: LETTER FROM BIOMEDICAL RESEARCH ETHICS.....	129
APPENDIX 9: LETTER FROM THE MINISTRY OF HEALTH .....	130

**LIST OF FIGURES**

FIGURE 1: CONCEPTUAL FRAMEWORK ..... 17

FIGURE 2: AUDIENCE ALONG A BEHAVIOUR CHANGE CONTINUUM ..... 18

FIGURE 3: AGE OF RESPONDENTS ..... 43

FIGURE 4: COMMUNITY INVOLVED IN PROVIDING HBC SERVICES ..... 50

FIGURE 5: DISTANCE TO THE NEAREST HBC ..... 59

## LIST OF TABLES

TABLE 1: PATIENTS ON ART MISSING PHARMACY APPOINTMENT DAYS.....	9
TABLE 2: VARIABLES AND THE CUT OFF POINTS .....	22
TABLE 3: GENDER OF RESPONDENTS.....	44
TABLE 4: MARITAL STATUS OF RESPONDENTS.....	44
TABLE 5: RELIGIOUS DENOMINATION OF THE RESPONDENTS .....	45
TABLE 6: LEVEL OF EDUCATION OF RESPONDENTS.....	45
TABLE 7: OCCUPATION OF RESPONDENTS .....	46
TABLE 8: LEVEL OF INCOME PER MONTH OF THE RESPONDENTS .....	46
TABLE 9: HEARD ABOUT HOME BASED CARE .....	47
TABLE 10: MEANING OF HOME BASED CARE .....	47
TABLE 11: SOURCE OF INFORMATION.....	48
TABLE 12: SERVICES OFFERED BY HBC CAREGIVERS.....	48
TABLE 13: RESPONSES ON BENEFITS OF HBC SERVICES .....	49
TABLE 14: RESPONDENTS’ REASONS FOR RESPONSES IN TABLE 13 .....	49
TABLE 15: RESPONDENTS’ KNOWLEDGE OF OTHER PLWHA .....	50
TABLE 16: ELIGIBILITY FOR HOME BASED CARE SERVICES .....	51
TABLE 17: KNOWLEDGE ON DURATION OF RESPONDENTS’ HIV POSITIVE STATUS .....	51
TABLE 18: KNOWLEDGE ON DISCLOSURE OF HIV STATUS .....	52
TABLE 19: RESPONDENTS’ REASONS FOR NON DISCLOSURE.....	52
TABLE 20: SUMMARY ON RESPONSES TO QUESTIONS ON KNOWLEDGE OF HBC.....	53
TABLE 21: RESPONDENTS ON ANTI RETROVIRAL TREATMENT .....	54
TABLE 22: TREATMENT SUPPORTERS OF THE RESPONDENTS .....	54
TABLE 23: REFERRAL TO HEALTH FACILITY FOR HIV TESTING AND ART.....	55
TABLE 24: RECEIVING HBC SERVICES .....	55
TABLE 25: PROVIDERS OF HBC SERVICE.....	56
TABLE 26: SERVICES OFFERED BY HOME BASED CAREGIVERS .....	57
TABLE 27: RATING OF CARE .....	57

TABLE 28: REASONS FOR RATING .....	58
TABLE 29: ENROLLED WITH HBC SERVICE PROGRAM .....	59
TABLE 30: ORGANIZATION PROGRAMME ENROLLED WITH .....	60
TABLE 31: NUMBER OF TIMES VISITED BY CAREGIVER .....	60
TABLE 32: GENDER INVOLVEMENT IN HBC SERVICE PROVISION .....	61
TABLE 33 A: REASONS FOR WHO IS MORE INVOLVED- WOMEN.....	61
TABLE 33 B: REASONS FOR WHO IS MORE INVOLVED- MEN .....	62
TABLE 34: INVOLVEMENT WITH HOME BASED CARE PROGRAMME .....	62
TABLE 35: COMING ON DOCUMENTED APPOINTMENT DATE .....	63
TABLE 36: UTILISATION OF HBC SERVICES IN RELATION TO AGE.....	64
TABLE 37: UTILISATION OF HBC SERVICES IN RELATION TO GENDER.....	65
TABLE 38: UTILISATION OF HBC SERVICES IN RELATION TO THE MARITAL STATUS .....	66
TABLE 39: UTILISATION OF HBC SERVICES IN RELATION TO RELIGIOUS DENOMINATION .....	66
TABLE 40: UTILISATION OF HBC SERVICES IN RELATION TO EDUCATIONAL LEVEL.....	67
TABLE 41: UTILISATION OF HBC SERVICES IN RELATION TO OCCUPATION.....	67
TABLE 42: UTILISATION OF HBC SERVICES IN RELATION TO INCOME LEVEL .....	68
TABLE 43: UTILISATION OF HBC SERVICES IN RELATION TO DEMOGRAPHIC VARIABLES.....	69
TABLE 44: UTILISATION OF HBC SERVICES IN RELATION TO MEANING OF HBC SERVICES .....	70
TABLE 45: UTILISATION OF HBC SERVICES IN RELATION TO HEARD OF HBC SERVICES .....	70
TABLE 46: UTILISATION OF HBC SERVICES IN RELATION TO TYPE OF SERVICE PROVIDER .....	71
TABLE 47: UTILISATION OF HBC SERVICES IN RELATION TO REFERRAL TO HEALTH FACILITY .....	72

## **LIST OF ABBREVIATIONS**

<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>ALU/LAC</b>	AIDS Law Unit from the Legal Assistance Centre
<b>APCA</b>	African Palliative Care Association
<b>ART</b>	Antiretroviral Therapy
<b>ASWC</b>	Adherence Support Workers
<b>BEN</b>	Bicycling of Empowerment Network Namibia
<b>CBoH</b>	Central Board of Health
<b>CBO</b>	Community Based Organization
<b>CETZAM</b>	Christian Enterprise Trust of Zambia
<b>CHBC</b>	Community Home Based Care
<b>CHW</b>	Community Health Worker
<b>CRS</b>	Catholic Relief Service
<b>DHM</b>	District Health Management Team
<b>ECR</b>	Expanded Church Response to HIV/AIDS
<b>FBO</b>	Faith Based Organization
<b>FGD</b>	Focus Group Discussion
<b>HAART</b>	Highly Active Ant- Retroviral Treatment
<b>HBC</b>	Home-Based Care
<b>HC</b>	Health Centre
<b>HCC</b>	Health Centre Committee

<b>HIV</b>	Human Immune Virus
<b>HRCI</b>	High Risk Corridor Initiative
<b>IEC</b>	Information Education Communication
<b>LWF</b>	Lutheran World Federation
<b>M &amp; E</b>	Monitoring and Evaluation
<b>MoH</b>	Ministry of Health
<b>NAC</b>	National AIDS Council of Zambia
<b>NG</b>	Non-Governmental Organization
<b>OIs</b>	Opportunistic Infections
<b>OVCs</b>	Orphans and Vulnerable Children
<b>PEPFAR</b>	President's Emergency Plan for AIDS Relief
<b>PEP</b>	Post- Exposure Prophylaxis
<b>PIT</b>	Pathfinder International Tanzania
<b>PHC</b>	Primary Health Care
<b>PLWHA</b>	People Living With HIV/AIDS
<b>PMTCT</b>	Prevention of Mother-to-Child Transmission
<b>PRSP</b>	Poverty Reduction Strategic Plan
<b>STI</b>	Sexually Transmitted Infection
<b>TACAID</b>	Tanzania Commission for AIDS
<b>TASO</b>	The AIDS Support Organization
<b>TB</b>	Tuberculosis

<b>UN</b>	United Nations
<b>UNAIDS</b>	Joint United Nations Program on HIV/AIDS
<b>UNDP</b>	United Nations Development Program
<b>USAID</b>	United States Agency for International Development
<b>VCT</b>	Voluntary Counseling and Testing
<b>VSO</b>	Voluntary Service Overseas
<b>WAAPO</b>	Women against AIDS and Poverty
<b>WFP</b>	World Food Program
<b>WHO</b>	World Health Organization
<b>ZNAN</b>	Zambia Network of AIDS
<b>ZAMBART</b>	Zambia AIDS-Related Tuberculosis Project

# **CHAPTER ONE**

## **1 INTRODUCTION**

### **1.1 BACKGROUND**

The National AIDS Council of Zambia (2008) reported that Zambia, with an estimated population of about 12.2 million (Central statistical Office (CSO) 2007, Census projections) is one of the hardest hit country by the HIV and AIDS pandemic in the world with an HIV prevalence rate of 14.3% (CSO, 2007).

In the early 1990s, as the number of people infected with HIV in Zambia began to increase, the formal health care system became overwhelmed by the numbers of people requiring hospitalization for long periods of time leading to widening of the gap between the demand for and the availability of health care services. Therefore, relying mainly on the family and community as caregivers, community home-based care has become a significant contributor in the treatment, care and support of those infected and affected by HIV/AIDS (National Aids Council, 2007).

The World Health Organization (WHO) defines Home-Based Care (HBC) as the provision of services in support of the HIV and AIDS care process that takes place in the home of the HIV infected person. It includes physical, psychosocial, palliative, spiritual and activities such as clinical monitoring and management of Opportunistic Infections (OIs), prophylaxis, treatment, counseling, food supplementation/Nutrition and clean water supply (WHO, 2002).

The HIV/AIDS epidemic has placed a huge burden on public health facilities in developing countries that are already functioning with limited resources. This has shifted the burden of care to families and communities, because public health services are often stretched beyond their capacities. A number of community/home-based care and services evolved in response to the identified needs (Ncama, 2008).



Home-Based Care (HBC) can also be defined as the care given to an individual in her/his own environment or home by family supported by skilled welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material and psychosocial needs. This care is also given to the affected families through family participation and community involvement. It is a collaborative effort between hospital, family and community (Kenya National AIDS/STD Control Programme, 2007; Muhammad & Gikonyo, 2005).

Home-Based Care organizations are other important care providers and consist of trained health workers, community volunteers linked to a hospital, Non-Governmental Organizations (NGO) or faith groups. The members make visits to the homes of the ill people for perhaps one to two hours and may assist with much of the care provided by families including household chores, providing and cooking food as well as administering pain relief medicines. They may also make referral for professional medical help (USAID, 2003).

In Chadiza District, the provision of HBC takes many forms, but typically it is provided by relatives, friends, neighbors or community caregivers working with Non-Governmental or faith-based organizations. Most home-based care organizations operate in resource-limited rural and urban settings. The Government has also been involved in training of community members as home based caregivers. For instance, there are two groups of HBC organizations in the District; Community Based Organizations (such as Women Against AIDS and Poverty (WAAPO), Tikambilane, Chikondi, Tafelansoni, Kadabwako, Naviluli) and Faith Based Organizations (Mtima Oyera and Good Samaritan HBC groups).

The main aim of home-based care is to improve the quality of life of clients and to lessen the burden on the family by encouraging and supporting the independence of the chronically- ill people and PLWHA inclusive (National HIV/AIDS/STI/TB Council, 2004).

According to Lindsey (2002), the goal of CHBC is to provide hope through high-quality and appropriate care that helps ill people and their families to maintain their independence and achieve the best possible quality of life.

HBC relates well to the traditional African way of responding to both acute and chronic illnesses whereby a family member or neighbor, usually female, would move over to attend to the sick, sometimes for a prolonged period of time. Such a person would then be responsible for seeing to it that the patient fed, personal hygiene, nursing care are done and even spiritual care is given if necessary (WHO, 2000). So if properly organized and made readily available, HBC services should be well utilized in a Zambian setting because it is already traditionally accepted.

The persons with HIV and AIDS often find that their family and community connections are shattered by illness, fear and stigma that may surround it. Therefore, the Ministry of Health's principle has been to restore sense of solidarity between People Living With HIV and AIDS and their communities. It emphasizes that the most constructive answer to improve the quality of life lies in home and community care and the participation of affected family and community members (Nation AIDS Council, 2007).

The community and home-based care movement in Zambia evolved, primarily as faith-based response to care for the chronically ill. Between 1988 and 1990, the Catholic Church and Salvation Army established large home-based care programmes. Working jointly with organizations such as the World Food Programme, they were also able to provide nutritional support to people living with HIV and those on Tuberculosis (TB) treatment (NAC, 2007). This encouraged participation and utilization of HBC services by PLWHA and their families.

Home-based care staff and caregivers train families how to care for PLWHA and when clients need referrals, caregivers serve as the primary link between the client and the health service provider. Caregivers monitor the client's condition and provide reports to

health centres. Many home-based care programs have strong connections to health centres and are supported by medical professionals, mainly nurses (NAC, 2007).

The World Health Organization (WHO) established that between 70% and 90% of HIV and AIDS care took place in their homes. Therefore PLWHA ought to access care in their communities although people have a choice to either utilize these services or not depending on their circumstances. Informal care includes care that is provided by members of nuclear and extended families, neighbors, friends and individual volunteers, as well as assistance organized through voluntary organizations such as religious groups (WHO, 2000).

### **1.1.1 TYPES OF HOME- BASED CARE SERVICES**

There are different types of home based care services that are provided by different organizations such as outreach services, volunteer home care, community centre services and hospices. These are further explained below.

1.1.1.1. In volunteer home based care, the community selects a member of the community who is then trained to provide preventive care, support services and work as a volunteer within the community (MoH, 2006). The volunteer is linked to the health facility for professional support, referral, monitoring, supervision and supplies. In this type of home based care, most of the work is done by the community volunteers while health care professionals provide support through supervision and training.

1.1.1.2. The outreach type of home based care services comprises health care and social workers and is organized at health facility level and travel to various places within a community usually on regular basis to provide various types of preventive, care and support services within a community (MoH, 2006).

1.1.1.3. The Community centre services are services where the health care providers and social workers in collaboration with the community establish a drop in centre within

the community where a team of health care providers and social workers provide several preventive, care and support services. Patients and clients requiring these services travel to the centre to receive the services (MoH, 2006).

1.1.1.4. A Hospice (Nursing Home) is established in the community to provide care and support services to chronically ill and the aged who can no longer be taken care of by the relatives in their homes but cannot be kept in a hospital. The services are very costly, such that the community and family members are expected to contribute to the running costs of the hospice (<http://www.myhospice.org/community-hospice/community-hospice-history.php>).

The development of home-based care models in Zambia was partly in response to the unprecedented costs within the health sector and the pressure on hospital beds. According to the Ministry of Health (2006) training package for HBC givers, the roles of volunteer caregivers in home-based care at community level are outlined as below:

### **1.1.2 GENERAL ROLE OF HOME BASED CARE PROGRAMMES**

The general role of Home Based Care programmes is to provide HIV and AIDS preventive information, stigma reduction, education and communication services to individual, families and communities and to maintain the quality of life through care and support services to those who are affected by HIV and AIDS (MoH, 2006). If these services were readily available and accessible, the chronically ill patients would utilize them and fully benefit from them.

### **1.1.3 SPECIFIC ROLES OF HOME BASED CARE PROGRAMMES**

Below are some of the specific roles of Home Based Care programmes:

- Mobilization and sensitization of communities on the existence, availability, location of HBC services and other related services by caregivers.

- Identification of new clients through regular visits to communities and families by caregivers.
- Providing emotional support such as comforting, empathizing and providing encouragement to persons infected or affected by HIV and AIDS/TB.
- Helping with activities of daily living for the chronically sick especially the bed ridden such as feeding, bathing, dressing and toileting and household activities which include cleaning the house, running errands and providing transportation
- Encourage adherence to prescribed medications so as to avoid unnecessary hospital admissions.
- Following up of clients both referred to a clinic and those not referred at community level for continuity of care.
- Working closely with other Community Based Volunteer (CBVs) involved in home based care in the area to avoid duplication of clients and overlapping of work in zone.
- Facilitating formation of support groups by HIV and AIDS clients who help follow clients and other chronic illnesses
- Encouraging clients to go for Counseling and Testing (CT) and ultimately enhance enrolment in the antiretroviral therapy service clinic.
- Providing on going psychosocial support to their clients.
- Providing new skills on how to provide care and how to cope with responsibilities to families and other care givers.

(Kenya National AIDS/STD Control Programme, 2007)

In Chadiza District, training of community members as caregivers have been conducted since the year 2000 by Ministry of Health, Non-Governmental Organizations such as Plan International Zambia, Lutheran World federation, Care International Zambia, Expanded Church Response to HIV/AIDS, Community Based Organizations such as Women Against AIDS and Poverty (WAAPO) and other small community-based HBC groups, Faith Based Organizations like the Catholic Church (Chadiza DHMT, 2009).

Trained volunteers conduct various activities during home visits not different from those for HBC programs such as providing basic nursing care with the aid of a Home Based Care kit which however, have not been available for the past 4 to 5 years. Other activities include providing psychosocial, spiritual support and adherence support, assisting patients with the activities of daily living, following clients who miss their appointment dates and teaching families how to take care of HIV and AIDS clients in their homes and safety measures for infection control.

The knowledge of the caregivers, however, is inadequate to face this challenge of providing care. In response to this, JHPIEGO has developed a training strategy that aims at enabling community-based organizations, faith-based organizations and caregivers to ensure that HIV-infected persons receive a recommended package of care services at home which include: medical care (both nursing and clinical), support and counseling, psychosocial support and spiritual support, AIDS education, health education, nutrition, hygiene and sanitation (JHPIEGO Zambia, 2001).

Strengthening of care teams is vital to improving the quality of care. Providing information to families and patients allows them to make appropriate informed decisions and empowers them to participate in providing care throughout the continuum of care.

Information provided to family members help them to provide appropriate care such as washing and caring for patient's personal hygiene, providing emotional support, prevention bed sores and re-infection and recognizing signs that necessitate referral (Pathfinder International Tanzania, 2006).

The Home-Based Care concept is an innovative approach to comprehensively meeting the needs of patients with chronic illnesses in resource-limited settings. It bridges the gap between health facilities and home care by enabling patients/clients to receive quality and dignified services in their homes, most often provided by family members.

## **1.2 STATEMENT OF THE PROBLEM**

In Zambia, Chadiza District inclusive, HIV and AIDS was declared an emergence by the Zambian Government because of what is being experienced by families, communities and the nation at large such as increased disease burden, loss of lives more of the reproductive age group, increased numbers of orphans. There is no aspect of life that has not directly or indirectly been affected by the pandemic (NAC, 2009).

According to Chadiza DHMT Annual Report (2009), from 2007 to 2009 20,075 clients were tested for HIV through Counseling and Testing (CT) and PMTCT services but there is no information as to the number that was referred by home based caregivers to establish utilization of the HBC services.

The client adherence form in the ART service clinic has a provision for the health provider to ask clients if they are receiving home-based care services. However, the information is not captured by the Health Management Information System such that for the community health workers and traditional birth attendants to see how HBC services are being utilized.

The annual report further states that 2,126 (11%) clients tested HIV positive, 1,925 were enrolled on ART (91%) out of whom 1,280 (66.5%) were receiving antiretroviral therapy while 645 (33.5%) were enrolled but not receiving antiretroviral therapy and caregivers are expected to follow up and encourage clients to enroll on ART.

The report also states that in 2008, 120 of 1,198 (10%) and in 2009 189 of 1,280 (15%) clients on ART were reported to be failing treatment. But in 2009, 410 out of 1,280 clients (32%) were reported to have missed their pharmacy appointment dates has become a concern to DHMT because of the assumption that patients may develop resistance to ARVs leading to complications related to failing of treatment and also loss of lives.

Home-based care is assumed to be one of the models for providing services for PLWHA and home-based care providers are expected to offer adherence counseling,

provide treatment support and follow up those who miss their appointment dates. Therefore, what is not known is whether the PLWHA are aware of the availability of HBC services and if they are utilizing the services in Chadiza District.

According to the records at the office of District AIDS Coordinating Advisor (DACA) records, there are ten (10) registered Community Based Organizations and Faith Based Organizations for HBC programmes for PLWHA in the district operating at community level (DATF data base, 2009). However, the number of caregivers and their performance could not be obtained due to unavailable records so as to establish the active groups (Chadiza DHMT Annual Report, 2009).

**TABLE 1: PATIENTS ON ART MISSING PHARMACY APPOINTMENT DAYS**

S/NO	DESCRIPTION	NO. OF PATIENTS	%
1	Active patients 1-30 days late for a pharmacy visit	116	9.06
2	Active patients 31-60 days late for a pharmacy visit	41	3.20
3	Active patients 61-90 days late for a pharmacy visit	13	1.02
4	Active patients 91-180 days late for a pharmacy visit	25	1.95
5	Active patients greater than 180 days late for pharmacy visit	215	16.80

Source: Chadiza DHMT, 2009.

Although the Ministry of Health has been involved in conducting trainings and has given material support such as bicycles for transport to follow up clients and referral when in need, there has not been much follow up to evaluate the programme. The District also has no records for the trained home-based caregiver and even on their performance.



### **1.3 CONCEPTUAL FRAMEWORK**

The conceptual framework for this study is illustrated in figure 1. Shows some factors that seem to influence utilization of Home Based Care services by People Living With HIV and AIDS and these include; socio-cultural, economic and service delivery factors.

#### **1.3.1 SERVICE RELATED FACTORS**

Service related factors may impact on utilization of home based care services and include availability of supplies, accessibility of service, Lack of knowledge, Negative attitude of staff/Home Based Care givers, personal preference, referral system, quality of service, health education, Inadequate staff/HBC training and inadequate counseling. These factors are discussed below:

- **Availability Home Based Care Services**

Availability of supplies such as washing and cleaning materials, medicines for pain relief for home-based care providers may influence PLWHA to use the services.

The established community home-based care groups may not only support people that are ill, but would at least partially relieve women and girls of the caring burden and hence improve their access to livelihood and educational activities HBC services must be made available for people to be able to utilize them.

- **Accessibility of HBC services**

Individuals and family members often experience difficulty in accessing care. The reasons for this may include lack of knowledge about HBC and other community resources such as lack of transport and stigma associated with HIV and AIDS (WHO, 2002). One of the reasons why more people may not use voluntary Counseling and Testing (VCT) services is lack of confidentiality, stigma and discrimination that follows the disclosure of one's status (NAC, 2004).

- **Lack of Awareness for HBC services**

Lack of knowledge and procedures of HBC services may hinder PLWHA from utilizing the services. It is therefore important for members of CHBC to find cases in the community and encourage other community members to refer ill people and family members needing the service. Sometimes the hospital and clinics may not be aware of CHBC programmes and as a result CHBC is missing in the hospital discharge plan for continuity of treatment, care and support. In addition, other community resources of agencies may not be aware of the CBHC services (WHO, 2002). This may apply to Chadiza District in particular in a way that the referral system of PLWHA and other patients back to the community through home-based care providers does not exist.

- **Negative attitude of staff and Home Based Care givers**

Throughout the world most of the caregivers are family members usually women and girls and these caregivers are valued as the main source of care for ill people (Lindsey, 2002). Volunteer caregivers have a critical role in direct service provision to PLWHA in home settings (Aslanyan, 2004).

Volunteers are not motivated and there is a high risk of burn-out which may lead to negative attitude towards PLWHA. Many HBC programs are aware of the effects of caregiver burn-out on service delivery (Pathfinder International Tanzania, 2006).

Good attitude of health care providers may promote utilization of HBC services and if the attitude is poor then PLWHA may shun away from using the services.

- **Personal preference for HBC services**

Some PLWHA do not want anyone else other than the clinic or hospital staff to know about their HIV positive status and this may prevent the patients to from utilizing HBC services and may be a problem for continuity of treatment, care and support by the family and community members (UNAIDS, 2003).

- **Referral system**

Referral system from the HBC and also from the health facility may not be effective enough to allow PLWHA who need HBC services to utilize them. In some instances the members of staff at the health care facility may not respect the referrals from home

based care givers as staff may not know the existence of HBC services in the community.

Therefore, linkages and referrals are critical components of comprehensive knowledge and utilization of care for PLWHA in home settings .One organization alone cannot provide the full range of care and support services needed to PLWHA and their families. Establishing and maintaining strong, multi-sectoral referral networks at the local and district level is important for communities to fully provide holistic HBC (NAC, 2008).

- **Quality of Service**

There may be inconsistent availability of HBC kit supplies and kit's drugs for management of minor complaints which may affect the quality of care for the PLWHA. Using home care kits, teams provide basic clinical care, which include treatment of HIV-related infections and conditions.

Limited training and support to caregivers may limit quality service provision to PLWHA (Ministry of Health & Child Welfare, 2004). In addition to quality care, high case loads may lead to HBC volunteer burn-out and this may affect provision of HBC services by caregivers.

- **Health Education**

Lack of a programme aimed at educating the community on home-based care services may contribute to poor attitude towards the programme. Tanzania HIV Indicator Survey (2005) results showed that 35 percent of the organizations identified to be providing HBC services also provide HIV and AIDS information services. The IEC activities target communities, family members and special groups such as youths and older population to address HIV and AIDS prevention and stigma reduction, attempts to instill sense of society responsibility for care and support of families affected by HIV and AIDS. Inadequate IEC may lead to PLWHA fearing to disclose their HIV status to family members or caregivers thus affecting utilization of home-based care services by PLWHA and the affected families (UNAIDS, 2003).

- **Inadequate staff/HBC training**

It is estimated that up to 90 percent of care for the sick is provided in the home by the untrained family and associates and up to 80 percent of AIDS related deaths occur in the home (UNAIDS, 2003).

Clinical management involves early diagnosis, rational treatment and planning for follow-up care of HIV-related illnesses. Lack of knowledge and skill to manage PLWHA may lead to delay in referral for ART, poor management and also delay of referral for other support services even for the affected family members (MOH/NAC, 2008).

- **Inadequate Counseling**

Counseling services create awareness to support services for PLWHA CSO (2007) reports that 69% of HIV-positive men and 49% of HIV-positive women had never been tested and may not have been aware that they were HIV-positive. People can look and feel well for a long time without knowing that they are infected with the virus. Knowing one's HIV status through testing is considered to be a key motivation factor for behaviour change. It helps individuals make decisions to reduce risks and increase safer sex practices, therefore an individual may only know that one has HIV when they are tested (MOH, 2006). HIV testing is the key to ART care and prevention of opportunistic infections.

Many people may be reluctant to come forward to be tested, but wait instead until they fall ill because they fear stigma and social rejection or because they think that knowing their status is of no advantage. This may mean inadequate counseling leading to inadequate knowledge on benefits of HIV testing which negatively affects utilization of HBC services by HIV and AIDS clients.

### **1.3.2 SOCIO-CULTURAL AND ECONOMIC RELATED FACTORS**

- **Lack of social support**

Studies have shown that the most effective home based care programmes involve ongoing support for their workers, support from local communities and integration within existing health systems (Ncama, 2008).

Sometimes, people with HIV and AIDS are abandoned by their families and are forced to live in destitution, resulting into psychological devastation. Relatives living nearby may visit the clients frequently and the one visit may be in a hurry. Inadequate family and community support may lead to poor drug adherence and non-disclosure of their disease status and thus many complications and later death may arise (Ncama, 2008). Inadequate support may lead to delayed decision making to utilize the HBC services.

- **Myths, fears and misconceptions about HBC services**

People Living With HIV and AIDS may have myths, fears and misconceptions which may prevent them from utilizing home-based care services change, attitude towards HIV and AIDS, for example diagnosis of HIV may mean death is at hand and this may make the HIV-positive clients not to be productive in any way because they think they will die soon.

- **Cultural beliefs about HBC services**

Cultural beliefs such the belief that home-based care services are meant for HIV and AIDS patients who are very sick and bed ridden may hinder utilization of services by any PLWHA. HIV- positive but with no signs or symptoms of AIDS may not want to be enrolled with home-based caregivers or even to be visited because of what the community associates home-based care services to.

- **Spiritual support**

HIV and AIDS affect both Christians and non-Christians because of the burden of taking care of the PLWHA and the affected families for example the orphans. Religion may

influence risk awareness of HIV and AIDS. Religious leaders may influence belief systems to ensure that HIV and AIDS are seen in a more positive light (UNAIDS, 2005).

This is done through education of church members on the importance of being faithful to sexual partners who can reduce the chances of HIV infection. Therefore, spiritual support by lay counselors and pastors who in most cases are team members of HBC may help improve the lives of PLWHA by way of them living positively because without spiritual support they may die prematurely (National AIDS/STD Control Programme, 2002).

- **Occupation of PLWHA**

It is not common for PLWHA to lose employment because employers think that they will not be productive and this makes PLWHA lose their income. Therefore, most of PLWHA fear to disclose their status at work and may not want to be enrolled with HBC groups who may wish to visit the client to see how they are coping up with their status. This may affect utilization of ART care services as well as HBC services.

- **Education level of PLWHA**

Educational level of PLWHA may influence understanding and accepting their HIV status and this may lead to delay in seeking treatment and poor adherence to antiretroviral therapy and other associated care and support services. PLWHA whose educational background is good may be able to identify the primary or alternative caregiver and may participate in the care process actively especially in making decisions on own welfare.

Older people who are less educated and those with less income are likely to be enrolled to HBC services because they may not have funds to pay for hospital admissions and relatives may not visit them regularly unlike the young, middle aged and with education who may have resources to afford hospital bills, transport to hospital and may give consent on caregivers and where the care was provided such as home or hospital especially during the terminal phase of the disease for fear of stigma (National AIDS/STD Control Programme, 2002).

- **Poverty**

Many families who are taking care of PLWHA face financial problems due to the disease burden and so they expect to be supported by the HBC programme and not only to be visited empty handed. If HBCS do not offer any financial or material support, the PLWHA may not be willing to use their services, for example when the HBC goes to visit the patient for the second time empty handed, the relatives may hide their patient (Pathfinder International Tanzania, 2006).

- **Stigma about HBC services**

Stigma refer to composition of a special, discrediting and unwanted “label” on a person, or group of persons that indicates that they are looked upon as fundamentally and in most cases shamefully different from “normal” persons. The label is imposed on persons who are believed to be deviant or to have a status that distinguishes them.

The effects of such a label may be experienced by a majority of those infected or affected by HIV/AIDS (Ministry of Health & Child and may weaken social relations that exist between HIV infected individuals and their families or their neighbors. This may eventually lead to rejection by community members, individual isolation of HIV positive clients and non-disclosure of their HIV status. Therefore, stigma may make PLWHA not to utilize the home-based care services (Welfare, 2004).

### **1.3.3 DISEASE RELATED FACTORS**

- **Perceived seriousness of the disease**

In Zambia, only 28 percent of adults aged 15-49 know their HIV status. Those who do not know their status and are infected with HIV can spread the virus to many others before they become ill, and without early diagnosis may not get the treatment and care they require. It is assumed that when people know the seriousness of HIV and AIDS, they would take precautions so that they may not get the disease.

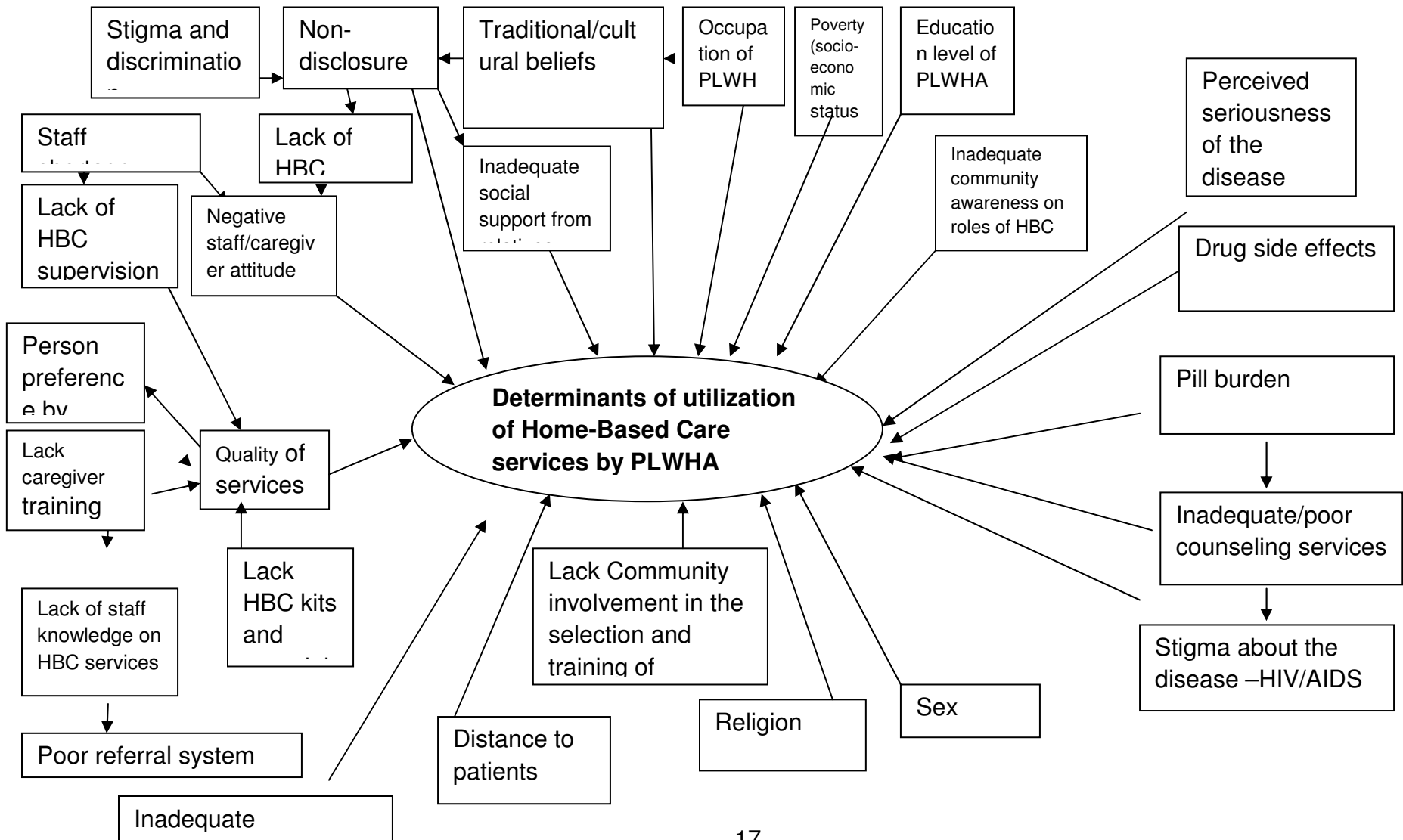
Home-based care providers through health education and counseling may help the community to go for HIV testing and to seek care and treatment early (NAC, 2002).

**FIGURE 1: CONCEPTUAL FRAMEWORK**

**SERVICE FACTORS**

**SOCIO-CULTURAL/ECONOMIC FACTORS**

**DESEASE RELATED FACTORS**

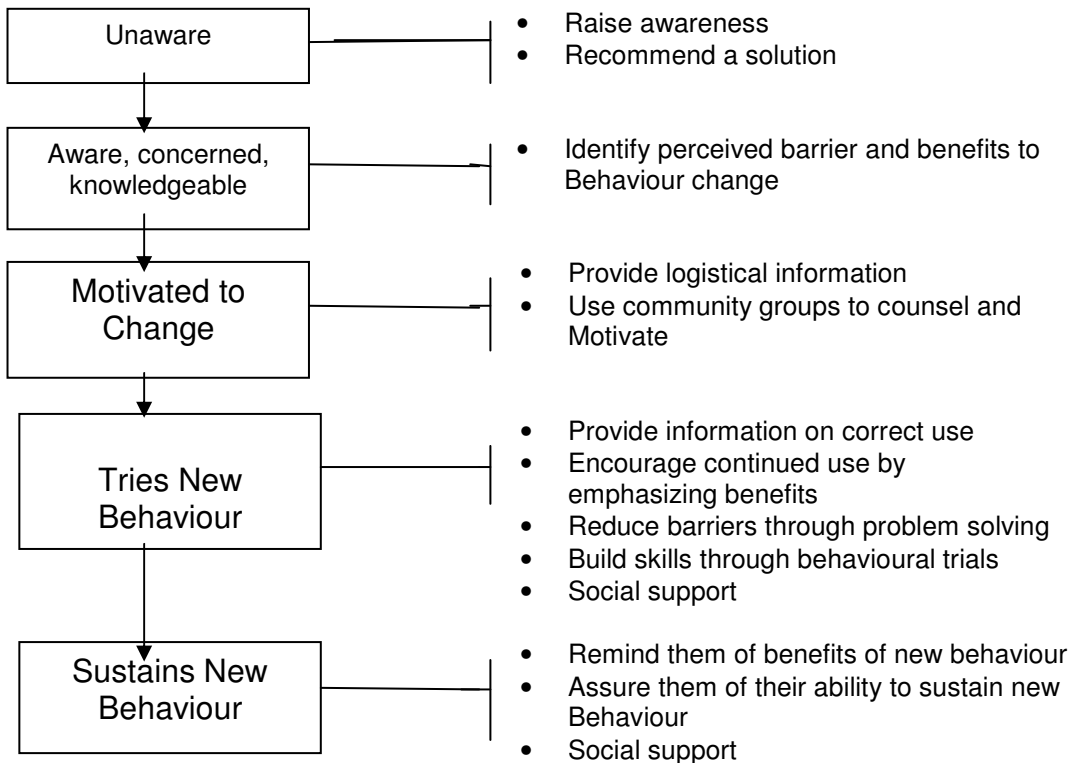




## 1.4 THEORETICAL FRAMEWORK

This study was guided by a change theory by Cabanero-Verzosa (1996). The model has five components: unaware, Aware, concerned and Knowledgeable; Motivate to change; tries new Behaviour and sustains new behaviour. When an individual's awareness is raised and a solution is recommended, he/she becomes aware, concerned about a situation and knowledgeable. Then he/she is likely to identify perceived barriers and benefits to behaviour change. This could be the right time to provide them with logistical information through community groups and use community groups to counsel and motivate the individual. When an individual tries to adopt the new behaviour, more information should be provided to them: Encourage them to continue by emphasizing the benefits of adopting the new behaviour. Reduce barriers through problem solving and establishment of social support. To sustain the new behaviour, remind them of the benefits of a new behaviour. Assure them of their ability to sustain the new behaviour and provide social support.

**FIGURE 2: AUDIENCE ALONG A BEHAVIOUR CHANGE CONTINUUM**



In figure 1.4, the Behaviour Change Continuum model can be related to the roles the home based caregivers, family care providers and the PLWHA can play while providing care. One of the responsibilities for Community caregivers is awareness-raising on HIV/AIDS and the available services for the infected persons. When awareness is created with a lot of health education on the modes of transmission, prevention and how to live positively then shall we see PLWHA change in behaviour may increase the necessity of the HBC reduction in stigma and discrimination of the infected and the affected.

The change in behaviour will increase accessibility of both health services such going for HIV testing, enrolment on ART and compliance to pharmacy appointment dates and utilization the HBC services not only by family members but also from trained home based caregivers and community home based care providers.

This model can be supported by ZDHS (2000) which states that access to information is essential to increase peoples' knowledge and awareness of what is taking place around them which eventually affect their perception and behaviour even when it comes to utilization of home based care services by PLWHA.

## **1.5 JUSTIFICATION**

In Zambia in general and Chadiza District in particular, little documented information is available on determinants of utilization of home-based care services by PLWHA. There is also information gap on the impact of HBC services since its inception despite a lot of support through training and materials such as bicycles for transport for the home-based caregivers through DHMT by the government and partners in health delivery.

One of the roles for Home-Based Care givers is to facilitate a process in communities so that PLWHA and their families are fully prepared to accept and adhere to ART and related treatment. Information on ART regimens, benefits, side effects, non-adherence and drug resistance should be made available to communities and care givers should

assist clients to become fully involved in their own treatment by encouraging them to take responsibility for taking medications.

Home-based caregivers act as the 'eye of the health center' and not only provide ART adherence support, but also refer patients who miss clinic appointments and those with severe side effects to health centres (Wringe, Cataldo, Stevenson & Fakoya, 2009).

The quality and scope of services is unknown and also there is limited evidence that PLWHA in Chadiza know about home-based care services and do utilize them. Therefore, there is information gap on the impact of HBC services. No research study has been conducted on knowledge and utilization home-based care services by PLWHA in Chadiza District.

This study investigated the determinants of utilization of the Home-Based Care services by PLWHA and therefore has an understanding on utilization of home-based care services by the PLWHA and what challenges they face in utilizing the services. The study will also assist to generate data as basis for subsequent studies and investigations. It is also hoped that findings of this study will be used by policy makers and health workers and all other stakeholders to improve utilization of HBC services by PLWHA.

## **1.6 RESEARCH QUESTIONS**

- (a) What factors affect utilization of HBC services by PLWHA in Chadiza district?
- (b) What measures were be employed to enhance utilization of the HBC services by the PLWHA?

## **1.7 RESEARCH OBJECTIVES**

### **1.7.1 GENERAL OBJECTIVE**

To investigate determinants of utilization of Home-Based care services by PLWHA in Chadiza District.

### **1.7.2 SPECIFIC OBJECTIVES**

1. To identify the common types of home-based care services preferred in the community.
2. To determine PLWHA's level of knowledge about Home-Based Care services
3. To determine demographic characteristics may influence utilization of HBC services by PLWHA
4. To establish whether socio-cultural factors influence utilization of Home-Based Care services by PLWHA.

## **1.8 HYPOTHESIS**

### **1.8.1 NULL HYPOTHESIS**

There is no association between utilization of HBC services and the following factors:

- a) Educational level of PLWHA
- b) Referral of clients
- c) Phase of the disease
- d) Availability of HBC supplies
- e) Knowledge of PLWHA on home-based care services

### **1.8.2 ALTERNATIVE HYPOTHESIS**

There is association between utilization of HBC services and the following factors:

- a) Educational level of PLWHA

- b) Referral of clients
- c) Phase of the disease
- d) Availability of HBC supplies

## 1.9 VARIABLES AND CUT OFF POINTS

**Variable** – An attribute that varies, that takes on different values (Polit & Beck 2008).

**Dependent Variable** – The variable hypothesized to depend on or be caused by another variable (Polit & Beck, 2008), such as utilization of home-based care services by PLWHA may depend on whether the PLWHA is aware of such services.

**Independent Variable** - The variable that is believed to cause or influence the dependent variable (Polit & Beck, 2008), such as knowledge may influence utilization of the home-based care services by PLWHA.

**TABLE 2: VARIABLES AND THE CUT OFF POINTS**

VARIABLE	CUT OFF POINTS	INDICATORS	Scale of measurement
<b>DEPENDENT VARIABLE</b>			
Utilization of HBC services by PLWHA	High  Low	Scoring 2-3 on a scale measuring services being provided by HBC providers  Scoring 0-1 on a scale measuring services being provided by HBC providers	Nominal
<b>INDEPENDENT VARIABLE</b>			
Knowledge about HBC services	High  Low	Scoring 4-8 on knowledge questions about HBC services.  Scoring less than 4 on knowledge questions about HBC services	Nominal
Types of HBCS	<b>Available</b>  Not available	Type of HBC s available	Nominal

VARIABLE	CUT OFF POINTS	INDICATORS	Scale of measurement
Socio cultural factors	Present Not present	Present Not present	Nominal

### 1.10 CONCEPTUAL DEFINITION OF TERMS

**CAREGIVER** – A member of the community providing care and support to PLWHA in their environment (Training Package for Community Home Based Caregivers, Module 1, First Version, 2006, WHO, 2002).

**COMMUNITY** – A community is a place where people live and a source of support and care to PLWHA and affected families (Training Package for Community Home Based Caregivers, Module 1, and First Version, 2006 WHO, 2002).

**HOME- BASED CARE** – This is treatment, care and support given to PLWHA in their homes by family members, friends, neighbors, trained caregivers or community members who belong to community based organizations offering HBC services (Training Package for Community Home Based Caregivers, Module 1, First Version, 2006, WHO, 2002).

**COMMUNITY HOME- BASED VOLUNTEER** – A community member who provides home-based care and support to People Living With HIV and AIDS in the community (Mohammad and Gikonyo, 2005).

**KNOWLEDGE** – What PLWHAs know about home-based care services or whether the PLWHA are aware of HBC services in their communities and who offers the services.

**PLWHA** – Refer to people who have the HIV and others who may be experiencing the signs and symptoms of HIV infection or patients within the advanced stage of HIV infection. (Training Package for Community Home Based Caregivers, Module 1, First Version 2006).

**UTILIZATION** – The ability or willingness of the PLWHA to use the home-based care services being offered by different community members or organizations (Mohammad and Gikonyo, 2005).

**TYPES OF HBC SERVICES** – These are different types of home based care that are provided by different organizations, outreach services, volunteer home care, community centre services and hospices (Training Package for Community Home Based Caregivers, Module 1,First Version, 2006).

**DEMOGRAPHIC FACTORS** – these are factors relating to personal characteristics such as age, gender, social class, level of education, family or race/ethnicity (<http://wiki.answers.com>, 06/07/12).

**SOCIO – CULTURAL FACTORS** – These are instruments of measurement to see how utilization of Home Based Care services by PLWHA can be influenced occupation (Mohammad and Gikonyo, 2005). In this study these included gender, age of respondents, marital status and educational level.

## **CHAPTER TWO**

### **2.1 LITERATURE REVIEW**

### **2.2 INTRODUCTION**

Literature review is a critical summary of research on a topic of interest often prepared to put a research problem in context (Polit and Beck, 2008). Nkhata (2003) states that Literature Review is an examination of books, journal articles, dissertations, Government reports, unpublished manuscripts, newspaper and others. In this chapter, the literature review will be discussed under three perspectives; global, regional and national perspectives. In this study, the literature review was based on primary sources contained in scientific journals and text books, reports; internet search published and unpublished research findings.

### **2.3 GLOBAL PERSPECTIVE**

The UNAIDS (2006) reported that by the end of 2006 an estimated 39.9 million people worldwide were living with HIV. This represents a considerable increase since 2001 when an estimated of 32.9 million people were living with HIV.

A study carried out in India, New Delhi and Bangalore on stigmatization and discrimination related to HIV and AIDS revealed ostracism and rejection of PLWHA. This caused individuals fear to disclose and withdrawal leading to secrecy about HIV status and self imposed social isolation and this led to difficulties in accessing community care and support services from HBC by PLWHA (UNAIDS, 2004).

A study by Aslanyan (2004) conducted in Eurasia Armenia on Integrating Psychosocial and Medical Support to address the needs of PLWHA revealed that community members such as friends, lay counselors, family members and NGOs were providing psychosocial support to PLWHA. Therefore, the PLWHA were utilizing the home-based care services.

WHO (2002), report on a study conducted by Lindsey in Thailand, Haiti, Cambodia, Botswana and Kenya on Community Home-Based Care in Resource Limited Settlements,



revealed that between 70 percent and 90 percent of illness care takes place within the home and that most PLWHA preferred to be cared for at home because effective home care improves quality of life for ill people and their family members. However, the report further states that some HIV and AIDS clients and family members who require CHBC may not be aware of the services and how to access home care.

WHO (2002) further reported that health and Social Welfare working in hospitals and clinics sometimes are not aware of CBHC programmes as a result CHBC is missing in the hospital discharge plan thus affecting continuity of follow up care at home by care givers. This showed lack of knowledge of HBC services leading to non utilization of the services by PLWHA.

Globally, there have not been studies done specifically on knowledge and utilization of home-based care by PLWHA or home-based care in the context of HIV/AIDS.

## **2.4 REGIONAL PERSPECTIVE**

A study conducted by Oyedele, et al (2002), on organizations providing support to PLWHA in Gauteng Province, revealed that PLWHA had low knowledge levels on HIV and AIDS related treatment and this led to clients missing the appointment dates for review.

In Malawi, Bangwe group care a Community Based Organization (CBO) provides medication, pain control, counseling and support to chronically ill patients and their families. They see more than 30 new patients and make over 300 home visits a month (Bowie, Alinafe, Marsh, Misiri & Clearly 2005). This indicates that PLWHA were utilizing the community home-based care services.

In a study conducted by Pathfinder International Tanzania (2006) on Mapping of Community Home-Based Care services in five Regions of Tanzania Mainland revealed that Tutunzane, a Community Home-Based Care group for PLWHA provided community support to PLWHA and their families through collaboration with a wide range of other community groups such as Faith Based Organizations (FBOs) to meet

the needs of PLWHA including material support, counseling and emotional, spiritual and legal aid. This project had reached more than 7000 HIV positive people.

A study by Tibeba, Mirriam and Belachew (2007) in Jimma, Ethiopia on Knowledge and attitude of PLWHA on HBC services showed that 91.6% of the PLWHA were knowledgeable about home-based care services and were utilizing the services.

The same study further revealed that caregivers found it difficult to manage caring for chronic illness and maintain a livelihood and other daily routines (Pathfinder International, 2006). This meant a gap in the provision of home-based care services.

In Swaziland, the United Nations Integrated Regional Information Networks (2007) reported that many patients with AIDS felt rejected because of judgment and fear of contracting the disease by the family members, friends and neighbors did not know how to cope with a person who was dying. This may indicate inadequate utilization of HBC services

Adenuga (2004) in a study conducted in Nigeria on strategy for care and support to PLWHA showed that PLWHA had experienced opposition from their community and the church inclusive. This meant poor psychosocial and spiritual support to PLWHA and thus non utilization of HBC services

## **2.5 NATIONAL PERSPECTIVE**

A study by Chandi (1997) on knowledge, attitude and practice of the community towards HBC services in Kitwe revealed that only 18% of the respondents had knowledge on home-based care services, 90% of the respondents had heard of Home-Based Care programme but were not aware of the activities of the programme and (70%) of care providers had negative attitude towards PLWHA thus non utilization of HBC services.

According to Silomba (2002), a study conducted in Chikankata on HIV/AIDs and Development: The Chikankata experience, communities felt that regular visits from the hospital would supplement the care that they were providing in the home setting and it was also noted that caring for PLWHA at home was economical because it did not cause unnecessary disruptions to family economic life.

UNAIDS (2003) reported that Bwafwano home-based care programme based in Chipata compound in Lusaka which started in 1996 has 280 caregivers looking after about 1,300 PLWHA in Chipata Compound and that there is a school for more than 220 orphaned and vulnerable children. It is further reported that Bwafwano HBC programme has a social worker who offer psychosocial counseling to many children who were observed not to concentrate. This is an indication that HBC services were known and being utilized by the intended groups.

According to Chadiza DHMT Annual report, (2009), from 2007 to 2009 20,075 clients were tested for HIV from CT and PMTCT points of service delivery. The report states that 2,126 of 20,075 (11%) tested HIV positive and 1,925 from the total of 2,126 HIV-positive were enrolled on ART (91%) and 1,280 (66.5%) were actually receiving antiretroviral therapy and 645 (33.5%) were enrolled but not receiving ARVs. However, there is no report indicating involvement of caregivers in the provision of services such as counseling and referral to health facility for HIV testing to determine utilization of HBC services by HIV and AIDS clients through counseling services.

Despite the large number of HBC programs in the District, statistics indicate an upward trend of PLWHA on antiretroviral therapy failing treatment and others missing their pharmacy appointment dates suggesting inadequate psycho support from caregivers. According to Chadiza DHMT (2008), 120 out of 1,198 (10%) HIV positive clients enrolled on ART were flagged to be failing treatment in 2008 and 189 out of 1,280 (15%) in 2009. The failure was based on clinical and immunological classifications. It is further reported that out of 1,280 clients, 410 (32%) were reported to have missed their pharmacy appointment dates as shown in table 2 (Chadiza DHMT, 2009).

## **2.6 CONCLUSION**

The studies such as those carried out by Chandi (1997) on knowledge, attitude and practice, Pathfinder International Tanzania (2006) where HBC care group provided support for PLWHA with difficulties, WHO (2002) results showed that 90 percent of care for PLWHA took place in their homes have revealed factors that may affect utilization of HBC services by PLWHA such as stigma and discrimination, Lack of disclosure of the HIV status by the patient and Cultural practices of caring for the sick being undertaken by females than males

There have been no studies conducted on determinants of utilization of HBC services Chadiza district.

## **CHAPTER THREE**

### **3.1 RESEARCH METHODOLOGY**

### **3.2 INTRODUCTION**

This chapter describes the research design and methodology employed in this study including the context of the research study, the study population and sample selection, inclusion and exclusion criteria, data collection tools and technique, validity and reliability, pretest and ethical considerations.

### **3.3 RESEARCH DESIGN**

This study used a mixed methods (Tashakkori & Teddlie, 2003) design, which is a procedure for collecting, analyzing and “mixing” both quantitative and qualitative data at some stage of the research process within a single study, to understand a research problem more completely (Creswell, 2002). The rationale for mixing the two approaches is that neither quantitative nor qualitative methods are sufficient by themselves to capture the trends and details of situations, especially in complex issues. When used in combination, quantitative and qualitative methods complement each other and allow for more complete analysis (Green, Caracelli & Graham, 1989; Tashakkori & Teddlie, 1998).

In quantitative research, a research relies on numerical data (Charles & Mertler, 2002). He/she uses post positivist claims for developing knowledge, such as cause and effect thinking, reduction to specific variables, hypotheses and questions, use of measurement and observation, and the test of theories. A researcher isolates variables and causally relates them to determine the magnitude and frequency of relationships. In addition, a researcher determines which variables to investigate and chooses instruments, which will yield highly reliable and valid scores.

Alternatively, qualitative research is “an inquiry process of understanding” where the researcher develops a “complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting” (Creswell, 1998)

In qualitative research, data is collected from those immersed in everyday life of the setting in which the study is framed. Data analysis is based on the values that these participants perceive for their world. Ultimately, it “produces an understanding of the problem based on multiple contextual factors” (Miller, 2000).

In a mixed methods approach, the researchers build the knowledge on pragmatic grounds (Creswell, 2003; Maxcy, 2003) asserting truth is “what works” (Howe, 1988). They choose approaches, as well as variables and units of analysis, which are most appropriate for finding an answer to their research question (Tashakkori & Teddlie 1998). A major tenet of pragmatism is that quantitative and qualitative methods are compatible. Thus, both numerical and text data, collected sequentially or concurrently, can help better understand the research problem.

While designing a mixed methods study, three issues need consideration: priority, implementation, and integration (Creswell et al, 2003).

Priority refers to which method, either quantitative or qualitative, is given more emphasis in the study. Implementation refers to whether the quantitative and qualitative data collection and analysis comes in sequence or in chronological stages, one following another, or in parallel or concurrently. Integration refers to the phase in the research process where the mixing or connecting of quantitative and qualitative data occurs.

This study used one of the most popular mixed methods designs in research: sequential explanatory mixed methods design, consisting of two distinct phases (Creswell, 2002; Creswell et al., 2003). In the first phase, the quantitative, numeric, data was collected first; using a questionnaire and the data was subjected to a discriminant function analysis. The goal of the quantitative phase was to identify potential predictive power of selected variables to allow for purposefully selecting informants for the second phase.

In the second phase, a qualitative multiple case study approach was used to collect text data through individual semi-structured interviews (FGDs) to help explain why certain factors, tested in the first phase, may be significant predictors of the determining the utilization of home based care services.

### **3.4 RESEARCH SETTING**

Research settings are the more specific places where data collection occurred. In some cases the setting and the site are the same as when the selected site is an institution and the data is collected within that setting (Polit & Hungler 1999). The study was undertaken in Chadiza District which is one of the eight (8) districts in Eastern Province. The District shares borders with Katete on the west and Chipata (the provincial capital of Eastern Province) on the South-East.

The District also shares international boundaries with Mozambique on the south and Malawi on the East. The district has a total population of 119,450 (Chadiza DHMT Action plan 2010). The District has eleven (11) health centres, four (4) health posts and one (1) mental rehabilitation centre. The district has two (2) ART sites (1 at the urban health centre and the other one at one Zonal health centre) and seven (7) mobile ART site (2 zonal and 5 other health centres). The study was undertaken at the ART sites during the clinic days. This setting was chosen because it was convenient for the investigator and the district provides ART services to PLWHA who are likely to use the home-based care services.

### **3.5 STUDY POPULATION**

The study population was PLWHA above 18 years old enrolled on ART. Home based care providers were also considered as secondary study population.

### **3.6 SOURCES OF DATA**

Secondary data for this study were collected by reviewing published materials on factors that affect the utilization of home based care services. The research was undertaken by both reviewing published materials such Government, civil society and other documents as well as searching various online resources.

### **3.7 SAMPLE SELECTION**

In this study, convenience sampling method was used to select respondents at the ART site. Convenience sampling entails using the most conveniently available people as study participants (Polit & Beck, 2008). In this sampling method, quota sampling method was chosen using two ART sites which proved static ART services. It was to determine as to how many participants are needed from each study site. The records for clients due for review on that particular day were checked for the inclusion criteria. (Polit & Hungler, 1999). The advantage for convenience sampling is that it is simple to use.

Purposive type of sampling was used to select the participants for Focus Group Discussions. Purposive sampling is a type of non probability sampling method in which the researcher selects participants for the study on the basis of personal judgment about which one was most representatives, (Polit & Hungler, 1999). Three group discussions were conducted with volunteers providing home-based care services and a group of PLWHA at a health centre where mobile ART were due at time of data collection.

#### **3.7.1 INCLUSION CRITERIA**

- i. PLWHA enrolled on ART
- ii. PLWHA above 18 years old who are able to give consent to participate in the study.
- iii. PLWHA residing in Chadiza district
- iv. Clients who have consented to participate in the study.



### 3.7.2 EXCLUSION CRITERIA

- i. PLWHA not enrolled on ART
- ii. PLWHA below the age of 18 years old
- iii. PLWHA not residing in Chadiza
- iv. Clients who have not consented to participate in the study.

### 3.8 SAMPLE SIZE

The sample size was calculated with the help of the computer software Epi-Info 6.0 version.

Total clients enrolled on ART	1,925
Expected frequency	18%
Worst acceptable	13%
Confidence Interval	95%
n=	203
Increased by 10%	20
n=	223

The sample size comprised of 223 PLWHA which has been calculated using Epi-Info statcalc calculator version 6.0 for a descriptive study with the help of the statistician. According to Chadiza DHMT (2009), 1,925 HIV-positive clients were enrolled on ART out of whom 645 were enrolled but not commenced on ART. Chandi (1997) revealed that 18 percent of the community had knowledge on the HBC services and that they were providing the home-based care services thus some degree of utilization of HBC services. This was used as an approximate prevalence rate of utilization levels for HBC services. The confidence interval (CI) is set at 95 percent. The non-response rate is set at 10% and the final sample size thus being 223.

In addition, three focus group discussions were conducted consisting of 8 participants in each group giving a total of 24 participants who were purposively sampled.

### **3.9 DATA COLLECTION TOOLS**

For the purpose of this study, there are two main sources of primary data:-

- Questionnaires completed by PLWHA
- Focus Group Discussions conducted mainly with HBC providers, caregivers and PLWHA

#### **3.9.1 SEMI STRUCTURED INTERVIEW SCHEDULE**

In this study, a semi structured interview schedule with both open and closed ended questions was used to collect data. The use of an interview schedule permits clarification of questions and ensured a high response rate. It also allows probing to elicit useful additional information than what was volunteered in the initial reply. The

The semi structured schedule comprised of three sections. Section A consisted of questions on demographic data, section B had questions to measure knowledge and section C had questions on utilization of HBC services by PLWHA. Respondents were interviewed with the help of the research assistants who were lay counselors. Open-ended questions were asked to allow participants to respond to questions in their own words. The interviewers then wrote down the responses verbatim.

The advantages of closed ended questions was that they were easy to administer, efficient as interviewers could manage to complete more closed open-ended questions than open-ended questions within a short period of time. The advantage of open-ended questions was that it allowed obtaining richer and full information.

The disadvantages of closed-ended questions were overcome by ensuring that the interview schedule had relevant number of questions. More closed than open-ended questions were asked to avoid making the interview schedule very lengthy and time consuming.

### **3.9.2 FOCUS GROUP DISCUSSION GUIDE (APPENDIX 6)**

Focus group discussion may be an efficient means of determining how people express their ideas relating to the construct (Polit & Beck, 2008). Three focus group discussions consisting of eight participants guided by a moderator were conducted. Prior to conducting the FGDs, respondents' criterion for inclusion was reviewed and the participants were invited three days in advance. The FGDs allowed more revelations and new ideas were generated on the topic. The focus group discussion guide comprised open ended questions which made respondents make explanatory responses. The FGD guide was divided into two sections. Section A comprises questions on knowledge about home-based care services and section B consists of questions on determinants of utilization of home-based care services by PLWHA. Probing questions by the interviewers were asked for further explanations.

The optimal number of participants for FDG is 8-10. If a group is too small, one person may dominate the discussion and it is too big then it may be difficult to control and thus the reason 8 participants per FGD was used in this study (<http://rrehoppers.net./2009/10/focus> group discussion).

The advantage of focus group discussion is that it accommodates illiterate participants to participate in the discussion and in-depth information may be obtained. However, the disadvantage may be that some people may not be comfortable to express their views in front of others.

### **3.9.3 VALIDITY-**

Validity is the degree to which an instrument measures what it is supposed to measure (Polit & Beck 2008). To measure validity of the data collection tools, extensive literature review were done before constructing the instrument and the variables understudy were included in the interview schedule. The sequence of questioning was the same in the questionnaire. The instrument was reviewed by experts and research supervisors.

### **3.9.4 RELIABILITY**

Reliability refers to the degree of consistency or dependability with which an instrument measures an attribute (Polit & Beck 2008).

Reliability of the instrument was measured by pre-testing it before use in the actual study. Data was collected to pre-test the interview schedule using a sample with similar characteristics. The research assistants were trained to help them understand the questions without distorting the meaning.

### **3.10 DATA COLLECTION TECHNIQUE**

#### **3.10.1 DATA COLLECTION TECHNIQUE FOR QUANTITATIVE DATA**

The data was collected by face to face interview with the help of the semi structured interview schedule. All the interviews were conducted between 08 -16 hours during ART clinic days after obtaining consent from the respondent. The Interviews were conducted in Chewa. Seven to eight participants were interviewed each day for 20-30 minutes in a private room at the health centre. Self introductions were made by the researcher and the research assistants to each participant before starting each interview to create rapport and make the participant relax. The purpose of the study was explained to each participant. Interviewers followed instructions on the interview schedule to standardize the interview technique. Questions were asked the way they are written without influencing the responses. Questions not understood were repeated without paraphrasing them or indicating the direction of the answer.

The investigator and data collecting assistants ensured that the respondents are comfortable all times by considering their priorities or where possible explaining to them. Patience was exercised and respondents were given time to think through the questions and respond. Respondents were politely asked to repeat answers not understood by the interviewers.

All the responses were recorded by use of not books and computer right away to avoid missing any of them. At the end of each interview, respondents were given time to ask questions which were answered accordingly. Respondents were thanked for their participation at the end of each interview.

### **3.10.2 DATA COLLECTION TECHNIQUE FOR QUALITATIVE DATA**

Three (3) Focus Group Discussions of eight participants each were conducted at the health facility in a private room that was provided using a focus group discussion guide. Eight participants participated for each FGD which allowed full participation during the discussions.

The discussions were moderated. A tape recorder was used to record the whole discussions. Before each discussion begins, the researcher introduced herself to the respondents and asked general questions for example about their families and this made participants feel at ease.

The purpose, risks and benefits of the study were explained to the participants and confidentiality was ensured. Permission was sought from the participants to begin the discussion. The discussions were conducted in Chewa which is the main language of the people of Chadiza district. Each discussion lasted approximately 40 minutes. At the end of the discussion, participants were given chance to ask questions and answers were provided accordingly. Each participant was thanked at the end of the discussions.

### **3.10.3 PRE-TEST**

The pre-testing for both the semi structured interview schedule and the focus group discussion guide was conducted at Chikoma Zonal health centre. Twenty (20) respondents were selected for the quantitative pre-test which is 10% of the sample and eight for the Focus Group Discussion (FGD). The participants for the semi structured interview schedule were selected using convenient sampling and purposive sampling for FGD during the mobile ART clinic at the centre and these participants did not participate in the actual study.

The pre-test was done in order to test validity and reliability of the data collection instrument in order to detect and solve unforeseen problems, detect any errors in the questionnaire for the main study, assess the duration of each interview schedule appropriateness and clarity of questions.

#### **3.10.4 ADJUSTMENTS MADE TO THE DATA COLLECTING TOOL**

When the data collecting tool both for quantitative and qualitative were tested, some adjustments were made to the tools especially on wording of the questions and rearrangement to allow proper flow of collected information.

Two questions from the quantitative data collecting tool were deleted because they were bringing out similar information despite being phrased differently. Adjustments done to the data collecting tools for both quantitative and qualitative were made after testing for appropriateness and clarity of questions such as question on 16 part a was reading less than 500km instead of less than 500m and questions on involvement of in ion were made. Adjustments and collections were done before data collection.

#### **3.11 ETHICAL CONSIDERATIONS**

Ethical considerations included protection of the research participants by ensuring that no harm or adverse effect occurred and that participation was voluntary. Privacy, anonymity and confidentiality were adhered to throughout the study by not writing the names of respondents on the interview form and the interview schedules. Two supervisors managed the research process. All sources of literature were acknowledged as accurately and completely as possible.

Approval for the study was obtained from the University of Zambia Biomedical Research Ethics Committee. Written permission to conduct the study was also obtained from the District Medical Officer for Chadiza DHMT, the District Development Coordinating Committee (DDCC) through the District Commissioner and the health centres.

The purpose of the study was explained to the study participants. Those who declined to participate were reassured that no privileges would be taken away from them and that they will continue receiving ART services in the usual way. Those who agreed to take part in the study were requested to sign a consent form. Those who participated in

the study were not to be remunerated in any way. In order to maintain anonymity, no documents bared a name of the respondents and codes were used instead.

## **CHAPTER FOUR**

### **4.1 DATA ANALYSIS AND PRESENTATION OF FINDINGS**

#### **4.2 INTRODUCTION**

Chapter four (4) provides an overview of the analysis and presentation of both qualitative and quantitative data obtained from study participants. Data analysis is the systematic organization and synthesis of research data (Polit & Beck, 2008). The quantitative findings are presented in the form of tables and figures and the qualitative data is presented in narrative form.

### **4.3 DATA PROCESSING AND ANALYSIS**

#### **4.3.1 QUANTITATIVE DATA**

After data was collected, every evening the semi structured interview schedules were checked for completeness, legibility, accuracy and consistency. This was done to ensure good quality of data. Numerical codes were then assigned to responses. Closed ended questions were assigned numerical codes. Coding being the method used to convert (translate) the data gathered during the study into symbols. Coding was done to ensure easy entry and analysis of data using computer software.

Open-ended questions were processed as follows; the investigator read through the data in its entirety so as to identify and group answers that belong together. This process is called categorization (Polit & Hungler, 1999). Following categorization, the investigator then assigned numerical codes (1, 2, 3, 4, 5...) to different categories. Categorization of open ended questions in this way enabled the researcher to report percentages of respondents giving answers that fell in each category. The codes were then entered and analyzed using SPSS version 16.0 soft ware computer package. The statistical test that was used to test for associations between independent and dependent variables is chi-square test. Confidence interval was set at 95 percent. A 5



percent level of significance and only P values of 0.05 or less was considered statistically significant thereby rejecting the null hypothesis.

#### **4.4 DATA PRESENTATION**

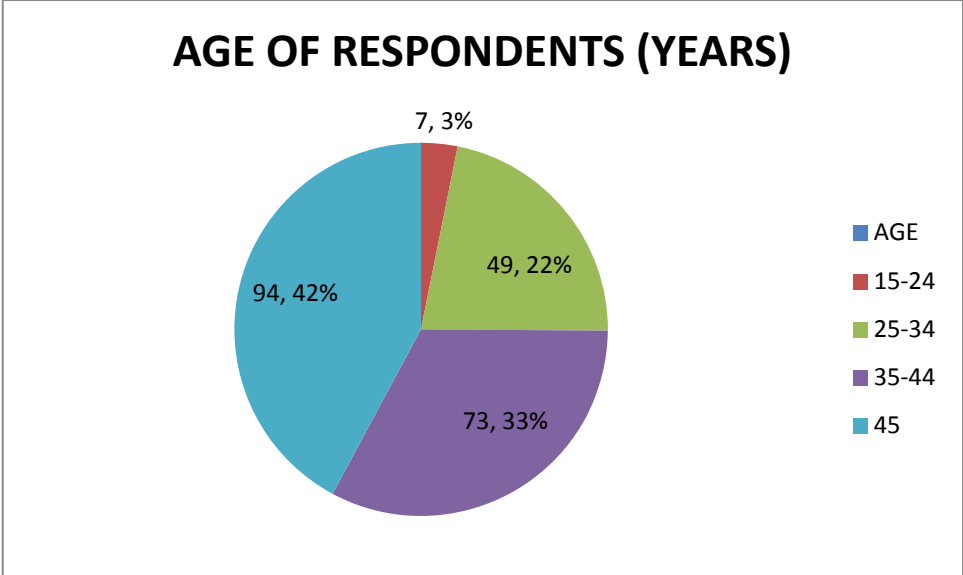
##### **4.4.1 QUANTITATIVE FINDINGS**

The research findings were presented based on the interview schedule lay out. Some variables have been analyzed separately but grouped together for easier presentation of the overall picture. Different forms of presentations were used in this study such as bar charts, tables and cross tabulations.

Tables make it easier to summarize findings in a meaningful way thus making it easy to understand. Cross tabulations were used in order to understand relationships between variables.

**SECTION A: DEMOGRAPHIC DATA**

**FIGURE 3: AGE OF RESPONDENTS**



Most of the respondents (42.2%) 94 were aged 45 years and above, 25-34 years, (32.7%) 73 were aged between 35-44 years, (22) 49 were aged between 25-34 years and 15-24 years (3.1%) 7 of respondents were aged between 15-24 years. The mean age of the respondents was 3.14. The median age was 3.00 and the standard deviation was 0.867

**TABLE 3: GENDER OF RESPONDENTS**

<b>Gender</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Female	137	61.4	61.4	61.4
Male	86	38.6	38.6	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100</b>

From table 3 61.4 percent (137) respondents were female while 38.6 percent (86) were male respondents.

**TABLE 4: MARITAL STATUS OF RESPONDENTS**

<b>Marital status of respondents</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative percent</b>
Single	41	18.4	18.4	18.4
Married	133	59.6	59.6	78
Divorced	4	1.8	1.8	79.8
Separated	15	6.7	6.7	86.5
Widowed	30	13.5	13.5	100
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100</b>

From table 4 (59.6%) 133 respondents were married followed by 18.4% (41) single, (1.8%) 4 divorced, (6.7%) 15 separated while (13.5%) 30 were widowed.

**TABLE 5: RELIGIOUS DENOMINATION OF THE RESPONDENTS**

Religious Denomination	Frequency	Percent	Valid Percent	Cumulative
Seventh Day Adventist church	8	3.6	3.6	3.6
Roman Catholic church	61	27.4	27.4	31
United Church of Zambia	3	1.3	1.3	32.3
Reformed Church of Zambia	57	25.6	25.6	57.9
Others, specify	94	42.2	42.2	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100</b>

This table shows most respondents (27.4%) 61 were members of the Roman Catholic church, followed by (25.6%) 57 who belonged to the Reformed Church of Zambia, (1.3%) 3 from United Church of Zambia and (42.2%) 94 of the respondents fell within the 'others' category (respondents from Pentecostal Based Churches, African Church, Apostolic Church).

**TABLE 6: LEVEL OF EDUCATION OF RESPONDENTS**

Level of education	Frequency	Percent	Valid Percent	Cumulative Percent
None	91	40.8	40.8	40.8
Primary	102	45.7	45.7	86.5
Secondary	27	12.1	12.1	98.7
College	2	.9	.9	99.6
University	1	.4	.4	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100</b>

From table 6 most of the respondents had attained primary education level (45.7%) (102) followed by 40.8% (91) respondent with no education, (12.1%) 27 secondary school education, (0.9%) 2 College education while (0.4%) 1 attained University qualifications.

**TABLE 7: OCCUPATION OF RESPONDENTS**

Occupation	Frequency	Percent	Valid Percent	Cumulative Percent
Housewife	57	25.6	25.6	25.6
Formal employment	17	7.6	7.6	33.2
Self employed	61	27.4	27.4	60.5
Unemployed	86	38.6	38.6	99.1
Others, specify	2	.9	.9	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

From table 7 most (38.6%) 86 respondents were unemployed followed by (27.4%) 61 self employed, (25.6%) 57 house wives, (7.6%) 17 in formal employment while (0.9%) 2 where in the others category.

**TABLE 8: LEVEL OF INCOME PER MONTH OF THE RESPONDENTS**

Level of income	Frequency	Percent	Valid Percent	Cumulative Percent
Below K500, 000 per month	24	10.8	10.8	10.8
Between K500, 000-K1, 000, 000 per month	8	3.6	3.6	14.3
Above K1 000, 000 per month	6	2.7	2.7	17.0
None	185	83.0	83.0	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

The table shows (83% 185 respondents had little or no income followed by (10.8%) 24 earned below K500, 000 per month, (3.6%) 8 earned between K500, 000 and K1, 000,000 per month while (2.7%) 6 earned above K1, 000,000 per month.

## SECTION B: PLWHA KNOWLEDGE LEVELS ON HOME BASED CARE SERVICES

### Introduction

This section presents results on the respondents' knowledge on home based care services.

**TABLE 9: HEARD ABOUT HOME BASED CARE**

Provider responsible	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	172	77.1	77.1	77.1
No	51	22.9	22.9	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100</b>

From table 9, most (77.1%) 172 respondents heard about home based care while (22.9%) 51 had not heard.

**TABLE 10: MEANING OF HOME BASED CARE**

Meaning of HBC	Frequency	Percent	Valid Percent	Cumulative Percent
Home based care is caring for the sick people at home	169	75.8	75.8	76
Don't know	54	24.2	24.2	100
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100</b>

From table 10 most (75.8%) 169 respondents were able to state the meaning of home based care while (24.2%) 54 were not able to state.

**TABLE 11: SOURCE OF INFORMATION**

	Frequency	Percent	Valid Percent	Cumulative Percent
Media	29	13.0	13.0	13.0
Health personnel	104	46.6	46.6	59.6
Family	24	10.8	10.8	70.4
Trained caregivers	26	11.7	11.7	82.1
Others, specify	40	17.9	17.9	100.0
Total	223	100.0	100.0	100.0

Majority of the respondents (46.6%) 104 respondents heard about HBC from the health personnel followed by (13%) 29 through media, (11.7%) 26 from trained caregivers, (10.8%) 24 from families members while (17.9%) 40 from other category of responses.

**TABLE 12: SERVICES OFFERED BY HBC CAREGIVERS**

	Frequency	Percent	Valid Percent	Cumulative Percent
Assist in domestic work	18	8.1	8.1	8.1
Health education, information distribution	10	4.5	4.5	12.6
Visiting, counseling and encouraging the sick	38	17.0	17.0	29.6
Encourage adherence to medicines	17	7.6	7.6	37.2
Take the sick to health facility	5	2.2	2.2	39.5
Provide material support	40	17.9	17.9	57.4
Offer general care	21	9.4	9.4	66.8
No response	74	33.2	33.2	100.0
Total	223	100.0	100.0	100.0

The table shows (33.2%) 74 of the respondents gave no response, (17.9%) 40 of the respondents mentioned that an HBC offered material support, (17%) 38 mentioned that HBC's visit, counsel and encourage the sick, (9.4%) 21 mentioned that the HBC offered general care to the sick, (8.1%) 18 mentioned that HBC's assist with domestic work, (7.6%) 17 mentioned that HBC's encouraged adherence to ART medication, (4.5%) 10 mentioned that HBC's offered health education and provide information, (2.2%) 5 mentioned that HBC's took the sick to health facilities in table 12.

**TABLE 13: RESPONSES ON BENEFITS OF HBC SERVICES**

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	174	78.0	78.0	78.0
No	9	4.0	4.0	82.1
Don't know	40	17.9	17.9	100.0
Total	223	100.0	100.0	100

The majority of respondents (78%) 174 of respondents affirmed that the HBC services are beneficial to PLWHA followed by (17.9%) 40 who did not know while (4%) 9 said that the services were not beneficial.

**TABLE 14: RESPONDENTS' REASONS FOR RESPONSES IN TABLE 13**

	Frequency	Percent	Valid Percent	Cumulative Percent
Assist in domestic work	2	.9	.9	.9
Health education, information distribution	11	4.9	4.9	5.8
Encourage adherence to medicines	42	18.8	18.8	24.7
Taking the sick to health facility	29	13.0	13.0	37.7
Provide material support	3	1.3	1.3	39.0
Offer general care	23	10.3	10.3	49.3
I do not see any benefit	32	14.3	14.3	63.7
I don't see them do any work	81	36.3	36.3	100.0
Total	223	100.0	100.0	100

From table 14, (18.8%) 42 of the respondents said HBCs' were beneficial followed by (13%) 29 said that HBCs' take sick people to health facilities, (10.3%) 23 said HBCs offered general care, (4.9%) 11 said HBCs offered health education and information, (1.3%) 3 said HBCs' provided material support, (0.9%) 2 HBCs' assisted with domestic work, (14.3%) 32 saw no benefit in HBC services while (36.3%) 81 did not see them doing any work.

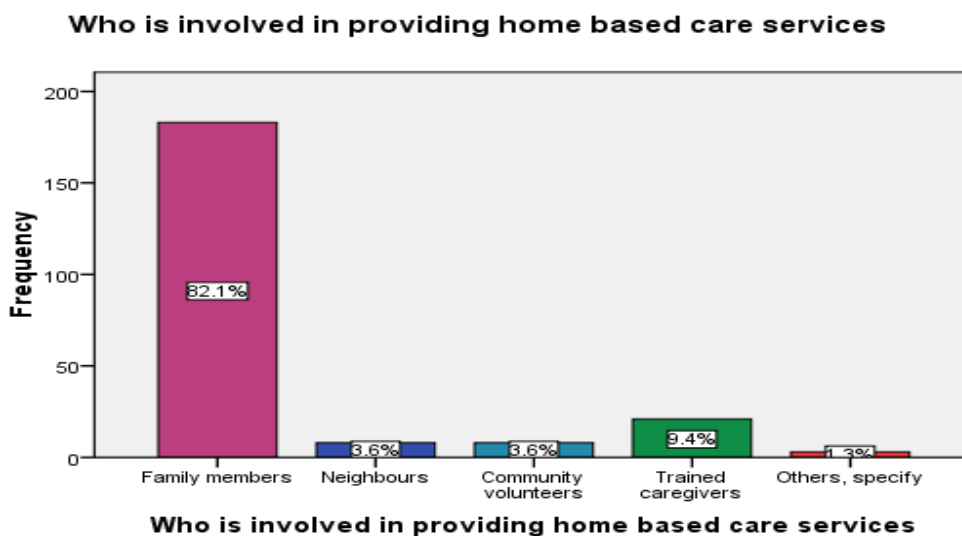


**TABLE 15: RESPONDENTS' KNOWLEDGE OF OTHER PLWHA**

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	157	70.4	70.4	70.4
No	66	29.6	29.6	100.0
Total	223	100.0	100.0	100

From table 15, (70.4%) 157 of the respondents knew other PLWHA while (29.6%) 66 did not.

**FIGURE 4: COMMUNITY INVOLVED IN PROVIDING HBC SERVICES**



From figure 4 most respondents (82.1%) 183 said family members were providing Home based care services, followed by (9.4%) 21 trained caregivers, (3.6%) 8 by Neighbors while (4.9%) 11 were other categories.

**TABLE 16: ELIGIBILITY FOR HOME BASED CARE SERVICES**

Eligibility	Frequency	Percent	Valid Percent	Cumulative Percent
HIV positive people but health looking	12	5.4	5.4	5.4
HIV positive people able to do some work with minimum help	3	1.3	1.3	6.7
HIV positive people, unable to do activities of daily living, bedridden	206	92.4	92.4	99.1
Don't know	2	.9	.9	100.0
Total	223	100.0	100.0	100.0

In this table majority of the respondents stated that (92.4%) 206 HIV positive people who were unable to do activities of daily living and were bed ridden, (5.4%) 12 stated that HIV positive people who were still looking healthy were eligible to receive HBC services, (1.3%) 3 were able to do some work and needed minimum help while (0.9%) 2 did not know.

**TABLE 17: KNOWLEDGE ON DURATION OF RESPONDENTS' HIV POSITIVE STATUS**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	<1 year	45	20.2	20.2	20.2
	1-2 years	47	21.1	21.1	41.3
	>2 years	131	58.7	58.7	100.0
	Total	223	100.0	100.0	100.0

From table 17, most (58.6%) 131 respondents knew their HIV positive status for more than 2 years followed by (20.2%) 45 knew for less than 1 year while (21.1%) 47 knew for 1 to 2 years.

**TABLE 18: KNOWLEDGE ON DISCLOSURE OF HIV STATUS**

<b>Disclosed status</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Yes	205	91.9	91.9	91.9
No	18	8.1	8.1	100.0
Total	223	100.0	100.0	100.0

From table 18, the most (91.9%) 205 respondents disclosed their HIV positive status while (8.1%) 18 did not disclose their HIV status.

**TABLE 19: RESPONDENTS' REASONS FOR NON DISCLOSURE**

<b>Reasons for non disclosure</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Do not want	9	4.0	4.0	4.0
Not free	3	1.3	1.3	5.3
Ashamed	6	2.7	2.7	8.0
Not applicable (Already disclosed)	205	91.9	91.9	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

From table 19, most (91.9%) 205 had already disclosed their HIV status, followed by (4%) 9 did not want to disclose their HIV positive status, (1.3%) 3 were not free to disclose their HIV positive status, while (2.7%) 6 attributed the non disclosure of their HIV positive status to feeling ashamed.

**TABLE 20: SUMMARY ON RESPONSES TO QUESTIONS ON KNOWLEDGE OF HBC**

<b>Variable</b>	<b>Correct responses</b>	<b>Non-correct responses</b>	<b>Mean</b>
Have Heard about HBC	172 (77.1%)	51 (22.9%)	1.23
Meaning of HBC services	169 (75.8%)	54 (24.2%)	2.18
Know of PLWHA receiving HBC services	157 (70.4%)	66 (29.6%)	1.67

From table 20, the summary of knowledge questions included had heard about home based care services, the results have been presented in table 13. The total score knowledge score was 3 as the scores of knowledge were divided into two categories namely low level of knowledge and high level of knowledge. Low level of knowledge ranged from 1-2 scores while high levels were above 3 scores.

## SECTION C: UTILISATION OF HOME BASED CARE SERVICES

### INTRODUCTION

Section C consist of findings on the respondents' responses on utilization of home based care services. The respondents answered the following questions; whether the PLWHA were currently utilizing the service, who the service provider was, availability of the caregiver and series provided by the caregiver, whether the services were good, how often the caregiver visits, whether they knew other PLWHA in their communities, access to ART and whether the PLWHA was given an appointment to visit the Home based care service.

**TABLE 21: RESPONDENTS ON ANTI RETROVIRAL TREATMENT**

Receiving ART	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	199	89.2	89.2	89.2
No	24	10.8	10.8	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

In table 21 above shows the respondents who were receiving Antiretroviral Treatment (ART). The majority of the respondents were on antiretroviral treatment (89.2%) 199 and (10.8%) 24 were not on ART.

**TABLE 22: TREATMENT SUPPORTERS OF THE RESPONDENTS**

Treatment supporters	Frequency	Percent	Valid Percent	Cumulative Percent
Family members	165	74.0	74.0	74.0
Trained caregivers	9	4.0	4.0	78.0
Neighbors	3	1.3	1.3	79.4
Community volunteers	7	3.1	3.1	82.5
None	39	17.4	17.4	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

Table 22 shows that most (74%)165 of the respondents use their own family members as their treatment supporters, (17.4%) 39 said that they had no treatment supporters at all, (4%) 9 mentioned trained caregivers as their treatment supporters. (3.1%) 7 of the respondents who received treatment support from community volunteers, (1.3%) 3 received support from their neighbors.

**TABLE 23: REFERRAL TO HEALTH FACILITY FOR HIV TESTING AND ART**

<b>Provider responsible</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Self	159	71.3	71.3	71.3
Community Volunteer	14	6.3	6.3	77.6
Caregiver from HBC	23	10.3	10.3	88.9
Family member	22	9.9	9.9	98.8
Others, specify	5	2.2	2.2	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100</b>

The majority of the respondents' referral for HIV testing and ART were self referred (71.3%) 159 followed by caregiver from HBCs (10.3%) 23 , family member (9.9%) 22 and others (2.2%) 5 .

**TABLE 24: RECEIVING HBC SERVICES**

<b>Are you receiving HBC services</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Yes	87	39	39	39
No	136	61	61	100
<b>Total</b>	<b>223</b>	<b>100</b>	<b>100</b>	<b>100</b>

The table shows (39%) 87 PLWHA were receiving while (61%)136 were not receiving.

**TABLE 25: PROVIDERS OF HBC SERVICE**

<b>Who are providing HBC services</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Health workers	11	12.6	12.6	12.6
Family members	30	34.4	34.4	47.0
HBC group	14	16	16	63.0
HIV support group	12	13.7	13.7	76.7
Faith Based Organization	6	6.9	6.9	83.6
No one	14	16	16	100.0
<b>Total</b>	<b>223</b>	<b>100</b>	<b>100</b>	<b>100</b>

Of the 87 respondents in table above who were receiving home based care services, (34.4%) receive 30 these services from their own family members, (16%) 14 were being looked after by home based care organizations, (16%) 14 of the respondents said no one was providing home based care to them, (13.7%) 12 were being looked after by PLWHA support groups, (12.6%) 11 were being looked after by health workers while (6.9%) 6 by Faith Based Organizations.

**TABLE 26: SERVICES OFFERED BY HOME BASED CAREGIVERS**

	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Counseling and encouragement	9	4.0	4.0	4.0
Provide ARV medicines	15	6.7	6.7	10.8
Provide basic necessities, help in domestic work	45	20.2	20.2	30.9
Teach about care and nutrition	6	2.7	2.7	33.6
Escort the sick to health facility	5	2.2	2.2	35.9
No services provided	143	64.1	64.1	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

From table 26, most 20.2% 45 respondents said HBCs' provide basic necessities, followed by (6.7%)15 provide ART medicines, (4%) 9 provide counseling and encouragement, (2.7%) 6 teach the sick about care and nutrition, (2.2%) 5 escort the sick to health facility while (64.1%) 143 said there were no services provided.

**TABLE 27: RATING OF CARE**

	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Good	58	26.0	26.0	26.0
Fair	70	31.4	31.4	57.4
Not good	95	42.6	42.6	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

From table 27 more than three quarters (42.6%) 95 of the study respondents related care as not being good while (26%) 58 related the care as being good.

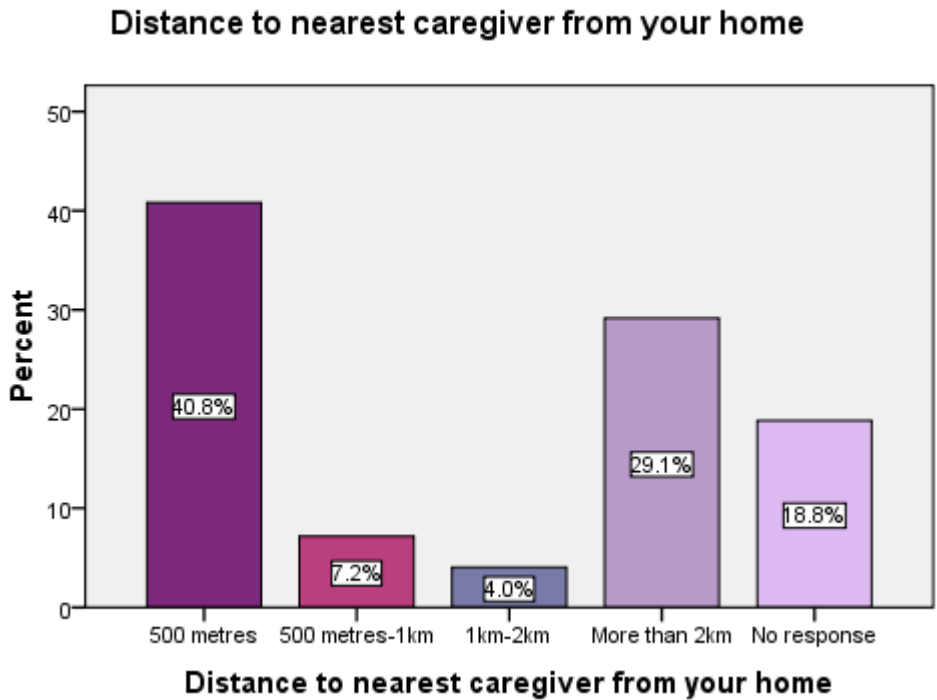


**TABLE 28: REASONS FOR RATING**

	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Always provide medicines	7	3.1	3.1	3.1
Support not adequate	26	11.7	11.7	14.8
I am fit now, thanks to their care	11	4.9	4.9	19.7
Rarely visit the sick	75	33.6	33.6	53.3
Service not available most times when people are in need	44	19.7	19.7	73.0
Inefficient service	31	13.9	13.9	86.9
Encourage and counsel	10	4.5	4.5	91.4
Take very good care	19	8.5	8.5	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

From table 28, (33.6%) 75 stated home based caregivers rarely visit the sick followed by and 8.5% 19 stated that they take care of the sick, (19.7%) 44 stated services were not available most times when people need it, (13.9%) 31 stated inefficient service, (11.7%) 26 stated the support they received from caregivers was not adequate, (8.5%) 19 stated caregivers took very good care of the clients, (4.9%) 11 of the respondents attributed their reason to getting better as a result of the good service they received from the HBC, (4.5%) 10 mentioned that they were encouraged and counseled while (3.1%) 7 mentioned that HBC always provided medicines,

**FIGURE 5: DISTANCE TO THE NEAREST HBC**



From figure 5 most (40.8%) respondents lived within 500 meters of the nearest caregiver followed by (29.1%) lived more than 2 kilometers, (7.2%) lived between 500 meters to 1 kilometer, (4%) lived between 1 kilometer to 2 kilometer of the nearest caregiver while (18.8%) of the respondents did not respond.

**TABLE 29: ENROLLED WITH HBC SERVICE PROGRAM**

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	105	47.1	47.1	47.1
No	118	52.9	52.9	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

Table 29 shows that (47.1%) 105 of the respondents stated that they were enrolled with an HBC program, (52.9%) 118 were not enrolled with any HBC program.

**TABLE 30: ORGANIZATION PROGRAMME ENROLLED WITH**

	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Faith based organization	12	5.4	5.4	5.4
Community based organization	1	.4	.4	5.8
PLHIV support group	91	40.8	40.8	46.6
Community volunteer caregivers	12	5.4	5.4	52.0
None	107	48.0	48.0	100.0
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

In table 30, most (40.8%) 91 respondents were enrolled in a PLWHA program followed by (5.4%) 12 by community volunteer caregivers, (5.4%) by faith based organizations, (0.4%) 1 with community based organization while (48%) 107 were not enrolled with any organization or program.

**TABLE 31: NUMBER OF TIMES VISITED BY CAREGIVER**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
1-2 times per month	36	16.1	16.1	16.1
Less than once per month	67	30.0	30.0	46.2
Not visited	120	53.8	53.8	53.8
<b>Total</b>	<b>223</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

Majority of respondents( 53.8%) 120 mentioned that they were not visited followed by (30%) 67, were visited by caregivers less than once a month (30%) 67 while (16.1%) (36) were visited 1-2 times a month by the caregivers.

**TABLE 32: GENDER INVOLVEMENT IN HBC SERVICE PROVISION**

Description	Frequency	Percent	Valid Percent	Cumulative Percent
Women	174	78.0	78.0	78.0
Men	34	15.2	15.2	93.2
Both	15	6.7	6.7	100.0
Total	223	100.0	100.0	100.0

Table 32 shows that majority respondents mentioned that women were the most involved in providing HBC services to the community at (78%) 174 while men were only (15.2%) 34 and (6.7%) 15 mentioned that both men and women are involved in providing the service.

**TABLE 33 A: REASONS FOR WHO IS MORE INVOLVED- WOMEN**

Description	Frequency	Percent	Valid Percent	Cumulative Percent
Women help in domestic work, prepare food for the sick	22	13.0	13.0	13.0
Know how to care, compassionate	53	31.4	31.4	44.4
Encourage to take ARV medicines	15	8.9	8.9	53.3
Most women do not work	7	4.1	4.1	57.4
Women volunteer easily	11	6.5	6.5	63.9
Visit the sick	4	2.4	2.4	66.3
Take care of the sick	57	33.7	33.7	100.0
<b>Total</b>	<b>169</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

**TABLE 33 B: REASONS FOR WHO IS MORE INVOLVED- MEN**

Description	Frequency	Percent	Valid Percent	Cumulative Percent
Men are busy at work	7	12.9	12.9	12.9
Take the sick to health facility	14	25.9	25.9	38.8
Men avoid this work	2	3.7	3.7	42.5
No response	31	57.4	57.4	99.9
<b>Total</b>	<b>54</b>	<b>99.9</b>	<b>99.9</b>	<b>100.0</b>

The table most respondents stated that taking care of the sick (25.6%) 57, followed by women know how to care for the sick better and are compassionate (23.8%) 53, (9.9%) 22 mentioned that there reason is that women help in domestic work, including preparing food for the sick.

**TABLE 34: INVOLVEMENT WITH HOME BASED CARE PROGRAMME**

Description	Frequency	Percent	Valid Percent	Cumulative Percent
<b>Yes</b>	105	47.1	47.1	47.1
<b>No</b>	118	52.9	52.9	99.1
<b>Total</b>	<b>223</b>	<b>100</b>	<b>100</b>	<b>100</b>

Majority of 34, (52.9%) 118 of the respondents mentioned that they were not involved with an HBC programme, (47.1%) 105 were involved with HBC programmes.

**TABLE 35: COMING ON DOCUMENTED APPOINTMENT DATE**

	<b>Frequency</b>	<b>Percent</b>	<b>Valid percent</b>	<b>Cumulative percent</b>
<b>Yes</b>	156	70	70	70
<b>No</b>	67	30	30	96
<b>Total</b>	<b>223</b>	<b>100</b>	<b>100</b>	<b>100</b>

In table 35 above (70%) 156 PLWHA had observed their appointment dates and (30%) 67 respondents did not observe the appointment dates.

## SECTION D:

### RELATIONSHIPS BETWEEN UTILIZATION OF HOME BASED CARE SERVICES, DEMOGRAPHIC DATA, SOCIO CULTURAL FACTORS AND KNOWLEDGE OF THE HOME BASED CARE SERVICES

#### INTRODUCTION

This section present results on the relationships between utilization of home based care services (dependent variable) with Knowledge of HBC by PLWHA (independent variable) and Demographic data of the respondents. The data is presented in tables, pie charts and bar chart

#### AGE OF THE RESPONDENTS

In order to determine whether the age of respondents influence utilization of HBC services, cross tabulation between ages and whether the respondents has received HBC services was done. Table 36 shows the relationship between the two variables.

**TABLE 36: UTILISATION OF HBC SERVICES IN RELATION TO AGE**

Utilization	Age of Respondents				
	15-24 years	25-34 years	35-44 years	45 years and above	Total
<b>Yes</b>	3	20	25	39	87
<b>No</b>	4	29	48	55	136
<b>Total</b>	<b>7</b>	<b>49</b>	<b>73</b>	<b>94</b>	<b>223</b>

From table 36 most (42.2%) 94 PLWHA were 45 years old and were receiving HBC services as compared to any other age groups. In order to determine the validity of these relationships, a Chi- square test was done. Chi-square test = 0.789, df =4 P Value < 0.10. The median age was 3.00 and the standard deviation was 0.867. Therefore, there is no statistically significant association between age and PLWHA receiving HBC services.

**TABLE 37: UTILISATION OF HBC SERVICES IN RELATION TO GENDER**

Utilization	Gender		
	Female	Male	Total
Yes	49	38	87
No	88	48	136
<b>Total</b>	<b>137</b>	<b>86</b>	<b>223</b>

The table shows majority of the respondents 137 (61.4%) were female while 86 (38.5%) were male. The table above shows that there was no association established between having had receiving home based care services and gender (Chi square test =0.21, df =2, P value < 0.10 (not significant).

#### **MARITAL STATUS AND UTILISATION OF HBC**

Like the other variables, marital status of the PLWHA under this sample was assessed in terms of how this influences PLWHA to receive Home Based Care services. A cross tabulation was also implemented in this case to assess relations between these two variables.



**TABLE 38: UTILISATION OF HBC SERVICES IN RELATION TO THE MARITAL STATUS**

Utilization	Marital Status					P value
	Divorced	Widowed	Separated	Married	Single	
Yes	0	7	6	60	14	0.06
No	4	23	9	73	27	
Total	4	30	15	133	41	

From table 34 majority married respondents (69%) 60 were receiving HBC services while (53.7%) 73 of the married ere not followed by (16.1%) 14 single were receiving HBC services while (31%) 27 were not.

**TABLE 39: UTILISATION OF HBC SERVICES IN RELATION TO RELIGIOUS DENOMINATION**

UTILISATION	RELIGIOUS DENOMINATION					Total
	Reformed Church	SDA Church	Roman Catholic Church	UCZ	Other	
Yes	16	2	28	1	40	87
No	41	6	33	2	54	133
<b>Total</b>	<b>57</b>	<b>8</b>	<b>61</b>	<b>3</b>	<b>94</b>	<b>223</b>

From table 37 majority (46%) 40 respondents receiving HBC services were from Pentecostal Churches, followed by (31.2%) 28 catholic church, (18.3%) 16 Reformed Church of Zambia, (2.3%) 2 Seventh Day Adventist while (1.1%) 1

**TABLE 40: UTILISATION OF HBC SERVICES IN RELATION TO EDUCATIONAL LEVEL**

Utilization	Educational Level					
	Primary	Secondary	College	University	None	Total
Yes	47	13	0	0	27	87
No	55	14	2	1	64	136
<b>Total</b>	<b>102</b>	<b>27</b>	<b>2</b>	<b>1</b>	<b>91</b>	<b>223</b>

From table 38 respondents with no education (31%) 27 were receiving Home Based Care services while (47%) 64 did not receive the services followed by primary (54%) 47 who received HBC services, (14.9%) 13 up secondary level were receiving HBC services while people with highest (10.2%) 14 did not receive.

**TABLE 41: UTILISATION OF HBC SERVICES IN RELATION TO OCCUPATION**

Utilization	occupation					
	Housewife	Formal employment	Self employed	Unemployed	Others	Total
Yes	18	6	34	27	2	87
No	39	11	27	59	0	136
<b>Total</b>	<b>57</b>	<b>17</b>	<b>61</b>	<b>86</b>	<b>2</b>	<b>223</b>

From table 39 majority unemployed respondents 43.3% (59) were not utilizing HBC services followed by (28.6%) 39 housewives, (19.8%) 27 self employed were utilizing the HBC services.

## INCOME OF RESPONDENTS

**TABLE 42: UTILISATION OF HBC SERVICES IN RELATION TO INCOME LEVEL**

Utilization	Income				
	Below K500,000.00	K500,000.00-1,000,000.00	Above 1,000,000.00	None	Total
Yes	17	1	0	74	87
No	7	7	6	111	136
<b>Total</b>	<b>24</b>	<b>8</b>	<b>6</b>	<b>185</b>	<b>223</b>

From table 40 above, majority respondents (85%) 74 had no income per month, followed by (19.5%) 17 earned below k500,000 per month with df=4 and p value of 0.008. Therefore, there is significant association between PWLHA and poverty levels. This may give an impression that PLWHA more especially women are in this large group of no income per month.

**TABLE 43: UTILISATION OF HBC SERVICES IN RELATION TO DEMOGRAPHIC VARIABLES**

Demographic characteristics	Received HBC services		Total	df	P – Value
	Yes	No			
<b>Age</b>					
15-24	3 (42.9%)	4 (57.1%)	7 (100%)	4	0.789
25-34	20 (40.8%)	29 (59.2%)	49 (100%)		
35-44	25 (34.2%)	48 (65.8%)	73 (100%)		
45 and above	39 (41.5%)	55 (58.5%)	94 (100%)		
<b>Gender (Sex)</b>					
Male	38 (44.2%)	48 (55.8%)	86 (100%)	4	0.086
Female	49 (35.8%)	88 (64.2%)	137(100%)		
<b>Marital status</b>					
Single	14 (34.1%)	27 (65.9%)	41 (100%)	4	0.086
Married	60 (45.1%)	73 (54.9%)	133 (100%)		
Divorced	0	9 (100%)	9 (100%)		
Separated	6 (40%)	9 (60%)	15 (100%)		
widowed	7 (23.3%)	23 (76.7%)	30 (100%)		
<b>Religious denomination</b>					
Reformed church	16 (28.1%)	41 (71.9%)	57 (100%)	4	0.260
Seventh Day Adventist	2 (25%)	6 (75%)	8 (100%)		
Roman Catholic	28 (45.9%)	33 (54.1%)	61 (100%)		
United Church of Zambia	1 (33.3%)	2 (66.7%)	3 (100%)		
Others	40 (42.6%)	54 (57.4%)	94 (100%)		
<b>Educational level</b>					
None	27 (29.7%)	64 (70.3%)	91 (100%)	4	0.080
Primary	47 (46.1%)	55 (53.9%)	102 (100%)		
Secondary	13 (48.1%)	14 (51.9%)	27 (100%)		
College	0 (0%)	2 (100%)	2 (100%)		
University	0 (0%)	1 (100%)	1 (100%)		
<b>Occupation</b>					
Housewife	18 (31.6%)	39 (68.4%)	57 (100%)	4	0.008
Formal employment	6 (35.3%)	11 (64.7%)	17 (100%)		
Self employed	34 (55.7%)	27 (44.3%)	61 (100%)		
Unemployed	27 (31.4%)	59 (68.6%)	86 (100%)		
Other	2 (100%)	0 (0%)	2 (100%)		
<b>Income levels</b>					
Below K500,000 per month	10 (41.7%)	14 (58.3%)	24 (100%)	4	0.228
Between K500,000-K1,000,000	4 (50%)	4 (50%)	8 (100%)		
Above K1,000,000 per month	0 (0%)	6 (100%)	6 (100%)		
None	73 (39.5%)	112 (60.5%)	185 (100%)		

The table gives a summary of the associations between demographic characteristics and utilization of Home based care.

**TABLE 44: UTILISATION OF HBC SERVICES IN RELATION TO MEANING OF HBC SERVICES**

Utilization	Meaning of HBC Services		
	HBC is caring for the sick at home	Do not know	Total
<b>Yes</b>	75	12	87
<b>No</b>	94	15	133
<b>Total</b>	<b>169</b>	<b>27</b>	<b>223</b>

From table 42 majority respondents (86.2%) 75 were able to identify the meaning of HBC also received HBC services. On the other hand (69.1%) 94 of those who correctly identified the meaning of HBC services did not actually receive the service. Chi square test=12.68, df =2, P value < 0.002 (Significant).

**TABLE 45: UTILISATION OF HBC SERVICES IN RELATION TO HEARD OF HBC SERVICES**

Utilization	Heard about HBC Services		
	Yes	No	Total
<b>Yes</b>	76	96	172
<b>No</b>	11	40	51
<b>Total</b>	<b>87</b>	<b>136</b>	<b>223</b>

From table 43 majority 71% (96) said did not hear about HBC services but were receiving while 76 who heard also received HBC services. A statistical significant relationship has been established between having heard about Home Based Care (87.3%) 76 and receiving Home Based Care services (Chi-square test 19.90 df =1, P value <0.003).

**TABLE 46: UTILISATION OF HBC SERVICES IN RELATION TO TYPE OF SERVICE PROVIDER**

Utilization	HBC service provider						
	Health Workers	Family Members	Care givers	HIV support group	Faith Based Organization	No Response	Total
Yes	11	30	14	12	6	14	87
No	0	1	1	0	1	133	136
<b>Total</b>	<b>11</b>	<b>31</b>	<b>15</b>	<b>12</b>	<b>7</b>	<b>147</b>	<b>223</b>

From table 44, (39%) 87 respondents who were receiving home based care services 30 34.4% (30) received from their own family members, (16%) 14 from home based care organizations, (13.7%) 12 from PLWHA support groups and (12.6%) 11 were being looked after by health workers. The non response rate is also notably higher at 14 (16%) 14 therefore posing some limitation. Chi square test=158.17, df =5, P value < 0.000 (not significant), indicating that there was no association between receiving home Based Care and the Provider of Home Based care service.

### **Referral of clients**

Effective client referral is very important for PLWHA to access Home Based Care services. But the referral system in this case has not been very effective and this variable tried to establish whether these inefficiencies could affect utilization of Home Based Care services.

**TABLE 47: UTILISATION OF HBC SERVICES IN RELATION TO REFERRAL TO HEALTH FACILITY**

Utilization	HBC service provider					Total
	Self	Community volunteer	Care givers	Family members	others	
Yes	64	6	12	4	1	87
No	95	8	11	18	4	136
<b>Total</b>	<b>159</b>	<b>14</b>	<b>23</b>	<b>22</b>	<b>5</b>	<b>223</b>

From table 45, out of 223 respondents (73.6%) 64 were self referred to health facilities followed by 10.3% (23) that were referred by HBC givers, (9.9%) 22 referred by family members, (6.3) 14 referred by community volunteers while (2.2%) 5 in the 'others' category. A cross tabulation between referral to health facility and respondents receiving Home Based Care services showed no statistical significance (Chi-square test=0.156, df=4, P value < 10).

## 4.4.2 QUALITATIVE FINDINGS

### 4.4.2.1 Introduction

Qualitative data from the focus group discussions was transcribed verbatim. Thematic data analysis is a system where data is classified according to codes and themes (Polit & Beck 2008). Data was then presented in summary quotations according to emerging themes.

Some of the questions asked to explore knowledge levels and utilization of HBC services included; “what do you know about HBC services, what HBC services are receiving and how often are you visited by caregivers and for caregivers; what is HBC and how many clients is your organization having on the register?” These and many other questions were used to measure factors affecting utilization of home-based care.

### 4.4.2.2 Knowledge on Home Based care by PLWHA

- **Definition of HBC**

Most of the FGD participants could not state the definition of HBC in their own understanding; this is reflected in this statement below by one participant:

***“Rural Male” -Caregivers.***

*“This is the way health workers provide care to the sick when they go to the clinic and the instructions given to take at home especially for those with AIDS”*

- **Role and services of HBCs**

With regards to role and services of HBC many participants were able to clearly identify the role and services it provides as indicated by these participant:

***Male participant from PLWHA group***

*“We know that when someone is sick, there is need for other people who are fine to go and visit such a person. There are normally a number of things that these sick people lack such as lack of water, firewood and washing help and so other people help do such things for them in their homes even taking some food for them.”*



**Female participant from the Community Based Organization group**

*“Home based care groups enlighten especially the people living with HIV or tuberculosis. They encourage them by educating that the fact that they have been diagnosed with this disease it does not mean they will die soon. But they need to go the hospital and receive the necessary help so that their life will be prolonged.*

**Male participant – PLWHA group**

*“We know that when someone is sick, there is need for other people who are fine to go and visit such as one. There are normally a number of things that these sick people lack such as lack of water, firewood and washing help. These things need people who are fine to help take care of a sick person in their homes.*

**Female participant \_ caregivers group**

*“Home based care groups enlighten especially the people living with HIV or Tuberculosis. They encourage them by educating that the fact that they have been diagnosed with this disease it does not mean they will die soon. But they need to go the hospital and receive the necessary help so that their life will be prolonged.*

- **Health conditions of people eligible for HBC**

Participants were also able to identify health condition of the people who should be served by HBC as reported by this participant:

**Female participant- HBCs**

*“I think caregivers are supposed to take care of people who are very sick and are not able to do any work on their own, for example those with AIDS and those who suffer from chronic cough like tuberculosis because they can spread to others” Rural male*

Most of the respondents, though could not state the definition of HBC, they were able to clearly identify the role, services it provides and the health condition of the people it

serves. Most people, however, pointed out that there are no HBC organizations active in the communities.

- **Organization involved in providing HBCs**

Participants were asked if they knew of any organization that provides home based care services. This raised a lot of contributions from participants and what came out strongly was summarized by one participant as follows:

*“We just hear that organizations were there some time back who were giving food like kapenta, cooking oil but now we don’t see them. We hear they had even received bicycles Government and PLAN Organization, ‘Kaya mwe’ female – PLWHA group”.*

***Most participants were uttering supporting murmurs as she spoke.***

#### ***4.4.2.3 Utilization of Home based care***

- **Clients who should access Home Based care services**

Some participants said that PLWHA or people who had Tuberculosis and were terminally ill should receive HBC services but those who were HIV positive but were strong and able to do some work to support themselves should not receive HBC services. Such individuals were referred to as suffering from AIDS.

#### ***Male participant - caregiver group***

*“For those who are terminally ill, there is need for the caregivers to visit them, see them, sit near them, talk to them nicely about things that will keep them happy, so that their illness should not last or cause them to think too much. Talk to them happily and peacefully so the patient can be a happy person.”*

Lack of a programme aimed at educating the community on home-based care services may contribute to poor attitude towards the programme. Tanzania HIV Indicator Survey (2005)

- **HBC services you are receiving**

Almost all the participants indicated that they were not chronically sick though being HIV positive to be eligible for HBC services. Some were able to talk about family members taking care of them.

***Male participant- PLWHA group***

*“My wife is taking care of me, she reminds when to take the drugs, in fact we come together to get drugs so we care for each other but not an outsider”*

- **Involved in providing HBC services**

Some participant did mention that it is traditional that when one is sick in the village, she/he should be visited. Even among ourselves when one is sick we visit each other to encourage the sick to continue our drugs because it is not good to stop taking these drugs – ARVs.

- **Men involvement in HBC services**

When asked as to what they think about men being involved in HBC provision. One male participant had this to say:

***Male participant- PLWHA group***

*“Yes! Men should be involved like escorting the sick to the clinic using a bicycle or an oxcart which most women would not manage to use but not washing for the sick because this is the job for women”*

*However, one woman was quick to comment on what the male participant had said “ these men they are not fair because they don’t stay home to nurse women, they go out to drink beer and they would rather call for your relative to nurse you” female participant.*

- **Challenges PLWHA face to utilize HBC services**

Some participants stated that they would not like to be enrolled or visited by the caregivers because they are not seeing any benefits and one participant had this to say:

*“ wouldn’t want to be visited as if I am almost dying and everyone in the village will start talking about me as being in desperate need, “No” people talk a lot in the village, it’s ok the way I come here with my wife and we are most of the time busy in the field and gardens”* **Male participant**

- **Suggestions to increase awareness**

Some participants stated that there will be need to educate them on the benefits of HBC services.

- *“During review dates the health workers do ask as if we are enrolled in HBC but they don’t tell us who are responsible to enroll us and the importance. So we need to be educated on this and we will know what to do next”* **Male participant**

#### ***4.4.2.4 Focus Group Discussions with community HBC providers and participants from a Community Based Organization***

#### ***4.4.2.5 Knowledge on HBC***

- **Meaning of HBC**

Most of the participants were able to correctly define Home Based Care and also say the roles caregivers play in taking care of the sick. *“HBC is the care we give to the chronically sick people in our communities”* **Female participant”**

- **Existence of the organization**

On the existence of their organization one participant said *“WAAPO has been in existence for more than six years now though I can’t remember the date when it started operating”* **Female participant”**

- **Supervising their work and submission of reports**

When asked as to who supervises the work and where they submit reports if at all they write any, participants from both groups did express some big concern on the matter because they said they worked with no supervisor and rarely do they write reports except for their colleagues from a Faith Based Organization who are supervised by the catholic church though also it goes with the serving father if he has interest in HBC.

*“We have no supervisor at the clinic, most of the health workers present don’t know much about HBC, they don’t even know our roles as a result they do not even refer any client they have tested and is HIV positive to us for follow up and this has made us to stop writing reports” **Female participant**”*

- **Income generating and funding**

The participant were asked if they had activities to help raise funds to sustain their operations and some participant had this to say in support of each other,

*“We used to keep broiler chickens for sale but some misunderstanding arose from accountability for the sales because we did not realize much from the project and so we stopped and even the capital money was used. “**Male participant**”*

*“In addition to what my friend has said, we no longer receiving funding from CRAIDS who supported us to start the organization” **Female participant**”*

#### **4.4.2.6 Utilization of HBC services**

- **Clients on their registers**

The participants were asked on the number of clients each one had on their registers. From the look of things most of them only had less than five clients but they were not using registers because they knew them. This was reflected in one participant response:

*“Why should we write in registers as though there is somebody to check on what we are doing, some of us we have even forgotten how to write reports”* **Female participant.**

- **Visits to clients**

Participants said they often visited clients who were nearby their homes twice per month with pain because they had no provisions to give such as food, soap among other things.

**Female participant- care giver group**

*“Food seems to be a very big problem because when we a visiting a sick person, according to our tradition, you need to carry some food and so these clients normally expect this, but we do not provide every time we visit them. And so these sick people begin to complain and become unwelcoming.”*

**Female participant” HBC group**

*“In some families there are serious food shortages and hunger for a number of years and to make matters even worse, they have an illness. You find that this person who is terminally ill becomes too weak. It becomes worse when we as caregivers visit such without anything to offer.”*

**Male participant – care givers group:**

*“When we are visiting the sick, in most cases we find that they lack food. Food is a very big problem especially in the communities we operate in.”*

**Male participant- Care givers group**

*“When CRAIDS was funding, our clients were free and happy to see us because we were helping with food stuffs and other things. Most of our clients have children who are too young to work and so visiting and providing them with food stuffs was very helpful as they had no other source of these things.”*

- **Challenges they face as they provide HBC services**

- **Inadequate HBC training**

One key factor that was mentioned was inadequate training for the HBC caregivers. Training of HBC providers mainly depended on other organizations not the HBC organizations themselves because most of them did not have funds and the trainers to conduct trainings. Therefore most HBC providers were not trained.

***Male participant HBC group***

*“Most of these new volunteers have not had any HBC training at all even though we work together.”*

- **Quality to services**

The quality of services provided is another very important factor that would influence the utilization of HBC services in communities. Most of the participants pointed out a number of critical inefficiencies in the HBC system in Chadiza.

***Female participant HBC caregiver***

*“Another thing is that we caregivers should use protective kits. We do not have protective kits to use especially in cases where you find the patient is too sick, mostly we just use bare hands without any protective kits.”*

These results are supported by study report conducted in Swaziland by the United Nations Integrated Regional Information Networks which reported that many patients with AIDS felt rejected because of judgment and fear of contracting the disease by the family members, friends and neighbors did not know how to cope with a person who was dying. This may indicate inadequate utilization of HBC services. (United Nations Integrated Regional Information Networks, 2007)

***Female participant-HBC care giver***

*“In addition, these people need to eat in order to live well. In a situation where you visit a patient and you have nothing to help them with even food it becomes difficult. It makes us the caregivers feel bad because these people are weak and need help from us. And this is one challenge on our side.”*

**Female participant – HBC group**

*“The first problem we encounter, especially when we are reaching out to people needing support is that we find these people in different places which are far apart. The problem is that when we are called to visit the sick, we do not have transport to these places.”*

**Male participant– PWLHA group**

*“The other problem is that in case I find a patient very seriously sick and needing medical attention, I am supposed to help to transport such a one to the nearest hospital. But now that I the caregiver do not have a bicycle, it becomes very difficult for me to find where to borrow a bicycle and take the patient to hospital.”*

**Peri Urban - Female**

*“Another important thing is that we go round providing HBC services without any form of identity.”*

Most of the issues discussed above are very critical in any effective HBC service provision. Most of the HBC's especially those represented by the participants from the above, it is clear that they are very ineffective because they do not have basic health care needs such as protective kits and thus exposing caregivers to infections.

Because most of the clients lived in extreme poverty and required at least basic necessities such as food, clothing, etc from the HBC providers, did not utilize the HBC which did not offer basic necessities of life.

Transport to go to the health facility and access health services is very important. The participants expressed that it was very difficult for them to even call on the HBC provider to take them to hospital because they had means of transport.



## **CONCLUSION**

In conclusion, the general picture of Home Based Care services in Chadiza is not an attractive one as most providers do not seem to be active. Most HBC organizations seem to be facing challenges with provision of food funding and lack most of the necessary equipment and supplies needed to effectively carry out their work. They have no transport facilities and worse off their relationship with the health facilities is not so conducive for them to thrive.

These challenges are among the major constraints affecting HBC organizations and thus constraining service provision.

## **CHAPTER FIVE**

### **5.1 DISCUSSION OF FINDINGS AND IMPLICATIONS**

#### **5.2 INTRODUCTION**

The overall objective of the study was to investigate determinants of utilization of Home-Based care services by PLWHA in Chadiza district. The study assessed a number of factors such as the most commonly preferred type of HBC, knowledge of HBC, demographic and socio-cultural factors and to what extent these factors determined the utilization of home based care services. The data was collected using an interview schedule and three (3) focus group discussions with PLWHA, home based caregivers and caregivers from a Community Based Organization (CBO).

#### **5.3 SOCIO DEMOGRAPHIC CHARACTERISTICS OF SAMPLE**

The socio-demographic characteristics of this study are presented in Chapter 4. Most of the respondents were in the age range 45 years and above 42.2 percent, followed by the 35-44 year age range at 32.7 percent.

The most plausible explanation for this distribution would be the fact that HIV and AIDS stigma is quite high among the younger people than the older ones. This made most of the younger people to shun accessing counseling, testing and antiretroviral services at health facilities as shown from the study results; most of the respondents were in the age range 45 years and above 42.2 percent, followed by the 35-44 year age range at 32.7 percent 25-34 year age range at 22 percent and 15-24 year age range had only 3.1 percent of the total number of respondents as shown Chi square test  $df=4$  P value  $<0.010$  (significant). This entails that there is association between age and utilization of HBC services.

Older people who are less educated and those with less income are likely to be enrolled to HBC services because they may not have funds to pay for hospital admissions and relatives may not visit them regularly unlike the young, middle aged

and with education who may have resources to afford hospital bills, transport to hospital and may give consent on caregivers and where the care was provided such as home or hospital especially during the terminal phase of the disease for fear of stigma (National AIDS/STD Control Programme, 2002). Qualitative data results also show that there were more female older participants than men who came to seek ART services than men.

According to the findings on gender, of the sample, 61.4 percent were female and only 38.6 percent were male. There were more women accessing antiretroviral services in the District according to records and therefore, it was easier for the researcher to capture more of them into the purposive sample than men. This is supported by results from Pathfinder International Tanzania (2006) more women 75 percent were enrolled in Community Home Based Care groups than men.

The most likely explanation for this kind of distribution is that women unlike men easily accepted and overcame the stigma and discrimination that comes with HIV positive status. The other clarification may be that HIV is most prevalent among women than men mainly due to their biological make up. "The prevalence was significantly higher among women, especially for those below the age of 35 (NAC, 2008). Overall, women (with prevalence rates of 17.8%) are 1.4 times more likely to be HIV positive than men (with prevalence rates of 12.6%). Chi square test was done to test the association, P value=0.086, df=4, P value <0.10 show some significant association between utilization of HBC services and gender.

The marital characteristics of the sample were that 59.6 percent reported being married representing the highest figures. 18.7 percent represented the single people in the sample, 13.5 percent represented the widowed section, 6.7 percent are separated and only 1.8 percent represented the divorced. NAC 2009) states that married people were vulnerable to HIV infections most likely that they did not use protection, trusted their partners, and seemed to have multiple and concurrent partnerships.

The most predominant religious denomination in the sample was the 'others section' 42.2 percent which was mostly Pentecostal, Roman Catholic at 27.4 percent, Reformed church at 25.6 percent, Seventh Day Adventist at 3.6 percent and United Church of Zambia at 1.3 percent. This basically implied that most of the respondents in the sample were Pentecostal and Roman Catholic. Chi square test=0.260, df=4, P value <0.010 indicating that there was no association between religious denomination and receiving HBC services.

The study results are related to results according to the Zambia Demographic Health Survey (2007), "A comparison of HIV prevalence by religion shows that HIV prevalence is highest among protestants (15%) followed by Catholics 13 percent." This may explain why most of these people captured in the sample were HIV positive and accessing treatment.

These results are also supported by UNAIDS report that HIV and AIDS affect both Christians and non-Christians because of the burden of taking care of the PLWHA and the affected families for example the orphans. Religion may influence risk awareness of HIV and AIDS. Religious leaders may influence belief systems to ensure that HIV and AIDS are seen in a more positive light (UNAIDS 2005).

MOH (2002), also states that strengthening existing faith and helping the PLWHA in spiritual group boosts the spiritual aspect of life and plays a great part in encouraging the person to have a positive view of life thus leading to seeking care and support through HBC services.

The educational attainments of the sample population showed that 45.7 percent had attained primary education, 40.8 percent had no education at all, 12.1 percent had attained secondary education, 0.9 percent had attained college and only 0.4 percent had attained university education. The results purely represent the picture reflected in most rural set ups of Zambia that education levels were very low. Most people manage only primary education. This is so because this population was ordinarily very poor and

could not afford to pay higher school fees in secondary schools, colleges and universities. (ZDHS, 2007). (See table 6)

The study results are also supported by National AIDS/STD Control Programme (2002) education level of PLWHA may influence understanding and accepting their HIV status which may lead to delay in seeking treatment and poor adherence to antiretroviral therapy and other support services such as HBC.

The sample was predominantly unemployed at 38.6 percent, followed by the self employed at 27.4 percent. 25.6 percent were housewives and only 7.6 percent were in formal employment as shown in table 7 (employment levels of respondents). Chi square test =0.008, df=4, P value <0.10 show statically significant between educational level and receiving of HBC services.

These results are supported by ZDHS (2007) where 72.2 percent men and 79.3 percent women are self employed in agriculture work and 38.2 percent and 64 percent are in non-agriculture work. Of these women, 71 percent work in agriculture seasonally.

This fits into the country's statistics of having very high unemployment rates especially in peri-urban to rural areas and thus affects the activeness of the Home Based Care programmes where material support is concerned and also time of getting involved in the delivery of services by family members, trained caregivers neighbours and religious denominations (ZDHS, 2007).

*"In addition, these people need to eat in order to live well.*

*"In a situation where you visit a patient and you have nothing to help them with even food it becomes difficult" female participant – PLWHA group.*

Most of the sample population 83 percent had none or negligible monthly income amounting, 10.8% had their monthly incomes below K500, 000, 3.6 percent had their income range between K500, 000 to K1, 000, 000 and only 2.7 percent had their

income above K1, 000, 000. According to International Monetary Fund (IMF), Zambia remains a country with widespread poverty. According to ZDHS (2007), poverty has remained more prevalent in rural areas than in urban areas with 80 and 34 percent respectively. Chi square test with  $df=4$  and P value 0.008 indicate significant association between PLWHA and poverty levels.

Income levels thus affect the HBC service provision where caregivers need to give material support to their clients as they visit them. Such challenges are supported by the results from the study by Pathfinder International Tanzania where many families who are taking care of PLWHA face financial problems due to the disease burden and so they expect to be supported by the HBC programme and not only to be visited empty handed. If HBCS do not offer any financial or material support, the PLWHA may not be willing to use their services, for example when the HBC goes to visit the patient for the second time empty handed, the relatives may hinder their patient (Pathfinder International Tanzania, 2006).

It was shown that most number of people above the age of 45 years accessed HBC services than any other age group 42.2 percent, followed by 32.7 percent, for the 25-34 years, 22 percent for the 35-44 years age and only 3.1 percent, for the 15-24 years. The most likely explanation for this relationship, maybe purely because there were more people above 45 years of age that were sampled, than any other age group as shown in figure 3. This idea is also supported by the chi square test results which show that the relationship is basically because of chance variation as shown by chi-square finding as  $df=4$ , p value 0.086 indicating that there was some relationship between marital status and utilization of home based care services

The gender variable show that more women 56.3 percent had accessed HBC services and only 43.7 percent men had received HBC services (See table 3) The women who did not access constituted 64.7 percent of the study sample and 35.3 percent men did not access the service. Women tend to be very receptive of health services and seem to easily deal with issues of stigma related to HIV and AIDS better than men. But the

other possible explanation for the result may be that there were more women accessing HBC services in this case because they were the most available in the sample.

Sixty-nine (69) percent of the married respondents accessed HBC services, 16.1 percent of the single respondents, followed by 8 percent widowed people, 6.9 percent separated and none that were divorced. This had been proved as a positive chi square test indicating that this strong relationship between married people and accessing HBC services was actually not by chance. According to NAC (2009), married people are more vulnerable to HIV and AIDS. Married people tend to have less stigma, care more about the future of their children and access services so that they have good health to see their children grow. They also receive a lot of encouragement from their families to do so. HBC caregiver.

#### **5.4 PLWHA'S LEVEL OF KNOWLEDGE ABOUT THE HBC**

According to results from the descriptive statistics on the variable 'heard about HBC', respondents representing 77.1 percent had actually heard about home based care services as compared to 22.9 percent who had not heard at all as shown in table 9 (Heard about home based care services).

These results are supported by the study by Chandi (1997) on knowledge, attitude and practice of the community towards HBC services in Kitwe revealed that only 18 percent of the respondents had knowledge on home-based care services, 90 percent of the respondents had heard of Home-Based Care programme.

According to table 10, most of the respondents were able to correctly identify the meaning of HBC as caring for the sick at home. This could be attributed to the respondents had been exposed to such kind of information before. Only 24.5 percent did not understand the meaning. It is therefore, evident that most of the respondents

actually knew what the correct meaning of HBC is. The results are as also shown in the focus group discussion on knowledge;

*“HBC is the care we give to the chronically sick people in our communities”*  
**Female participant PLWHA - group”**

The respondents’ source of information on HBC has been presented in table 11. From the results, it is clearly evident that most of the respondents had heard about HBC services from health personnel 46.6 percent than through media 13 percent, caregivers 11.7 percent and even their own families 10.8 percent. Most respondents seem to utilize more of the health personnel to learn about HBC than all the other people, probably because these are available and are more knowledgeable to advice on such issues. People tend to trust asking for advice from them than learning from any other source.

With regards to services offered by caregivers, the respondents stated that they visited, counseled, encourage the sick and provided material support (see table 12). This result indicates that the respondents knew the role of the care givers. This was mentioned by one focus group discussion participant as indicated below:

*“We know that when someone is sick, there is need for other people who are fine to go and visit such as one. There are normally a number of things that these sick people lack such as lack of water, firewood and washing help. These things need people who are fine to help take care of a sick person in their homes.”* **Rural Male**

According to table 13, most respondents (78%) knew the benefits of home based care services as compared to only 4 percent who did not see any benefit at all. This is so because most of these PLWHA had at one time benefited from services offered by HBCs.



According to table 14, most respondents attributed their satisfaction with services to the fact that HBCs' were beneficial because they encouraged adherence to taking antiretroviral treatment, and took the sick to the health facility. In most communities, HBC caregivers make referrals and most times make arrangements to transport the sick to the clinic.

The findings show that Home based care services provided by family members were more preferred by the terminally ill (TB or AIDS) than those offered by the HBC organizations (see 25).

WHO (2002), report on a study conducted by Lindsey in Thailand, Haiti, Cambodia, Botswana and Kenya in 2000 on Community Home-Based Care in Resource Limited Settlements, revealed that between 70 percent and 90 percent of illness care takes place within the home and that most PLWHA preferred to be cared for at home because effective home care improves quality of life for ill people and their family members. However, the report further states that some HIV and AIDS clients and family members who require CHBC may not be aware of the services and how to access home care.

Refer to the findings of other studies.

The implication therefore is that very few people may actually use HBC organizations hence low utilization of these services.

Ninety-two (92) percent of the respondents stated that people who should receive home based care services were those who are HIV positive, were weak, unable to do some work and possibly bedridden (Table 16). This implied that this sample had good knowledge about the kind of people who should receive home based care services.

In summary 77.1 percent had heard about home based care services, 46.6 percent had health personnel as their major source of knowledge, 75.8 percent could clearly figure out what home based care meant and 92.4 percent correctly identify what kind of health status a person who received this care should be and it was correct to assume that knowledge about home based care in this community was therefore essentially

high. And with these levels of knowledge, the expectation is that there should be more of home based care services, but findings on accessing these services suggest the contrary.

Out of the 39 percent respondents receiving home based care services, 34.4 percent received these services from their own family members, 16 percent received these services from home based care organizations, 13.7 percent received this service through PLWHA support groups and 12.6 percent received this care through health workers. The non response rate was also notably high at 16 percent therefore posing some limitation. Chi square test=158.17, df =5, P value < 0.000 (not significant). The study results are supported by WHO (2002) that revealed that between 70 percent and 90 percent care of the sick took place in their homes.

Most respondents who are self employed and unemployed at all seem to access home based care services more than other categories such as the employed. When statistically tested, the results show that this relationship is real and not by chance. The reasons for such an occurrence may be that people who are not working or some of those that are self employed may have very little income to keep themselves very well with good nutrition and so HIV quickly drifts into AIDS causing them to be terminally ill and need to access home based care services unlike those that are employed.

Another reason may be stigma related to HIV. Most people who are educated and employed tend to fear stigma and this deters them from accessing services such as home based care.

## **5.5 UTILIZATION OF HOME BASED CARE SERVICES**

Table 19, shows that 91.9 percent of the respondents had already disclosed their HIV status and this means they were ready to freely access care services when need

arises. HBC services are mostly accessed by those who accept their HIV positive status unlike those that live in self denial.

On the other hand these study results are not consistent with some previous studies. For example, one conducted in India, New Delhi and Bangalore on stigmatization and discrimination related to HIV and AIDS revealed ostracism and rejection of PLWHA. This caused individual fear to disclose and withdrawal leading to secrecy about HIV status and self imposed social isolation and this led to difficulties in accessing community care and support services from HBC by PLWHA (UNAIDS, 2004).

According to table 20, most of the respondents did not disclose their HIV status because they were ashamed to do so as a result of stigma. This may be due to the fact that stigma is common in the communities.

The label is imposed on persons who are believed to be deviant or to have a status that distinguishes them. The effects of such a label may be experienced by a majority of those infected or affected by HIV/AIDS (Ministry of Health & Child Welfare, 2004) and may weaken social relations that exist between HIV infected individuals and their families or their neighbors. This may eventually lead to rejection by community members, individual isolation of HIV positive clients and non-disclosure of their HIV status. Therefore, stigma may make PLWHA not to utilize the home-based care services.

Most of the respondents mentioned that they were self referred for testing and treatment at 71.3 percent (see table 23). This may imply that most of the respondents due stigma they preferred to privately access testing and ART though most of them later disclosed especially when they needed more care and support as indicated in table 19. . A cross tabulation between referral to health facility and respondents receiving Home Based Care services showed no statistical significance (Chi-square test=0.156, df=4, P value < 10).

Out of 223 respondents, 39 percent confirmed that they actually received HBC services and 61 percent did not receive HBC services (Table 24). It is therefore evident that very few respondents are actually receiving HBC services. Many people seem to shun HBC and this may be due to poverty, poor quality of service delivery and lack of adequately trained Care givers.

Providing basic necessities and helping with domestic work comes out more strongly from most respondents when asked about services HBCs provide. This seems to mean that most people in this area have come to know that HBCs are supposed to primarily provide basic necessities such as food, blankets, and help with domestic work all the terminally ill. Mostly this is because of what they see with most HBCs in the operating within the area.

The respondents were asked to state quality of care in HBC services was. Majority of the respondents 42.6 percent stated that the quality of care was poor and 31.4 percent stated that it was 'fair' (Table 27). 26 percent of the respondents reported that the quality of care was good. This means that the services are not up to the desired standard.

41 percent of the respondents lived within 500 meters of the nearest caregiver, 29.1 percent lived more than 2 kilometers, 7.2 percent lived between 500 meters to 1 kilometer and 4 percent lived between 1 kilometer to 2 kilometer of the nearest caregiver (see figure 5). It is clear that most of the respondents live very near to the nearest caregiver. This may be because there are more caregivers around this area.

A good number of the respondents were enrolled in home based care programs at 47.1 percent, while 52 percent were not enrolled in any HBC program. Of those that were enrolled, most were actually enrolled with PLWHA support groups at 40.8 percent, while some minorities were enrolled with faith based organizations and other community based organizations. The PLWHA support groups are groups comprising of

PLWHA whose role is to support one another as PLWHA to live positively and adhere to treatment

Most of the respondents 53.8percent mentioned that they were not regularly visited by caregivers from HBCs'. Among 30 percent those who were visited most of them reported less than one visit per month (Table 31). This could be attributed to lack of resources by the HBCs such as lack of funding, staff and so on. This sentiment was also expressed by the focus group participants as reflected in theses statement:

*“When we are visiting the sick, in most cases we find that they lack food. Food is a very big problem especially in the communities we operate in.” **Male participant***  
*Rural co unities usually have seasonal periods when food is usually available*

More than 70 percent PLWHA knew of other PLWHA living in their neighborhood and only 24.4 percent did not. This may be attributed to heavy involvement in PLWHA support groups, interacting during HIV and AIDS programmes or meeting at health facilities during appointment dates or any other day.

Women seem to be more involved in HBC provision 78 percent than men 11.2 percent. It is culturally assumed that it is women's responsibility to take care of the sick unlike men. Therefore, whenever there are sick people in the community women willingly take up the responsibility than men. This may explain the reason why most people mentioned that more women are involved in care than men (see table 32).

The respondents were asked to give reasons why caring was regarded as a woman's responsibility. Most respondents stated that caring was a woman's responsibility (25.6 percent and 23.8 percent said that women knew how to care and they were compassionate (Table 33).

Table 34, 59.6 percent of the respondents' stated that they were involved in providing care and 35.4percen said that they have not at all been involved in providing care. The

implication, therefore, is that most PLWHA have participated in HBC provision. Most of those who participated in HBC provision mentioned that they visited, counseled and encouraged the sick, others assisted in domestic work, others encouraged adherence to medication while others provided information.

According to the PLWHA's identity card, it was observed that 70 percent were keeping appointment dates as documented in their identity cards. Only 30 percent were not keeping appointment dates. Keeping appointment dates is important because it shows that the PLWHA are adhering to the pharmacy schedules for refilling and also other appointment times for routine investigations as required.

According to the study results, the factors that may be said influence utilization of Home Based Care services are age where most respondents accessing HBC services were 45 years and above, gender where there were more women interviewed and education level where respondents with no education did not receive HBC services.

Therefore, there is an association between utilization of HBC services and education level, referral of clients, educational level, age sex and knowledge and thus rejection of the null hypothesis.

## **5.6 CONCLUSION**

It is clear that there are a number of factors that affect utilization of home based care by PLWHA. All of these factors are so inter related and complementary to each other such that a weakness in one of them makes the others ineffective. As the situation stands, we cannot, therefore point out a single factor that is culpable to high or low utilization of HBC.

From the findings, it is evident that utilization of HBC is low, it is also quite clear that some socio-cultural and mainly service related factors such as availability, accessibility, lack of funding for HBC organizations, general poor quality of service delivery are the

some of the concerns even though they have been identified as very important in the effective utilization of these services.

Though increasing the educational attainment level of people seems to show a positive relationship with utilization of HBC services, further education beyond the basic level seemed to alienate people from these services.

Occupation also seemed to be an active determinant of utilization of HBC services as those in formal employment access less of HBC services than those in informal sector.

## **5.7 IMPLICATIONS TO NURSING**

The following were the main implications derived from the findings of this study:

### **5.7.1 NURSING PRACTICE**

The findings of this study demonstrate that very few respondents utilize home based care. Only 39 percent of the sampled population actually utilizes this service while 61 percent does not. There are a number of reasons that contribute to poor utilization of home based care services. Among them is poor quality of services in that the service is offered by people of little or no training at all, lack of funds and lack of supplies. Knowledge about home based care seems to be considerably high among this population but still in depth knowledge about HBC seems to be lacking.

The professional nurses should provide PLWHA with information concerning home based care regularly so that they understand this subject in depth and learn more of its benefits so that they can utilize the services. Provision of protective clothing to caregivers and training younger caregivers will improve HBC service delivery.

### **5.7.2 NURSING ADMINISTRATION**

From this study it is evident that PLWHA are not utilizing HBCs adequately; there is need for the nursing administrators to provide the necessary guidance and supervision to caregivers in the District in order to improve the quality of services and encourage PLWHA utilize the HBC service. In addition, evidence from this study indicates that there is an undesirably low skill in most of these providers.

For the HBCs to work effectively there is need to ensure proper coordination of the HBC service programmes in the district with the CBOs, FBOs and also community caregivers. Provision of resources such as to the HBC is also necessary to encourage PLWHA to utilize the HBC services. Therefore, nursing administrators should ensure that the home based caregivers receive adequate supplies and support to offer the services required.

### **5.7.3 NURSING RESEARCH**

Evidence has overwhelmingly shown that home based care is a very vital component of delivery of good health to the people. But in Zambia this service seems not to be well taken care of under our health delivery system.

Nursing research therefore, needs to focus efforts to understand what other factors may determine effective utilization of these facilities. Effective home based care system will offer a lot of benefits to the health care system and these will include de-congestion of health facilities.

## **5.8 LIMITATIONS OF THE STUDY**

There are several limitations to this study and these are listed below:

- The use of HIV lay counselors as research assistants may have influenced data collection through their own understanding and might influence responses through their physical presence or interview bias.



- There might also have been information bias from incorrect information by respondents because of face to face interview (Polit & Beck, 2008).
- Due to the nature of qualitative research, the data obtained in the second phase of the study was subjected to different interpretations by different readers.
- Limited financial resources to be able to fully support the study.
- The results of discriminant analysis had limited generalizability. Usually they generalized only to those populations from which the sample was obtained (Tabachnick & Fidell, 2000).
- The convenience sampling used in the quantitative phase of the study, that made the sample was representative of the population (Creswell, 2002).
- In the quantitative phase of the study there was potential risk of a non-response error that is problems caused by differences between those who responded and those who did not in the event of a low response rate (Dillman, 2000).

Despite all these limitations, this study provides variable information on determinants of utilization of HBC services by PLWHA.

## **5.9 RECOMMENDATIONS**

In order to overcome all the impediments to effective utilization of HBC services the following items need to be fully implemented;

1. Home based care should stand out clearly within the new national HIV and AIDS policy (2010-2015) and other relevant policies stressing the care for the terminally ill, caring for caregivers and possible funding by Government through the Ministry of Health. Issues of transport, supplies, motivation training, quality monitoring and control should either be partially or totally assumed by Government as the contribution of home based care to a functional national health system is enormous.
2. It is necessary to develop robust strategies to enhance health education and promote use of HBC's especially among the highly educated, those who are in formal employment, traditional leaders and general community.

3. Vigorous stigma reduction campaigns are a priority if the educated, employed, youth and unmarried PLWHA are to utilize HBC services.
4. Capacity and system strengthening of HBC organizations such as community based and Non-Governmental Organizations should be prioritized by Donors and funding organizations operating in Chadiza District.
5. There is need to carry out another study of this sort but at a larger scale covering a number of Provinces of Zambia. This will produce results that are more authentic and can easily be generalized.

The nursing administration need to devise policies that clearly outline the framework in which home based care organizations operate. This policy needs to ensure that there are deliberate measures to continuously capacity build the home based care providers.

Policies for health facilities to work with HBC organizations and care providers should also be put very clear. It has come out very clear in this study that health facilities seem to have a disconnection with HBC organization and care providers. This has led to a very ineffective HBC service without basic supplies. It is, therefore, critical that there is a strong connection between health facilities and HBC providers because they depend on these for their daily medical supplies and guidance.

## REFERENCES

Adenuga, O.O. (2004), **“Strategy for Care and Support to PLWHA”**, International Conference on AIDS, Lagos: Nigeria.

**“A Review of Home-Based Care Models and Services for People Living With HIV/AIDS Within and Outside Africa”**, (2004), African Palliative Care Association (APCA): Kampala. Uganda.

[http://www.palliativecaremalawi.org/data/HBC%20review%20report%20\\_2\\_.pdf](http://www.palliativecaremalawi.org/data/HBC%20review%20report%20_2_.pdf).

Accessed on 04/07/2010

Aslanyan, A. (2004), **Integrating Psychosocial and Medical Support: Addressing the needs of PLWHA**, Eurasia: Armenia.

Ayaba, A. & Kerner B. (2008), **Home-Based Care Community Needs Assessment for PLWHA**. Care International, Butare: Rwanda.

**Baseline Study on Accessibility and Utilization of RNTCP services by PLWHA.**

[http://www.tbccindia.org/pdfs/BaselineStudy-on-Accessibility and utilization of RNTCP services by PLWHA-ORG-CSR.pdf](http://www.tbccindia.org/pdfs/BaselineStudy-on-Accessibility%20and%20utilization%20of%20RNTCP%20services%20by%20PLWHA-ORG-CSR.pdf). (Accessed 20/09/2010)

Bowie, C. Alinafe, L., Marsh, Misiri, H. & Clearly, P. (2005), **Bangwe Home-Based Care Project in Malawi**, Bangwe: Malawi.

Central Statistics Office, (2007), **Zambia Demographic Health Survey**, Government Printers: Lusaka.

Chadiza DHMT (2009), **Chadiza District Annual Report**, DHMT: Chadiza.

Chambers Student Learners' Dictionary, (2009), Chambers Harrap Publishers Ltd: Italy.

Chandi, E. (1997), **Study to determine the knowledge, attitude and practice of the Community towards Home Based Care**. University of Zambia: Lusaka.

Chela, C.M. & Shankanga, Z.C. (1991), **Chikankata AIDS Care and Prevention Department**, Mazabuka: Zambia.

United Nations, (2006), **Community- Based Health Volunteers Key in Fighting HIV/AIDS**, Integrated Regional Information Networks, Kinshasa: Congo.

Continuum of care – linkages, (2005), **General HBC reporting to government clinics**, Continuum of Care, Linkages: Lusaka. Zambia.

Creswell, J. W., & Miller, D. (2002), **Determining validity in qualitative inquiry**, *Theory into Practice*, 39 (3), 124-130

Creswell, J. W., Plano Clark, V. L., Guttman, M., Hanson, W. (2003). **Advanced mixed methods research designs**. In: A. Tashakkori & C. Teddlie (Eds.), *Handbook on mixed methods in the behavioral and social sciences*, pp. 209-240.

Ebun, W.M., Esther, A., Devis, T., Juliet, P.O. & Paul, K. (2006), **An Assessment of Home-Based Care Programs in Uganda**, Kampala: Uganda.

Fox, S., Fawcett, C., Kelly, K. & Ntlabati, P. (2002), **The Centre for AIDS Development, Research and Evaluation**, Johannesburg: South Africa.

Hansen, K., Woelk, G., Jackson, H., Kerkhoven, R., Manjonjori, N., & Maramba, P. (1998), **The Cost of Home-Based Care for HIV/AIDS Patients in Zimbabwe**, Country HIV/AIDS Programme for Sub Sahara Africa, AIDS campaign Team for Africa: Harare. Zimbabwe.

Hermann, K., Damme, etal, (2007), **Community Health Workers for ART in Sub-Saharan Africa**, Kampala: Uganda.

Hunt, J. McSmith, D. Negash, S. & Tekle, Y. Sr. (2008), **Evaluation on Strategies for Care and support for People Living With HIV/AIDS**, Global Health Technical Assistant Project: Ethiopia. Kenya.

Bicycling of Empowerment Network Namibia (**BEN**), **International Community O Women Living With HIV/AIDS (ICW-Namibia) & AIDS Law Unit From the Legal Assistance Centre (ALU/LAC) (2007), Impact of Transport on Access to Health Care Services for PLWHA in Namibia**, BEN Namibia: Namibia.

International Organization for Migration (2006), **Overview of the IOM Global HIV/AIDS Programme**, Geneva: Switzerland.

JHPIEGO. (n.d), **Home-Based Care for People Living with HIV/AIDS: Course Notebook for Trainers**, JHPIEGO: Lusaka. Zambia.

Johnson, A. B. and Khanna, K., S. (2004), **Community Health Workers and Home-Based Care Programs for HIV Clients**, Nyanza: Kenya.

Kenyan National AIDS/STD Control Programme (NAS COP) (2007), Nairobi. Kenya

Kwapa, P., Chela, C. & Meika, R. (1993), **Implementing home based care in Zambia national AIDS programme**, International AIDS Society: Berlin.

Marge, B. (1993), **Women and HIV / AIDS: an International Resource Book**, Hamper Collins publishers: London.

Ministry of Finance and National Planning, (2002), **Zambia Poverty Reduction Strategy Paper 2002-2004**, Government Printers: Lusaka. Zambia.

Ministry of Finance and National Planning (2004), **Second PRSP Implementation Progress Report 2003- 2004**, Government Printers: Lusaka.

Ministry of Health/CBOH (1999), **HIV/AIDS in Zambia: Background, Projections, Impact and Interventions**, Government Printers: Lusaka. Zambia.

Ministry of Health, (2001), **National strategic framework for expansion of HIV/AIDS care and Support 2001/2-2006/7**, Ministry of Health of Uganda, Kampala: Uganda.

Ministry of Health (2002), **National HIV/AIDS/STI/TB/ Policy**, Ministry of Health: Lusaka.

Ministry of Health (2005), **National HIV/AIDS Sero□Survey 2005**, Ministry of Health of Uganda, Kampala: Uganda.

Zambia Nurses Association, (2005), **HIV/AIDS Workplace Guidelines on Prevention, Care and Support for Nurses and Midwives**, Zambia Nurses Association: Lusaka, Zambia.

Ministry of Health, (2005), **HIV/AIDS/STI/TB Policy**, Ministry of Health: Lusaka, Zambia.

Ministry of Health / UNDP, (2005), **Human Development Report, Ministry of Health**: Lusaka, Zambia.

Ministry of Health, (2006), **a training Package for Community Home-Based Caregivers**, 1<sup>st</sup> Ed., Lusaka, Zambia.

Ministry of Health/USAID, (2006), **Health Care within the community, Health Promotion Information for NHCs and CBOs**, 6<sup>th</sup> Edition, Ministry of Health: Lusaka, Zambia.

Ministry of Health, (2008), **National Guidelines on Management and Care for People Living with HIV and AIDS**, Ministry of Health: Lusaka, Zambia.

Mohammad. N. And Gikonyo, J. (2005), **Operational Challenges, Community and Home-Based Care for People Living With HIV/AIDS for Sub-Saharan Africa**, AIDS Campaign Team for Africa: Nairobi. Kenya.

National AIDS Council, (2003), **National HIV/AIDS/STI/TB Intervention Strategic Plan 2002-2005**, National AIDS Council: Lusaka.

National AIDS Council, (2004), **the HIV/AIDS Epidemic in Zambia**, National AIDS Council: Lusaka, Zambia.

National AIDS Council, (2007), **Zambia National Minimum Standards for Community and Home-Based Care Organizations**, NAC Technical Working Group on VCT/HBC, National AIDS Council: Lusaka, Zambia.

National AIDS Council, (2008), **Joint Mid-term Review of the National AIDS Strategic Framework**, National AIDS Council: Lusaka, Zambia.

National AIDS Council, (2009), **National Referral Guidelines for HIV and AIDS Related Services**, National AIDS Council: Lusaka, Zambia.

National HIV/AIDS/STI/TB Council, (2009), **National Strategy for the Prevention of HIV and STIs**, National HIV/AIDS/STI/TB Council: Lusaka, Zambia.

National AIDS Council, (2009), **Joint Mid-term Review of the National AIDS Strategic Framework 2006-2010**, National AIDS Council: Lusaka, Zambia.

Ncama, P. B. (2008), **Models of Community/Home-Based Care for People Living With HIV/AIDS in Southern African**, Johannesburg: South Africa.

Nkhata, L. (2003). **Methodological Options in Policy-Oriented Social Research**, 2<sup>nd</sup> Edition, Zambia Publishing Company: Lusaka, Zambia.

**Non-Government Organizations providing Support groups for PLWHA in Gauteng Province.** <http://web.wik.ac.za/NR/rdonlures/5FE79C9C-034f-45DA-AFA3-700B0553CCFE/01/B60a.pdf>. (Accessed 24/09/2010).

Nweneka, V.C. **Access to Care and Treatment for People Living With HIV/AIDS**, Nairobi: Kenya.

Odero, K.K., (2004), **a scoping study on community response to HIV/AIDS transit corridors and other areas of intense transport operations**, Harare: Zimbabwe.

Opiyo, P.A., Yamano, T. & Jayne, T.S. (2008), **HIV/AIDS and Home-Based Care**, Nairobi: Kenya.

Pathfinder International Tanzania (2006), **Mapping Community Home-based Care Services in the Five Regions of Tanzania Mainland**, Dar es Salam: Tanzania.

Policy and practice; voices from the global south (2006), <http://www.developmenteducationreview.com/issue4-viewpoint.html> (Accessed 05/09/2010).

Polit, F. D. & Hungler, P.B. (1999), **Nursing Research, Principles and Methods**, 6<sup>th</sup> Edition, Lippincott Williams & Wilkins: Philadelphia.

Polit, F.D. & Beck T.C (2008), **Nursing Research: Generating and Assessing Evidence for Nursing Practice**, 8<sup>th</sup> Edition, Lippincott Williams & Wilkins: New Delhi.

Silomba W. (2002), **HIV/AIDS and Development: The Chikankata Experience, Manager-AIDS Management & Training Services**, Chikankata, Zambia.

**Review of Home-Based Care Models and Services for People Living With HIV/AIDS Within and Outside Africa**, (2004), The African Palliative Care Association.

[http://www.palliativecaremalawi.org/data/HBC%20review%20report%20\\_2\\_pdf](http://www.palliativecaremalawi.org/data/HBC%20review%20report%20_2_pdf)

(Accessed 04/07/2010).

SHARE Series (2004), **Children and Home-Based Care integrating support for children affected by HIV and AIDS into home-based care programmes**. Southern African AIDS Trust: Harare, Zimbabwe.

**Sub - Saharan Africa – HIV/AIDS Statistics**, 2008, UNAIDS.

<http://www.avert.org/africa-hiv-AIDS-statistics.htm> (Accessed 17/07/2010).

Tashakkori, A., & Teddlie, C. (1998), **Mixed methodology: Combining qualitative and quantitative approaches**. *Applied Social Research Methods Series*, 46.

Thousand Oaks, CA: Sage Publications. The ACTION Project, (2009), **Impact of Community and Home-Based Care on HIV/AIDS Patients and their Families**, Institute of Human Virology: Lagos. Nigeria.

Tibeba, B.G., Mirriam, A. & Belachew, T. (2007), **Knowledge and Attitude of PLWHA on Home-Based Care**, Jimma: Ethiopia.



UNAIDS (2002), **Report on the Global HIV / AIDS Epidemic**, Geneva: Switzerland.

UNAIDS (2003), **Where there is a will there's a way, Nursing and midwifery champions in HIV/AIDS care in Southern Africa**, Geneva: Switzerland.

UNAIDS (2003), **Reaching out, scaling up: Eight case studies of Home and Community care for and by PLWHA- Best Practice Collection** UNAIDS (2004). **Report on the Global AIDS Epidemic- 4<sup>th</sup> global report**, Geneva: Switzerland.

UNAIDS (2004), **Human Resource for Health Training and Regular Mentoring**. <http://www.human-resources-health.com/content/7/1/31>. (Accessed 16/04/2010).

UNAIDS (2006), **HIV and sexually transmitted infection prevention among sex workers in Eastern Europe and Central Asia**, Geneva: Switzerland.

UNAIDS (2006), **HIV Prevention Needs and Successes: a tale of three countries**, Geneva: Switzerland.

UNAIDS/WHO, (2008), **2008 Report on the Global AIDS Epidemic**, UNAIDS/WHO: Geneva: Switzerland.

USAID/Policy Project (2003), **Khomanani: Reaching out, Scaling up: Report of the First South African National Home/Community Based Care Conference**, Johannesburg: South Africa.

United Nations (2007), **HIV/AIDS Careers to be Taught ART Management**, Integrated Regional Information Network, Mozambique

Vuthy, S. (2007), **Influences of Stigmatization and Discrimination on Care for People Living With HIV/AIDS**.

WHO (2002), **Community Home-based Care in Resource-limited Settings: a framework for Action**, Geneva: Switzerland.

WHO (2000), **Home-Based Long-Term Care**, WHO Geneva: Switzerland.

WHO (2002), Community Health Based Care in resource limited settings; A framework for action, Geneva. Switzerland.

World Health Organization (2006), **Health**, WHO Geneva: Switzerland.

WHO (2010), **Community Involvement in Care and Support**.  
[http://www.afro.who.int/index.php?option=com\\_content.&view=article&id=2234:-  
brief-profile-of-community](http://www.afro.who.int/index.php?option=com_content.&view=article&id=2234:-brief-profile-of-community) (Accessed 22/08/2010)

Wringe, A., Cataldo, F., Stevenson, N. & Fakoya, A, (2009), **Shifts in Home-Based Care for PLWHA in the Era of ART**: Oxford University Press in Association with the London School of Hygiene Tropical Medicine: London.

ZAMBART Project Alliance (2010), **Evidence for Action**, ZAMBART: Lusaka. Zambia.

## APPENDIX 1: GHANT CHART

S#	ACTIVITY	RESPONSIBLE PERSON	APR 2010	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	JAN 2011	FEB	MAR	APR	MAY	JUN	JUL	
1	Development of research proposal	Researcher	█																
2	Presentation of research proposal to the lecturers	Researcher							█										
3	Presentation to the Post Graduate studies	Researcher							█										
4	Submission to REC for approval	Researcher								█									
5	Obtaining consent from REC	Researcher									█								
6	Briefing DHMT, DDCC	Researcher										█							
7	Pilot study/revision of tool	Researcher										█							
8	Data collection	Researcher											█	█					
9	Data analysis	Researcher												█	█				
10	Report writing	Researcher													█	█	█		
11	Submission of draft report	Researcher																█	
12	Submission of final report	Researcher																█	
13	Dissemination of results	Researcher																█	

## APPENDIX 2: BUDGET

BUDGET CATEGORY	UNIT COST (ZMK)	QUANTITY	TOTAL
<b>STATIONERY</b>			
(a) Bond paper	30,000.00	X10	300,000.00
(b) Flash disc	150,000.00	X1	150,000.00
(c) Pens	1,000.00	X10	10,000.00
(d) Pencils	500.00	X10	5,000.00
(e) Rubbers	1,000.00	X5	5,000.00
(f) Note books	8,000.00	X3	24,000.00
(g) Tippex	10,000.00	X1	10,000.00
(h) Stapler	50,000.00	X1	50,000.00
(i) Staples	10,000.00	X1	10,000.00
(j) Lap top	5,000,000.00	X1	5,000,000.00
(k) Bag for the interview schedules	150,000.00	X1	150,000.00
(l) Tape recorder	2,500,000.00	X1	2,500,000.00
(m) Batteries	5,000.00	X8	40,000.00
<b>SUBTOTAL</b>			<b>8,254,000.00</b>
<b>PERSONNEL</b>			
Lunch allowance			
(a) Principal researcher	50,000.00	1 X 30	1,500,000.00
(b) Research assistant	30,000.00	3 X 30	2,700,000.00
<b>Subtotal</b>			<b>4,200,000.00</b>
<b>MISCELLANEOUS SERVICES</b>			
(a) Photocopying research proposal	300.00	100 X 5	150,000.00
(b) Ethics committee	250,000.00	250,000.00	250,000.00
(c) Photocopying questionnaire	300.00	10 X 350	1,050,000.00
(d) Photocopying application forms (ethics)	300.00	X 20	60,000.00
(e) Data entry	500,000.00	X 1	500,000.00
(f) Data analysis	1,000,000.00	X 1	1,000,000.00
(g) Binding	70,000.00	X 5	350,000.00
(h) Photocopying reports	300.00	X 400	120,000.00
<b>SUBTOTAL</b>			<b>3,480,000.00</b>
<b>TOTAL</b>			<b>15,934,000.00</b>
<b>CONTINGENCY FUND 10%</b>			<b>1,593,400.00</b>
<b>GRAND TOTAL</b>			<b>17,527,400.00</b>

## **JUSTIFICATION FOR THE BUDGET**

### **STATIONERY**

The 10 reams of bond paper will be used for the research proposal development and the final report. The paper was required to make extra copies of the proposal for submission to the Research Ethics Committee and the board of graduate studies. In addition, the interview schedule consisted of nine pages which were photocopied. The bag for interview schedules was for the researcher to ensure that the interview schedules were kept safe. The flash disc was for copying data for safe keeping of research data.

The lap-top was to facilitate typing and storage of information for the investigator.

The tape recorder helped the researcher to record discussions during focus group discussions. The other accessories such as the pens, pencils, rubbers, stapler, staples and note books were required for data collection.

### **PERSONNEL**

Data collection was done throughout the day as such the researcher needed lunch allowance and also some upkeep for the research assistants. The research was for 30 days which allowed adequate time for administration of interview schedules and observations.

### **SECRETARIAL SERVICES**

Funds for photocopying services and binding of the research proposal and report were required. One copy was printed and thereafter photocopies were made to cut down on the cost of printing. The researcher needed five copies of the proposal to submit to Post Graduate Research Committee for dissertation and dissemination.

### **CONTIGENCY**

Contingency fund which was 10% of the total budget was required for any extra costs due to inflation and for any eventualities.

### **APPENDIX 3: INFORMATION SHEET**

**Title of Study: DETERMINANTS OF UTILIZATION OF HOME-BASED CARE SERVICES BY PEOPLE LIVING WITH HIV/AIDS IN CHADIZA DISTRICT.**

My name is Ruth Tubangile Mbukwa; a student of Masters of Science in Nursing at the University of Zambia who is kindly requesting for your participation in the research study mentioned above. Before you decide whether to participate in this study, I would like to explain to you what Home-Based Care is all about, any risks or benefits and what is expected of you.

Home based care is the care for the chronically sick people in their own homes by family members, friends and community volunteers trained as caregivers. Some of the main aims of home-based care are to improve the quality of life of People Living with HIV/AIDS and to lessen the burden on the family by encouraging and supporting the independence of the PLWHA. The general objective is to investigate determinants of utilization of Home-Based Care services by People Living with HIV and AIDS in Chadiza district.

The specific objectives are; to identify the common types of HBC services preferred in the community, determine knowledge levels of PLWHA about the HBC services determine demographic characteristics and establish whether socio-cultural factors may influence utilization of the HBC services in Chadiza district.

Participation in this study is voluntary and therefore, you should be free not to answer questions that deem personal and that your withdrawal at any time will not interfere with benefits you enjoy in or out of the study. Your health services at this centre will not be affected either.

If you are willing to participate, you will be asked to sign consent as an agreement to participate but this will not result in any immediate benefits. Please ask where you do not understand.

## **PURPOSE OF THE STUDY**

The study will assess knowledge and utilization of home-based care services by People Living With HIV/AIDS. The information obtained will help the policy makers and implementers of the programme in the MOH and other stakeholders re-direct programme implementation in order to improve the knowledge and utilization of home-based care services in the district.

## **PROCEDURE**

The study involves a face-to-face interview with the help of research assistant who will ask you a set of questions using a structured questionnaire. Consent will be obtained before you participate in the face- to-face interview and Focus Group Discussions. You will be requested to sign a consent form. The responses you will provide will be recorded on the questionnaire. A tape recorder will be used to record the discussions during Focus Group Discussions. However before the discussions is recorded permission will be sought from you.

## **RISKS AND DISCOMFORTS**

There is no risk involved in this research though part of your time will be utilized to answer some questions. Some questions may seem to be sensitive and personal. If you will need further discussion, it will be offered to help you understand the topic more.

## **BENEFITS**

There is no direct benefit to you by participating in this study, but the information which will be obtained will help the policy makers and implementers to take measures that will ensure that People Living with HIV/AIDS know about the home-based care services and utilize the services. No money will be given in exchange for information obtained but education will be given on the benefits of utilizing the home-based care services.

## **CONFIDENTIALITY**

Your research records and any information you will give will be confidential to the extent permitted by law. You will be identified by a number, and personal information will not be released without your written permission except when required by law. The Ministry of Health, the University of Zambia Research Ethics Committee or the School of Medicine may review your records again but this will be done with confidentiality.



## APPENDIX 4: INFORMED CONSENT FORM

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

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

I \_\_\_\_\_

(Names)

agree to take part in this study.

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

(Participant)

Participant's signature or **thumb print**

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

(Witness)

Signed: \_\_\_\_\_

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

## **PERSONS TO CONTACT FOR PROBLEMS OR QUESTIONS**

1. Ruth T Mbukwa, University of Zambia, Post Basic Nursing Department, P.O. Box 50110, Lusaka. Cell: 0977714074.  
Email: [rmwafulirwa@yahoo.com](mailto:rmwafulirwa@yahoo.com)
2. The Head of Department, University of Zambia, Department of Nursing Sciences, P.O. Box 50110, Lusaka. Telephone Number 252453.
3. The chairperson, Research Ethics Committee, University of Zambia. P.O. Box 50110, Lusaka. Telephone Number 256067.

## **APPENDIX 5: STRUCTURED INTERVIEW SCHEDULE**

**THE UNIVERSITY OF ZAMBIA**

**SCHOOL OF MEDICINE**

**DEPARTMENT OF POST BASIC NURSING SCIENCES**

### **STRUCTURED INTERVIEW SCHEDULE ON DETERMINANTS OF UTILIZATION OF HOME-BASED CARE SERVICES BY PEOPLE LIVING WITH HIV AND AIDS**

**DATE OF INTERVIEW** : \_\_\_\_\_

**PLACE OF INTERVIEW** : \_\_\_\_\_

**NAME OF INTERVIEWER:** \_\_\_\_\_

**SERIAL NUMBER** : \_\_\_\_\_

#### **INSTRUCTIONS FOR THE INTERVIEWER**

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

**SECTION A: DEMOGRAPHIC DATA**

1. Age at last birthday (age)

Tick the area of response

official use

- 1. 15– 24 years
- 2. 25- 34 years
- 3. 35-44 years
- 4. 45 and above


2. Sex (sex)

- 1. Female
- 2. Male


3. What is your marital status? (Marital)

- 1. Single
- 2. Married
- 3. Divorce
- 4. Separated
- 5. Widowed


4. What is your religious denomination? (church)

- 1. Reformed church
- 2. Seventh Day
- 3. Roman Catholic
- 4. United Church of Zambia
- 5. Others specify \_\_\_\_\_


5. What is your educational Level? (Edu lev)

- 1. None
- 2. Primary
- 3. Secondary
- 4. College
- 5. University


6. What is your occupation? (Occupatn)

- |                        |                          |                          |
|------------------------|--------------------------|--------------------------|
| 1. Housewife           | <input type="checkbox"/> |                          |
| 2. Formal employment   | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Self employed       | <input type="checkbox"/> |                          |
| 4. Unemployed          | <input type="checkbox"/> |                          |
| 5. Other, specify..... |                          |                          |

7. What is your income? (Income)

- |   |                          |                          |
|---|--------------------------|--------------------------|
| 1. Below K500, 000 per month                | <input type="checkbox"/> |                          |
| 2. Between K500, 000- K1, 000,000 per month | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Above K1, 000,000 per month              | <input type="checkbox"/> |                          |
| 4. None                                     | <input type="checkbox"/> |                          |

**SECTION B: KNOWLEDGE ON HOME-BASED CARE SERVICES**

8. Have you heard about Home-Based Care? (HBCS)

1. Yes



2. No

9. If yes to question 14, what is the meaning of home-based care?

1. Home-based care is the caring of the sick person at home.

2. Don't know



3. Others, specify.....

10. What was the source of your information?

(Tick all if appropriate)

1. Media

2. Health personnel

3. family

4. Trained caregivers

5. Others specify\_\_\_\_\_

11. What services are offered by home-based caregivers?

.....

.....

.....

12. In your own opinion, are home-based care services

beneficial for PLWHA?

1. Yes

2. No



3. Don't know

4. No response

13. Give reasons for your answer to question 12 (Explain).

.....  
.....

14. Do you know of PLWHA in your community

receiving home-based care services?

1. Yes

2. No

15. Who are involved in providing home-based care services?

1. Family members

2. Neighbors

3. Community volunteers

4. Trained caregivers

5. Others, specify.....

16. Who do you think should receive home-based care services?

1. HIV-positive but health looking

2. HIV-positive and able to do some work with minimum help

3. AIDS patient-unable to do activities- bed ridden.

4. Don't know

**SECTION C: UTILIZATION OF HOME-BASED CARE SERVICES**

17. How long have you known to be HIV positive?

- 1. < 1 year
- 2. 1 – 2 years
- 3. > 2 years

18. Have you disclosed your status to someone?

- 1. Yes
- 2. No

19. If your answer to question 9 is no, give reasons for your response (Explain).

.....

.....

20. Are you taking antiretroviral treatment?

- 1. Yes
- 2. No

21. Who is your treatment supporter?

- 1. Family member
- 2. Trained caregiver
- 3. Neighbor
- 4. Community volunteer
- 5. None

22. Who referred you to the health facility for testing and ART

- 1. Self
- 2. Community volunteer
- 3. Caregiver from HBC organization
- 4. Family member
- 5. Other, specify.....



23. Are you receiving home-based care services?

- 1. Yes
- 2. No


--

24. If the answer to question 23 is yes, mention who are providing the mentioned services?

.....

.....

25. If the answer to question 23 is yes, what services do they provide?

.....

.....

26. How would you rate the care in question 25?

- 1. Good
- 2. Fair


--

27. Give reasons for your answer in question 26.

.....

.....

28. How far is the nearest caregiver to your home?

- 1. Less than 500 m
- 2. 500 – 1 km
- 3. 1km – 2 kms
- 4. More than 2 kms


--

29. Are you enrolled with any HBC service programme?

1. Yes

2. No

30. If the answer to question 28 is yes, which organization are you enrolled with?

1. Faith Based Organization

2. Community Based Organization

3. PLWHA support group

4. Community volunteer caregiver

31. How often are you visited by caregivers?

1. 1-2 times per month

2. Less than once a month

3. Not visited

32. Who are more involved in providing home-based care in your community?

1. Females

2. Males

33. Give reasons for your answer to question 34.

.....

.....

34. Have you ever been involved in providing

Home-based care programme?

1. Yes

2. No

35. Did the patient come on the documented appointment date?

(Interviewer to check the client's identity card for the date).

1. Yes

2. No

## **APPENDIX 6: FOCUS GROUP DISCUSSION GUIDE**

### **FOCUS GROUP DISCUSSION GUIDE FOR PLWHA ON DETERMINANTS OF UTILIZATION OF HOME-BASED CARE SERVICES BY PLWHA**

Number of participants .....

Composition of participants .....

Language used during discussion .....

Date.....

Duration .....

Place .....

#### **INSTRUCTIONS**

1. Welcome the participants
2. Introduce yourself, show the recorder and explain the use to the participants
3. Allocate numbers to participants.
4. Explain the purpose of the discussion
5. Assure the participants of confidentiality and anonymity and encourage them to participate freely.
6. Respect each participant's views.
7. Thank the participants at the end of the discussion.

## **QUESTIONS**

### **Knowledge on home-based care services**

1. What do you know about home-based care services?
2. What are the roles of HBCs?
3. Can anyone who is HIV- positive receive home-based care services?
4. Do you know of any organization involved in providing home-based care services?

### **Utilization of Home-Based Care services**

1. What home-based care services are you receiving?
2. Who is providing the services?
3. How often are you visited by caregivers?
4. What support do you receive from home-based care programmes?
5. Are you involved in providing the home-based care services to other PLWHA?
6. Should men participate in providing home based care services?
7. How is a person who is visited by caregivers perceived by the community?
8. What are some of the challenges PLWHA face when utilizing home-based care services?

### **Suggestions for increasing utilization of HBC services**

1. What do you think may be done to create awareness of home-based care services among the PLWHA?

**We have come to the end of our discussion. Thank you very much for your contributions and for participation as well as your time.**

## **APPENDIX 7: FOCUS GROUP DISCUSSION**

### **FOCUS GROUP DISCUSSION GUIDE FOR VOLUNTEER CAREGIVERS ON DETERMINANTS OF UTILIZATION OF HOME-BASED CARE SERVICES BY PLWHA**

Number of participants.....

Composition of participants.....

HBC Organization.....

Language used during discussion.....

Date.....

Duration.....

Place.....

### **INSTRUCTIONS**

8. Welcome the participants
9. Introduce yourself, show the recorder and explain the use to the participants
10. Allocate numbers to participants.
11. Explain the purpose of the discussion
12. Assure the participants of confidentiality and anonymity and encourage them to participate freely.
13. Respect each participant's views.
14. Thank the participants at the end of the discussion.

### **Knowledge of home-based care services for PLWHA**

1. What is home-based care?
2. How long has your organization been in existence?
3. Who is involved in supervising your activities?
4. Do you write reports on the services you are providing and where do you submit your reports?
5. Do you have income generating activities to sustain your service provision?
6. Does your organization receive any form of support from any organization to sustain your service provision?

### **Utilization of home-based care services by PLWHA**

1. How many clients is your organization having on the register?
2. What roles are you doing in terms of service provision?
3. What type of support do you provide to PLWHA?
4. How often do you visit your clients?
5. What challenges does your program face?
6. What suggestions do you have to make this program known by PLWHA and that they should utilize these services?
7. If you have a question to ask, you can ask now.

**We have come to the end of our discussion. Thank you very much for your contributions and for participation as well as your time.**

## APPENTIX 8: LETTER FROM BIOMEDICAL RESEARCH ETHICS



**THE UNIVERSITY OF ZAMBIA**  
**BIOMEDICAL RESEARCH ETHICS COMMITTEE**

Telephone: 260-1-256067  
Telegrams: UNZA, LUSAKA  
Telex: UNZALU ZA 44370  
Fax: + 260-1-250753  
E-mail: unzarec@unza.zm  
Assurance No. FWA00000338  
IRB00001131 of IORG0000774

Ridgeway Campus  
P.O. Box 50110  
Lusaka, Zambia

11 March 2011.

Our Ref: 016-12-10

Ms Ruth Tubangile Mbukwa,  
Chadiza DHMT,  
P.O Box 520031,  
Chadiza.

Dear Ms Mbukwa,

**RE: RE-SUBMITTED RESEARCH PROPOSAL: "DETERMINANTS OF UTILIZATION OF HOME-BASED CARE SERVICES BY PLWHA IN CHADIZA DISTRICT"**

The above-mentioned research proposal was re-submitted to the Biomedical Research Ethics Committee on 03 March, 2011 with recommended changes. The proposal is approved.

**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.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- **Ensure that a final copy of the results is submitted to this Committee.**

Yours sincerely,

Dr E. M. Nkandu  
CHAIRPERSON

Date of approval: 11March, 2011

Date of expiry: 10 March 2012



# APPENDIX 9: LETTER FROM THE MINISTRY OF HEALTH

All Correspondence should be addressed to the  
Permanent Secretary  
Telephone: +260 211 253040/5  
Fax : +260 211 253344



## REPUBLIC OF ZAMBIA MINISTRY OF HEALTH



NDEKE HOUSE  
P.O. BOX 30205  
LUSAKA

8<sup>th</sup> June 2011

Ms Ruth Mbukwa  
University of Zambia  
School of Medicine  
Department of Nursing Sciences  
P.O Box 50110  
LUSAKA



Noted  
*(Signature)*

Dear Ms Mbukwa,

### Re: Request for Authority to Conduct Research

The Ministry of Health is in receipt of your request for authority to conduct a study on “**Determinants of Utilization of Home-Based Care Services by PLWHA in Chadiza District**”. I wish to inform you that following submission of your research proposals to my Ministry, our review of the same and in view of the ethical clearance, my Ministry has granted you authority to carry out the study on condition that:

1. The relevant Provincial and District Directors of Health where the study is being conducted are fully appraised;
2. No biological material transfer be made outside the country, without clearance by NHREC;
3. Progress updates are provided to MoH quarterly from the date of commencement of the study;
4. The final study report is cleared by the MoH before any publication or dissemination within or outside the country;
5. After clearance for publication or dissemination by the MoH, the final study report is shared with all the relevant Provincial and District Directors of Health where the study was being conducted, and all key respondents.

I consider your research topic to be of policy relevance in home-based care services.

Yours sincerely,

*(Signature)*  
Dr. P. Mwaba  
Permanent Secretary  
**MINISTRY OF HEALTH**

c.c Director Public Health and Research

