

**COMMUNITY HOME BASED CARE FOR HIV AND AIDS PATIENTS: A  
MALAWIAN EXPERIENCE**

**by**

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## **DEDICATION**

This work is dedicated to Ramsey, Anzathu and Tonse with all my love. Ramsey and our two lovely sons supported and encouraged me wholly during the time I pursued my studies. May God bless you and I love you all.

## DECLARATION

I certify that this thesis **Community Home Based Care for HIV and AIDS Patients: A Malawian Experience** is my own original work that has not been previously submitted for degree purposes in any other institution of higher learning. Also, that this thesis does not contain any information or references that have not been appropriately acknowledged.

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Date

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## **ABSTRACT**

The purpose of this study was to describe the experiences that HIV and AIDS patients who are on Community Home Based Care Programme have in the Lilongwe district of Malawi. Finally; concrete propositions were developed for the implementation of quality community and home based care programmes in Malawi.

A qualitative research design using an interpretive phenomenology was used. The study took place in semi-rural and urban areas of Lilongwe district using patients from 3 major organizations dealing with people living with HIV and AIDS. Purposive sampling technique was used to choose the sample and a total of 15 in-depth interviews were conducted. Data was analyzed using *ATLAS ti version 5*.

Findings revealed that the majority of the participants were concerned that they were living with HIV and AIDS. Most of them expressed anxiety, worries and fears of death. Another majority complained about the burden of opportunistic infections. Almost half of the participants felt guilty bringing misery to their families and complained of stigma and discrimination. However, a minority group of participants felt that to live with HIV and AIDS is not the end of life. Relatives were mentioned as the main care providers to HIV and AIDS patients. However, they were also cited high as a source of stigma.

Conclusions were made that women and girls are at the highest risk as they bear the burden of care. It was therefore recommended that the Government of Malawi and all Non Governmental Organizations should develop women social economic status through promotion of education, provision of loans and provision of Gender Sensitive trainings. Formal training for care of HIV and AIDS patients should be introduced to all primary caregivers to render quality care in the homes and therefore this study has developed and pre-tested an educational program for this group.

**Key Terms:** Community Home Based Care, HIV epidemic, HIV and AIDS

Patients, AIDS Crisis, Quality of life, HIV Experience, Attitude, Perception, Stigma and Discrimination, Community Care Providers, Impact, Quality care

## **DEFINITION OF KEY CONCEPTS**

In this study, the following terms are defined as follows:

### **AIDS**

AIDS stands for Acquired Immunodeficiency Syndrome. It is a diagnosis given to a collection of certain symptoms and illnesses which show that the body's immune system has been severely damaged by HIV. When a person living with HIV is unable to fight further infections he/she is said to have AIDS. In this study, it was necessary to assess the understanding of participants because they are living with it (Malawi National AIDS Commission, 2003).

### **A Child**

Any person below the age of 18 years is regarded as a child or minor according to Malawian law. In this study, it was necessary to find out who are the care givers of the HIV and AIDS patients in order to ascertain the quality of care that patients are receiving at home (Malawi Community Home Based Care policy and Guidelines, 2005).

### **Adult person**

In accordance with the Malawian law any person from 18 years of age and above is considered an adult. In Malawi, Community Home based Care Policy and Guidelines emphasizes that care of patients in their homes shall be provided by any male or female adult. Therefore, in this study, it was important to find out who is providing care to patients at home (Malawi Community Home Based Care policy and Guidelines, 2005).

### **Attitude**

It is the way one reacts to stimulus. An attitude can be a complex tendency of a person to behave in a positive or negative way or to respond in a favourable or

unfavourable manner to social objects in his or her environment. In this study, attitude can be in the form of thinking or showing an action through behaviour..Attitude of care givers and its impact has been the emphasis in this study.

## **Care**

Care refers to any form of physical, emotional, social or spiritual assistance which is provided and which aims to reduce suffering, facilitate healing, promote dignity or support persons with chronic or terminal illnesses and/ or their orphans/ vulnerable children.

## **Community Home Based Care**

Community Home-Based Care is the care provided to chronically or terminally ill patients such as those with HIV and AIDS, TB and cancer; clients affected by the illness of their relatives and friends; vulnerable and at risk groups in their homes supported by family and community members using available resources and support from the formal health worker (Malawi Community Home Based Care policy and Guidelines, 2005).

## **Community Care Provider/ Volunteer**

A Community member identified by the community and trained in Community Home Based Care to render direct patient care to chronically/terminally ill persons and other vulnerable persons in their homes (Malawi Community Home Based Care policy and Guidelines, 2005).

## **Experience**

An occurrence, incident or even an activity ensuing a lesson learned by affected person. It can be pleasant or unpleasant. In this study, these are mainly experiences to do with living with either HIV and /or AIDS.



## **HIV**

HIV stands for Human Immunodeficiency Virus. The virus breaks down the body's immune system making it deficient. As a result the body is unable to protect itself against diseases. In this study, it was important to assess participants' knowledge on HIV transmission and prevention to prevent reinfections and infecting others since participants under study are living with the virus (Malawi National AIDS Commission, 2003).

## **Impact**

Any noticeable effect of the intervention. In this study, it also refers to the influence of the Community Home Based Care programme on the lives or general well-being of the affected person in Malawi. In this study, the use of the concept "impact", concerns mainly the attitude of those who are providing care to HIV and AIDS patients. This impact could be positive or negative as long as it influences the quality of life of the patient.

## **Opportunistic infections**

These are diseases or infections that frequent the patient as a result of HIV. Persons can live with HIV for many years without feeling sick - but they are still able to pass on HIV to others during this time. Eventually viral load will increase and HIV will damage the body's defence against infection called the immune system. A person with a weakened immune system due to HIV will begin to develop illnesses specific to people living with HIV called opportunistic infections. The more opportunistic infections a person with HIV experiences, the more damaged his/her immune system becomes. When a person living with HIV is unable to fight further infections he/she is said to have AIDS (Malawi CHBC Training manual, 2005).

## **Perception**

It is the capacity to understand things or view things according to individual judgment or opinion. It was necessary in this study to find out how participants

perceive the care they are receiving and also how they perceive the attitude of the ones who provide care to them to determine if the care rendered to these patients would improve their quality of life or not (Tsasis, Tsoukas and Deutsch, 2000).

### **Primary Caregiver**

These are family members, relatives, and friends, as well as neighbours who are directly involved in the provision of care to chronically / terminally ill persons and spend most of the time with the patient (Malawi CHBC Policy and guidelines, 2005).

### **Standards/ guidelines**

A written description of the desired level of performance, containing the characteristics associated with excellence, for measuring and evaluating actual performance or service delivery (Youth Friendly Health Service National Standards, 2007).

### **Stigma**

AIDS related stigma refers to the prejudice and discrimination directed at people living with HIV and AIDS and the groups and communities that they are associated with. It can result in people living with HIV and AIDS being rejected from their community, shunned, discriminated against or even physically hurt (Avert, 2008).

### **Training/ education**

This is an enabling process and strategy of transferring skills, knowledge and resources to the patients, care givers and stakeholders involved in home care so they can become empowered to take charge of their destiny. In this research it was necessary to affirm if relatives and other family care givers who are always with the patient have received knowledge on HIV and AIDS and how to take care of such patients. This would promote reduction in transmission of HIV and AIDS and it would promote quality care to the patients at home (Malawi CHBC Training manual, 2005).

## **LIST OF ACRONYMS USED IN THE STUDY**

<b>AEC</b>	:	African Evangelical Church
<b>AIDS</b>	:	Acquired Immunodeficiency Syndrome
<b>ARVs</b>	:	Anti-retrovirals
<b>CBO</b>	:	Community Based Organization
<b>CDC</b>	:	Center for Disease Control and Prevention
<b>CHAM</b>	:	Christian Health Association of Malawi
<b>CHBC</b>	:	Community Home Based Care
<b>EHP</b>	:	Essential Health Package
<b>FBO</b>	:	Faith Based Organization
<b>GNP</b>	:	Gross National Product
<b>HAART</b>	:	Highly Active Antiretroviral Therapy
<b>HIV</b>	:	Human Immunodeficiency Virus
<b>IDI</b>	:	In – depth Interviews
<b>IEC</b>	:	Information Education and Communication
<b>MDHS</b>	:	Malawi Demographic Health Survey
<b>MLG</b>	:	Ministry of Local Government
<b>MNHP</b>	:	Malawi National Health Plan
<b>MOH</b>	:	Ministry of Health
<b>MSCE</b>	:	Malawi School Certificate of Education
<b>NAC</b>	:	National AIDS Commission
<b>NAPHAM</b>	:	National Association for People living with HIV/AIDS in Malawi
<b>NGO</b>	:	Non Governmental Organization
<b>PLWHA</b>	:	People Living With HIV and AIDS
<b>PMS</b>	:	Poverty Monitoring System
<b>POW</b>	:	Programme of Work
<b>PSLC</b>	:	Primary School Leaving Certificate
<b>SADCC</b>	:	Southern African Developing Coordinating Conference
<b>TB</b>	:	Tuberculosis
<b>UNAIDS</b>	:	United Nations Programme on HIV and AIDS
<b>UNFPA</b>	:	United Nations Population Fund
<b>UNICEF</b>	:	United Nations Children’s Fund

**UNISA** : University of South Africa  
**US** : United States  
**USAID** : United States Agency for International Development  
**WHO** : World Health Organization

## **ORGANIZATION AND STRUCTURE OF THE STUDY**

### **Chapter 1:**

This chapter outlines the Malawian health profile to give an overview of the setting in which the study was conducted. The background to this research has also been presented to introduce the reader to Community Home Based Care program in the Malawian and sub-Saharan Africa context. The problem statement, study purpose, study questions and significance of the study have been outlined. Operational definitions have been included to explain and clarify terminologies used in subsequent chapters of this research project.

### **Chapter 2: Literature Review**

This chapter presents a review of literature pertaining to the Malawian Community Home Based Care Program mostly for people living with HIV and AIDS (PLWHA). A search of the existing literature on CHBC yielded several sources. The concept of CHBC has received attention from different authors. The literature review has included related research studies which were done previously in relation to issues of CHBC both internationally and locally.

### **Chapter 3: Conceptual framework**

This chapter has outlined the framework which has been used to guide the study. Donabedian's elements of quality of care which are structure, process and outcome form the major basis of the framework.

### **Chapter 4: Research Design and Methodology**

The chapter focuses on the research methods which have been used in the study. The research design, the setting, the sample and sampling methods, data collection methods, the research tools used as well as reliability and validity issues have been described. The last part of the chapter has outlined measures which were observed in the execution of the study.

## **Chapter 5: Data Analysis and Presentation of Research Findings**

The chapter has focused on analysis of research data, presentation and its interpretation. Majority of data have been presented in a qualitative manner. However, descriptive statistics have also been used in the presentation of demographic data findings in the form of graphs and tables.

## **Chapter 6: Development of the Primary Caregivers Teaching Manual**

This chapter describes the development of the primary caregivers teaching manual / program in response to one of the findings of this study. The chapter will describe the process that has been followed in the development of the Primary Caregivers Teaching Manual and the pilot study which was done to pre-test the teaching program.

## **Chapter 7: Conclusions and Recommendations of the study**

Summary of the findings and the main conclusions have been presented. Recommendations of the findings are also part of this chapter.

## LIST OF TABLES

Table 1.1	Sub-Saharan Africa: Regional HIV and AIDS estimates by 2003.....	8
Table 1.2	International Sampling of people living with HIV and AIDS by 2007 ..	9
Table 5.1	Key .....	58
Table 5.2	Occupational status of participants.....	62
Table 5.3	Participant's level of education.....	63
Table 5.4	Participants knowledge of HIV and AIDS .....	68
Table 5.5	Experience of living with HIV and AIDS.....	71
Table 5.6	Who stigmatizes the patients .....	78
Table 5.7	Common reasons for anxiety .....	83
Table 5.8	Facts .....	94
Table 5.9	Daily activities of the patients .....	103
Table 5.10	Need profile of HIV and AIDS clients.....	105
Table 5.11	Feelings of not benefiting from the program.....	116

## LIST OF FIGURES

Figure 3.1	Framework for quality of care in CHBC Program .....	34
Figure 5.1	Age category of participants.....	59
Figure 5.2	Gender distribution .....	60
Figure 5.3	Participant's marital status .....	64
Figure 5.4	Religion of participants .....	66
Figure 5.5	Reasons for getting worried .....	74
Figure 5.6	Patient feelings of stigma .....	76
Figure 5.7	Common symptoms of anxiety .....	82
Figure 5.8	Gender of family caregivers .....	87
Figure 5.9	Main care providers.....	89
Figure 5.10	Type of carer .....	90
Figure 5.11	Willingness of participants to have their relative trained.....	98
Figure 5.12	Activities done by the patients.....	103
Figure 5.13	Patient's house which was not in good order .....	107
Figure 5.14	Patients on ARVs .....	110
Figure 5.15	Information giving to patients .....	113



## LIST OF APPENDICES

Appendix 1: Information letter to participants .....	163
Appendix 2: Consent form.....	165
Appendix 3: Map of Malawi .....	166
Appendix 4: In-depth Interview Guide .....	167
Appendix 5: Sample of a Transcript of one of the interviews .....	171
Appendix 6: Letter to Research and Publication Committee .....	178
Appendix 7: Letter to Chinsapo CHBC Area – pilot – study .....	179
Appendix 8: Letter to Light House – main study .....	180
Appendix 9: Letter to Lilongwe Diocese .....	181
Appendix 10: Letter to NAPHAM.....	182
Appendix 11: Clearance certificate from UNISA.....	183
Appendix 12: Clearance certificate from Ethics Committee, Malawi .....	184
Appendix 13: Primary Caregiver's Teaching Manual.....	185

## TABLE OF CONTENTS

Content	Page
Dedication .....	i
Declaration .....	ii
Acknowledgements .....	iii
Abstract .....	v
Definition of terms used in the study .....	vi
List of acronyms .....	x
Organization and structure of the study.....	xii

### CHAPTER 1

<b>OVERVIEW OF THE STUDY .....</b>	<b>1</b>
1.1 Background of Malawi .....	1
1.1.1 Socio-economic context .....	2
1.1.2 Basic health indicators .....	3
1.1.3 Health Care Delivery in Malawi .....	3
1.2 HIV/AIDS situation in Malawi .....	4
1.3 Background to the study .....	5
1.3.1 Community Home Based Care in Malawi.....	5
1.3.2 CHBC Volunteers .....	6
1.3.3 Community Home Based Care situation in SADC region.....	8
1.4 Problem Statement .....	9
1.5 Purpose of the study .....	11
1.6 Study Questions .....	11
1.7 Significance of the study .....	12
1.8 Conclusion.....	12

### CHAPTER 2

<b>LITERATURE REVIEW.....</b>	<b>13</b>
2.1 Introduction.....	13
2.2 HIV/AIDS and Quality of life.....	15
2.3 HIV/AIDS Patient's Perception of their care.....	16
2.4 HIV/AIDS and CHBC Experiences .....	17

2.4.1	Uganda.....	19
2.4.2	Tanzania .....	19
2.4.3	South Africa.....	20
2.4.4	Botswana .....	21
2.4.5	Zimbabwe.....	22
2.4.6	Ghana .....	23
2.4.7	Malawi .....	24
2.4.8	Needs of primary caregivers .....	25
2.4.9	Why HIV and AIDS in the Home .....	27
2.5	Conclusion.....	27

### **CHAPTER 3**

<b>CONCEPTUAL FRAMEWORK .....</b>		<b>29</b>
3.1	Introduction.....	29
3.2	Concept of quality of life .....	30
3.3	Concept of quality of care .....	30
3.4	Attributes of quality of care .....	32
3.5	Application of CHBC to the framework .....	35
3.5.1	CHBC Policy .....	35
3.5.2	Resources .....	35
3.5.3	Professional supervision .....	37
3.5.4	Minimum Package.....	38
3.5.5	Collaboration with stakeholders .....	39
3.6	Conclusion.....	39

### **CHAPTER 4**

<b>RESEARCH DESIGN AND METHODOLOGY .....</b>		<b>40</b>
4.1	Introduction.....	40
4.2	Research design.....	40
4.3	Research setting.....	43
4.4	Population and Sample.....	44
4.5	Inclusion criteria.....	45
4.6	In-depth Interviews .....	46
4.7	Interview Guide.....	46

4.8	Trustworthiness .....	47
4.8.1	Credibility .....	48
4.8.1.1	Prolonged engagement.....	48
4.8.1.2	Triangulation .....	49
4.8.1.3	Peer debriefing.....	49
4.8.1.4	Member checks.....	49
4.8.2	Transferability.....	50
4.8.3	Dependability .....	50
4.8.4	Confirmability .....	50
4.9	Pilot Study .....	51
4.10	Recruitment of study participants .....	52
4.10	Ethics and human rights issues.....	52
4.11	Conclusion .....	54

## **CHAPTER 5**

	<b>DATA ANALYSIS AND PRESENTATION OF FINDINGS.....</b>	<b>55</b>
5.1	Introduction.....	55
5.2	Data coding, organization and reduction.....	56
5.3	Study Findings.....	58
5.3.1	Demographic Characteristics .....	59
5.3.1.1	Age Distribution.....	59
5.3.1.2	Gender Distribution .....	60
5.3.1.3	Occupation.....	61
5.3.1.4	Level of Education .....	62
5.3.1.5	Marital Status .....	64
5.3.1.6	Religion .....	65
5.4	Problems of the participants .....	67
5.5	Living with HIV and AIDS.....	70
5.6	HIV/AIDS patients face Stigma.....	75
5.7	Anxiety, Worries and Fears .....	81
5.8	Care providers for the patients .....	85
5.9	Attitude of care providers.....	92
5.10	HIV/AIDS Education .....	95
5.11	Patient's Quality of life .....	99

5.12	Common Needs of patients .....	104
5.13	Provision of Information .....	112
5.14	Benefits of Nursing a patient at home.....	116
5.15	Challenges of HIV and AIDS patients.....	119
5.16	Conclusion.....	121

## **CHAPTER 6**

<b>DEVELOPMENT OF PRIMARY CAREGIVERS TEACHING MANUAL.....</b>		<b>122</b>
6.1	Introduction.....	122
6.2	Purpose of Primary Caregivers Teaching Manual .....	124
6.3	Selected studies primary caregivers knowledge.....	125
6.4	Organizational structure of the manual.....	127
6.5	Development of the manual.....	127
6.6	Piloting of the manual.....	128
6.7	Details of group sessions.....	128
6.8	Conclusion.....	130

## **CHAPTER 7**

<b>SUMMARY, CONCLUSIONS AND RECOMMENDATIONS .....</b>		<b>131</b>
7.1	Introduction.....	131
7.2	Summary .....	131
7.3	Main Findings .....	133
7.4	Conclusions and Recommendations .....	139
7.5	Conclusion.....	150

<b>BIBLIOGRAPHY .....</b>	<b>151</b>
---------------------------	------------

<b>APPENDICES... ..</b>	<b>163</b>
-------------------------	------------

# **CHAPTER 1**

## **OVERVIEW OF THE STUDY**

### **1.1 BACKGROUND OF MALAWI AND HEALTH SERVICES**

Malawi is a land-locked country situated in Central Africa. It shares borders with United Republic of Tanzania to the North and Northeast; the Republic of Mozambique to the East, South and Southwest; and the Republic of Zambia to the West and Northwest. It has a population of 11,937,934 million with an annual growth rate of 1.9% (Malawi Demographic Health Survey, 2004). Females comprise 51% of the total population, of whom 42.2% is in the reproductive bracket (15-49years). Eighty six (86%) of the population live in rural areas. Malawi is divided into three main administrative areas: the Northern Region, the Central Region and the Southern Region. The most densely populated of the three, the Southern region, is surrounded by Mozambique and harbours Malawi's largest city, Blantyre (pop. 826,322, in 1998). The Central region, where the capital city, Lilongwe (pop.1,337,777 in 1998) is located and the Northern region lie between Lake Malawi to the east and Zambia to the West. Tanzania is situated to the north east of Malawi (Malawi Demographic Health Survey, 2004).

Below the regional level, there are 27 districts, six in the Northern Region, nine in the Central Region, and twelve in the Southern Region. Within each district there are administrative subdivisions known as Traditional Authorities which are presided over by chiefs. The smallest administrative unit is the village (Malawi National Statistical Office, 1997:1).

Malawi is a former British colony that was administered alongside Northern and Southern Rhodesia (now Zambia and Zimbabwe) and therefore has much in common with those countries. Since independence in 1964, Malawi is a republic with a president as head of state and government. Independence marked the beginning of single – party rule, which ended in 1994 with the country's major transition to a multiparty democracy. However, traditional village leaders and ethnic group authorities are still active (Malawi Government Gazette, 1998).

### **1.1.1 Socio-economic context**

Economically, Malawi is classified as one of the least developed countries in the world. According to the United Nations Population Fund (UNAIDS, 2002), Malawi was ranked as the ninth poorest country in the world in Gross National Product (GNP) per capita (US \$170) in 2000. It still suffers from serious inequities in the distribution of income, with over 65% of the population living below the absolute poverty line (Malawi National Health Plan, 1999 – 2004). According to the Poverty Monitoring System (PMS) policy, the most vulnerable segments of the population are the urban poor, female headed households and children. Poverty is worse in the rural areas and the Southern region is the poorest of the three regions (Malawi Ministry of Health Programme of Work (2004 – 2010). Literacy is very low with only 39% of the adult population able to read and write. Up to 80% of rural women can neither read nor write. There is however a notable difference between urban and rural areas in schooling with higher illiteracy rates in rural areas. The Northern region has higher level of school attendance among both men and women than the Central and Southern regions (Malawi National Statistical Office, 1997).

Agriculture is the backbone of Malawi's economy and accounts for 90% of employment and 40% of the nation's GDP. Malawi's economy is still suffering the damage of major crop failures following a number of the nation's worst droughts of the century. Climatically, Malawi has a tropical continental climate with maritime influences; consequently rainfall and temperature vary depending on altitude and proximity to the lake. From May to August, the weather is cool and dry; September to November, the weather becomes hot. The rainy season begins in October and continues up to April.

The doubling of the population over the last twenty years has exerted extreme pressure on land and natural resources, national and household food security, the labour market and on the provision of essential social services. These hardships have resulted in severe economic difficulties in the 1990s, rapid inflation, a huge fiscal deficit and a fluctuating GDP (Malawi Ministry of Health Programme of Work, 2004– 2010).

### **1.1.2 Basic health indicators**

Though improving, Malawi's health indicators are among the worst in the world. Life expectancy is estimated to have dropped from 44 to 38 years as a result of HIV/AIDS and it may fall below 38 by 2010 (UNAIDS, 2002). Infant and Child Mortality Rates in rural areas are twice as high as in urban areas but the urban poor are not much better off than their rural counterparts. Among women, mortality due to pregnancy and childbearing are extremely high 984/100,000 live births (Malawi Demographic Health Survey, 2004). Major determinants of maternal mortality are reported to be high fertility, a large percentage of high – risk pregnancies, poor access to essential obstetric services and the poor quality of services. According to the Malawi National Health Plan (1999-2004), the major health problems in Malawi are high child mortality and morbidity, high maternal mortality and morbidity, high sero-prevalence and deaths due to HIV/AIDS related illnesses and high morbidity and mortality in the general population (Malawi National Health Plan, 1999- 2004).

### **1.1.3 Health Care Delivery in Malawi**

In Malawi, nearly all formal health care services are provided by three main agencies: Government through the Ministry of Health (MOH) provides 60%, the Christian Health Association of Malawi (CHAM) 37% and the Ministry of Local Government (MLG) 1%. Other providers such as private practitioners, commercial companies, armed forces and non governmental organizations (NGOs) provide 2% of health services. The Ministry of Health being the main agency has the primary responsibility of developing policies, strategies and programmes for health care in Malawi. The overall objective of the MOH is to develop a health delivery system that is proactively responsive to the prevailing needs and problems – a health care delivery system that addresses the current and foreseeable health, disease and health care management problems by focusing on the provision of a minimum package of essential health services to the people of Malawi with the emphasis on the poor, women and children. According to the Malawi MOH, Programme of Work (2004), the health status of Malawians is challenged by important social and environmental factors:



- Low levels of education and literacy, particularly among women
- Frequent outbreaks of cholera, dysentery and other communicable diseases
- Limited supplies of clean, safe drinking water in some areas
- Widespread poverty with almost half the population living on less than \$1 a day
- Regional disparities in access to and consumption of health services

## **1.2 HIV AND AIDS SITUATION IN MALAWI**

HIV and AIDS are the greatest challenge Malawi is facing today. Despite the increasing number of Community Home Based Care programs, Malawi is still leading in estimates of adults and children who have died from HIV and AIDS related diseases between 1985 and 2004 in comparison to the five SADC countries of South Africa, Kenya, Mozambique and Namibia (UNAIDS, 2004). In 2001, Malawi's national adult prevalence (15 – 49 years) was estimated at 14%, translating into almost 740,000 adults living with HIV and AIDS (Malawi National AIDS Commission, 2001). In 2004, the prevalence was at 12.8% (Malawi Demographic Health Survey, 2004). No cure is available for AIDS and the disease still continues to threaten the social and economic well being of the country.

Every day 237 people are infected and 139 people die from AIDS related illnesses (UNAIDS, 2004). Heterosexual transmission accounts for 90% of HIV infection in the country. Available data estimates that 65,000 children aged below 15 years are HIV infected. About 75% of all AIDS cases occur among people in the most economically productive age group of 20 to 45years (Malawi National AIDS Commission, 2003).

The HIV and AIDS pandemic has exerted serious impacts on the already overburdened Malawi health service delivery system which is also functioning with limited resources. Currently, there is an increasing number of HIV and AIDS patients admitted in hospitals. AIDS accounts for more than 60% of all in-patient admissions. It also complicates efforts to deal with growing cases of opportunistic

infections such as Tuberculosis (TB). Most of the chronically ill patients who are discharged require ongoing care in the homes. This means shifting the burden of care to families and communities because health services are often stretched beyond their capacities (Malawi CHBC Policy and guidelines, 2005).

The national response to the problem of HIV and AIDS has been the development of the National HIV and AIDS Policy and the National HIV and AIDS strategic Framework which was launched in 2000. This framework specifies priority areas, one of which is the provision of equitable treatment for people living with HIV and AIDS (PLWHA) and mitigation of the impact of HIV and AIDS including improvement of the quality of life of PLWHAs and others affected by the epidemic. One of the strategies to achieve this goal is through the provision of Community Home Based services which is also an intervention at community level in the Essential Health Package (EHP) of the Malawi Ministry of Health. Community Home Based Care (CHBC) provides a continuum of care for persons with chronic illnesses from health facility to the home environment. It also gives hope through quality and appropriate care that helps family caregivers and sick members to maintain their independence and achieve the best possible quality of life (Malawi CHBC Policy and guidelines, 2005).

### **1.3 BACKGROUND TO THE STUDY**

#### **1.3.1 Community Home Based Care in Malawi**

Home based care of HIV and AIDS patients is a health need recommended but not often available in Africa. It is an established component of the continuum of care and support advocated by WHO and UNAIDS and planned by many African countries including Malawi (WHO/UNAIDS 2000; Malawi National AIDS Commission, 2003). Home Based Care has existed in the past in different societies. It draws on two strengths that exist throughout the world: families and communities. These form the basis of CHBC. CHBC is one of the interventions under care and support for the HIV and AIDS patient. In Malawi, CHBC is defined as the care provided to chronically and terminally ill patients suffering from diseases such as HIV and AIDS, TB, Cancer, Stroke and other chronic diseases. It

also includes care of those affected by the illness, the vulnerable and the at risk groups. Families are the central focus of care and they form the basis of the CHBC team. Together with community members they provide the care in homes with support from the formal health and social worker. The aim of CHBC is to restore, promote and maintain a person's maximum level of comfort, function and health, including care towards a dignified and peaceful death.

In Malawi, formal community and Home Based Care services for HIV and AIDS patients were initiated through the National AIDS Commission in 2001. The Commission was formed in order to lead and coordinate the national response to the HIV epidemic (Malawi National AIDS Commission, 2003). Due to the growing number of patients, communities were mobilized to provide care to the sick in their homes through volunteers. Since then, the number of institutions providing CHBC services has increased. According to the Malawi CHBC policy guidelines (2005), the goal of CHBC programme is to make appropriate quality health services available to all chronically ill people including those with HIV and AIDS, affected by HIV and AIDS and other vulnerable groups in the community. The aim is to help the patients and the caregivers to maintain their independence and achieve the best possible quality of life.

### **1.3.2 CHBC Volunteers**

In Malawi, volunteers, commonly known as community care providers, play a great role in care and support of PLWHA (Malawi Ministry of Health (MOH), 2005). Usually, volunteers are the key human resource within the program and they come from within the community and some of them may be PLWHA. Women form the majority of volunteers in Malawi. The entry criteria for the volunteers is interest to assist the chronically and terminally ill people (MOH, 2005). The Government and Non Governmental Organizations train the volunteers on how to take care for HIV and AIDS patients at home. They are trained and supervised by professional health workers such as nurses, clinicians and Doctors. Their training takes ten days and it is mostly theory. Although the government has set such training standards, in some circumstances training is done for a period of less than ten days (Chikalipo, 2007). This implies that necessary skills to meet the needs of HIV

and AIDS persons are likely not to be gained by the trainees. Volunteers are expected to assist and supervise the primary caregivers during home visits.

The main sources of patient referral to the CHBC are from the hospital wards and the clinics. The patients are usually those who have been tested and diagnosed as having HIV and AIDS, though some patients are also referred based on symptomatic HIV infection. This happens in cases where HIV testing is not possible due to lack of resources. On discharge, the patient is referred to a CHBC that is located nearest to the patient's residential area (Zimba and McInerney, 2001).

According to the study which was done by Mohammad and Gikonyo (2005), CHBC is an example of the community-driven initiatives focusing on HIV and AIDS care and treatment activities. Research shows that an effective and affordable CHBC for PLWHA, has the potential to positively impact the health and social status of patients, families and the community as a whole. However, research has also shown that CHBC area is facing a multitude of challenges and limitations which not only adversely affect their ability to carry out their activities, but also have the potential to exacerbate poverty and existing gender inequalities among affected families and communities (Mohammad and Gikonyo, 2005).

According to the African Evangelical Church (year not given), it is bringing Christ's love to the sick and suffering of Malawians through the AEC home based care project. The project is working in three villages and their "HOPE for AIDS" volunteers are ministering to over 135 patients. They visit the homes of those who are sick regardless of religion. They offer a listening ear, counsel and bring hope from the scriptures. These acts of service have made a wide impact in entire communities. Through the tangible ministry of compassion, they are giving HIV and AIDS victims a longer, better quality of life, dignity in death and healing for eternity (African Evangelical Church, (year not given). Volunteers follow Christ as an example of love and acceptance to everyone in the community, regardless of which church, if any, they attend.

### **1.3.3 Community Home Based Care situation in SADC region**

Sub-Saharan Africa remains by far the region worst affected by the AIDS epidemic with HIV prevalence rate of 7.5% among the adults and an estimated 2.2 million AIDS related deaths in 2003 (UNICEF, 2004). As the number of AIDS cases and associated deaths continue to rise, the provision of effective CHBC has become not only a priority, but an absolute necessity.

As shown on Table 1.1 below; UNAIDS (2004) indicate that adult prevalence rate in the Sub-Saharan Africa is at 7.5. The Malawi Network of People Living with HIV/AIDS (MANET, 2003) also stated that approximately 96% of the 33.6 million living with HIV reside in the developing world and of these, 70% live in sub-Saharan Africa. Three quarters of all children with HIV are African and 80% of all AIDS deaths to date have occurred on the African continent. In countries such as Swaziland, Botswana and South Africa up to a third of the population is HIV positive. African leaders, the World Bank and the international community at large have recognized the need for quick, forceful, and sustained action against the pandemic (UNICEF, 2004). Undoubtedly, there is a great need for services and support provided by community home based care programmes to persons infected and affected by HIV and AIDS.

**Table 1.1: Sub-Saharan Africa: Regional HIV and AIDS estimates by 2003**

Adult (15-49) HIV prevalence rate	7.5%
Adults (15-49) living with HIV	22 million
Adults and children (0-49) living with HIV	25 million
Women (15-49) living with HIV	13 million
Women (15-24) HIV prevalence rate	6.9%
All AIDS deaths in 2003	2.2 million

**SOURCE: UNAIDS (2004) Report on the global AIDS Epidemic**

**Table 1.2: Inter-continental sampling of people living with HIV and AIDS by 2007**

<b>Country</b>	<b>Estimate</b>
Malawi	800,000
South Africa	5.4 million
India	3.7million
Ethiopia	3 million
Nigeria	2.7 million
Kenya	2.1 million
Zimbabwe	1.5 million
Tanzania	1.3 million
Mozambique	1.2 million
DRC	1.1 million
Zambia	870,000
Uganda	820,000

**Source: UNAIDS (2007)**

Table 1.2 displayed above was derived from the UNAIDS (2007) data-base, stating the estimates of people living with HIV and AIDS by 2007. The UNAIDS (2007) also states that more than 68% of worldwide infections and 76% of all HIV and AIDS deaths in 2007 were from the Sub-Saharan countries – the statistics above seem to justify the rationale for the high mortality.

#### **1.4 PROBLEM STATEMENT**

Nearly every individual in Malawi has been affected by the HIV and AIDS pandemic. Today, despite 15 years of national response, the impact remains devastating and the efforts are still inadequate, given the pace of spread of HIV and AIDS. Illness and death have increased exponentially; AIDS is now one of the leading causes of death in Malawi and it has left about 1.2 million children orphaned (Malawi National AIDS Commission, 2003).

While HIV and AIDS presents enormous challenges, it is encouraging however to see that in Malawi, the Public and Private Sector Institutions have all become engaged in various ways in the fight against HIV and AIDS and in activities and interventions that seek to mitigate its impact on individuals, families, communities and institutions. The emergence of CHBC programs, often organized by people living with HIV and AIDS, has become one of the outstanding features of the epidemic. They are playing a key role in easing the impact.

In Malawi, just like in many other Sub-Saharan countries the concept of CHBC is not new. Between 70% and 90% of illness care takes place within the home. Research evidence shows that most people would rather be cared for at home and that effective home care improves the quality of life for ill people and their family caregivers. Family and Community members are always valued as the main source of care for chronically ill patients or patients with incurable diseases in their homes using available local resources. CHBC is therefore the best way for most people to be cared for and to die peacefully. In Malawi, it is now being used more and more because of the high prevalence of HIV and AIDS. Patients on CHBC can either have HIV or AIDS. Those with HIV alone will be enrolled for observation and for health education. Most of the patients who are on CHBC are referred from health facilities (hospital wards and clinics). There is a good relationship between health facilities and CHBC centres. Eligibility for CHBC is based on clinical manifestations since most of the health facilities do not have voluntary and testing centres. Drugs for CHBC are supposed to be replenished by nearest health facilities although in most of the times these facilities do not have adequate capacity to cope with the increased number of HIV and AIDS patients (NAC, 2003). In addition to family and community members, the government and its partners are playing an active role in caring for victims of the scourge. Their main role is to strengthen the existing efforts, including capacities of support groups (Malawi National CHBC Policy and guidelines, 2005). Funding of CHBC services is done by Government and its partners.

A number of individuals, institutions and organizations have done commendable HIV and AIDS related research in Malawi. However, with the experience that the researcher has gained while working in the community with CHBC patients/clients,

it has been observed that since the introduction of CHBC programme in Malawi, very few or no research has been conducted to find out if the programme is benefiting patients/clients enrolled. Little is known concerning effectiveness of the care to patients and for how long patients are staying alive on the CHBC programme. Relatively very few studies if any have been done to explore problems that HIV and AIDS patients are facing and their quality of life while on the programme. While it is believed that Home Based Care is not cheap, it is still an affordable option for the care of people living with HIV and AIDS. Therefore, it was the aim of this study to describe the experiences of HIV and AIDS patients who have been on Community Home Based Care programme in the Lilongwe district, Malawi.

## **1.5 PURPOSE OF THE STUDY**

The purpose of this study was to explore and describe the experiences that PLWHA who are on Community Home Based Care Programme have in Lilongwe district of Malawi and develop practical guidelines for the implementation of quality home care in Malawi.

## **1.6 STUDY QUESTIONS**

- What does it mean to live with HIV and AIDS in Malawi?
- How do HIV and AIDS patients perceive the care, support and treatment provided to them at home?
- What are the health needs of HIV and AIDS patients in Malawi?
- What information, education and communication (IEC) messages are provided to HIV and AIDS patients at home?
- Does the current Community Home Based Care programme improve the quality of life for the HIV and AIDS patients in Malawi?
- What challenges or problems are faced by Community Home Based Care patients in Malawi?



## **1.7 SIGNIFICANCE OF THE STUDY**

In Malawi, there has been an increase in community home based care following a shift from hospital care to CHBC because of the HIV and AIDS epidemic. Despite the increasing number of CHBC programs and such endeavours, statistics still indicate a large number of re-admission to hospital of patients with numerous complications suggesting poor quality care at home. Caring for those with AIDS is a substantial burden and yet little is known about HIV patients' care experiences. This study therefore was aimed at determining the clients' experiences of their illness and the care they receive. PLWHA were fully explored from their own perspective concerning the effectiveness of the care being provided and the challenges that are faced. One of the guiding principles for CHBC program in Malawi is conducting research and share evidence based practices to promote quality of CHBC services. As such, findings of this study shall make substantive contribution to strengthening of health systems in Malawi. The results shall have implications for policy making, CHBC provision, education and research arena. Using recommendations that have been suggested in this study, policy makers will understand the characteristics of HIV and AIDS CHBC program available in Malawi and it will be able to improve, change or strengthen policies related to provision of community home based care. Care providers will be assisted in designing and developing appropriate information, education and communication (IEC) messages that will target factors which bar PLWHA to use home care services in time. Interventions that will help in the provision of quality CHBC services will also be developed. In addition, educators will incorporate findings of the study in the teaching and training of students.

## **1.8 CONCLUSION**

This chapter has outlined the Malawian health profile to give an overview of the setting in which the study was conducted. The background to this research has also been presented to give an introduction to Community Home Based Care program in the Malawian and sub-Saharan Africa context. The problem statement, study purpose, study questions and significance of the study have also been described. Operational definitions have been included to explain and clarify terminologies used in subsequent chapters of this research project. In the next chapter, a review of literature has been presented.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

This chapter presents a review of literature pertaining to the Malawian Community Home Based Care Program mostly for people living with HIV and AIDS (PLWHA). A search of the existing literature on CHBC yielded several sources. The concept of CHBC has received attention from different authors. The literature review has included related research studies which were done previously in relation to issues of CHBC both internationally and locally. The descriptors for literature review are related to the goals to be accomplished in this study: to explore and describe the experiences that HIV and AIDS patients who are on Community Home Based Care Programme have in Lilongwe district of Malawi and later develop practical guidelines for the implementation of quality home care in Malawi.

The concept of home health care started in the 20<sup>th</sup> century when hospitals were few or unavailable. As Stanhope and Lancaster (2004) attest “people did not always go to the hospital when they became ill”. Home health care is that component of a continuum of comprehensive health care whereby health services are provided to individuals and families in their places of residence for the purpose of promoting, maintaining or restoring health, or maximizing the level of independence while minimizing illness (Stanhope and Lancaster 2004). This definition is similar to the Malawian definition of CHBC which states that “ it is the care provided to chronically and terminally ill patients suffering from diseases such as HIV/AIDS, TB, Cancer, Stroke and other chronic diseases” (Malawi CHBC Policy and Guidelines, 2005).

HIV and AIDS is a chronic condition characterized by progressive immuno-suppression. It is not currently curable (WHO, 2004). In most countries, the health care system has been slow to respond to this growing threat. Public interest has focused on AIDS as an acute illness while ignoring the chronically ill, homebound

majority of persons with AIDS (Alexander, 1995). As the number of AIDS cases and associated deaths continue to rise, the provision of effective Community Home Based Care has become not only a priority, but an absolute necessity (Caring for AIDS patients at home in Malawi, 2008).

In most parts of the country, communities have mobilized themselves and are providing care for PLWHA, with the aim of rendering care using the available resources in their homes (Kamphinda, 2004). The most important local resource is the community members who are involved in rendering the care as caregivers. As more individuals are living with AIDS, more people are needed to provide services. Volunteer services are increasingly more valuable. According to Held and Brann, (2007), providing services for people with HIV/AIDS is a rewarding experience; however, stress, depression and frustration can play a role in their experiences. Therefore there is need for emotional and social support to be given to the volunteers to cope with stressors associated with providing services for people with HIV/AIDS. Higher levels of social support are associated with better adjustment, coping and treatment adherence among HIV patients (Miller, Bishop, Herman and Stein, 2007).

In Malawi as in many African countries, CHBC approach was mainly developed because of AIDS and is an established component of the continuum of care and support advocated by the WHO and UNAIDS (Malawi Community Home Based Care Policy and Guidelines, 2005). The CHBC program is one of the best care and support strategies that offer health care services to support the care process in the home of the HIV/AIDS infected person. The program aims to alleviate human suffering and pain and mitigate the impact of HIV/AIDS. An example of such projects in Malawi is Oxfam which is working with local home based care groups to address the needs of those affected by HIV and AIDS. According to the local leaders in the areas where Oxfam is working, “the lives of orphans and the sick have improved so much that some are able to go back to their work and do things for themselves, go back to school, work in their gardens – that’s the impact it is having” (Oxfam International, 2006).

## **2.2 HIV AND AIDS AND QUALITY OF LIFE**

The health and quality of life of persons with HIV and AIDS are affected by suppression of the immune system with attendant opportunistic infections and complications and by direct action of the virus resulting in fatigue, wasting neurological disease and other manifestations (WHO, 2004). People with HIV and AIDS are also affected by discrimination, mental health problems and poverty which can be both a cause and effect of infection. It is always assumed that people need other people and that being needed promotes quality of life so too is the case with PLWHA. This is true with the findings from a study done by Bertero, Eriksson and EK (1997) entitled 'Assessing the quality of life of patients in phase 1 & 2 anti-cancer drug trials: Interviews versus questionnaires. Results of this study revealed that a person enjoys a good quality of life when she/he is active and has a good relation with others, has self esteem, and a fundamental mood of happiness.

Quality of life is a multidimensional construct that communicates an individual's overall sense of well-being and life satisfaction. It is an individual and personal experience, but there might be some common components that give life meaning. According to Youssef, and Wong, (2002) in their study of Educating Clinicians to Assess Quality of Life in patients with chronic illness, the concept of Quality of Life is changing over time. With the current shift of health service emphasis from hospital based care to home based care, family members' responsibility for providing direct care to their relatives has increased and this move therefore has clearly affected the quality of care, family caregivers, and the health care providers. According to WHO/UNAIDS (2000), all individuals have a right to psychosocial care and an adequate quality of life in addition to well-being. The WHO (2000) has defined quality of life as an "individual's perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, standards and concerns". Quality of life therefore consists of four dimensions which are: physical, psychological, social and spiritual well-being. It has been acknowledged that quality of life is subjective, based on the patient's self report, always changing, dynamic and a multidimensional concept (Youssef and Wong, 2002).

When measuring quality of life patients have to be asked questions concerning recent pain, stress, depression, anxiety, sleeplessness and vitality related to their daily activities. According to Bertero et.al (1997) the cause, duration and severity of a current activity limitation that an individual may have in his or her life need to be established. Unhealthy days are an estimate of the overall number of days during the previous 30 days when the respondent felt that either his or her physical or mental health was not good. Healthy days are the positive complementary form of unhealthy days. Healthy days estimates the number of recent days when a person's physical and mental health was good or better and is calculated by subtracting the number of unhealthy days from 30 days. According to Bertero et.al (1997), several organizations have found these Healthy Days measures useful at the national level. They identify health disparities, track population trends and build broad coalitions around a measure of population health. This is compatible with the World Health Organization's definition of health i.e. "Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity" (WHO/UNAIDS, 2000).

### **2.3 HIV/AIDS PATIENT'S PERCEPTION OF THEIR CARE**

Patient satisfaction has gained widespread recognition as an important indicator of quality of care that patients receive. It allows a provider to evaluate the degree of quality that patients find in their care by addressing the critical psychosocial factors that characterize the interaction between patients and providers. The assessment of interpersonal quality of care and levels of satisfaction offer some important insights into how HIV/AIDS patients perceive their care and serve to clarify what specific characteristics of patients' care are related to satisfaction (Tsasis, Tsoukas and Deutsch, 2000). According to the study which was done by Lawton (2002) titled 'A two way model of care giving appraisal psychological wellbeing' which aimed at assessing home based care program in Uganda with emphasis on perception of patients, caregivers and leaders; findings showed that 78% of caregivers were satisfied with the adequacy of their work and 77% were satisfied with their orientation and training. The study reported that caregivers were active in community education, awareness programs for CHBC, stigma reduction and

behavioural change in the communities which then brought a great impact in the communities (Lawton, 2002).

Tsasis et al, (2000) conducted a study entitled Evaluation of Patient Satisfaction in a Specialized HIV/AIDS Care Unit in Canada. The study analyzed quality of care in correlation with patient satisfaction using a random sample of 193 HIV/AIDS patients. Results of the study indicated that the overall satisfaction of quality of care for HIV/AIDS patients was mainly affected by the patient's perception of his/her health status, level of professional or family support and the patient's level of involvement in decisions on treatment modalities. The researchers recommended use of a multidisciplinary approach to care for HIV/AIDS patients because it might provide a reasonable alternative to patients with little or no support outside a clinical setting.

## **2.4 HIV/AIDS AND CHBC EXPERIENCES**

The AIDS pandemic continues unabated in poorly resourced countries. There are 40 million people currently living with HIV or AIDS mainly in sub – Saharan Africa (UNAIDS, 2002). Each day 1,600 children die from AIDS in Africa as opposed to 500 per year in Europe (UNAIDS, 2002). Despite the increasing use of home care, it has only been evaluated to a limited extent in terms of its effects on health status and quality of life and with regard to its costs (Borgia, Schifano, Spadea, Milanese, Fabrizi, Abeni, Perucci, and Rocci (2002). Well managed and supported home care can improve the quality of life of patients of all ages and caregivers alike (WHO, 2004). In almost all the countries including Malawi, the family has always been and still is the major provider of long term care for patients with chronic conditions including HIV and AIDS. However, the heavy burden of care cannot be shouldered by families alone (Caring for AIDS patients at home in Malawi, 2008). But the question which most people would ask could be “who is qualified to provide primary care for HIV/AIDS patients”.

According to the Malawi Ministry of Health Programme of Work (POW), 2004 – 2010), providing quality health services is about making sure there are enough resources to meet minimum standards, whether good care is delivered and

whether patients are satisfied with the services they have received. This means ensuring that health service staff are well trained, that buildings and equipment are well maintained and that there is a regular drug supply. It also involves building better participation at community level to ensure there is effective communication between those who deliver and those who receive health services (POW, 2004 – 2010). According to WHO (2004), a range of health outcomes might be considered as quality of care indicators in patients with HIV/AIDS. Such outcomes can be length of survival or hazard of death, disease progression and subjective health status.

A study which was done by Kitahata (2003) entitled “Quality Primary Care for HIV/AIDS: How much HIV/AIDS experience is enough” examined the importance of physicians/health workers to have clinical experience in HIV/AIDS care which would assist their patients to have long term survival with AIDS. The study used 197 male AIDS patients cared by HIV/AIDS experienced physicians and others by less experienced staff. Results of the study indicated that patients of the most experienced physicians had significantly longer survival times with AIDS than did patients of the other staff (26.1 months compared to 17.0 months for moderately experienced and 16.5 months for least experienced). These findings suggest that the most experienced physicians were able to target the level of care to the patients` needs and thus achieve better outcomes compared to the other physicians. Family caregivers need guidance, support and skills to manage complex care.

According to a study which was done by the Malawi Network of People Living with HIV/AIDS (MANET+, 2003) on stigma and discrimination issues as they affect PLW HA in Malawi, it was found that PLWHA feel that Home Based Care has a role to play in care, treatment and support of PLWHA only if these programs are supported adequately. The study also found that PLWHA express concern that attitudes and misconceptions on HIV/AIDS have a great impact on the overall well being of HIV/AIDS patients. Providers who have negative attitudes and misconceptions towards HIV/AIDS will not provide good quality care to the patients therefore affecting patient’s quality of life.

### **2.4.1 Experiences of Uganda**

According to O'hare, Venables, Nalubeg, Nakakeeto, Kibirige and Southall (2005), the population of Uganda is almost 25 million, with 50% aged less than 15 years. HIV prevalence has gone down to 5% in the adult population, mainly due to the government active promotion of a national response to HIV/AIDS (O'hare et.al 2005). At the end of 2001, there were 110,000 children infected with HIV in Uganda and the need to support HIV-positive children living in Kampala, by providing care in their homes and supporting their families was crucial. The Doctor/patient ratio in rural Uganda is 1:50,000 (Campbell, 2004). According to the author, for PLWHA, there are clear psychological benefits to the home care given through family care givers, trained volunteers or health and social support care providers. Uganda's home based care program also takes care of children and their families who are HIV positive. They provide physical, psychological and social support to the families. Carers feel they benefit from the program (O'hare et.al, 2005). While home care has many benefits in Uganda, it often has its constraints such as shortage of resources and time which in the end makes it difficult to support the patients.

### **2.4.2 Tanzania**

In Tanzania, since the first cases were reported in 1986, AIDS has become a major public health problem (Berhane and Zakus, 1995). The situation is not different in the rest of the sub-Saharan countries. Studies previously carried out in Ethiopia have shown that knowledge about AIDS is neither accurate nor consistent and at the same time high risk behaviour for HIV infection is common (Berhane and Zakus, 1995). AIDS is imposing a huge burden on the limited hospital beds available in Tanzania hence home care for people living with AIDS seems to be the only feasible option and one of the main strategies to provide support to PLWHA in the country (Berhane and Zakus, 1995).

According to the study which was done by Berhane and Zakus (1995) in Ethiopia titled "Home care for persons with AIDS: community attitudes in Ethiopia", it was found that knowledge about AIDS was very high, misconceptions about the



disease were observed as well. More than half of the respondents expressed willingness to give home care for persons with AIDS. Most of the obstacles to providing home care for persons with AIDS were related to fear and misconceptions associated with the disease. The author therefore recommended strengthening public education to create a more favourable attitude in a community towards the provision of home care for persons with AIDS (Berhane and Zakus, 1995).

### **2.4.3 South Africa**

The HIV/AIDS pandemic has reached catastrophic proportions in sub-Saharan Africa. In 2002, the incidence rate in South Africa was estimated to be 2% and the prevalence rate for the total population to be 14.2% (Jelsma, Maclean, Hughes, Tinise and Darder, 2005). According to these authors, projections indicate that, in the absence of ARVs, the number of deaths due to AIDS is expected to result in a cumulative total of five to seven million by 2010.

In South Africa just like in many countries, many people are becoming increasingly chronically ill, requiring care over long and extended periods and therefore necessitating to be taken care of at home (Uys, 2003). HIV/AIDS is an illness that not only has no cure, but it is also stigmatized, and the prevalence rate makes it a potential catastrophe for population and the health service. According to Uys, 2003, most PLWHA have no access to drugs such as ARVs and can only be offered palliative care. This increases the importance of home based care.

The integrated community based home care model was developed in a rural hospice in South Africa in the mid 1990s to deal with the HIV/AIDS pandemic. This home care model aims to provide a continuum of care for PLWHA from diagnosis to death and it includes counselling and support for people who are relatively symptom free while placing emphasis on palliative and terminal care. The model specifically aims at developing a care system that is effective and sustainable in the context of a developing country (Uys, 2003).

#### **2.4.4 Botswana**

In Botswana, there has been an increase in community home based care (CHBC) following a shift from hospital care to CHBC because of the HIV/AIDS epidemic (Shaibu, 2006). According to this author, Botswana is one of the countries with high prevalence rate (17%) of HIV/AIDS in the world. The population of Botswana is just 1.7 million. Hospital bed occupancy rate has increased from 65% in 1999 to 70% in 2003 and the number of people on home based care has also increased significantly due to the increase in the number of HIV/AIDS cases (Shaibu, 2006). According to Browning (2008), the epidemic has already claimed the lives of over 18,000 citizens since its start and approximately 120,000 children have lost at least one parent to the disease.

The concept of community home based care was first introduced in Botswana in 1992, when it became clear that the public health sector was unable to cope with the increasing number of patients suffering from HIV related illnesses. Many districts in Botswana are now beginning to initiate a more structured home based care programme including counseling and training to involve the community in providing care for their ill relatives at home (Ndaba-Mbata and Seloilwe, 2000). It is encouraged that the care should be provided by family and community members with the support of skilled health and social workers who work as a team. In spite of such endeavours, statistics indicate an alarming rate of readmission to hospital of patients with numerous complications, suggesting poor quality care at home. In addition there have been anecdotal records of elderly caregivers being diagnosed as HIV positive indicating that transmission might have occurred during the process of care giving (Ndaba-Mbata and Seloilwe, 2000). According to Shaibu (2006), "most clients on Home based care in Botswana are the elderly or terminally ill patients".

According to the study which was done in Botswana titled "home based care of the terminally ill in Botswana: Knowledge and perceptions", it was discovered that families lack knowledge and skills for providing appropriate care. They were also not aware of the resources available and they lack professional and material support. While the situation is like this in Botswana, literature search indicates that

families who receive detailed information about the condition of the patient manifest more vigilant coping skills compared with families who receive little information (Ndaba-Mbata and Seloilwe, 2000). Although many people are being cared for at home, families as carers are not well informed and are ill prepared about what they have to do. The author recommends that for caregivers to give a good quality of care to their relatives, they need to have appropriate skills and information about how to provide this care. There should also be a good referral and follow up system for effective implementation of home based care with appropriate procedures for monitoring and evaluation.

Just like in many developing countries, there are several problems facing the implementation of home based care in Botswana. There is shortage of staff both from the nursing side and social workers and because of that some patients die before they are attended to. Difficulties with transportation, poor referral system, financial constraints, fear of stigma and discrimination, overburdening of family members, inadequate support structures for caregivers and poor documentation are also some of the challenges being faced in the implementation of CHBC and threatening the sustainability of CHBC program in Botswana (Shaibu, 2006, Browning, 2008).

#### **2.4.5 Zimbabwe**

The AIDS epidemic is also escalating rapidly in Zimbabwe as it is elsewhere in the region. According to Avert (year not given), between 2002 and 2006, the population is estimated to have decreased by four million because of HIV and AIDS. Average life expectancy for women who are particularly affected by Zimbabwe's AIDS epidemic, is 34, the lowest in the sub-Saharan region. By the end of 1980s, around 10% of the adult population were thought to be infected with HIV. This figure rose dramatically in the first half of the 1990s, peaking and stabilizing at 29% between 1995 and 1997. Since this point, the HIV prevalence is thought to have declined, making Zimbabwe one of the first African nations to witness such a trend (Avert, year not given). Home care for HIV/AIDS patients has been developed in response to the rising economic costs of hospital care and the shortage of beds, and in recognition of the limited benefits of hospitalization for

many patients. By 1997, over 67 different HIV/AIDS home care programmes had been established through out the country (Hansen, Woelk, Jackson, Kerkhoven, Manjonjori, Maramba, Mutambirwa, Ndimande, and Vera, 1998).

In Zimbabwe, medical services are experiencing growing demand because of AIDS and hospital services are increasingly strained owing to escalating case loads and continued budget reductions (Zimbabwe National AIDS Coordination Programme). The home based care programme costs are high, and schemes do not generally assess effectiveness or cost effectiveness. The high cost of home visits leads to less frequent visits leaving a larger part of both the burden and the cost of care to the families and the patients. A large proportion of these costs are not of direct benefit to the patients (Hansen, et al, 1998).

Most people feel that the Zimbabwean government's response to the AIDS crisis has been relatively good in comparison with their performance in other areas (Avert, year not given). Prevention and treatment initiatives have been scaled up and the national HIV prevalence seems to have declined.

#### **2.4.6 Ghana**

In Ghana, secrecy because of stigma, surrounds HIV/AIDS illness and this poses a major barrier to the provision of home care especially for patients with AIDS in Ghana (Radstake, 2003). One of the expected outcomes of caring for an AIDS patient in the home is to maintain the highest quality of life through the support of the care giver. The author therefore urges that in this situation, openness is important in home care especially in patients and families living with HIV/AIDS illness regarding the need for care. Secrecy is a prerequisite for care of persons with AIDS (Radstake, 2003). Unfortunately, this brings conflict in the patient between the secrecy attached to the disease (AIDS) and the openness that is required in order for the family and care givers to provide support and services in a home care program. Unfortunately, most of the times this acts as a barrier in the implementation of care to AIDS patients. This attitude also impacts on disclosure of the disease to other people and traditional patterns of seeking help making the PLWHA shy away from others because of fear of stigma (Baker, 1999).

#### **2.4.7 Malawi**

Malawi like its neighbours in the sub-Saharan Africa has been severely affected by the HIV and AIDS epidemic. Almost two decades have passed since the first case of AIDS in the country was diagnosed in 1985. Malawi's national adult prevalence (15 – 49 years) is estimated at 14%, and 760,000 adults are living with HIV/AIDS (Malawi National AIDS Commission, 2003). HIV prevalence is almost twice as high in urban areas at 25% as in rural at 13%. There are 70,000 HIV positive children under the age of 15 in the country (NAC, 2003). In hospitals, HIV/AIDS conditions occupy more than 50% and most of the patients that are discharged from the hospital still require on going care in their home. As a result of this epidemic, Malawi's health policy is emphasizing a move towards community care through home based care services. A needs assessment survey carried out in Malawi in 1990 identified that patients were willing to be cared for at home (Zimba and McInerney, 2001).

In Malawi, provision of equitable treatment for PLWHA and mitigation of the impact of HIV/AIDS including improvement of the quality of life of PLWHA and others affected by the epidemic has been emphasized at all levels. Community Home Based services have been incorporated at community level in the Essential Health Package (EHP) of the Ministry of Health in order to provide a continuum of care for persons with chronic illnesses from health facility to the home environment. However, the CHBC program is not without problems. Malawi has been faced with a lot of challenges to support implementation of CHBC program such as shortage of professional health workers, material resources and stigma and discrimination of HIV/AIDS patients. A number of attempts to operationalize the program have experienced several obstacles. Poverty, inadequate space, heavy workload on the family and insufficient information about the infection to the care giver has been paramount (Zimba and McInerney, 2001). While CHBC is supposed to alleviate human suffering and pain, and mitigate the impact of HIV/AIDS through comprehensive care package, it is worth noting that CHBC programs do not reach all the affected communities (Malawi National AIDS Commission (NAC), 2003). According to the analysis of the Community Home Based Care program in Malawi done by Chikalipo (2007), most home based care support groups are located in

the urban centres because of the proximity of NGOs and Faith Based Institutions to which they are affiliated. Independent support groups on the other hand are located within the proximity of persons that facilitated formation of the groups (NAC, 2003)

#### **2.4.8 Needs of Primary Caregivers**

A number of studies have been done in Malawi in relation to HIV, AIDS and CHBC. According to the study done by Zimba and McInerney (2001) on “the knowledge and practices of primary caregivers regarding home based care of HIV/AIDS children in Malawi, it was observed that in reality, people who are very sick or dying, this includes HIV and AIDS patients, spend most of their illness at home especially when they know that the hospital is not likely to provide a cure for their disease. These authors also observed that the Malawian community is overburdened and unable to meet the caseload as a result of the escalating referrals due to the increasing numbers of patients becoming ill with AIDS`.

According to the study done by Chikalipo (2007) on “Analysis of Community Home Based Care in Malawi”, it was discovered that most of the carers feel stressed and burdened by the caring role. The author emphasized that once the role of primary carer is taken, it is a life – long commitment and rarely shared with others resulting in isolation from opportunities to maintain social contacts. Needs of primary caregivers have been more extensively studied among caregivers of chronically ill patients than among caregivers of HIV and AIDS patients (Hinds, 1995). According to this author in his study to determine needs of families that care for a patient with cancer at home, it was found out that 30% of the carers were coping poorly with the physical care of the patients. The study also found out that most families expressed needing assistance with physical care and a place where they could turn to discuss their fears.

Kamphinda (2004) in her study of “Lived Experiences of children from families with HIV/AIDS home based care patients in Malawi” found out that children in the study had more negative experience in relation to their bio-psychosocial well being. They

had unnoticeably and unrecognized assumed care taking roles which were disturbing their development, health and education.

A number of studies reveal that being a primary caregiver is a great challenge. Caregivers face emotional, physical and financial burn as a result of this new responsibility. The study identified symptoms of caregiver burnout as aching limbs, stomach complaints, high anxiety, low self esteem, sleep loss and depression. Caregivers were also feeling isolated, hopeless and helpless in their role. The most appropriate strategy for dealing with stress among primary caregivers therefore is provision of social support and information. They require appropriate information and support from both the health professionals and the community in order to meet the needs of the HIV and AIDS persons. According to the study done by Nkhoswe (2001) titled "Knowledge and Attitudes of the family members towards HIV/AIDS Home Based Patients in Malawi" it was found that the care of AIDS patients from hospital to home-based might have an impact on the family members because of the fears and lack of knowledge on how to care for an AIDS patient at home. The author also emphasized that most of the times when people have limited knowledge on HIV and AIDS, they tend to have negative attitude towards PLWHA. In this study, findings showed that family members caring for AIDS patients found greater peace in accepting and coping with AIDS when they received information and support from the home based care team. According to this study, many family members had myths related to HIV transmission such as through sharing of dishes or cups with the patient could infect them which was an indication of lack of knowledge.

White, D'Abreu, Aret, Graham & Duggan (2008) in their study titled "Learn now; Live well: an educational programme for caregivers" results showed that most family caregivers identified caregiving as stressful. Most of them acknowledged negative consequences including financial difficulties, ineffective coping strategies, depression and stress. However, participants confirmed that despite the burden of hardship that occurred, they still wanted to continue in this role.

Similar to this, Tshililo and Davhana-Maselesele conducted a qualitative study in 2009 in the rural Limpopo Province, South Africa to explore family experiences of

home caring for patients with HIV/AIDS. Findings of this study revealed that the family members experienced negative feelings, characterized by sadness, pain, anger, depression and frustration as they care for their loved ones within the context of extreme poverty. The study also identified that quality care was compromised in situations where basic resources were not available. The study therefore developed guidelines to assist families in caring for their loved ones with HIV/AIDS at home.

#### **2.4.9 Why HIV and AIDS care in the Home?**

In Malawi, because of the low social economic status, given chance people would rather die at home than in the hospital. PLWHA during their lifetime will require care treatment and support so as to deal with their illness and live as comfortably and productively as possible. A great deal of this care will be provided at home by immediate family and friends. According to Avert (year not given), a potential benefit of being cared for at home is that sick people are continually surrounded by people they love and are familiar with, so they can also receive more flexible and nurturing care. Patients feel less isolated from family and friends and potentially feel psychologically and spiritually more supported, comforted and better able to cope. They will also not be exposed to hospital-based infectious diseases.

As people with terminal illness generally spend their final moments at home, strengthening the capacity to be cared for also removes the cost and distress of travelling to and from the hospital when they are weakest (Zimba and Mc Inerney, 2001). According to these authors, Home based Care services permit better follow up and is the best way to provide educational opportunities for personal messages about AIDS prevention.

## **2.5 CONCLUSION**

Literature has revealed that in most developing countries the prevalence of HIV and AIDS is high and that efforts have been made to deal with this epidemic through CHBC services. However, there are a lot of constraints in the implementation of the CHBC program especially in poor countries like in the sub-



Saharan Africa. CHBC assumes that families have the capability to care for patients in their homes, but what most of the times is forgotten is the fact that in most poor resource countries, often these families have no adequate resources and materials to care for their sick patients in the community. Literature has also revealed that one of the greatest challenges for primary caregivers is lack of knowledge on care of the patient at home and in most cases this has proved CHBC projects to be worthless. The next chapter will discuss the conceptual framework that was used to guide the study.

## **CHAPTER 3**

### **CONCEPTUAL FRAMEWORK**

#### **3.1 INTRODUCTION**

A conceptual framework is an integrated model of care designed to meet the health needs of the patients, families and communities. According to Stanhope and Lancaster (2004), it is important to have a conceptual framework in research because it gives a basis for making decisions and establishing priorities. It also gives the researcher an opportunity to examine programmes systematically for deficiencies to deal with potential problems. Lastly, conceptual framework serves to explain why things are done in a particular way. The conceptual perspective which has been described in this chapter to guide the present study is quality of care which can determine the quality of life for PLWHA. Through the thick descriptions of the experiences from the participants in this study, it was possible to determine the deficiencies in the implementation of CHBC to PLWHA in Malawi.

The Malawi National HIV/AIDS Strategic Framework has HIV/AIDS management through a home based care approach as one of the major components. Government, under the Global Fund initiatives introduced a community home based care and treatment (Malawi National AIDS Commission, 2003). The objective was to encourage an integrated approach in caring for victims of HIV and AIDS. In this context, care refers to any form of physical, emotional, social or spiritual assistance which is provided and which aims to reduce suffering, facilitate healing, promote dignity or support persons with chronic or terminal illnesses and/or their orphans/ vulnerable children.

In Malawi there are a number of organizations that are involved in the care of PLWHA, either through institutionalized care or through CHBC. With the advent of HIV/AIDS epidemic, CHBC has been a common practice in the care of PLWHA in Africa for generations (Kiwombojjo, 2001).

An ancient proverb from Chinese folk philosophy states, “the patient’s recovery of health depends on three tenths of cure and seven tenths of care” (Kiwombojjo, 2001). This proverb reflects the fact that care is an essential part of nursing.

### **3.2 CONCEPT OF QUALITY OF LIFE**

Quality of life is a major goal in the care of patients with terminal illness. In addition to symptom management, psychological care and provision of support, being cared for at home is considered to be an important determinant of patient well being (Peters and Sellick 2006). Thus symptom management, psychological care and support are of paramount importance in ensuring a comfortable death with dignity and optimal quality of life for both patient and family. Quality of life of chronic/terminal illness varies according to disease severity, the psychological and social state. The past decade has witnessed a major shift in the focus of care for terminally ill patients from institution based to home based services. This change was predicted on the view that being cared for at home provides patients with better quality of life (Peters and Sellick 2006).

The primary goal of CHBC is helping patients to achieve optimal quality of life. Patients cared for at home experience fewer adverse effects from their symptoms, have greater control over the effects of their illness and have better health status and therefore CHBC remains one of the most important intervention strategies in reducing hospital admissions (Peters and Sellick 2006). When patients are cared for at home, they benefit from easy access to both psychological and material support provided by the family, relatives and the community at large (Kiwombojjo, 2001). Therefore, home based care may be the preferred option for patients who are in better health, wish to remain independent, believe that they have control over the effects of their illness and who have supportive networks at home (Peters and Sellick 2006).

### **3.3 CONCEPT OF QUALITY OF CARE**

Quality of care determines quality of life. According to Donabedian (1988), quality of care is the extent to which actual care is in conformity with present

criteria of good care. Similarly Peters and Sellick (2006) defined quality care as the degree to which health services for individuals and populations increase the likelihood of desired outcomes and are consistent with current professional knowledge. Quality therefore refers to optimizing material inputs and care taker skill to produce maximum health. Quality health service is an important issue in the implementation of a CHBC programme for many reasons. First of all, quality CHBC services will be cost-efficient. This means that patient's health needs will be met without too many problems and delays. Similarly, quality services are always equitable meaning that quality care will be provided within the parameters of existing resources to all who need them (WHO /UNAIDS, 2000). Quality services are effective. When care takers have adequate resources and other support, they are able to manage health problems more effectively, reducing deaths and chronic ill-health. This will lead to community members appreciating and valuing the services hence utilization will be adequate. Care taker's morale is improved by good quality services. Care takers are likely to have more positive attitude toward their work and to perform better when they receive the support and resources they need to provide essential services, and when their work is valued by the community. Most important, good quality services can save patients lives. Access to the health care system is required to obtain the care that maintains or improves health, but simple access is not enough; the system's capacities must be applied skilfully (Donabedian, 1988).

Quality of CHBC services requires that the care providers have adequate resources, clinical skills and that are sensitive to the patient's and their family needs. The care providers should have necessary equipment and supplies and that the referral system should function well enough so that those patients with essential complications get treatment. Such care should maintain sound managerial and financial performance. A transparent managerial system (standards, policy and guidelines) is believed to be necessary in improving quality of care (Campbell, 2004).

### 3.4 ATTRIBUTES OF QUALITY OF CARE

Donabedian, the father of quality of care emphasizes assessing quality through the use of three main elements of quality of care and this has gained acceptance by many researchers. A combination of structure, process and outcome approaches may produce the best assessment of quality of care

The elements are structure, process and outcome.

- **Structure** assesses the quality of care under the setting which care takes place e.g. the CHBC program takes place in a home setting. It addresses the underlying systems and structure: are systems in place and are the right people assembled in the right way to allow for the provision of quality care? (Peters and Sellick, 2006). It includes; adequacy of human resources such as the volunteers, health workers and family members in the CHBC program (number, variety, qualification of professionals), adequacy of facility/material resources such as infrastructure, tools or equipment (e.g. CHBC kits), technology, and organizational characteristics for example administrative process, presence of teaching and research, as well as supervision of care. In most settings the question 'why do health providers perform badly?' needs to be addressed before designing strategy to improve quality of care. Regular refresher courses, frequent quality supervision and giving of incentives to motivate good performance would assist to improve qualities of care providers. (Donabedian, 1988) assumes that given proper settings and organizational structures, good patient care will tend to follow.
- **Process** This denotes what is actually done in giving and receiving care. It includes adherence to good standards of care (e.g. following CHBC Policy and Guidelines), proper physical examination and diagnostic tests, justification of diagnosis, treatment reliabilities, evidence of prevention and patient education that are usually carried out by professional personnel and acceptability of care to the patients and their families. This can also mean

giving education to carers of PLWHA such as family members and volunteers on HIV and AIDS care by CHBC trainers. It also involves the technical competence of the care provider and the interactions between caregivers and patients which assume that given the proper procedures (process), good health outcomes will tend to result (Peters and Sellick, 2006).

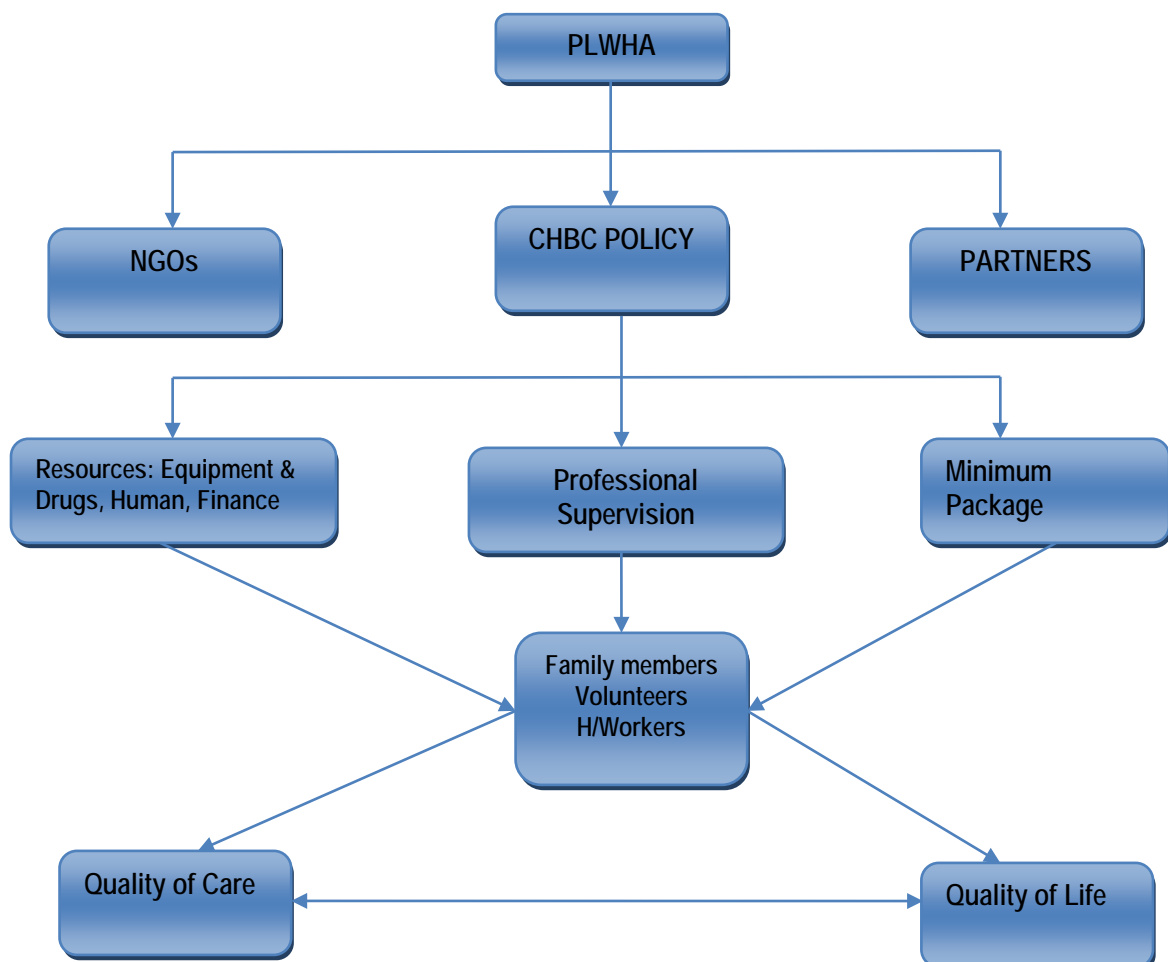
- **Outcomes** It considers whether changes in an individual's current and future health status can be attributed to health care received. The changes can be desirable or undesirable, encompassing morbidity and mortality of patients or groups of patients e.g. PLWHA. Outcome can be measured in terms of health status. These can include change in health status such as recovery, restoration of function and survival, deaths, or disability-adjusted life years. It also involves examining knowledge acquired by family members that may influence future health care changes in behaviour and it also include satisfaction of patients and their families with the care received (WHO,2004).

In summary, quality of care is measured on providers and recipient perspective. A model on the next page illustrates a conceptual framework which has been used to illustrate quality of life in PLWHA after receiving quality care. It is a modified Donabedian (1988) concept of quality and shows its determinants for assessment of quality of care in the Community Home Based Care Programme. Different researchers use different conceptual frameworks to measure quality of care. Quality of care has a variety of definitions. This study has used a definition of quality of care based on the framework provided by Donabedian (1988). The framework has assisted the researcher in identifying the quality of care that community home based care clients/patients receive in their homes in order to achieve quality of life. The main focus has therefore been on structure which is looking at the home setting where CHBC takes place, providers of care at home in CHBC such as family members, volunteers and health workers and whether there has been any training or education given to the these people. The process attributes have looked at the policy and standards which have been used in the

implementation of the care to PLWHA. Lastly, outcome of quality of care particularly looking at changes in the health status of PLWHA which translated to their quality of life.

To measure quality of care one needs to have a standard against which quality is measured. This study utilized the Malawi Ministry of health policy guidelines which were developed in 2005 and emphasize on providing minimum standards for the provision of quality of care to chronically and terminally ill including PLWHA in their homes. However, it is important to note that any quality assurance system must be based on standards and on the monitoring of adherence to those standards. It should also be anticipated that standards change over time as expectations and medical practice evolve and therefore if quality is of concern, then it needs to be assessed repeatedly over time in a comprehensive manner (Donabedian1988).

**Fig 3.1: Framework for quality of care in CHBC Program**



The above conceptual framework illustrates the provision of quality of care that is necessary to patients. In Community Home Based Care policies and guidelines are important in the implementation of care. Without these, implementers would not have a guide. According to the Malawi National CHBC Policy and guidelines, (2005), implementers are directed to the type of resources required, the type of supervision to be given and the packages needed for the care. If all these are used quality of life will be achieved by the patient.

### **3.5 APPLICATION OF CHBC PROGRAM TO THE FRAMEWORK**

#### **3.5.1 CHBC Policy**

Quality of care may be perceived differently by clients and providers. Implementation of CHBC to PLWHA focuses on the national policy and guidelines on CHBC which acts as an umbrella. In order to ensure coordination, equity and standardization of the quality of care, national policy and guidelines on community home-based care are vital. According to the Malawi National CHBC policy and guidelines (2005), the goal of the policy and guidelines is to provide standards for the provision of quality care for the chronically and terminally ill including at risk groups and other vulnerable persons in the home/community. It promotes availability, access and utilization of quality and comprehensive care for chronically and terminally ill and it also strengthens the capacity of individuals, families, communities and institutions to deliver safe and quality community and home based care services. The policy provides guidance in CHBC services and it also stipulates various levels of responsibilities in the implementation of CHBC. According to Donabedian (1988), the process is important in quality care and he assumes that given the proper procedures (process), such as good standards of care, good health outcomes will always be achieved.

#### **3.5.2 Resources**

According to Donabedian (1988) this is what is referred as the structure of quality of care. In Malawi, most CHBC services take place in the homes. According to the Malawi National CHBC policy guidelines (2005), the professional health worker



shall be provided with a supervisor's kit whilst a community care provider shall be provided with provider's kit. Equipment, supplies and drugs for the kits shall be replenished by the nearest government facility, NGOs, FBOs and CBOs funding the programme. Supervisors may prescribe or administer only those drugs that are licensed by their professional bodies.

Many studies have highlighted many factors that affect quality of patient care. Supply shortages, infrastructure problems, and inadequate human resources to provide the care have been cited as major factors (Jelsma et.al, 2005). Many facilities especially in developing countries lack basic supplies and equipment. While the health facilities are committed to replenish the HBC kits, they do not have adequate capacity to cope with the increasing numbers of HIV and AIDS patients and this results into shortage of supplies most of the times (NAC, 2003). CHBC Drugs and other supplies such as gloves are irregular, erratic and inadequate for providing care (UNICEF, 2004). This implies that simple physical illnesses cannot be treated at home.

Usually the infrastructures are in debilitated conditions. As a result the providers become frustrated and this affects their interaction with patients seeking care. In some cases delays in referrals from community to health facility and facility to facility is another problem that might arise due to shortage of resources. In most developing countries even if the cases are referred in good time from the community many rural health centers do not have means of communication [telephone, radio and transport]. This leads to delays in dealing with CHBC patients who require referral for immediate attention. Studies of quality of care from low income settings also indicate lack of stewardship of finances as a barrier to quality of care (WHO, 2000).

In Malawi, the situation is the same and has resulted into limited care being given by community based care providers. Although communities are willing to assist, they do not have the capacity because of the chronic poverty and stigma. CHBC requires adequate resources and coordination between health sector and the implementers of CHBC (Chikalipo, 2007).

### **3.5.3 Professional supervision to Caregivers**

According to Donabedian (1988) this is what is referred as the process of quality of care. In Malawi, Community Home Based Care shall be provided by: family members, trained community members including traditional birth attendants and healers, trained extension workers and trained health workers who are supposed to provide professional supervision. To ensure that Community Home Based Care providers have necessary knowledge and skills, they shall be specially trained in Community Home Based Care. Both care providers and trainers shall undergo formal training as prescribed by the policy. Trainers in CHBC shall be certified health workers such as Nurses, Medical Assistants, Clinical Officers and Doctors. They shall have successfully completed a ten days formal training in community home based care, principles of teaching and adult learning. Government approved CHBC manuals shall be used in the facilitation of training of trainers, health workers and service providers. Care providers shall undergo ten days training in home based care. A refresher for previously trained care providers and trainers will be conducted depending on identified needs. It shall be conducted for five days. Trained care providers shall transfer skills to the primary caregiver during each home visit as basic nursing care skills are being provided (Malawi National CHBC Policy and guidelines, 2005).

Poorly supervised care providers will bring in substandard care. Many care providers also lack adequate training or refresher courses to upgrade their skills and therefore lack decision making power and do not even recognize complications. Usually people in the community can not recognize serious problems due to inadequate information (WHO.1998). According to the Malawi National CHBC policy guidelines (2005), emphasis is placed on ensuring that CHBC care providers have necessary skills and knowledge and that there shall be individuals that are specially prepared to train CHBC providers.

Community care providers shall be supervised in the following areas: home assessment, practices on infection prevention and control, provision of basic nursing care, knowledge and skills, drug usage and storage, utilization of supplies and storage, record-keeping, documentation and report writing, patient referral

system, patient response and satisfaction with care, provision of health education to patients, clients and families and adherence to scope of practice. Lack of supervision of the volunteers which could have strengthened their skills through mentorship compounds the problem even more (Chikalipo, 2007).

A key component of quality is relationship between clientele and the care providers. The relationship establishes the general manner of interaction during individual service delivery and this can easily be identified during supervision. Good relationships can bring patient satisfaction with care being given. It often determines patient's willingness to comply with treatment (Moore, Armubruster, Graeff, Copeland, 2002). In Malawi several studies have identified staff attitudes as hindrance to provision of quality care, (Malawi Network of People Living with HIV/AIDS (MANET, 2003). Lack of motivation of service providers is one important reason for poor attitudes (Prual, Bouvier-Colle, de Bernis, and Braeart, 2000). According to Donabedian (1988, both structure and process are very important in quality care. The process involves the technical competence of the care provider and the interactions between caregivers. He emphasizes that regular refresher courses, frequent quality supervision and giving of incentives to motivate good performance would assist to improve qualities of care providers.

#### **3.5.4 Minimum package**

According to the Malawi National CHBC policy guidelines (2005), implementation of comprehensive CHBC package could be feasible with adequate financial, human, material resources, strong community mobilization and participation.

Every CHBC implementing institution should provide a *minimum package* of community home based care services to patients. Care providers shall at each visit to the patient implement the package as determined by individual patients needs. The minimum package shall comprise basic nursing care, management of common health ailments in the home/community, prevention, identification and referral of opportunistic infections, palliative care including psychosocial and spiritual care, support to the primary care giver, infection prevention and control in the home, nutrition education and food supplementation where feasible,

monitoring of the patient on Cotrimoxazole prophylaxis, ARV and TB treatment, IEC on prevention of HIV, TB and Malaria to patient and family members, promote use of Insecticide Treated Nets by chronically ill patients, discharge planning and referral to appropriate services and ongoing counseling.

For efficient and effective implementation of the CHBC policy and guidelines adequate financial, human and material resources are required. Government, donors and development partners shall assist in the provision of the needed resources. This will enable delivery of quality services by implementing institutions.

### **3.5.5 Collaboration of Stakeholders (Government, NGOs, Partners)**

Collaboration amongst stakeholders is important (Chikalipo, 2007). Indications are that there is a strong will by most stakeholders to play a complimentary role to each other. Although NAC is responsible for coordinating care and support activities for HIV and AIDS persons, they are incapacitated by the fact that the majority of the CHBC support groups are facilitated by Non Governmental Organizations that have their own interests which may not be likely in line with the interests of the government (Chikalipo, 2007). It can be concluded therefore that when resources are pooled together, the likelihood of providing a comprehensive care package is high and that however binding policy may be as long as there are several players to provide support disjointedly, the collective outcome will fall short of meeting the overall objective although individually the stakeholders will have achieved their objectives (NAC, 2003).

## **3.6 CONCLUSION**

This chapter has outlined the framework for quality of care for CHBC in Malawi as a conceptual perspective which has been described to guide the present study. Donabedian`s (1988) elements of quality of care which are structure, process and outcome have been applied in the Malawian National CHBC programme to determine the deficiencies in its implementation to PLWHA in Malawi. The next chapter has described the methodology which is the approach which was taken to execute the study.

## **CHAPTER 4**

### **RESEARCH DESIGN AND METHODOLOGY**

#### **4.1 INTRODUCTION**

This chapter describes the methodological approach used to conduct this study and answer the research questions. The research strategy assisted to explore the quality of care and whether the Malawian CHBC program is responding to the health problems/ needs of the HIV and AIDS patients in Lilongwe District, Malawi. The design was meant to ensure rigour and trustworthiness in the study. The research setting, sampling methods, data collection techniques, the instrument which was used and the trustworthiness of the instrument are described in the sections that follow. The chapter concludes with an overview of ethical considerations and the measures which were observed to protect the rights of the study participants.

#### **4.2 RESEARCH DESIGN**

In order to meet the aims and answer the questions of this study, a qualitative research design using hermeneutical phenomenology which studies interpretive structures of experience was used. Qualitative research examines life experiences (i.e. the lived experience) in an effort to understand and give them meaning (Byrne, 2001). This usually is done by systematically collecting and analyzing narrative materials using methods that ensure credibility of both the data and the results. Phenomenology is one of the many types of qualitative research that examines and describes the lived experiences of humans. Phenomenology offers nurse scholars and clinicians an approach to inquiry that has a good fit with nursing philosophy and nursing art: understanding unique individuals and their meanings, interactions with others and the environment (Lopez and Willis, 2004).

Phenomenology as a research approach was conceived by the German philosopher Husserl, at the beginning of the 20<sup>th</sup> century to investigate

consciousness as experienced by the subjects. According to him, the researcher is interested in how respondents give meaning to their experience, in other words how they perceive their world. The phenomenologist investigates subjective phenomena in the belief that essential truths about reality are grounded in people's lived experiences (Polit and Hungler, 1999; Burns and Grove, 2005: 55). A phenomenological study often involves four steps which are bracketing, intuiting, analyzing and describing (Polit and Hungler, 1999; Polit & Beck 2004: 253).

The phenomenological method, which examines subjective human experiences, is commonly used in answering questions that are foundational to sound nursing science. However, there is more than one philosophical school of phenomenology, and the research findings generated will depend on which philosophical approach is used. The two main phenomenological approaches evident in the nursing literature include descriptive (Eidetic) phenomenology and interpretive (Hermeneutic) phenomenology (Lopez and Wills, 2004). This study has chosen the interpretive (hermeneutic) phenomenological approach. In a hermeneutic study, theory is not used in a formal way, that is, to generate hypothesis to be tested (Lopez and Wills, 2004). Instead, a theoretical approach can be used to focus the inquiry where research is needed and is used to make decisions about sample, subjects and research questions to be used (Lopez and Wills, 2004). A question that interpretive inquiry asks is "how does the life world inhabited by any particular individual in this group of participants contribute to the commonalities in and differences between their subjective experiences". For example in this study, the researcher encouraged the participants to describe interactions, relations to others, experiences of the body and experiences of time to place the lived experience in the context of daily living practices and socialization.

The interpretive approach does not negate the use of a theoretical or conceptual framework as a component of inquiry (Lopez and Wills, 2004). If a framework is used, the study should provide evidence that it does not have a biasing effect on the narratives of the participants and the framework will be used to interpret the findings. According to Lopez and Wills (2004), the technique of bracketing as described by descriptive phenomenologists is inconsistent and questionable within

a hermeneutic approach although making preconceptions explicit and explaining how they are being used in the inquiry is part of the hermeneutic tradition.

In this research, the interpretive (hermeneutic) design was therefore chosen because it is especially suited to the study of clients' experience of illness and the care they receive. As the word hermeneutic is derived from the name Hermes, a Greek god who was responsible for making clear or interpreting messages between gods, it was also expected that in this study, the approach will be used to bring out and make manifest what is normally hidden in human experience and human relations. Lopez and Wills (2004), attest that in relation to the study of human experiences, hermeneutics goes beyond mere description of core concepts and essences to look for meanings embedded in common life practices. It was the expectation of this study therefore, that these meanings are not going to be apparent to the participants but can be gleaned from the narratives produced by them. The focus of a hermeneutic inquiry is on what humans experience rather than what they consciously know (Lopez and Wills, 2004).

Phenomenology affords nursing a new way to interpret the nature of consciousness and of an individual's involvement in the world. As phenomenology has evolved as a philosophical context for nursing research and as a research method, the traditional data collection strategy has been the qualitative, in-depth interview. The output of the interview is a narrative account by the participant of his or her knowledge and experiences related to the topic of study. Using a phenomenological approach in this study therefore, has given a chance to PLWHA to be fully explored from their own perspective (i.e. capturing the lived experience). Based on the research purposes, the approach also focused on individuals' interpretation of their experiences and the ways in which they expressed them. As stated earlier, the purpose of this study was to explore and describe the experiences that HIV and AIDS patients who are on Community Home Based Care Programme have in Lilongwe district of Malawi and later develop practical guidelines for the implementation of quality home care in Malawi. With specific focus on i) What it means to live with HIV and AIDS in Malawi? ii) How do HIV and AIDS patients perceive the care, support and treatment provided to them at home? iii) What are the health needs of HIV and AIDS patients in Malawi? iv) What

information, education and communication (IEC) messages are provided to HIV and AIDS patients at home? v) Does the current Community Home Based Care programme improve the quality of life for the HIV and AIDS patients in Malawi? vi) What challenges or problems are faced by Community Home Based Care patients in Malawi?

Since the goal of phenomenology is to describe lived experiences of people, this means that only those who experienced the phenomena were therefore capable of communicating them to the outside world (Polit and Hungler, 1999). This study focused on what people living with HIV/AIDS experienced in regard to care they receive in their homes and how they interpreted these experiences. The study has therefore provided an understanding of whether the current CHBC program is responding to the health problems/ needs of the HIV/AIDS patients in Malawian.

#### **4.3 RESEARCH SETTING**

In qualitative research, data is collected in real world, naturalistic settings (Polit and Beck, 2004:248). This study took place in semi rural and urban areas of the Lilongwe district of Malawi to capture the experiences of all PLWHA. Lilongwe is the administrative capital city of Malawi and is one of the highly populated districts with a total population of 1,346,360 people. There is a lot of movement to and from the city and HIV prevalence is high (Malawi Demographic Health Survey, 2004). According to UNAIDS (2002), Lilongwe district is one of the districts whose HIV prevalence is higher than the national HIV prevalence of 12% for people aged 15 – 49 years. This study has used patients from 3 major organizations dealing with PLWHA in Lilongwe district. These are: the Light House which is a public/ government institution, NAPHAM (National Association for people living with HIV and AIDS in Malawi), and Lilongwe Diocese. The Light House has in total 339 patients on CHBC program based in 14 Community Based Organizations (CBOs). These are located in urban, semi urban and rural areas. Out of these patients, 292 are HIV positive. NAPHAM has over 200 patients in 10 CBOs while the Lilongwe diocese has also over 250 patients on CHBC program in 10 CBOs. These three major organizations were chosen because they are the ones registered with a lot



of PLWHA and also they were the first ones to start formal CHBC services in Malawi and therefore the researcher hoped to have a lot of people with rich experiences concerning HIV/AIDS and CHBC.

#### **4.4 POPULATION AND SAMPLE**

The study population comprised PLWHA aged 14 years and above living in Lilongwe district. In qualitative research, experiences, events, and incidents are more the focus of sampling than people (Burns and Grove, 2005: 352). The researcher attempted to select subjects who were going to be able to provide extensive information about the experience or event being studied. Also according to Morse (2000), selection of participants in qualitative research must be both appropriate and adequate. Appropriate implies the degree to which the choice of participants and method of selection fit the purpose of the study. It is important to note that this study also included minors (less than 18years) as participants. This was so in order to get their experiences with CHBC apart from adults only. Proper procedures were followed before enrolling minors in the study. A nurse working in the organizations who was used as a go between in recruiting participants had to seek consent from parents or guardian available like any other participant in the study. After acceptance of the parent/ guardian the nurse explained to the minor as well in order for her/him to understand the situation then later on thus when the participant was handed over to the researcher for interviewing.

Phenomenological studies involve a small number of study participants (Burns and Grove, 2005:358). Although numbers have a less prominent place in qualitative research, they are integral to qualitative data. According to Sandelowski (2001), as in quantitative research, numbers e.g. in the form of demographic, epidemiologic and survey data are used in qualitative research to establish the significance of a research problem, to document what is known about a problem, and to describe a sample. In this study therefore, a non-probability sample was used because it was more appropriate for qualitative research since the purpose was to contribute to an understanding of phenomena and therefore this sample best provided the required data. A purposive sampling technique was also used to choose the sample i.e. the researcher purposefully selected the specific participants who were willing to

provide rich information needed in order to gain an insight and discover new meaning on issues specifically affecting the PLWHA in relation to those who have had an experience of being on CHBC. The researcher was however aware that in Malawi, HIV is still a sensitive issue and therefore not all people could be comfortable to disclose their sero-prevalence status. According to Patton (1990), adequacy is also an important issue in non-probability samples. In this study therefore, to achieve efficiency and quality of data, the researcher ensured that the number of participants were adequate only when saturation of information was achieved i.e. data were collected until no more new information emerged (data saturation). A total of 15 in-depth interviews were conducted both in semi rural and urban areas of Lilongwe district. These were intense interviews where the researcher actively engaged participants in a dialogue and probed to understand what the participant meant by his/her comments. The aim was to gain an in-depth understanding from this purposefully selected sample and not to generalize the findings. Each in-depth interview lasted approximately 45–60 minutes.

#### **4.5 INCLUSION CRITERIA FOR PARTICIPANTS**

The participants were those whose sero-prevalence was positive. They had known their sero-prevalence status and they were willing to disclose this information to the researchers. They were aged 14 years old and above and enrolled on CHBC program for a minimum period of 6 months. They were also willing to share their experiences with the researchers.

The above criteria was chosen considering that in Malawi, all chronically ill people (3months or more) including adults and children suffering from chronic diseases such as HIV/AIDS, TB and Cancer in the community are eligible for CHBC services (Malawi National CHBC Policy and Guidelines, 2005). In Malawi very few health facilities have machines to test CD4 count and therefore eligibility into CHBC for HIV/AIDS clients is symptomatic.

## **4.6 IN-DEPTH INTERVIEWS**

Data were collected by the researcher herself in the homes of patients. The study used services of two research assistants. To maintain consistency in asking of the questions and probing, it was decided that only the researcher was to carry out this task whilst one of the assistants was used to recruit participants in each of the organizations where participants were coming from. The other participant took care of issues of logistics as well as taking field notes to make sure that everything was captured. Data were collected over a period of two months. Visits for interviews in the homes were done on Tuesdays and Fridays because these were the days the researcher was advised by the nurse who was recruiting participants from organizations. While at the home of the participant, a private room was identified by the owner and intense interviews were conducted in Chichewa which is the common language for Lilongwe district. Each interview lasted approximately 45 – 60 minutes. A tape recorder was used to capture the discussions after getting prior permission from the participants. Where participants were not willing to have their responses recorded on the tape recorder, the researcher recorded all the responses as notes. Field notes were written by the researcher and the assistant throughout the data collection period regardless of tape recording. Observations on mood and behaviour patterns was noted and recorded as notes.

## **4.7 INTERVIEW GUIDE**

In a phenomenological inquiry, the main source of data typically is in-depth conversations in which the researcher and the participant are full co-participants (Polit and Beck, 2004). Through these in-depth conversations, the researcher gained entrance into the participants' world and had access to their experiences as lived. In order to facilitate these conversations therefore, an in-depth interview (IDI) guide was developed by the researcher for the study.

### **4.7.1 Construction of the Research Questions**

The construction of the question items was influenced by the objectives of the study and ethical issues. Items in the interview guides included those addressing

the type and extent of care that people living with HIV and AIDS (PLWHA) receive at home. An in-depth study of relevant literature was undertaken to derive the content for the in-depth interview (IDI) guide (see appendix 5). The experience which the researcher has had while working with PLWHA in the community setting for many years also served as a framework to construct the tool.

The tool mostly comprised of open ended questions that required lengthy narratives from the participants. The use of open-ended questions is advocated to guide interviews in qualitative research (Polit and Beck, 2004). The guide used, allowed for flexibility in response patterns and probing tactics. Qualitative researchers are encouraged to make use of probes in order to deepen the response to a question, increase richness and depth of responses, and give cues to the interviewee about the level of response that is desired (Malata, 2004). According to Patton (1990:372), a probe is a follow up question used to go deeper into interview responses. As such, the author emphasizes that, probes should be conversational, offered in a natural style and voice, and used to follow up initial responses.

In this research, areas of emphasis from the tool were: Quality of home care for HIV and AIDS patients, Quality of life the patient's experienced, and the perceptions of the participants to improve quality of CHBC program in Malawi (see appendix 5). Apart from use of the tool, the researcher also observed the non-verbal cues coming from the participants and these were part of the field notes.

#### **4.8 TRUSTWORTHINESS**

Trustworthiness refers to credibility and validity of qualitative research. In a qualitative study, the main goal is not to generalize the results but to accurately represent participants' experiences and perceptions coming from their rich descriptions in a truthful manner (Burns and Grove, 2005). According to Polit and Hungler (1999), many qualitative researchers ensure validity and reliability by evaluating the quality of their data and findings. In this study issues of validity and reliability in the individual in-depth interviews were considered important by the researcher. This is called trustworthiness and it was established using the four

criteria namely: credibility, transferability, dependability and confirmability. The following section will explain in detail how trustworthiness was ensured in this study.

#### **4.8.1 Credibility**

Credibility ensures that research findings are in accordance with the reality of participants i.e. how true the findings of a study are within the context in which it was done (Polit and Beck, 2004). In this research, steps have been taken to improve and evaluate the credibility of the data obtained i.e. quality data have been presented to gain confidence in the truth of the data. This was done through peer review where interpretations of the data was discussed with experts in the field of community home based care and also discussions were done with the research supervisor at UNISA. The data were reviewed and comments regarding the plausibility of the emerging findings were sought. Credibility of qualitative data and the resulting findings is the aspect of data quality (Polit and Hungler, 1999; Malata, 2004).

##### **4.8.1.1 Prolonged engagement and experience**

This refers to investment of sufficient time in the data collection activities in order to have an in-depth understanding of the views or phenomenon of the group under study. This process is important when dealing with qualitative research (Polit and Hungler, 1999). The researcher of this study is a nurse who has vast experience working with PLWHA in the community for many years. The researcher's qualifications, trainings received in HIV and AIDS and CHBC, and the experience gained were very important in establishing confidence in the data that was obtained. Adequate time was set aside to spend with the participants during data collection in order to build a trusting relationship. Persistent observation was also done on the participants in their natural environment i.e. data were collected from their homes or from the places where normally PLWHA gather. Conversations which were in-depth were only those that were relevant to the phenomenon being studied.

Since the study used research assistants, it was made sure that these were also nurses with some experience in HIV and AIDS. This also assisted the research assistants to develop adequate experience on HIV and AIDS issues.

#### **4.8.1.2 Triangulation**

Triangulation refers to the use of multiple data sources, research methods and multiple investigators to study a phenomenon (Burns and Grove, 2005). In this study, method triangulation was done. In-depth interviews and observations were used concurrently to address the research questions. Use of multiple referents to draw conclusions about what constitutes the truth about this research has been vital in this qualitative research (Polit and Hungler, 1999; Morse, 2000).

#### **4.8.1.3 Peer debriefing**

In qualitative research, peer debriefing refers to discussion of the researcher's interpretations and conclusions with another person not directly involved (Burns and Grove, 2005). In this study, the interview guide was reviewed by experts who have experience and knowledge of the phenomenon being studied namely HIV and AIDS Care (CHBC). These experts reviewed and explored various aspects of the inquiry. The experts critically looked at the relevance of the questions and assessed the degree to which the study variables adequately represented the phenomenon being studied.

#### **4.8.1.4 Member checks**

Member checking is also one of the most important techniques for establishing the credibility of qualitative data. It entails providing feedback to the study participants regarding the data and the researcher's emerging findings and interpretations in order to secure participants' reaction (Polit and Hungler, 1999). In this research, in order to be sure that participants' reality had been presented, the researcher continually asked participants for clarification on what they had said. By doing this participants were provided with an opportunity to change information which was given by mistake and at the same time assessed the researcher's understanding

and interpretation of the data. At the end of the interview, the participants were given a summary of what they had said and an interpretation of the interview to check on the researcher's accuracy and understanding of the information.

#### **4.8.2 Transferability**

Transferability refers to the degree to which the results of qualitative research can be generalized or transferred to other contexts or settings (Burns and Grove, 2005). The researcher had a responsibility to provide adequate descriptive data in the research report in order for people to evaluate the applicability of the data to other settings or groups. When transferability is considered, the participants should be representative (Polit and Beck, 2004). In this study, purposive sampling was used so that participants were suitable and representative of the group under study. These participants provided rich data on the phenomenon under study. The researcher has therefore made available thick description of data to people who might need it in order to permit judgments about contextual similarity.

#### **4.8.3 Dependability**

The dependability of qualitative data will always tell the stability of data over time and over conditions. There can be no credibility in the absence of dependability (Polit and Hungler, 1999; Morse, 2000). Dependability determines whether findings would be consistent if the inquiry were to be replicated with the same participants in a similar context (Polit and Beck, 2004). In this study, the findings of the research were checked and audited by external checks in order to be dependable.

#### **4.8.4 Confirmability**

Confirmability refers to the degree to which the results could be confirmed or corroborated by others (Polit and Beck, 2004). In qualitative research, the issue of confirmability does not focus on characteristics of the researcher but rather on characteristics of the data. Inquiry audits can be used to establish both dependability and confirmability of the data. In this study, reflexivity assisted the

researcher to be free of bias in processing the data. This was done by making sure that information was audio taped and transcribed and therefore this minimized researcher bias and it also ensured that data can be confirmed. In qualitative research, objectivity or neutrality of the data, which brings an agreement between two or more independent people about the data's relevance or meaning is necessary (Polit and Hungler, 1999; Sandelowski, 2001).

#### **4.9 PILOT STUDY**

Pre-testing of the interview guide was done prior to the actual study to determine if the instrument would bring out desired information, how long the instrument would take to administer and to identify difficulties or ambiguous questions. Pre-testing also determined relevance and appropriateness of the tool. The other reason for pre-testing the tool was to train the nurse who assisted with data collection in the study.

According to Polit and Beck (2004:51), a pretest of an instrument is a trial run to determine, in so far as possible, its clarity, research adequacy and freedom from bias. This pilot therefore, assisted to clarify questions which would possibly be misinterpreted during the actual study. Questions which were not clear were modified and rephrased.

During the month of June, 2008, three patients were identified at Chinsapo location in Lilongwe district where there were patients on CHBC program. All issues to do with ethics and human rights were followed (see section 4.11). Adequate information was given to them about the study to be conducted which was given through information sheet and that had been translated into the vernacular language Chichewa. After the patients understood and accepted to take part in the pilot, three in-depth interviews were conducted. These patients/ individuals were not eligible for data collection for the main study later. Training of the assistants on recruitment of participants and on how to take field notes was also done during the pre-testing period. After pre-testing, the tool was finalized and was made ready for use in the data collection process.



Two nurses were identified to assist in this study. One of these nurses was supposed to be working in the organizations where participants were taken in order to help with recruitment process. The other nurse worked in the field of community home based care but not at the places where the study was taking place to avoid potential bias during taking of field notes. These nurses were chosen and considered suitable for these roles because of the knowledge of research which they had acquired during the time they pursued General Nursing course. Training took two days. During the first day, theory was imparted covering the following areas: the purpose of the study, method of data collection, tools to be used in collecting data, administration of the tool to participants and clarifications on terminologies used in the tool including use of Chichewa language during interviews and how to audiotape the interviews. The nurse who was responsible to take field notes was advised to be accurate in recording the responses from participants i.e using the exact words of the participants to avoid changing the meaning of the message. The importance of establishing and maintaining trust with participants, sensitivity of HIV and AIDS issues and therefore need for confidentiality were also emphasized during this training. The nurses were also trained on the right language or terminologies when addressing issues of HIV and AIDS to avoid frustrating the patients.

#### **4.10 RECRUITMENT OF STUDY PARTICIPANTS**

To recruit the participants, a nurse working in these organizations was used as a go between to explain to the participant for possible participation in the study. Using an information letter to participants, the nurse explained in detail about this study. Upon acceptance, the participant was handed over to the researcher to continue with interviews.

#### **4.11 ETHICS AND HUMAN RIGHTS ISSUES**

When humans are used as study participants as they usually are in nursing research, care must be exercised in ensuring that the rights of those humans are protected (Polit and Beck, 2004:141). Since this study involved human

participants, formal approval of this research protocol was obtained from ethical committees of the following Institutional Review Boards: UNISA ethics committee, Kamuzu College of Nursing and College of Medicine from Malawi. Consent was also obtained from the three major organizations dealing with people living with HIV and AIDS (PLWHA) and these were: The Light House, NAPHAM and the Lilongwe Diocese.

Human beings need to be treated as autonomous agents who have the freedom to conduct their lives as they choose without external controls (Burns and Grove, 2005; Polit and Beck, 2004:147). To observe this, informed consent was obtained from all the participants after being given adequate information concerning the nature and purpose of the study, methodology, the possible benefits and risks associated with participation in the study. Participation in this study was voluntary. This means that prospective participants had the right to decide voluntarily whether to participate in this study without risking any penalty or prejudicial treatment. It also meant that people had the right to ask questions, to refuse to give information, to ask for clarification, or to terminate their participation.

In this study therefore, only those participants who were willing to take part were included. To give their consent participants were asked to sign an informed consent form (See Appendix 2) and those who could not write were asked to provide a thumb print on the consent form in place of a signature. For those that were uncomfortable to sign verbal consent was also acceptable. In addition, participants had the right to withdraw from the study at any time they wanted without a penalty. They were assured that withdrawal from the study would not make them suffer any harm or discomfort.

Participant's rights to confidentiality were protected by making sure that their identity was not known by any other people and the information given was not made available to other people other than those involved in the research. Sources of raw data, interview guides, signed consent forms and computer diskettes were secured in a locked filing cabinet in the office of the principal researcher at Kamuzu College of Nursing in Malawi. Access to raw data files on the computer was protected by a password known only to the principal researcher.

Participants' names were not used during the discussions and neither were they written on the interview guides in order to guarantee confidentiality. Participants were allowed to generate their own identification codes. This code was to be identified on each form that was completed for that participant. Furthermore, participants' names were not mentioned in the tapes. Consent was also sought from the participants to have their pictures taken and included in the thesis report.

Virtually all research with humans involves intruding into personal lives (Polit and Beck, 2004:149). Researchers should ensure that their research is not more intrusive than it needs to be and that participants privacy is maintained throughout the study. In this research therefore, all interviews were conducted in private e.g. in a room where people who were not involved in the discussion would not have access to the information. No data was linked to any participant.

There were no known risks or harm to people who participated in this study. However, in case of psychological or emotional upset, provisions were made to offer counselling to the participants. According to Polit and Beck (2004:144), psychological consequences of participating in a study are usually subtle and thus require close attention and sensitivity. It was also made known to participants that they were free to leave out any question that they felt uncomfortable to respond to avoid psychological trauma.

#### **4.12 CONCLUSION**

This chapter has described the research methodology which was used for this study. The research design, the setting, the sample and sampling methods, data collection methods, the research tools used as well as reliability and validity issues have been described. The chapter concludes by outlining measures which were taken to ensure ethical practice and to safeguard participants' rights. The next chapter will discuss analysis of data and presentation of findings of the study.

## **CHAPTER 5**

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

#### **5.1 INTRODUCTION**

The analysis of research data and the findings of this study will be presented in this chapter. Data were obtained from individual in-depth interviews with fifteen (15) clients who are living with HIV and AIDS in the Lilongwe district of Malawi. The chapter begins with the description of the analytic process which includes data coding, organization and reduction as described by Greenlagh (2007:79); Polit and Beck (2004:573) as data management. The authors assert that identification of themes or concepts and sorting them is crucial at this level.

In the preceding chapter, I stated the purpose of this study as to explore and describe the experiences that HIV and AIDS patients who are on Community Home Based Care Programme had in Lilongwe district of Malawi. The study used these six research questions: (i) What does it mean to live with HIV and AIDS in Malawi? (ii) How do HIV and AIDS patients perceive the care, support and treatment provided to them at home? (iii) What are the health needs of HIV and AIDS patients in Malawi? (iv) What information, education and communication (IEC) messages are provided to HIV and AIDS patients at home? (V) Does the current Community Home Based Care programme assist to improve the quality of life for the HIV and AIDS patients in Malawi? (vi) What challenges or problems are faced by Community Home Based Care patients in Malawi?

The researcher utilized data collection techniques carefully in order to promote quality of the process of obtaining data from participants which has produced credible results. The researcher used a guide to interview participants. It is worth stating that some questions on the guide had to be probed further in order to arrive at the theme of the study. Participants were free to respond in the language that they were familiar with. Almost all participants responded in Chichewa which is the common language in Malawi.

The study was conducted in the months of June and July, 2008. Two nurses who were currently working in the field of community home based care assisted in the study. Interviews took place in the homes of participants and at certain points; pictures were taken after seeking consent from the owners. Considering that issues of HIV and AIDS are still sensitive in Malawi, a one to one discussion was done in a private room where nobody else could listen to the discussions. At the end of the interviews, participants were given chance to ask questions or to give any comments they had concerning the theme of the discussions.

## **5.2 DATA CODING, ORGANIZATION AND REDUCTION**

Qualitative analysis is a process of fitting data together, of making the invisible obvious, of linking and attributing consequences to antecedents. This is also a process of conjecture and verification, of correction and modification of suggestion and defence (Polit and Beck, 2004:572). These authors assert that the major sources of data in qualitative research are audiotapes and field notes. In this study therefore, during data collection, the unstructured interviews were recorded on audiotape and the purpose of doing this was to ensure that the narrative statements denoted the original and true meanings of the first speakers. This process also helped not to leave out any information from the participants.

Since the information collected through the interviews from PLWHA was available in the tapes, the researchers then listened to the audiotape several times to get to know the data with the research concerns in mind. Text that was relevant and related to the specific research concerns was taken. The interviews were transcribed verbatim. According to Polit and Beck (2004:572), verbatim transcription is a critical step in preparing for data analysis. Researchers therefore need to ensure that transcriptions are accurate, that they validly reflect the totality of the interview experience, and that they facilitate analysis (Polit and Beck, 2004). In this research, each typed transcript was checked thoroughly against the audiotape by reading and re-reading the text. Impressions were written down as the data was being read with the hope that it might be useful later. During transcribing, the researcher used a second person to listen to the tapes which were in vernacular language and comparisons were made with the transcribed

data. This ensured accuracy in the translated data into English and hence promoted content validity of the various statements provided by participants as it is evidenced by Polit and Beck (2004:263) who said that in qualitative studies, content analysis is a must.

The transcribed text was then imported into a qualitative data analysis software package “*ATLAS. Ti*” version 5. *ATLAS.ti* was chosen as the type of scientific ware because it is a powerful program for qualitative data analysis. It offers tools to manage, extract, compare, explore and reassemble meaningful pieces from large amounts of data (*ATLAS. ti* manual, 2004). Its emphasis is on qualitative, rather than quantitative analysis i.e. determining the elements that comprise the primary data material and interpreting their meaning which is compatible with this current research. The process of organizing and integrating narrative qualitative information according to emerging themes and concepts was followed. The first step involved creating a project or a Hermeneutic Unit to enclose all the findings, codes, memos and structures. Then data files were assigned. The transcribed data from each interview were read and key words/ themes and significant statements were selected and reviewed. The researcher noted that different participants often used the same or similar words and phrases to express the same idea. These ideas shed light on my research concerns and these formed themes. Similar themes were then grouped together. Key words (codes) were assigned and memos that explained my thinking about the data were written. Basing on the codes assigned, data segments were compared. Code directorate was used to check whether the definitions of the codes were true and valid. Using families; primary documents, codes, and memos were organized with the aim of building semantic, prepositional or terminological networks from the codes created. This also helped to interpret the findings by attaching meaning and significance to the analysis.

### 5.3 STUDY FINDINGS

The findings are presented in sections mirroring the various study questions and also according to the major themes that were identified from the data collected. As stated before, this was a qualitative study and therefore the majority of data in this chapter are presented in a qualitative manner. The readability of the qualitative reports is usually enhanced by the inclusion of verbatim excerpts taken directly from the narrative data (Polit and Hungler, 1999).

The following conventions will be used in reporting the results of the study: **Italics** are used to identify direct quotes or direct words spoken by the participant. **Lines (---)** are used to indicate a reaction that came from the patient especially crying, sobbing or laughing. **Dots (...)** indicate that the client paused in the conversation during the discussion. Where necessary, participants were directly quoted word for word. The following scales were also used as may be appropriate for the quantification of the qualitative data:

**Table 5.1: Key**

"Majority/Most" refers to $\frac{3}{4}$ of participants
"Almost all or all" refers to more than $\frac{3}{4}$ of participants
"Minority/Few" refers to $\frac{1}{4}$ of participants and below.
"Always" refers to all the times
"Most frequently/most often" refers to $\frac{3}{4}$ of the time.

Although most of the results are qualitative in nature, some areas of inquiry were enriched through blending of qualitative and quantitative data. Multimethod research enhances validity of the research findings (Polit and Hungler1999). In this research therefore, descriptive statistics have been used in the presentation of demographic data findings in the form of graphs and tables.

## SECTION A

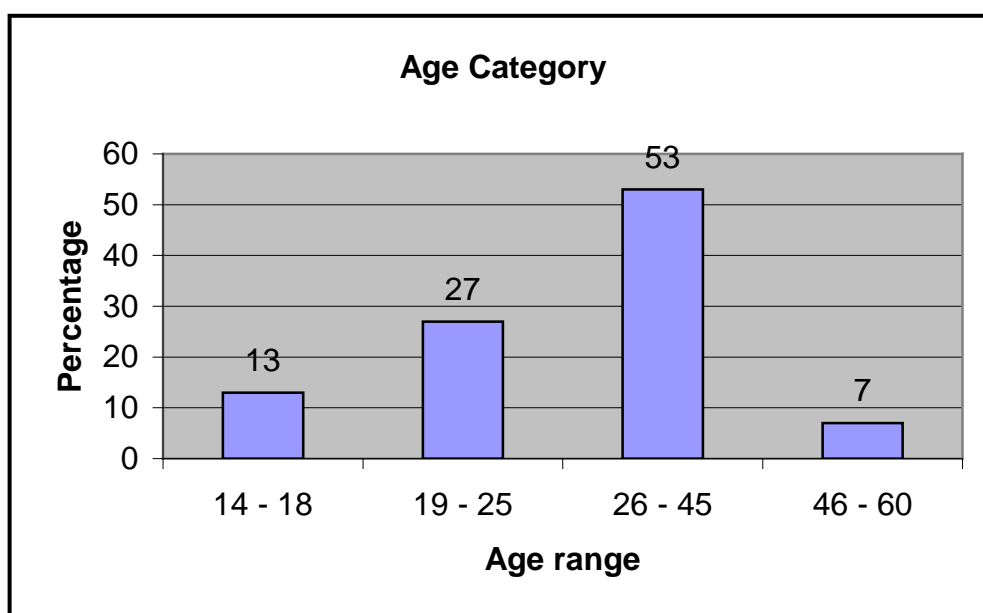
### 5.3.1 Demographic Characteristics of participants

This section consisted of six areas. Although these areas were not directly concerned with the purpose of the study, demographic information was collected and analyzed to determine the characteristics of the participants under study. The data comprised the age, sex, employment status, level of education, religion and marital status of the participants. Fifteen (15) participants took part in the study. Data yielded the following results:

#### 5.3.1.1 Age Distribution

Participants were asked to state their ages which are depicted in figure 5.1 below. Most of them, 53% (n=8) were between the ages of 26 and 45 years and 4 participants (27%) were between 19 and 25 years. Two participants (13%) ranged between 14 to 18 years while only one participant (7%) was within 46 to 60 years. The mean age of the participants was 28years.

**Figure 5.1 Age Category of participants (N = 15)**



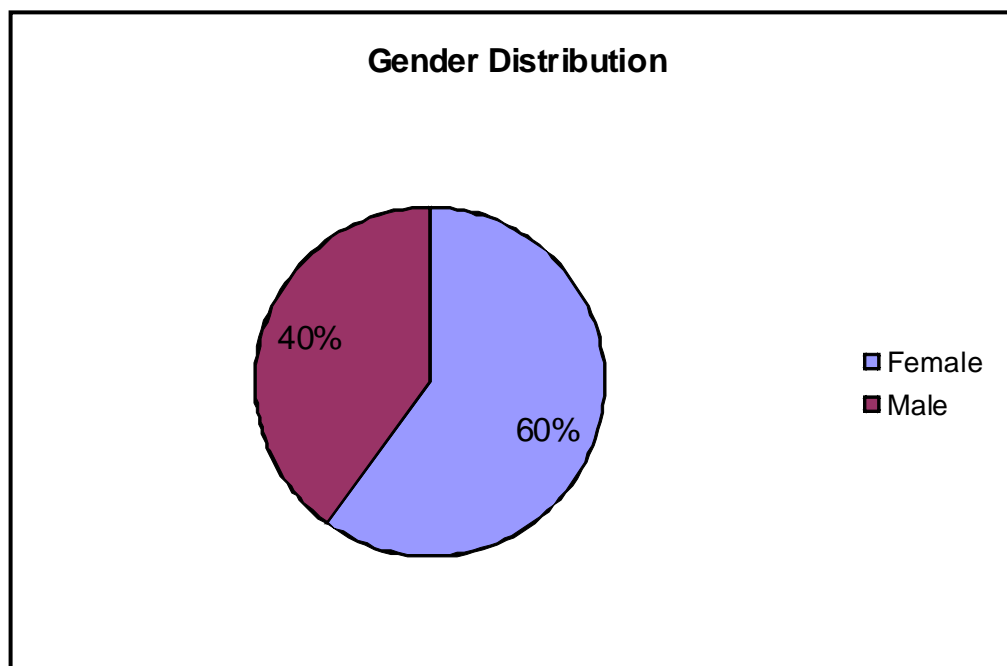


In Malawi, about 75% of all AIDS cases occur among people in the most economically productive age group of 20 to 45years (Malawi National AIDS Commission, 2003). This age category is the one that commonly are receiving Community Home Based Care services in Malawi. Indeed, girls who marry young in Africa are mostly from poor families and have low levels of education. Traditionally, if they marry men outside their village, they must move away which may expose them to loneliness, abuse and the risk of the deadly HIV and AIDS infection (Mbirimtengerenji, 2007). Due to some cultures, young girls are forced to get married. In these circumstances, not only are husbands on average older than their boyfriends, but they are also more likely to be HIV infected.

#### **5.3.1.2 Gender Distribution**

Out of the 15 participants interviewed, 60% (n = 9) were females while 40% (n = 6) were males. The males interviewed were aged between 26 and 45 years. This shows that the majority of the participants were women. Fig 5.2 presents the percentage of males and females interviewed.

**Figure 5.2: Gender Distribution (N=15)**



The AIDS pandemic has presented women with a massive dilemma in their sexual relationship with men, making prevention of HIV transmission through safer sexual practices problematic for them. The Centre for Disease Surveillance and Reporting (2000) has reported that over 95% of all cases and 95% of AIDS deaths occur in the developing world mostly among young adults 20 – 45 years and increasingly among women. The incidence of HIV infection in women is growing at a proportionately faster rate than in any other population group with heterosexual transmission being the most significant source of infection (De Bryun, 1992).

Gender – based factors have been associated with an increased risk for HIV in women from many perspectives including sexual power imbalance, economic issues and traditional socialization of men and women. Biological, social and cultural factors commonly referred to as gender-based factors place women at an increased risk to HIV infection hence receiving Community Home Based Care services in the homes. De Bryun (1992) notes that the impact of HIV and AIDS is particularly great for women for the following reasons:

- Various factors related to gender, place women at increased risk for exposure to HIV infection.
- Women's social position makes it difficult for them to undertake prevention measures.
- The psychological and social burden are greater for women than for men
- Biological differences between men and women in body structures place women at increased risk for exposure to HIV infection.

#### **5.3.1.3 Occupational status**

Table 5.2 explains participants' employment status. Five categories of employment status were included. The majority of the participants 40% (n=6), were housewives with no other type of work. Three participants (20%) stated that they do some business on a small scale. Of the three participants, two were males and one was a female. Another 20% (n=3) of participants had permanent jobs and these were all males. Three participants were employed, two were watchmen and the third

participant was a primary school teacher. One participant (n=7%) was a pensioner and two were school dropouts (see table 5.2).

HIV infection is mostly confined to the poorest, who constitute the most of those infected in Africa (Mbirimtengerenji, 2007). This is not simply that information, education and counseling activities are unlikely to reach the poor but that such messages are often irrelevant and inoperable given the reality of their lives (Mbirimtengerenji, 2007). Poverty is a crucial factor in the spread of HIV and AIDS. Similarly, poverty play a central role in perpetuating teenage marriages. Although findings are like this, CHBC services are common to all occupations.

**Table 5.2 Occupational status of participants (n = 15).**

<b>Type of occupation</b>	<b>Frequency</b>	<b>Percentage (%)</b>
House wife	6	40
Small scale business	3	20
Employed	3	20
Pensioner	1	7
School dropout	2	13
<b>Total</b>	<b>15</b>	<b>100%</b>

#### **5.3.1.4 Level of education**

Three major levels of education were used following the schooling system in Malawi. Level one comprises eight years of primary school education from standard one to eight. On successful completion learners receive a Primary School Leaving Certificate (PSLC). Level two comprise four years of secondary education namely form one to form four after which learners are given a Malawi School Certificate of Education (MSCE). Tertiary education comprises university education, college, technikon and various tertiary institutions where education and training is offered. On successful completion, learners receive degrees, diplomas

or certificates. Table 5.3 presents the years of schooling completed by the participants.

**Table 5.3: Level of education of participants (n = 15)**

<b>Level of education</b>	<b>Frequency</b>	<b>Percentage</b>
Never attended school	3	20
Primary school	8	53
Secondary school	4	27
Tertiary education	0	0
<b>Total</b>	<b>15</b>	<b>100%</b>

Findings indicated in Table 5.3 display a total of 53% respondents (n=8) who went through primary school education. Of the eight participants who had primary school education, 4 were males and another 4 were females. Four participants (27%) had secondary school education and out of these, two were males and another two were females. None of the participants went as far as college or university level. However, 20% of the participants (n = 3), stated that they never attended any type of school and all these were females.

It is important to note that the same male respondents who had some education are the ones who had jobs and are involved in some business. It was also noted that the women (n = 2) running a business, and primary school teacher are the ones who received primary school and secondary school education respectively. Participants who never attended school were housewives and unemployed.

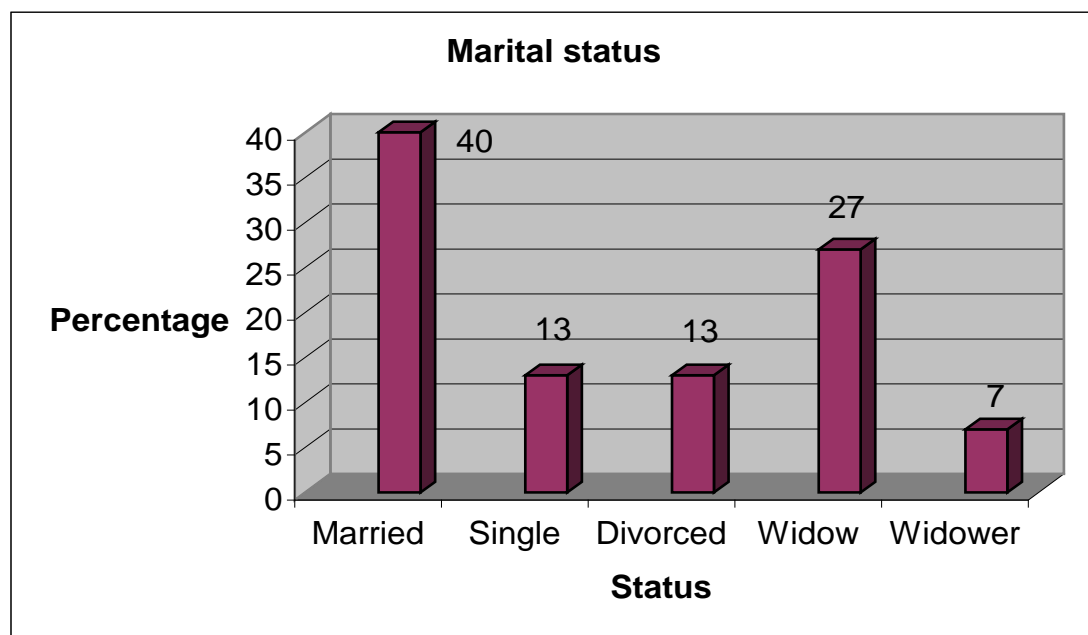
It is also important to note that literacy rate in Malawi is very low with only 39% of the adult population able to read and write. According to the Malawi National Health Plan (1999-2004), 48% of women and 30% of men have not attended school and up to 80% of rural women can neither read nor write. Younger men and women are typically more educated than older men and women. Once in school, males tend to progress further in their schooling than females. Secondary

school enrolment is only eight percent for males and three percent for females in rural areas (Malawi National Statistics Office, 1997). In Malawi, “education for all” has not yet been achieved though the importance of education especially for females has been emphasized in the country. Despite free primary school education which was introduced in 1994, limited access to education, poor quality of education, high rates of drop out and failures especially for females are still the underlying constraints (Malawi National Health Plan, 1999-2004). It is worth noting that in Malawi, most of the patients nursed at home (CHBC), are of lower class because the higher class are reluctant to be identified as having HIV/AIDS.

#### 5.3.1.5 Marital status

Findings indicate that the majority of the participants, 40% (n=6) were married and still living together at the time when interviews were conducted. Two participants (13%) were single and another 13% of the participants (n=2) were divorced and these were both females. Four participants (27%) were widows and one participant (7%) was a widower. As shown in Figure 5.3 the marital status of the participants appear.

**Figure 5.3: Participant’s marital status (n = 15)**



Throughout the world, marriage is regarded as a moment of celebration and a milestone in adult life (Mbirimtengerenji, 2007). Sadly, the practice is not the same when one is a victim of HIV and AIDS in the family. Sometimes young married girls are exposed to torture, abuse and the risk of the deadly HIV and AIDS infection. Women living with HIV and AIDS may be treated very differently from men in some cultures. This is common where they are economically, culturally and socially disadvantaged. Women are sometimes mistakenly perceived to be the main transmitters of sexually transmitted diseases such as HIV and AIDS. Men are more likely than women to be excused for the behaviour that resulted in the infection. Even a married woman who has been infected by her husband will be accused by her in-laws and end up divorced. In such a male dominated society no one ever accepts that the man is actually the one who did something wrong (Avert, 2008).

The fact that the majority of the participants (40%) are married, chances are high that HIV and AIDS can easily spread. It is therefore important that married couples should be expected to embrace fidelity which might decrease the spread of HIV and AIDS among themselves (Netangaheni, 2008). An observation made from the findings of this study is that, the majority of the participants who were married were men. Another observation important to be made is that, all the participants who were divorced were females. This brings the assumption that when women are found HIV positive, they are divorced. At the same time one may conclude that men who are found HIV positive receive full support from their spouses.

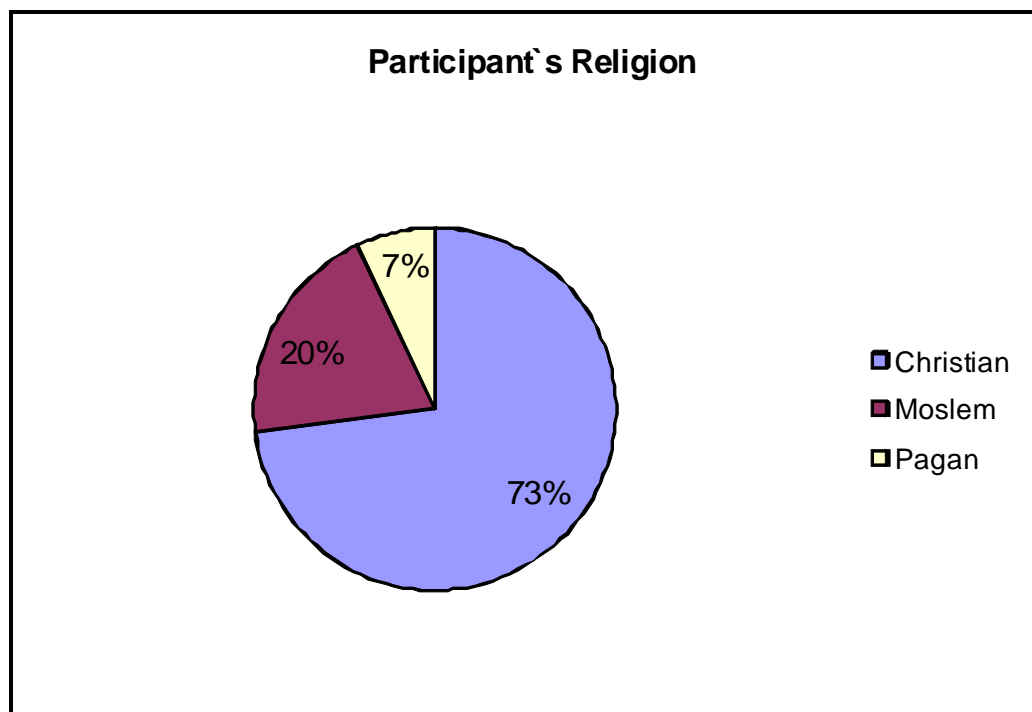
#### **5.3.1.6 Religion**

HIV and AIDS problem is the responsibility of the whole community including the church. Lack of support to HIV and AIDS patients would lead to unnecessary psychological problems.

Participants were asked to state their religion. Three categories of religion were identified according to the common practice in Malawi. These included category of Christians, Moslems and those who did not belong to any religion. An overwhelming majority of the participants 73% (n=11), affirmed they were

Christians belonging to a variety of churches. Three participants (20%) were Moslems and one participant was a non believer meaning that he did not belong to any religion by the time of the interviews. Fig 5.4 indicates the type of religion participants belonged to.

**Figure 5.4: Religion of participants (n = 15)**



The role of the church is to support and bring a message of hope to HIV and AIDS patients. In Malawi, religion has often been tolerant, welcoming and currently, Christianity has flourished in the whole country. What is surprising is that even up to now; some churches and church members still believe that HIV and AIDS is a punishment from God as a result of sinful behaviour (Stigma and HIV AIDS, year not given). Because of lack of knowledge on issues of HIV and AIDS, some church members stigmatize their fellow members. This behavior might bring a lot of fear and suffering to the HIV and AIDS patients. HIV and AIDS is incurable and deadly and this brings misery to HIV and AIDS patients especially because the main mode of transmission is sexual.

## **SECTION B: NARRATIVE STATEMENTS**

This section presents the narrative statements that were given by participants in this study. The following are the themes that were identified and discussed in the study:

- Theme 1: Living with HIV and AIDS in Malawi
- Theme 2: HIV and AIDS Patients face stigma
- Theme 3: Feelings of anxiety, worries and fears of death
- Theme 4: Care Providers for HIV and AIDS Patients
- Theme 5: Attitude of Care Providers
- Theme 6: HIV and AIDS Education
- Theme 7: Patient's Quality of Life
- Theme 8: Common Needs of HIV /AIDS Patients while on CHBC Program
- Theme 9: Provision of Information to HIV/AIDS Patients
- Theme 10: Benefits of Nursing an HIV/AIDS Patient at Home
- Theme 11: Challenges of HIV/AIDS Patients while on CHBC Program

### **5.4 WHAT PROBLEMS DID YOU HAVE TO BE ENROLLED IN COMMUNITY HOME BASED CARE?**

The first question that was put forward to all participants during the interviews was what problems they had that resulted in the enrolment into community home based care. Participants gave different problems and different reasons to be enrolled on community home based care. However an overwhelming majority identified that they were not feeling well for sometime and they were advised by someone either at home or at the hospital to go for an HIV test and thereafter they were enrolled into the program for observations. The following narrative statements generally reflect the causes of their problems and what led to an HIV test:

**Participant:** *"I started not feeling well in 2005 and that was a year after the death of my husband. I was on and off the hospital until late 2006 when I was advised by*



*health workers to go for an HIV test which I did in November the same year and I was found HIV positive”.*

Majority of the responses showed that the respondents became suspicious after losing a spouse or after identifying some signs which they suspected to be HIV related. This motivated them to go for an HIV test.

**Participant:** *“I don’t know what caused the death of my husband but I have no doubt..... (patient paused) that he died of the same condition”.*

When the participant was asked why she thought that her husband died of the same condition that she had, she said:

*“Because he had the same signs that I am having and I believe strongly that he is the one who gave me the HIV. “I have not slept with any other man apart from him, so why should I doubt about him?”*

It should not be overlooked or ignored any further, especially that generally, from the answers that were given showed that the participants had adequate basic knowledge of HIV and AIDS transmission; prevention and treatment (see table5.4). Participants were asked some questions that could reflect their level of awareness about how HIV was transmitted to them and other related issues including treatment for HIV and AIDS.

**Table 5.4: Participants` knowledge of HIV and AIDS (n=15)**

<b>Knowledge of HIV and AIDS</b>	<b>Percentage %</b>
HIV and AIDS has no cure	Majority
ARVs are not for cure	Majority
ARVs can prolong life	Half of the participants
HIV main mode of transmission is sexually	Almost all
Mentioned any one preventive measure	Almost all

A majority response appearing in the Table 5.4 above is an indication that participants suspected getting the HIV from their partners. These participants knew that HIV and AIDS are still incurable and that ARVs are used to prolong life by avoiding further multiplication of the virus. The knowledge of this aspect by a majority of participants suggests that they have been well informed about HIV and AIDS which is a requirement to HIV and AIDS patients. Following are some of the narrative statements indicating knowledge on HIV/ AIDS:

**Participant:** *"HIV is a deadly disease which comes with its own complications, so I am not an exception".*

**Participant:** *"There is no cure for HIV and AIDS and that means anything can happen to me anytime".*

**Participant:** *"Most people in the country are already infected. The whole country is crying, although people do not want to change their behaviour. I know I am in this situation because of my husband who was naughty. He couldn't listen to what I was advising him. HIV is a killer".*

**Participant:** *"I know there are ARVs available but they do not cure HIV and AIDS and many people have died before while on ARVs so I am not secured. Once you get it, it kills slowly".*

**Participant:** *"ARVs are important because they prolong life. The only problem lies on the distance to where we get the drug so sometimes we go without drugs especially if there is no transport available".*

**Participant:** *"Even married couples can use condoms to prevent getting HIV. I use them in my family the only problem is that my husband sometimes refuses to use condoms. Many times we have struggled to use condoms".*

**Participant:** *"It is unfortunate that I got married when I was still young. Otherwise I know the best way for me that time was to abstain. Now that I already have the virus and married I can just use condoms".*

## **5.5 WHAT DOES IT MEAN TO LIVE WITH HIV AND AIDS IN MALAWI?**

### **Theme 1: Living with HIV and AIDS**

After participants told the researcher that they were HIV positive, the researcher asked them to explain to me what it meant to them to live with HIV and AIDS and the following responses were given: The major fact is that, it is not easy to live with HIV and AIDS. In all the interviews, participants showed some concern that they were living with HIV and AIDS. The following statements indicate that participants affirmed the view that:

- It is disappointing to live with HIV and AIDS
- They feel bad about it.
- They feel guilty of bringing miseries to families
- They are subjected to frequent opportunistic infections
- They would be exposed to stigma and discrimination.
- They have feelings of anxiety, worries and fears of death.

Table 5.5 shows the experiences of HIV and AIDS patients in Malawi. Out of the 15 participants the majority of them indicated feelings of anxiety, worries and fears of death. Another majority of participants felt disappointed to live with HIV and AIDS and said that they were subjected to frequent opportunistic infections. Another half of the participants complained of experiencing stigma and discrimination and felt guilty of bringing miseries to the families. A minority group said they had no problems living with HIV and AIDS (see table 5.5).

**Table 5.5: Experiences of living with HIV and AIDS (n=15)**

<b>Experiences of living with HIV and AIDS</b>	<b>Frequency</b>	
Disappointing to live with HIV and AIDS	Almost all	
Guilty of bringing miseries	Majority	
Subjected to frequent opportunistic infections	Majority	
Exposure to stigma and discrimination	Almost half	
Feelings of anxiety, worries and fears of death.	Majority	
No problems	Few	

The following are narrative statements from the participants indicating their experiences.

**Participant:** *“it is very disappointing to live with HIV and AIDS. I feel bad within myself. At the beginning what came to my mind was that I was going to die”.*

**Participant:** *“I have too much fear over my life. I can not even describe the magnitude of my fears/ worries. Sometimes I feel its better I die now than to suffer a lot of diseases and infections which I have witnessed in other patients. I feel it were not me----- (patient sobbing) neither can I want this to happen to any of my relatives more especially my children”.*

**Participant:** *“I feel I am the cause of all the miseries that my family is facing. I am a widow, I don’t know what caused the death of my husband but I have no doubt..... (patient paused) that he died of the same condition”.*

**Participant:** *“I am helpless. I live a miserable life most of the times. Life is not the same as before. I cannot perform normal duties as a man of his own house. I always depend on other people on basic things. As a bread winner, life is very difficult and miserable”.*

**Participant:** *"I am discriminated by a lot of friends even fellow church members though not openly. My fear is on my children because they are still small. I feel I am causing unnecessary trauma to my family more especially my wife".*

Most of the participants felt they were discriminated because they have HIV and AIDS.

**Participant:** *"Now I know that I am a victim of experiencing stigma and discrimination. I don't blame anybody when I am discriminated. I always feel anxious and afraid of death because I have small children and I don't have a husband. I wish I had gone first before him----- (patient sobbing)".*

Most participants also acknowledged the presence of opportunistic infections due to having HIV and AIDS. The majority also were aware that HIV and AIDS have no cure.

**Participant:** *"having this disease means I..... (patient paused for along period head cast down) I will be suffering from different diseases and infections". It is very dangerous to live with HIV and AIDS and I feel very sorry for a person like myself to be in this situation because there is no cure for HIV and AIDS, all you have to do is to wait for death. I ----- (patient sobbing) I feel it were not me".*

**Participant:** *" I feel it is difficult and dangerous to live with HIV and AIDS. I feel sad because there is no treatment to cure AIDS. This means death is near and therefore I am waiting for death myself ----- (patient laughed). I live with hope because I know one day there will be treatment to this disease whether I will still be alive or not but that will be wonderful".*

**Participant:** *"I am very thankful to the Government of Malawi. There is no treatment for HIV and AIDS and yet the Government decided to give us ARVs which is helping very much. I was very ill the time I was put on CHBC program, but now look at me----- (patient smiled). I am now able to bath on my own, eat on my own and sometimes I even wash clothes for my children. Thank you very much, please let the government know this".*

However, a minority of the participants felt that to live with HIV and AIDS is not the end of life. Such participants affirmed the statement that it is important to know that HIV and AIDS are like any other disease such as malaria and therefore they would seek treatment in the same way they would do with other diseases. These participants also suggested firstly that worries would facilitate death and therefore it is better just to live like any other patient to avoid dying earlier. Following are some of the narrative statements indicating the need to take HIV and AIDS like any other condition.

**Participant:** *“I feel there is no problem. I do not have too many worries because I know worries can facilitate my death. I know HIV and AIDS is like any other disease that I or any other person can suffer such as malaria”.*

**Participant:** *“Whenever I feel sick, I go and receive treatment at the hospital and I get better so why should I get worried”.*

**Participant:** *“In fact, I feel courageous and I am ready for death because I know the truth about myself. The only time that I am challenged and feel worried is when I see the only child that I have getting sick frequently and therefore his sickness reminds me of my status and therefore I feel sorry not for myself but for my son because he does not know anything since he is young”.*

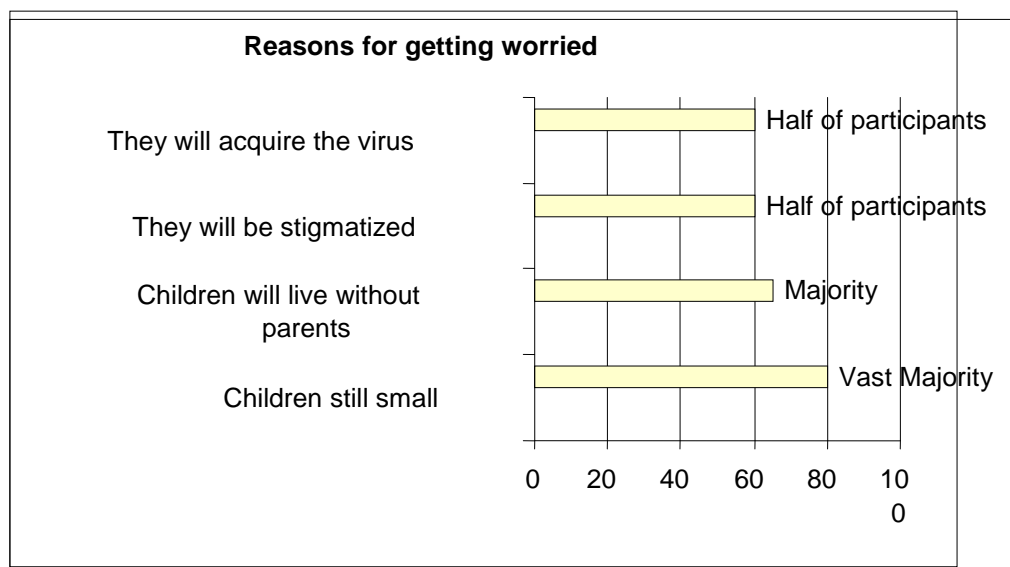
**Participant:** *“There is no need to get worried. After all, everybody is going to die when his/her time comes. The reason why the Government and other Non Governmental Organizations have established Community Home Based Care services is for us to be helped although resources are not always available but somehow we are being assisted very much”.*

Fear and worries could not be hidden by the participants as an experience of living with HIV and AIDS. Majority of the participants felt disappointed to live with HIV and AIDS and most of them blamed themselves as being the ones bringing miseries to their families especially to their children who are still young and need care from them as parents.

In this study, it was noted that most participants were worried about their children due to their status of having HIV and AIDS. When participants were asked to state the reasons why they felt sorry, a vast majority of them mentioned that their children were still young, and that children are going to be left without parents. Another majority of participants said that they were worried that the children would acquire HIV and be subjected to stigma and discrimination. Figure 5.5 illustrates the reasons which were given by participants.

The schematic presentation below displays some of the reasons respondents mentioned for their apprehension.

**Figure 5.5: Reasons for getting worried (n=9)**



The following are some of the narrative statements from participants on the reasons why they were worried.

**Participant:** *“Indeed I am worried on what will happen to my children when I die. I know everyone will die alright, but if I am being stigmatized myself, then what more with my children when I am not there? They will be in problems. Nobody will mix with them because people will say your father had HIV and we don’t want you to give us HIV. That is my major worry madam”.*

**Participant:** *“As you know madam, children grow well and health when their parents are there assisting them. Even though I am not feeling well, but still I manage to see to it that my children should have food and they should go to school. What will happen when I die? My children will live without parents because their father died some time back so it means nobody to take care of them shame”-----*(patient sobbed).

**Participant:** *“The only child that I have is still small. Although I do not know when I will die, but definitely my child needs my care, please God help me to live a little bit longer”.*

**Participant:** *“Thanks to CHBC services because they are making sure that my children are taken care of. I know they will continue to do so even in future”.*

### **5.5.1 HIV and AIDS and Stigma**

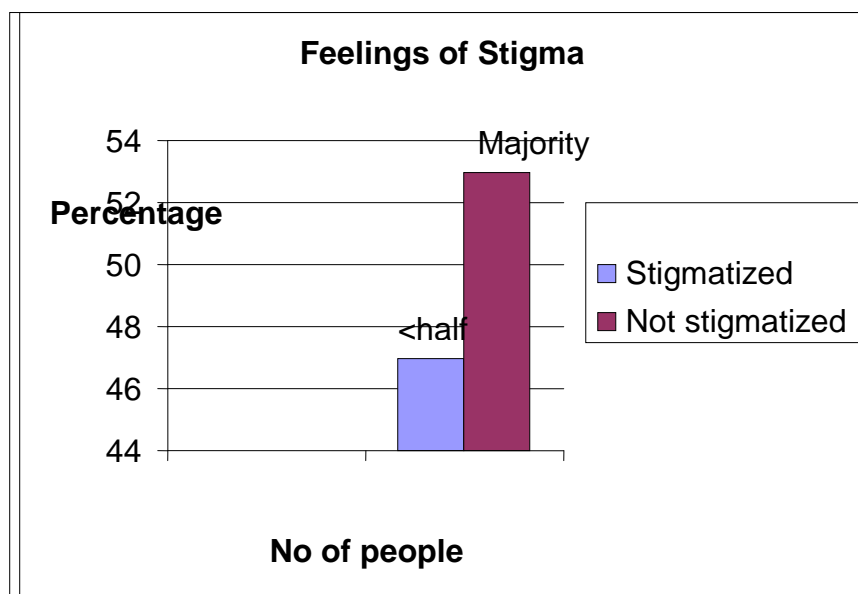
#### **Theme 2: HIV and AIDS Patients face Stigma**

That almost half of the participants indicated that they are facing stigma and discrimination, is abundantly evident that the issue of stigma emerges high and that it is important in HIV and AIDS patients. This therefore is an indication that this issue should not be ignored or overlooked in the care of HIV and AIDS patients. Further questions were given to the participants to ascertain who stigmatizes them, how they know they are being stigmatized and what actions are demonstrated to show stigma and discrimination. These questions yielded the following results:

Figure 5.6 below shows slightly more than half of participants not facing stigma and close to half (majority) of the participants experiencing stigma and discrimination.



**Figure 5.6: Patient feelings of stigma (n=15)**



The following narrative statements generally reflect participants' feelings of suspecting themselves being stigmatized:

**Participant:** *"remember I told you that sometimes they don't want to talk to me or to visit me, I know they are avoiding me. I have no doubt I am being stigmatized".*

**Participant:** *"I am discriminated by a lot of friends even fellow church members though not openly. Some church members that I used to chat with before I got sick do not come to visit me any more. For example, when prayers are taking place at my house, some members do not come What does that mean? And what are they afraid of, they are not away but they don't come. I know that they are afraid of getting HIV from me".*

**Participant:** *"You know madam; I am a victim of stigma and discrimination in this village. Even some of my relatives stopped coming to my house long time ago when they just suspected that I am HIV positive. Some times if they are passing by and I greet them, they do not answer me and I do not know why. One day God shall give me the answers. I am just worried about my children because they are*

*still young. What will happen to them if I die? Who will take care of them? Still no answers”.*

**Participant:** *“Madam, as long as HIV/ AIDS is there, stigma will always be there too. Who wants to get HIV today? Nobody. So I don’t blame them, let them discriminate me and one day they will understand when they have a member in their family with HIV. I did not invite HIV myself. I got it from my husband and where he got it I don’t know either. God knows everything”.*

**Participant:** *“Sometimes it pains me when I see my friends not wanting to stay with me for longer periods as we used to do in the past. I know most of my friends are still friendly to me but there are few who have changed tremendously”.*

When participants who stated that they were stigmatized were asked to state the actions which indicated being stigmatized, the following statements were given: Most participants said people stopped visiting them, Another majority of the participants said people did not want to talk to them and few of the participants mentioned people not attending to their call. Gossiping was also mentioned by a minority group of participants.

#### **5.5.1.1 Who stigmatizes**

Most of the participants cited relatives, friends and church members as the ones who stigmatize the patients. The majority response from participants indicated that relatives are the main source of stigma and discrimination to the participants. The following narrative statements by the participants indicate sources of stigma from their communities.

**Participant:** *“I am discriminated by a lot of friends even fellow church members. Though they do not show openly, but I can tell through their actions that they are discriminating me. For example sometimes when we are in a group, and we want to form smaller groups, some people are not willing to be in the same group with me and later on to sit near me. They will always give an excuse to make sure I am not near them and as an adult I know what it means, I just keep quiet”.*

**Participant:** *“some of my relatives stigmatize me, especially those with a distant relationship. They do not give me any assistance. When they see members of the CHBC team coming to my house, they take advantage and laugh at me for having HIV and AIDS ”.*

**Participant:** *“my father doesn’t want to see me and he doesn’t want me to be part of the family because I misbehaved earlier by running away from the family to get married to a certain man and since that time he makes sure that I do not exist anymore. Health workers tried to explain to him on the importance of accepting me but he does not seem to understand. Anyway I am happy that the health workers and my volunteer do not discriminate me.”*

**Participant:** *It is difficult to live with HIV and AIDS because I am experiencing a lot of challenges such as being stigmatized by my relatives and friends but I know it is not everybody.*

**Participant:** *“It is normal to be discriminated and I don’t get worried because even some people who do not have HIV are also discriminated especially those who are poor so what more with me? Until the time when everybody will understand what HIV is then we shall be one. I am happy that my volunteer does not discriminate me instead she is discriminated because she is associated with CHBC services.*

Table 5.6 and fig 5.10 illustrates groups of people who participants suggested are their source of stigma.

**Table 5.6: who stigmatizes the patients (n=7)**

Who stigmatizes?	Frequency
Relatives	Majority
Parents	Minority
Church members	Few
Friends and relatives	Majority
Health Workers	Very few

From the findings above, it is clear that some of the participants are faced with some kind of stigma. Stigma directed at people living with HIV and AIDS (PLWHA) can bring in a lot of implications on the fight against HIV and AIDS. It does not only make it more difficult for people trying to come to terms with and manage their illness on a personal level, but it also interferes with attempts to fight the AIDS epidemic as a whole. This implies that stigma can make people reluctant to access HIV testing, treatment and care.

AIDS related stigma refers to the prejudice and discrimination directed at people living with HIV and AIDS and the groups and communities that they are associated with. It can result in people living with HIV and AIDS being rejected from their community, shunned, discriminated against or even physical hurt (Stigma, discrimination and attitudes to HIV and AIDS, 2008). The findings of this study are in congruent to the information obtained from the above mentioned article which acknowledges that AIDS stigma and discrimination have been seen all over the world. The article further supports the idea with a quotation from the UN Secretary-General Ban Ki Moon as follows:

*“Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps to make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world”.*

**Source: Stigma, discrimination and attitudes to HIV and AIDS (2008)**

According to a recent report by the Pan American Health Organization (PAHO), stigma and discrimination threaten the quality of patient care as well as efforts to control the epidemic's spread (HIV patients face stigma in region's health sector new PAHO report, 2008). The WHO also cites fear of stigma and discrimination as the main reason why people are reluctant to be tested, to disclose HIV status or to take antiretroviral drugs. These factors all contribute to the expansion of the epidemic and a higher number of AIDS related deaths. Unwillingness to take an HIV test means that more people are diagnosed late, when the virus has already

progressed to AIDS, making treatment less effective and causing early death (Stigma, discrimination and attitudes to HIV and AIDS, 2008).

The fact that there are some responses from participants indicating discrimination by church members, it implies that churches are also a source of stigma to HIV and AIDS patients. Religion has always been part of social life in most of the countries including Malawi. Religion has always been an important form of social control especially in the areas of sexuality. It provides important ethical guidelines for living, for interpreting natural events including disasters and misfortune, and for coping with life's milestones, from birth through illness to death (Stigma, discrimination and attitudes to HIV and AIDS, 2008). HIV and AIDS pose new challenges to religion. The fact that its main mode of transmission is sexual, HIV and AIDS intensifies the tensions that are present around sexuality. Many have had ambivalent attitudes towards sexuality (Stigma, discrimination and attitudes to HIV and AIDS, 2008). The epidemic is interpreted by some people as divine punishment for sexual transgressions from premarital sex to homosexuality.

The stigma posed by religion can be powerful. People often avoid working with or supporting HIV and AIDS people because they are seen as sinners who deserve to become infected. Religious prejudices, mixed with misconceptions about HIV and AIDS, become a dangerous and volatile mixture that sends many people to their deaths (Stigma, discrimination and attitudes to HIV and AIDS, 2008). Perhaps the issue of concern here is: could it be true that HIV and AIDS is a punishment for sinners? The following statements were from Religious Leaders speaking out on HIV and AIDS at a conference:

*"Perhaps the AIDS crisis is God's way of challenging us to care for one another, to support the dying and to appreciate the gift of life. AIDS need not be merely a crisis: It could also be a God given opportunity for moral and spiritual growth, a time to review our assumption about sin and morality. The modern epidemic of AIDS calls for a pastoral response".*

**Bishops of Southern Africa, June 1990**

*“God loves you all, without distinction, without limit. He loves those of you who are elderly, who feel the burden of the years. He loves those of you who are sick, those who are suffering from AIDS. He loves the relatives and friends of the sick and those who care for them. He loves us all with an unconditional and everlasting love”.*

**Pope John Paul 11, California, September 1997**

*“For us, an encounter with people infected with HIV and AIDS should be a moment of grace – and opportunity for us to be Christ’s compassionate presence to them as well as to experience His presence in them”.*

**Bishops` Conference of the Philippines, 1993.**

**Source: AIDS ACTION (2000)**

On the other hand contrary to what was found in this study, MANET (2003) in their study with HIV patients identified that the patients preferred to be cared by PLWHA volunteers than those without. They observed that PLWHA are able to relate to service users and offer peer support which help infected individuals feel that they are not alone in their struggle. Nettleton (1995) also observed that stigma is not easy to fight because of its social construction. He further argues that while medicine has its own meaning of the body in relation to illness and health as reflected in the signs and symptoms, individuals have their own social meanings for these signs and symptoms and these differences may pose difficulties in curbing stigma (Nettleton, 1995).

#### **5.5.1.2 Anxiety, Worries and Fear of death**

#### **Theme 3: Feelings of anxiety, worries and fears of death**

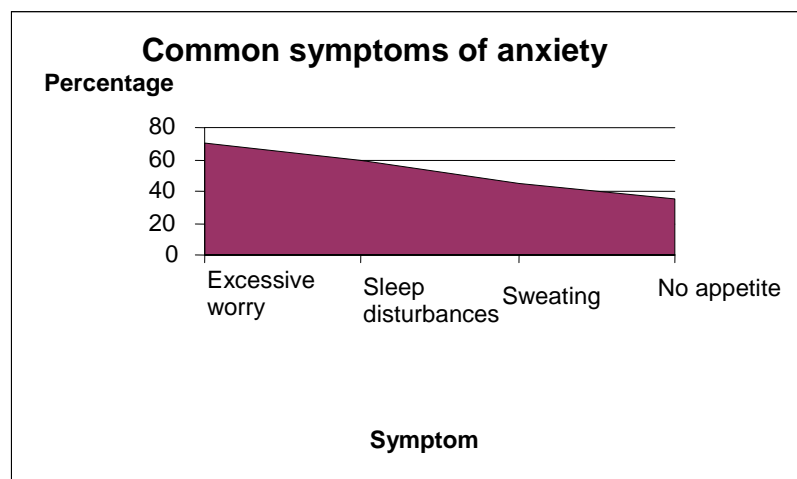
Anxiety is a blanket term that covers a wide range of emotional responses and disorders (Lavick and Vaccaro, 2007). It is a normal emotional response to stress and the perception of danger. The baseline for anxiety is simple fear. Fear and anxiety cannot be entirely circumvented. The welfare and survival of the individual depend on them (Lavick and Vaccaro, 2007).

Anxiety is a common response to extreme stressors, but it can also be a symptom of a more significant underlying anxiety disorder. A report from mental health providers indicated that HIV positive people and others living with serious medical conditions are more prone to anxiety symptoms due to the stress of managing a chronic illness (Lavick and Vaccaro, 2007). In this report, it is indicated that up to 70% of people with HIV, report persistent anxiety symptoms, and up to 40% meet the criteria for an anxiety disorder.

Anxiety can be a prominent symptom following initial HIV diagnosis and anxiety symptoms can frequently recur and escalate in response to disease progression. Therefore, with the explanation above, it is perfectly reasonable for HIV positive individuals to feel anxious about such health indicators as declining CD4 cell counts or the appearance of opportunistic infections.

As indicated earlier, in this study, a vast majority of the participants affirmed that they have had feelings of anxiety and fear of death. Fig 5.7 illustrates some of the common symptoms of anxiety that participants experienced in this study. Most of the participants stated that they always have excessive worry, disturbances in their sleep, sweating and flushing while few participants indicated that they do not have appetite when they are anxious.

**Figure 5.7: Common symptoms of anxiety (n=11)**



Participants were further asked to explain the reasons for their anxiety and fear. Majority of the participants who expressed feelings of anxiety stated that they were worried because they think of their children who are still young. Most of the respondents affirmed that they were worried about their HIV and AIDS status which has no cure up to now. Another majority of participants indicated presence of infections as the cause of their worries. A minority group of participants explained that they get worried because their condition was deteriorating and also because of too much pains which they were feeling. Another minority group of participants acknowledged fear of facing divorce after disclosure of HIV status to their partners as the reason for their worries. Table 5.7 below illustrates common reasons for anxiety in the participants under study.

**Table 5.7: Common reasons for anxiety (n=11)**

Reason for anxiety	Frequency
Worry about HIV and AIDS status	Majority
Presence of infections	Majority
Condition deteriorating and feeling of too much pains	Minority
Worry about children	Majority
Fear of facing divorce after HIV status disclosure	Minority

The following narrative statements by the participants indicate experiences of anxiety, fear and worries at one point or the other:

**Participant:** *“Some of the days, I have a lot of fears and I am anxious. This is the scariest feeling of my life. Sometimes I sit in my bedroom alone sweating and my heart pumping hard. I sit for some hours quiet, looking for signs that I know will confirm my worst fear and I remind myself that yes I have got HIV and AIDS”.*

One of the client who complained of having feelings of anxiety, worries and fear of death. said that most of the times she is alone and people do not understand her problems. She also feels anxious because most of the days she has no food.



**Participant:** *"Sometimes I sit on a veranda with my family. When I look at my husband and my children, I think of ways how I am going to disclose my status to them. Something just grabs my throat and it is painful and immediately I know that as soon as I tell him (my husband) that I am HIV positive, he is going to dump me, while if I tell the children, they will not understand and therefore they will be crying every time they see me. You can imagine madam the situation in which I am most of the times".*

**Participant:** *"Most of the times I am fine, but the only time that I have fears and feel worried is when I see the only child that I have getting sick frequently and therefore his sickness reminds me of my status and therefore I feel sorry not for myself but for my son because he does not know anything since he is young I am not sure as to what will happen to him in future and may be by that time I will be dead who will facilitate access to medication for him? You know what I am referring to.....(patient pauses) anyway I mean ARVs if they will be needed. "*

**Participant:** *"Sometimes, I can not sleep the whole night. I don't even have an appetite even if the food is good. I think of all these infections that I am having every now and then. I have cancer but I am also struggling with other infections, why? Up to when? -----(patient sobbing) I don't have answers to all these questions. I know death is coming.....(patient pauses) not immediately, but it will still come".*

**Participant:** *"I live a miserable life most of the times. Life is not the same as before. I am always worried and anxious because I cannot perform normal duties as a man of his own house. I can not find food for my family; I can not satisfy my wife any more since I am always weak. I really don't know what is happening to me".*

Sometimes individuals can spend some time thinking over the right way and time to disclose their HIV positive status to friends, lovers and family members. Unfortunately predicting another person's response is virtually impossible. Often an HIV positive person discloses in order to gain support, only to end up

comforting and supporting the person being disclosed to (Lavick and Vaccaro, 2007). The following extract is giving an expression of the patient (not from this study) who felt reluctant to disclose his HIV status and yet silently suffered anxiety, fears and worries:

*“I had lost friends and close friends by telling them I had HIV and I was afraid of losing her” he said of the woman he infected. “It was just the fact that I didn’t know how she would react to me telling her. I thought she would turn around and leave me like everyone else. I was in love with her at the time”.*

**Source: Australian Court finds man guilty of spreading HIV/AIDS (2006)**

Anxiety about HIV health is absolutely normal; the trick is recognizing when anxiety has escalated into an anxiety disorder. The mental, emotional and physical stress caused by managing a chronic disease can render HIV positive people highly susceptible to anxiety disorders. Unfortunately, anxiety has been shown to contribute to poor adherence to antiretroviral regimens, putting people with HIV at greater risk for disease progression and setting them up for further anxiety (Lavick and Vaccaro, 2007).

## **5.6 HOW DO HIV AND AIDS PATIENTS PERCEIVE THE CARE, SUPPORT AND TREATMENT PROVIDED TO THEM AT HOME?**

### **Theme 4: Care Providers for HIV and AIDS Patients**

Participants were asked a number of questions on this area such as who is their main care provider, what role does the care provider play, what role does the patient play in order to care for himself, attitude of the care providers towards the patient and the impact of that attitude towards the well being of the patient.

#### **5.6.1 Who is the main care provider**

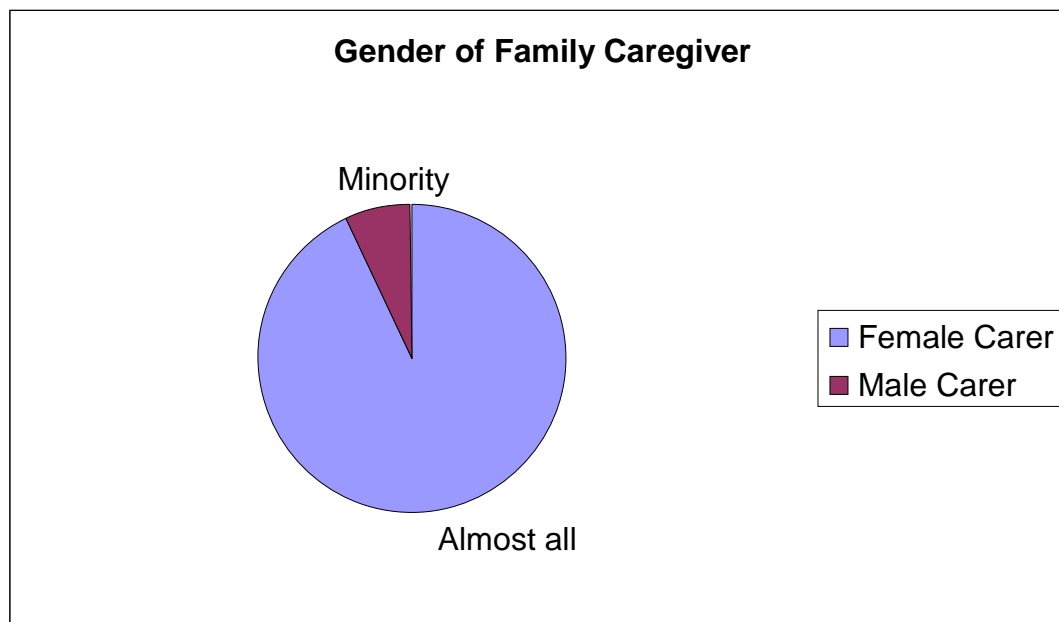
It is not easy for an HIV and AIDS person to be cared for by distant relations worse still by someone who is not a relative at all. In the majority of developing countries,

families are the primary caregivers when somebody falls ill. There is clear evidence that families play an important role in providing support and care for people living with HIV and AIDS. However, not all family responses are positive. HIV and AIDS infected members of the family can find themselves facing a lot of challenges including stigma and discrimination within the home (Stigma, discrimination and attitudes to HIV and AIDS, 2008 (Author not given)).

Perhaps the main concern here is that, women and non-heterosexual family members are more likely than children and men to be mistreated. From the interviews done, an overwhelming majority of the participants affirmed the view that relatives (family members) are the ones who provide most of the care to them at home. The vast majority of respondents reported that their household care giver was a female. The problem falls on the ages of these care givers. The majority of the participants are looked after by their children who are still young and at school. Their ages ranged between 12 and 18 years. This suggests high chances of losing school opportunities and therefore difficult life in future. This is clearly supported by the Global Coalition on Women and AIDS which states that AIDS frequently forces girls and young women to withdraw from school to fulfill care giving duties and to help compensate for lost family income – heightening their risks of sexual exploitation and HIV infection (Support women caregivers: Fight AIDS (author and year not given)).

There is need to pay special attention to the children and adolescents, especially girls, who become caregivers. Many of these children are also coping with the death of their parents or relatives due to AIDS and struggle with HIV related stigma and an increasingly uncertain future of their own. Fig 5.8 outlines gender of family care givers in this study.

**Figure 5.8: Gender of family caregiver (n=15)**



In addition, due to the demands of caring for others, many female caregivers have less time to earn an income, produce food, go to school, and maintain the rest of the household. Indeed this creates a vicious cycle, whereby women and their families are more likely to be malnourished, in poor health, or economically destitute – all factors that further increase their risk for HIV infection (Support women caregivers: Fight AIDS (author and year not given)).

When the participants were asked on the relationship between the patient and the caregiver, the bulk of the household care giving is provided by immediate family member (spouse, daughter, mother, sister or brother). The following narrative statements reflect the caregivers for the participants in this study:

**Participant:** *“my wife is the main care provider and she provides most of the care because I am with her most of the times. I have five children and the first born daughter also assists her mother in providing care to me. Otherwise everybody in our house take part in assisting me although the main one is my wife. If you talk of the volunteer, yes she comes but it is only once a week and most of the times she finds that my wife has already done everything so she just chats with me. Her presence relieves my wife anyway”.*

**Participant:** *“my daughter does most of the care. She cooks and gives me food. She cares for the home and the whole house though she is only 14 years. It is not easy to find food and other necessities since I am a widow and I am not working. My elder sister and my cousin also assist my children to give care to me. My volunteer visits me once or sometimes twice a week”.*

**Participant:** *“My wife, my relatives, community members and nurses from the hospital provide care to me”.*

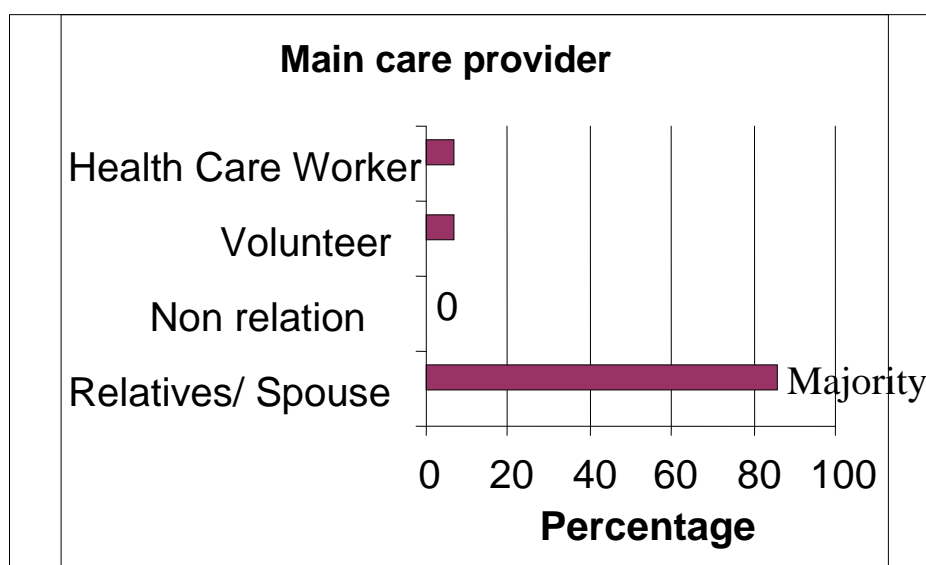
When the participant was asked to choose one out of the list, he said:

*If I have to choose one then my wife is the main care provider because most of the times she is the one near me and therefore she is the one who looks after me. In her absence, then my daughter provides the care to me”. My volunteer comes once or sometimes twice a week. When I am very sick, then she visits me frequently”.*

**Participant:** *“My family members provide most of the care because I am with them most of the times. I have three children and the first born daughter is the one who does most of the care”. She is 17 years and married. She agreed with her husband to come and stay near my house so that she can take care of me adequately. She is very good because she makes sure that i receive good care even in the times when my volunteer is with me, my daughter makes sure that she is around too”.*

Fig 5.9 illustrates main care providers for participants in the study. Relatives or spouses comprised the majority of caregivers followed by health care workers and volunteers. No participant mentioned a caregiver who had no relationship with the patient.

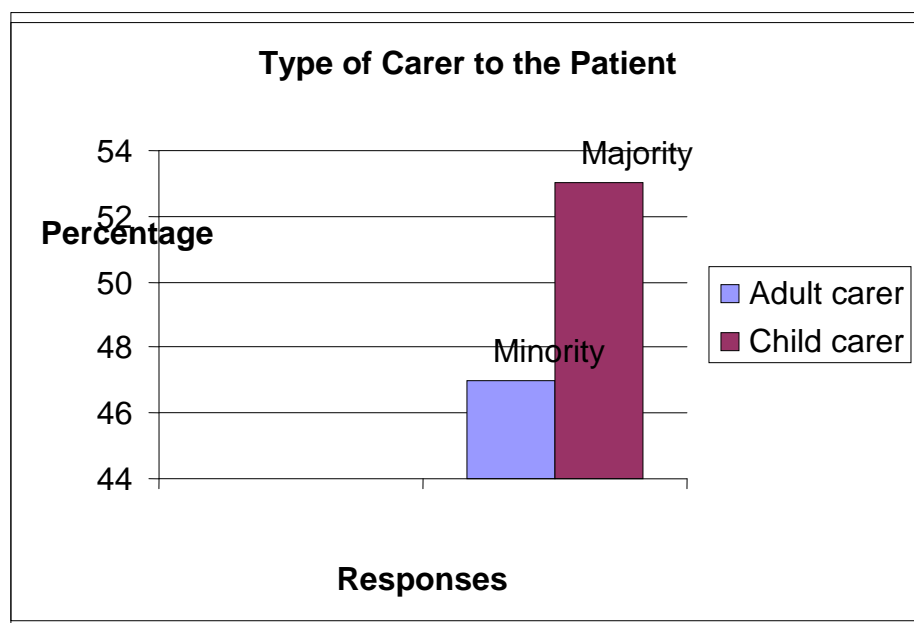
**Figure 5.9: Main Care Provider (n=15)**



Majority of the participants agreed to the view that being taken care of at home is good. Most of them affirmed the view that relatives should give care and support to the HIV and AIDS patients at home. On the other hand, half of the participants indicated that although the common situation is like this, some relatives are not happy and willing to provide care to patients who are HIV positive. This then gives an impression that there are still some people in Malawi who are not aware that HIV can not be transmitted through caring for a patient as long as protective measures are taken.

Kipp, Tindyebwa, Rubaale, Karamagi and Bajera (2007) had similar findings in their study titled “family caregivers in rural Uganda, the hidden reality”. According to this study, family caregivers reported huge problems associated with providing the necessary psychological, social and economic care. They also reported that the physical and emotional demands of caregiving were overwhelming daily challenges. The study found out that most support to AIDS patients were provided by family, friends and the churches. The study highlighted the great burden of caregivers in sub-Saharan Africa who most often are elderly women and young girls.

**Figure 5.10 Type of Carer to HIV and AIDS patients (n=15)**



### **5.6.2 Role of the care provider**

The AIDS epidemic is taking a devastating toll on families and communities worldwide (Support women caregivers: Fight AIDS (author and year not given). In its wake lies a growing burden of caring for the sick, the dying, and those left behind. In most countries, the care for people living with HIV and AIDS takes place in the home. As stated earlier, in almost all the countries including Malawi, the family has always been and still is the major provider of long term care for patients with chronic conditions including HIV and AIDS. However, the heavy burden of care cannot be shouldered by families alone. Again, the question still remains: “who is qualified to provide primary care for HIV/AIDS patients?”

Some caregivers go to great effort to not only hide their patients but also their care giving activities resulting in the social isolation of both patients and their caregivers (Mwinituo and Mill, 2006:369). According to these authors, many caregivers live in secrecy, not sharing their family member’s diagnosis with extended family members. As a result, they receive limited support from the extended family. Stigma results in negative attitudes of neighbours, relatives and even health care workers towards caregivers and their patients. According to the Malawi Ministry of Health Programme of Work (POW, 2004 – 2010), providing quality health

services is about making sure there are enough resources to meet minimum standards, whether good care is delivered and whether patients are satisfied with the services they have received. Similarly, according to the conceptual framework which has been used in this study, quality of life in the patients can be attained only if there are adequate resources in the care. Lack of basic supplies and equipment, drugs and other supplies such as gloves are common and this brings inadequate care for patients. Since most care providers are staying with the patients, they cook food for the patient, they bath the patient, look after the comfortability of the patient and many more activities that the patient can not do alone. The challenge that lies with careproviders is lack of resources to use in the care of their patients.

Following are some of the narrative statements indicating roles of the participants care providers:

**Participant:** *“my wife is the one who looks after me. She cooks food and eats with me. She provides water for my bath and when I am weak she baths me. She is my friend and therefore she makes sure that I am always happy. The main problem that we always face is lack of adequate resources especially basic resources as you know I am not working now that I am bed ridden so in most of the cases we run out of basic resources”.*

**Participant:** *“Some times when I am not able to take my bath my cousin gives me a bed bath. My daughter is still young so some of the roles she is assisted by my cousin. The problem is lack of resources to use in the care. However, some community members bring some resources like water, firewood and sometimes they chat with me when I am able to do so”.*

**Participant:** *“My relatives take me to the hospital when there is need to do so but when I am admitted nobody stays at the hospital except my daughter and that means she absents herself from school during those days. I still thank my relatives because they do a lot of things for me in addition to what my daughter does every day”. Most of the times my daughter lacks necessary resources to use for my care*



*e.g. soap, sugar for my porridge etc. At times, my relatives come in and give a hand.*

### **5.6.3 Attitude of care providers**

#### **Theme 5: Attitude of care providers**

Based on this study, participants were also asked to explain the attitude of their care providers. Almost half of the participants said that they had no problems with the attitude of their care providers and the other half said that it depended on what relationship the patient had with the care provider. The following narrative statements reflected caregivers attitudes towards their patients:

**Participant:** *"I have problems with the attitude of my relatives. I know they change their attitude everyday because of tiredness which I have already mentioned before. But so far I haven't noticed any change in the attitude from my wife, and my children who are my main care provers. May be I am just lucky with them".*

**Participant:** *"when I am admitted nobody stays at the hospital except my daughter and my volunteer who comes often to see me in the hospital. My relatives don't even visit me until I come back home. I don't even ask them because they have always said that they are relieved when I am admitted at the hospital so it was a relief to them I know they have negative attitude towards me because of my HIV status'."*

**Participant:** *"No, I have no problem with the attitude of my care providers may be they will start later but not now because they are caring for me very well. But few friends I think they discriminate me but this is normal I have no problem over that. I have no problem with the attitude of my volunteer too. She takes care of me without problems. May God bless her and her family".*

**Participant:** *"It varies with the relationship madam". `` With my daughter I haven't seen any change when it comes to caring. For the other relations the attitude or*

*their mood is not static neither are they same every day. Some days they seem to be caring, happy and cheerful with you but other days they don't want to talk to you. It is really difficult to know what they are thinking about you. When you send a word requesting them to come, the response is that they are not at home which is not true most of the times. Then what else can you do, you just keep quite. But I have no problem with my volunteer's attitude".*

**Participant:** *"Ah madam, I have no problem with the volunteers nor the nurses and doctors. I know they are busy people. The only request I can give is that they don't stay long in my home may be because they want to visit other patients as well, but to tell you the truth they are always in a hurry".*

**Participant:** *"Madam, there is one nurse, always when she comes, she shouts at me even if I give genuine complaints. Please nurses should understand that patients are like children and therefore they need to be sympathetic with us. I prefer the way the volunteer talks to me when she comes alone than when she comes with the nurse because then she copies what the nurse does. But when the volunteer comes alone, she listens to me very well and she is nice".*

No epidemic in the world today attracts as much attention, publication, debate and controversy as HIV and AIDS. Fear of contagion coupled with negative, value-based assumptions about people who are infected leads to high levels of stigma surrounding HIV and AIDS (Stigma, discrimination and attitudes to HIV and AIDS, 2008 (author not given). The fact that HIV and AIDS is a relatively new disease also contributes to a lot of mixed reactions from people. The fear surrounding the emerging epidemic in the 1980`s is still fresh in many people's minds. At that time very little was known about the transmissibility of the virus, which made people scared of those infected due to fear of contagion Stigma, discrimination and attitudes to HIV and AIDS, 2008 (author not given).

Even within one country, reactions to HIV and AIDS will vary between different groups of people and individuals. Religion, gender, sexuality, age and levels of AIDS education can all affect how somebody feels about the disease. The fact that

the following factors will always exist, attitudes towards the epidemic and those affected will vary massively (Table 5.8).

**Facts:**

**Table 5.8: Facts**

- HIV/AIDS is a life-threatening disease
- HIV infection is associated with behaviors such as prostitution or promiscuity, homosexuality and drug addiction
- Most people become infected with HIV through sex. Sexually transmitted diseases are always highly stigmatized
- There is a lot of inaccurate information about how HIV is transmitted
- HIV infection is often thought to be the result of personal irresponsibility
- Religious or moral beliefs lead some people to believe that being infected with HIV is the result of moral fault (such as promiscuity or deviant sex) that deserves to be punished.

**Source: (Stigma, discrimination and attitudes to HIV and AIDS, 2008).**

In 2003, when countries were launching a major campaign to scale-up treatment in the developing world, World Health Organization (WHO) claimed that:

*“as HIV and AIDS becomes a disease that can be both prevented and treated, attitudes will change, and denial, stigma and discrimination will rapidly be reduced”* (Stigma, discrimination and attitudes to HIV and AIDS, 2008 (author not given)).

Findings of this study do not match with the statement above as stigma and discrimination is still present among HIV and AIDS patients despite the introduction of antiretroviral therapy (ARVs) in Malawi.

Attitude can be positive or negative and can affect the behaviour of an individual. Attitudes serve a primary function of bringing together the diverse experiences to which an individual is exposed and forming them into a cohesive, organized whole. It is through the attitude and belief systems of an individual that environmental perception acquires meaning. The danger is that attitudes may become so rigidly

adhered to that instead of assisting an individual in understanding his environment and the events taking place within it, they become the perception.

According to the information obtained from (Stigma, discrimination and attitudes to HIV and AIDS, 2008), sometimes attitude of caregivers would affect quality of life of the patient. In this article, a patient was quoted complaining about the attitude of her primary care giver as follows:

*“When I was in hospital, my father came once. Then he shouted that I had AIDS. Everyone could hear. He said: this is AIDS, she is a victim. With my brother and his wife I wasn’t allowed to eat from the same plates, I got a plastic cup and plates and I had to sleep in the kitchen. I was not even allowed to play with the kids”.* (HIV positive woman, Zimbabwe).

In conclusion, it has been noted that attitude of the caregivers will always influence the patient either positively or negatively. Positive attitude from caregivers motivate the patient and gives some hope of life. On the other hand negative attitude from the caregivers will bring along problems to the patient and affect his/her quality of life.

## **5.7 HAVE THE FAMILY MEMBERS HAD ANY HIV AND AIDS EDUCATION/ TRAINING?**

### **Theme 6: HIV and AIDS Education**

Home and community based care for people living with HIV and AIDS remain integral to the global AIDS response (Support women caregivers: fight AIDS (author and year not given). Alongside dramatic expansions in access to antiretroviral treatment and HIV prevention, AIDS strategies must provide better and more coordinated support for patients and their caregivers. Caregivers need information on HIV prevention and care, access to basic supplies, training and referrals for medical care, as well as social assistance to support vulnerable and orphaned children (Support women caregivers: fight AIDS (year not given). Caregiving takes an enormous physical, psychological, and economic toll on its providers. Accordingly, caregivers need access to psychosocial support,

counseling, and economic assistance to help them sustain this physically and emotionally draining, yet vitally important work (Support women caregivers: fight AIDS (author and year not given).

From the interviews done in this study, it was indicated that primary care givers (relatives) of the majority of participants did not have any formal HIV and AIDS education. Only few participants affirmed that their caregivers received some education while another minority stated that they were not sure.

This is a true reflection that care, counselling and social support which are particularly important prerequisites for home based care, were conspicuously lacking in the caregivers. According to the conceptual framework which has been used in this study on “quality of life, the CHBC policy is emphasizing the importance of giving education to all caregivers. The framework states that “to ensure that Community Home Based Care providers have necessary knowledge and skills, they shall be specially trained in Community Home Based Care. Both care providers and trainers shall undergo formal training as prescribed by the policy”.

Those participants who said their caregivers did not receive education and those who were not sure, were asked to explain if they would be interested to have their carers educated on HIV and AIDS. A vast majority of them indicated an interest to have their relatives receive training or education in HIV and AIDS. However, a minority of the participants still were not sure if their relatives would accept to be trained on HIV and AIDS. Those who said were interested stated that the reason was due to the seriousness of the threat posed by HIV and AIDS and also due to a lot of misconceptions and myths that surround HIV and AIDS issues among care givers in Malawi. These participants stated that most relatives are afraid to care for HIV and AIDS patients because they do not have adequate knowledge on the subject.

The following narrative statements illustrate the status of HIV and AIDS training among caregivers of this study and willingness of the participants to have their caregivers trained in HIV and AIDS.

**Participant:** *"None of my relatives have received any education concerning my care at home. This is very unfortunate because I have seen them sometimes questioning among themselves what to do sometimes when i am very sick. Thanks to the volunteer who comes to rescue them. I will be happy if atleast one of them is invited to a training session especially my wife who is the main careprovider. I know she can not refuse and she will be happy".*

**Participant:** *"I don't think any relative of mine has undergone the training that you are talking about, not to my knowledge. I hope they would accept otherwise since I have not disclosed my status I am not sure how they would receive the news. But I know this education would be helpful to them and myself as a patient because care will be improved".*

**Participant:** *"Yes, my mother was given some information on concerning my care but that was when we were still in the hospital before I was discharged. She was told on what to do if I am no feeling well at home, how to give me drugs and many more things. I am sure that is why she looks after me without problems".*

**Participant:** *"I would be happy if my carer receives the training which you are explaining. Otherwise my daughter uses her own knowledge with the help of my volunteer in order to give care to me but I know she would do much better if she received the education. Please madam, speak on our behalf that our carers should receive the training you are talking about, it sounds interesting and important".*

**Participant:** *"With any illness, education is very important. How do you expect these young ones who are taking care of us to know how to do a good job in caring? They need somebody to tell them how to do it. Adults are better off because they have seen and nursed different illnesses in their life, but not these young ones, sometimes I even feel pity of my daughter. Let her receive the training if possible please".*

These findings are supported by a study which was done in Botswana by Ndaba-Mbata, (2000) entitled "home based care of the terminally ill in Botswana: Knowledge and perceptions", it was discovered that families lacked knowledge

and skills for providing appropriate care. They were also not aware of the resources available and they lacked professional and material support. The author recommended that for caregivers to give good quality of care to their relatives, they needed to have appropriate skills and information about how to provide this care. The study demonstrated that providing education and support to the family caregivers can reduce their strain and enhance their quality of life.

**Figure 5.11: Willingness of participants to have their relatives trained (n=15)**

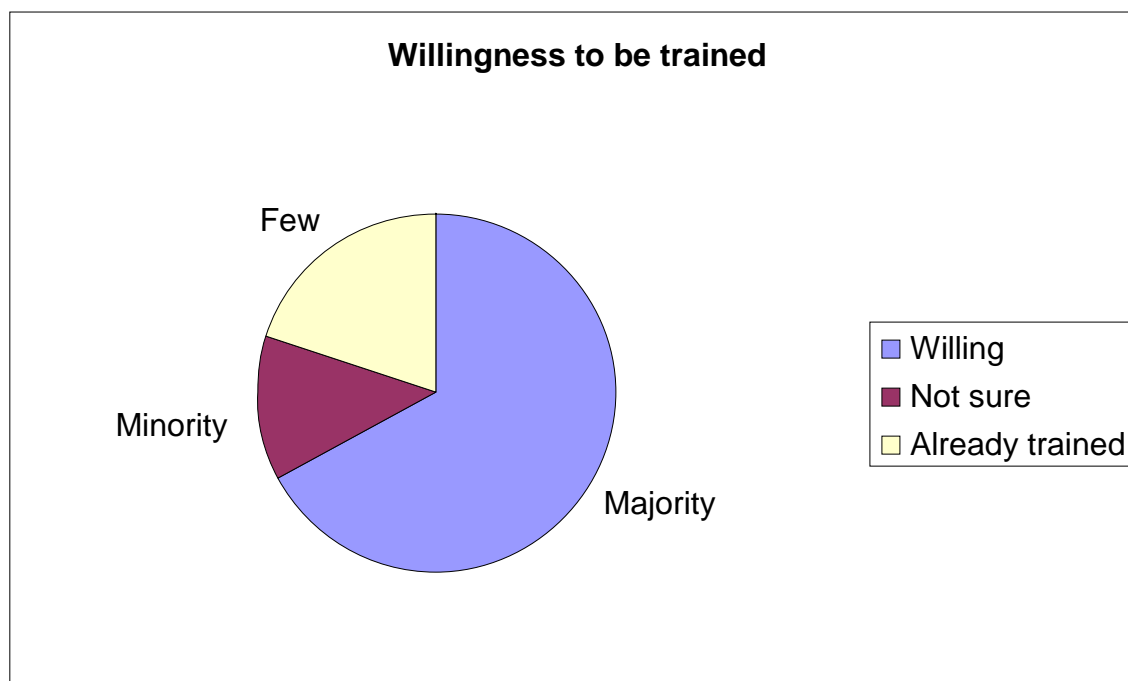


Figure 5.11 above shows the number of participants who said that they were willing to have their relatives to receive training in HIV and AIDS care. This is also strongly supported by the study which was done by Olenja (2004) on assessing community attitude towards home based care for people living with AIDS in Kenya. Findings of this study indicated that due to inadequate information about the disease and care expectations, people were ambivalent towards the sick and in some instances outright rejection prevailed. This therefore formed their basis for their preference for institutional based care as opposed to home based care. This author concluded by saying that training in the care of AIDS patients is crucial yet lacking at the family and community level. Very few caregivers had appropriate training and were worried about their lack of knowledge and yet they had to care

for patients. It was evident that they lacked a framework that would provide the capacity to facilitate home care (Olenja, 2004: 187).

Another author who also supported the idea strongly is Boswarva (1991) who stated that several authors attribute fear of contamination primarily to inadequate knowledge regarding AIDS. The author said that AIDS education can reduce fear of contagion and negative attitudes. Boswarva quoted Aggleton and Homans who described lay beliefs from their research as follows:

*“...there are many who still believe that AIDS spreads like a miasma through the air, that AIDS may lurk endogenously within us all or that AIDS only affects those who have in some way sinned against God”.*

## **5.8 IMPACT OF THE ATTITUDE TOWARDS THE PATIENT’S QUALITY OF LIFE**

### **Theme 7: Patient’s quality of life**

In the chapter which described the framework of this study, it was stated that quality of life is a major goal in the care of patients with terminal illness. In addition to symptom management, psychological care and provision of support, being cared for at home is considered to be an important determinant of patient well being (Peters and Sellick 2006). Thus symptom management, psychological care and support are of paramount importance in ensuring a comfortable death with dignity and optimal quality of life for both patient and family. In this study therefore, quality of life simply refers to the absence of pain or the ability to function in day to day life. It also includes feelings of well being in relation to happiness, morale and satisfaction. Determining the impact on the quality of life in HIV and AIDS patients is important for estimating the burden of the disease. This is true because AIDS has a chronic debilitating course and the long term adverse side effects of current treatment modalities are uncertain (Wig Lekshmi, Pal, Ahuja, Mittal & Agarwal, 2006). The social stigma attached with the proclamation of HIV sero-positivity may at times affect the patient and force the individual to change the place of living or



job, putting further stress on the already weak economic situation. This further leads to progressive deterioration of health, low morale, repeated consultation, abstinence from work and low productivity (Wig, et al, 2006). This vicious cycle thus goes on, economic deprivation and social isolation takes its tolls on the quality of life.

This section therefore, looks at the impact of the caretaker's attitude towards the patient's quality of life. The majority of the participants were quick to note that those relatives who portray good attitude to their patients in return give encouragement and hope to the patients.

The following narrative statements were given by participants explaining their feelings towards their caregiver's attitude:

**Participant:** *"This good attitude from my relatives gives me courage and some hope for better life. This also encourages me that I am not different from any other person because of my HIV status. I live a happy life. The pain that is in me is always lessened because they always comfort and encourage me. I thank God for this situation. With the ARVs that I am able to receive, nowadays I have very good life".*

**Participant:** *"This makes me to have some courage and hope for the future". It gives me strength and I can even force myself to eat and chat with people because I know they love me. I want even to live longer because they are not bothered with my sickness. When they are happy, I am also more than happy. Because of the encouragement that I get from my family members, I can move up and down with happiness and I know this means my life is improving".*

On the other hand, the other half of the participants affirmed the view that negative attitude towards the patient implies loss of hope, giving up life quickly and therefore poor quality of life. The following narrative statements indicate impact of negative feelings towards the patient's quality of life.

**Patient:** *"This makes me to be miserable and sometimes I wish I could die early because I know I am bothering innocent lives. Sometimes I don't want to eat and I know my life is going down slowly".*

.

**Patient:** *"It makes the patient feel bad because you know you are very ill and therefore your condition goes down". In my case in such situations, I don't want to eat. I feel I am a burden to the people and it is better if I die and relieve them. Sometimes it reminds me of my late husband and I cry the whole day".*

**Patient:** *"I don't feel good. I don't have an appetite to eat. I think of the same situation happening to my children when I die. Then I cry internally the whole day with no comfort".*

Radstake (2003) supports these findings by stating that one of the expected outcomes of caring for an AIDS patient in the home is to maintain the highest quality of life through the support of the care giver. The author therefore urges that in this situation, openness is important in home based care especially in patients and families living with HIV and AIDS illness regarding the need for care. Similarly, the author compares these results with what happens in Ghana. He said, secrecy is a prerequisite for care of persons with AIDS in Ghana (Radstake, 2003). Unfortunately, this brings conflict in the patient between the secrecy attached to the disease (AIDS) and the openness that is required in order for the family and care givers to provide support and services in a home based care program.

### **Activities that the patient is able to do to help himself**

In order to determine quality of life, participants were also asked to explain day to day activities that they are able to perform. Most participants indicated that they are able to do most of the basic things except in times when they are not well or when they have an infection. A minority group of participants affirmed that they can only do little basic things, another minority group of participants stated that they can not do anything on their own while only one participant said he can do everything on his own without problems. The following are the narrative statements from the participants:

**Participant:** *"I can manage some of the basic things like eating, walking to outside, cleaning plates. I walk but not very far. This is much much better than I used to be in the past. I have improved tremendously. Thanks to God"*

**Participant:** *"I can only walk around the home". `` I am able to eat on my own. Most of the times I bath on my own. I know very soon I will start doing my normal duties which I used to do before".*

**Participant:** *"I can manage most of the basic things like eating, walking around, bathing myself, and even chatting with other people. I only need help when I am not feeling well".*

However, there were also some participants who acknowledged that they can not do most of the activities on their own as they used to do before they fell sick.

**Participant** *"In the past I used to do almost everything for my self, but now most of the things I am being helped. If someone prepares food for me, I can eat but I can not do other normal things which I used to do before I started getting sick".*

**Participant:** *"Most of the times I am weak and therefore I am assisted with most of the activities e.g. my cousin gives me a bed bath".*

**Participant:** *"Nowadays I can not work and that means food is a problem at my house. I cannot perform normal duties as a man of his own house. I always depend on other people on basic things".*

**Participant:** *"I can not do other heavy duties which I used to do before I started getting sick such as what I told you earlier (being a man in the house), madam as a man at least not frequently----- (patient gives a weak laugh). You know what I mean madam----- (patient gives a weak laugh. I have a wife who is not even aware of my condition. She is still very young, I can not satisfy her at present and any body can take her you know I am very worried about this. She has not been tested for HIV, maybe she also has the virus then what will happen to the children?"*

Table 5.9 and figure 5.12 below illustrates activities done by the participants to achieve their quality of life.

**Table 5.9: Daily activities of the patients (n=15)**

Activity	Frequency
Able to do most of the basic things alone e.g eating, bathing, walking around	Majority
Can do little basic things alone	Few
Can not do any of the basic things alone	Minority
Able to do everything alone	One

**Figure 5.12: Activities done by patients (n=15)**

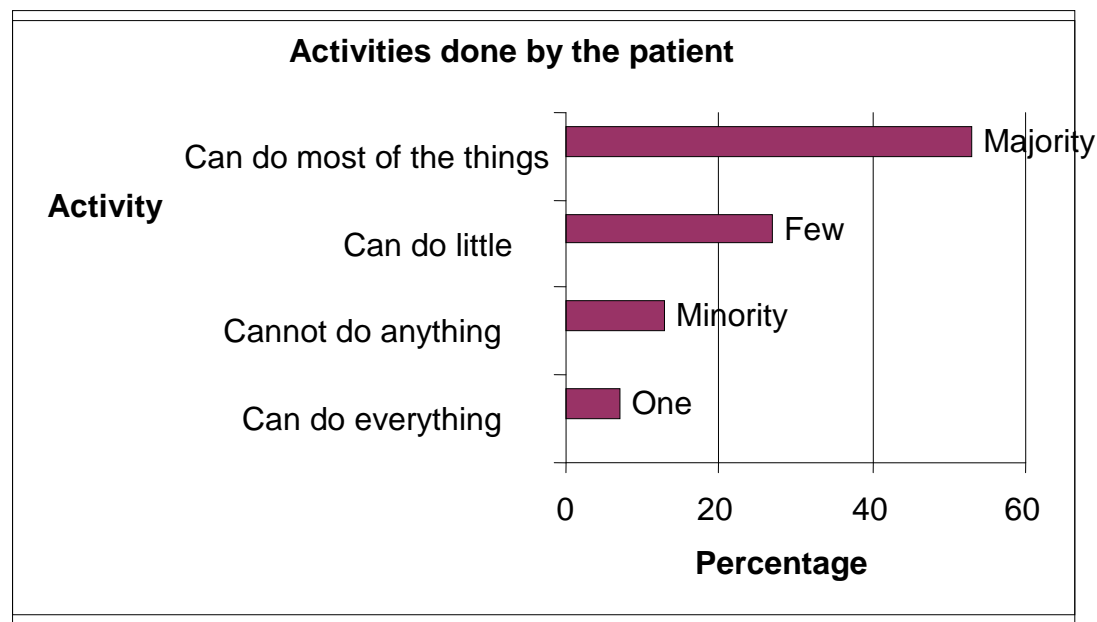


Figure 5.12 shows activities that participants acknowledged they were able to do. Majority of participants said they were able to do most of the things alone, few said they can do little and another minority group said they could not do anything.

## **5.9 WHAT ARE THE HEALTH NEEDS OF HIV AND AIDS PATIENTS IN MALAWI?**

### **Theme 8: Common needs of HIV and AIDS Patients**

Hospitals alone cannot deal with the needs of AIDS patients effectively. The patients are discharged to be care for at home (Tshililo & Davhana-Maselesele, 2009).

Participants were also asked to explain what they would consider as their health care needs in relation to HIV and AIDS. The overall distribution of type of need across all clients is shown in table 5.10. The most common need expressed by the vast majority of participants was need for nutrition (food). Participants said they needed food because due to long illnesses, patients can not access food adequately. This was followed by need for nursing care which was also mentioned by most participants. By nursing care, participants meant situations where they would be provided with medication for different infections and ARVs to prolong their lives. Another majority of participants acknowledged that they required counselling services where emotional and spiritual support would be provided. Needs for financial support to run small scale businesses and transport especially during referrals were also cited by almost half of the participants.

The remaining of the needs such as information giving on HIV and AIDS, need for shelter and physical care e.g. bathing, eating, dressing etc were mentioned by less than half of the participants. The need to be assisted with household chores and care for other family members were cited by very few of the participants (see table 5.10).

**Table 5.10: Need profile of HIV and AIDS Clients (n=15)**

Health Care Need	Frequency
Support with Food (Nutrition)	Vast Majority
Support with nursing care(provision of medications to treatment of opportunistic infections and ARVs, pain management, treating wounds)	Majority
Counseling on HIV and AIDS issues (emotional/ spiritual support) even to be extended to our families	Majority
Support with transportation during referrals	Almost half
Economic/ financial support i.e. support to people living with HIV and AIDS with income generating activities (small scale business), support with basic resources e.g. soap, sugar etc	Almost half
Physical care (bathing, dressing, eating etc	Less than half
Information/knowledge on HIV and AIDS	Less than half
Shelter (Good place to sleep)	Less than half
Family care (care for other family members)	Very few
Adequate rest	Very few
Household chores	Very few

The following narrative statements by the participants of this study indicate their needs as people who are living with HIV and AIDS:

**Participant:** *“I always lack money to buy food in my house. That is the main problem that I have. As I told you before I am taking medication everyday but I don’t feel well when I take it without food”.*

**Participant:** *"I need a lot of things madam such as food, a good place to sleep, some resources such as soap for bathing and washing so that when my beddings are spoiled my relatives can use for washing. Currently, people from my church, though some discriminate me but they are able to provide me with these resources only that it is not at frequent intervals. My brother and my elder sister also assist me quite a lot".*

**Participant:** *"I need adequate and nutritious food. You know I am on ARVs and it is always a problem to take these medications on empty stomach. I am weak and I can not access food. I also need resources like sugar, salt, soap for bathing and washing".*

**Participant:** *"I need food, a good place to sleep, look at this house, anytime it can fall down. I don't have a husband who can build one for me. Some day there will be an accident in this house (see fig 5.13). I also need some resources such as soap for bathing and washing so that when my beddings are spoiled my daughter can use for washing. This can be possible if I am supported financially".*

**Participant:** *"Sometimes when I am very sick, I lack transport to take me to the hospital. Sometimes i stay for days before my daughter finds some money for transport. Madam this is a major problem to most pof us because we are not working and therefore we have no income to support us the government should really do something to assist us".*

**Participant:** *"This disease is still new to some of us and for me I need adequate information to understand how to take care of myself. Sometimes my volunteer does tell me a little bit of the information but i know this is not adequate thus why I need the nurse to come at my home frequently. I am on ARVs and I need this to continue because it makes me to feel much better everyday".*

**Participant:** *"What else would I need madam apart from food to feed my family. I have no energy to go and fetch for food and sometimes I go to bed with empty stomach. You can imagine after taking too much drugs..... (patient pauses) I mean ARVs anyway".*

**Figure 5.13: Picture of the house of the patient that was not in good shape**



The picture above is one of the houses to one of the participants who complained that it is not in good condition and anytime it can fall down. This participant said there was nobody to rebuild the house and she was worried about it.

According to the study which was done by Chikalipo {2007) titled “Analysis of Community Home Based Care in Malawi,” it was found that needs for PLWHA and their families are multiple and they vary from person to person and from one community to another. As such, the author recommended that stakeholders in Malawi such as primary care givers, health care system, community volunteers, NGOs and Government, need to work together to address these needs.

As stated earlier, there is clear evidence that families play an important role in providing support and care for people living with HIV and AIDS. The economic status of the household/ family plays a major part on the type of support provided to the patient. According to the study which was done by Homan, Searle, Williams, Aguirre, Mafata, Meidany, Oosthuizen (2005) titled “Exploring the role of family caregivers and home based care programs in meeting the needs of people living with HIV/AIDS,” it was found that many of the households in the study which were



served by home based care programmes were very poor and linking home based care programme with income generation activities may have alleviated some of the financial burdens they faced. According to Olenja (2004) in his study titled “Assessing Community Attitude Towards Home Based Care for People with AIDS (PWAS) in Kenya”, it was discovered that sheer poverty militates against providing adequate home care in as much as families may be willing to do so. The heavy burden of care cannot be shouldered by families alone. According to the conceptual framework used in this study, it has emphasized use of the Malawi National CHBC Policy and guideline (2005) which states that, home based care shall be provided by family members, trained community members and trained health workers who are supposed to provide professional supervision. These people shall be specially trained to ensure quality care.

As might be expected, not all needs are addressed by the outside caregivers. The extent to which the programme fulfils a client`s needs is influenced by the skills of the outside caregivers as well as the ability of the household members to contribute towards addressing the needs (Homan et al. 2005). In most of the times, the outside caregivers are involved in helping the household with the majority of situations where a client has a given need. The problem comes when this heavy reliance upon the outside caregivers may create situations of dependency by the household on the outside caregivers. However, even in the situation where the outside caregivers are involved in the provision of services, on average, the household caregivers spend more time assisting the sick person than the outside caregivers (Homan et al. 2005).

It is important to also note that the needs of a chronically ill and especially a person with HIV and AIDS are varied. It is therefore obvious that there is no single organization that can meet all the needs comprehensively. As such, referral and networking is a critical element in any home based care programme (Home Based Care in Tanzania, 2008 (author not given). According to the Malawi CHBC Policy and guideline (2005), every CHBC implementing institution should provide a *minimum package* of community home based care services to patients. Care providers shall at each visit to the patient implement the package as determined by individual patients` needs.

The minimum package shall comprise basic nursing care, management of common health ailments in the home/community, prevention, identification and referral of opportunistic infections, palliative care including psychosocial and spiritual care, support to the primary care giver, infection prevention and control in the home, nutrition education and food supplementation where feasible, monitoring of the patient on Cotrimoxazole prophylaxis, ARV and TB treatment, IEC on prevention of HIV, TB and Malaria to patient and family members, promote use of Insecticide Treated Nets by chronically ill patients, discharge planning and referral to appropriate services and ongoing counselling.

#### **5.9.1 Patients' Need for ARVs**

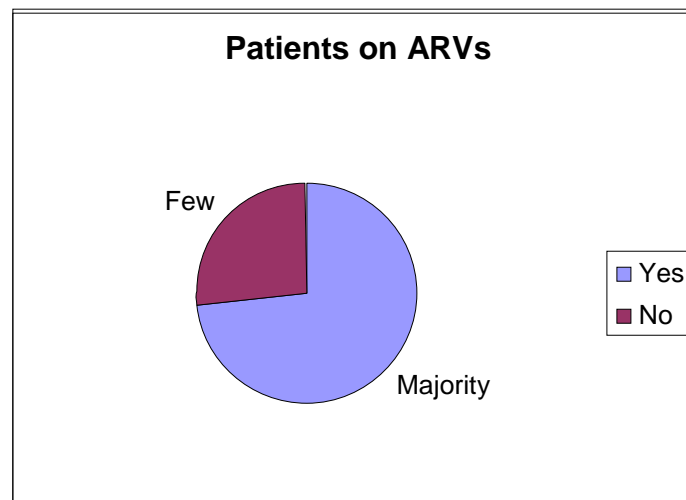
While there is no known cure for HIV and AIDS yet, there are many things that people living with HIV and AIDS (PLWHA) can do to live a long and healthy life. Anti-retroviral (ARV) drugs are special drugs that have been created to treat HIV and help PLWHA stay healthy. Patients and Caregivers need to know that ARVs do not cure HIV and AIDS and that while on ARVs, people living with HIV or AIDS can still transmit HIV and can still become re-infected with HIV. It is also important that PLWHA are aware that ARVs are taken for life.

In this study, as stated earlier under participants' knowledge on HIV and AIDS, responses which were given by the participants reflected that ARVs are important in the fight against HIV and AIDS. The most important part of it is that most participants were aware that ARVs do not cure HIV and AIDS and that ARVs can prolong life. The strength that has been observed from this study is that majority of the participants who are HIV positive are on ARVs because they were eligible to the treatment.

The study results are congruent to the study done by Jelsma, Maclean, Hughes, Tinise and Darder, (2005) in South Africa. These authors stated that projections indicated that in the absence of ARVs, the number of deaths due to AIDS is expected to result in a cumulative total of five to seven million by 2010 (Jelsma et.al, 2005). On the other hand, another author also stated that, in South Africa,

most PLWHA have no access to drugs such as ARVs and can only be offered palliative care. This increases the importance of home based care (Uys, 2003).

**Figure 5.14: Patients on ARVs (n=15).**



Findings of this study are also supported by Bhatia and Narain (2005) who stated that the primary objective of the antiretroviral therapy is to prolong the survival as well as improve the quality of life of the people living with HIV and AIDS. By bringing down the HIV viral load to sustained undetectable level, it is expected that ART will contribute also to HIV prevention.

These authors assert that all people with HIV for whom ART is clinically indicated should have access to it. Increasing ART coverage is a key goal of many countries. But people with HIV should also benefit from basic HIV prevention and care, including a core set of effective interventions that are simple, relatively inexpensive, can improve the quality of life, prevent further transmission of HIV, and for some interventions, delay progression of HIV disease and prevent mortality (Bhatia and Narain, 2005).

In September 2003, WHO declared that failure to provide antiretroviral therapy to patients in developing countries is a global public health emergency. Accordingly, WHO with UNAIDS and partners set a target of providing 3 million people in developing countries with antiretroviral treatment by the end of 2005 (the “3 by 5”

initiative). While this is an interim target, long-term goal is of universal access to ART for all those who need it (Bhatia and Narain, 2005).

### **5.9.2 ARVs and Nutrition for HIV and AIDS patients**

One of the commonest needs that participants brought in this study was food. Just like the findings of this study, literature supports strongly that one of the greatest needs of people living with HIV is adequate nutrition. While factors contributing to lack of food in the households are many, poverty is one of them. HIV infection is often associated with poor nutrition due to many factors, including increased energy needs, decreased appetite, symptoms of HIV or opportunistic infections that lead to swallowing difficulty and malabsorption, and environmental factors such as lack of resources and inaccessibility of foods (<http://www.iolhivaids.co.za>). Nutritional status of an individual is a major determinant of host resistance to infection and it can counteract opportunistic infections (Chikalipo, 2007).

Good food is no substitute for ARVs. AIDS patients are more desperate for food than ARVs. ARVs are more effective and cause fewer side effects when taken with food. Adequate nutrition is also essential for delaying the progression of the HI Virus and the need for ARVs. According to Dr Reynold Grand Pierre of GHESSKIO, a non governmental research and training organization in Southern Coast of Haiti, “it is difficult to assure ARV drug adherence without food support (AIDS patients more desperate for food than ARVs, 2008 (author not given). The author of this article stated that if someone has social and economic problems, ARVs are not a priority. Patients are more concerned about finding food than picking up their ARVs. Sometimes patients miss their consultations because they are going to the food distribution.

## **5.10 WHAT INFORMATION, EDUCATION AND COMMUNICATION (IEC) MESSAGES ARE PROVIDED TO HIV AND AIDS PATIENTS AT HOME?**

### **Theme 9: Provision of Information to HIV and AIDS Patients**

In this study, participants were asked to explain information and education which they received from the hospital or community care providers concerning community home based care before they were put on the program. Participants were also asked to explain the information and education which they get at home in order to live a healthy life. Participants gave the following responses:

#### **Before put on Community Home Based Care:**

The vast majority of participants indicated that they were not given adequate information concerning community home based care and its benefits. A minority group of participants were given adequate information as shown by their responses. These participants were told what community home based care is all about including referral of the patients and the supervision they will receive. The following narrative statements indicate the type of information participants were given.

**Participant:** *“When I was about to be discharged from the hospital. I was told that I needed to be receiving care at home and that the volunteer would visit me at home in order to give me care. I was also told that when I have problems with ARVs (side effects), I should tell the volunteer and I will be referred back to the hospital. I was told never to share my drugs with someone. I was also told that drugs will be available for me at home”.*

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**Participant:** *“I was not told anything apart from telling me that the volunteer will be visiting me at home in order to take care of me. I was not given any chance to ask questions. I was wondering anyway because I was discharged from the hospital while I was still sick so I did not see any reason for discharging me”.*

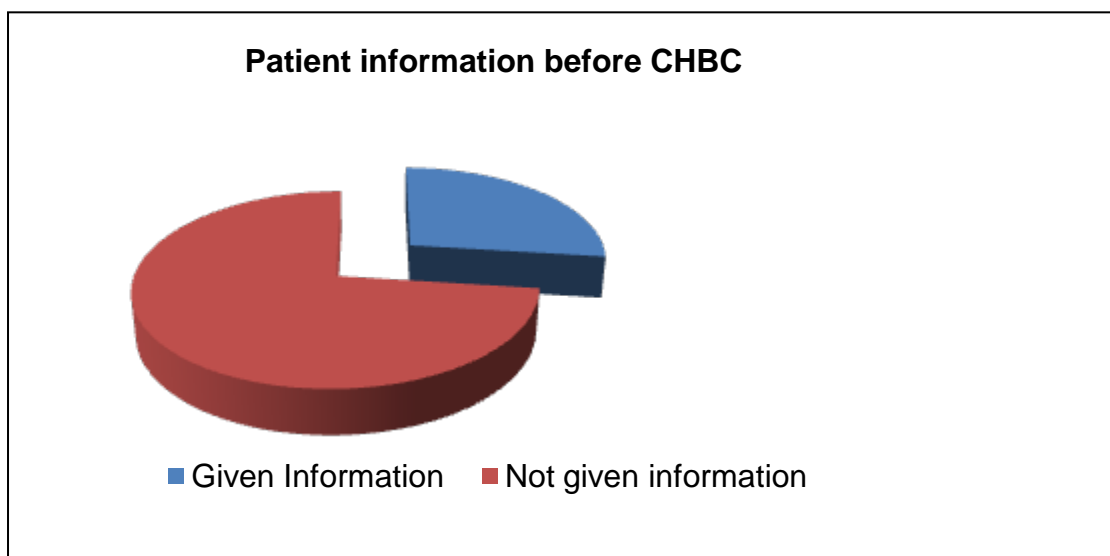
**Participant:** *“I was only told that my condition required to be put on home based care and that means I will be taken care of at home. I was fortunate that when I came my volunteer came to welcome me and she has been telling me information concerning community home based care from that time up to now”.*

**Participant:** *“I remember one of the health workers told me that I needed to be receiving care at home and that the people who are going to take care of me will be my own relatives and some volunteers from my village. I was also told the benefits of being nursed at home than the hospital. I was also told that whenever I am not feeling well at home I should visit the nearest hospital for treatment and care. I was also told that people from the hospital will be coming at times to see me”.*

**Participant:** *“I was told that it would be safer to be nursed at home than the hospital.”* When the participant was asked to explain why it would be safer at home, he did not seem to know and this is what he said: *“but the reasons were not explained to me may be the doctor explained to my wife who is my care provider”.*

Figure 5.15 below gives a picture of participants who were given information before they were enrolled on community home based care.

**Figure 5.15: Information giving to patients (n=15)**



These findings are supported by a study which was done in Botswana by Ndaba-Mbata, (2000) entitled "home based care of the terminally ill in Botswana: Knowledge and perceptions", it was discovered that family caregivers are the primary source for ongoing care and support. While family members accompany patients during their hospitalization, they receive little information about how to assist their relatives and as a result feel inadequately trained, poorly informed and dissatisfied with the support that is available after discharge (Ndaba-Mbata, 2000). The study therefore, found out that families lacked knowledge and skills for providing appropriate care. They were also not aware of the resources available and they lacked professional and material support. While the situation is like this in Botswana, literature search indicated that families who receive detailed information about the condition of the patient manifested more vigilant coping skills compared with families who received little information (Ndaba-Mbata, 2000). Although many people are being cared for at home, families as carers are not well informed and are ill prepared about what they have to do. The author recommended that for caregivers to give good quality of care to their relatives, they needed to have appropriate skills and information about how to provide this care. There should also be a good referral and follow up system for effective implementation of home based care with appropriate procedures for monitoring and evaluation.

#### **5.10.1 Type of Information given while patient is on the program**

At least all the participants mentioned something as education which they are receiving at home from their community care providers. The common information given to participants were: infection prevention at home which included home and personal hygiene, nutrition for HIV and AIDS patients, drug adherence and issues concerning income generating. A minority group of participants also stated that volunteers transfer their skills to family caregivers as they are discharging their duties the only challenge with them giving information was that volunteers do not come to visit patients frequently.

The following statements from the participants indicate information which they received from their care providers at home:

**Participant:** *“The volunteer teaches my relatives on how to take care of me. They also educate me not to have worries because worries facilitate death. I am also every time reminded of the importance of observing hygiene measures to avoid infections”.*

**Participant:** *“She told me to avoid getting pregnant. But I don't worry about that because my husband died and I live alone with my children. Sometimes she tells us to keep the home clean to prevent infections”.*

**Participant:** *“The nurse tells us to use condoms in our home to prevent infecting each other. She also tells us to eat nutritious food (6 groups of food) although I know it is difficult for us to find even food of one group, anyway we just listen” ----- (patient laughed very loudly).*

**Participant:** *“She told me to avoid getting pregnant. But how can I observe that since I am still young. When she tells me that I just say yes to please her but I know it will not be easy”.*

Providing information to HIV and AIDS patients including their caretakers is important and it forms an integral part of community home based care. Providing information to HIV and AIDS patients would empower them. If these patients knew about their health and relevant issues of HIV and AIDS, they would be more inclined to know what actions to take. Information is knowledge and knowledge is power (Malata, 2004).

The high illiteracy rate among Malawians especially women poses a lot of challenge in provision of information. According to the study done by Malata (2004) titled “the development and evaluation of a child birth education program for Malawian women”, the ability to read is an important personal asset as it increases opportunities in life. In Malawi, only 39% of the adult population is able to read and write. According to the Malawi National Health Plan (1999-2004) 48% of women and 30% of men have not attended school and up to 80% of rural women can neither read nor write.



## 5.11 DOES THE CURRENT COMMUNITY HOME BASED CARE PROGRAMME BENEFIT THE HIV AND AIDS PATIENTS IN MALAWI?

### Theme 10: Benefits of Nursing an HIV an HIV/AIDS Patient at Home

In this study, participants were also asked to state whether being in the community home based care program is benefiting them as patients living with HIV and AIDS. Almost all participants affirmed the fact that home based care is important and that it has to be encouraged. However, there were mixed reactions as to whether they are benefiting from the program themselves.

Majority of the participants affirmed that the program is benefiting them while few participants said they had reasons for opposition. These participants said they were experiencing a lot of problems while on community home based care and therefore gave the following reasons why they thought they aren't benefiting from the program.

Table 5.11 presents participants feelings of not benefiting from the program and their reasons.

**Table 5.11: Feelings of not benefiting from the program**

Care at home	Care at the hospital
<i>It's a burden to relatives and family. Very tiresome</i>	<i>Nurses, doctors and others are always available to help each other</i>
<i>Drugs are given only by the nurse once a week and very little</i>	<i>Adequate drugs are given daily 3-4 times a day. Drugs can be changed any time</i>
<i>When there is a problem, referral is usually late because of transport problems. You can take even a week looking for transport</i>	<i>Vehicles are always available to take patients</i>
<i>We are seen by nurses only once a</i>	<i>Patients are seen every day by</i>

<i>week and sometimes even after more than a week. You have to be very sick for you to be seen by a nurse</i>	<i>different kind of health workers. Patients are observed frequently</i>
<i>When there is no food at home, patient sleep on empty stomach</i>	<i>Food is always available for patients three times a day</i>
<i>Stigma is high in the homes because the community is near us and they are watching us.</i>	<i>Less stigma because health workers are afraid of rules and regulations from their work places</i>

The majority of participants who said they were benefiting from the program gave the following narrative statements: The researcher opened with the following question: A lot of times people have commented that people living with HIV and AIDS (PLWHA) would benefit much if they are being cared for at home. How is this experience with you?

**Participant:** *“That is true madam. For example here at my house I am happy and free to do anything that I want such as to go outside if I want to bask in the sun but this was not the same when I was at the hospital. When you are in the hospital there are a lot of infections too which you can also acquire as a patient”.*

**Participant:** *“That is true. For example when I was in hospital, only my daughter was with me in the hospital and I had always wished my other children could visit me but they had no money for transport. Now I have most of my relatives with me at home and I still feel it is better to be nursed at home than the hospital”.*

**Participant:** *“Oh madam, yes it is true. You know when you are at home the environment is different. You don't fear anything nor your relatives because at the hospital we are afraid of nurses who shout at patients because they feel the patient is difficult”.*

Home based care has benefits to the patients, family and the community (Home Based Care Services in Tanzania, 2008, author not given). It enables patients to be cared for in a familiar environment, as well as allowing them to participate in

and contribute to family life and make them part of their families and community. It reduces the cost of caring for patients away from the family.

Home based care helps to hold the families together with the objective of caring for the patient (Home Based Care Services in Tanzania, 2008 author not given). It helps the family to accept the patient's condition thus making it easier for care and support. It reduces costs of care as well as enabling the family to attend to other tasks as they care for the patient.

Home based care raises awareness among community members about HIV and AIDS. It reduces stigma and thus prevents spread of HIV and gets rid of myths and misconceptions about HIV and AIDS. This helps communities to understand issues of HIV and AIDS. It also makes it easier to provide support by tapping all possible community resources and helping to bring the community together to combat HIV and AIDS and advocate for more services (Home Based Care Services in Tanzania, 2008 author not given).

According to the study which was done by Zimba and McInerney (2001) titled "The Knowledge and practices of primary caregivers regarding home based care of HIV/AIDS children in Malawi", it was indicated that community home based care benefit both the patient and the family. These authors explain that patients in home based care feel less isolated from family and friends. Patients potentially feel psychologically and spiritually more supported, comforted and better able to cope. In many instances, people prefer to face ill-health or death in familiar surroundings rather than in a hospital setting. On the other hand relatives are able to take care of patients while attending to other chores (Zimba and McInerney, 2001).

## 5.11 WHAT CHALLENGES OR PROBLEMS ARE FACED BY HIV AND AIDS PATIENTS IN MALAWI?

### Theme 11: Challenges of HIV and AIDS Patients in Malawi.

Participants were also asked to mention the challenges they are facing due to HIV and AIDS while on community home based care program. All the participants acknowledged presence of challenges because of living with HIV and AIDS. The common challenges were: lack of food, presence of opportunistic infections, unable to perform their normal duties, stigma and discrimination, bad attitudes from the care providers, lack of care to the children, spouses and even to relatives. The following are some of the narrative statements that participants gave to indicate their challenges.

**Participant:** *“relatives get tired to take care of the patient at home for long periods. After some months they start showing signs of tiredness. In this situation they change the attitude from good to bad. Most of the times I am weak and therefore I am assisted with most of the work and I feel challenged as a man”.*

**Participant:** *“Problems are always there madam. Currently, I can not work and that means food is a problem at my house. I am frequently suffering from diarrhea and fevers which makes me fear. Sometimes I live a miserable life especially when I think of my children who will not enjoy my care as a father”.*

**Participant:** *“Problems are always there. I am afraid of death. I am frequently suffering from diarrhoea and malaria which makes me smell death. Sometimes I live a miserable life especially when I think of my children that they will be left without parents and also because some of my relatives stigmatize me. Resources for care are not adequate at home and sometimes you are not feeling better but the nurse doesn’t come to give you drugs since my volunteer doesn’t carry drugs with her. So it is all misery”.*

**Participant:** *“Challenges are there like lack of food some of the days, presence of opportunist infections such as diarrhea, and fear of the health of my child when I*

*am admitted nobody stays at the hospital except my daughter and that means she absents herself from school during those days in those days vl feel challenged. Should I send her to school? What about me, who will take care of me. But I know without school she will suffer in future”.*

**Participant:** *“The only time that I am challenged and feel worried is when I see the only child that I have getting sick frequently and therefore his sickness reminds me of my status and therefore I feel sorry not for myself but for my son because he does not know anything since he is young and innocent”.*

These results are supported by a study which was done in Botswana by Shaibu (2006) titled “Community Home Based Care in a Rural Village: Challenges and Strategies”. This author stated that, just like in many developing countries, there are several problems facing the implementation of home based care in Botswana. There is shortage of staff both from the nursing side and social workers and because of that some patients die before they are attended to. Difficulties with transportation, poor referral system and poor documentation are also some of the challenges being faced in the implementation of CHBC in Botswana (Shaibu,2006).

Similar challenges are also being experienced in Uganda especially by caregivers. According to the study which was done by Kipp, Tindyebwa, Karamagi, & Rubaale, (2007b) titled “How much should we expect? Family caregiving of AIDS patients in rural Uganda”, it was found that family caregivers reported serious work overload and low health status. This high burden of caregiving puts family caregivers at risk for decreased health status, increased social isolation and depression.

Similarly, Malawi is not exceptional. Malawi’s Community Home Based Care program is not without problems. Malawi has been faced with a lot of challenges to support implementation of CHBC program such as shortage of professional health workers, material resources and stigma and discrimination of HIV/AIDS patients (NAC, 2003). A number of attempts to operationalize the program have experienced several obstacles. Poverty, inadequate space, heavy workload on the

family and insufficient information about the infection to the care giver has been paramount (Zimba and McInerney, 2001). As the requirements for family caregiving are often overwhelming for women under the conditions as they exist in Malawi and in other developing countries, it constitutes a gender issue of great importance that has not been appreciated fully in the international literature (Chikalipo, 2007). In many poor countries, family caregiving is the most common and often the only care that AIDS patients receive because clinic-based care often is not available close to home or is not affordable (Kipp, Tindyebwa, Rubaale, Karamagi, & Bajenja, 2007a).

Greeff and Phefilhu (2007) in their study attest that stigma and discrimination is also one of the challenges faced by community home based care programs worldwide. These authors found out that AIDS stigma and discrimination continue to impact on those living with and affected by the disease particularly in Southern Africa where the burden of AIDS is so significant. These authors concluded that unless stigma is conquered, the illness will not be defeated.

## **5.12 Conclusion**

This chapter has discussed the analysis of research data and the findings of this study. Findings have been presented and discussed in sections according to the themes that were identified from the data collected. Majority of the data has been presented in qualitative manner. Verbatim excerpts have also been included.

## **CHAPTER 6**

### **DEVELOPMENT OF THE PRIMARY CAREGIVER'S TEACHING MANUAL / PROGRAM**

#### **6.1 INTRODUCTION**

Knowledge deficit is a common factor among caregivers in the home. The literature on caregivers experience highlights that many caregivers face an increased amount of stress when caring for someone at home which may be experienced physically and emotionally (White, et al, 2008). Emotional stress can lead to caregivers suffering burnout and being unable to continue caring. Most research has shown that support and education can reduce caregiver burnout and ensure that caregivers continue their role. This chapter, therefore, describes the development of the primary caregivers teaching manual / program in response to one of the findings of this study. The manual has included eleven (11) topics in the form of units that will be offered to the primary caregivers. Content used in the development of these units was derived from the literature searched, Malawi Ministry of Health service providers training manual and from the individual in-depth interviews with PLWHA. The chapter will describe the process that has been followed in the development of the Primary Caregivers Teaching Manual/ Program and pilot study which was done to pre-test the teaching program.

No epidemic in the world today attracts as much attention, publication, debate and controversy as HIV and AIDS. HIV and AIDS has been declared a national emergency in countries throughout the world. The AIDS crisis has affected all sectors of society and Malawi continues to suffer from the connecting problems of poverty, famine and AIDS (Avert, 2008). Undoubtedly, there is a great need for services and support provided by community home based care programme to persons infected and affected by HIV and AIDS (Mohammad and Gikonyo, 2005). An effective CHBC program for PLWHA can yield major health and social benefits starting from the patients and their families and consequently to the entire community.

One of the major issues that came out clearly in this study was that relatives/ family members were mentioned as the main care providers to HIV and AIDS patients. However, the same relatives were also cited high as a source of stigma and discrimination to patients. Half of the participants in this study confirmed a positive attitude from their primary caregivers/relatives while the rest experienced a negative attitude. Furthermore, primary care givers (relatives) of the majority of the participants in this study did not receive formal education on care of HIV and AIDS patients at home except very few. This means that infected people are inadequately looked after despite the best efforts of their carers and families who face economic, psychological and social difficulty.

The biggest challenge that lies with primary care providers/ relatives is lack of knowledge to be used when taking on a primary care giving role. The fear surrounding the emerging epidemic (HIV and AIDS) is still present in many primary caregivers. Most of them are still scared of those infected due to fear of contagion hence stigma and discrimination and poor attitudes towards their HIV and AIDS patients.

There is clear evidence from this study that families play an important role in providing support and care for people living with HIV and AIDS in Malawi. No participant in this study mentioned a caregiver who had no relationship with the patient. It should also be remembered that volunteers who have received training to care for HIV and AIDS patients in the homes, cannot attend to patients around the clock. In normal circumstances, volunteers are expected to undertake home visits to patients who are under their care during which time they are supposed to assist the primary caregivers in terms of information, physical care and psychological support and refer patients for further management where necessary. This situation is not always the case. Participants in this study reported that volunteers in their areas visited patients' homes only once or twice a week and most of the times patients were with their relatives.

Findings of this study are similar to the study which was done by Homan et.al. (2005) titled "Exploring the role of family caregivers and home based care



programs in meeting the needs of people living with HIV/AIDS". In this study, it was reported that even in the cases where the outside caregivers are involved in the provision of services, on average, the household caregivers spend more time per week assisting the sick person than the outside caregivers. According to these authors, the outside caregivers serve more as a complement to the household caregivers than a substitute. Homan et.al (2005) therefore strongly recommended the need for home based care programs to work more closely with household members. Interventions to educate families on caregiving are needed as household caregivers may lack the necessary skills for caregiving. This was evidenced by the substantial proportion of household caregivers who wished to receive more information and education on caring for people living with HIV/AIDS. The study also observed that many of the households served by home based care programs were very poor and linking home based care programs with income generation activities may alleviate some of the financial burdens they faced (Homan et.al, 2005). Families can certainly be instrumental in providing care and support, but they cannot do it alone. They need effective partnerships and real determined leadership at the local, regional and national levels (Browning, 2008).

Findings of this study has therefore strongly recommended that the government of Malawi should introduce HIV and AIDS training to all primary caregivers to enable them render quality care to patients at home. Just like it is with community care providers, a training manual has to be developed for family care givers to be used in their training. The purpose of this chapter therefore is to develop a teaching manual to be used in the training of primary caregivers on care of AIDS patients at home.

## **6.2 Purpose of the primary caregivers teaching manual**

The purpose of this manual is to provide knowledge and support to primary caregivers on how to care for AIDS patients at home. Its specific aims are to:

- Provide primary caregivers with practical skills in caring for terminally and chronically ill such as AIDS patients at home

- Increase awareness of existing community resources for caregiving at home
- Increase primary caregivers' confidence through knowledge and information
- Promote the concept of community home based care

Major areas to be focused in this course therefore will be as follows:

- What HIV and AIDS are, how HIV is transmitted and how to prevent its transmission
- Benefits of nursing a patient at home
- How to recognize common signs and symptoms experienced by HIV and AIDS patients such as: fever, diarrhoea, pain, cough, difficult breathing, mouth and throat problems, weakness, anaemia, skin problems and depression.
- How to manage these signs and symptoms at home
- When, where to take the patients for appropriate care if home management fails
- How to assist their patients to live positively with HIV and AIDS.

### **6.3 Selected studies on lack of knowledge by primary care givers**

Several studies have been identified which are supporting and explaining lack of knowledge by primary caregivers in many countries and the importance of providing knowledge and skills to them. Studies reveal that primary caregivers of HIV and AIDS patients face physical, emotional and financial burdens. Knowledge is one of the major factors that promotes adherence to treatment regimens (Zimba and McInerney, 2001). According to these authors, with the current trends worldwide of home and community based services for the management of HIV and AIDS patients, knowledge of caregivers about the home care of these patients will determine the success of the CHBC programs. This study revealed a gap in knowledge among primary caregivers. The study also found out that lack of prior preparation for home based care among caregivers and their patients acted as a

major factor contributing to the lack of knowledge. The study therefore recommended the need to put into place mechanisms that will ensure that all primary caregivers are adequately prepared in good time for home care services (Zimba and McInerney, 2001).

In the study done by Edward and Fleiser (2007) on “Safety in Home Care” the results emphasized the importance of knowledge to caregivers as they have a key role in the care of their patients. When clients and caregivers know what is happening or what is going to happen to them, they cooperate and implementation of care becomes easy from both players since they will be working together (Edward and Fleiser, 2007).

Similar to this are the findings from another study done by McInerney and Brysiewicz (2005). These authors looked at experiences of caregivers in providing home based care to persons with HIV and AIDS in Africa. Findings of this study revealed that the provision of care to terminally ill persons places a heavy burden on the family and that this can place a great strain on the caregivers. The study also found out that the primary caregiver has both physical and emotional demands made on his/her own health such as risk of infection, stigma, fear and omnipresence of death (Brysiewicz and McInerney, 2005). The study therefore recommended that primary caregivers in the community should be better equipped with knowledge and resources so that their practices can improve.

Similar findings were also found in the study which was done in 2003 by Nkosi, Kipp, Lang & Mill titled “family caregiving for AIDS patients in the Democratic Republic of Congo where 12 caregiving women, six home based care workers and five key informants were interviewed via focus group discussions. Findings indicated that most women reported huge problems in providing care to their spouses due to inadequate knowledge. Psychological, social and economic factors were also mentioned as the problems most of the caregivers were facing. The secrecy around HIV/AIDS issues and care was a significant theme in the findings (Nkosi, et al, 2003).

Campbell and Foulis (2004) in their research on “creating contexts for effective home based care of people living with HIV and AIDS, identified multi-level factors that undermined carers in performing their role. These included lack of knowledge, skills and support both at the individual and organizational levels, physical and psychological burnout etc. Ndaba-Mbata and Seloilwe (2000) in their study of “Home based care of the terminally ill in Botswana: knowledge and perceptions found out that families lacked knowledge and skills for providing appropriate care. Participants were not aware of the resources available and they lacked professional and material support. These authors recommend that for caregivers to give good quality of care to their relatives, they need to have appropriate skills and information about how to provide this care. The study also recommended that a good referral and follow up system should be in place for effective implementation of home based care with appropriate procedures for monitoring and evaluation. Education can help carers regain a sense of control over their lives as they are able to make informed choices concerning care (White et.al (2008).

#### **6.4 Organizational structure of the primary caregivers teaching manual**

The manual includes a Title page, Acknowledgements, an Introduction, a Table of contents and the actual teaching program with objectives, content and suggested teaching and learning methods for each topic. This teaching manual is presented as an appendix 13 in this document.

#### **6.5 Development of the primary caregivers teaching manual**

The following topics have been included in the primary caregivers teaching manual:

- Basic facts and information about HIV and AIDS in Malawi
- Benefits of Community Home Based Care
- Communicating with a patient effectively
- Basic skills for nursing a patient at home
- Infection prevention and control measures in the home
- Management of common HIV and AIDS related conditions in the home

- Management of patients' drugs at home
- Nutrition of PLWHA
- Positive living with HIV and AIDS
- Referral of CHBC patients
- Care of Carers

## **6.6 Training of health workers to pilot the teaching manual**

After development of the manual, it was presented to a group of three CHBC trainers who reviewed the manual especially on the topics and its content. These trainers were chosen because they are also involved in training of CHBC volunteers. The manual was then refined and piloted. Two other nurses were trained to pilot the program. These nurses were taken from one of the organizations dealing with PLWHA. Both nurses were already trainers in the training of service providers (volunteers). Teaching skills were reviewed to be certain of the ability of the nurses to impart knowledge. Training took one full day. These trainers were requested to choose topics to teach which were distributed according to experience and knowledge. Piloting of the manual took three days. After the pilot few areas were amended depending on the comments made by the trainers who pilot the manual. The manual was then refined again.

## **6.7 Details of group sessions during piloting of the manual**

The following are the details of the activities of the teachings for the three days of piloting. The group of primary caregivers which was used in the pre-testing of the manual comprised 20 members for optimum learning experience to take place. Three trainers (including the researcher) were used to facilitate the training. At the end of the training, participants were asked to evaluate the training and all the participants appreciated having attended the course and said the knowledge gained will improve their caring for their patients. Results of the pilot indicated that most of the primary caregivers had knowledge on transmission and prevention of HIV but lacked knowledge on basic skills to nurse patients at home, management of common problems faced by HIV and AIDS patients and their management at

home. Infection prevention in the home was also demonstrated as a problem to most of these primary caregivers.

### **Day 1:**

The following activities were performed during the first day of the primary caregivers training.

- Recruitment of participants
- Pre-test
- Topics taught:       Basic facts and information about HIV and AIDS in Malawi  
                              Benefits of Community Home Based Care  
                              Communicating with a patient  
                              Basic skills

### **Day 2:**

These were the activities for the second day of training.

- Review of day 1 content
- Infection prevention and control measures in the home
- Management of common HIV and AIDS related conditions in the home
- Management of patients' drugs at home

### **Day 3:**

These were the activities for the last day of training.

- Review of day 2 content
- Nutrition of PLWHA
- Positive living with HIV and AIDS
- Referral of CHBC patients
- Care of carers
- Post-test
- Closure

## **6.8 Conclusion**

This chapter has presented the process which was followed during the development and piloting of the primary caregivers teaching manual. Details of content, teaching strategies and objectives are presented in the appendix 13 as the Primary caregivers Teaching Manual.

## **CHAPTER 7**

### **SUMMARY, MAJOR CONCLUSIONS AND RECOMMENDATIONS**

#### **7.1 INTRODUCTION**

This chapter concludes the research report with a summary of the findings. Significant issues extracted from the findings of the study have been presented. The conclusions drawn from the study and the recommendations made in order to improve provision of quality of community home care to HIV and AIDS patients in Malawi have also been included. Finally, factors that placed limitations on the research study have been identified and described in the chapter.

#### **7.2 SUMMARY**

The preceding chapters have shown that living with HIV and AIDS is a challenge. Participants in the study have described HIV and AIDS as disappointing because it brings misery, stigma and anxiety. Just like in many countries, in Malawi people living with HIV and AIDS have their needs which most of the times are not met. Most of the findings obtained in this study correspond with the literature that has been presented earlier on. Findings of this research have identified certain factors that impinge on the quality of life to the people living with HIV and AIDS in Malawi. The main findings and a summary of the research study has been presented.

##### **7.2.1 Study Purpose**

The purpose of this study was to explore and describe the experiences that HIV and AIDS patients who are on Community Home Based Care Programme have in Lilongwe district of Malawi and later develop practical guidelines for the implementation of quality home care in Malawi. One practical guideline that has been identified in this study is the importance of training primary caregivers because they are the ones giving care to the patients almost all the times. A teaching manual for the primary caregivers has therefore been developed and piloted in this study. The study used patients from 3 major organizations dealing



with PLWHA in Lilongwe district. These are: the Light House which is a public/ government institution, NAPHAM (National Association for people living with HIV and AIDS in Malawi), and Lilongwe Diocese. The study addressed the following research question:

### **7.2.2 Study Questions**

- What does it mean to live with HIV and AIDS in Malawi?
- How do HIV and AIDS patients perceive the care, support and treatment provided to them at home?
- What are the health needs of HIV and AIDS patients in Malawi?
- What information, education and communication (IEC) messages are provided to HIV and AIDS patients at home?
- Does the current Community Home Based Care programme improve the quality of life for the HIV and AIDS patients in Malawi?
- What challenges or problems are faced by Community Home Based Care patients in Malawi?

### **7.2.3 Methodology**

To achieve the purpose of the study, a qualitative research design using an interpretive phenomenology was used.. The researcher did not find an existing tool which was closely related to the study objectives, and therefore, a new data collection tool was compiled and validated. Data were collected by the researcher. Interviewing (In-depth) and observation were used as the methods of data collection for the study. An in-depth interview guide comprising mainly open ended questions was used to interview individual persons in 15 households. A pilot study was conducted using subjects similar to those of the actual study to pre-test the interviewing guide and also to validate the study. Since the study involved human participants, appropriate measures were taken to ensure ethical practice and to safeguard participants` rights.

#### **7.2.4 Population and Sample**

The study population comprised of all PLWHA aged 14 years and above living in Lilongwe district. A purposive sampling technique was also used to choose the sample i.e. the researcher purposefully selected the specific participants who were willing to provide rich information needed in order to gain an insight

### **7.3 MAIN FINDINGS**

The major findings of the study were as follows:

#### **7.3.1 Demographic Characteristics**

The mean age of the respondents was 28 years. Females comprised 60% (n=9) of the sample. It was determined that 53% (n=8) of the sample had primary school education, 27% (n=4) had secondary school education and 20% (n=3) of the sample had no education at all. The majority of the sample 40% (n=6) were house wives followed by those running a business and those employed 20% (n=3) respectively. Majority of the participants, 40% (n=6) were married. Two participants (13%) were single and another 13% of the participants (n=2) were divorced. Four participants (27%) were widows and one participant (7%) was a widower. 73% (n=11) affirmed they were Christians belonging to a variety of churches. Three participants (20%) were Moslems and one participant was a pagan meaning that he did not belong to any religion.

#### **7.3.2 Problems to be enrolled in CHBC Program**

An overwhelming majority of participants identified that they were not feeling well for sometime and they were advised by someone either at home or at the hospital to go for an HIV test and thereafter they were enrolled into the program for observations.

The study has also identified that majority of the responses showed that the respondents became suspicious after losing a spouse or after identifying some

signs which they suspected to be HIV related. This motivated them to go for an HIV test.

### **7.3.3 Living with HIV and AIDS**

The majority of the participants affirmed the statement that it is not easy to live with HIV and AIDS. All participants showed some concern that they were living with HIV and AIDS. Majority of the participants acknowledged that it is disappointing to live with HIV and AIDS and therefore they felt bad about it. Another majority of participants complained about the existence of opportunistic infections as a result of having HIV and AIDS. About half of the participants complained of experiencing stigma and discrimination and felt guilty of bringing miseries to their families.

Fear and worries could not be hidden by the participants as an experience of living with HIV and AIDS. The study noted that the vast majority of participants expressed feelings of anxiety, worries and fears of death. Majority of them were worried about their children due to their status of having HIV and AIDS. The major reasons given were that the children were still small, they would also acquire the virus, they would face stigma and that they would live the rest of their lives without parents.

The study noted with interest that a minority of participants felt that to live with HIV and AIDS is not the end of life. These participants affirmed the statement that it is important to know that HIV and AIDS are like any other diseases in the world for example malaria and therefore people would seek treatment in the same way they would do with other diseases.

### **7.3.4 HIV and AIDS Patients face Stigma**

Findings indicated that almost half of the participants indicated that they are facing stigma and discrimination because of having HIV and AIDS. Most of the participants cited relatives as the main source of stigma and discrimination to the participants. This was followed by friends and church members.

Participants presented some actions that indicated as signs of being stigmatized. Majority of the participants mentioned people stopping visiting the patient for no reason. Another majority mentioned that people did not want to talk or to come near the patient. Ignoring a call from patient was presented by another group and a minority of them mentioned gossiping about the patient.

### **7.3.5 Feelings of anxiety, worries and fears of death**

In this study, the majority of the respondents affirmed that they have had feelings of anxiety and fear of death. Most of the participants stated that they were worried because they thought of their children who are still young, their HIV and AIDS status which has no cure, presence of infections as the cause of their worries and a minority group of participants explained that they get worried because their condition was deteriorating and also because of too much pains which they were feeling. Another minority group of participants acknowledged fear of facing divorce after disclosure of HIV status to their partners as the reason for their worries.

Participants gave the following as signs of anxiety. Most of them stated that they always have excessive worry, disturbances in their sleep, sweating and flushing while minority said they do not have appetite when they are anxious.

### **7.3.6 Care Providers for HIV and AIDS Patients**

An overwhelming majority of them affirmed the view that relatives (family members) are the ones who provide most of the care to them at home. The study also noted that this majority of participants agreed to the view that being taken care of at home is good. They all affirmed the view that relatives should give care and support to the HIV and AIDS patients at home. However, half of the participants indicated that although the common situation is like this, some relatives are not happy and willing to provide care to patients who are HIV positive.

It has been noted that the vast majority of respondents, their household care giver was a female and half of them were looked after by their children who are still young and at school. Their ages ranged between 12 and 16 years. This suggested

high chances of losing school opportunities and therefore difficult life in future. The study also noted that the bulk of the household care giving is provided by immediate family member (spouse, daughter, mother, sister or brother).

### **7.3.7 Attitude of care providers**

Half of the participants said that they had no problems with the attitude of their care providers meaning that their attitude was positive while the rest said that it depended on what relationship the patient had with the care provider. These participants said that the attitude varies with the relationship. The more close the relationship, the positive attitude the provider portrayed. However all these participants said the attitude of their caregivers was negative.

It was noted that attitude of the caregivers had an influence on the patient's wellbeing either positively or negatively. Positive attitude from caregivers motivated the patient and gave some hope of life. On the other hand negative attitude from the caregivers brought along problems to the patient and affected his/her quality of life.

It was also noted that fear of contagion coupled with negative, value-based assumptions about people who are infected led to high levels of stigma surrounding HIV and AIDS.

### **7.3.8 HIV and AIDS Education**

The study indicated that primary care givers (relatives) of the majority of participants did not have any formal HIV and AIDS education. Only a minority group affirmed that their caregivers received some education on how to take care of a patient at home. Another minority of participants stated that they were not sure if their caregivers received any education on HIV and AIDS. A vast majority of them indicated an interest to have their relatives receive training or education in HIV and AIDS due to the seriousness of the threat posed by HIV and AIDS and also due to a lot of misconceptions and myths that surround HIV and AIDS issues among care givers in Malawi. These participants stated that most relatives are

afraid to care for HIV and AIDS patients because they do not have adequate knowledge on the subject.

#### **7.3.9 Patient's quality of life**

Patient's quality of life was looked at in relation to the impact of the caretaker's attitude towards the patient's quality of life. The majority of the participants were quick to note that those relatives who portray good attitude to their patients in return give encouragement and hope to the patients. On the other hand, the other half of the participants affirmed the view that negative attitude towards the patient implies loss of hope and giving up life quickly.

Most participants indicated that they were able to do most of the basic things except in times when they were not well or when they had an infection. A minority group affirmed that they could only do little basic things and another minority stated that they could not do anything on their own. Only one participant said he could do everything on his own without problems. On overall, this indicated good quality of life to most of the participants.

#### **7.3.10 Common needs of HIV and AIDS Patients**

The most common need expressed by majority of the participants was need for nutrition (food). This was followed by need for nursing care where participants would be provided with medication for different infections and ARVs to prolong their lives. Another majority of participants acknowledged that they required counseling services where emotional and spiritual support would be provided. Needs for financial support to run small businesses and transport especially during referrals were cited by more than half of the participants. Information giving on HIV and AIDS, need for shelter and physical care e.g. bathing, eating, dressing etc were mentioned by less than half of the participants. The need to be assisted with household chores and care for other family members were cited by just a minority group of participants.

### **7.3.11 Provision of Information to HIV and AIDS Patients**

The vast majority of participants indicated that they were not given adequate information concerning community home based care and its benefits before they were enrolled in the program. A minority group of participants were given adequate information as shown by their responses given.

The common information given to participants were: infection prevention at home which included home and personal hygiene, nutrition for HIV and AIDS patients, drug adherence and issues concerning income generating. A minority group of participants also stated that volunteers transfer their skills to family caregivers as they were discharging their duties.

### **7.3.12 Benefits of Nursing a patient at home**

Almost all participants affirmed the fact that home based care is important and that it has to be encouraged. The majority of participants affirmed that the program is benefiting them while a minority group said they were not benefiting from the program. Those on the negative side explained that it is a burden to relatives to nurse patients at home, drugs are not available everyday, referral is late and that stigma is high at home than at the hospital.

### **7.3.13 Challenges of HIV and AIDS Patients**

All the participants acknowledged presence of challenges because of living with HIV and AIDS. The common challenges were: lack of food, presence of opportunistic infections, unable to perform their normal duties and stigma and discrimination.

## **7.4 CONCLUSIONS AND RECOMMENDATIONS**

Basing on the findings presented in this study, the concluding issues are as follows

### **7.4.1 Demographic Characteristics of Participants**

From the findings of this study, it is concluded that women and girls are at the highest risk of HIV infection in Malawi and that they bear the burden of care and suffer worse consequences than men when infected.

In this study it was noticed that the vast majority of respondents, their household care givers were females where almost half of the participants were looked after by their children who are still young and at school and these were all girls. It was also noted that most of the participants were females which gives an impression that females are at higher risk of acquiring HIV infection than men.

The study has also revealed that a large number of participants, were housewives with no other type of work. A good number of them stated that they never attended any type of school and all these were females. All the participants who were divorced were females. This brings the assumption that when women are found HIV positive, they are divorced. At the same time one may conclude that men who are found HIV positive receive full support from their spouses. It can therefore be concluded that women with HIV infection are facing socio-economic stressors that exacerbate the negative consequences of HIV for physical and mental well-being.

World Health Organization (2004) strongly supports these conclusions. On the World AIDS Day Campaign in 2004, WHO stated that not only are women vulnerable to the impact of AIDS, they are susceptible to infection (WHO, 2004). Monogamous women, infected from their husbands now account for the bulk of new HIV infections in the world. In Malawi women are socially and economically subordinate to men. Based on these findings the researcher strongly recommends the following to be done.



#### **7.4.2 Developing women economic status**

- The Government of Malawi through Ministry of Gender and Child Services, should promote women's and girls' education. In Malawi, up to now, 80% of the women population cannot read and write. This is the commonest hindrance to women development. People with less education generally have less access to HIV and AIDS information (WHO, 2004). In countries like Malawi where HIV prevalence is high, enrolment in schools has dropped. As evidenced from this study, girls leave school to care for the sick, help run the household or support the family. This deepens the poverty level. With the current free primary education in Malawi communities should be encouraged to attend school.
- Women should be empowered. Gender sensitive trainings are needed for women including those from the remote areas to promote socio-cultural changes. Gender sensitive trainings will help to make all people to become gender sensitive. Ministry of Gender, Nongovernmental Organizations (NGOs) including women's advocacy groups could play a key role in partnerships with health workers and policy makers helping to overcome Gender Based Violence. These groups would also help to advise on how best to respond to women's needs and interest thereby empowering women in decision making.
- Nongovernmental Organizations (NGOs) such as Finance Trust for Self Employed should work hand in hand with the Government to provide financial assistance to women through the provision of loans to help them to remain independent. Agriculture is the backbone of Malawi's economy and accounts for 90% of employment. As evidenced from this study many HIV and AIDS patients can not perform their normal duties such as cultivating their lands hence they always experience food shortages. Given loans, HIV and AIDS women would run small businesses and support their families. Earning an income fosters independence and empowerment. According to WHO (2004), women with limited options for income are more likely to endure abusive relationships.

- Government and all partners should encourage the community to take the role of caring for HIV and AIDS patients at home. The study has shown that many children are failing to attend school because they are caring for their HIV and AIDS parents and relatives. All community home based care implementers should sensitize the community on their role towards HIV and AIDS patients. According to the policy of community home based care, any person under the age of 18 is not eligible to be a care provider. This was done deliberately to relieve children from work and give them chance to attend school.

#### **7.4.3 Participants' knowledge of HIV and AIDS**

From the findings of this study, it is concluded that the participants of this study had adequate basic knowledge of HIV and AIDS transmission, prevention and treatment. The fact that majority of participants suspected getting the HIV from their partners, is an indication that participants knew the major mode of transmission as being sexual. These participants were also able to pick that HIV and AIDS has no cure and that ARVs are used to prolong life by avoiding further multiplication of the virus. The knowledge of this aspect by a majority of participants suggests that they have been well informed about HIV and AIDS which is a requirement to HIV and AIDS patients.

From the findings above, it is recommended that health workers and community care providers should continue informing patients on issues concerning HIV and AIDS because knowledge is power. However, it is also important that the same knowledge should be imparted to the family caregivers who according to the study seemed to lack knowledge of HIV and AIDS (see chapter 6).

#### **7.4.4 Living with HIV and AIDS**

##### **Feelings of anxiety, worries and fears of death**

HIV and AIDS pose major challenges in Malawi. From these study findings, conclusions are made that people who are living with HIV and AIDS are

experiencing a lot of anxiety, worries and fears as indicated by the majority of the participants. These patients are also miserable because of the frequent attacks of opportunistic infections and exposure to stigma and discrimination. The other conclusion from this study is that although it is perfectly reasonable for HIV positive individuals to feel anxious, it may bring damage to the patient. Out of all the challenges faced by HIV and AIDS patients, anxiety outweighs all. The major reason of feeling anxious worried and fear is because of children who are still young.

With the findings of this study, it is clear that living with HIV and AIDS is not easy. The study therefore recommends the following.

The Malawi Government through Ministry of Health and all its partners including the Non Governmental Organizations should work hand in hand in trying to mitigate the impact of HIV and AIDS. Frequent counselling services provided to HIV and AIDS patients should be an integral part of the care. These counselling services should be done by people who have knowledge and capacity to do it. Counselling should be given to both the patients as well as to their caregivers. Spiritual counselling should be part and parcel of the services.

From the findings, anxiety was mainly due to worry about the children. It is recommended therefore that care of HIV and AIDS patients should include care of those who are affected such as the children. Community care providers should ensure successful preparations for the future of the children for their patients.

The government (Ministry of Health), together with Nongovernmental organizations should train more health workers and community care providers who would visit HIV and AIDS patients homes frequently in order to counsel and mitigate the impact of HIV and AIDS. Currently, one of the biggest challenges facing Malawi is the lack of human resources available within the country (Avert, 2008).

The results have also shown that some of the patients had feelings of anxiety because they lacked needs like food and other things. The Malawi community

should be sensitized on issues of HIV and AIDS. It is also important that communities should be aware that the responsibility of caring for HIV and AIDS patients is for everyone. In this case therefore they have a responsibility to share resources with patients within their community.

The most encouraging aspect of the HIV and AIDS issue is that in Malawi, there are many organizations involved in activities geared towards minimizing the spread of HIV and AIDS. It is important therefore that the Government and NGOs should take also a responsibility to provide needs of the patients if available.

#### **7.4.5 HIV and AIDS Patients face Stigma**

In most cases HIV-related stigma and discrimination severely hamper efforts to effectively fight the HIV and AIDS epidemic. This study has revealed that patients who are living with HIV and AIDS are facing stigma. Even churches are involved in stigmatizing and discriminating patients. The fact that the main mode of transmission is sexual, churches have interpreted the epidemic as divine punishment for sexual transgressions from premarital sex to homosexuality. At the time when the Government is advocating for HIV counselling and testing, the stigma can make people reluctant to access HIV testing, treatment and care.

Based on findings of this study, the following recommendations are made.

The Ministry of Health and its partners should make an effort to continue to sensitize the general public on various issues of HIV and AIDS including effects of stigma and discrimination. Some individuals stigmatize patients because they are not aware of the consequences of the practice.

All HIV and AIDS implementing partners in conjunction with the government should support HIV and AIDS patients facing stigma and discrimination. This could be done by providing counselling to the patients and those who are affected. Most NGOs are playing an important role in the fight against HIV and AIDS. They are involved in out reach programs, counselling and income generating activities. It is recommended that apart from what the organizations are already doing, efforts

should be made to promote issues of community training and education on HIV and AIDS which would also address stigma and discrimination.

Considering that even churches are involved in the issue, it is recommended that an effort should be made to involve faith based organizations in HIV and AIDS meetings, workshops and even trainings. This will sensitize them in order to extend to the rest of the church community. Churches should be made aware that the stigma posed by religion can be powerful.

Education or sensitization should also be made to influential leaders on issues of HIV and AIDS including stigma and discrimination since they have the power to influence people in the community. These would be political leaders, church leaders, traditional leaders and different group leaders. Emphasis should be placed on that stigma and discrimination can make people reluctant to access HIV testing, treatment and care and therefore it must be discouraged.

An effort should be made at each and every meeting or gatherings to deliberately remind people on the effects of stigma and discrimination. These gatherings would be at funerals, churches, political rallies or even at weddings.

Stigma and discrimination are barriers to effective prevention of HIV and AIDS. The public should therefore be reminded that practicing stigma and discrimination against people living with HIV and AIDS is violation of their human rights and that they can be punished by law. Stigma and discrimination have a negative impact on HIV testing as many shy away for fear of being discriminated (Kaiser Daily HIV/AIDS Report, 2008 (author not given).

#### **7.4.6 Care Providers for HIV and AIDS Patients**

From this study it is concluded that in Malawi, females are the main care providers to HIV and AIDS patients. It is also concluded that the caregivers mainly are close relatives such as mother, daughter, spouse and they provide the bulk of the care to patients.

While it is not easy for an HIV and AIDS person to be cared for by distant relations or by someone who is not a relative, it should be made clear that the responsibility of caring for HIV and AIDS patients lies in the hands of the whole community. The following recommendations are therefore made.

Community leaders should encourage community members to play a vital role in providing home based care to HIV and AIDS patients. This will create openness and it will promote good health seeking behaviours like access to voluntary counselling and testing, treatment and care. This will bring hope and will mitigate the impact of HIV and AIDS.

Government, health workers and all its partners should make communities aware that caring for patients in the homes is traditional and therefore it has to be encouraged. This will encourage communities to take part in the care of HIV and AIDS patients and it will make patients appreciate the importance of being nursed at home rather than the hospital.

Government through the Ministry of Health should take a major responsibility in making sure that HIV and AIDS patients are cared for in the proper manner and avoid exploiting communities by simply leaving government responsibilities to communities alone.

Supervision of community home based activities should be done at all level from national to community level to ensure that care of patients is done by the right people to promote patient's quality of life. According to the Malawi National policy, providers of care will include trained volunteers. It is therefore important that volunteers should transfer their skills to family caregivers in order to promote quality care to patients.

Government should ensure that family caregivers are given adequate resources to use in the care of patients. This is a requirement as it is stipulated in the Malawi National Community Home Based Care policy and guidelines, (2005).

#### **7.4.7 Attitude of care providers**

In this study, it has been shown that HIV and AIDS is still a relatively new disease and that it has attracted a lot of mixed reactions from people. The study has also shown that stigma and discrimination is still present among HIV and AIDS patients despite the introduction of antiretroviral therapy (ARVs) in Malawi. From the findings, it is therefore concluded that the majority of HIV and AIDS patients are receiving positive attitude from their caregivers.

As a result of these findings in this study, the following recommendations are made:

- All implementers of community home based care should sensitize the general public on issues of HIV and AIDS in order to promote positive attitudes towards people living with HIV and AIDS.
- Community Care providers should provide correct information about HIV and AIDS to the families to reduce stigma of HIV and AIDS. These providers must also ensure positive speaking on issues concerning HIV and AIDS in the community. Dispel the fears of family care providers about contracting HIV through casual contact. This can be done through proper education on HIV and AIDS.
- Community Home Based Program should aim at restoring hope in patients and improve quality of life for people living with HIV and AIDS and those who are affected. This can be done by identifying necessary human and material resources to use in the care of the patients.
- Implementers of the program should empower people living with HIV and AIDS to make informed decisions about their lives and encourage them to live positively by means of offering counselling services to the patient and those affected.

#### **7.4.8 HIV and AIDS Education**

The fact that the majority of primary caregivers did not receive any education concerning HIV and AIDS explains why most relatives are afraid to care for HIV and AIDS patients. This shows that they do not have adequate knowledge on the subject. It can therefore be concluded that these caregivers are not safe in their caring for an HIV and AIDS patient.

It is therefore strongly recommended that the government should introduce HIV and AIDS training to all primary caregivers if the quality care is to be rendered to patients at home. Just like it is with community care providers, a training manual has to be developed for family care givers to be used in the training. In view of this proposal, the researcher has facilitated the development of the manual. This manual is called “Primary Caregivers Teaching Manual”. Piloting of the program has already been done. It is expected that implementation of this manual will start soon by all CHBC implementers in Malawi.

The manual has been written in a user friendly manner and mechanisms have been put in place to ensure that the manual is understood by all expected to use it (see chapter 6 for development of the manual). At least one family member/ caregiver per patient will receive education in the care of HIV and AIDS patients at home. This developed manual will be disseminated to all organizations which are implementing community home based care in Malawi.

This manual will later be advocated to become part of the National CHBC policy and guidelines and therefore all stakeholders will be encouraged to use it during training of family caregivers. The primary caregiver teaching manual is presented as an appendix 13 in this document.

It is necessary that all organizations dealing with HIV and AIDS should make an effort to increase their educational efforts to communities and patients in order to achieve better understanding of the disease.



#### **7.4.9 Common needs of HIV and AIDS Patients**

The economic effects of AIDS are felt mostly by individuals and their families. The economic status of the household/ family plays a major part on the type of support provided to the patient. In Malawi, over 65% of the population live below the absolute poverty line (Malawi National Health Plan, 1999 – 2004). Needs of an HIV and AIDS patient are varied. From the finding of this study, one common need expressed by majority of the participants was nutrition. There is a strong mutual association between nutrition and HIV and AIDS. Any immune impairment that results from HIV and AIDS leads to malnutrition (Geubbels and Bowie, 2006). It is therefore concluded that nutrition required priority attention from these participants. As a result of these findings in this study, the following recommendations are made:

Implementers of home based care should assist people who are infected and affected by HIV and AIDS to find access to the necessary needs and services. If resources can not be provided by themselves, then referral should be done to organizations and services where patients can get additional help.

Encourage people living with HIV and AIDS to form or join self help programs available in the country such as having vegetable gardens, needle work or home craft work to have money to assist themselves. There is need to identify someone who can give them training on the site for sustainability.

Food shortage severely threatens patient's life. Food is paramount in the fight against HIV and AIDS as it may help reduce wasting that occurs due to nutrient malabsorption, reduction in food intake and changes in metabolism. In addition food may alleviate symptoms as well as prolong survival of people living with HIV and AIDS. In Malawi PLWAs are extremely food insecure as they are less able to work on the farms and they receive no income. Social support is therefore a crucial element in the care of people with HIV and AIDS. If possible implementers of community home based care should minimize suffering caused by HIV and AIDS through material or financial support.

NGOs such as WFP should support various programs taking place in Malawi to provide food especially to people living with HIV and AIDS in order to address the challenges that HIV and AIDS patients are facing.

#### **7.4.10 Provision of Information to HIV and AIDS Patients**

In the study it was noted that patients are not given adequate information before being enrolled in the program. It is therefore concluded that HIV and AIDS patients lack knowledge of the nature of community home based care services that they should expect to receive from the program. The following recommendations are therefore put forward.

HIV and AIDS programs must always address issues of information giving to patients and their families in all the activities provided. Information should be given to the patient some time before enrolment even before discharge from the hospital to enlighten the patients services that will be available to him.

When reviewing the training manual for training of health care workers and community care providers in community home based care, an effort should be made to include in the manual information to be given to the participants to prepare patients for community home based care.

The revised training manual should be disseminated to all stake holders to use in the training. Benefits of home based care should also be emphasized in the content.

All CHBC programs should emphasize the importance of communication to patients. This IEC will aim at encouraging and empowering people infected and affected by HIV and AIDS to cope with the disease and the related problems. This is supported by Neuhann et al (2004) who said that the current momentum to increase access to ART in countries like Malawi requires appropriate communication with patients about the chronic treatment of HIV infection. An information, education and communication (IEC) strategy has to take this into account. Group counselling is also an appropriate way of communicating HIV and

AIDS related topics including ART. The strategy should be reviewed frequently to ensure continued appropriateness.

#### **7.4.11 Further Research**

Based on the findings of this study, it is recommended that further research should be done to assess the impact of food supplements on nutrition and survival so as to guide programs. It is also recommended that the same study should be extended to include primary caregivers, volunteers and health care workers.

### **7.5 CONCLUSION**

This chapter has concluded the research thesis. It has described the significant findings of the study, the conclusions which were drawn from the findings and the recommendations made in order to improve access to quality care to HIV and AIDS patients at home

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## **APPENDIX 1: INFORMATION LETTER TO PARTICIPANTS**

Welcome. Thank you for coming and agreeing to assist me with my research. You have been chosen to take part in a study called “Community Home Based Care for HIV/ AIDS patients: A Malawian experience”. In this study, HIV/AIDS patients who are on Community Home Based Care programme in various communities in Lilongwe District will provide the experiences that they have had. The purpose of the study is to assess if the current Community Home Based Care Program in Malawi is responding to the health problems/ needs of the HIV/AIDS patients. As PLWHA, your opinions may therefore help the researcher to design practical guidelines that may promote the CHBC Programme in Malawi to respond to your needs.

This study is being done by Mercy Pindani of Kamuzu College of Nursing. The research has been approved by the College of Medicine Research and Ethics Committee as well as UNISA Ethics Committee. Participating in this study is voluntary.

The discussions will last between 45 minutes to one hour. There are no direct personal benefits for participating in the study. You will spend about 45 – 60 minutes answering questions about CHBC and PLWHA. As the moderator of the discussion, my job is to make sure that we stick to the topic at hand. I will ask you a series of questions to which you should feel free to respond or not. There are no right or wrong answers to these questions. You are the experts and I am here to learn from you. I would like to tape record the discussion so that I can go back over your responses to my questions. If this recording is a problem let me know and I will simply write your responses on paper. I will be taking notes to help me remember what you said during the discussion.

### **Discomfort**

The risks to you of participating in this discussion are minimal. Some of the questions I will ask may make you uncomfortable. You are not required to respond



to any particular question, and if at any time during the discussion you would like to stop, just tell me and we may end the discussion.

### Benefits

There are no direct personal benefits for participating in the study. Your participation in this discussion may benefit other people in this district and in Malawi in the future. I will offer you some drinks and snacks during the discussion, but other than that there are no direct benefits to you for participating. At the end of the discussion if you have questions about anything we have discussed, I can take some time to discuss them or, if you prefer, I can make an appointment with another qualified person to talk to you.

### Confidentiality

You should be assured that I consider this discussion to be confidential. Your responses will be heard or read by only those people involved in this research. No names will be used on the data collection tools used. The tape and written documents recording your responses will be kept in a safe and locked place. If you have any questions concerning participating in the study feel free to contact: M. Pindani, Kamuzu College of Nursing, P/Bag 1, Lilongwe. Phone: 01 751 622 or 08 896 970.

Now if you have no objections, to show that you have been provided with adequate information about this study, please sign the consent form on the next page and I will turn on the tape recorder so that we can start our discussions.

## **APPENDIX 2:        CONSENT FORM**

I have clearly understood the requirements and contents of this letter and I therefore willingly agree to participate in the study.

Participant's signature: .....        Date:

Researcher's signature:.....        Date:

APPENDIX 3: MAP OF MALAWI



## **APPENDIX 4: IN-DEPTH INTERVIEW GUIDE**

### **A. DEMODRAPHIC DATA**

Date of interview -----

Name of village -----

Code No of participant -----

Age category -----

Sex -----

Religion -----

Tribe -----

Marital Status -----

Education level -----

Occupational Status -----

No of children -----

### **B. KNOWLEDGE ON HIV AND AIDS**

When were you diagnosed with HIV?

When were you enrolled on CHBC program?

Can you tell me what is it like for you to live with HIV and AIDS?

### **C. ROLE OF FAMILY/ CHBC PROVIDERS**

- Who is your main care provider (who provides most of your care?)
  - ▶ Family
  - ▶ Community care providers (Volunteers)
  - ▶ Community Health workers
- What role does your family play in the care that you receive to help you maintain your independence and achieve the best possible quality of life?
- What role does a community care provider play in the care that you receive?
- How would you describe the frequency of access to your care provider?
- From your own experience, how would you describe the knowledge level of your care providers in relation to caring for PLWHA
- A lot of times people have commented that PLWHA would benefit much if they are being cared for at home. How is this experience with you?
- According to your experience, what are the attitudes of family and community care providers towards giving care to PLWHA?
- What impact does this attitude have on your overall well-being as a patient?

### **D. QUALITY OF LIFE**

- Quality of life mean differently to different people. Would you like to tell me what the concept “quality of life” mean to you?
- Can you describe your quality of life since you were enrolled in CHBC?
- In general what would you say your health is like (excellent, very good, good, fair or poor)

- What activities are you able to do in order to care for yourself? (live normally)
- In your own opinion, how can your family improve your quality of life?
- How can community care providers in your area improve your quality of life?

#### **E. HEALTH NEEDS/ PROBLEMS OF PLWHA**

- What would you say are your needs/ health problems as a person living with HIV and AIDS?
- How do you meet these needs?
- The goal of CHBC programme in Malawi is to make appropriate quality health services available to all chronically ill people including those with HIV/AIDS. What is your experience in relation to this goal?

##### **Probe: Access to**

- ▶ Basic care and support
- ▶ Treatment including ART
- ▶ Appropriate referral system
- What symptoms do you commonly experience and how severe are these symptoms?
- In some situations, PLWHA would experience poor physical, mental or psychological health which would keep them from doing usual activities such as self care, work or recreation. How has this been to you?
- What information do you receive from your care providers concerning
  - ▶ Transmission of HIV
  - ▶ Guarding against infections

## **F. IMPROVING CHBC PROGRAM**

- From your own experience, what are the challenges of CHBC for HIV/ AIDS patients in Malawi?
- What would you have loved to be done/ included in the programme in order to improve CHBC in Malawi?

## **G. FINAL QUESTION**

Do you have any final thoughts or comments you would like to share with me about Community Home Based Care of PLWHA in Malawi?

## **WRAP UP**

This is the end of our discussion. Thank you very much for your participation. This has been a very fruitful discussion. If you have any further questions or comments

## **APPENDIX 5:       SAMPLE OF TRANSCRIPT OF ONE OF THE INTERVIEWS**

### **PATIENT 1: (F)**

**Malemba Village: 20/06/08**

**Int:** How are you madam?

**Resp:** *A little bit well and how are you our visitor.*

**Int:** As you were told, I have come to your home today at Malambe, am I right about the place?

**Resp:** *You are right*

**Int:** Today as you were informed by one of your nurses about my research, I have come here to ask your permission again if you could be one of the clients to participate in this research which I am conducting.

**Resp:** *Yes you can go a heard because the nurse explained everything concerning what you are doing and she reassured me that there will not be any problems even if I discontinue the interview later in the course.*

**Int:** Yes that is true and since the research was already explained to you, now let us get started and not waste much of the time

**Resp:** *Yes, I am ready.*

**Int:** I will be asking you a question at a time and then you should be responding freely and you should also speak very clearly and loud so that your voice should be taped and recorded if you don't mind about taping I hope the nurse explained to you about this.

**Resp:** *Yes, there is no problem I will try to speak loud though I am a little bit weak.*

**Int:** To start with, I would like to know, what problems do you have for you to be on CHBC?

**Resp:** *I started not feeling well in 2005 and that was a year after the death of my husband. I was on and off the hospital until late 2006 when I was advised by health workers to go for an HIV test which I did in November the same year.*

**Int:** Then what happened after the HIV test?

**Resp:** *I continued not feeling well and my condition was getting down and down until in January 2007 when I was put on ARVs and I saw things started improving*

**Int:** So when were you enrolled on CHBC program?



**Resp:** *The same month that I started ARVs and that was last year January, 2007*

**Int:** Now that you have told me that you have HIV, can you tell me what it is like for you to live with HIV and AIDS?

**Resp:** *That is not easy but I will try to explain how I am feeling. I have too much fear over my life. I can not even describe the magnitude of my fears/ worries. Sometimes I feel its better I die now than to suffer a lot of opportunistic infections which I have witnessed in other patients. I feel it were not me neither can I want this to happen to any of my relatives more especially my children. I feel I am the cause of all the miseries that my family is facing. I am a widow, I don't know what caused the death of my husband but I have no doubt ..... (patient paused) that he died of the same condition.*

**Int:** Why do you think that he died of the same condition that you have?

**Resp:** *Because he had the same signs that I am having and I believe strongly that he is the one who gave me the HIV because I was innocent and faithful to him.....(patient paused again), You know what I mean madam.*

**Int:** Did you say you have too much fear over your life?

**Resp:** Yes

**Int:** Why do you have fears?

**Resp:** *I am worried and what worries me most is that there is no cure for HIV and AIDS and that means I will also die I dont know when .....(patient paused facing down) but I know I am dying definitely.*

**Int:** What makes you feel you are dying?

**Resp:** *Sometimes I have infections so frequently, one after another, you can imagine. Of course after getting treatment I always feel better.*

**Int:** Now that you are on CHBC, I would like to know who is your main care provider i.e who provides most of your care at home.

**Resp:** *My family members provide most of the care because I am with them most of the times. I have three children and the first born daughter is the one who does most of the care.*

**Int:** What do you mean by saying that she does most of the care?

**Resp:** *She cooks and gives me food. She cares for the home and the whole house. My elder sister and my cousin also assist my children to give care to me. Some times when I am not able to take my bath my cousin gives me a bed bath. My relatives take me to the hospital when there is need to do so but when I am admitted nobody stays at the hospital except my daughter and that means she absents herself from school during those days. I still thank my relatives because*

*they do a lot of things for me in addition to what my daughter does every day.*

**Int:** How old is your daughter?

**Resp:** *She is only 14 years. It is not easy for her to find food and other home necessities since I am a widow and I am not working but she tries. Sometimes some community members bring other resources like water, firewood and sometimes they chat with me when I am able to do so.*

**Int:** What about the community care provider (Volunteer), how does she help you?

**Resp:** *Some times she comes alone other times she comes with the nurse and thus the time when she gives medicines when I complain. In our community there is one volunteer who helps me. She chats with me to lessen my worries. Sometimes she brings some food to feed me when I don't have some. She dresses my wound some of the days.*

**Int:** How often does your volunteer or nurse visit you?

**Resp:** *No it is not good to cheat you. My volunteer comes only once a week unless if she hears that I am not well then may be twice a week but this is not common. The nurse visits our area every Mondays. If you have problems then she will visit your home that Monday but if you don't have problems she will not come to your home she will just visit other patients with problems.*

**Int:** Who dresses your wounds during the days that she is not there?

**Resp:** *She has given my daughter bandages and other supplies to dress my wound when she is not there but my daughter is afraid to do it because she is young and therefore the wound would remain for a week without being dressed if the volunteer doesn't come.*

**Int:** What about your other relatives that you have mentioned, can't they assist your daughter to dress the wounds?

**Resp:** *You know there are other works that these relatives can not feel free to do for me especially the dirty works, only my daughter can do everything and I don't blame them.*

**Int:** Many times people have commented that PLWHA would benefit much if they are being cared for at home. How is this experience with you?

**Resp:** *That is true. For example when I was in hospital, only my daughter was with me in the hospital and I had always wished my other children could visit me but they had no money for transport. Now I have most of my relatives with me at home. However, being cared for at home has its own problems. A lot of people when they visit you they feel sorry and it makes the patient feel bad because you know you are very ill and therefore your condition goes down. Also when you think of the frequency of getting drugs at home, it is not the same as it is in the hospital.*

**Int:** Why do you say the frequency is not the same, can you explain more?

**Resp:** *Because in the hospital you receive drugs three or four times in the day but here at home the nurse or doctor visits you only once a week and they give you very little drugs which cannot last for a week and they say if you continue having the problem please come to the hospital so I don't feel good about it.*

**Int:** Can't you get drugs from the volunteer apart from the nurse or doctor who are very far away from you?

**Resp:** *The volunteer does not keep drugs at home but the nurse or doctor who comes only once a week. If there is need for a patient to get drugs, it will only be on a Monday when the nurse comes.*

**Int:** You mentioned that your relatives and community care providers take care of you at home. What do you think is their attitude towards giving care to you as a person living with HIV and AIDS?

**Resp:** *It varies with the relationship madam.*

**Int:** What do you mean that it varies with the relationship?

**Resp:** *With my daughter I haven't seen any change when it comes to caring. For the other relations the attitude or their mood is not static neither are they same every day. Some days they seem to be caring, happy and cheerful with you but other days they don't want to talk to you. It is really difficult to know what they are thinking about you. When you send a word requesting them to come, the response is that they are not at home which is not true most of the times.*

**Int:** Then what do you do in that case?

**Resp:** *What else can you do, you just keep quite.*

**Int:** You have talked about the attitude of your relations, what about the attitude of the volunteer and the nurses who visit you?

**Resp:** *Ah madam, I have no problem with the attitude of the volunteer nor the nurses and doctors. I know they are busy people may be thus why they come only once in a while.*

**Int:** Then what impact does this attitude from your other relatives have on your well-being as a patient?

**Resp:** *Most of the times this makes me to be miserable and sometimes I wish I could die early but I think of my young children also.*

**Int:** What activities are you able to do in order to care for yourself?

**Resp:** *I can manage some of the basic things like eating, walking to outside, cleaning plates. In the past I used to do almost everything for myself, but now*

*most of the things I am being helped. If someone prepares food for me, I can eat but I cannot do other normal things which I used to do before I started getting sick.*

**Int:** As someone living with HIV and AIDS, what would you say are your health needs while you are on CHBC programme?

**Resp:** *I need food, a good place to sleep, some resources such as soap for bathing and washing so that when my beddings are spoiled my daughter can use it for washing. Currently, people from my community such as my church are able to provide me with these resources but not at frequent intervals.*

**Int:** Are there some more things that you need apart from the above?

**Resp:** *As I said earlier, I also need medication including ARVs.*

**Int:** The goal of CHBC programme in Malawi is to make appropriate quality health services available to HIV and AIDS clients. What is your experience in relation to this goal?

**Resp:** *Yes, the Government is trying to give us care that we need through nurses, doctors and volunteers.*

**Int:** Are you on ARVs?

**Resp:** *Yes, I am given ARVs every month to take at home*

**Int:** Have you ever been referred to the hospital from home?

**Resp:** *Yes twice. Whenever I was not well I was referred to the hospital by the nurse.*

**Int:** What symptoms do you commonly experience that would also lead to referral to hospital?

**Resp:** *Frequent diarrhea and malaria.*

**Int:** What information did you receive concerning community home based care?

**Resp:** By who?

**Int:** Either a nurse, doctor or volunteer

**Resp:** *I was told that I need to be receiving care at home and that the volunteer will visit me at home.*

**Int:** Who told you this information?

**Resp:** *A nurse from the hospital on discharge*

**Int:** When the volunteer came, did she explain anything on your being on CHBC?

**Resp:** *No, she did not.*

**Int:** What information/education do you receive from your care providers during the time they are taking care of you at home?

**Resp:** *They teach my daughter on how to take care of me. They also educate me not to have worries because worries facilitate death.*

**Int:** What do you mean when you say they teach your daughter on how to take care of you?

**Resp:** *They told her that she should always be near me, give me food and that when I am not feeling well she should go and report to the volunteer as soon as possible.*

**Int:** What other education are you given?

**Resp:** *To avoid getting pregnant. But I don't worry about that because my husband died and I live alone with my children.*

**Int:** What challenges are you facing as a person living with HIV and AIDS on Home Based Care?

**Resp:** *Problems are always there. I am afraid of death. I am frequently suffering from diarrhoeas and malaria which makes me fear. Sometimes I live a miserable life especially when I think of my children that they will be left without parents and also because some of my relatives stigmatize me.*

**Int:** Did you say some relatives stigmatize you?

**Resp:** *Yes sometimes and not all of them*

**Int:** How do you know they stigmatize you?

**Resp:** *Remember I told you that sometimes they don't want to talk to me or to visit me even if I try to call for them*

**Int:** What else makes you feel that you are stigmatized?

**Resp:** *The reasons I have given you are strong madam, if you don't want to believe me leave it but I know what I am saying.*

**Int:** No it is not that I don't believe you, only that I wanted to know more.

**Resp:** Alright, thank you that you understand.

**Int:** Finally, What would you have loved to be included in the programme in order to improve CHBC services in Malawi?

**Resp:** *I have no idea but I wish drugs could be given to us when we are sick all the time.*

**Int:** Which drugs are you talking about?

**Resp:** *Please, I am not talking about ARVs. I mean other drugs when we are not feeling well at home like malaria drugs.*

**Int:** Any more ideas?

**Resp:** *Some of the questions that you have asked me are now giving mw cues to think of how to support CHBC services.*

**Int:** Can you explain them then?

**Resp:** *You know I was thinking some of the reasons why some relatives do not want to come and talk or chat with me.*

**Int:** And what do you think are the reasons?

**Resp:** *May be they are afraid that I will pass the virus to them*

**Int:** Why do you think so?

**Resp:** *I have no idea I was just thinking within my self*

**Int:** Have any of your relatives been taught anything about care of HIV/AIDS people at home?

**Resp:** *Not to my knowledge, but I think no.*

**Int:** Would any of your relatives accept to be educated on care of a patient like yourself at home?

**Resp:** *I think they would, especially my elder sister who assists my daughter most of the times.*

**Int:** Do you have any question or comments you would like to share with me about CHBC of PLWHA in Malawi?

**Resp:** *No that is all I had.*

**Int:** This is the end of the discussion. Thank you very much for your active participation. This has been a very fruitful discussion. Once again thank you and have a good rest.

**END OF INTERVIEW**

## APPENDIX 6: LETTER TO RESEARCH AND PUBLICATION COMMITTEE

Kamuzu College of  
Nursing  
P/Bag 1  
Lilongwe

20<sup>th</sup> November, 2007

The Chairperson  
Research and Publication Committee  
Kamuzu college of Nursing  
P/Bag 1  
Lilongwe

Dear Sir,

### **CLEARANCE TO CONDUCT RESEARCH IN LILONGWE**

My name is Mercy Pindani a lecturer in community health nursing at Kamuzu College of Nursing and currently pursuing PhD studies with University of South Africa. In accordance with the requirements for the degree, I am expected to conduct a research study on the topic of my choice. The title of my study therefore is **“Community Home Based Care for HIV/AIDS patients: A Malawian Experience.”** The purpose of this study is to explore and describe the experiences that HIV/AIDS patients who are on Community Home Based Care Programme have in Malawi and later to develop practical guidelines/ standards for the implementation of quality home care in the country.

The study is expected to take place in August and September, 2008 in the rural and urban areas of Lilongwe district. Therefore, I write to seek clearance to conduct the study.

Yours faithfully

Mercy Pindani (Mrs)

## APPENDIX 7: LETTER TO CHINSAPO CHBC AREA – PILOT STUDY

University of Malawi,  
Kamuzu College of  
Nursing,  
Private Bag 1,  
Lilongwe.

30<sup>th</sup> May, 2008

The Director,  
Light House,  
Lilongwe.

Dear Sir,

### **PERMISSION TO CONDUCT A PILOT STUDY AT CHINSAPO CHBC AREA**

My name is Mercy Pindani a lecturer in community health nursing at Kamuzu College of Nursing and currently pursuing PhD studies with University of South Africa. In accordance with the requirements for the degree, I am expected to conduct a research study on the topic of my choice. The title of my study therefore is **“Community Home Based Care for HIV/AIDS patients: A Malawian Experience.”** The purpose of this study is to explore and describe the experiences that HIV/AIDS patients who are on Community Home Based Care Programme have in Malawi and later to develop practical guidelines/ standards for the implementation of quality home care in the country.

The pilot study will be conducted at Chinsapo CHBC Area. The study participants will be the HIV/AIDS patients who are on CHBC programme. The main study will be conducted during the months of August and September, 2008. I would, therefore, like to seek permission to carry out the pilot study at your institution.

Yours faithfully

Mercy Pindani (Mrs)



## APPENDIX 8: LETTER TO LIGHT HOUSE

University of Malawi,  
Kamuzu College of  
Nursing,  
Private Bag 1,  
Lilongwe.

30<sup>th</sup> May, 2008

The Director,  
Light House,  
Lilongwe.

Dear Sir,

### **PERMISSION TO CONDUCT A STUDY AT LIGHT HOUSE**

My name is Mercy Pindani a lecturer in community health nursing at Kamuzu College of Nursing and currently pursuing PhD studies with University of South Africa. In accordance with the requirements for the degree, I am expected to conduct a research study on the topic of my choice. The title of my study therefore is **“Community Home Based Care for HIV/AIDS patients: A Malawian Experience.”** The purpose of this study is to explore and describe the experiences that HIV/AIDS patients who are on Community Home Based Care Programme have in Malawi and later to develop practical guidelines/ standards for the implementation of quality home care in the country.

The study will be conducted using patients from the Light House, Lilongwe Diocese and NAPHAM. Study participants will be HIV/AIDS patients who are on CHBC programme. The study will be done in the month of August and September, 2008. I would, therefore, like to seek permission to carry out this study at your institution.

Yours faithfully

Mercy Pindani (Mrs)

## APPENDIX 9: LETTER TO LILONGWE DIOCESE

University of Malawi,  
Kamuzu College of  
Nursing,  
Private Bag 1,  
Lilongwe.

30<sup>th</sup> May, 2008

The Director,  
Lilongwe Diocese,  
Lilongwe.

Dear Sir,

### **PERMISSION TO CONDUCT A STUDY AT CHINSAPO - CHBC AREA**

My name is Mercy Pindani a lecturer in community health nursing at Kamuzu College of Nursing and currently pursuing PhD studies with University of South Africa. In accordance with the requirements for the degree, I am expected to conduct a research study on the topic of my choice. The title of my study therefore is **“Community Home Based Care for HIV/AIDS patients: A Malawian Experience.”** The purpose of this study is to explore and describe the experiences that HIV and AIDS patients who are on Community Home Based Care Programme have in Malawi and later to develop practical guidelines/ standards for the implementation of quality home care in the country.

The study will be conducted using patients from the Light House, Lilongwe Diocese and NAPHAM. Study participants will be HIV/AIDS patients who are on CHBC programme. The study will be conducted during the months of August and September, 2008. I would, therefore, like to seek permission to carry out this study at your institution (Chinsapo CHBC Clinic).

Yours faithfully

Mercy Pindani (Mrs)

## APPENDIX 10: LETTER TO NAPHAM

University of Malawi,  
Kamuzu College of  
Nursing,  
Private Bag 1,  
Lilongwe.

30<sup>th</sup> May, 2008

The Director,  
NAPHAM,  
Lilongwe.

Dear Sir,

### **PERMISSION TO CONDUCT A STUDY AT NAPHAM**

My name is Mercy Pindani a lecturer in community health nursing at Kamuzu College of Nursing and currently pursuing PhD studies with University of South Africa. In accordance with the requirements for the degree, I am expected to conduct a research study on the topic of my choice. The title of my study therefore is **“Community Home Based Care for HIV/AIDS patients: A Malawian Experience.”** The purpose of this study is to explore and describe the experiences that HIV and AIDS patients who are on Community Home Based Care Programme have in Malawi and later to develop practical guidelines/ standards for the implementation of quality home care in the country.

The study will be conducted using patients from the Light House, Lilongwe Diocese and NAPHAM. Study participants will be HIV/AIDS patients who are on CHBC programme. The study will be conducted during the months of August and September, 2008. I would, therefore, like to seek permission to carry out this study at your institution.

Yours faithfully

Mercy Pindani (Mrs)

## APPENDIX 11

**UNIVERSITY OF SOUTH AFRICA**  
**Health Studies Research & Ethics Committee**  
**(HSREC)**  
**College of Human Sciences**

**CLEARANCE CERTIFICATE**

Date of meeting: **16 November 2007**      Project No: **3659-862-3**

Project Title: **Community home based care for HIV/AIDS patients: A Malawian experience.**

Researcher: **M Pindani**

Supervisor/Promoter: **Prof O Makhubela -Nkondo**

Joint Supervisor/Joint Promoter: **Prof CL Obi**

Department: **Health Studies**

Degree: **D Litt et Phil**

**DECISION OF COMMITTEE**

**Approved**



**Conditionally Approved**



**12 November 2007**

Date: .....

**Prof L de Villiers**  
**RESEARCH COORDINATOR: DEPARTMENT OF HEALTH STUDIES**

**Prof SM Mogotlane**  
**ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

**PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES**

## APPENDIX 12



### UNIVERSITY OF MALAWI

Principal

Prof. R.L. Broadhead, MBBS, FRCP, FRCPCH, DCH

Our Ref.:

Your Ref.: COMREC/P.01/08/611

College of Medicine  
Private Bag 360  
Chichiri  
Blantyre 3  
Malawi  
Telephone: 677 245  
677 291  
Fax: 674 700  
Telex: 43744

19<sup>th</sup> August, 2008

Mrs Mercy Pindani  
K.C.N.  
P/Bag 1  
Lilongwe

Dear Mrs Pindani,

**RE: P.01/08/611 – Community health based care for HIV/AIDS patients: A Malawian experience**

I write to inform you that COMREC reviewed your resubmission of the above mentioned proposal and I am pleased to inform you that your proposal was approved after considering that you addressed all the issues which were raised in an earlier review.

As you proceed with the implementation of your study we would like you to take note that all requirements by the college are followed as indicated on the attached page.

Sincerely,

Prof J. M. Mfutso Bengo

**SECRETARY - COMREC**

JMB/ri

**APPENDIX 13: PRIMARY CAREGIVER'S TEACHING MANUAL**

**COMMUNITY HOME BASED CARE**

**Primary Caregiver's teaching Manual**

***JUNE 2009***

## **ACKNOWLEDGEMENTS**

I would like to thank all individuals who contributed to the development and review of the community home based care primary caregivers teaching manual. The following organizations are also recommended for the support rendered in the development of this teaching manual:

### **Organizations:**

Ministry of Health

Community Health Dept, University of Malawi, Kamuzu College of Nursing

Light House, Kamuzu Central Hospital

Lilongwe District Health Office

National AIDS Commission

Malawi College of Health Sciences

## **LIST OF ACRONYMS AND ABBREVIATIONS**

<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>ARV</b>	Anti-Retroviral
<b>ART</b>	Anti-Retroviral Therapy
<b>CBO</b>	Community Based Organization
<b>CHBC</b>	Community Home Based Care
<b>FBO</b>	Faith Based Organization
<b>IEC</b>	Information Education and Communication
<b>HSA</b>	Health Surveillance Assistant
<b>HIV</b>	Human Immunodeficiency Virus
<b>MOH</b>	Ministry of Health
<b>NAC</b>	National AIDS Commission
<b>NGO</b>	Non Governmental Organizations
<b>ORS</b>	Oral Rehydration Salts
<b>PLWHA</b>	People Living with HIV/AIDS
<b>TB</b>	Tuberculosis
<b>VCT</b>	Voluntary Counselling and Testing



## Table of contents

	Pages
1. Basic facts and information on HIV/AIDS	191
2. Prevalence of HIV/AIDS in Malawi	196
3. Benefits of community home based care	198
4. Communication with a patient	202
5. Community Home Based Care skills	205
6. Infection prevention and control in the home	214
7. Management of common HIV/AIDS related conditions	219
8. Nutrition of patients and PLWHAs	241
9. Living positively with HIV/AIDS	248
10. Referral of CHBC patients	250
11. Care of CHBC Carer	253
 <b>Appendices</b>	
1. Training time table	257
2. Registration form	259
3. Pre-test and post test	260
4. Pre-test answer guide	264
5. Training evaluation form	267
 <b>References</b>	270

## **INTRODUCTION**

### **About the teaching manual**

This teaching manual is a tool guide which will be used in the training of primary caregivers in the care of HIV and AIDS patients in the homes. It has two main areas of content namely:

- Primary Caregivers training content
- Appendices which include pre and post tests and answers, training timetable, registration form, patient referral form and training evaluation form.

### **Course description**

This course will take three days and it is designed to prepare primary caregivers acquire knowledge and basic skills that will assist them to render quality care to HIV and AIDS patients in the homes.

### **Goal**

The goal of this manual is to provide the primary caregivers with knowledge and skills needed to care for HIV and AIDS patients in the home.

### **Participant learning objectives**

By the end of the three days training course, the participants will be able to:

1. Describe facts and information about HIV/AIDS in Malawi
2. Explain benefits of community home based care
3. Explain how to communicate effectively with a patient
4. Demonstrate basic CHBC skills.
5. Describe infection prevention and control measures in the home
6. Describe the management of HIV/AIDS related conditions.
7. Explain how to manage patients drugs at home
8. Describe nutrition of patients and PLWHAs
9. Discuss living positively with HIV/AIDS
10. Describe referral system for PLWHA
11. Discuss the IGAs which can be done by families

12. Identify resources available in the community that can be used in the home based care programme.

### **Suggested Teaching and Learning Materials**

The following teaching and learning materials will be used. Use of locally available resources will also be encouraged.

- Chalk and chalkboard
- Posters and fliers on the topics in the manual
- Flipchart and markers
- Overhead projector and transparency papers where possible

### ***Suggested Teaching and Learning Methods***

The following participatory teaching methods will be used. Participants will also be encouraged to reflect and share experiences that relate to topics under discussion.

- Group discussions and presentations
- Role plays
- Question and answer
- Lecture
- Brainstorming

### **Participant evaluation**

- Pre-test
- Post-test

These tests can be either written or oral depending on the literacy rate of the participants. Evaluation of the course will be done at the end of training and it can be in a form of written or oral.

### **Suggested participant and trainer composition**

Participants will be primary caregivers and trainers will be those trained as trainers of CHBC. Each session will have 20 participants against 2 – 3 CHBC trainers

## **UNIT 1      BASIC FACTS AND INFORMATION ABOUT HIV AND AIDS**

**Time allocation:**                      **1 hour**

### **Purpose**

Participants will gain knowledge on the basic facts about HIV and AIDS

### **Learning objectives**

By the end of this unit participants should be able to:

- Define HIV and AIDS
- Explain how HIV is transmitted
- Explain how HIV is not transmitted
- Discuss prevention of HIV/AIDS transmission
- Describe how HIV attacks the body
- Describe signs and symptoms of HIV and AIDS
- State the relationship between HIV/AIDS and sexually transmitted infections

### **Suggested teaching and learning methods**

Lecture, discussions, role plays

### **Suggested teaching and learning materials**

Chalk and chalkboard, condom models, flip charts, markers, posters, transparencies and overhead projector

#### **A. Definition of HIV and AIDS**

**HIV** is the virus that causes AIDS. It attacks the immune system – the body's defence against disease. HIV lives in blood, breast milk, semen and vaginal fluids.

- **H**        -        **H**uman
- **I**        -        **I**mmunodeficiency
- **V**        -        **V**irus

**AIDS** is the name given to a group of certain symptoms and illnesses in HIV positive people. These are illnesses that arise when PLWH are no longer able to fight off infection because of lowered immunity.

- **A**        -        **A**cquired
- **I**        -        **I**mmuno
- **D**        -        **D**eficiency
- **S**        -        **S**yndrome

Understanding the acronym:

- Acquired because it is not hereditary
- Immune deficiency since the immune system is weakened
- Syndrome is a collection of signs and symptoms

## **B. Transmission of HIV/AIDS**

### **How HIV/AIDS is transmitted**

The virus that causes AIDS is found mostly in body fluids such as blood, semen, vaginal secretions and breast milk. HIV is transmitted through three ways:

- unprotected sexual intercourse with an infected partner
- contact with infected blood and blood products, e.g. sharing sharp objects (razor blades), injection needles, receiving infected unscreened blood through transfusion
- Infected mother to child during pregnancy, delivery or breast feeding

### **How HIV is not transmitted**

Some people spread wrong information on how HIV is spread. HIV is **not** spread through the following:

- being bitten by mosquitoes
- using the same eating utensils such as plates, cups and spoons with a person who has HIV or AIDS
- shaking hands
- sharing clothes or beddings
- sharing toilet facilities with an infected person
- playing with an infected person
- coughing or sneezing
- air
- chatting with an infected person

There is no scientific evidence that one can acquire HIV from wet kissing, however research has shown that the virus has been found in saliva, sweat, urine and faeces.

## **C. Prevention of HIV/AIDS transmission**

HIV can be prevented and controlled by use of the following:

- Control of sexual behaviour
  - Abstinence

- Mutual faithfulness to one's partner
- Consistent and correct use of condoms
- Avoid alcohol and drug abuse
- Safe practices when handling human blood and blood products
  - giving screened blood during transfusion
  - using gloves and plastic bags when handling other people's body fluids including blood
  - thorough hand washing with soap before and after handling patients
  - covering open wounds when taking care of patients with HIV/AIDS
  - Use new or sterilised needles
- Preventing mother to child transmission
  - encouraging VCT to all women and men of child bearing age
  - counsel HIV patients and or couples to avoid pregnancy
  - use of ARVs to minimise the risk of mother to child transmission
  - Advise on infant feeding options

#### **D. Signs and symptoms of HIV/AIDS**

There are no signs of HIV unless the person gets tested for HIV. The following are common signs and symptoms of AIDS.

- persistent cough
- generalised skin rash
- oral thrush
- shingles
- enlarged lymph nodes
- unexplained loss of body weight
- chronic diarrhoea
- prolonged fever
- skin cancers
- severe headaches and neck stiffness
- mental confusion
- chest pains
- tuberculosis

A person with HIV/AIDS infection may have some or all of the presented signs and symptoms.

### E. Relationship between HIV/AIDS and STIs

- HIV/AIDS and STI's are both sexually transmitted.
- When someone has a sexually transmitted infection it becomes easier for HIV to enter her/his body especially if there are sores in the genital areas
- People with HIV infection are vulnerable to STIs because their immune system is weakened therefore need to be counselled on HIV/AIDS

### F. How do I know if I am HIV positive?

The only way to know your HIV status for sure is to get tested. You can learn your HIV status by making use of Voluntary Counselling and Testing (VCT) Services in your community.

### G. VCT services can be offered by:

- All Government Health Facilities
- Private Hospitals
- CHAM Hospitals
- Local clinics and hospitals
- Special clinics set up just for VCT e.g. MACRO
- A mobile unit that offers services in your community.

### H. What is the difference between being HIV positive and having AIDS?

Persons first infected with HIV will have a high level of virus in their blood. The amount of HIV in an infected person's blood is called **viral load**.



Persons can live with HIV for many years without feeling sick - but they are still able to pass on HIV to others during this time!



Eventually viral load will increase and HIV will damage the body's defence against infection called the **immune system**. A person with a weakened immune system

due to HIV will begin to develop illnesses specific to people living with HIV called **opportunistic infections**.



The more opportunistic infections a person with HIV experiences, the more damaged his/her immune system becomes. When a person living with HIV is unable to fight further infections he/she is said to have **AIDS**.

### **I. Is there any hope for People Living With HIV and AIDS (PLWHA)?**

YES! Advances in science and increased knowledge make HIV and AIDS what is now called a **chronic manageable condition** like diabetes or high blood pressure.

While there is **no known cure** for HIV and AIDS (yet), there are many things that PLWHA can do to live a long and healthy life.

**Anti-retroviral (ARV)** drugs are special drugs that have been created to treat HIV and help PLWHA stay healthy.

### **J. What is positive living?**

Positive living is a term used to describe steps taken by people living with HIV and AIDS that enhance their lives and increase their health.

#### **Positive living includes:**

- Knowing your HIV status
- If HIV negative – staying negative
- If HIV positive – preventing transmission
- Good nutrition, treating OIs, accessing health care
- A positive and healthy outlook on life
- Joining a support group.



## **UNIT 2      PREVALENCE OF HIV/AIDS IN MALAWI**

**Time allocation:**                      **1 hour**

### **Purpose**

This unit is intended to give the picture of the magnitude of the problem of HIV/AIDS in Malawi so as to prepare primary caregivers on the importance of their service to HIV/AIDS patients/clients.

### **Learning objectives**

By the end of this unit, participants should be able to:

- describe the prevalence of HIV/AIDS in Malawi
- explain the impact of HIV/AIDS on the family, community and the nation

### **Suggested teaching/learning methods**

Lecture, discussions, songs and brainstorming

### **Suggested teaching/learning materials**

Flip chart paper, statistical data on HIV/AIDS prevalence, markers, chalk and chalkboard, posters

#### **A. Overview of prevalence of HIV/AIDS**

- The estimated HIV/AIDS prevalence in adults aged between 15 to 49 years in Malawi is 14%.
- The first AIDS patient was reported as far back as 1985.
- By June 2001, over 845,000 HIV infected people were officially reported. These patients tested positive through health care facilities. However, there are many people with HIV who are not officially reported.
- The National AIDS Commission estimates that from 1985 to 2001, over 265,000 people have suffered from AIDS.
- It is estimated that out of 11 million people in Malawi, about 1 million people are infected with HIV. 86,000 dying per annum as a result of AIDS

## **B. Impact of HIV/AIDS on the family, community and nation**

The magnitude of HIV/AIDS pandemic in Malawi.

- The burden of HIV/AIDS is being borne by many Malawians. Most families have lost a loved one to AIDS.
- The productive age group of 15-49 years is the most affected.
- An increasing death rate has resulted in fewer adults working to support the young and elderly.
- The problems children face as a result of HIV/AIDS begin long before the death of a parent or guardian.

### **Family and Community**

- These children face loss of family and identity, increased malnutrition and reduced opportunity for education.
- Relatives and neighbours spend long hours caring for an ill relative.
- Thousands of children are orphaned by AIDS, and it is estimated that in 2001 there were 937,000 children under the age of 15 years who had lost their mothers to AIDS and projected to over a million by 2004.
- These children lack parental care and guidance, lose out educational opportunities and become exposed to child labour and various forms of abuse which increases their vulnerability to HIV infection.
- Without good care and support many of these children will lose out on opportunities for a healthy life and will be exposed to child labour, abuse and increased risk of HIV infection.

### **Nation**

- Crowding in hospitals.
- Less people working in the country.
- High medical bills.
- Payment of premature death benefits.
- Increased cost due to absenteeism.
- Funeral costs.
- Difficulty to replace highly qualified personnel or influential people within the community.

## **UNIT 3      BENEFITS OF COMMUNITY HOME BASED CARE**

**Time allocation:**                      **1 hour**

### **Purpose**

This unit introduces primary caregivers to Community Home Based Care concept that is designed for the care of chronically, terminally ill patients, clients and those infected and affected with HIV/AIDS.

### **Learning objectives**

By the end of this unit, participants should be able to:

- Define the term 'community home based care'
- Describe the benefits of community home based care to the patients, members of the family, community and the nation
- Identify eligibility criteria for CHBC
- Describe the components of CHBC package
- Identify people who can provide CHBC
- Describe characteristics of CHBC providers
- describe the roles of community home based care providers
- Describe community institutions that can support CHBC services
- Identify the structure of CHBC in Malawi

### **Suggested teaching/learning methods**

Lecture, discussion, brainstorming

### **Suggested teaching and learning materials**

Chalk and chalkboard, flip chart paper, pentel markers, transparencies and overhead projector, audio visual aids

### **Teaching and learning activities**

#### **A.    Definition of CHBC**

Community Home-Based Care is the care provided to chronically or terminally ill patients such as HIV/AIDS, TB and cancer; clients affected by the illness of their relatives and friends; vulnerable and at risk groups in their homes by family and community members using available resources and support from the formal health worker.

## **B. Benefits of CHBC**

- allows a patient to be taken care of by his/her relatives within his/her home environment
- allows family members and relatives to take care of the patient while undertaking other chores in the household
- helps to integrate care with HIV/AIDS education that promotes acceptance of the disease by the patient, family members and community as well as prevention of HIV/AIDS infection
- promotes long-term family support and strengthening of family-community bonding
- reduces overcrowding in hospitals
- reduces expenses in travelling
- allows more people to assist with the community home based care
- allows patients to continue with treatment under supervision

## **C. Criteria for eligibility to CHBC**

**All chronically/terminally ill people of all age groups including vulnerable groups in the community shall be eligible for CHBC**

- a. Chronically ill people includes adults and children (0-18) suffering from chronic diseases such as HIV/AIDS, Tuberculosis and Cancer, stroke and other chronic illnesses will benefit from CHBC
- b. Vulnerable groups of people in the community include PLWHAs, orphans and vulnerable children, at risk pregnant mothers and the elderly.
- c. Both male and female patients/clients of all age groups in the category above regardless of sero status are eligible for CHBC services
- d. Patients/clients in the hospital or community shall give consent to receive community home based care

## **D. CHBC providers**

**They can be:**

- family members
- community members
- health workers
- Teachers and other social workers

## **E. Characteristics of primary caregivers**

- a. Should be staying in the same community with his/her clients/patients
- b. Should be trustworthy, committed and willing to work
- c. Should be honest, friendly and easy to associate with
- d. Should be able to maintain confidentiality.

## **F. Roles of primary caregivers**

These are family members, relatives, and friends, as well as neighbours who are directly involved in the provision of care to chronically / terminally ill persons and spend most of the time with the patient. Their roles shall be as follows:

- Provision of direct patient care by assisting patient with bathing, feeding, mouth wash, turning the patient, pressure area care, assisting with elimination and ambulation
- Ensure a healthy home environment for the patient
- Managing simple ailments at home such as cough, fever, diarrhoea, vomiting, skin problems and others.
- Provide social and nutritional support patients/clients
- Take patients/clients to health and other support services and groups (e.g. religious groups) as required
- Ensure patient is adhering to ART, TB and other drugs
- Provide supporting information to his/her patient as required
- Avoid stigma and discrimination

## **G. Where can families go for support for patients**

Care for the chronically, terminally ill and vulnerable groups requires participation and support of groups found at the district and community level. These groups can provide physical and psycho social support.

Potential groups that can be identified at district and community levels include but not limited to:

### **Religious groups**

Religious groups can:

- Provide care through spiritual counselling, moral support, provision of resources like food, soap and clothes
- Educate people about HIV/AIDS and other health issues
- Help with households chores
- Help households raise money for their needs

- Help in providing food and promotion of food security programmes
- Train caregivers
- Identify individuals who can be trained to be volunteers

### **Existing community groups and organisations**

These can help in:

- Training of caregivers
- Educating people about HIV/AIDS and family health issues
- Counselling family members and the general community
- Providing physical care
- Helping households with chronically ill patients raise money for their needs
- Helping to provide food and promote food security.

### **Political parties and other influential leaders**

These can play the role of:

- Mobilising and providing resources
- Educating people about HIV/AIDS and related health issues
- Role modelling in the society
- Advocacy
- Identify individuals who can be trained to be volunteers

### **Health Facilities**

- Training of caregivers
- Supporting care of carers
- Provision of drugs and supplies for CHBC

### **NGOs**

Non-governmental organisations can assist through:

- Training of caregivers
- provision of resources
- advocacy

### **General community**

The general community can play the role of:

- Assisting the sick with household chores, for example, gardening, smearing the house, fetching water and firewood, digging refuse pits and latrines
- Assisting household caregivers and volunteer care givers in care provision
- Assist in generating income e.g. maintaining communal garden.
- Taking patients to health care facilities
- Providing moral support
- Promoting non-discriminatory practices
- Promotion of food security

## **UNIT 4      COMMUNICATION WITH PATIENTS**

**Time allocation:**                      **1 hour**

### **Purpose**

This unit is intended to equip primary caregivers with appropriate knowledge and skills in communication. This will in turn assist them to communicate effectively with their clients/patients in order to meet their needs.

### **Learning objectives**

By the end of this unit, participants should be able to:

- Define the term 'communication'
- Explain the aims of communication
- Describe the types of communication
- Explain the communication process
- Identify the main components in the communication process
- State the factors for effective communication
- Identify common barriers to effective communication
- Explain communication techniques
- Demonstrate some of the communication skills necessary for the primary caregiver

### **Suggested teaching/learning methods**

Brainstorming, discussions, lecture, role play and demonstration

### **Suggested teaching/learning materials**

Chalk and chalkboard, flip charts, posters, case studies, pentel markers, flip chart stand, radio cassette

#### **A.    Definition of communication**

Communication may be defined as a process through which messages are transmitted from one person to another. The messages may be in the form of information, instruction, thoughts, feelings, signals or activities and are transmitted most effectively when communication is a two-way process between the sender or initiator and the intended receiver.

## B. Aims of communication

- The overall aim of communication is to enable the sender to send his/her message to the targeted receiver in a clear and effective manner. For the CHBC provider this means the ability to effectively counsel, transmit information, instructions, guidance, advice, feelings, or thoughts to his or her client.
- The major purpose of a CHBC provider in communicating with the community may be to encourage the community to accept its responsibility in the fight against HIV/AIDS.

## C. Types of communication

- Verbal communication: this involves use of spoken words. It is most effective on conveying factual information.
- Nonverbal communication includes a wide range of ways that people use such as body movement, facial expression, gestures, eye contact, touch, and posture to which people assign meaning and perception of intended messages. It is most effective for conveying such information as feelings, emotions and attitudes.

### **.Important!**

Caregivers must be very sensitive to their own and clients' non verbal communication as clients may not be able to express themselves through use of words. Similarly, the Caregivers' non verbal communication also sends messages to the client. The providers should therefore be conscious of the messages their non verbal communication conveys.

## D. Communication process and components

- the **sender** is the source of the message
- the **message** is the idea or information that is communicated
- the **channel** is the means through which a message is transmitted from the source to the receiver
- the **receiver** is the person to whom the message is addressed and who interprets the message
- **Feedback** is the message sent back to the source/sender from the receiver to demonstrate a common understanding. In other words, it is the response or reaction of the receiver of the message that was sent.



## **E. Factors for effective communication**

- Appropriate language: easy for both sender and receiver to understand and must be socially acceptable
- Age and experience of receiver (client/patient): in introducing a new idea the CHBC provider should consider the age of the intended receiver of the message together with his/her cultural experiences
- Environment: This may refer to economic levels, availability of food, social and physical environments.
- Personal characteristics: especially in facial and other body expressions and gestures of the sender of the message

## **F. Barriers to effective communication**

### **Physical barriers**

These include environmental factors that may prevent or reduce opportunities for the communication process to occur, such as:

- lack of privacy
- lack of time
- polluted environment, e.g. noise, bad smell, poor ventilation or lighting
- lack of physical comfort for the client

### **Social, cultural and psychological barriers**

These are barriers that arise from the judgements, attitudes, emotions, social values and beliefs of people, such as:

- level of economic ability
- level of education
- religion, gender and age
- judgemental or biased attitudes
- lack of trust or respect
- cultural practices and beliefs
- political beliefs and values
- mode of dressing

## **G. Communication techniques**

- active listening
- being receptive
- effective questioning
- paraphrasing/summarising
- reflective feelings
- prompting
- repeating

## **UNIT 5      BASIC COMMUNITY HOME BASED CARE SKILLS**

**Time allocation:    3 hours**

### **Purpose**

This unit intends to provide participants with knowledge and basic skills in patient care

### **Learning objectives**

By the end of this unit, participants should be able to:

- Describe a home assessment
- Explain basic patient care skills required for community home based care patients
- Identify resources for basic patient care
- Demonstrate basic nursing care skills

### **Suggested teaching/learning methods**

Discussions, lecture, demonstrations

### **Teaching and learning materials**

Flip charts and markers, overhead projectors and transparencies, basin, soap, cup, bed, pillow, mattress, spoon.

### **Basic nursing care**

#### **Introduction**

Basic nursing care should aim at improving quality of life for the patient. It shall consist of assisting the sick person to live in a healthy environment, assisting with activities of daily living and relief of symptoms in the home.

Basic nursing care should be provided as required with special attention given to the following areas:

- Skin care
- Mouth care
- Pressure area care
- Elimination
- Ambulation and range of motion exercises
- Health education including HIV/AIDS prevention counselling.
- Nutritional counselling and support
- Psychological and spiritual care

Patient shall be assisted with relief of symptoms for example managing cough, diarrhea, nausea and vomiting, dehydration, loss of appetite, tiredness and weakness, sore mouth and throat, fever and pain relief

## **A. Home assessment**

### **Everyday a primary caregiver shall:**

- Assess general cleanliness of patient's home surroundings.
- Make sure that safe water and food for the patient is available
- Ensure safe waste and sewage disposal

### **Caring for sick people: Everyday**

- Check the general condition of your patient
- Ask patient for any problems/complaints
- Check on the treatment/drugs to be taken
- Ask about feeding pattern and any feeding problems
- Ensure patient is clean and comfortable

## **B. Basic CHBC skills and resources**

### **Bathing a patient**

#### **Objectives**

By the end of the session the participants shall be able to:

- Explain the reasons for bathing a patient.
- Discuss the precautions to be taken when bathing a patient in bed.
- State the resources required for bed bathing a patient.
- Explain the procedure of bed bathing a patient
- Demonstrate how to bed-bath a patient.

#### **Purpose**

Bathing a patient may be undertaken in order to:

- remove dirt from the skin and reduce sweat
- stimulate the action of the skin and improve circulation
- refresh the patient and relieve fatigue
- lower body temperature
- stimulate an atmosphere for easy communication

#### **Precautions to be taken when bathing a patient**

The following precautions should be considered:

- Wear protective clothing where necessary
- Prevent the patient from chilling by:
  - closing windows
  - keeping the patient covered during the bath, exposing only the part to be washed

- working carefully and quickly
- drying the patient well
- Avoid leaving the patient alone during the procedure
- Give special attention to the umbilicus, axillae, pubic area and perineal area
- Be sure the water is at the correct temperature
- Give special care to hair and nails if needed

### **Resources required during bathing**

- warm water in a basin
- soap
- vaseline/body lotion
- a piece of cloth/face towel/bath towel/or a soft sponge
- a comb
- razor blade
- gloves or plastic bags
- clean clothes/beddings

### **Procedure for bed bathing**

During bed bathing of a bedridden chronically or terminally ill patient, the following procedure should be followed:

- Explain procedure to patient and guardian, talk to patient throughout bathing
- remove the blanket and cover the patient with a bed sheet or chitenje
- assist the patient to take off his/her clothes
- place towel under patient's head, find out if patient wants soap used on face
- Wash face, neck and ears, rinse and dry, then remove the towel.
- expose arm further away from you, place towel underneath, then wash from
  - finger tips to shoulders, including axilla. Rinse and dry, then remove towel.
  - Do the same to the other arm.
- place towel towards under sides of chest to protect bedding. Wash abdomen and chest paying special attention to umbilicus and folds of skin under the breast. Rinse and dry, then remove towel and cover chest and arms with a bed sheet or blanket.
- expose leg further away from you. Make sure the genital area is covered. Place towel under it.
- Wash the legs from toes to groin and hips, paying special attention to area between toes.
- Wash bottom of foot, either using face towel or put foot into a basin of water. Rinse, dry and cover with blanket or sheet. Follow same procedure

for the other leg if feet are very dirty, leave till both legs are washed, then place them in the basin one at a time for washing

- discard dirty water and put clean water in the basin
- turn patient on to his/her side, let him/her face away from you. Expose the back and place a towel under the patient. Wash back and buttocks. Examine pressure areas and give care if needed.
- turn patient onto back, place towel under buttocks. If patient is able to wash genital area give him/her a soapy face cloth or sponge and let him/her wash, then rinse and give the towel to patient to dry him/herself. If patient is unable to do it, put on gloves and do it for him/her. Remove towel under buttocks.
- cut nails if necessary remove dirty linen and replace them with clean ones
- wash hair if necessary (collect more warm clean water) comb hair after washing
- apply body lotion if desired
- leave the patient comfortable
- reopen the windows
- remove equipment from the patient's side
- clean and put equipment in good place
- handle soiled linen carefully, rinse them out before washing with soap or hot water; rinse and hang to dry the bathing towels and face towels
- record and report any abnormalities
- Assist the patient with mouth care

### **Mouth care for the chronically/terminally ill patient**

#### **Objectives**

- Explain purposes of mouth care
- State resources required for mouth care
- Explain the procedure to the patient
- Demonstrate how to give mouth care

#### **Purpose:**

- To eliminate/prevent halitosis or infection.
- To promote appetite
- To refresh the mouth.

#### **Requirements**

Bowl of salty water

Vaseline

Spatula

Clean fresh chewing stick

Small clean cloth  
Gloves

**Procedure:**

- Explain to patient and guardian about the procedure
- Turn patient to lateral position with head on the side
- Place towel under the chin
- Wash hands with soap and water and put on gloves if necessary
- Gently open patient's mouth and place spatula to depress the tongue
- Cover the stick with clean cloth and wet in salty water
- Clean teeth, gums and tongue using stick until mouth is clean
- Use towel to wipe the mouth and apply Vaseline to the lips
- Remove equipment, clean dry and keep safely (spatula should be discarded) provide mouth care as needed

**Care of pressure areas**

These are areas on the body that are bony (eg hips) and where pressure and friction are prolonged as a result of confinement in bed.

**Objectives**

- Define pressure sore
- State the purpose for caring the pressure areas.
- Mention the pressure areas on the body.
- Mention the likely patients to get the pressure sores
- State the equipment necessary for pressure are care.
- Explain the procedure.
- Demonstrate pressure area care

**Pressure sore**

A pressure sore is a break in the skin after lying in one position for a long time.

**Purposes**

The purpose of caring for a pressure area is to:

- stimulate circulation to prevent breaking of skin and underlying tissue into
- open wounds or ulcers
- relieve or remove pressure on an area
- keep the skin dry

## **Pressure areas on the human body**

On the human body, the following are the pressure areas:

- a) back of the head
- b) scapula
- c) elbows
- d) knees
- e) vertebrae (backbone)
- f) sacral area (lower back)
- g) hips
- h) ankles
- i) heels

## **Types of patients who are likely to get pressure sores**

Patients who are likely to get pressure sores are those who are bed-ridden and have the following characteristics:

- are wasted or obese
- the elderly
- have lowered immunity
- Incontinence
- are unconscious
- have edema
- have diabetes

## **Prevention of pressure sores**

- encourage patients to move and turn if they are able
- turn patients and massage pressure areas every 2 hours
- keep beddings dry, clean, free from wrinkles, cramps and sand
- avoid chipped pans or clay pots with sharp edges for urinating and defaecation
- Soiled beddings should be removed as soon as possible

## **Resources for care of pressure areas**

The following are some of the resources required in the care of pressure areas:

- a basin of warm water
- a towel
- a clean sheet/chitenje
- soap
- big plastic sheet
- powder/lotion/cream or vaseline

## **Preparation**

The following should be done when preparing to care for pressure areas:

- explain procedure to patient
- collect equipment to patient's side
- observe privacy

## **Procedure**

To care for pressure areas effectively, this procedure should be followed:

- Expose area to be cared for
- Wear protective clothing where necessary
- Wash and dry hands
- Work from head to toe
- Protect bed with a plastic/sheet and towel
- Wash pressure areas with soap and water
- Rinse and dry them
- Massage pressure areas using soap or vaseline in a circular motion, dress the patient and prepare the sleeping area; making sure it is free from cramps and wrinkles
- Open windows
- Clean and store equipment used
- Treat soiled linen carefully
- Record and report findings to supervisor

## **Feeding a patient**

### **Objectives**

- Explain purposes of feeding a patient
- Discuss precautions to be taken when feeding a patient
- State resources required for feeding a patient
- Explain the procedure for feeding a patient
- Demonstrate how to feed a patient

### ***Purpose of feeding a patient***

The purpose of feeding a patient is to ensure that he/she is getting enough food to meet his/her nutritional requirements.

### **Precautions**

The following precautions should be considered when feeding a patient:

- Give small frequent amounts with proper consistency
- Serve food in an attractive manner
- Be cheerful and pleasant when serving food



- Serve food at the right temperatures and avoid reheating
- For patients who can feed themselves, food can be placed where it can easily be reached
- Food should be well prepared but not overcooked
- Food must be kept in clean containers
- Serving dishes and the person serving must be clean
- The kitchen itself must also be clean
- Store perishable foods in a cool place and do not let it stay for too long
- Prepare food away from the patient
- Prepare food just enough for one meal

### **Requirements**

- an extra person to hold the patient if necessary
- Covered food
- salt if necessary
- water in a basin
- a glass of water
- a spoon
- hand towel

### **Procedure**

- Bring food to patient's side
- Assist the patient to sit up, the assistant should support him/her if necessary
- If a towel is available, put it around the patient's chest to protect beddings
- Wash hands with soap and water
- If patient is used to praying, pray with him/her.
- Encourage patient to eat
- If unable to eat, feed the patient. Remember the following:
  1. feed slowly
  2. offer the food in small amounts
  3. offer liquids after meals to promote digestion.
  4. talk to the patient while feeding him/her
- remove dishes to a washing area
- wash patient's hands and mouth
- assist patient into a comfortable position
- clean dishes and keep them in a clean place
- record and report findings

## **Practical work on CHBC skills**

### ***Step 1***

The trainer should demonstrate CHBC skills on the following

- bathing a patient
- Care of pressure area
- Oral care
- feeding a patient

### ***Step 2***

Participants to observe and practice procedures.

### ***Step 3***

The trainer and participants to evaluate the performance of procedures

## **UNIT 6      INFECTION PREVENTION AND CONTROL IN THE HOME**

**Time allocation:**                      1hour

### **Purpose**

This unit aims at providing information on infection prevention and control practices at home.

### **Learning objectives**

**By the end of this unit, participants should be able to:**

1. Define the term infection prevention
2. Describe the purpose of infection prevention
3. Describe the disease transmission cycle
4. Explain methods of disease prevention

### **Suggested teaching/learning methods**

Lecture, discussion, brainstorming, demonstration

### **Suggested teaching/learning materials**

Chalk, chalkboard, flip chart, pentel markers, overhead projector, transparencies, cup, basin towel.

## **A. DEFINITION OF INFECTION PREVENTION**

**Infection prevention** is placing barriers between a susceptible host and the micro-organisms to reduce/prevent spread of infection. The protective barriers that help prevent the spread of infectious micro-organisms from person to person and from equipment, instrument and environmental surfaces to people include physical barriers, mechanical, or chemical processes.

## **B. PURPOSE OF INFECTION PREVENTION**

The purpose of infection prevention is:

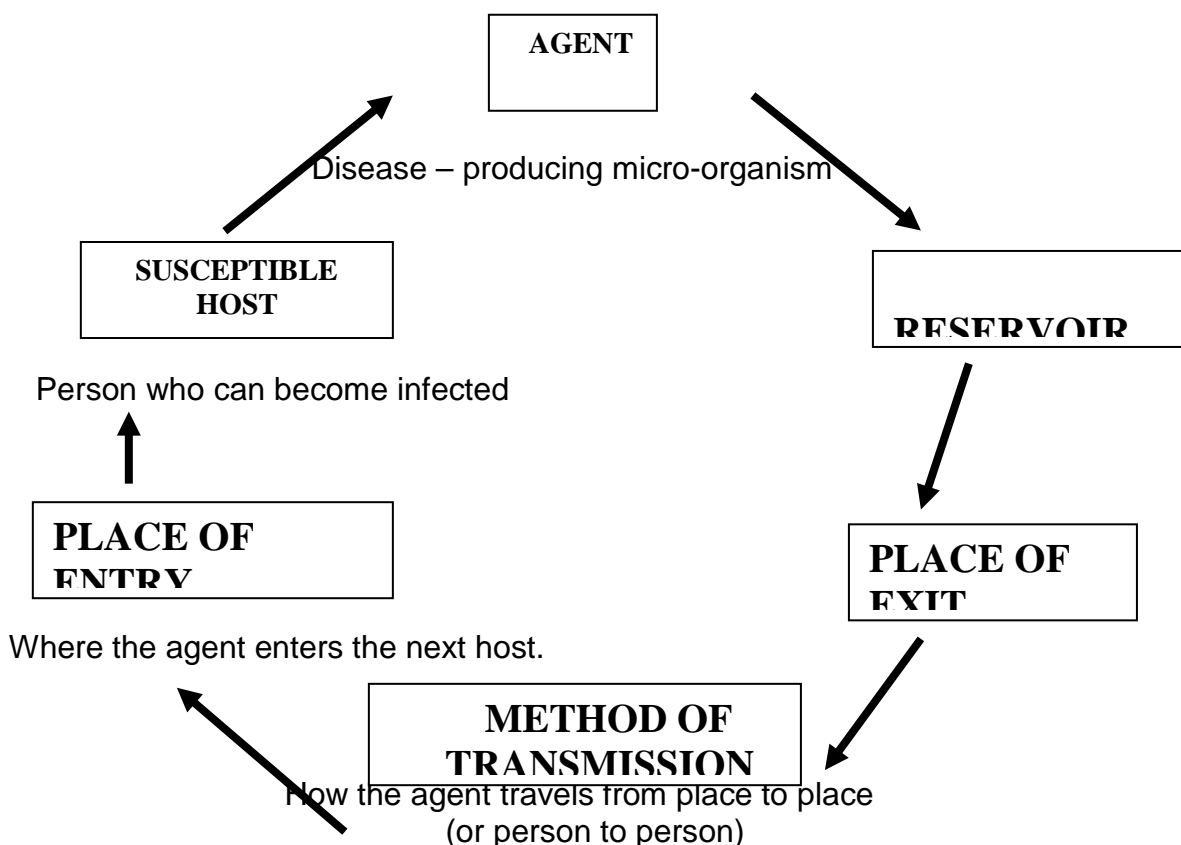
- To prevent the transmission of serious diseases such as hepatitis B virus and HIV
- To control the spread of infections.

### C. THE DISEASE TRANSMISSION CYCLE

- Micro organisms are found everywhere in our environment. Humans normally carry them on their skin and in the upper respiratory, intestinal and genital tracts. In addition micro organisms live in animals, plants, soil, air and water.
- Some micro organisms, however, are more pathogenic than others, that is, they are more likely to cause disease.
- Given the right circumstances, all micro organisms may cause infection.
- All humans are susceptible to bacterial infections and also to most viral agents.
- When organisms come in contact with bare skin, infection risk is quite low. All of us touch materials that contain some organisms every day. When the organisms come in contact with mucous membranes or non intact skin, infection risk increases.

**NB:** Infection risk increases greatly when micro-organisms come in contact with normally sterile body sites, and that the introduction of only a few micro-organisms may produce disease. For bacteria, viruses and other infectious agents to successfully survive and spread, certain factors or conditions must exist and these are:

#### ESSENTIAL FACTORS FACILITATING DISEASE TRANSMISSION DISEASE TRANSMISSION CYCLE



## SPREAD OF DISEASES

The diseases are spread mainly in these ways:

- **Agent**

There must be an agent – something that can cause illness (virus, bacteria, fungi etc)

An agent must have a way to move from its host to infect next susceptible host

- **Host/ Reservoir**

The agent must have a place where it can live (host) such as humans, animals, plants, soil, air and water. Many micro organisms that cause disease in humans multiply in humans and are transmitted from person to person.

The agent must have the right environment outside the host to survive. When it leaves the host, it must have a suitable environment in which to survive until it infects another person.

- **Place of Exit**

Where the agent leaves the host

- **Method of Transmission**

How the agent travels from place to place or from person to person

- I. **Airborne** – Through the air (chicken pox, mumps) Blood or body fluid – If blood or body fluids contaminated with HBV or HIV in contact with another person, such as through 9 needle stick, he or she may become infected.
- II. **Contact** – Either direct (touching an open wound or draining pustule) or indirect (touching an object contaminated with blood or other body fluids).
- III. **Fecal – Oral** – Swallowing food contaminated by human or animal faeces (e.g. putting fingers in your mouth after handling contaminated objects without first washing your hands).
- IV. **Foodborne** – Eating or drinking contaminated food or liquid that contains bacteria or viruses (hepatitis from eating raw oysters).
- V. **Animal or insect-borne** – Contact with infected animals or insects through bites scratches, secretions or waste.

- **Place of Entry**

Where the agent enters the next host.

- **Susceptible Host**

A person who can catch the disease (susceptible host) and get infected.

People are exposed to disease causing agents every day but do not always get sick.

To catch an infectious disease s/he must be susceptible to that disease.

Infection prevention deals primarily with preventing the spread of infectious diseases through the air, blood or body fluids, and contact, including fecal-oral and food borne.

Because it is not always possible to know in advance whether or not a person may be infected with HIV contaminated instruments, needles and syringes as well as other items from all persons must be handled as if they are contaminated.

## **METHODS OF DISEASE PREVENTION**

Preventing the spread of infectious diseases requires removing one or more of the conditions necessary for transmission of the disease from host for reservoir to next person/susceptible host by:

- Inhibiting or killing the agent (e.g. applying an antiseptic agent to the skin before surgery).
- Blocking the agent's means of getting from an infected person to a susceptible person (hand washing or bring a water less, alcohol-based antiseptic hand rub to remove bacteria or viruses acquired through touching an infected patient or contaminated surface).
- Making sure that people are immune or vaccinated.
- Providing community care provider and primary care givers with the right protective equipment to prevent contact with infection agents (e.g. heavy duty gloves).

## **STANDARD PRECAUTIONS KEY COMPONENTS**

Because no one really knows what organisms client or patients may have at any time, it is essential to note that standard precautions be used at all the time and consider every person as potentially infectious and susceptible to infection.

- **Wash hands** – the most important procedure for preventing cross contamination (person to person or contaminated object to person). Wash hands after touching blood, body fluids, secretions, excretion and contaminated items. Wash hands immediately after removing gloves and in between patient contact.
- **Wear gloves** (both hands) before touching anything wet, broken skin, mucous membranes, blood or other body fluids, or soiled instruments and contaminated waste materials. Wearing gloves does not replace the need for hand washing.
- **Use physical barriers** (protective gowns, face masks and aprons) if splashes and spills of any body fluids are likely e.g. when cleaning instruments and other items.
- **Safely dispose off infectious waste materials** to protect those who handle them and prevent injury or spread of infection to the community.
- **Process instruments, gloves and other items** after use by first decontaminating and thoroughly cleaning them.
- **Patient care equipment** – handle soiled equipment in a manner to prevent contact with skin or mucous membranes and to prevent contamination of clothing or the environment. Clean reusable equipment prior to reuse.

- **Linen** – handle soiled linen to prevent touching skin or mucous membranes.
- **Environmental hygiene** – routinely clean the patients` environment i.e sweeping, dusting to maintain a clean, healthy and pleasing patient and home environment.
- **Personal hygiene** – routinely take a bath daily and put on clean clothes.
- **Food hygiene** – avoid eating poorly processed and contaminated food.
- **Patient Placement** – place patients who contaminate the environment or cannot maintain appropriate hygiene in private rooms.

## **2. Processing soiled instruments and other items**

- **Decontamination.** It is the process that makes inanimate objects **safer** to be handled by people before cleaning (i.e. inactivates micro organisms and reduces, but does not eliminate, the number of other contaminating microorganisms).
  - It is the first step in processing soiled instruments, gloves and other items especially if they will be cleaned by hands.
  - Ideally, soiled surgical instruments, gloves and other items should always be handled by people wearing gloves or using forceps.
  - Because this is not always possible, it is safer first to soak these soiled items for 10 minutes in 0.5% chlorine solution, to make them safe to be handled during cleaning especially if it will be done by hands.
- **Cleaning.** It is the process that physically removes all visible dust, soil, blood or other body fluids from inanimate objects as well as removing sufficient number of microorganisms to reduce risks for those who touch the skin or handle the object.
  - It consists of thoroughly washing with soap or detergent and water, rinsing with clean water and drying. Clean instruments under water.
  - After cleaning instruments or linen they may undergo High Level Disinfection such as boiling.
- **Boiling.** It is the process that eliminates all microorganisms except **some** bacterial endospores from inanimate objects. Instruments or linen should be boiled for not less than 10 minutes from the time water has started boiling.

## **UNIT 7        MANAGEMENT OF COMMON HIV/AIDS RELATED CONDITIONS AT HOME**

**Time allocation:    5hours**

### **Purpose**

This unit is intended to provide primary caregiver with information on the signs and symptoms of AIDS related conditions and how they can be managed at home.

### **Learning objectives**

By the end of this unit, participants should be able to:

- identify conditions related to HIV/AIDS
- manage signs and symptoms of the identified conditions at home
- determine when to take the patients to the hospital or other facilities for further management

### **Suggested teaching/learning methods**

Lecture, discussions, brainstorming, demonstrations

### **Suggested teaching/learning materials**

Sample of drugs, posters, flip charts, markers, chalk and chalkboard

#### **A.    Conditions related to HIV/AIDS**

- fever
- diarrhoea
- chronic pain
- coughing and difficulty in breathing
- nausea and vomiting
- mouth and throat problems
- skin problems
- wounds, boils and abscesses
- anaemia
- tiredness and weakness
- anxiety and depression
- genital problems
- pulmonary tuberculosis



## **B. Causes, management and referral of HIV/AIDS related problems**

### **Fever**

#### ***General information***

- Is when a person's body temperature is higher than normal body temperature
- Is not a disease in itself but a sign of the presence of an infection or something wrong in the body
- Can make a patient feel uncomfortable
- Is dangerous if not managed properly
- Can cause fits in children, confusion and dehydration in adults



**Figure 1: Patient with Fever**

#### ***Possible causes***

Some of the causes are as follows:

- Common diseases like malaria, pneumonia and tuberculosis
- HIV/AIDS related infections, e.g. cryptococcal meningitis
- In many instances the cause is not known

#### **What the care provider can do at home**

##### ***How to recognise fever in a patient***

- Place the back of one of your hands on the patient's forehead and the back of your other hand on your forehead. Note the difference in temperatures. If the sick person feels warmer, then he/she has a fever. This applies when the care provider has no fever.
- The patient may tell you that she/he is feeling uncomfortably warm or cold. This may mean that he/she has fever.

## **How to lower fever in a patient at home**

The caregiver should help the patient to do the following:

- Remove extra clothing and blankets
- Open windows, sit outside in the shade or any other cool place
- Have a luke warm bath
- Drink plenty of fluids like water, tea, thobwa, fruit juice and soup even when the patient does not feel thirsty
- Fan the patient using cloth or any other material
- Take pain killers with meals three times a day e.g. panadol

Where the patient is unable to do the above tasks him/herself, the Care Provider should help the patient. In addition, he/she can:

- wipe the patient with a lukewarm wet cloth
- keep the skin clean and dry to prevent sores and rashes

A patient with an acute fever must therefore be assessed clinically and usually be treated presumptively for malaria with anti-malaria drugs in standard doses.

## ***When to take the patient to hospital***

Take the patient to a health care facility if:

- The fever does not subside with the above management
- There is coughing, difficulty in breathing and loss of weight
- If in addition to fever, the patient has:
  - lost consciousness
  - A stiff neck
  - Severe body pains
  - Yellow eyes
  - Sudden severe diarrhoea
  - Fits
  - Signs of confusion
- She is pregnant, has recently delivered or miscarried
- The fever has not subsided after treatment with other anti-malaria drugs
- There is discharge from the vagina/penis and lower abdominal pain

## **Diarrhoea**

### ***General information***

- Diarrhoea is the passing of more than three loose or watery stools in a day (24 hour period)
- Diarrhoea causes dehydration due to the loss of a large amount of water and salts

- Diarrhoea can cause malnutrition and make it worse because:
  - food components are lost from the body in the stools
  - people with diarrhoea often do not have appetite
  - some people think wrongly that they should not eat when they have diarrhoea because they feel it will worsen the condition
- As a result of the dehydration and lack of appetite leading to the patient not eating, and lack of mobility can cause the patient's body to become too weak to protect itself from other infections, e.g. pneumonia.
- Diarrhoea is one of the most common conditions in HIV positive patients



**Figure 2: Patient with Diarrhoea**

### ***Possible causes of diarrhoea***

- Poor hygiene
- Diseases such as malaria, malnutrition
- Intestinal infections from contaminated food or water e.g. cholera, dysentery, typhoid
- HIV related infections
- Worm infestation in the stomach and intestines
- Other factors such as drugs and alcohol

### ***Signs of dehydration***

- patient expressing that he/she feels thirsty
- In children, failure to suck during breastfeeding
- Sunken eyes
- Little or no urine
- Dry mouth
- Feeling dizzy when standing
- Skin going back slowly when pinched
- Irritability or tiredness of the patient

### ***What the Care Provider can do at home***

The primary caregiver should encourage the patient to:

- Drink safe water
- Drink and eat as much as possible
- Eat uncontaminated food frequently
- Use toilets at all times

- Wash hands after using a toilet
- Wash hands before and after eating
- Drink more fluids than usual, eg soup, juices, boiled rice, water, tea, and thobwa
- Continue eating nutritious food but avoid eating uncooked vegetables, fruit peels or spiced food In case of a baby, encourage the parents to continue breastfeeding
- Keep the anal area clean and dry at all times
- Check for severe dehydration e.g. loss of elasticity of the skin



**Figure 3: Checking for Dehydration**

### ***Precautions against diarrhoea***

The primary caregiver should ensure the following precautions all the time:

- Water used for bathing the patient and washing soiled linen should be discarded into a pit latrine and never be reused
- Wear gloves if available or un torn plastic bags when washing soiled linen and clothes or wiping the patients
- Soak soiled linen in jik for 10 minutes, and then wash with soap. If jik is not available boil soiled linen for 20 minutes after the water has started boiling before washing it with soap
- If possible, use separate basins/buckets/pots for bathing the patient or washing soiled linen and clothes
- In case of severe diarrhoea, dress the patient in a clean cloth (napkin) to avoid soiling the beddings
- Put plastic paper under the buttocks to protect beddings
- Clean the mat with soap and dry it
- Wash hands before and after taking care of the patient
- Prepare ORS and give the patient to drink one cup-full after each stool discharge (adults)
- Limit the number of care providers to prevent spread of infection

## **Additional notes for care providers of children**

Dehydration happens faster in infants and young children. In the case of breastfed infants with diarrhoea, the caregiver should encourage the mother to continue to breastfeed and try to do so more often than usual. It is particularly important to encourage children with diarrhoea to drink a lot of fluids particularly after each loose stool. It is also important to encourage young children with diarrhoea to eat. Some children will need extra food after the diarrhoea has gone to help them regain the weight they have lost.

### ***When to take the patient to hospital***

Take the patient to a health facility if the patient:

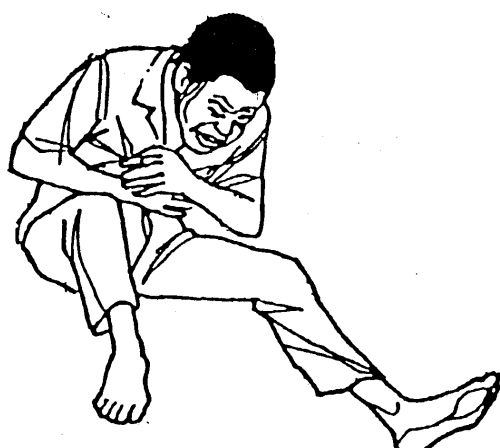
- is severely dehydrated
- is too weak to eat/drink
- is passing bloody stools
- has high fever
- is unconscious
- is vomiting severely
- is complaining of severe abdominal pains
- shows no improvement despite the management of diarrhoea at home

## **Chronic pain**

### ***General information***

Pain is commonly experienced in chronic illnesses and HIV/AIDS. Pain sometimes alerts an individual or a health worker to the possibility of an underlying medical problem. Expression of pain may vary depending on an individual's personality.

Some expressions include groaning, verbal grimaces and verbal expression by the patient.



**Figure 4: Patient in pain**

### ***Possible causes***

The possible causes of chronic pain include:

- infections such as shingles, candida (oral and vaginal), meningitis, malaria and pneumonia
- muscle aches due to limited movements and wounds
- cancer
- HIV neuropathy
- psychological factors, e.g. depression and anxiety
- unknown causes

### ***What the CHBC Provider can do at home***

The CHBC Provider should help the patient to do the following:

- maintain a comfortable position
- change positions in bed or move about frequently
- do simple active and passive range of motion exercises
- talk to a friend or any other person
- take a warm bath
- take pain killers with meals three times a day (morning, afternoon and at night) and when necessary
- meditate or pray, according to his/her faith

### ***What the Community Home Based Care Provider should do***

The community home based care provider should:

- observe signs of pain in the patient
- gently massage sore muscles
- give the patient a warm bath
- apply hot or cold compress
- encourage the patient to do light activities to relieve anxiety
- have patience, love, understanding and a listening ear

### ***When to refer the patient to a health facility***

The CHBC provider should refer the patient to a health facility for further management if:

- pain becomes severe
- pain is associated with new symptoms such as headaches, neck stiffness and fever
- the patient is unconscious
- the management described above does not help

## **Coughing and difficulty in breathing**

### ***General information***

Coughing is the body's way of cleaning the respiratory system and getting rid of excess mucus. Respiratory problems are quite common in people with chronic illnesses and HIV/AIDS and can be very serious.



Common symptoms include:

- Chronic cough
- Shortness of breath
- Chest pains
- Productive cough
- Fever

**Figure 5: Patient Coughing**

### ***Possible causes***

The causes of coughing and difficulty in breathing may include but are not limited to:

- colds and influenza
- pneumonia
- tuberculosis
- fluid in the chest
- heart problems
- allergies
- asthma
- foreign bodies
- worm infestation
- cancer

### ***What the CHBC Provider can do at home***

The CHBC Provider should help the patient to do the following:

- take plenty of fluids e.g. safe plain water
- sit up whenever possible
- use back of left hand to cover the mouth when coughing
- spit into a container with sand and cover
- throw away the sputum in a latrine/toilet or bury it
- take steam inhalation
- take throat soothing remedies, e.g. tea with lemon juice and/or honey
- keep warm if one of the signs is common cold or influenza
- take pain killers with meals: morning, afternoon and at night and when necessary
- avoid shaking hands

### ***In addition, the Care Provider can advise the family care providers to:***

- place the patient in a well ventilated room
- sit with the patient because difficulty in breathing can be very frightening
- provide support to the patient to sit up
- talk with and counsel the patient
- educate the patient or family care providers on care of handkerchiefs eg washing separately from other laundry

### ***Notes for care providers of children***

- clear the nose of the child if it is blocked. This can be done with a cloth that has been twisted and moistened in salt water ( $\frac{1}{4}$  teaspoon of salt in a cup of water)
- children with a cough should drink plenty of fluids. Give the child more fluids by spoon or cup and increase breast feeding
- fast or difficult breathing in children may be dangerous and needs to be referred to a health facility immediately

### ***When to refer the patient to a health facility***

The patient should be referred to a health facility if:

- sudden fever develops
- there is severe chest pain
- there is discomfort and severe breathlessness
- patient is coughing blood
- patient is coughing bad smelling sputum
- cough continues for more than three weeks.
- patient does not respond to the management mentioned above



## **Nausea and vomiting**

### ***General information***

Nausea and vomiting can be a problem in people with HIV/AIDS and other chronic illnesses because they can cause dehydration and malnutrition.

### **Possible causes of nausea and vomiting**

The causes include:

- medicines that may have been taken by the patient
- worm infestation
- cancer
- HIV and other infections
- severe pains
- stomach and intestinal problems

### ***What the care provider can do at home***

The care provider should help the patient to do the following:

- avoid odours
- take frequent meals in small amounts
- if vomiting or nausea is severe the patient should not take any food or drink for 1-2 hours. Then gradually start taking fluids in small amounts
- frequently rinse the mouth with salt water, clean teeth
- lick a lemon frequently in order to remove bad taste and refresh the mouth
- let plenty of fresh air into the house or room
- watch for signs of dehydration

### ***When to refer the patient to a health facility/worker***

The patient should be referred to a health facility/worker if there is:

- vomiting every time a patient eats/drinks within a 24-hour period
- the person vomiting has pain in the stomach
- the person has a high fever
- severe vomiting
- the vomitus is dark, dark green or dark brown
- it smells like stool or has blood in it
- the person has signs of dehydration
- does not eat or drink for 6 hours

## **Mouth and throat problems**

### ***General information***

- Soreness in the mouth and throat, causing painful swallowing is a common symptom in patients with HIV/AIDS and chronic illnesses. This can prevent a person from eating normally.
- The person may become weak and malnourished and unable to fight against infections.

### ***Possible causes***

Some of the causes of mouth and throat problems are:

- thrush: these are white patches in the mouth and throat caused by fungal infections
- blisters and sores on the lips
- cracks and sores in the mouth
- malnutrition
- unknown causes

### ***What the care provider can do at home***

The care provider can help the patient to do the following:

- clean the mouth with warm salt water
- for oral thrush, suck lemon if it is not too painful
- eat soft foods as needed, eg porridge, soft nsima but avoid uncooked vegetables
- drink plenty of fluids and soups
- eat raw garlic
- apply gentian violet
- take pain killers with meals, morning, afternoon and at night

### ***When to refer the patient to a health facility/worker***

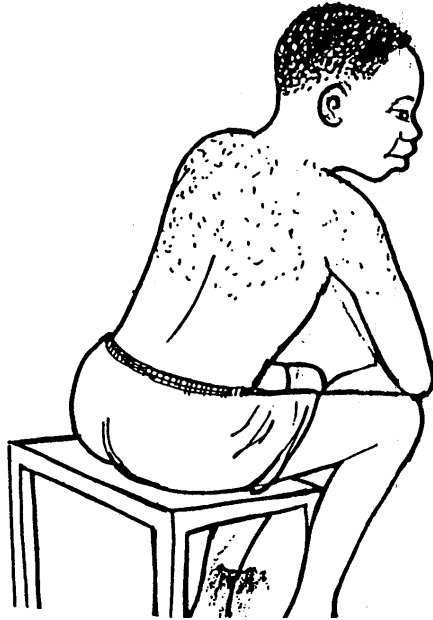
The patient should be referred to a health facility/worker if:

- there are signs of dehydration
- the patient has fever
- the patient is having difficulty in breathing
- the patient does not improve with the above management

## Skin problems

### *General information*

Skin problems in people with HIV/AIDS and chronic illnesses are common and tend to be chronic. These can be controlled with treatment and rarely can they be completely cured.



Skin conditions may present in the form of :

Rashes, itching skin, painful sores on the skin, increased skin dryness, slow healing wounds, boils and abscesses.

### **Possible causes**

Some of the causes of skin problems:

- poor hygiene
- allergies to common substances
- other infections such as syphilis and fungal infections
- measles
- diarrhea

**Figure 6: Skin problems**

- heat
- incontinence

### ***What the Care Provider can do at home***

The Care Provider should help the patient to do the following:

- clean the skin with warm water and soap
- always keep the skin clean and dry
- apply prescribed skin lotions, e.g. calamine or Whitefield ointment
- eat enough varied nutritious food
- keep the area uncovered and open to air and sunlight
- apply gentian violet to open ulcerations when necessary
- encourage the patient to be out of bed as much as possible
- change position frequently and gently massage the pressure areas
- for open wounds, clean with mild salt water and put a clean dressing daily
- give adult patients pain killers with meals three times a day, morning, afternoon and at night or when necessary

### ***Notes for Care Providers of children***

- to prevent babies from ulcerating themselves, cut their fingernails very short
- for children in nappies who have diarrhoea or yeast infections, the buttocks area will need special care. For example:
  - leave the baby's buttocks exposed to air as much as possible
  - soak the baby's buttocks with warm water between nappy changes
  - remove or change wet nappies or clothes as soon as they become soiled
  - avoid wiping the buttocks area, instead squeeze water from a cloth or pour water over the area and then pat dry
  - use simple vaseline/lotions to help cure rashes in the nappy area.

### ***When to refer the patient to a health facility/worker***

The patient should be referred to a health facility if:

- there is fever
- the wound becomes infected
- pain worsens
- there is bleeding
- infected areas are swollen and hot
- the patient does not respond to the above management

## **Care for wounds, boils and abscesses**

### ***General information***

- A wound is a breakage in the skin
- Sores, boils and abscesses are also common in chronically ill and HIV/AIDS persons.

### ***Possible causes***

The causes of wounds, boils and abscesses include:

- injury
- pressure on the skin
- infection
- skin cancer

### ***What the Care Provider can do at home***

The Care Provider should always use gloves or untorn plastic bags when dressing wounds.

### ***General care of wounds and sores***

- Wash the wound with clean water, preferably boiled and cooled, mixed with salt (one teaspoonful of salt in three coca-cola bottles filled with water) or gentian violet if available

- Wash hands before and after dressing a wound
- Wash around the edge of the wound first, then wash from the centre out to the edges. If possible use separate pieces of cloth for each wipe
- Protect the wound by covering it with clean gauze bandages or cloth, wrapped loosely. If the wound is dry you may leave it open
- Change dressing at least once a day and look for signs of infection
- If the wound has pus or blood, cover the area with a clean piece of cloth or bandage
- If the wound is on the leg or foot raise the affected area. Some walking may be helpful
- Soak soiled clothes and bandages in jik for 10 minutes and wash in soapy water.
- Rinse, and or boil soiled clothes and bandages for 20 minutes, then wash with soap and water
- If the clothes and bandages will not be reused, burn them or discard them in a pit latrine
- Give pain killers when necessary
- Encourage patient to eat citrus fruits e.g. oranges

### ***Care for infected wounds and sores***

Wounds and sores are infected if they:

- Begin to smell
- Have pus,
- Become red, swollen, hot or painful

If the wound shows the above signs, treat infected area as in steps outlined in general care of the wounds above. However, also do the following:

- put a hot compress over the wound for twenty minutes four times a day
- clean wounds with an antiseptic if available (cetrimide or soda water)

### ***Care for boils and abscesses***

Boils and abscesses are raised and painful lumps on the skin. They are more common in the groin, buttock, back and upper legs. At home, the Care Provider can do the following:

- if there is a painful red lump under the skin, use a warm compress four times a day over twenty minutes. This may make the lump open up and drain the pus
- keep on applying clean warm compress until the pus stops coming out, then continue with management as for an infected wound
- honey or sugar may be put on the wound. This helps the bacteria to feed on the sugar while the wound is healing

### ***When to take the patient to a health facility/worker***

Take the patient if the following happens:

- the patient has fever
- the red area around the wound is getting bigger
- there are swollen glands in the neck, groins and armpits
- if the bleeding can not be stopped
- if there is smell or the wound turns black
- if it does not respond to the above treatment

### **Anaemia**

#### ***General information***

Anaemia is defined as haemoglobin (Hb) concentration lower than normal for age and sex of individuals.

- It is a serious illness
- Anaemic patients are more likely to get other illnesses
- Their ability to work is also affected.



#### ***Possible causes of anaemia***

Anaemia is caused by:

- Poor nutrition especially not eating enough foods rich in iron eg green leafy vegetables like pumpkin leaves
- Worm infestations
- Blood loss due to wounds and ulcers
- Blood destruction, e.g. by malaria parasites

#### **Figure 7: Checking Anaemia**

- Chronic diseases, e.g. cancer and diabetes
- Bloody diarrhoea
- Heavy or prolonged menstruation.

#### ***Signs and symptoms***

The signs and symptoms of anaemia include:

- Pale eyes, tongue and nail beds
- Tiredness
- Weakness
- Dizziness

- Heart palpitations
- Swelling of feet
- Shortness of breath
- Fainting

### ***What the Care Provider can do at home***

The Care Provider should help the patient to do the following:

- Control bleeding
- Eat more iron rich foods, eg green leafy vegetables, yellow fruits and meat if possible
- Take one iron tablet once a day with a meal until the condition improves
- Take any other prescribed treatment for malaria or worm infestation
- Rest as much as possible
- Avoid strenuous activities

### ***When to take the patient to a health facility***

The patient who has anaemia can be referred to a health facility if he/she:

- Is too weak
- Has difficulty in breathing
- Has swelling hands and feet
- Bleeds continuously
- Has fever
- Does not improve with the above treatment

### **Tiredness and weakness**

#### ***General information***

Chronic illness including HIV/AIDS can make a person feel tired and weak, particularly in the later stages of the disease.



**Figure 8: Sign of tiredness and weakness**

***Possible causes***

Tiredness and weakness may be caused by:

- Chronic illnesses e.g. TB, cancer and diabetes
- HIV infection and other HIV related conditions
- Malnutrition
- Anaemia
- Depression
- Diarrhoea and dehydration
- Infections like malaria and pneumonia

***What the Care Provider can do at home***

The Care Provider should help the patient to do the following:

- Have enough rest
- Sit when bathing
- Use a walking stick if necessary
- Eat adequately, especially energy giving foods like nsima and sweet potatoes
- Drink plenty of fluids eg thobwa and fresh fruit juices
- get treatment for the cause
- Ask for help when needed
- Accept assistance when offered

***The Care Provider can also do the following***



- Help the patient with bathing, going to the toilet, eating, getting in and out of bed or put the patient on a chamber if he/she is too weak to get out of bed
- If the person cannot get out of bed, gently move the arms and legs several times a day
- Turn patient from side to side and massage pressure areas every few hours
- Keep patient company and listen to his/her concerns
- Advise the patient to avoid undertaking activities that demand a lot of energy, e.g. walking long distances

### ***When to take patient to a health facility/worker***

The patient suffering from tiredness and weakness should be referred to a health facility if:

- The patient becomes very weak eg unable to walk or feed
- There is high fever, headache and confusion
- The patient does not improve, after home management.

## **Anxiety and depression**

### ***General information***

- patients with chronic illnesses such as HIV/AIDS may have disturbances in mood as a result of anticipated loss brought about by the illness
- such patients are usually unhappy and require reassurance constantly
- anxiety is the feeling of nervousness and fear
- depression is the feeling of sadness and hopelessness
- anxiety and depression are normal when someone has been told that they have a chronic illness such as HIV/AIDS
- it is considered abnormal when these feelings last a long time and interrupt daily activities

### ***Possible causes***

Anxiety and depression may be caused by:

- anticipated loss e.g. death and self care
- reaction of people towards the patient
- fatigue due to physical illness
- side effects of certain medicines
- loss of a loved one/family member
- concern for a sick family member, money, food, job and disagreements within the family
- concern of no cure for illness

### ***Signs and symptoms of anxiety and depression***

Signs and symptoms could be either physical or mental.

#### **Anxiety**

Some of the signs and symptoms of anxiety include:

- lack of appetite
- shaking/trembling
- sweating
- inability to concentrate on anything
- feeling worried
- sleeplessness
- breathlessness

#### **Depression**

- hopelessness
- feeling tired and weak
- irritability
- insomnia
- difficulty waking up in bed, feeling of not wanting to get out of bed
- feeling neglected
- may have suicidal ideas
- being withdrawn
- eating too much or being unable to eat
- no longer caring about personal hygiene or physical appearance

#### ***What the Care Provider can do at home***

The Care Provider should help the patient to do the following:

- talk to somebody about his/her problems
- visit friends
- have physical problems treated at a health facility
- seek counselling and spiritual guidance
- involve the client/patient in various activities eg listening to music of preference, radio and sweeping

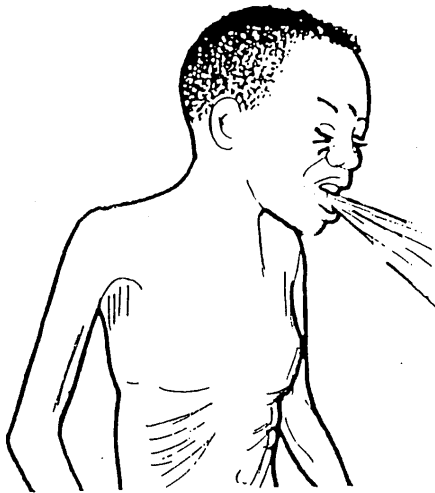
#### ***When to take patient to a health facility/worker***

Take the patient when there is a prolonged anxiety and depression and it interrupts with daily activities.

## **Pulmonary tuberculosis (TB)**

### ***General information***

- tuberculosis (TB) is a chronic contagious disease that is caused by bacteria
- it attacks all age groups especially those who are poorly nourished or live with someone who has the disease and is not getting treatment.
- it can be cured even in the presence of HIV/AIDS with the correct treatment if diagnosed early.
- it is important for people to get early diagnosis
- it is important for people to get early diagnosis through sputum examination
- the infected person can develop resistance if treatment is not completed



### ***Predisposing factors***

- HIV infection
- malnutrition
- contact with an untreated TB person
- overcrowding in the presence of an untreated TB patient

**Figure 9: Patient with TB**

### ***Signs and symptoms***

- productive cough for three weeks or more with or without weight loss which gets worse just after waking up and sputum may contain blood.
- weight loss
- fever
- chest pains
- loss of appetite
- sweating at night
- general body weakness
- swollen glands
- upper back pain

### ***What the Care Provider can do at home***

The community home based care provider should advise and assist the patient to do the following:

- seeking early assessment and care from a health facility
- covering the mouth with the back of the left hand when coughing
- taking treatment as prescribed by a health worker with the support of relatives
- eating adequate and nutritious foods
- drinking plenty of fluids especially fresh fruits and milk
- resting and avoid strenuous activities
- sleeping in a well ventilated room
- stop smoking and drinking alcohol
- going for regular check-ups as advised by the clinician
- sitting up when possible
- spitting into a container with sand and covering it
- throwing away sputum in a latrine, toilet or burying or burning
- taking treatment regularly
- seeking counselling when depressed

### **Health Education for TB treatment to patients and care providers**

- Two weeks of daily treatment.
- Six weeks of intermittent treatment.
- Then six months of continuous treatment
- The choice of hospital, health centre, to be treated.
- Sputum smear examination at 2, 5 and 7 months.
- Adherence to treatment.
- Importance of taking all the drugs.
- Importance of completing the full course of treatment.
- Reporting adverse reactions to the TB officers.
- Any other important information about the total course of treatment.

### ***When to refer patient to a health facility***

The care provider should refer the patient to a health facility if she/he

- shows signs of TB
- shows signs of TB drug reaction such as:
  - itching
  - skin rash
  - jaundice
- defaults treatment
- shows no signs of improvement while on treatment
- vomits after taking drugs
- shows signs of mental confusion

### ***Tuberculosis in relation to HIV/AIDS***

- in communities where TB is very common, most people can readily recognise the signs and symptoms of the disease. If someone has HIV infection, chances of getting TB are high because of low immunity
- a person with HIV/AIDS may also develop uncommon TB symptoms such as:
  - persistent fever without cough
  - enlarged lymph nodes in the neck, groins, and armpits. The enlarged nodes may open and drain pus

## **UNIT 8      NUTRITION FOR PATIENTS AND PLWHA**

**Time Allocated: 2 hrs.**

### **Purpose:**

The purpose of this unit is to provide the participants with knowledge and skills to improve nutritional status for chronically ill people including PLWHA.

### **Learning Objectives:**

By the end of this unit participants should be able to:

1. Define the term nutrition
2. Describe the 6 food groups
3. Explain the relationship between HIV/AIDS and Nutrition.
4. Explain nutritional management of common HIV and AIDS related conditions.
5. Explain hygienic food handling practices.
6. Describe recommended practices for improving nutritional status for PLWHAs

### **Suggested teaching/learning methods**

Group discussions, lecture, demonstrations.

### **Suggested teaching/learning materials**

Training manual, Posters, food items, flip-charts, pental markers, papers, six food group pie charts, vicious-cycle of malnutrition and HIV/AIDS.

### **A. Definition of Nutrition**

Nutrition is the process by which the body provides materials for its structural and functional needs.

There are 6 food groups namely:

1. Animal products (Zanyama)
2. Legumes (zanyemba)
3. Staples (zokhutitsa)
4. Fruits (Zipatso)
5. Oils and fats (zamafula)
6. Vegetables (zamasamba)

## **B. RELATIONSHIP BETWEEN NUTRITION AND HIV/AIDS**

- A well-nourished person has strong immune system that helps to fight diseases.
- When a person or child has HIV/AIDS ability to fight diseases is weakened/reduced.
- When a person living with HIV/AIDS is not well fed, the body gets weaker and is more likely to get sick more often and develop AIDS faster.

Diseases and related conditions that a person or child with HIV/AIDS suffers from, may lead to poor nutritional status due to:

### **1. Inadequate intake of nutritious foods:**

People with HIV/AIDS may not be able to eat enough and a variety of foods to meet their nutritional requirement due to loss of appetite as a result of:

#### **Depression**

People with HIV/AIDS may experience some depression from dealing with a disease that has no cure, fear of death and because of possible stigma from spouse, family members and community. In some cases depression reduces one's appetite to eat.

#### **Diseases**

People with HIV/AIDS suffer from more frequent episodes of illness such as malaria and fever that may make them not to want to eat. Some conditions like sores in the mouth and throat may make chewing and swallowing difficult.

#### **Drugs**

Drugs taken by people with HIV/AIDS for treating disease and antiretrovirals (ARVs) may cause nausea and loss of appetite as side-effects, hence they eat less.

### **2. Poor absorption of food**

HIV infection and some of the HIV related infections interfere with the body's ability to digest, absorb and utilise food properly.

Some drugs may interfere with digestion, absorption and utilization of food by the body.

### **3. Shortage of nutritious food at home**

Due to long illness, the person is not able to work and produce enough food for the family, they may spend more money and other resources on medical

care and they may not have enough money to buy nutritious foods for themselves and the family.

A person with HIV/AIDS needs additional amounts of nutrients to help fight the burden of the virus and related infections, maintain weight, prevent weight loss and loss of muscle mass.

A person needs to eat appropriate foods that will give them nutrients in the right amount and proportion in order to maintain their nutrition and health status.

**Note:**

- People with HIV/AIDS have increased energy needs due to increase in opportunistic infections.
- When symptomatic, energy requirements increase by approximately 20-30% in adults and children by 50-100% over normal requirements in children experiencing weight loss.

**C. NUTRITIONAL MANAGEMENT OF COMMON HIV RELATED CONDITIONS**

**Anorexia (loss of appetite)**

- Drink sips of (but frequent) high-energy and high protein fluids such as soured milk (chambiko), thobwa and fruit juices. Natural fruit juices are better than processed ones.
- Eat small but frequent portions of soft foods with pleasing aroma if it does not affect you negatively (5 or more times a day).
- Serve the food in an attractive way.
- Eat nutritious snacks like boiled pasteurized and soured milks, nuts, bean patties (chipere), bananas, pineapples, boiled cassava and sweet-potatoes.
- Eat favourite food.
- Drink liquids often (at least 2 litres per day).

**Fever**

- Eat foods rich in energy and other nutrients such as soups made from a mixture of a variety of foods eg potatoes, carrots, maize, mashed vegetables.
- Eat small frequent meals that contain a variety of foods.
- Drink plenty of fluids beyond thirst especially clean boiled water to prevent dehydration.
- Sponging or take cool bath.
- Rest.



### **Change or loss of taste**

- Use flavour enhancers e.g. salt, lemon and spices.
- Chew food well and move it around in the mouth to stimulate receptors.
- Clean mouth every day.

### **Sore mouth and throat**

- Avoid sugary, fried and spicy foods.
- Chew raw garlic.
- Eat soft foods, e.g. porridge, mashed potato, yoghurt, soups.
- Rinse the mouth with warm, salt water or baking soda at least 4 times.

### **Nausea and vomiting**

- Eat small quantities of food at frequent intervals. Avoid an empty stomach.
- Eat boiled rather than fried foods.
- Drink diluted fruit juices and clean and safe water.
- Drink after meals and limit fluid intake with meals.
- Eat small salt quantities and dry foods to calm the stomach.
- Eat soups and crackers (non-sweet biscuits).
- Eat foods which do not have strong aroma. Avoid spicy foods.
- Rest between meals but avoid lying down immediately after eating (wait at least 20 minutes) to avoid vomiting.

### **Loose Stools or diarrhea**

- Drink a lot of fluids (soups or diluted fruit juices, thobwa, rice water, boiled water or ORS) to avoid dehydration.
- Avoid strong citrus fruits such as oranges, lemons as they may irritate the stomach.
- Continue eating during and after illness to facilitate recovery and weight gain and nutrient recovery.
- Eat foods rich in soluble fibre such as bananas, peas, mashed fruits, soft rice or millet porridge.
- Eat soft and easy to digest foods such as cooked mashed green bananas, carrots or potatoes, millet, rice or maize porridge, sweet potatoes.
- Eat smaller meals more often.
- Eat foods which contain less fat.
- Reduce dairy products except those that are fermented e.g. chambiko and yoghurt.
- Reduce gas forming foods such as carbonated drinks or sodas, cabbage, onions.
- Eat boiled or steamed foods other than fried.
- Observe all standard hygiene rules.

## **Constipation**

- Eat foods high in fibre e.g. mgaiwa, fruits with edible skin, whole-wheat bread, green leafy vegetables, beans.
- Avoid processed or refined foods.
- Drink plenty of fluids (at least 2 litres of clean safe water/ fluids every day).
- Do not use enema unless directed by a doctor.
- Take regular exercise daily.

## **Weight loss**

Eat high energy foods such as bananas, avocado, nuts, chiponde, butter, cheese, potatoes, fatty fish, beans, porridge, protein drinks and milk shakes (use in conjunction with above advice.)

## **Muscle wasting**

- Increase amount of food and eating frequency.
- Eat a variety of foods from the six food groups. Eat more foods that are rich in protein such as fish, meat and starchy foods (cereals, potatoes, green bananas, rice).
- Eat small frequent meals. Do regular exercise to build muscles.

## **Anaemia**

- Eat foods rich in iron e.g. meats, dark green leafy vegetables.
- Eat more raw tomato and more fruits like oranges, lemons bwemba, pine apple with a meal.
- Ensure you are treated for malaria, hook worms.
- Reduce intake of tea, coffee immediately after meal as they contain substances that inhibit iron absorption.
- Take iron supplements with advice from a health worker.

## **Oral Thrush**

- Eat soft mashed foods such as mashed potatoes, bananas, carrots or scrambled eggs, soups, porridge. Eat food at room temperature.
- Avoid hot foods.
- Avoid strong citrus fruits and juices, spicy, salty or sticky foods as these may irritate the mouth sores.
- Avoid sugary foods, they encourage yeast to grow.
- Rinse mouth with boiled warm salty water after eating to reduce irritation and to keep infected areas clean so that yeast does not grow.
- Drink plenty of fluids.
- Avoid alcohol.
- Seek medical treatment.

## **D. FOOD SAFETY AND PERSONAL HYGIENE**

### **Personal hygiene:**

- Always wash hands with clean water and soap or ashes before food preparation, eating or after the use of toilet.
- Keep your nails short and clean.
- Cover cuts/sores to prevent contamination of food during preparation.

### **Drinking water:**

- Drink water from a protected source.
- Boil drinking water for 10 minutes if the source is not protected.
- Keep drinking water in a clean and covered container.
- Do not dip hands or cups in the water where there is no cup. Use one cup to draw water from one utensil to the other.

### **Food Preparation:**

- Keep all surfaces and utensils clean.
- Use food before the sell-by-date (expiry date).
- Wash fruits and vegetables in safe running water.
- Cook foods thoroughly but do not over-cook vegetables.
- Cook animal-products like meat, fish, and eggs at a high temperature and until well done (do not under-cook).
- Eggs should be hard-boiled, do not eat eggs with runny yolks or food prepared with raw eggs.
- Do not mix fresh and cooked foods. Serve food immediately after cooking.

### **Food Storage**

- Cover and store foods away from insects and pests.
- Prevent raw meat dripping on foods. Pack meat into daily portions before freezing.
- Left-over foods should be avoided where necessary.
- Fruits and vegetables should be checked regularly.

## **E. RECOMMENDED PRACTICES FOR IMPROVING NUTRITIONAL STATUS**

- Eat variety of foods from the six food groups everyday.
- Eat foods that are not highly refined for example; eat whole wheat brown bread rather than white bread, mgaiwa other than white maize-flour.
- Eat fermented foods such as chambiko, yoghurt, thobwa.
- Eat a lot of fruits and vegetables every day.
- Eat boiled or steamed or roasted foods other than fried foods (they are more easily digested).

- Observe all the hygiene rules to avoid germs that may cause diseases e.g. prepare food in a clean environment; ensure that fruits and vegetables are washed well.
- Drink at least 2 litres of clean safe water/fluids every day.
- Do regular exercise to keep fit.
- Get treatment for any illness as soon as possible as each infection decreases your immune system.
- Eat food with less sugar added as it decreases the immune system and encourages the growth of yeast (e.g. thrush/candidiasis).
- Reduce the intake of coffee and tea as they deplete water and reduce absorption of certain nutrients e.g. iron.
- Avoid alcohol and tobacco as they suppress the immune system.
- Include foods that are rich in: selenium, vitamin A, zinc, vitamin B complex, vitamin C, folic acid, magnesium, iron, calcium, vitamin E, iodine.

## **Unit: 9      LIVING POSITIVELY WITH HIV/AIDS**

**Time allocation:    1 hour**

### **Purpose**

The unit is intended to equip the participants with knowledge, skills and attitudes in helping people infected and affected with HIV/AIDS to live positive life.

### **Learning objectives**

- Define the term positive living
- Explain factors that promote positive living
- Explain how to plan for succession and inheritance

### **Suggested teaching/learning methods**

Discussions, lecture, impromptu speech, demonstrations, experiential learning

### **Suggested teaching/learning materials**

Posters of food items and a model of will

### **A. Living positively**

Positive living means accepting ones HIV positive status, taking care of oneself in the best way possible in order to prolong and improve one's quality of life. It also involves making efforts to be productive in spite of HIV infection or terminal illness.

### **B.      Factors that promote positive living**

- Proper nutrition – food to be nutritious, adequate and properly prepared
- Good hygiene and sanitation
  - Personal hygiene – bathing, care of clothes, beddings and hand washing practice
  - Environmental hygiene care of surroundings, good ventilation, proper waste disposal, safe drinking water and availability of a pit latrine
- Physical fitness which includes adequate rest, doing exercises, avoid smoking and beer drinking and seeking early medical care whenever necessary.
- Avoiding sexually transmitted infections through abstinence, being faithful to each other and proper use and disposal of condoms.
- Psychosocial support e.g. counselling assists the HIV/AIDS patient to do the following:
  - To accept their HIV sero status or chronic illness
  - Live positively with HIV/AIDS
  - Cope with discrimination and stigma

- Cope with loss and grief

### **C. Planning for succession and inheritance**

Planning for the future is important for every individual, including people living with HIV/AIDS and the chronically ill. Therefore, chronically ill and HIV/AIDS patients should be encouraged/assisted to seek information about and prepare a succession plan through writing a will or a memory book. (see appendix I). They should write a will in the presence of a lawyer, church or community leader or a significant person.

## **UNIT 10      REFERRAL OF PATIENTS IN CHBC**

**Time allocation:**    1 hour

### **Purpose**

To assist participants acquire knowledge and skills in networking, discharge planning and referral in order effectively meet the needs of people living with HIV and AIDS.

### **Specific objectives**

By the end of the session participants should be able to:

- Define networking and referral
- Explain the need for effective multi-sectoral approach in CHBC.
- List existing services to which people living with HIV and AIDS can be referred.
- Identify when it is appropriate to refer.
- Develop a framework for effective referral.

### **A. Definition**

#### **Networking**

Net working is the sharing of experiences amongst individuals, groups, organisations with a common goal/same interest in improving quality of care of HIV/AIDS patients/clients and families. It involves the establishment of a clear mechanism of communication

#### **Referral**

Referral is the process of transferring a sick person from one care provider to another, e.g. home to health facility or from health facility to an organized body in a community, such as a home-based care group.

Referral is sometimes carried out within health sectors, that is, by means of transferring a person from one health institution to another or within a hospital environment, e.g. referral from health clinic to health centre or hospital, or referral from an outpatient department to laboratory.

### **B. Multi-sectoral approach in CHBC**

- People living with HIV and AIDS can have a range of needs that include physical, medical, social, psychological and spiritual.
- The natural progression of HIV is such that people can live symptom-free for many years. Once HIV-positive individuals begin to develop symptoms, they can remain health and active for along time with effective care and support.

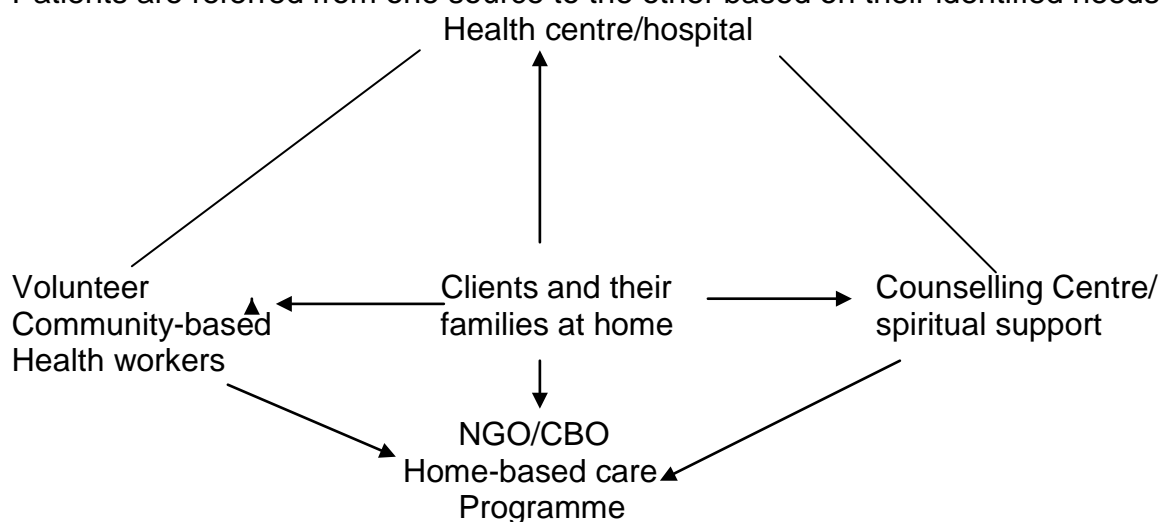
- Over the many years that people can live with HIV and AIDS, they and their families will need to access support from a range of agencies. E.g.
  - counselling services,
  - health services,
  - religious organizations,
  - NGOs,
  - Schools.

This implies that a multi-sectoral approach is needed and that links between organizations in different sectors need to be developed and strengthened.

- Health care workers should assess the needs of individual clients and their families and plan care appropriately.
- They should teach caregivers how to recognise signs and symptoms of sickness so that referral can be made quickly to a professional health care provider when necessary.
- To ensure quality and continuity of care, there should be effective communications and clear lines of referral between the client, their family, volunteer/professional carers and agencies from other sectors.

### Circle of referral

Patients are referred from one source to the other based on their identified needs.



### C. Community referral

#### Community resources for referral

Many resources are available in the community for the purpose of referral such as:

- Hospitals
- Health centres/clinics
- Private clinics
- Religious organisations
- Community based organisations



## **D. Key- elements of effective referral mechanisms**

### **When to refer**

While many common complaints can be managed well at home, it is important for care providers to know when a client should be referred to a health care facility.

#### **Prompt referral should be made when a client has:**

- Thrush in the food pipe,
- Severe dehydration.
- A high or recurrent fever.
- A persistent cough.
- Persistent diarrhoea (one week or more).
- Confusion.
- Several vomiting.

#### **Note:**

For other conditions requiring referral refer to the topic on management of HIV/AIDS related conditions

### **How to refer a patient**

- A person in out patient department (OPD) is advised either to return to OPD or to the nearest health facility for follow-up care
- During hospital discharge, a referral form is filled and given to the patient to take it home to e.g. the person's health facility, TBA, CHBC provider and traditional healer
- The CHBC provider fills a form (refer to Appendix) and the patient/client takes it to the nearest referred health facility

#### **Basic elements of a good referral:**

- Clear, specific and up-to-date information.
- Confidentiality.
- Multi-sectoral approach.
- Present different options to allow individuals to choose.
- Clear communication between the voluntary counselling and testing centre and referral services.
- Non-discriminatory actions followed by service provider.
- Documentation of referral.
- Follow-up.

## UNIT 11 CARE FOR CHBC CARERS

**Time allocation:** 1 hour

### **Purpose:**

This unit highlights the need to take care of care providers who have a responsibility of caring for the sick and vulnerable persons.

### **Learning objectives**

By the end of this unit, participants should be able to

- Identify a carer
- Identify signs of stress and burnout syndrome in a carer
- Describe challenges encountered by carers
- Explain strategies of managing challenges encountered by carers

### **Suggested teaching/learning methods**

Lecture, discussions, role plays, experiential learning

### **Suggested teaching/learning materials**

chalk and chalkboard, transparencies and overhead projector, markers

#### **A. Identification of carers**

A carer, also referred to a care provider, is an individual involved in provision of care to clients/patients.

A carer can either operate at primary or secondary level:

- *Primary level* – those involved in direct provision of care eg members of the family
- *Secondary level* – CHBC providers and health care workers other than the family. These include volunteers, clinical staff at health facilities and community members.

The concept of caring for carers mostly deals with burn out syndrome among care providers

#### **Possible carers**

- 
- Family members
- Volunteers
- Traditional birth attendants (TBAs)
- Traditional healers
- Health workers e.g. nurses and clinicians

- Community based organisations (religious, social, non-governmental organisation)
- Policy based organisations e.g. government line ministries and NGOs

## **B. Signs of stress and burn out syndrome in a carer**

Stress among carers in HIV/AIDS programmes manifest itself in a wide range of signs and symptoms which can be, psychological, behavioural and physical.

These include:

- loss of interest to work
- loss of commitment to achieve positive results
- loss of punctuality and neglect of duties
- feelings of inadequacy, helplessness and guilt
- loss of confidence and self esteem
- tendency to withdraw both from client/patients and colleagues
- loss of quality in performance of work
- irritability
- difficult in getting on with other people
- tearfulness
- loss of concentration
- sleeplessness
- excessive fatigue
- depression
- bowel disturbance
- the carer may show signs of going through the grieving process
- resignation
  - the carer stops doing some activities which he/she is supposed to do
  - if the stress continues, the carer stops caring about important activities in his/her work
  - if no intervention is made the carer stops working

## **C. Problems encountered by carers**

- inadequate resources e.g. personnel and materials
- heavy workloads leading to pressure of work
- lack of recognition and incentives by employees/communities
- personal identification with the suffering of the chronically ill
- inadequate skills and preparation for their work
- inadequate supervision of their work
- family level carers may suffer from isolation, insecurity and fear for the future especially for volunteers
- effect of HIV/AIDS on personal relationships and family dynamics

## **D. Ways for managing problems encountered by carers**

Care of carers can be undertaken at different levels such as:

### ***Community level***

At community level, care of carers would be assisted through:

- community meetings
- formation of support groups/associations
  - Income generating activities
  - Information sharing and networking with other community support organisation
  - Recognition by community/public
  - Provision of incentives

### ***Work place***

- development of strategic plans for work places/organisation on care of carers
- implementation of the plans
- monitoring and evaluating the implementation

## **What care providers can do**

The care providers can report and share information with relevant authorities regarding programmes or activities within one's area.

The following may assist a carer to deal with issues of stress and burn out:

- acknowledge formally that their work is stressful and that feelings of distress are legitimate and not signs of personal weakness or lack of professionalism
- carers at all levels need to be relieved of responsibility for things they cannot help.
- knowledge is empowering, it gives people confidence, control and choice in life and has lasting value. Training including refresher courses plays a central role in managing stress and burn out among carers.
- carers at all levels must know that their work is recognised and valued.
- poverty reduction is a top priority, IGAs are much needed and valued by the carers at community level.
- to relieve anxieties of dependency and insecurity, there is need to develop and use sustainable measures or support from donors.
- Initiate peers counselling groups

## **HIV/AIDS programmes**

Stress and burn out management is a necessity and not a luxury in AIDS programmes. Effective measures to manage burnout in these programmes include:

- realistic work targets, clear job descriptions and good referral mechanism

- health care provision and paid sick leave
- team work and regular meetings to discuss issues and share problems
- appointment of carer counsellors
- effective voice for carers in decisions that affect them
- regular retreats for carers
- disposal of emotional burden by assigning different people to deal with emotionally taxing tasks
- government to look carefully at how existing laws and policies affect the operation of AIDS care programmes, and how they might be modified to make the work of carers easier and more secure. Signs of burn out should never be neglected, suppressed or allowed to accumulate. Burn out should be managed as soon as signs occur.

## **Appendix 1: Sample training schedule**

### **Day 1:**

07:00 – 08:00	:	Arrival of participants at the workshop venue
08:00 – 09:00	:	Registration of workshop participants
		Administrative announcements
		Workshop objectives and modalities
09:00 – 10:00	:	Pre test
10:00 – 12:00	:	Climate setting
	:	Basic facts and information about HIV/AIDS
	:	Prevalence of HIV/AIDS in Malawi
12:00 – 01:00		Lunch break
01:00 – 02:00	:	The concept of community home based care
02:00 – 03:00	:	Communication
03:00 – 03:30	:	Refreshments
03:30 – 04:00	:	Basic CHBC skills
04:00 – 05:00	:	Basic CHBC skills
05:00 – 05:30	:	Facilitators meeting

### **Day 2:**

07:00 – 08:00	:	CHBC skills practicals
08:00 – 09:00	:	Infection Prevention and Control
09:00 – 10:00	:	Managing HIV/AIDS related problems
10:00 – 10:30	:	Refreshments
10:30 – 12:00	:	Managing HIV/AIDS related problems
12:00 – 01:00	:	Lunch break
01:00 – 02:00	:	Managing HIV/AIDS related problems
02:00 – 03:30	:	Management of HIV/AIDS related problems
03:30 – 04:00	:	Refreshments
04:00 – 05:00	:	Nutrition for patients and PLWA
05:00 – 05:30	:	Facilitators meeting

### **Day 3:**

07:00 – 08:00	:	Nutrition for patients and PLWA
08:00 – 09:00	:	Living positively
09:00 – 10:00	:	Care of carers
10:00 – 10:30	:	Refreshments

10:30 – 12:00	:	Referral of CHBC Patients
12:00 – 01:00	:	Lunch break
01:00 – 02:00	:	Post Test
02:00 – 03:00	:	Refreshments
03:00 – 03:30	:	Training Evaluation
03:30 – 04:30	:	Closing Ceremony
04.30 – 05.30	:	Facilitators meeting

## Appendix 2: CHBC PROVIDERS TRAINING REGISTRATION FORM

[illegible]



### Appendix 3: Pre and Post Training Test for CHBC Provider

#### 1. Meanings

(a) Give the meaning of the following acronyms:

(i) HIV: \_\_\_\_\_

(ii) AIDS: \_\_\_\_\_

6 marks

(b) What do you understand by the following terms ?

(i) Fever: \_\_\_\_\_  
\_\_\_\_\_

(ii) Diarrhoea: \_\_\_\_\_  
\_\_\_\_\_

(iii) Coughing: \_\_\_\_\_  
\_\_\_\_\_

(iv) Communication: \_\_\_\_\_  
\_\_\_\_\_

(v) Community home based care  
Kit: \_\_\_\_\_

(10 marks)

2. (a) Mention Six ways in which HIV may be transmitted

(i) \_\_\_\_\_

(iv) \_\_\_\_\_

(ii) \_\_\_\_\_ (v) \_\_\_\_\_

(iii) \_\_\_\_\_

(vi) \_\_\_\_\_

(6 Marks)

(b) Six ways in which HIV is not transmitted

(i) \_\_\_\_\_ (iv) \_\_\_\_\_  
\_\_\_\_\_

(ii) \_\_\_\_\_  
\_\_\_\_\_

(v) \_\_\_\_\_  
\_\_\_\_\_

(iii) \_\_\_\_\_ (iv) \_\_\_\_\_  
\_\_\_\_\_

(6 Marks)

3. Tick ( ) in the correct box to indicate signs and symptoms of HIV/AIDS.

(a)	Skin cancer		(k)	Alcoholism	
(b)	Persistent cough		(l)	Generalized skin rash	
(c)	Scabies		(m)	Sneezing	
(d)	TB		(n)	Dry mouth	
(e)	Short temper		(o)	Chronic bilharzias	
(f)	Shingles		(p)	Headache	
(g)	Oral thrush		(q)	Unexplained loss of body weight	
(h)	Toothache		(r)	Frequent urination	
(i)	Shyness		(s)	Chronic diarrhoea	
(j)	Prolonged fever		(t)	Enlarged lymph nodes	

(20 marks)

4. (a) When was HIV/AIDS first discovered in Malawi ? (Tick ( ) your answer)

A. 1945      B. 1964      C. 1985      D. 1986      E. 1994  
(1 mark)

(b) HIV/AIDS now has a cure (Tick ( ) Your answer)

A. True      B. False      ( 1 mark)

1. What are the basic nursing care skills required in community home based care?

a. \_\_\_\_\_  
\_\_\_\_\_

b. \_\_\_\_\_  
\_\_\_\_\_

c. \_\_\_\_\_  
\_\_\_\_\_

- d. \_\_\_\_\_  
\_\_\_\_\_
- e. \_\_\_\_\_  
\_\_\_\_\_

5 marks

2. Describe 2 important points in the management of the following conditions at home.

a. Fever

d. Vomitting

e. Diarrhoea

6 marks

3. What resources can be found in your community? List 5

a. \_\_\_\_\_

b. . \_\_\_\_\_

c. \_\_\_\_\_

d. \_\_\_\_\_

e.

5 marks

4. Give five examples of positive living

a. \_\_\_\_\_  
\_\_\_\_\_

b. \_\_\_\_\_  
\_\_\_\_\_

c. \_\_\_\_\_  
\_\_\_\_\_

d. \_\_\_\_\_  
\_\_\_\_\_

e. \_\_\_\_\_  
\_\_\_\_\_

5 marks

5. What education would you give to a family on how to handle body fluids for an HIV positive patient?

a. \_\_\_\_\_  
\_\_\_\_\_

- b. \_\_\_\_\_  
\_\_\_\_\_
- c. \_\_\_\_\_  
\_\_\_\_\_
- d. \_\_\_\_\_  
\_\_\_\_\_
- e. \_\_\_\_\_  
\_\_\_\_\_
- f. \_\_\_\_\_  
\_\_\_\_\_

5 marks

## Appendix 4: PRE AND POST TEST ANSWER GUIDE

### 1. Meaning of terms

- i. **HIV** : Immuno deficiency virus
- ii **AIDS** : Acquired immuno deficiency syndrome
- iii **Fever** is when a person's body temperature is higher than the body normal temperature
- iv **Diarrhoea** is passing of loose stools three or more times a day.

**Coughing** is one way of helping to clear the throat

vi **Communication**: a process through which messages are transmitted from one person to another.

vii **Community home based care kit**: contains drugs and supplies designed to support the needs of the chronically ill patient in the community

### 2. a. **Six way in which HIV can be transmitted**

- Unprotected sexual intercourse with an infection person
- Contact with infected blood & blood products
- Infected mother to child during pregnancy, birth and breastfeeding

### **B Six ways in which HIV cannot be transmitted**

- Being bitten y mosquito
- Using the same eating utensils
- Sharing toilets
- Playing with an infected person
- Chatting with an infected person
- Shaking hands

### 3. **Signs and symptoms of HIV**

- Skin cancer
- Persistent cough
- TB
- Shingles

- Oral thrush
- Prolonged fever
- Generalised skin rash
- Unexplained loss of body weight
- Chronic diarrhoea
- Enlarged lymphs

4. a. 1985                      b False

**5. Basic nursing skills are:**

- Assisting the patient with a bath
- Assisting the patient with mouth Care
- Pressure area care
- Assisting the patient with feeding patient
- Wound care

**6. Important points in management of :**

**Fever:**

- a. remove unnecessary clothing blankets
- b. drink plenty of fluids like water, juices

**Chronic pain**

- a. Take a warm bath
- b. Change positions in bed or move about frequently

**Skin rash**

- a. Keep skin clean and dry all the time
- b. Apply prescribed skin lotion eg calamine or whitefield ointment

**Vomitting**

- a. Advise patient to wash mouth and suck lemon

- b. Assist patient to take to take small frequent meals
- c. Watch for signs of dehydration

### **Diarrhoea**

- a. Keep patient clean, dry and comfortable
- b. Prepare ORS and give patient a cupfull after each loose stool

### **7. Drugs and supplies in the CHBC kit:**

- a. Panadol
- b. Fansidar
- c. Cotton wool
- d. Plaster

### **8. Examples of positive living**

- a. Good nutrition
- b. Exercises
- c. Follow up with care
- d. Adherence to drugs
- e. Seeking medical attention when sick

### **9. Benefits of CHBC**

- a. Allows patient to be cared for by members of the family and community within his or her own environment
- b. Reduces overcrowding in hospitals
- c. Reduces expenses in travelling

### **10. Education given to families pertaining to handling of body fluid for an HIV positive patient includes:**

- a. Wear gloves before touching body fluids
- b. Wash hands after touching body fluids and contaminated items
- c. Safely dispose off infectious materials
- d. Decontaminate soiled linen

## Appendix 5: Training evaluation questionnaire

### Question 1

You are required to give your opinion of the relevance or importance of the following topics by ticking in the appropriate column.

	<b>A Relevant</b>	<b>B Not relevant</b>
a. Basic facts and information about HIV/AIDS		
b. Prevalence of HIV/AIDS in Malawi		
c. The Concept of CHBC		
d. Human rights and community home based care		
e. Gender and CHBC		
f. Communication		
g. Counselling		
h. Basic community home based care skills		
i. Infection Prevention and Control		
j. Managing HIV/AIDS related problems		
k. HIV/AIDS in pregnancy		
l. Antiretro viral Therapy		
m. Care of children affected & suspected of HIV/AIDS		
n. Nutrition & Living positively with HIV/AIDS		
o. Sexual health		
p. Conflict Management		
q. Discharge planning and referral system		
r. Palliative care		
s. Care for carers		

2. Using the letter (a) to (s) for the topics above, give your own assessment of how you generally understand these topics by writing the numbers of the relevant topic from the table in question 1 on the appropriate space below. (e.g. d = human rights and CHBC) which you generally found most interesting.

- (i) \_\_\_\_\_ (ii) \_\_\_\_\_  
 (iii) \_\_\_\_\_ (iv) \_\_\_\_\_  
 (v) \_\_\_\_\_



B. Five topics which you generally found fairly interesting.

- (i) \_\_\_\_\_ (ii) \_\_\_\_\_  
 (iii) \_\_\_\_\_ (iv) \_\_\_\_\_  
 (v) \_\_\_\_\_

C. Five topics which you generally found not interesting

- (i) \_\_\_\_\_ (ii) \_\_\_\_\_  
 (iii) \_\_\_\_\_ (iv) \_\_\_\_\_  
 (v) \_\_\_\_\_

D. Which topics would you like to be repeated?

- (i) \_\_\_\_\_ (ii) \_\_\_\_\_  
 (iii) \_\_\_\_\_ (iv) \_\_\_\_\_  
 (v) \_\_\_\_\_

3. For each statement below tick the answer which best describes how you feel about this training. Give your reasons by making brief comments in the space provided. If you have more to say please use the spare sheet of paper which you have been given:

Statement				Reason in brief
	Yes	No	Not sure	
1. The general objectives of the workshop were clear				
2. The specific objectives of the topics/units were clear				
3. The teaching/learning materials used were relevant and useful				
4. The length of the workshop was enough to cover the number of topics/units.				
5. The presentation and explanation of the information and skills by the facilitators were generally good.				
6. The facilitators were very helpful				

7. The methodology used by the facilitators was suitable for adult learners.				
8. The arrangements made for the workshop were good (transport, meals, practical works, timetable, accommodation, health issues, etc)				
9. This workshop was participatory, involving the participants adequately				

3. Comments

4. \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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