



UNIVERSITY OF MALAWI

KAMUZU COLLEGE OF NURSING

**KNOWLEDGE, PRACTICES AND PERCEPTIONS OF CAREGIVERS OF
CLIENTS DIAGNOSED WITH HIV/AIDS ON HOME BASED CARE.**

**A RESEARCH DISSERTATION SUBMITTED TO THE FACULTY ON
NURSING IN PARTIAL FULFILMENT OF THE AWARD OF THE BACHELOR
OF SCIENCE IN NURSING.**

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DECLARATION

I Mercy Kulanga declare that this document is the product of my own, except where otherwise quoted and it has not been submitted nor presented for any other degree.

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4th December, 09

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DEDICATION

I dedicate this research work to my mother and my late father for the motivation that success comes with hard work, I don't take it for granted but I realize what you meant.

ACKNOWLEDGEMENTS

My sincere thanks goes to the God Almighty for the life and my success without him all things are impossible, may his name be glorified.

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May the good lord bless you all.

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ACRONYMS

AIDS	Acquired Immune deficiency Syndrome
CBO	Community Based Organization
CCG	Community care giver
CHBC	Community Home Based Care
DHO	District health Officer
FBO	Faith Based Organization
FCG	Friend / family care giver
GF	Global fund
HIV	Human Immunodeficiency Syndrome
HBC	Home based Care
IMR	Infant Mortality Rate
MMR	Maternal Mortality Rate
MDHS	Malawi Demographic Health Survey
MOH	Ministry of Health
NAC	National AIDS Commission
NGO	Non Governmental Organization
PMTCT	Prevention of Mother to Child Transmission
UNAIDS	United Nations Agency for AIDS
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

ABSTRACT

This descriptive qualitative research was conducted to establish and determine the knowledge, attitudes and perceptions of caregivers with clients diagnosed of HIV and AIDS on home based care. The prevalence of HIV infections are increasing world wide and Literature shows that 2.2 million people were living with the virus at the end of 2007 and 1.9 million individuals are being infected every year. In the health sector this has contributed to congestion in hospitals, premature discharges, poor quality of care and inadequate resources. These are not conducive to speedy recovery and in view of these mentioned issues the government has extended care giving in the community where caregivers take lead, therefore the need for conducting the study.

Theory of reasoned action by Ajzen and Fishbein was the theoretical framework that was used to guide the study. It takes into account that caregivers behavior is determined by their behavioral intention to perform it and the intention is determined by the persons attitude and subjective norms to perform the behavior. It is an essential tool for determining people's attitude and practices towards patients with HIV and AIDS.

Data was collected using a structured interview guide and convenient sampling was used. The guide was interpreted in local language for proper communication. Data was analyzed manually and results were presented using bar graphs and pie charts.

The results of the study have shown that the care givers are meeting with problems that are influencing care giving in area 25 Home Based Care where the study was done. These problems include: social economic, psychological and physical problems. It is quite clear that these caregivers need more assistance and trainings to update their knowledge.

The results of the study may be included to nursing education curriculum so as to equip nursing students with care givers knowledge, perceptions and practices towards patients with HIV and AIDS on home based care. Government can benefit from these results by adopting the recommendations hence improving caregiver's knowledge, practices and perceptions hence promoting health of the nation.

CHAPTER ONE: INTRODUCTION

Malawi has one of the highest HIV and AIDS prevalence in the world. The national prevalence rate of 16.4% is higher than the average adult prevalence rate of 8.4%. For the rest of sub-Saharan Africa prevalence rate is higher in urban areas at 23% than in rural areas at 12.4%. The problem is concentrated in the 15-49 year age group. There are approximately 900,000 Malawians infected and approximately 500,000 people have died since the start of the epidemic in 1985 (National Aids Commission (NAC) 2004:7).

The impact of the epidemic has been felt at all levels and all sectors of the Malawi society. Socio economic and health impacts are striking for example in the health sector, Maternal Mortality Rate (MMR) has doubled since ten years ago from 620 to 1120 maternal deaths per 100,000 live births. Furthermore, people suffering from HIV and AIDS related illnesses occupy more than 50% of medical ward beds and more than 70% of patients with pulmonary Tuberculosis also have the infection (Malawi Demographic Health Survey (MDHS) 2000:50), hence the need for home based care.

In sub Saharan Africa, there were 26-28.2% million people living with HIV and AIDS in 2003. Of these 2.0-2.4 million people were newly infected. Prevalence rate was 7.9%-8.6%. Adult and children deaths due to AIDS were between 2.2-2.4 million people (www.who.int/1/103/2004). These figures indicate that the sub-Saharan Africa has the highest HIV prevalence rate in the world in proportion to the global HIV /AIDS statistics.

Current information shows that the Sub Saharan Africa is more heavily affected by the HIV /AIDS than any other region of the world. An estimated 2.2 million people were living with HIV and AIDS by the end of 2007 and approximately 1.9 million additional people were infected with the HIV during that year. It has claimed the lives of an estimated 1.5 million people in the region; more than eleven million people have been orphaned by AIDS.

1.1 BACKGROUND

Malawi is one of the poorest countries in the world with more than 65% of the people living below the poverty line (vision 20:20 for the health sector 1999:11). Poverty levels are overwhelming and the majority of Malawians fail to manage their economic affairs. The burden that HIV and AIDS have exerted on families is enormous. Households are struggling to manage patients for their basic needs like food, clothing, soap, transport and shelter. The report on the national Health accounts highlight that 2% of the total health costs in the sector are from out of pocket expenditures. This implies that communities support their sick by purchasing medications from drug stores, traditional healers, Traditional Birth Attendants (TBAs) and even vendors. Thus the poorest of all households spend between 7.4% and 10% of their annual consumption of health care. Due to this factor, the majority Malawians avoid to hospitals as it is considered expensive, moreover the coverage and quality of health services have been adversely affected by severe shortages of staff at facility level. It is estimated that the vacancies on established posts are up to 50% at some institutions (National Health Plan 2000-2004:33-54) this explicitly raises issues of affordability and accessibility. In view of this Home Based Care (HBC) remains the best option for HIV and AIDS patients as well as the government.

According to the United Nations Agency for AIDS (UNAIDS, 2003), The Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) has become a worldwide epidemic. Globally HIV and AIDS killed more than Three million people in 2003 and estimated Five million acquired the Immunodeficiency Virus (HIV) bringing to over Forty Million the number of people living with the virus around the world. (AIDS Epidemic Update 2003).

The latest statistics on the world epidemic of AIDS and HIV were published by UNAIDS/WHO in July 2008. The estimates shows that Thirty three million people were living with HIV /AIDS in 2007 of which more than twenty five million people have died of AIDS since 1981. At the end of 2007, women accounted for 59% of all adults living with HIV world wide and 50% in Sub-Saharan Africa. Young people less than 25 years old account half of all new HIV infections Worldwide. In developing and transitional countries 9.7 million people are

in immediate need of life saving AIDS drugs. Of those, only 2.99 (31%) are receiving the drugs.

With the increasing levels of chronic illness due to immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) most AIDS care occurs in the home. Ordinarily women and girls are the ones who care for the sick in the home. Caring for people suffering from AIDS poses enormous challenges for these care givers. Some of the challenges include meeting the basic needs like food and medicine for those who are critically ill. Consequently the care givers become vulnerable to psychological stress.

1.2 PROBLEM STATEMENT

Statistics on the prevalence of HIV infections and Aids are increasing worldwide. The sub Saharan Africa has the highest incidence of about 2.2 million people are living with the virus at the end of 2007 and approximately 1.9 million people were infected with the HIV during the year. In the health sector, the pandemic has contributed to the following: congestion, premature discharges, poor quality of care and inadequate resources. These are not conducive to speedy recovery. In view of the above mentioned issues, government has advocated for extending care giving in community settings where caregivers take lead. Practical experience has shown the roles and functions of these caregivers to have psychological and sociological impact on them because of the severity of illness. This is aggravated by the fact that these caregivers are lay people. Therefore the need to provide the care givers with emotional(Psychological), educational support can not be overlooked or underestimated therefore the need to conduct the study to explore on the type of knowledge, perceptions and practices.

To contribute to this end, limited research has been done to assess the needs of caregivers and develop supportive programmes. It is ironic that the care givers who are giving care to these patients are sidelined.

1.3 SIGNIFICANCE OF STUDY

The findings of this study will provide nurses, other health care providers and other policy makers with information to develop HIV/AIDS education messages for family members caring for people living with AIDS. The findings will also provide

information to the family members to improve their attitudes towards people living with AIDS. Furthermore the findings will be used to influence the National AIDS Control Programme to formulate AIDS control, feasible and sound home based care policies.

Currently the government of Malawi is facing a major problem of shortage of staff, increased workload and inadequate resources. This has been made worse with the influx of AIDS patients. However if primary caregivers have adequate knowledge, it is hoped that will reduce the hospital workload as a result of minimal unnecessary readmissions of HIV/AIDS patients. Lastly the findings will identify gaps and elicit the need for further research.

1.4 BROAD OBJECTIVE/ PURPOSE OF RESEARCH

To determine knowledge, perceptions and practices of care givers of clients diagnosed with HIV and AIDS on home based care in Area 25 home based care setting.

1.5 SPECIFIC OBJECTIVES

The objectives of the study are to:

1. Assess the caregiver's knowledge on transmission and prevention of HIV and AIDS and home based care.
2. Identify caregivers perceptions and practices on patients who are on home based care
3. Describe the support caregivers with patients on Home Based Care receive in the community and from health workers
4. Explore the challenges care givers face in caring patients on home based care as a result of HIV and AIDS.

1.6 DEFINITIONS OF TERMS

PERCEPTIONS

Process/processes by which organisms interpret and organize sensations to produce meaningful experience of the world.

PREVALENCE

The number of cases or events or conditions in a given population at a particular point in time

CLINIC/HEALTH CLINIC

A place where western/ modern health care services are provided.

COMPLIANCE/ADHERENCE

This is a term that describes the primary caregiver's behavior that concedes with the health advice given.

HOME BAESD CARE

This is the provision of needed health services by a primary caregiver to a patient or families at home.

HOME BASED CARE CENTRE

This is the centre that is located within the community where HBC staffs assist with home based care services.

KNOWLEDGE AND PRACTICE

Information, understanding, skills the primary care givers have acquired.

ORPHAN

A child who has lost one or both parents

PRIMARY CARE GIVER

This is an informal caregiver that may be the biological mother, father, grandparent, friends and foster or adoptive parents who provide most of the care to the HIV and AIDS patient at home.

PATIENT

A person who is sick and has been diagnosed with Human Immune Deficiency Virus following reliable screening test.

AIDS (Acquired Immune Deficiency Syndrome)

It is a condition where by a person's immune system has been deteriorated so much that he or she starts becoming ill with life threatening illnesses.

1.7 SUMMARY

This chapter has looked at the background of the study, problem statement, and purpose of study, significance and objectives of the study. The terms relevant to this study have been defined. The next chapter will describe the literature review.

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter will outline the background against which the study will be conducted. The study will focus on the knowledge, perceptions and practices and challenges that caregivers encounter as they care for their patients in their homes. The study shall also look into the support provided to caregivers with HIV and AIDS patients on home based care. The need for support will be reviewed in the context of managing Human Immune Deficiency Syndrome in the home environment. In order to clearly understand the project literature review has also covered home based care, Human Immunodeficiency virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) as well as studies done worldwide since the issues are inherently connected.

2.2 .RELATED STUDIES ON HOME BASED CARE AND HIV/AIDS WORLD WIDE

Statistic presented earlier demonstrate that countries in the sub-Saharan Africa have high rates of HIV and AIDS and Malawi is no exception. The epidemic continues to have profound impact on that health care delivery system as well as on patients. There is congestion, shortage of qualified personnel and increasing costs on health care. Consequently, communities and households have become responsible for most of the burdens created by AIDS and caregivers as they care for their patients in their homes. Studies have been done on the knowledge, perceptions and practices of home based for HIV/AIDS patients by their caregivers.

One study was conducted by Tibebu, Marriam and Balachew- Jima town from June – August 2005 to determine the level of knowledge, attitude and practices of caregivers regarding home based care for people living with HIV and AIDS in Ethiopia- one of the largest HIV infected population in the world. This was a cross sectional community based study conducted among 274 family caregivers regarding home based care for people living with HIV and AIDS. The class revealed that over $\frac{3}{4}$ of the studied subjects (91% were knowledgeable about home based care and 88.7% showed favorable attitude. 92.8% agreed that home is the better place for the care of people living with AIDS than the hospital.

Single caregivers were about four times more likely to be knowledgeable about home care as compared to their counterparts (or =3.98 (95% CI :50, 8808) but the findings were not statistically significant ($p>0.05$). Neighbors and friends were to time more likely to have favorable attitude towards HBC as compared to family members (or=1.96 (95% CI 0.74, 5.21) but the findings is not statistically significant. The study highlighted that the majority of family members / caregivers had good knowledge and attitude towards home based care and over half favored this care.

Another study on HIV and AIDS and home based care by Opiyo, Yamano , Jayne in Kasama Zambia highlighted the social economic impacts of HIV and AIDS on women . It argues that the social cultural beliefs that value the male and female lives differently lead to differential access to health care services . The position of women is exacerbated by their low financial base especially in the rural community where their main source of livelihood, agricultural production does not pay much. But even their active involvement in agricultural production or any other income ventures is hindered when they have to give care to their sick and bed ridden friends and relatives. This in itself is a threat to house food security. The paper proposes that gender sensitive policies and programming of intervention at community level would lessen the burden on women who bear brunt of AIDS as caregivers and likely-hood generators at household level. Improvement of medical facilities and quality of services at local dispensaries is seen as feasible since they are in the rural areas. Other interventions should target freeing women and girls for education and involvement in income generating ventures..

Another study about the opinion of respondents regarding provision of a group home in their neighbor-hood for the care of persons experiencing a range of medical and social conditions which include HIV and AIDS, mental handicap, previous jail term , physical disability, mental illness and drug abuse at University of Ibadan in Nigeria by oluwanuga, Lasekabikan, Gureje. A representative sample of 2040 was selected using a clustered stratified selection procedure was studied in Ogun, Oyo and Osun states.. Of the respondents 906 (144.4%) were males and

1134 (55.65%) were females. The mean age was 43.5 (19.72) over 71% of the respondents disagreed or strongly disagreed with the location of residential for people living with HIV and AIDS in their residential area. This level of rejection was only comparable to that of drug addicts and alcoholics. People with HIV and AIDS were more likely to be rejected than ex-convicts for whom about 55% expressed rejection. The results suggest a deep seated prejudice against the provision of a group home for the people living with HIV and AIDS.

Msumi Z., Lengani L (2002) conducted a study assessing on the existing procedures in community participation in home based care for chronically ill patients including HIV and AIDS in Bagamoyo District 1999. Data collection was done in Bagamoyo District through in depth interviews with respondents and discussions held with various groups where a selection of 7-10 households in each village was done and heads of the households, patients and patients attendants were interviewed. The study collected views and opinions on the situations on patient care services before the intervention of home based care and found that the communities varied in the ways in which they provided the services to chronically ill patients. On the other hand it was found that there were little or no community participation in providing services for fear of contracting the illness. The CONCLUSION was the community education on home based care will facilitate acceptance and adoption of the home based care, the community expressed fear of contracting the HIV./AIDS when caring for these patients, relatives neighbors and the local community at home can provide care for the terminally ill patients including HIV and AIDS if trained properly and impact of HBC can be improved through close collaboration with others who provide social support to patients and their families.

A study done in Durban, South Africa by Ncama on acceptance and disclosure of HIV status through an integrated community/home based care programme. The findings revealed that the community/home based care was effective in improving acceptance and disclosure of the HIV positive status by people living with HIV and AIDS in the programme. PLWHAs did not find disclosure of their HIV status difficult and disclosed it to more people than those who were not in any programme. These people not only disclosed their HIV status within their family network and households but also disclosed to the community in general, sports

groups, religious groups and other social networks. In conclusion the study revealed that community/home based care programmes can serve as a catalyst for acceptance and disclosure of a positive HIV status by PLWHAs.

Another study was done by Agbonyitor in the Plateau State, Nigeria to assess the challenges that people with HIV and AIDS in the programme face while maintaining their health and livelihoods. The frustrations that volunteers endured in performing their work as also described as the weaknesses and benefits of the programme from the perspective of people living with HIV and AIDS and their volunteer care givers. From the study the main/major challenges facing PLWHA emerged: discrimination towards PLWHAs, the lack of food, money and transport to health care centers and the desire for closer antiretroviral drug access.

A study was done in MALAWI by Masika E. (2000) on Home Based care and gender where the study attempted to give a clear picture of the current HBC practice and its efficiency in meeting the needs of the target groups. Home care puts women in extra vulnerable positions since health and care is traditionally their domain. Women not only take care of their own families but also for others in the community. The results of the study revealed that in order to improve HBC not only community involvement needs to be strengthened but also HBC needs to be linked with other forms of care in the community. This implies the need for formal and informal trainings to be more adapted to local needs customs and available resources incorporating/addressing gender issues should be a priority.

2.3 SUMMARY

This chapter looked at home based care in general and in Malawi including the benefits and the limitations. It further looked at the background information on HIV and AIDS. From the literature review above, it shows that although home based care is practiced worldwide Malawi in particular, it still poses some challenges at government and household level. Therefore governments especially in Africa including Malawi, need concerted efforts of stakeholders to support caregivers in their care giving role. The next chapter discusses the Theoretical framework.

CHAPTER THREE: THEORETICAL FRAMEWORK

3.1 THEORY OF REASONED ACTION

The conceptual framework that will be used in this study is the theory of reasoned action developed by Martin Fishbein and Icek Ajzen (Ajzen I., Fishbein 200; 665-682)

The Theory explains that a care givers behavior is determined by its behavioral intention to perform it. This intention is itself determined by the person's attitude and his subjective norms toward the behavior. The Theory deals with the relationship among beliefs, attitudes, intention and behavior. The theory assumes that changing a given practice or behavior requires changing the cognitive or mental structure that underlies the behavior. Simply put the model looks like this:

ATTITUDE >> INTENTION >> BEHAVIOUR

In this Theory caregivers attitudes toward a behavior consist of three things: The first thing is a belief that a particular behavior leads to certain outcome. A belief is defined as the person's subjective probability that performing certain behavior will produce specific results. If the outcomes seems beneficial to the individual he /she may then intend to or actually participate in a particular behavior.

On the other hand subjective norm is a care givers perception of what others around him/her believe that the individual should do and this is a type of peer pressure in its purest essence. Whether or not a caregiver participates or intends to participate in any behavior is influenced strongly by people around them which include friends , peer groups, family , co-workers , church congregation members and community leaders. A belief that women are carers or can do well in caring will change an individual's attitude towards caring and may lead them to participate in caring behaviors.

Care givers may also be inclined or not inclined to participate in a behavior based on the desire to comply with others. Laws or rules prohibiting a behavior may have an impact on ones attitudes towards participating in a behavior. Ultimately ones attitude towards a behavior can lead to an intention to act or not and this may lead to a particular behavior.

3.2 APPLICATION OF THE THEORY OF REASONED ACTION

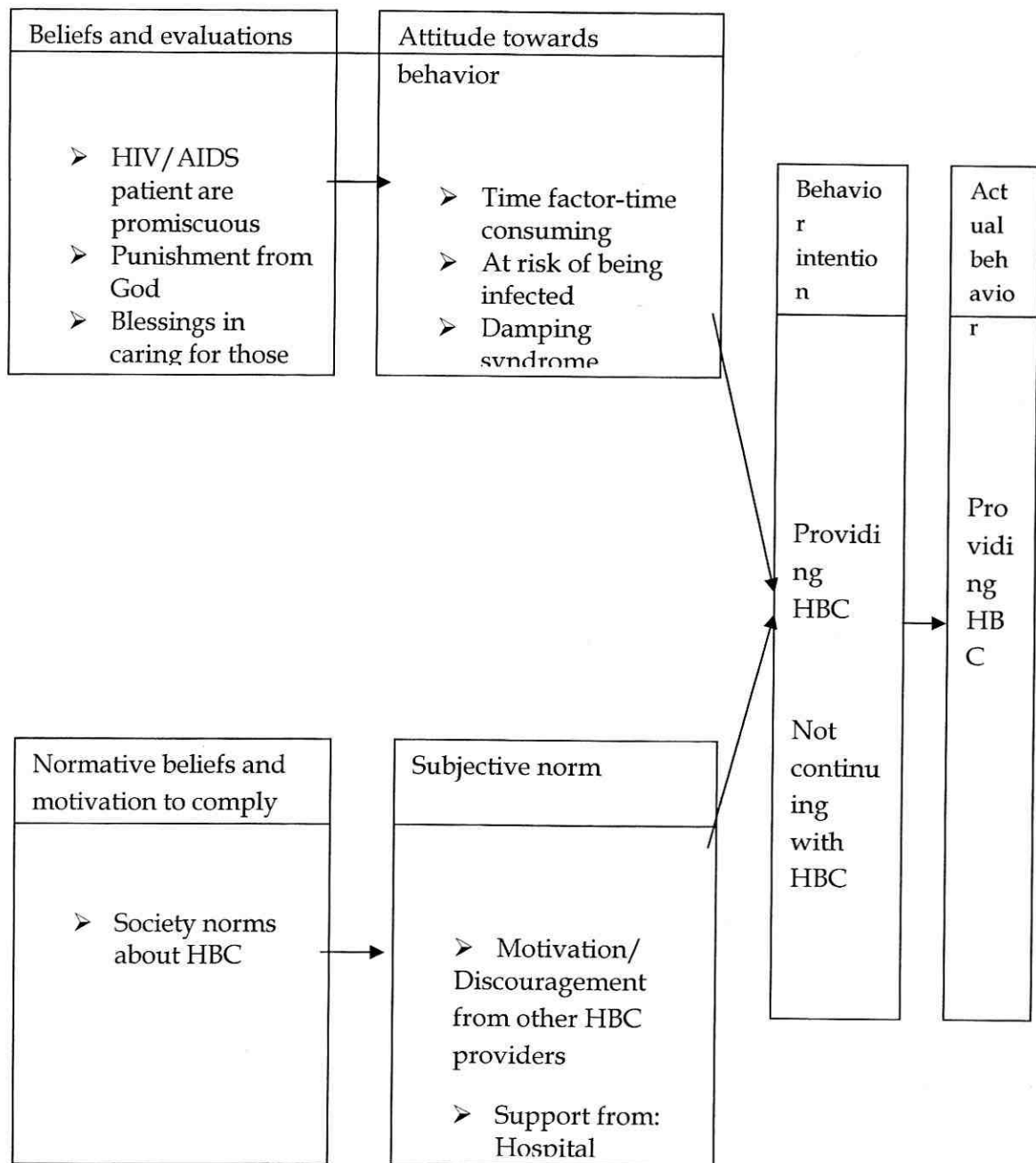
It is assumed that a care givers behavior is the result of the intention to perform the behavior which is influenced by the individuals attitudes towards the behavior and the norms associated with the behavior. This is to say if a caregiver with a patient on home based care due to HIV and AIDS has the knowledge about HIV transmission and believes that she/ he is at risk of contracting the virus as a result of being in contact with the patient's body fluids this will predict his/her behavior towards prevention. On top of that if caregivers stresses on the use of protective wear when handling body fluids this again affect the caregivers attitude towards prevention. These two combined (attitude and subjective norms) will lead the caregivers to use gloves when caring for these patients especially if they feel there is a t risk of becoming in contact with body fluids . The care giver will be very comfortable and will continue with the care because she will feel being protected hence preventing cross infection.

On the other hand if the caregiver believes that patient will benefit from home based care (nutritionally, Complying to treatment because this will be done in their usual environment he is more likely to make sure that the patient eats balanced diet , and does not miss any dosage prescribed. On top of that if the faith based organizations motivates him or her to continue with care based on commandment of love for one another he/ she is more likely to care which is the actual behavior.

On top of that if a caregiver believes that home based care is expensive and a dumping place when the health workers have failed in the hospitals he/ she is more likely to be discouraged in providing care. However if the society encourages care on people who are sick and assist this care giver by being involved in the actual care

and sometimes provision of necessary materials for example food, clothes ,
beddings and ideas on how she can find money she is more likely to give care to
the patient which will be of beneficial to the client hence quick recovery.

3.3 DIAGRAMMATIC PRESENTATION OF THE THEORY OF REASONED ACTION



Theory of reasoned action Ajzen and Fishbein 2002

CHAPTER FOUR: METHODOLOGY

4.1 INTRODUCTION

This section aims at describing the research methodology that will be used in describing knowledge, perceptions and practices of caregivers of clients diagnosed with HIV/AIDS on home based care, information on the study design and its rationale, sample type and setting, instruments developed, plan for data collection, pilot study, analysis procedures, ethical considerations and dissemination of results are part of this section.

4.2 RESEARCH DESIGN

The study design of this study was descriptive qualitative type which was done to describe the knowledge, practices and perceptions of caregivers of clients diagnosed with HIV and AIDS on home based care. Since nursing is both a science and an art use of qualitative studies combines the scientific and artistic natures of nursing to enhance the understanding of the human health experience. According to Boyd (2003) qualitative study is a term encompassing a variety of Philosophical underpinnings and research methods. One to one interviews are the most commonly form of data collection involving conversation with a range from formal to informal. Unlike the other conversations they are set up to elicit information from one side only. Therefore an asymmetrical relationship exists. AS defined by Groove and Burns (2003, P.356) qualitative research is a systematic interactive and subjective approach used to describe the experiences and give them meaning and according to Haber and Wood (2002, P. 126) states that qualitative research also refers to the naturalistic research in which the researcher goes to the natural setting where phenomenon being studied takes place.

Descriptive qualitative studies aims at discovering important characteristics of persons, situations, groups and frequency in which they occur. Approach focus on meanings and interpretations of participants feelings about particular experiences. It involves use of broadly stated questions about human experiences and realities are studied through sustained contact with people in their environment generating rich descriptive data that helps us to understand experiences and used when little is

known about the domain (Haber and Wood , 2002, P.127). Since this study aimed at describing knowledge, perceptions and practices of caregivers of clients diagnosed with HIV/AIDS on home based care , qualitative study design was used. This Descriptive study used both open ended questions that gave an opportunity to the participant to express themselves about feelings hence appropriate to explore /describe knowledge , perceptions and practices of caregivers of clients diagnosed with HIV /AIDS on home based care.

4.3 POPULATION

A population is the entire aggregation of cases that meet specified criteria (Polit and Beck, 2006,P.259) or it refers to all the individuals or objects with common defining characteristics (Polit and Beck, 2006, P.56). The population consisted of primary caregivers of clients diagnosed of HIV and AIDS on home based care between 15-65 years regardless of gender.

4.4 SETTING

This is a physical location and conditions in which data collection takes place in the study (Polit and Beck , 2006). Qualitative researcher's engage in field work in natural settings because they are interested in the contexts of people's lives and experiences. The study was to be conducted at Likuni Home Based Care area in Lilongwe District of Malawi but due to difficulties to get the participants the study was conducted at area 25 home based care because the area had more care givers than Likuni Home Based Care hence a change in terms of setting.

4.5 SAMPLING/SAMPLE

Sampling refers to the process of selecting the sample from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest(Brink,2003,p.133). According to Polit et al 2004, sampling is the process of selecting a portion of the population to represent the entire population. The convenient sampling of 10 caregivers was used. According to Polit and Hungler 2004: convenient sampling entails the use of most conveniently available people or

objects for use as subjects in the study. This meant that any caregiver who was accessible was eligible for selection until the sample size was adequate.

4.6 PILOT STUDY /PRE-TESTING

According to Brink 2003 a pilot study is a small scale version or trial run done on a limited number of subjects from the same population intended for the eventual project. The purpose was to investigate the feasibility of the proposed study and to detect possible flaws in the data collection instruments. The pre testing was done to investigate the feasibility and validity of the interview guide and it was to be done at Matawale catchment area, Zomba District but failed due to late responses from the home based care to authorize me to do the study as a result the pilot study was conducted at the same center where research was conducted (AREA 25 HOME BASED CARE CENTRE).

4.7 INSTRUMENTATION

A structured interview guide/schedule was developed by the researcher which acted as a tool for gathering data from the recruited participants. This interview guide consisted of both open and close ended questions which gave the respondents an opportunity to express their views. Whereas the close ended questions invited respondents to select from a pre-designed categories of responses. The interviews were in local language (Chichewa) after translating the questions to allow effective communication. The interview guide consisted of knowledge of these caregivers on HIV and Home based care, their perceptions as well as challenges they meet as they care for their patients (Refer to appendix A).

4.8 DATA COLLECTION

Data collection is defined as the precise systematic gathering of information relevant to the research purpose or the specific objectives, questions and hypothesis of the study (Burns et al 2001p.794).According to Polit and Beck(2006) it is the process of gathering information to address a research problem. Data was collected through a semi structured interview guide. The use of an interview guide ensured that respondents were not restricted in all the issues discussed and each participant was taking 15-25 minutes to be interviewed and the researcher was recording the responses from the caregivers . The interviews were in local language after translating

the guide to Chichewa since the participants were of different educational levels. This allowed the researcher to be in a position to correct misinterpretations and determine the clarity of the questions.

4.9 DATA ANALYSIS

This is a systematic organization and synthesis of research data and in most Qualitative studies the testing of research hypothesis using those data (Polit 2006). Data was analyzed using content analysis which is analysis by topic. First the interview were transcribed and then categorized according to topics or themes that were identified during the data analysis process and these categories were described. Then some concepts that were central to the research were tabulated and descriptive statistics were used to analyze the number of times these concepts were discussed in the interviews. This shows that data was analyzed manually. Different tables, bars graphs and pie charts were used. This helped to draw up the conclusion of the study.

4.10 ETHICAL CONSIDERATIONS

The subjects in this study were caregivers who had their own rights. Therefore the researcher sought permission from the Committee for Research Kamuzu College of nursing, Likuni Home Based Care Centre and respondents before the interviews. The primary caregivers were requested to sign a consent form to show their willingness to give out the information. They were also assured of absolute confidentiality and respect of information they gave. The participants were also told that they had the right to withdraw at any time without punishment followed. Before the process of data collection, an explanation about the purpose, and the significance of study were provided to the participants to get consent before they participated in the study and this ensured self determination in the participation. No names were used on the data collection tools instead codes were used to ensure anonymity of the subjects. The results of this study would be kept in confidence only the responsible institutions will have access to the results. Consent to conduct the study at Area 25 Home Based Care was through phone from the Director responsible for home based care Mrs Moyo. Letters seeking permission to conduct a study were written to the relevant authorities. (Appendices B-F (ii))

4.11 LIMITATIONS OF THE STUDY

The selection of the District for study limited the generalizability of the findings because the district has been chosen based on non probability sampling. In addition the sample size was small only 10 subjects participated in the study. In view of this, the responses did not represent the views of all caregivers of HIV and AIDS patients on Home Based care in Lilongwe District, for this reason the results can not be generalized.

4.12 DISSEMINATION OF RESULTS.

The findings of the research study will be communicated through a written report. Copies of the research will be available at Kamuzu College of Nursing Library for other students to broaden their knowledge, Likuni Home Based care and Area 25 home based care centre where the research was done.

4.13 SUMMARY

This chapter has described the methodology of the study which includes: the study design, setting, population, Ethical considerations, an instrument that was used, limitations of the study and Dissemination of results. The next chapter is the presentation of the study findings.

CHAPTER FIVE: PRESENTATION OF FINDINGS

5.1 INTRODUCTION

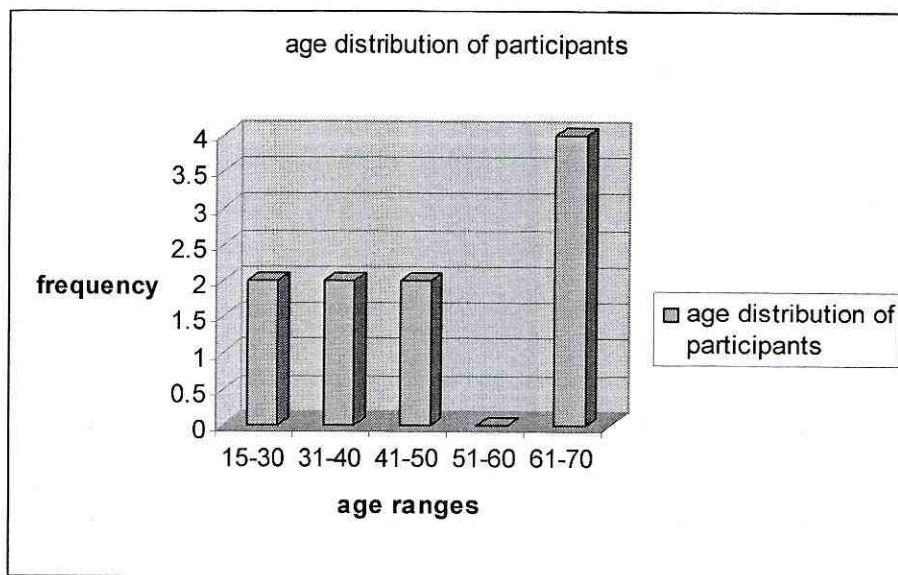
This chapter discusses the study findings using bar graphs, pie charts and tables.

5.2 DEMOGRAPHIC DATA

5.3 AGE

Age is very important when assessing knowledge, perceptions and practices since the older one is, the greater are the experiences. A total of ten [10] participants were interviewed and their ages ranged from 19-67years. The majority of the participants were above the age of 20.

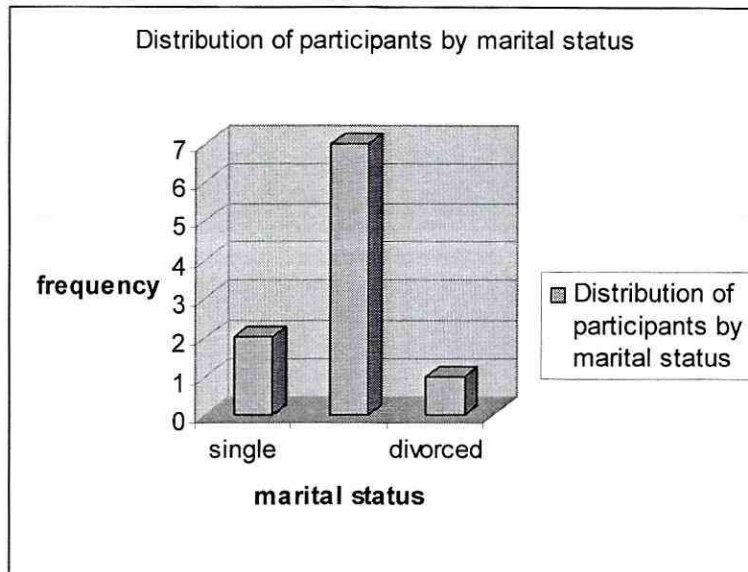
Figure 1: Depicts the distribution of participants by age.



The study revealed that 20% of the participants {n=2} were within ages 10-30, another 20% of the participants {n=2} were within the ages of 31-40, 20% were within 41-50 {n=2}, there were no participants within the ranges of 51-60 and there were n=4 {40%} of the participants within the range of 61-70. The age findings clearly indicated the majority of the participants were experienced adults. See table one

5.4 MARITAL STATUS

Figure 2: Distribution of participants by marital status



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KAMUZU COLLEGE OF NURSING
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The study revealed that 70% of the participants {n=7} of the participants were married, 10% of the participants {n=1} was a widow, 20% of the participants {n=20} were single.

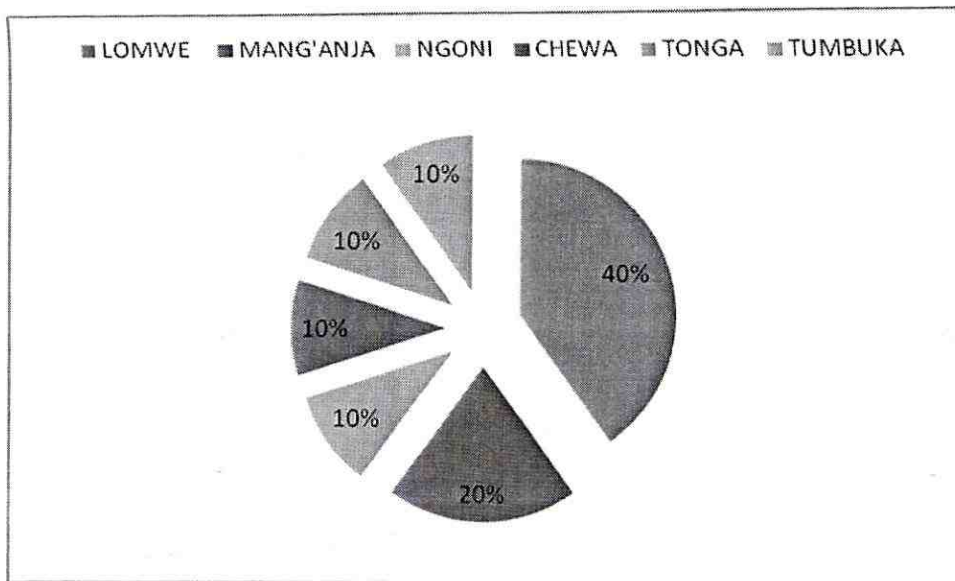
5.5 GENDER (SEX)

The study revealed that all participants were females which represents a 100%. This showed that in our culture most of the care is provided by women.

5.6 TRIBE

Tribe influences caring in different cultures. The study revealed that the participants belonged to different tribes found in Malawi. 40 % of the participants {n=4} belonged to Lomwe Tribe, followed by the Mang'anjas 20% [n=2}, then 10% of the participants belonged to Ngoni tribe, 10% of the participants (n=1) belonged to Chewa tribe, 10% belonged to the Tonga and 10% belonged to the Tumbuka tribe.

Figure 3: Tribes of participants



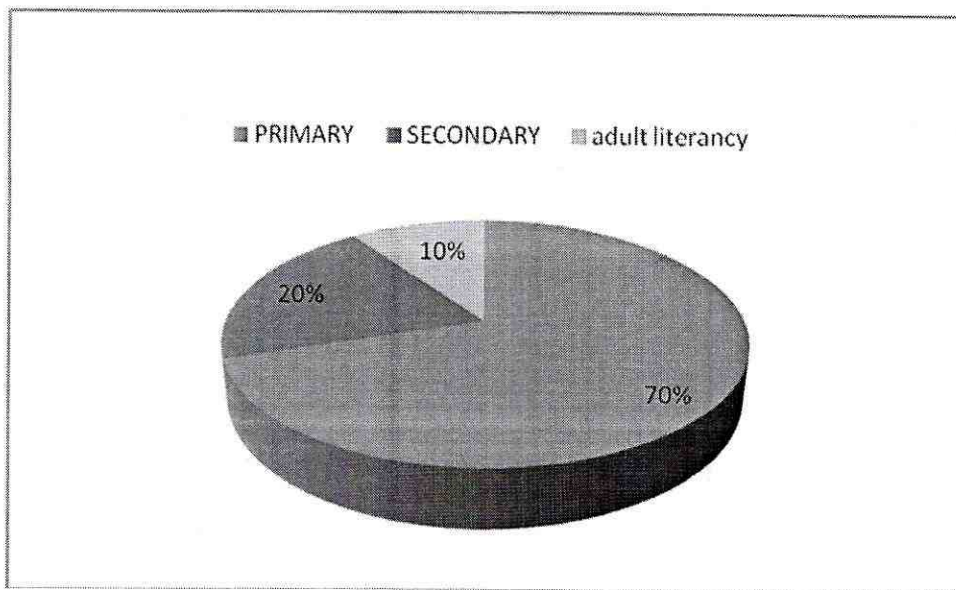
5.7 RELIGION

Religion is important when caring for patients whether on home based care or not because it brings a sense of hope about their situation based on their faith. The findings revealed that the respondents belonged to the Roman Catholic Church. They were all Christians.

5.8 EDUCATION BACKGROUND

Education is important because it promotes understanding. The study indicated that the majority of the respondents attended primary education 70% (n=7), 20% of the participants went up to secondary school and 10% (n=1) attended adult literacy education.

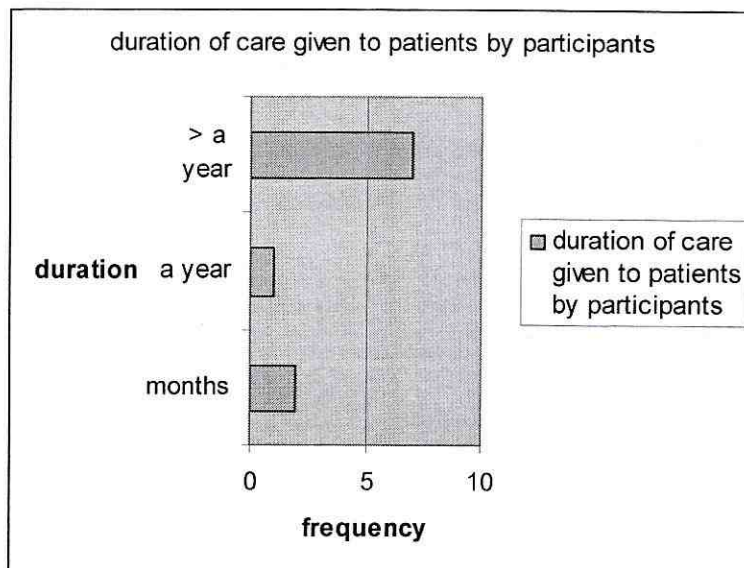
Figure 4: Education background of the participants



5.9 DURATION OF CARE GIVEN TO PATIENTS

The study revealed that most of the participants had different durations on how they cared for their patients. 70% of the participants (n=7) had cared for their patients for more than a year, 10% for a year and 20% for months.

Figure 5: Duration of care given to patients



5.10 KNOWLEDGE ABOUT HIV AND AIDS

Knowledge about HIV and AIDS will help the caregivers to avoid being infected since they will know how the disease is spread. On knowledge the findings revealed that all participants {100%} had heard about HIV and AIDS and had knowledge on what it is.

5.11 SOURCES OF INFORMATION

Most of the participants had knowledge on HIV and AIDS, 70% of the participants indicated that they heard the information from the radio, friends, church, school, hospital, newspapers, neighbors and home based care centre while 10% of the participants heard it only from school, church, radio and 20% of the participants reported to have heard it only from church, radio and friends and I quoted some participants and she said ‘ *I heard this information from a good number of sources which included radio, church school and neighbors*’ and the second participant said ‘ *I happened to hear this information from church ,radio and school*’ .Source of information is very important when it comes to information about HIV and AIDS because there are so many rumors and misconceptions surrounding this disease. From the findings it shows that most of the participants got the information from reliable sources like the hospital, radio, newspapers, schools and churches. This shows that all the misconceptions were ruled out and these participants got the real information.

5.12 CAUSES OF AIDS

The study revealed that the majority of the participants knew what causes AIDS and 90% of them said it is caused by a virus called HIV .One participant said ‘*from the source I got the information they said AIDS is caused by a small virus that can not be seen with our naked eyes called HIV*’. The other participant said ‘*it is from the radio where I heard that AIDS is caused by a virus and when I heard it from our church and the other sources it was not surprising*’. However 10% of the participants (n=1) reported that AIDS is caused by unprotected sexual intercourse and borrowing of razor blades and this participant said ‘*my neighbor told me that AIDS is caused by unprotected sexual intercourse and borrowing razorblades with an infected person*’

This shows that most of the participants know what causes AIDS and they will be in a better position to prevent as much as possible.

5.13 KNOWING THAT SOMEONE HAS HIV AND AIDS

The study findings revealed that 90% of the participants found it difficult to know that an individual has HIV and AIDS unless one goes to the hospital for blood test and that's when we can know one has the virus. One of the respondents said *'there are some diseases that present just the same as HIV and AIDS like malnutrition, such being the case it is difficult to know, it is only the hospital that can do that'* Another participant said *'from the information I got when we went for group session, it is difficult to know whether somebody has the virus or not, it is only through blood test which takes place at the hospital'*. The third participant reported *'I can know that someone has HIV and AIDS only if the result from the hospital shows that'*. However 10% of the respondents (n=1) reported that someone with HIV and AIDS can be known through the symptoms they present with and I quoted *'someone with HIV and AIDS loses weight such being the case he/she gets thinner and thinner and she or he easily gets attacked with different types of diseases'*.

5.14 PEOPLE AT GREATER RISK OF BEING INFECTED WITH HIV AND AIDS

40% of the respondents reported that everyone is at greater risk provided he /she comes in contact with fluid and blood from another individual without protection/or protective materials while 20% of the participants revealed that people who have unprotected sex with an individual with the virus is at a greater risk and one participant was quoted *'As sex involves the exchange of body fluids, any unprotected sex with an infected person results in transmission'*. However 30% of the participants said *'the youth's boys and girls are at a greater risk because they are exploring life and they end up having unprotected sex with an infected person'*. Another participant was quoted *'HIV gets transmitted from one person to the other through blood and body fluids, anyone coming in contact with these is at risk of contracting the viruses'*.

In addition 10% (n=1) of the participants reported that people who drink, prostitutes, drivers and women are at greater risk of being infected and she reported

'men are vulnerable to contract the disease because they move a lot (drivers) as such when they get infected they transfer it to their wives and hence putting women at a greater risk and she added prostitutes seek money and they can sleep with anyone without protection, they can either get the virus or they can transmit the virus which renders these men and their spouses at risk. She continued to say when an individual is drunk his/her thinking becomes impaired and can be involved into sexual intercourse hence being infected, this explains how drunkards become vulnerable to HIV infection'.

5.15 KNOWLEDGE ON TRANSMISSION

Knowledge promotes understanding, when asked on who can transmit the HIV virus 60% of the respondents (n=6) reported that anyone male, female infected and has unprotected sex with another one is the one who can transmit the virus while 20% reported that prostitutes and drunkards transmit the virus intentionally. However 20% of the participants reported *'men are transmitting the virus because most of the times they have an extra marital affair that's where they transmit if they have or they both get it and transmit to their spouses'.*

5.16 WORRIES ON CONTRACTING THE DISEASE

On whether they get worried when they are caring for their patient who is HIV positive and that they will be infected 20% of the participants (n=2) said *'I do not worry because I am doing a good job and after all the patient is my relative and God will protect me'* and the other participant said *'It is not worrisome provided I have protective wear at all times'* while 80% of the participants expressed a concern that they fall within the risk group and I quoted participants *'I mostly get worried because my patient has skin rash that peels off at times and ooze fluid and blood, so if I don't have gloves, I get worried'*. And the other participant said *'I feel sorry that I do not have any other option but to give care, I even use plastic papers at times'*. The other participants were also quoted and he *'said I get worried that protective materials like gloves are so scarce, I come in contact with things I am not comfortable with'* and the last participant reported *'I wish we had enough gloves in our hospitals so that I would be as comfortable as possible when giving care'*.

5.17 HIV PREVENTION

The study results revealed that 100% of the participants (n=10) knows that HIV can be prevented by use of gloves, plastic papers when coming in contact with their patients body fluids and blood and one participant added *'to those who are caring for their partner it is better to use condoms when they want to sleep with their partner to prevent further infection'*

5.18 UNDERSTANDING HOME BASED CARE

The study findings revealed that all the participants (100%) were able to give an explanation on HBC which shows that they were aware of what they were doing and participants were quoted *'HBC is the care given to individual with chronic conditions at home by the guardians but with assistance from the hospital, churches and other HBC organizations'*, and the other participant said *'HBC is the care given at home by the guardians'*. A third participant reported *'home based care is the care patients receive at home'* and the fourth participant reported *'it is the assistance patients receive at home by guardians'*. From the few quoted phrases it shows that the answers were almost the same that *'it is the care patients receive at home but it is given by guardians with the assistance from the health personnel'*.

5.19 KNOWLEDGE ON HBC

90% (n=9) of the participants said they have the knowledge and they are able to apply it, however since things are changing on daily basis so they still feel they need to acquire the updated information and these participants were quoted *'I were given information on home based care but things have change so I need new information'*. Another participant said *'the way we used to manage patients conditions on home based care has really changed'*. The other participant also reported *'I have the information but we are leaving in a world where things are constantly changing so I need to be updated so that I am well equipped to give care'*. However 10% of the participants (n=1) said *"I have enough information and I give the best care, all I need are the materials to assist me in giving care"*

5.20 ASSISTANCE OR TRAINING

The study results revealed that 90% of the participants want trainings except one who wanted materials as presented above. However when asked on which areas they need

trainings the results were quite different in that 50% of the participants wanted refresher courses on medication and care given to patients and were quoted '*knowledge is very important but I need refresher courses on medications and patient care*' while 30% of the participants wanted trainings on medication, care and nutrition and one participant said '*I do not know the new food groups at least if they gave us a refresher course and even provision of the nutritional supplements*'. 10% wanted on side effects of medication and she said '*I really don't understand what happens when one takes these medications, so many problems results I really want to understand the side effects and the management of these side effects*' and 10% participant just wanted the materials to give care, the food to give to the patient and medications and she said '*The information keeps me going, the knowledge I have am using it but I need materials to give care, food and other medications*'.

5.21 ADVANTAGES OF HOME BASED CARE

On the advantages of home based care the participants had almost the same answers and three participants were quoted and one said "*HBC makes some household and other activities that one does continue, care is not left to one individual as it is the case with the hospital since there are so many relatives at home and on top of that money is saved in terms of transport at the hospital*"

Another participant said '*I get encouraged since so many friends and relatives come to encourage me, hospital congestion is also reduced and I become so free as I care for the patient at the usual home*'. The third respondent responded '*I still work (my farming) and the money I would have been using for transport I buy the patients food*' and the other participant said '*I do not worry much since here at home some relatives who can not manage to come to the hospital can visit me and some helps me in caring for my patient and my patient feels happy in the natural setting*'.

5.22 PROBLEMS CAREGIVERS FACE WHEN CARING FOR THEIR PATIENTS

The study results revealed that the problems that the caregivers face were in three groups: physical, social economic and psychological factors. On physical problems the findings indicated that 20% of the participants experienced physical problems

while 80% of the participants experienced social economic problems and psychological problems. On physical problems the main problems were tiredness, lack of gloves and medications. One respondent said *"I sometimes feel sick (body malaise) due to tiredness since I have to care for my patient and do the household chores at the same time I have to source money"* and the other participant said *'materials are so scarce, I do not know what to do'*

On social economic problems the study revealed that 50% of the participants reported to have experienced social economic problems, two of them reported *"since am caring for my patient I find it not enough to feed the whole family so I lack food for my patient and soap"* and the other respondent said *"when my patient falls sick at home, I find it very difficult to take her to the hospital because of transport issues"* and another participant added *'my patients kids lack food, uniforms and school fees so I feel concerned'*.

On psychological problems the findings indicated that 30% of the participants were psychologically affected and two of them reported *"It's not easy to hide and disclose the status and suffering of my patient to my friends when asked as to why she/he is on home based care."* *I feel concerned when people comments that am caring for somebody who is HIV infected so I will be infected as well"*

5.23 WAYS OF DEALING WITH THE PROBLEMS ENCOUNTERED

On ways of dealing with the problems identified the respondents responded according to their problems they face all the participants responded to the questions. 20% of the respondents reported that they go to the hospital to get help when their patient is not getting well and needs medical assistants. The study also revealed that 50% of the participants they go to the HBCC in their area when they see that the problem is beyond their control. One participant was quoted *"when there is no food at home and no gloves I go to area 25 HBCC where I get assistance"* and 20% of the participants said they go to church where they help them with prayers and they get encouraged that they are doing the work of God. 10% of the participants said they have a garden where food, vegetables are planted for consumption and the surplus is sold and with that life continues.

5.24 ADQUACY OF ASSISTANCE

When asked if the assistance they get is enough or not almost all the respondents reported that it is not enough since things have gone up these days in terms of prices so to meet the living standards its not easy and these participants were quoted *'Not everywhere we seek assistance we get assisted so the assistance is not adequate'* and the other participant said *'its not easy to manage life these days, food and other materials are expensive'*.

5.25 ADVICE TO GOVERNMENT, HBCCs, HBC ORGANISATIONS THAT ASSIST PEOPLE WHO ARE HIV POSITIVE ON HBC

Almost all the participants had a word to share to the above mentioned organizations pertaining to patient care in the homes and one participant said "When one falls sick the system becomes disturbed and when the patient is a bread winner it means the whole system will suffer so it is good that these people are remembered, since they can not work they lack nutritious food, soap for bathing and washing, transport to the hospital, gloves, medications {pain killers} and support to their children in terms of school. The volunteers are trying their best but still they lack nurse's expatriate knowledge, they can not be enough but they should be trying to visit the patients at least once in a while so that their problems are heard. One participant complained *'On top of that when we invite nurses to give us some expatriate skills at home we get worried because they want to be paid by us whilst we still have a problem that limit us from acquiring more skills, so government should train more HBC nurses so that these problems can be minimized'*

5.26 SUMMARY

This chapter described the findings of the study making use of graphs, pie and tables. The results showed that the caregivers were not well to do so assistance was minimized. Another important thing most caregivers interviewed belonged to the Roman Catholic Church and was all women. The most common problems the caregivers encounter were lack of food, transport to the hospital, soap, clothes, medication, stigma and discrimination and shortage of materials like gloves. Furthermore the study revealed that the caregivers had received prior preparation for

home care for HBC so were knowledgeable. The next chapter will be the summary, limitations and recommendations of the study done

CHAPTER SIX: DISCUSSION OF FINDINGS.

6.1 INTRODUCTION

The study findings have described the experiences of caregivers of clients diagnosed with HIV and AIDS on home based care at AREA 25 Lilongwe District. The discussion describes the demographic data, knowledge on HIV and AIDS, home based care, participants perceptions on home based care and practices to prevent cross infections, the problems they face when caring for the patients, the type of assistance they receive its adequacy and other comments from the caregivers.

6.2 DEMOGRAPHIC DATA

Demographic data revealed that 60% of the participants were between the ages of 30-70. This indicated that most of the participants were mature enough to contribute something to the study. The results revealed that 70% of the respondents were married hence have children which means apart from caring for the patient they have and they are also caring for their children and hence they understand the concept of caring.

The findings showed that the majority of the respondents attended formal education while .It was indicated that 20% of the participants (n=2) reached secondary education, 70% primary level {standard 8) and 10% (n=1) adult literacy education. This indicated that the caregivers had some knowledge on HIV and had proper reasoning when caring for their patients hence they were able to make sense out of the questions asked and they responded maturely.

The findings have revealed that the caregivers were predominantly women .This is in consistent with the findings of Masika (2000).In his study he attempted to give a clear picture of the HBC practice and its efficiency in meeting the needs of the target groups. In his study he found that home care puts women in extra vulnerable positions since health and care traditionally their domain.

The results also revealed that the respondents had cared for their patient for more than a year this again contributed to their experience in caring for their patients. The results also revealed that the majority of the respondents were Lomwe by tribe .There is no explanation as to why there were many Lomwes in the Central Region but the

possible reasons could be marriage and work despite central region being dominated by the Chewas.

It was indicated by the results that the respondents were all Christians belonging to the Roman Catholic Church. This shows that the participants had a chance to learn more on HIV and AIDS through their religious places and had a sense of hope about their situation based on their faith. The study results also indicated that the majority of the participants earned a living by doing some activities such as farming, business and office work. This is an indication that the mothers were able to feed themselves and their families depending on their earnings. However some of the respondents relied on their spouses earnings.

6.3 KNOWLEDGE ON HIV AND AIDS

Knowledge is important when we are talking about HIV and AIDS because it helps a person to be empowered and give care without problems because one knows how HIV is transmitted and how it can be prevented. The findings indicated that 100% of the participants (n=10) had heard about HIV and AIDS and had knowledge on what it is. Tibebe et al 2005 agreed with the importance of knowledge in relation to home based care the results revealed that $\frac{3}{4}$ of the studied population had knowledge on home based care.

6.4 SOURCES OF INFORMATION

As indicated earlier on the study results revealed that most of the participants had heard about HIV and AIDS and 70% reported to have heard the information from the radio, friends, church, school, hospital, newspapers, neighbors and home based care centers which were reliable sources and this shows that these caregivers had genuine facts about HIV and AIDS.

6.5 CAUSES OF AIDS

Knowing the causes of something makes an individual to be in a position to take an action so as to prevent the problem. The study findings revealed that 90% of the participants (n=9) had knowledge on what causes AIDS and they will be in a better position to prevent it.

6.6 KNOWLEDGE ON HBC

As explained above, 90% of the participants knew what home based care is and they agreed that they have knowledge of HBC and what should be done however they expressed a concern that things are changing on daily basis so there is a need of acquiring more knowledge (needs to be updated and one participant said the knowledge is enough all she needs are the materials to use.

6.7 ADVANTAGES OF HBC

On the advantages of HBC almost all the participants gave several advantages on home based care and as quoted on the presentation of findings. This shows that they preferred HBC than hospital care and this showed that they were not panic by being sent home to care for their patients at home.

6.8 PROBLEMS THEY FACE WHEN CARING FOR THEIR PATIENTS AT HOME

Despite all the list of advantages of HBC there are so many problems the participants expressed they face at which were physical, psychological and socio-economic problems. As with the study done by Agbonyitor to find /assess the challenges people face when caring for patients in the homes and the study revealed that discrimination towards PLWHAS, lack of food, money and transport to health care centers and the desire for closer antiretroviral drug access are some of the challenges which are in line with the problems the participants gave which were

When asked if the assistance they receive was enough, the majority of the participants said it is not enough and they lack gloves, medications, lack of transport, lack of food (nutritious) and discrimination just to mention a few. They said things are expensive hence very difficult to meet the needs of the patients at home which makes care difficult in terms of drugs, transport and refresher courses. This called on the issue of seeking for assistance from different organizations so that these patients are not sidelined despite the caregiver's trial to give the best care.

This also prompted the issue of trainings so that they are updated. A study done by Masika where he attempted to give a clear picture of HBC practice and its efficiency in meeting the needs of the target groups, the study revealed that in order to improve

HBC and problems not only should community involvement should be strengthened but also HBC needs to be linked with other forms of care in the community, this implies the need for formal and informal trainings to be more adapted to the local needs, customs and available resources incorporating gender issues should be a priority since most of these caregivers economic status are so difficult to meet the needs of their patient.

6.9 DEALING WITH THE PROBLEMS

The participants had different ways of dealing with the problems identified based on the type of problem. On the physical problems most of them said they go to the hospital to get treated, get gloves and medication. On social economic problems the caregivers said they do small scale businesses, farming and they consult the home based care centers in their area. On Psychological problems most of the participants said they go to church to be encouraged and they trust in God. Above all social economic problems were the main problem.

6.10 PERCEPTION ON HBC

On perception of the caregivers on home based care, most of the participants enjoyed giving care at home and had favored the idea of home based care with the knowledge they had. A study done by Tibebu to determine the level of knowledge, attitude and practices of the caregivers on home based care. The study highlighted that most of the caregivers had a good knowledge and attitude towards home based care and almost half had favored this programme which was the case with the caregivers who took part in my study.

6.11 ADVICE TO GOVERNMENT, HBCC, NON GOVERNMENTAL ORGANISATION THAT ASSIST PEOPLE WHO ARE HIV POSITIVE AND ARE ON HBC.

Almost all the participants /caregivers (100%) had a word to the above said organizations and government and these are the words they said "When one falls sick the system becomes disturbed and when the patient is a bread winner it means the whole system will suffer so it is good that these people are remembered, since they can not work they lack nutritious food, soap for bathing and washing, transport to the hospital, gloves, medications {pain killers} and support to their children in terms of

school. The volunteers are trying their best but still they lack nurse's expatriate knowledge, they can not be enough but they should be trying to visit the patients at least once in a while so that their problems are heard.

CHAPTER SEVEN: SUMMARY, LIMITATIONS AND RECOMMENDATIONS OF THE STUDY.

7.1 SUMMARY

Knowledge is one of the major factors that promote adherence to treatment regimens, prevention and the ability to give quality care. With the new trends of community programmes for the management of HIV and AIDS patients' knowledge of the caregivers about home care of these patients will determine the success of the programmes.

The purpose of this study was to describe the knowledge of caregivers of clients diagnosed of HIV and AIDS on home based care at Area 25 Lilongwe District Malawi. Literature has said little on the knowledge, perception and practices of caregivers on home based care. Knowledge helps to allay anxiety, promotes confidence and promotes cooperation when giving care. The researcher was motivated to conduct this study because the HIV pandemic has contributed to congestion, premature discharges, poor quality of care and inadequate resources. These are not conducive to speedy recovery and in view of the above mentioned issues government has advocated in extending the care giving in the community settings where the caregivers take lead, so the knowledge, practices and perception can no be under estimated. To contribute to this end limited research has been done to assess the needs of caregivers and develop supportive program. It is ironing that the caregivers who are giving care to these patients are sidelined.

7.2 METHODOLOGY

A descriptive study design was used. The sample respondents consisted of 10 randomly selected caregivers with clients diagnosed of HIV and AIDS on HBC under Area 25 HBCC in Lilongwe District Malawi. A structured interview guide /schedule were used to collect data. The data was collected in a day and ethical considerations to patients were maintained throughout the study.

7.3 OBJECTIVES

The objectives of the study were to:

_Assess caregiver's knowledge on transmission and prevention of HIV and AIDS

And Home based care

_ Identify caregiver's perceptions and practices on patients who are on home based care

_ Describe the support caregivers with patients on home based care receive in the community

_ Explore the challenges caregivers face in caring patients on home based care as a result of HIV and AIDS.

7.3 DATA ANALYSIS AND DISCUSSION

Data was analyzed manually and the results were presented in tables, pie charts and graphs. The results revealed that

-Most of the caregivers that were caring for the clients were women within the age ranges of 19-67. The majority had no reliable source of earning a living apart from relying on their husbands and the majorities were from low income families.

-Most of the care givers had received formal preparation for the provision of home care for the clients diagnosed with HIV and AIDS but some of the information outdated hence a need for trainings for updating their knowledge.

-The majority of the caregivers interviewed belonged to the Roman Catholic Church.

-Most of the caregivers had a good perception towards home based care.

-The most common problems faced by these care givers are: lack of gloves, medications, lack of transport, lack of food (nutritious) and discrimination just to mention a few.

-The caregivers dealt with physical problems by escorting their patient to the hospital, Psychological problems were dealt with by going to church to get encouraged and social economic problems were dealt with by getting assistance from the HBCC, church and through farming.

-Almost all the caregivers interviewed were happy with the idea of HBC services and were certain to continue providing care for as long as necessary.

Generally the study findings indicated that social economic problem is one of the burdens that limit home based care amongst the participants apart from the other problems identified. Patients on home based care need nutritious food, clean clothes, their children should go to school, and transport problems on specified days for follow up, psychological issues of stigma and discrimination needs to be addressed rigorously.

The study ended up in a discussion on the possible ways of reducing the problems faced by the caregivers. It was the discussed that the government should be providing materials (gloves) , medications, food supplements , education support, loans to the caregivers so that care is given. It was also discussed that nurses should visit the patients in their homes to demonstrate some skills in caring for the patient and identify some problems faced by these caregivers so that problems are addressed properly. Finally it was discussed that the government, churches, HBC organizations should organize trainings where caregivers will be trained so that they remain with current management as they care for their patients.

7.4 LIMITATION OF THE STUDY

The findings of the study must be interpreted with the following limitations:

-The choice of the city under study was based on non probability sampling that limits the generalization of the findings and the study relate to the small sample size of primary caregivers that may not be a representative of the entire population of primary caregivers in Lilongwe.

-The results of the study were formulated based on caregivers recall and reliability. Literature demonstrates that in order to get accurate information on knowledge, practice and perceptions. Data collection should be done through participant observation where a researcher will live with the family and record the care done. However it is very difficult and beyond the scope of this study.

-The unavailability of literature on the topic was also a serious limiting factor on its own.

7.5 RECOMMENDATIONS

The following recommendations can be made:

7.6 FOR PRACTICE

- The need for food supplements was emphasized by most of the caregivers; hence the need for government to identify strategies for the sustainability of food supplements to these families. This would help to relieve the suffering to at least a certain extent.
- The centers that provide other activities in addition to the support of HIV and AIDS should be encouraged to continue. However the government should support the other HBCCs to do the same. These centers should be providing income generating activities, vegetable gardens, gardens, social gatherings. At the same time this could be the other way of reducing stigma and discrimination associated with HIV and AIDS and increase the acceptability of care centers.
- Nurses should do follow up of patients in their homes.
- The non governmental organizations should be giving loans to the care givers to do businesses and improve their social economic status.
- The nurses should establish good interpersonal relationship with guardians so that they can easily be approached when the caregivers have problems.
- Transport arrangements should be made in health centers to take patients to the hospital.
- The home based care leaders should ensure regular home visits for proper supervision and reinforcement of information given.

7.7 FOR EDUCATION

- Caregivers need to be informed fully of their patients' diagnosis, nature of medical treatment and the care patient requires.
- Caregivers need to be educated on the pros and cons of current therapies.

-HBCC, Nurses and the government should make sure that extensive education on risks of transmission is given to caregivers.

-The government, hospitals should make sure that they train more HBC nurses to decrease the workload that limit the few home based care nurses from performing other activities.

7.8 FOR RESEARCH

-There is need to conduct same study under a large sample so that results can be generalized.

-The findings demonstrated poor ways of dealing with the problems identified so there is need to conduct a research to find out how much information is given in regards to the problems identified

-Nurses should utilize the research findings to provide nursing in the homes.

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APPENDICES

Appendix A(I): INTERVIEW GUIDE

DATA COLLECTION TOOL

CODE:

TITLE: DESCRIBING THE KNOWLEDGE, PERCEPTIONS AND PRACTICES OF CAREGIVERS WITH CLIENTS DIAGNOSED OF HIV AND AIDS ON HOME BASED CARE

PART A: DEMOGRAPHIC DATA

1. How old are you?

16-25 []

26-35 []

36-45 []

46-55 []

56-65 []

Above 65

2. Sex Male []

Female []

3. To which church do you belong to?

CCAP []

SDA []

RC []

ISLAM []

JEHOVAS WITNESS []

Others, specify.....

4. What is your education level?

None []

Primary []

Secondary []

College []

University []

Adult literacy []

5. How many days have you been involved in the care of the patient?

1-10

11-20

21-30

Above

30.....

.....

6. To which tribe do you belong to?

-Chewa

-Tumbuka

-Lomwe

-Yao

-Others, Specify.....

7. Marital status

Married

Single

Divorced

Widow/widower

On separation

Others, Specify.....

PART B: KNOWLEDGE ABOUT HIV AND AIDS

8. Have you ever heard about HIV and AIDS?

Yes

No

9. If yes, where did you learn about HIV and AIDS?

10. What cause AIDS?

11. How do you know that someone has HIV and AIDS?

12. Who are at greater risk of getting infected with HIV?

13. How can a person get HIV?

14. Do you sometimes get worried of contracting HIV by being in contact with someone who has HIV and AIDS?

15. How can AIDS be prevented?

PART C: KNOWLEDGE ON HOME BASED CARE

16. What is home based care?

17. Do you think you have enough knowledge of providing care to patients who are on home based care?

18. Do you have areas you need training or assistance?

19. What do you think are the advantages of caring for our patient on home based care?

PART D: PERCEPTION AND PRACTICES TOWARDS HIV/AIDS AND HOME BASED CARE

20. How do you perceive home based care?

21. Would you like to be nursed in home settings?

22. How are your home caring skills?

23. Are you comfortable to nurse a very sick patient?

24. From your perception which is the best place for caring a chronically HIV and AIDS patient and why?

25. What type of support do you think should be given to AIDS patients?

26. What materials do you use when you are bathing or feeding your patient?

27. Do you have cultural beliefs concerning HIV/AIDS patients on home based care?

PART E: SUPPORT SYSTEM AND CHALLENGES

28. Where do you get assistance when you have needs?

29. Is the assistance enough?

30. If no, What other sources do you use to find needs for your patients and any other comments?

Appendix A (ii)

**MUTU: KUFUFUZA KADZIWIDWE, MAGANIZIDWE NDI
MACHITIDWE A ANTHU OYANG'ANIRA ODWALA MATENDA A
EDZI KUNYUMBA KWAWO.**

NDONDOMEKO YA MAFUNSO

GAWO LOYAMBA: MBIRI

1. Kodi muli ndi zaka angati?

16-25

26-35

36-45

46-55

56-65

Kuposa

65.....

2. Ndinu Mai
 Bambo

3. Kodi mumapemphera mpingo wanji?

CCAP

SDA

RC

Chisilamu

Mboni za yehova

Tchulani

zina.....

.....

4. Kodi munapitako ku sukulu?

Ayi

Pulaimale

Sekondale

Koleji

Univesite/yaukachenjede

Yakwacha

5. Kodi mwakhala masiku ochuluka bwanji mukusamalira odwalayu

1-10

11-20

21-30

KUPITILIRA 30

6. Kodi ndinu a mtundu wanji?

Chewa

Lomwe

Tumbuka

Yao

Tchulani,

zina.....

6. Muli pabanja?

Ayi

Eya

GAWO LACHIWIRI: MATENDA A EDZI NDI KUFALA KWAKE

8. Kodi mudamvapo za matenda a EDZI?

Eya

Ayi

9. Ngati mudamvapo, mudamvera kuti?

10. Kodi Chimayambitsa matenda a EDZI ndi chani?

11. Kodi mungadziwe bwanji kuti munthu ali ndi kachilombo koyambitsa matenda a Edzi

12. Kodi ndi anthu ati amene ali pachiosezo chotenga matenda a EDZI?

13. Nanga munthu angatenge bwanji kachilombo koyambitsa matenda a EDZI?

14. Kodi zilipo nthawi zimene mumadandaula kuti mutha kutenga kachilombo koyambitsa matenda a EDZI chifukwa mukusamalira odwala amene ali ndi kachilomboka?

15. Kodi munthu angapewe bwanji matendawa

GAWO LACHITATU: ZA CHITHANDIZO CHIMENE ODWALA AMALANDIRA KUNYUMBA

16. Tanthauzirani chithandizo chakunyumba?

17. Mukuganiza kuti mukudziwa momwe odwala ayenera kusamalilidwa kunyumba?

18. Kodi pali madela ena amene mukufuna anthu akuthandizeni kapena kukuphunzitsani?

19. Inu mukuganiza kuti ubwino osamalira odwala kunyumba ndi otani?

GAWO LA CHINAYI: MAGANIZO ANU NDI MACHITIDWE ANU KWA ODWALA AMENE AKULANDILIRA CHITHANDIZO KUNYUMBA.

20. Kodi chisamaliro cha anthu odwala matenda a EDZI kunyumba mumachiona bwanji?

21. Kodi mutadwala mungasangalale kuti mudzilandilira chithandizo pakhomu?

22. Kodi nanga masamalilidwe anu a odwala kunyumba ali bwanji?

23. Mumakhala omasuka kusamalira odwala yemwe wadwalika kwambiri?

24. MMaganizo anu , mukuganiza kuti malo abwino kusamalira odwalawa ndi ati , nanga mchifukwa chani?

25. Kodi ndi chithandizo chotani chomwe chiziperekedwa kwa odwala wathu?

26. Ndizipangizo ziti zimene mumagwiritsira ntchito posambits komanso kudyetsa odwala wathu?

27. Kodi pali zikhulupiro zina ziri zones zimene mumakhulupilira zokhudzana ndi odwala matenda a EDZI?

GAWO LACHISANU: CHITHANDIZO NDI ZOVUTA

28. Kodi mukapezana ndi zovuta , mumathandizidwa bwanji komanso ndi ndani?

29. Chithandizocho chimakhala chokwanira?

Inde

Ayi

30. Ndimavuto ati amene mumakumana nawo mukamasamalira odwala wanu?

Appendix B: Letter to the research publications committee

The University of Malawi,
Kamuzu College of Nursing,
Private bag 1,
Lilongwe
Date:

The Chairman,
Research Publications Committee,
Kamuzu College of Nursing,
Private Bag 1,
Lilongwe.

Dear Sir/Madam,

RESEARCH PROPOSAL APPROVAL

I am a forth year student pursuing a Bachelor of Science in Nursing. In partial Fulfillment of the degree I am expected to conduct a research study.

The aim of this letter is to seek approval for me to conduct the proposed research study. This research will be conducted at Likuni Home Based Care Centre. The Title is "Describing the knowledge, perceptions and practices of caregivers of clients diagnosed with HIV and AIDS on home based care" The subjects will be asked questions relating to their awareness and views.

Looking forward to your favorable considerations,

Yours faithfully,

MERCY KULANGA.

Appendix C: Letter to Likuni Home Based Care Centre

The University of Malawi

Kamuzu College of Nursing,

Private Bag 1,

Lilongwe.

24th August, 2009.

The Director,

Likuni Home Based Centre,

Private bag

Lilongwe.

Dear Sir/Madam,

**REQUEST TO UTILIZE CAREGIVERS WITH HIV AND AIDS PATIENTS
AT LIKUNI HOME BASED CARE AS RESEARCH SUBJECTS.**

I am a fourth year student pursuing a bachelors Degree in nursing at Kamuzu College of Nursing. In partial fulfillment of the requirements for the degree, I am required to do a research in my area of interest and write up a dissertation. My research project is on knowledge, perception and practices of caregivers of clients diagnosed with HIV and AIDS on home based care in your catchment area.

The purpose of this letter therefore is to request for your permission to enable me utilize about 10 care givers in your catchment area as research subjects. The subjects of this study will be both males and females from fifteen years to sixty five or above. An interview guide shall be used.

I will be grateful if my applications meet your favorable consideration

Yours faithfully

MERCY KULANGA.

Appendix D: WORK PLAN

TASK TO BE PERFORMED OR ACTIVITY	RESPONSIBLE PERSON	Y MAR	E APR	A MAY	R JUNE	2 JULY	0 AUG	0 SEPT	9 OCT	NOV
Research topic identified	Researcher									
Literature Review, proposal writing and submission of proposal										
Obtaining clearance										
Pretesting										
Data collection and analysis										
Report writing										
Binding and submission of Dissertation										
Dissemination of results										

Appendix E: PROPOSED RESEARCH BUDGET

STATIONARY

UNITS	ITEM	COST
3	Realms of photocopying papers @ K800.00 each	K2400.00
1	Realm of ruled papers@ k800.00	K800.00
6	Writing pens @k25.00 each	K150.00
1	Pencil sharpener@ k100	K100.00
1	Tippex set @ k200.00	K200.00
2	Lever arch files at k300 each	K600.00
2	Folders @ k100 each	K100.00
1	Flash Diskette @k2500	K2500.00
5	Small envelops at k10 each	K50.00
10	A4 envelops at k50 each	K500.00
3	Note pads for rough notes @ k200 each	K600.00
	SUB TOTAL	K8000.00

PRINTING, PHOTOCOPYING AND BINDING

UNITS	ITEM	COST
4	Proposals	K3000.00
10	Interview guides	K2000.00

TRANSPORT

TRIPS	COST
KCN to and from Likuni	K1000.00
Preceptorship placement to Likuni for data collection	K5000.00
SUB TOTAL	K6000.00

Telephone bills for appointment booking = K1000.00

Contingency =K3000.00

GRANDTOTAL =K26,000.00

Appendix F: JUSTIFICATION OF BUDGET

The Budget gives an overview of what facilities will be required and funds to cover items required in the course of study.

STATIONERY

Enough stationery will be required for proposal development and dissertation. Plain papers will be required for typing, printing and photocopying. Ruled papers will be used for write ups for the supervisor to check the work that has been done. The stamps and envelopes for posting clearance letters. The flash disk will be used for storage of raw data to be used in the proposal and dissertation.

SECRETARIAL SERVICES

Funds will be needed for travel costs From Kamuzu College of Nursing to the proposed site for data collection and from preceptor placement to the proposed site for data collection.

TELEPHONE BILLS AND CONTINGENCY

Telephone bills will be used for booking appointments to the supervisor. Funds will also be needed for emergency when need may arise during the research process.

Appendix G (i): CONSENT FORM

CONSENT TO PARTICIPATE IN THE STUDY TO EXPLORE ON THE KNOWLEDGE, PERCEPTIONS AND PRACTICES OF CAREGIVERS OF CLIENTS DIAGNOSED WITH HIV AND AIDS ON HOME BASED CARE.

Dear Participant,

I am Mercy Kulanga forth year student from Kamuzu College of Nursing persuing a Bachelor of Science in Nursing. In partial fulfillment of the Degree, I am required to carry out a research study on the 'Knowledge, perceptions and practices of caregivers with clients diagnosed with HIV and AIDS on home based care. The purpose of this letter therefore is to request your consent to take part in the study.

In participating in the research study, you will be required to respond to questions. No harmful procedures will be performed on you and you will be free to express your ideas during the interview. Everything you are going to say will be kept in confidence and no one is going to have access to the information without your consent. The rights of privacy, anonymity will be respected in this study and no names will be included in the interview guide, instead code numbers will be used for each participant. Should you choose to withdraw your participation during the study, you will not be denied permission for your wish and no penalty shall be assigned. Your participation in the study will have either direct or indirect benefits to you and it I will assist the rest of the caregivers with HIV and AIDS patients on home based care as they care for their patients.

I the undersigned have fully understood the above information and wish to give consent to participate in the study.

Signature of participant.....Date.....

Signature of researcher.....Date.....

Thanks for sparing your time!

Appendix G (ii)

**KUPEMPHA CHILOLEZO KUTI MUTENGE NAWO MBALI
MUKAFUKUFUKU WOFUNA KUDZIWA ZOMWE OSAMALIRA ODWALA
MATENDA A EDZI KUNYUMBA AMADZIWA, KUGANIZA KOMANSO
ZIMENE AMACHITA.**

Okondedwa otengambali,

Ndine Mercy Kulanga wophunzira pa sukulu ya ukachenjede ya unamwino ya Kamuzu Koleji. Ndipo ndili mu chaka chachinayi chomwe chili chomaliza. Ndalembe kalatayi kuti ndipemphe chilolezo kuti mutenge nawo mbali mukafukufukuyu.

Potenga nawo mbali mukafukufukuyu ameneyi mudzafunika kuyankha mafunso amene mudzafunsidwa. Mukutsimikiziridwa kuti ndinu omasuka kufunsa mafunso onmwe simukuwamvetsetse ndipo sipadzakhala kuyesa kulikonse. Ndinu omasuka kusiya kutenga nawo mbali mukafukufukuyu ngati mwaona kuti mkwabwino kutero ndipo simudzakakamizidwa kipitiliza. Palibe chilango chuilichonse chomwe chidzaperekedwa pakutero. Mukutsimikizilidwa kuti zonse zomwe mundiuze zidzasungidwa mwachinsinsi .

Kutenga nawo mbali mukafukufukuyu kukhoza kuthandiza inu komanso anthu ena amene akusamalira odwala matenda a EDZI kunyumba.

Ine ndikuvomeleza kutenga nawo mbali mukafukufukuyu,

Saini ya otenga mbali.....Tsiku.....

Mwini kafukufuku.....Tsiku.....

Zikomo chifukwa chotenga nawo mbali!



University of Malawi
Kamuzu College of Nursing

RESEARCH AND PUBLICATIONS COMMITTEE

APPROVAL CERTIFICATE

TITLE: Knowledge, Practices and Perceptions
of Caregivers of Clients Diagnosed
with HIV/AIDS on HOME BASED Care.

INVESTIGATOR(S):

Mercy Kulunga

YEAR OF STUDY:

2009 (year 4)

REVIEW DATE:

24/08/09

DECISION OF THE COMMITTEE:

Approved

SIGNATURE:

[Signature]

DATE:

24/08/09

DEAN OF POSTGRADUATE STUDIES AND RESEARCH

CC: supervisor:

Mrs F. Chilumba

DECLARATION OF INVESTIGATOR(S)

I/We fully understand the conditions under which I am/we are authorized to carry out the above mentioned research and I/We guarantee to ensure compliance with these conditions. In case of any departure from the research procedure as approved, I/We will resubmit the proposal to the committee.

DATE:

24/08/09

SIGNATURE(S):

[Signature]

Appendix I: PERMISSION TO CONDUCT THE STUDY

Likuni Diocese,
Likuni Home Based Care,
P.O Box
Lilongwe.

Mercy Kulanga
Kamuzu College of Nursing
Private Bag 1
Lilongwe.

Dear Madam,

Re: APPLICATION FOR PERMISSION TO CONDUCT A RESEACH STUDY AT
AREA 25 HOME BASED CARE

This study was done at Area 25 Home Based Care as started in the methodology and
consent was granted through phone from the director Mrs Moyo.

Yours faithfully,

Mercy Kulanga