

**Midlands State
University**
Established 2000



FACULTY OF ARTS

DEPARTMENT OF DEVELOPMENT STUDIES

**CHALLENGES FACING COMMUNITY HOME BASED CARE GIVERS OF
PEOPLE LIVING WITH HIV/AIDS, CASE OF HOPE HUMANA CARE PROGRAM
IN MABVUKU**

BY

EVERNICE TAYISEPI

R125518Z

**DISSERTATION SUBMITTED TO THE FACULTY OF ARTS IN PARTIAL
FULFILMENT OF THE BACHELOR OF ARTS HONOURS DEGREE IN
DEVELOPMENT STUDIES AT MIDLANDS STATE UNIVERSITY**

(NOVEMBER 2016)

SUPERVISOR: MR MAKAYE

DECLARATION

I Evernice Tayisepi do hereby declare that this dissertation for Bachelor of Arts Honours Degree in Development Studies submitted to the faculty of Arts at Midlands State University has not been submitted previously for any degree at this or another university. It is original in design and in execution and all reference material contained therein has been acknowledged.

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APPROVAL FORM

Topic. Challenges facing community home based caregivers of people living with HIV/AIDS, case of Hope Humana Care program in Mabvuku

I. TO BE COMPLETED BY THE STUDENT

I certify that this dissertation meets the preparation guidelines as presented in the Faculty Guide and Instructions for preparing dissertation

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II. TO BE COMPLETED BY THE SUPERVISOR

This dissertation is suitable for presentation to the Faculty. It has been checked for conformity with the Faculty Guidelines

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DEDICATION

This dissertation is dedicated to my late parents Mr W. M. Tayisepi and Mrs J Tayisepi and to the late Witness Tayisepi Jnr. I also dedicate it to my siblings and the rest of Tayisepi family.

ABSTRACT

The researcher sought to study on the Challenges facing Community Home Based Care Givers of people living with HIV/AIDS. The research was well furnished with a couple of theories, relevant literature by other authors and previous studies that supported the research. The participants were sampled using purposive sampling. The research comprised of Hope Humana staff, Hope Humana Voluntary Caregivers and the HIV/AIDS affected individuals who made up a total of thirty two respondents who had an unequal representation of males and females. Interviews and a focus group discussion which constituted questions that were meant to highlight the challenges facing caregivers of the HIV/AIDS infected people were used. Data was analysed using qualitative descriptive methods and was presented in the form of discussion. Major findings were that caregivers of the chronically ill have been neglected in so many ways by their parent Organisations and even the Government which as a result strains them as they cope with the caregiving stresses. The study also revealed that the most common sources of stress included lack of support, financial burdens, inadequate caregiving material to do the caregiving duties, workload and lack of counselling. Recommendations to the mother project were given in order to curb the challenges faced by the caregivers of people living with HIV/AIDS. The recommendations include frequent trainings and counselling, formation of support groups, provision of caregiving materials as well as incentives for motivation.

ACKNOWLEDGEMENTS

Firstly I thank the Lord God Almighty for guiding me throughout the research process and for making the research successful. My heartfelt gratitude also goes to my dissertation supervisor Mr Makaye who has been supervising and guiding me as I wrote the dissertation. I would also like to thank my other lecturers who have been providing me with ideas and the Midlands State University as a whole for making the whole study a success.

I would like to express my sincere gratitude to my family. Thumps up to my siblings who have always been there for me to make the research a success. They have been supporting me financially and providing me with emotional and spiritual support. I thank them also for their encouragement and motivation.

My appreciation also goes to Tawanda Zarura for the moral and financial support. I am also grateful for the motivation from my friends Glorious, Dumisani, Christine, Sithabile, Cynthia, Yeukai and Melinda.

ACRONYMS

HIV.....	Human Immunodeficiency-virus
AIDS.....	Acquired Immuno- Deficiency Syndrome
PLWHA.....	People Living With HIV/AIDS
CHBC.....	Community Home Based Care
NAC.....	National Aids Council
ZAN.....	Zimbabwe Aids Network
ZNASP.....	Zimbabwe National HIV/AIDS Strategic Plan
IEC.....	Information, Education and Communication

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1.0 CHAPTER ONE: INTRODUCTION TO THE STUDY

1.1 Introduction

Chapter one is an introduction to the study. It examines and discusses the background of the study, statement of the problem, purpose of the study and its significance. It airs out the research questions including the main question that is, challenges facing community home based care givers of people living with HIV/AIDS. This chapter justifies the research questions. Definitions of terms are provided and limitations as well as delimitations are highlighted and discussed.

1.2 Background of the study

The United Nations and World Health Organization alludes that 33.2 million people were living with HIV/AIDS in 2007. HIV and AIDS remains a major public threat in the country with a prevalence of 15% among the adult population (Dr P. D Parirenyatwa 2013). The introduction of Community Home Based Care Programs has revolutionised the care and management of HIV and AIDS and has transformed the disease from being a life-threatening infection into a chronic and manageable condition.

The HIV and AIDS epidemic has had terrible impacts on individuals and communities throughout Africa. In Zimbabwe, the Ministry of Health and Child Welfare (2006) estimates that 1,610,000 (2005 National estimates) Zimbabweans out of a total population of 11.6 million are living with HIV/AIDS. Although Zimbabwe has demonstrated a declining trend in prevalence in the adult age group (15-49) primarily attributed to behaviour change, the prevalence of HIV continues to be unacceptably high simultaneously with the HIV/AIDS related deaths. The Care and support needs of people living with HIV/AIDS and their families have been well documented yet over the years, the increasing demand of care and support has burdened already financially stretched hospitals and local clinics. The capacity of these health institutions to provide long term care and support to chronically ill patients and their families has been eroded therefore it is against this background that Home Based Care Programs have emerged as a valuable alternative to institutionalised Medical care (Irish Aid 2007).

The rapid spread of HIV/AIDS throughout Zimbabwe has created a burden on the already underdeveloped public health care delivery system. Hospitals and tertiary care facilities are becoming increasingly unable to look after their HIV/AIDS patients. Even though the wealthiest 10% of the country's population account for 51% of the country's income, Zimbabwe has one of the highest level of income inequality in the World and the health sector remains inadequately funded and resourced. Much of the burden of caring for the HIV/AIDS infected people consequently falls onto households and communities. Community Home Based Care programs have been established in the country and have since been bolstered by increased government grants and training for community health workers. Community Home Based Care services are necessary and important in addressing the complex needs of those affected by HIV/AIDS. The needs of people living with HIV/AIDS have formed the foundation for the development of a model of Community Based Home Care that could be applied in order to alleviate some of these needs.

Many of the caring tasks previously done by health care professionals are these days handled by Community Home Based care givers who are selected, trained and monitored by local authorities and local Organizations. Little attention however is given to the challenges facing the caregivers as they support the HIV /AIDS infected and affected people. This has led to high HIV/AIDS related deaths. It is against this background that the researcher sought to identify and present the challenges facing caregivers of the chronically ill as well as to identify the needs of people living with HIV/AIDS and their caregivers. People are dying due to lack of access to Anti-retroviral drugs, poor nutrition and lack of access to other resources that may be needed by the caregivers in the caregiving and supporting process.

Community Home Based Care (CHBC) has received wider attention in Zimbabwe for its capability to provide care for the chronically ill and PLWHA in their home environment. Community Home Based Care services are provided in a relatively cost effective, sustainable and comprehensive manner. CHBC has therefore been hailed for reducing congestion in hospitals, thereby reducing health/hospital expenditures in the face of increasing number of chronically ill. Apart from providing care and support to clients/patients, the programme also seeks to enhance or build the capacity of clients' families to offer affordable, quality care to patients.

The goal of Community Home Based Care is to provide hope through high quality and appropriate care that helps ill people and families to maintain their independence and to

achieve the best possible quality of life (WHO 2002). Families are the central focus of care and form the basis of the Community Home Based Care givers/ team from the community. Communities are places where people live and a source of support and care to individuals and families in need.

However in most cases, the caregiving program has failed due to various challenges the study seeks to discover and identify. It is the duty of the family, friends and the community to look after the sick however in some cases, people living with HIV/AIDS are neglected by their families as none of the family members will be willing to take care of them. Among this group, the provision of care falls disproportionately to women and older people which might be one of the challenges that will be discussed. In the case that the ill people are neglected, it is a full responsibility of Community Home Based Care Organizations and Voluntary Community Home Based Caregivers to take care and look after the sick people. The caregiving however fails or is ineffective due to a number of challenges.

The HBC project aims at reaching the most vulnerable people that is, the poorest households with PLWHA. Although this has proved difficult, it has been more effective in urban areas where HIV testing is available and needs assessments are carried out by social welfare departments. The home based care programme has focused on addressing the immediate needs of PLWHA. However, the Hope Humana Care Project is aware that it needs to identify strategies that target the medium- to long-term food security of other household members. Poor households are very often unable to find paid employment, which would enable them to purchase the food they need. In fact, they end up selling their assets in attempting to buy medicines and services to help PLWHA. Increasing access to income could play a key role in improving food security.

Although food provision remains an important part of the HBC, Hope Humana Care project is faced with a number of fundamental challenges including the capacity of the existing volunteer base. Growing needs and an increasingly diverse set of priorities within the Community Home Based Care program mean that volunteers are stretched to their limits so some are retiring which in the end will create a sad result as the HIV/AIDS related death rate will rise if the sick in communities are not attended to. It is within this context that the researcher found need to address issues affecting the Community Home Based Care programs in Zimbabwe, with specific attention to Hope Humana Home Based Care Program in

Mabvuku and then recommend measures that can be taken to address the challenges.

1.3 Statement of the Problem

Since the turn of the new millennium, Africa has been experiencing high HIV/AIDS related deaths due to poverty, failure of health institutions such as clinics and hospitals to support and care for the HIV/ AIDS people, lack of access to Anti-retroviral drugs and other reasons. It is this challenge which led to the emergence of Community Home Based Care programs for HIV/AIDS infected persons and other terminally ill people. Many of the caring tasks previously done by health care professionals are these days handled by caregivers and the situation seems to suggest that they will continue offering the bulk of care to the infected, however little attention is given to the caregivers needs and to the challenges or stresses they experience. HIV/AIDS is claiming so many lives, regardless of the Community Home Based Care program for people living with HIV/AIDS.

In spite of the numerous advantages of family care giving and the heavy care giving work placed on families and households by the HIV and AIDS epidemic, FCGs may not be adequately prepared in terms of support and resources.

HIV and AIDS care support programmes usually tend to concentrate on the care of PLWHA and not on the caregivers, especially the family members. As Limanonda (2004) observes, not much attention has been paid to the needs of family members who act as caregivers, most of whom are women. Yet, these caregivers are in a vulnerable position since they have to carry out other household chores in addition to providing care for PLWHA. It is within this context that the researcher raised concern over the challenges facing Community Home Based Caregivers of people living with HIV/AIDS and other chronically ill persons in Mabvuku. This study therefore seeks to discover the experiences, needs and gaps in the care giving program of Hope Humana in Mabvuku.

1.4 Purpose of the study

The study seeks to identify the challenges that Community Home Based Care Givers of people living with HIV/AIDS face as they look after the chronically ill people in

communities. After identifying the challenges the study provides coping strategies that can be implemented in dealing with the problems encountered by the care givers.

1.5 Research objectives

- ❖ To identify the challenges facing Community Home Based Care givers.
- ❖ To find out the type of support and resources available for the caregivers in HIV/AIDS programmes.
- ❖ To find out the appropriate support, caring or empowerment needed for the caregivers to continue with the charity work.
- ❖ To recommend various measures to curb the challenges.

1.6 Research questions

- ❖ Are there any impediments faced in the care giving program?
- ❖ If there are any, what are the challenges?
- ❖ What are the caring needs of the Community Home Based Caregivers?
- ❖ What is the available type of support from the parent Organization (Hope Humana)
- ❖ How can the caregivers in HIV/AIDS programs be empowered to deal with the challenges and for the sustainability of Community based care programs for the sick?

1.7 Significance of the study

The study was worthy carrying as it helped in understanding the challenges that affect Community Home Based Caregivers as they try and give care to the HIV/AIDS infected people and other ill people in the area. Besides enhancing the researcher's research skills, the study exposes the gaps left by other researchers in this field. Much focus has been on the effectiveness and the advantages of Community Home Based Care Programs so this study is significant as much focus is on the gaps left by other researchers. It enlightens people about the challenges facing Community Home Based Care givers of people living with HIV/AIDS and other terminally ill people.

The purpose of this study is to ensure that needs and gaps in the Caregiving program for people living with HIV/AIDS and other ill people are met and to come up with measures to deal with the challenges being faced. The study helps in encouraging people in Mabvuku and the whole of Zimbabwe at large to support the caregiving program for the betterment of their lives and for the sake of reducing impacts of HIV/AIDS in the community. The study is significant as it aimed at improving the quality of life and survival of people living with HIV/AIDS (PLWHA) and other ill people thereby reducing the impact of HIV/AIDS on individuals, families and Communities at large.

1.8 Conceptualisation/ definition of terms

Community Home Based Care is defined as any form of care given to ill people in their homes (WHO 2002). Such care encompasses the spiritual, physical, psychosocial and palliative activities. The International Federation of Red Cross and Red Crescent societies and National Societies (2003) defines Community Home Based Care as the support and care that people living with HIV/AIDS and other chronic illnesses receive in their homes, through their families and communities.

According to the UNAIDS (2003), the Community Home Based Care program aims to meet health and psychological needs of individuals, families and communities who are most in need. The main objective being to improve the quality of life and survival of people living with HIV/AIDS and other ill people in communities and also to maintain their dignity. It also helps in the reduction of stigma and discrimination of people living with HIV/AIDS and the further spread of the virus hence reducing the impact of HIV/AIDS on individuals, families and communities.

Community Home Based Care (CHBC) encompass the provision of care for the chronically ill and PLWHA in their home environment. It provides services in a relatively cost effective, sustainable and comprehensive manner, in a complementary approach to institutional care. CHBC has therefore been adopted for reducing congestion in hospitals, thereby reducing health/hospital expenditures in the face of increasing number of chronically ill. Apart from providing care and support to clients/patients, the programme also seeks to enhance or build the capacity of clients' families to offer affordable, quality care for their relatives.

Community home based care includes the provision of nutritional support to patients, training of caregivers, services rendered to patients by care givers, and most recently access to AIDS related treatment. Most of the caregivers have received some form of training, indicating some significant levels of capacity among care givers. However gaps still remain in terms of quality, duration, standardisation and inadequate refresher courses.

Hope Humana Care Program is a caregiving program by some people in Mabvuku who have volunteered to provide care and support to the HIV/AIDS infected people in Mabvuku under a certain Project Called Hope Humana People to People. The project operates internationally for the sake of the HIV/AIDS infected and affected people and for community development. This study will focus mainly with Hope Humana Care Program in Mabvuku (Harare).

The Hope Humana Harare project recognized the increasing vulnerability of households to HIV/AIDS as early as 2002 when it set up the Community Home Based Care Program for People Living with HIV/AIDS (PLWHA). The Hope Humana Care Program started in 2002 in Mabvuku when the project was established with a focus on prevention and fighting against HIV/AIDS. The project now focuses on three main areas that is, Prevention of transmission of sexually-transmitted infections (STIs) and HIV/AIDS, Care and support for People Living with HIV/AIDS and their families as well as advocacy.

In Zimbabwe there are currently more than 22 Home Based Care projects. Hope Humana Harare project trains volunteers recruited from Mabvuku community, often themselves infected with HIV, to become care facilitators. Currently the project has been working with four caregivers three female and one male. These volunteer care facilitators then support households with PLWHA in various ways, such as providing hygiene training for infection management, disseminating key health and nutrition messages, helping the bedridden clients to take their drugs as well as doing other basic domestic chores. They also work to reduce the stigma associated with HIV/AIDS.

The program however has been facing various challenges prior to the current crisis. The clients of HBC often lack basic needs such as food, shelter and clothing. In order to meet these needs the Hope Humana Project started to distribute small hampers to the HBC clients. However, due to funding constraints, distribution became erratic and the project is now unable to meet the ever- growing needs.

1.9 Limitations

With little time available for the researcher, the researcher hardly reached the participants. It was a rush program even though all target groups were reached therefore there was no time for the researcher to probe. The distance from where the researcher stays and the study area is short however despite that, the researcher struggled to get transport money to carry out the research for many days. Therefore due to financial problems the research was done within a short period of time.

1.10 Delimitations

The area under study is close to where the researcher stays. It is less than 50km from where the researcher stays thus it was easy for the researcher to get to the study area. The other advantage to this was that, the researcher had enough room to experience the whereabouts of the Community Home Based Caregivers in their operational areas. Also Hope Humana Care program, which is part of the study is where the researcher did her Work related learning so it was easier to carry out the research since the researcher had already familiarised with the area and with the targeted participants.

1.11 Ethical considerations

Ethical considerations are norms in research used for conduct. The researcher will make use of informed consent. All ethical considerations such as volunteerism of participants was observed. Participants were notified of the objectives of the research and of no rewards after participating. They were not forced to give information and were allowed to withdraw at any time. Participants were well informed about the purpose of this study in order to promote transparency and security of the participants.

The researcher also valued protection and prevention of participants from any harm, be it physical, emotional or psychological harm, meaning the questions that were asked were not sensitive on the part of participants. The ethic of privacy and confidentiality was observed in this research to ensure participants to share information freely without. To achieve this, participants' names were not taken down neither their phone numbers. Questionnaires guides were numbered for the analysis of data.

1.12 Conclusion

In this chapter, the researcher has given the background of the study, statement of the problem, purpose of study, research questions and defined key terms such as CHBC and PLWHA. Chapter two is an exploration into the literature related to the study.

2.0 CHAPTER TWO: REVIEW OF RELATED LITERATURE

2.1 Introduction

This chapter mainly focuses on literature that is in relation to the research topic, challenges facing community home based caregivers of people living with HIV/AIDS. The chapter looks into literature that is relevant to the study. There are many scholars who wrote about the coping challenges faced in the caregiving of people living with HIV/AIDS so the chapter seeks to explore literature from other scholars and to get rid of the gaps left by other researchers. The chapter also highlights when the Community Home Based Care Program was initiated in Zimbabwe, its history and formation, conceptualisation of CHBC and other important terms.

In Zimbabwe the HIV/AIDS epidemic began to spread in the 1980s after the first reported case of HIV/AIDS in 1985. Research on home based care indicate that most people cared for at home do not necessarily wish for it but accept it because the scale of HIV/AIDS epidemic and the inadequacy of health budgets in developing countries require it.

Zimbabwe is a landlocked country in southern Africa with a population of 15 764 255 people as of January 2016. Zimbabwe is currently experiencing its worst economic crisis since attaining independence from British rule in 1980, with an estimated 80% of the population living below the poverty datum line (United Nations Development Programme (UNDP) Human Development Index (2008).

Against this background, Zimbabwe is also experiencing one of the world's worst HIV epidemics. Since the first reported case of HIV in 1985, the epidemic has become a serious health, social and economic problem in the country. The global HIV/AIDS statistics state that since 2000, 38.1 million people have become infected with HIV and 25.3 million people have died of AIDS related illness. It is thought that over 3200 people die each week from AIDS-related illnesses (UNAIDS 2005), which also account for some 75% of all hospital admissions.

The impact of HIV, extremely harsh economic conditions and reduced funding from international donors have all combined to severely strain the delivery of health services throughout the country which led to the emergence of Community Home Based Care groups.

2.2 Formation/ evolution of Community Home Based Care

Understanding how Community Home Based Care in Zimbabwe has evolved is key in shaping future policies and implementation of CHBC activities in Zimbabwe. The HIV and AIDS epidemic has had terrible impacts on individuals and communities throughout Africa. Although Zimbabwe has demonstrated a declining trend in prevalence in the adult age group (15-49) primarily attributed to behaviour change, the prevalence of HIV continues to be unacceptably high simultaneously with the HIV/AIDS related deaths. Home Based Care arose as an alternative to the sad impacts brought by the epidemic.

Irish AID (2001) stated that the evolution of Home-based is not a new concept among African people. There has always been an expectation of providing care and support within families and communities. Traditionally, women were entirely responsible for caring for the sick while men provided support in the form of food, firewood, shelter and water.

The home care services offered to chronically ill persons prior to and soon after independence in the 1980s focussed on people who were terminally ill with illnesses such as TB, cancer and hypertension. The hospital environment was not congested, and could afford to care for ill patients longer. There was adequate medication for most ailments, including opportunistic infections. During this period, when terminally ill patients were discharged from hospitals to home care, the respective hospital assigned a community nurse to follow up on the patient, advice on basic nursing care and provide psychosocial support. This was a medical approach to care with a palliative (pain alleviation) focus. There were few terminally ill patients so hospitals could afford to assign community nurses for follow-up, while most households were able to accommodate a relative who was discharged for home care.

The Silent Epidemic (1980-1985) as early as 1981, AIDS was identified in the United States among the 'gay' community. Internationally prevention messages began to be communicated yet there was a general denial of the disease's existence in Africa. During this post-independence period, Zimbabwe experienced a silent epidemic until 1985 when the first case of AIDS was identified, but there was no publication of infection rates or illness. During this period there was also a notable increase in reported Sexually Transmitted Infection cases.

2.3 Medication, Sensation and Moralisation (1986-1990)

This period was characterised by the Government's shift from denial phase to acceptance and action. Government established the National AIDS Control Programme and engaged in the mobilisation of resources towards prevention. A key activity during this period was the production and dissemination of fear-inducing IEC materials. Messages such as "AIDS kills. Beware!" and pictures of skulls and crossbones and coffins were used on posters about HIV. The nature and character of the virus was sensationalised primarily by service providers, while at the same time, churches moralised about HIV and linked it to promiscuity and sin.

The Care and support needs of people living with HIV/AIDS and their families have been well documented yet over the years, the increasing demand of care and support has burdened already financially stretched hospitals and local clinics. The capacity of these health institutions to provide long term care and support to chronically ill patients and their families has been eroded therefore for many, Home Based Care Programs have emerged as a valuable alternative to institutionalised Medical care (Irish Aid 2007).

When the HBC program was introduced after the first reported case of HIV infection in Zimbabwe in 1985, it was characterized by fear, stigma and discrimination. In that same year, the Minister of Health and Child Welfare (Dr Parirenyatwa) established the National AIDS Coordination Programme (NACP) to manage the national response to the epidemic. Despite the fact that, Auxilla Chimusoro became one of the first individuals in Zimbabwe to open up about her HIV-positive status in 1985. From the single case identified in 1985, numbers of infected people increased to 10 551 by 1991, which put a lot of pressure on the health sector which was already strained by the Economic Structural Adjustment Program. The cumulative impact of neglect on non-productive sectors, such as health, caused a serious decline in the quality of services and shortages of essential drugs. Hospital beds became constantly occupied, resulting in more discharges and strict pre-admission screening processes.

As a result, hospitals began to send home people suspected of living with HIV when it appeared that they were not responding to the available treatments. Communities and families interpreted what they saw as a clear example of dumping of responsibilities by government.

The HBC offered from 1991–1995 took place within the context of a deteriorating economy but at the same time an increasingly intensive response to the HIV epidemic. During this period, many health-service indicators declined under the combined burdens of HIV, economic crisis and drought. However, many HIV focused Non-Governmental Organizations

(NGOs) came into being during this phase. In the absence of significant domestic investment, external donors funded many HIV-related programmes.

Caring from within organizations also began providing care and support to People Living with HIV/AIDS. In 1991, the Zimbabwe AIDS Network (ZAN) was formed to coordinate the activities of HIV service organizations in the country. More People Living with HIV/AIDS came forward to support advocacy and care for people infected and affected by the epidemic.

From 1999-2000 it was a period of recognition of HBC as an important approach in the response to HIV. With a weakening economy and a growing number of PLHIV, the government recognized that the health system alone could not cope with the impact of the epidemic hence there was need for help from the community.

It was at this time that HBC programmes and HIV/AIDS based NGOs engaged in the extensive training of volunteers and primary carers in order to meet the anticipated demand for HBC services. The delivery model shifted from a primary focus on volunteers as primary care providers to volunteers becoming facilitators of care by training family members as primary caregivers.

Between 2001 and 2005, it was estimated that approximately 3000 people were dying of AIDS related conditions every week (UNAIDS 2005). During this period, inflation skyrocketed and many people in Zimbabwe were unemployed. At this time, close to 500 organizations were providing HBC services and support. Economic challenges in the country had already resulted in a substantial 'brain drain' of professional talent from Zimbabwe, including health-care workers, which contributed to the disintegration of the hospital-linked models of HBC. HBC programmes became increasingly dependent on churches, NGOs and communities with only minimal support from either the government. In addition, communities and programme implementers began to recognize the significant 'gendered' aspects of HBC provision, which placed the burden of care squarely on the shoulders of women, and calls were first heard for more male involvement in HBC.

In 2001, the Community Home-Based Care (CHBC) Policy came into being. Its purpose was to ensure that there would be continuity of care from health-care institutions to the community. It prescribed a minimum package of care to highlight the value of community home-based care to the people of Zimbabwe. The policy also helped to raise awareness about available resources, encouraged support for the community and local health-care providers, and provided an overall framework for caregivers in the implementation of CHBC priorities.

However, most HBC programmes and services fell short in terms of the quality and effectiveness of their service provision.

The National Community Home-Based Care Standards (2004) and the National Home-Based Care Training Manual (2005) were developed to help standardise HBC activities, training and other processes. Their purpose was to give programme managers and care providers a foundation from which to identify gaps in their services and to seek the training and support they needed. In addition to these HBC focussed efforts, one of the most significant changes in AIDS care also came to Zimbabwe in 2001. A 'Plan for the Nationwide Provision of anti-retroviral therapy' launched that year recommended that ARV treatment be introduced initially at a limited number of central sites and gradually decentralized to the provinces as more health personnel received in service training. Availability, affordability and accessibility of ARVs were identified as important gaps in HIV programming in the country.

The sixth stage is the current state of HBC in Zimbabwe, beginning in 2006. Although the government has shown political support for HIV, responding to the crisis has largely been hampered by political problems and diminished international humanitarian support for the country. Many HBC programmes and services are operating under terrific strain and hardship, with very little support. In 2006, the government launched the Zimbabwe National HIV/AIDS Strategic Plan (ZNASP), which articulated the direction and targets for the national response to HIV during the period 2006 to 2010.

The plan introduced the concept of universal access to prevention, care and treatment services. It also highlighted the need to care for volunteers and to enhance male involvement in HBC programmes, however, the economic fallout and growing poverty in the country have thrown a serious blow to HBC activities. Many funding organizations have either reduced or frozen aid to humanitarian activities in Zimbabwe. In 2005, UNICEF estimated that the average amount of international HIV-related funding available each year in the southern Africa region was US\$ 74 per person infected with HIV, but in Zimbabwe 22 Caring from within that figure drops to US\$ 4.

Although Zimbabwe has a high rate of HIV prevalence, the available resources are far below the needs of the national response (UNGASS 2007). Reduced donor support is currently undermining the effectiveness of HBC programmes as organizations either scale down or reach out to clients with very limited services. Although volunteer caregivers are keenly

aware of the needs of PLHIV, their efforts are hampered by a lack of basic provisions: medication, gloves, soap, food and other basic supplies.

Many of the caring tasks previously done by health care professionals are these days handled by Community Home Based care givers who are selected, trained and monitored by local authorities and local Organizations. Little attention is however given to the challenges facing the caregivers as they support the HIV /AIDS infected and affected people. This has led to high HIV/AIDS related deaths. It is against this background that people are dying due to lack of access to Anti-retroviral drugs, poor nutrition and lack of access to other resources that may be needed by the caregivers in the caregiving and supporting process.

2.4 Benefits of community home based care

Much of illness care takes place within the home. Much of the care for people living with HIV/AIDS and other ailments is provided at home by other family members, friends as well as Home Based Care Organizations. Providing care for such people has benefits for both the infected and the affected people, yet there are many failings in the support given by careers. Most people would rather be cared for at home and the effective home care improves the quality of life for all sick people and their family caregivers.

The benefit of the Community Home Based Care Program is that at home, ill people are usually surrounded by close relatives and other members of the Community whom they love and are familiar with as well as understanding their situation better. Therefore they can easily receive more flexible and nurturing care. They will also not be exposed to various hospital based infectious diseases. Strengthening the capacity of being cared for also removes the cost and distress of travelling to and from the hospital when they are weakest. It also promotes one on one care, independence, confidence and comfort for the client thereby promoting peace of mind. This is so because Community Home Based Care bridges the gap between family/community on the other hand and the health system and services on the other of which full support of both sides is needed.

Griswold care foundation alludes that Home based care keeps the comforts of home:

The things the patient loves are kept close by. S/he can use the chair s/he loves, can take the food. At home one gets the most wanted company contrary to when one is in hospitals with people from various backgrounds (strangers).

2.5 Conceptual framework

Community Home Based Care is defined as any form of care given to ill people in their homes (WHO 2002). Such care encompasses the spiritual, physical, psychosocial and palliative activities. The International Federation of Red Cross and Red Crescent societies and National Societies (2003) defines Community Home Based Care as the support and care that people living with HIV/AIDS and other chronic illnesses receive in their homes, through their families and communities. Much of the illness takes place within the home. Much of the care for people living with HIV/AIDS and other ailments is provided at home by other family members, friends as well as Home Based Care Organizations. Providing care for such people has benefits for both the infected and the affected people, yet there are many failings in the support given by careers. Most people would rather be cared for at home and the effective home care improves the quality of life for all sick people and their family caregivers.

The goal of Community Home Based Care is to provide hope through high quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life (who 2002). Families are the central focus of care and form the basis of the Community Home Based Care givers/ team from the community. Communities are places where people live and a source of support and care to individuals and families in need.

2.6 Theoretical framework

Gill and Johnson (1997), accurately observed that, every decision we make or take in life is grounded in theory. This section therefore will explore various theories that explains better issues related to the research topic.

2.6.1 Human Development Index

The United Nations Development Programme Human Development Reports allude that development is termed development if the human being is developed first. The human being is developed if educated, has got access to education and health services. The human development index by Amartya San was created to emphasize that people and their capabilities should be the ultimate criteria for assessing the development of a country, not

economic growth alone. It is a summary measure of average achievement in key dimensions of human development, a long and healthy life, being knowledgeable and having a decent standard of living.

The Human Development Index states that the health dimension is assessed by life expectancy at birth, the education dimension is measured by mean of years of schooling for adults aged 25 years and more and expected years of schooling for children of school entering age. The index only captures part of what human development entails.

This theory is applicable in the study considering the study is health related and in assessing whether the needs of the caregivers are met or not and this includes quality education as well as health facilities. The theory in this essence therefore promotes the fact that caregivers should be educated and have access to good health services before they reach out to patients. If the basic needs (education and health) are not met, that is a clear pointer to the challenges being faced in the caregiving program. If challenges are identified there will then be need to adopt coping strategies to the various challenges faced. The coping theory identifies and explains the coping techniques which can be adopted in the field to get rid of the challenges facing the caregivers.

2.6.2 Feminism theories

The Marxist feminism theory states that men are relegated at the top of the economic hierarchy whilst women are relegated at the lowest ends, undertaking unpaid work as mothers and wives. In most cases, women are regarded as the property of men, therefore it is in this line that the caregiving program becomes a burden for the caregivers, considering in most communities, 90% of the caregivers are women. They suffer transient poverty as they are regarded a property for men and this means they won't be able to meet the financial needs for the caregiving program.

The African feminism theory by Chimamanda Ngozie Adichie also states that the African women is more oppressed as compared to the European lady, due to culture, religion and ethnicity. This explanation on its own points to the reason behind failure of the Community Home Based Care Program in some instances, who are the Caregivers in communities are largely oppressed by culture which forces them to be reliant on men. They cannot have the strong financial stance to fund and meet the needs in the Community Home Based Caregiving process and that lack of financial muscle and voice in homes is a challenge on its own, which

is impeding the Community Home Based Care giving program. The research will help in bringing out more challenges that are impeding Community Home Based Care Givers of people living with HIV/AIDS and other terminally ill persons.

2.6.3 Coping theories

Antonovsky A quotes Richard Lazarus and Susan Folkman who stated that coping constitutes the actions taken by individuals and animals when faced with stressful events in order to lessen the threat to them. Stress is a state of tension felt in the presence of an object or a task that is perceived as presenting a challenge to one's safety or self-esteem. Stress emanates when there is a perceived discrepancy between environmental demands and one's ability to meet those demands. Stress has both psychological and physiological causes and effects. For an individual to continue functioning in an adaptive way, s/he must learn to cope with stress.

There are many ways to cope, varying from avoiding stress or denial of stress at one extreme to seeking and confronting the source of stress. According to Magill coping attempts either to reduce the demand, to reduce its effects, or to help one change the way one thinks about the demand. It also attempts to eliminate or moderate the initial source of the stress reaction, reduce the magnitude of the stress response (response-directed coping), or change the way the stressor is perceived (cognitive coping). For individuals such as caregivers in the HIV and AIDS field, both the internal factors (such as knowledge) and external (such as money or friends) are necessary to help one cope with a stressful event. Social support or resources provided by other people to enhance one's self-esteem, psychosocial support, and assistance are critical in helping the coping process.

2.7 Challenges facing caregivers of people living with HIV/AIDS

2.7.1 Lack of Knowledge

The plight of caregivers of people living with HIV/AIDS arise from the social, cultural and political dimensions of caring as defined by society. Jackson and Anderson (2001) posit that the burden of caring for the HIV/AIDS patients falls increasingly on family members who do not only lack knowledge and information but in most cases do not know the patient's diagnosis although they may think it is Aids. This therefore appears to be the number one challenge of community home based caregivers of people living with HIV/AIDS. They lack

knowledge hence the caregiving work can be a difficult task for them since they would not be knowing what is required of the sick person.

Adding on to that, lack of knowledge by the caregivers has posed a serious risk of contracting HIV/AIDS. There is very little training if any for caregivers yet they are expected by the health team and community to provide care given the multiple roles and problems caregivers are faced with. Phaladze (1999) reported that the risks of perceived cross infection in CHBC was big. He reported that he always shivers when he thinks of a situation where an entire family could be wiped out due to cross infection in CHBC because the family has not been fully prepared to handle AIDS clients.

Nodding (1984) posits that for care giving to be complete, it has to be recognised by the cared-for person, which is at times hard to establish. For untrained care givers, another potential risk associated with caring for HIV I AIDS clients is the increased probability of contracting the virus due to exposure. For instance, if the caregiver has become too committed to caring for the other, they cannot be preoccupied with self, thus compliance with universal precautions to prevent cross- infection could be neglected, and as a result the caregivers' own health needs may be compromised hence leading to the contracting of HIV. Similarly, Jagger and Bordon (1992) point out that the essential aspect of caring is that it involves a displacement from one's own interests to the interests of the one cared for. Caring affects the one caring because she must become engrossed in the other. It also affects the cared-for because that individual's needs are met by others, and because that individual must somehow respond and accept the care offered. They further argue that caring cannot simply be a romanticised notion of selflessness, nor can it occur if the self remains aloof. Family care giving as a social phenomenon implies that there is a social and political dimension to it. To gain some understanding in home based care a review of the concept is critical.

2.7.2 Poverty/ financial costs

Narayan (2000) concurs that poverty is pain, poor people suffer physical pain that comes from little food and long hours of work, emotional pain stemming from the daily humiliations of dependency and lack of power. The HIV/AIDS epidemic has introduced a new long term trend in impoverishment especially in the developing countries. If the victim of the epidemic is the breadwinner, the household of the victim if s/he lacks family support becomes poorer. This then strains the caregiver of the victim as he or she will be forced to cater for the food expenses, expenditure on travel to get the antiretroviral drugs and hospital fees.

Jack and Anderson (2001) supports the view as they pointed out that AIDS is a major factor in the impoverishment of families as they lose productive household and subsistence. Many families resort to spending savings, selling productive assets and removing children especially the girl child from school and reducing their long term security to finance the present crisis. This clearly shows that Community Home Based Caregiving is not a cheap task for the families and the care givers involved.

Steinberg et al (2002) shared the same sentiments when he said ,where someone was either sick or had died due to HIV/AIDS related illnesses, more than 20% of the caregivers had diverted time from work or informal income generating activities to provide care in the home. They also asserted that paying for medicine or hospital bills especially once the opportunistic strike had taken up most of the income. Therefore literature reveals some of the economic constrains caregivers face as they look after the chronically sick in communities. This does not motivate the caregivers but rather demotivates them and cause some of them to retire from the caregiving work.

The challenge of finance concurs with observations from the research carried out in Kenya pertaining Home Based Care, NACC (2000) asserts that ARVs are free in Kenya since early 2005 but the user bears that cost of medical support services such as tests, medication and treatment for opportunistic infections as well as transport. The caregivers more often than not meet the costs. From the research one of the caregivers' response was ' My economic status has gone down, I have stopped building rental houses I had started, when I get little money all goes to medication and feeding of the sick'. This is a vibrant indicator of the economic or financial hassles caregivers of people living with HIV/AIDS face as they try to help their relatives, friends and community members recover from the illness.

Jackson and Anderson (2001) report in relation to the stated challenge adds on to say, AIDS is a major factor in the impoverishment of families as they lose productive household and subsistence labour. The Botswana Human Development Report (2000) supports the assertion as it goes on to state that, 47% of the population in Botswana is reported to have been living in poverty. The poor sanitary conditions in both urban and rural areas pose real danger to both the patients and caregivers as well. This shows that financial constraints on the part of the caregivers is the one of the major impediments in the caregiving of people living with HIV/AIDS hence the challenge is to be addressed.

2.7.3 Stigma

WHO/MOH (2000) reports that the experiences of stigma goes beyond issues of HIV/AIDS and is also experienced by people and families living with other chronic illnesses. Literature reveals that stigma prevents people living with HIV/AIDS from accessing health care services. It was reported that some families have refused care because they did not want their neighbours to see an NGO or Community Home Based Care team member enter their homes, for fear of isolation. This therefore can be a challenge to the caregivers who are supposed to look after HIV/AIDS infected members of such families as they sometimes lack motivation, encouragement and support. Noberck et al (1991) in support of the view asserts that, Findings from caregivers' studies of stigmatised conditions also show a consistent pattern reflecting lack of support. If they are voluntary caregivers from the local community, reports are that they are regarded as HIV/AIDS infected too hence the caregivers sometimes are discriminated or isolated by their neighbours or the nearby community.

2.7.4 Lack of Social Support

Noberck et al (1991) Shaibu (1997) asserts that caregivers experience a lot of difficulties while caring for their loved ones which include acceptance of the patient's diagnosis, commitment by others to the patient, informational needs related to the illness and management for helping accessing resources, need for respite care and direct help with care giving activities. In some instances however the community home based care givers lack support and commitment by even the client or patient being looked after.

Robinson and Austin (1995) posit that depressed caregivers might perceive caregiving problems to be more severe and resources might seem less available to them than they really are. This is true of the challenges facing caregivers however there are gaps as literature does not specify society perceptions on the Community home based caregivers of which that might be an issue of concern when discussing about the challenges facing community home based caregivers of people living with HIV/AIDS. The researcher will research more on that and other gaps in literature concerning the coping challenges facing community home based caregivers of people living with HIV/AIDS specifically in Mabvuku.

2.7.5 Fear of death

Robinson and Austin (1995) observed that, depressed caregivers might perceive caregiving problems to be more severe and resources might seem less available to them than they really

are. More to that, if the caregiver experiences an actual or perceived lack of support, it may intensify the impact of negative feelings. It is a challenge to the care givers especially elderly people as they would be worried of what would happen to the terminally ill person and wondering if they should die before themselves. The major source of caregiving suffering is that fear of the inevitable death of clients suffering from HIV/AIDS. The fact that HIV/AIDS has no cure and all patients suffering from the disease will eventually die is a threat to the caregivers. Although many believe that death is part of life, caregivers have faced difficulties in dealing with the losses currently experienced as a result the pandemic. Therefore it is noted that if not well counselled, Community home based care givers will always suffer from depression as they fail to accept the reality of life and the depression may further negatively impact the caregiving process by reducing the energy to build and maintain supportive relationships with clients.

2.7.6 Gender imbalance

It is observed that women occupy the bigger percentage of those who are into caregiving. There is little scholarly attention on issues of Gender in Community Home Based Care program therefore this study will fill in the gaps left by other researchers. In Zimbabwe, Irish Aid report of Community Home Based Care program in Mutasa District states that in 2000, out of the 300 caregivers, there were only 6 men and the rest were women. The issue of gender imbalance poses to be a serious challenge facing community home based caregivers not only in Mabvuku but in many African countries, considering the position women hold in African societies as elaborated by the feminist theories. When there is gender imbalance the caregivers find it difficult to deliver the appropriate and required services to clients, for instance a female caregiver cannot bath a male client even when there is need.

Therefore, from this observation, the researcher focuses on the gaps in literature concerning challenges faced by community home based caregivers of people living with HIV/AIDS.

2.8 knowledge gap

There is a huge informational gap pertaining to challenges facing community home based care givers of people living with HIV/AIDS. There is little data published in Zimbabwe, only the Irish Aid has managed to come up with a report concerning some of the caregiving hassles, however it is not everything which was touched on. Literature left a lot to be desired

and researched. Only external challenges are exposed in literature however it is of the researcher's knowledge that there are also internal factors or challenges that caregivers encounter as they carry out their caregiving roles such as emotional destruction, stress and demotivation by even their clients, among many other challenges to be presented.

The available literature is not current and it does not explore current information since now. The research findings cannot be generalized, what can be a caregiver's challenge in Europe might not be a challenge in Zimbabwe because of differences in economies, technological advancement, and cultural values hence strategies employed by American caregivers might be different from strategies that can be employed in Zimbabwe.

More to that, there is little information on strategies to cope with caregiving stress and to get rid of the challenges, of which the research under study seeks to highlight on the section of recommendations.

2.9 Conclusion

Chapter 2 revealed literature related to the challenges faced by Community Home Based Care Givers of People living with HIV/AIDS, how the Community Home Based Care program came into action in Zimbabwe, why it was initiated, its goals and benefits. It clearly stated how the challenges faced can affect the care givers and the effectiveness of Home Based Care Programs. The next chapter focuses on the research methodology used by the researcher in carrying out the study.

3.0 CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

This chapter focuses on the research methodologies used in carrying out this study. It discusses and explains the research design, target population, sample and sampling techniques. Data collection instruments to be used are also discussed in this chapter as well as the advantages of using the research instruments. The chapter also highlights data collection procedures used.

3.2 Qualitative research methods

Qualitative research is a method of inquiry employed in many different academic disciplines including in the social sciences and natural sciences but also in non- academic contexts including market research, business and service demonstrations by non-profits. Qualitative research methods were used specifically to give an insider perspective, allowing one to view the World through the eyes of the actors themselves (Babbie and Mouton 2001). Qualitative methods examine the why and how of decision making, not just what, where, when or who. The research methods produce information only on the particular case studies. In the 2000s it has also been characterised by concern with everyday categorization and ordinary story telling. Qualitative research methods are mostly theoretical and descriptive unlike quantitative whereby data is presented in statistical terms. Qualitative methodologies include interviews, focus group discussions and participant observation among many other research instruments and for the research, interviews and focus group discussions were employed, not forgetting participant observation during the interviews.

3.3 Research design

According to Robinson, Research design is a blueprint for research, dealing with at least four problems: which questions to study, which data is relevant, what data to collect and how to analyse the data. It can be classified into fixed and flexible designs.

Fraenkel and Wallen (1996) define research design as an overall plan for collecting data in order to answer a research question. It also refers to specific data analysis or techniques the researcher intends to use. Gilbert et al (2002) state that a research design is a framework or plan for a study used as a guide in collecting and analysing data. It is a blueprint that is followed in completing a study. In this case, the researcher used a case study. A case study research is one of the approaches to qualitative research. A case study is defined by Borg and Gall as an in depth study of instances of a phenomenon in its natural context and from the perspective of the participant involved in the case being studied.

According to Best and Kahn (1993, 12), a case study examines a social unit as a whole and it is a longitudinal approach showing development over a long period of time. Creswell (1994) says case studies are a type of qualitative research in which the researcher explores a single entity or phenomenon bounded by time and activity (programme, event, process, institution or social group) and collects detailed information by using a variety of data collecting procedures in a sustained period of time. Therefore from the scholars' explanation, a case study examines a social unit as a whole. The unit may be a school, hospital, community or any social institution or even a person. A case study thus shades more light on a phenomenon which is of interest to the research. In this case, the researcher focused mainly on Hope Humana Care Program in Mabvuku, Eastern part of Harare. Gwimbi and Dirwai (2003) posed that a case study is studied in its own right and not as a sample population. A case study probes and analyses interaction between members in the unit, thus it should make the researcher reach solutions to certain problems. The important part being to understand the life or important part of a unit.

A phenomenon normally has many aspects and the researcher has to choose a specific aspect for investigation. In this case the research focuses on the coping challenges facing community home based care givers of people living with HIV/AIDS. This provides a reasonable study area that is coverable within the limit of time and resources. The researcher chose a case study because it investigates and analyses deeply groups and individuals. It also focuses attention in one specific area and this enables the researcher to spend more time in studying one major issue within the study area. The other advantage of a case study is that findings of the research can be used to foretell the challenges faced by Care givers in the future. This will help in putting measures that will mitigate the negative impact of the challenges encountered by caregivers as they care for the chronically ill in societies.

Though useful, the case study has some limitations because the findings of the research may only be relevant to the specific area under study and may not apply to the whole world. The researcher however felt that the shortcomings were not significant enough to remove the validity of the research findings.

3.4 Population

Population is a set of people to which statistical inferences are to be drawn, according to Castillo (2009). The scholar says, target population is the entire group of individuals to which the researcher is interested in generalising the conclusions and usually has varying characteristics, hence also known as theoretical population. Charles (1988) also defines a population as all the individuals who have in common a particular trait that causes them to be recognized as a group. This therefore means that a population is a group of people with one or more characteristics in common, which are of interest to the researcher. In this study, the target population is made up of Hope Humana staff, Voluntary Community Home Based Care givers in Mabvuku and families in Mabvuku with chronically ill people or people living with HIV/AIDS (PLWHA).

3.5 Sample

A sample is defined as any group on which information is obtained. It is a portion of the overall population that one wishes to study (Leddy 1993). For this study, the researcher drew her samples from the population comprising of Hope Humana Harare staff members and Voluntary Care givers in Mabvuku as well as families with the HIV/AIDS infected patients being cared for. This was done to ensure minimum bias on the obtained information.

The researcher's duty was to choose participants for the focus group discussions and informants for the interviews. The researcher selected only two of Hope Humana Project Staff to give general information about the project and challenges faced in the care program. With the help of other staff members, the informants were asked to give their views about the challenges faced by Hope Humana Voluntary Caregivers of people living with HIV/AIDS and how it impacts their coping strategies for the patients. The caregivers and affected

families have been included in the sample since they are the ones being affected by the challenges in caring for the HIV/AIDS infected people.

Woods (1985) defines sampling as a process of selecting a number of individuals for a study in such a way that the individuals accurately present the larger group from which they are selected. Sampling gives one the allowance to study a small portion of the population rather than the entire population. According to Best and Kahn (1993), a sample should not be haphazardly selected but should be chosen deliberately. Non probability sampling was used in this case.

For this study, the researcher used purposive sampling. Purposive sampling is a sampling method whereby elements are basing on a specific purpose of study. The researcher chose a sample best appropriate for the study as recommended by Fiske (1996) who says, ‘The researcher will choose a sample based on who they think will be appropriate for the study. This method was relevant because it reduces time consumption in enquiring people who are irrelevant to the subject hence reducing the time cost for carrying out the research.

Gender is a sensitive variable that may affect the outcomes of the research study, therefore the researcher allowed the participation of both males and females even though there was a slight imbalance between the male participants and female participants since most of the caregivers are women. The researcher had a target population of six (4) key informants (two from Hope Humana project and two secondary caregivers), 10 Hope Humana Voluntary Care Givers and 20 HIV/AIDS affected and infected families in Mabvuku. All in all the sample size was thirty two (32) considering the two caregivers who participated in the interviews are the same who participated with the other eight caregivers in focus group discussions.

3.5.1 Sample size table

SAMPLE	SAMPLING TECHNIQUE	SAMPLE SIZE
Hope Harare caregivers	Purposive sampling	10
HIV/AIDS patients/ affected individuals	Purposive sampling	20
Key informants (two of Hope Harare staff, two lead matrons of the caregivers)	Purposive sampling	4

3.6 Data collection instruments.

These are instruments or tools used to collect data or information from participants. Instruments need to be valued, reliable and must be understood by respondents so that the researcher gathers correct data. Data collection instruments encompass Interviews, questionnaires, participant observation and focus groups among many other methods.

For this research, the researcher made use of the most common methods of data collection in qualitative research, this encompass in-depth interviews, focus group discussions and participant observation for various reasons that will be discussed below. The researcher carried out a discussion with all the ten caregivers and conducted in-depth interviews with the four key informants, two of Hope Humana Staff and two secondary caregivers. Half of the targeted HIV/AIDS affected or even infected individuals was reached for interviews, being ten from the affected families.

3.6.1 Interviews

The researcher made use of in-depth interviews. Three interview guides were prepared for the sample. One set of questions was administered to Caregivers' key informants and the rest of Hope Humana caregivers in a focus group discussion, the other set of questions was used to interview the patients and affected individuals whilst the third set of questions was used for Hope Humana staff/ key informants. Open ended questions were used and they allowed the researcher to probe whenever it was necessary.

According to Robson (1997) an interview is a conversation between the interviewee and the interviewer with a purpose. The interviewer initiates it for the specific purpose of obtaining relevant information for the research (Cohen and Manion 1995). The interview technique was used to obtain information from professionals, the patients and caregivers who have the first-hand knowledge about the caregiving program and its challenges.

Advantages of using interviews

Open ended questions were used and they allowed the researcher to probe when necessary. Face to face interviews were held with the key informants, that is two of Hope Humana staff and two secondary caregivers and two members from the affected families. Interviews are a flexible and adaptable way of data collection. Interviews are also preferred as they give instant feedback to the interviewer. Interviews also offer the allowance to modify one's enquiry thus one could easily follow and probe interesting issues rising during the interview, which cannot happen if using a questionnaire.

According to the Mountain States Group (1999), Key informant interviews from a wide range of sectors allows to look at varying perspectives and underlying issues or problems. Detailed and rich data can also be gathered in a relatively easy and inexpensive way and it provides an opportunity to build or strengthen relationships with important community stakeholders.

Interviews provide a deeper understanding of social phenomena than would be obtained in quantitative methods such as questionnaires. Interviews also allowed the researcher to have control over the conversation and the interviewees did not see the researcher's questions before they were asked to respond therefore interviews promotes transparency and allows the interviewer to gather proper and correct information. It was most appropriate for the study as it guards against non-response from the participants, which is common when using

questionnaires. Also, in an interview one can observe non-verbal responses from the participants either through facial expressions or any other non-verbal actions which are important in bringing out possible changes in the meaning of some aspects. Therefore interviews helped to show the researcher the attitude, opinions and judgements of respondents. They also motivated respondents to give more valid answers on the challenges facing community home based caregivers of people living with HIV/AIDS.

Disadvantages of interviews

Every data collection instrument has its pros and cons. Interviews If not carefully coordinated, the interviewer might end up gathering irrelevant information to the study. Interviewees also can give information that they think is of best interest to the interviewer. Also if not well managed, interviews are tiresome and time wasting to the interviewer. Interviews are tiresome as they required the researcher to seek permission first from the local authorities and the project leaders to carry out research in their area and under the stated Organisation. The researcher had to make arrangements as well with the interviewees and had to visit them therefore interviews from this side of the coin are a tiresome method. However despite all that, the interview technique remained a useful method of gathering information from the caregivers' representatives and their leaders.

3.6.2 Focus group discussions

Focus groups are a qualitative data collection method that emerged in the 1940s with the work of Merton and Fiske who used focus groups to conduct audience studies. A focus group is a form of qualitative research in which a group of people are asked about their perceptions, opinions, beliefs and attitudes towards a product, service, concept, advertisement, idea or packaging.

Questions were asked by the researcher in an interactive group setting where the caregivers were free to talk with other group members. During this process, the researcher took notes and recorded the vital points arising from the group. For the focus group discussion with the caregivers, the researcher used one set of discussion questions which had been used to interview two of the secondary caregivers.

Advantages of using focus group discussions

Group discussions produce data and insights that would be less accessible without interaction found in a group setting. The other advantage is that, listening to others' verbalized experiences stimulate memories, ideas and experiences in participants (Lindlof and Taylor, (2002). In group discussions also, group members discover a common language to describe similar experiences. This enables the capture of a form of native language or vernacular speech to understand the situation. Lutgen-Sandvik and Alberts (2006) alluded that focus group discussions also provide an opportunity for disclosure among similar others in a setting where participants are validated, therefore use of focus groups serve as both an efficacious and ethical venue for collecting the required data.

Focus group discussions in this study were desirable as they helped the researcher to hear the caregiving experiences of every caregiver which strongly helps the researcher in addressing the research problem, in this case being the challenges facing community home based care givers of people living with HIV/AIDS.

Disadvantages of focus group discussions

The challenge with focus groups is the use of observer dependency, that is, the results obtained are influenced by the researcher or his or her own reading of the group's discussion. Another issue with focus groups is that participants may either hold back on their responses and try to answer the researcher's questions with answers they think the researcher wants to hear, therefore in the end the researcher might not get the proper data he or she should get. Focus groups can also create severe issues of external validity, especially the reactive effects of the testing arrangement which creates bias.

3.6.3 Participant observation

Participant observation is one type of data collection method typically used in qualitative research. According to Babbie and Mouton (2001), observation can be in form of simple observation, where the research remains an outside observer or participant observation where the participant becomes a member of the group being observed.

It is a widely used methodology in many disciplines. Its aim is to gain a close and intimate familiarity with a given group of individuals. During the interviews, the researcher observed the attitudes and the way participants responded which gave the researcher an insight of the current community home based care situation and of the challenges being faced by the caregivers of people living with HIV/AIDS. Participant observation was also used during the focus group discussion with all caregivers.

Advantages of participant observation

Participant observation gives the researcher access to situations and people where questionnaires and interviews are inappropriate to use. The researcher is able to get an insider viewpoint and the information may be much richer than that obtained through systematic observation.

Disadvantages of participant observation

Events are interpreted through the single observer's eyes. It generally involves taking extensive notes and writing down one's impressions of which there can be bias in interpreting people's expressions or reactivity to questions. This thereby deceives the interviewer and gives him or her wrong feedback.

3.7 Sampling procedures

The following steps were used by the researcher to enhance the collection of comprehensive data from the field. Much attention was on the use of simple and clear language to ensure that the instruments bring out exactly what the researcher wanted to know from the research. Interviews and participant observation were consolidation measures to the focus group discussion. The interviews were carried out after revealing a letter from the Midlands State University for transparency reasons and for emphasis on the value of the study. The researcher got permission from the Midlands State University. Again permission was given by the project leader of Hope Humana Project in Mabvuku, which is the mother board for the voluntary care givers of people living with HIV/.AIDS in the area where the research was being carried out (Mabvuku). Informed consent was obtained from the respondents and the

researcher moved around the caregivers and patients' homesteads. Interviews were conducted with the key informants mentioned and a focus group discussion was carried out the following day, whereby the researcher looked closely at participant observation in collecting data.

3.8 Data analysis procedures

As Leedy (1996) Data analysis involves the ways and means of measuring figures. After collecting data, it is organised, presented and analysed to give meaning to the research finding. The researcher will use qualitative analysis. Data analysis will assist the researcher in making decisions and generalising the research area. The researcher summarised the answers from respondents to give a clear picture of the findings and meaning to the obtained data. Information from interviews was written down on sheet of papers according to the way it was conducted. Discussions were used to present data obtained from the research as will be presented or addressed in chapter four (4).

3.9 Conclusion

In this chapter the researcher described the research methodologies used and presented the research design, sample, sampling procedures. Instruments used to collect data were also stated and justified. Data analysis procedures were explained. The next chapter will focus on data presentation and discussions.

4.0 CHAPTER FOUR: DATA PRESENTATION, ANALYSIS AND DISCUSSION

4.1 Introduction

Chapter four constitutes data presentation analysis and discussion. Data found from the research will be presented and discussed in the chapter, that is, the impediments encountered by Caregivers of people living with HIV/AIDS. The findings are presented according to research questions. The demographic rate of respondents is also presented in the chapter.

4.2 Demographic characteristics of respondents

The researcher used a sample of thirty two (32) participants. Ten of the respondents were the Caregivers of people living with HIV/AIDSs, the other targeted twenty were individuals (both the infected and affected) from the HIV/AIDS affected families whilst the last two respondents were Hope Humana Project key informants.

4.2.1 Sex

Of the ten (10) caregivers who participated in the research, nine of them were women whilst the tenth is male, being the only male caregiver under Hope Humana Project. From the HIV/AIDS affected families, only ten people were participated in outlaying the data. Of the ten affected individuals, five were women whilst five were men. From the mother Organisation, one was male and the other one female.

4.2.2 Age and marital status

The age of all caregivers range approximately from fifty (50) and above. Interviewees from Hope Humana Project are approximately 35 years of age whilst individuals from the affected families were of approximately 30 years and above. All respondents disclosed their marital status and all of them were married except only one who disclosed his HIV status and said he is single. He is one of the patients.

4.2.3 Response rate

Target group	Targeted sample	Responses	Response rate
Caregivers	10	10	100%
Hope Harare informants	2	2	100%
Patients	20	10	50%
Caregivers' key informants	2	2	100%

Three sets of interviews were used and most of the respondents participated but the patients did not all participate. Only ten HIV/AIDS affected individuals out of the targeted twenty responded. The reason being that some were not comfortable to disclose the information concerning the challenges they face as well as those faced by their caregivers. They feel the fact that they are HIV/AIDS is a too sensitive issue to discuss about, therefore ten of the approached infected and affected individuals refused to participate.

4.3 Community Home Based Care Situation

In essence, contemporary community home-based health care encompasses caring for HIV and AIDS patients so that they live longer, mainly through educational measures as its mandatory issue, asserted Van Dyk (2005). Nevertheless, many people are dying at a higher rate than would be expected in Mabvuku and in other parts of Zimbabwe. The present situation in Zimbabwe therefore leaves much to be desired in terms of addressing the problems of the community home-based care system. It is against this background that this study attempts to determine what hinders community home-based health care from meeting its goal of ensuring a relatively longer life for HIV and AIDS patients and other related diseases, since a vast number of people is dying at a very high rate, as proven by high rate of HIV/AIDS related deaths as well as the high rate of orphans in the country.

The Zimbabwean government through the National Aids Council has come to the realization that Home-Based Care (HBC) plays a vital role in the response to HIV/AIDS. This is a key strategy to an overwhelmed public health and welfare system. With the weakening economy combined with the growing number of people living with HIV and AIDS the government

recognized that the health system alone could not cope with the impact of the epidemic and supported the Home Care program.

Even though caregivers are keenly aware of the needs, their efforts are turned down by a lack of basic provisions: medication, gloves, soap, food, and other basic supplies. The quality of care in many HBC activities is severely compromised as a result of significant and unmet needs. HBC programmes are having to make do with very few resources and are in desperate need of material support. Some of the challenges reported to be encountered by the caregivers are lack of knowledge, inconsistent training, stigma, gender bias in society towards caregiving, lack of motivation, lack of donor support, risk of infection, staff turnover, stigma and discrimination and lack of social support.

4.4 Challenges facing the caregivers of people living with HIV/AIDS

From the research, it was noticed that caregivers are facing various challenges as they look after the chronically ill/ HIV/AIDS patients. There are both internal and external factors that affect the caregivers and the challenges vary from socio-economic and political situation in Zimbabwe. The researcher starts by presenting the research question which will then be followed by findings that answer the question.

Despite the good implications brought about by CHBC in communities and in contributing to the continuum of care and support of the chronically ill and PLWHA, there still exist a number of challenges that compromises quality, efficiency and effectiveness of the Community Home Based Care Programs. These challenges include Lack of training, lack of knowledge, poverty, stigma, gender bias that contributes to low male involvement in care giving, inadequate counselling and psychosocial support, fear of death, emotional harm, lack of motivation and incentives, long periods between refresher courses, staff turnover and lack of support from the affected families, the infected people and the community at large.

RESEARCH QUESTION: Are there any impediments faced in the care giving program, if there are any, what are the challenges?

LACK OF KNOWLEDGE

The main duties of the caregiver of people living with HIV/AIDS entail helping clients to take their antiretroviral drugs or medication on a regular basis, to provide information on positive living and infection control, teaching primary caregivers or those newly joining the Home Based Care Program on how to care for the HIV/AIDS and on how to avoid cross infection, to refer patients to clinic and to provide psycho-social support to the sick and their families. However this can only be learnt through trainings conducted by professionals in HIV/AIDS Organisations.

Hope Humana caregivers in a discussion with the researcher reported that since the time they were recruited to serve the community, they have not received refresher courses or training from Hope Humana Care Program, which is their mother board. This has led to one of the caregivers testifying that she is still scared to look after bedridden patients. She does the caregivers' tasks or duties but she does not have the confidence and courage because she does not have the adequate knowledge on how to cater for bedridden patients without risking her health.

They say knowledge is power, therefore without enough knowledge the caregiving process becomes futile and that is why Mabvuku has a high HIV/AIDS related death toll and many orphans who are catered for by another Organisation (Mavambo Trust) which is located in the area.

On the contrary the other caregiver who was trained long before the newly recruited caregivers indicated that the time they were recruited in the late 1980s they received regular trainings which she claims it made her grow since becoming a caregiver. She went on to say, before getting the refresher courses she was scared to know what to do with a bedridden patient or how to feed someone but after the regular trainings under Hope Humana, she got to realise that she can do it and is able to pass the skills on. She is now prepared for life, its challenges, choices and for any way of relating to people.

Therefore from the view indicated, it can be clearly noted that one of the impediments encountered by Hope Humana caregivers is of lack of training which deprive them of getting the appropriate knowledge required for any giver to have. Hope Humana staff is supposed to

conduct caregivers' training regularly so that they stay updated and well informed on how to care and look after the HIV/AIDS patients.

Jackson and Anderson (2001) concurs with the view as they also cited that, the plight of caregivers of people living with HIV/AIDS arise from the social, cultural and political dimensions of caring as defined by society. They posit that the burden of caring for the HIV/AIDS patients falls increasingly on family members who do not only lack knowledge and information but in most cases do not know the patient's diagnosis although they may think it is Aids. This therefore appears to be the number one challenge of community home based caregivers of people living with HIV/AIDS. They lack knowledge hence the caregiving work can be a difficult task for them since they would not be knowing what is required of the sick person.

There is very little training if any for caregivers yet they are expected by the health team and community to provide care given the multiple roles and problems caregivers are faced with. Phaladze (1999) reported that the risks of perceived cross infection in CHBC was big. He reported that he always shivers when he thinks of a situation where an entire family could be wiped out due to cross infection in CHBC because the family has not been fully prepared to handle AIDS clients.

ILLITERACY AND LACK OF TRAINING

On literacy level, one of the caregivers said she has never been to school, four of them had only primary education, while the other five (5) had only secondary education. None of the caregivers has tertiary education. Illiteracy was found to have negative influence on caregiving quality and making coping or caregiving process difficult. This is because most of the low-literate caregivers (who are also elderly) have problems of accessing care-giving educations, following the medical and hygiene protocol, and following disease progression of their clients.

To support the stated view, The AIDS/STD unit (1996) reports that the quality of care in CHBC as currently practised is below standard except from the point of view of emotional support. This means that, caregiving is best effective or best practised in giving emotional support but there are so many challenges faced in the process due to lack of training.

Inconsistent training poses to be one of the challenges facing Hope Humana voluntary community home based care givers of people living with HIV/AIDS. It is only through the trainings that caregivers get to know much on how to look after the HIV/AIDS patients without posing a serious risk or threat to their health. The training teaches the caregivers how to approach a homestead, to work with a patient, introduce himself or herself to the HIV/AIDS affected family and how to share skills with the family members. It is also through trainings that the caregivers are taught on how to bath patients, to check on a patient's uptake of medicine, to treat bed sores and changing of bed linens among many duties of caregivers.

For untrained care givers, another potential risk associated with caring for HIV I AIDS clients is the increased probability of contracting the virus due to exposure. For instance, if the caregiver has become too committed to caring for the other, they cannot be preoccupied with self, thus compliance with universal precautions to prevent cross- infection could be neglected, and as a result the caregivers' own health needs may be compromised hence leading to the contracting of HIV.

In collaboration with the identified challenge, Jagger and Bordon (1992) point out that the essential aspect of caring is that it involves a displacement from one's own interests to the interests of the one cared for. Caring affects the one caring because she must become engrossed in the other. It also affects the cared-for because that individual's needs are met by others, and because that individual must somehow respond and accept the care offered. They further argue that caring cannot simply be a romanticised notion of selflessness, nor can it occur if the self remains aloof. Family care giving as a social phenomenon implies that there is a social and political dimension to it. To gain some understanding in home based care a review of the concept is critical.

LONG PERIODS BETWEEN REFRESHER COURSES

Refresher courses provide stakeholders with an opportunity for experience sharing and updating each other with current debates and information. However, this has not been fully prioritized by many organisations and health institutions. Despite the fact that some of caregivers had once received refresher courses, the majority of them had received them within a period of 1 and 2 years and some within a period of 3 to 4 years. One of the caregivers said

.....‘we were trained in 2003 and received our first refresher course in 2007 and up to date we have never received any other training or refresher course, I can’t even remember all the issues that were covered in the training, it’s going with age. We need refresher courses, especially on ARVs and herbs’.

Interviews with the key informants at Hope Humana Project highlighted that the caregivers had never received consistent refresher courses since 2007 which poses a threat to the success and effectiveness of the care program. From the Human Development Index, the human being should be well equipped with information and health knowledge therefore refresher courses are a necessity to the caregivers. Reports from the interviews carried out with two clients were that the caregivers no longer have the confidence and courage to do some of the caregiving tasks because they are forgetting some skills for instance catering for bedridden patients.

From the research, observations were that although Hope Humana Project and other health institutions perceived their training as adequate because they were using national guidelines and had also included issues of access to treatment and nutrition in their programmes, caregivers and other stakeholders are of the opinion that there are some gaps which exist in the training they receive. They were of the opinion that they needed further training in counselling, basic nursing care, infection control, first aid, herbal therapy, and report writing skills.

Therefore from the findings, one can note that Caregiver training is still not yet fully standardised, especially in terms of selection of caregivers, content and duration of trainings and this has become a challenge to the caregivers as it has largely attributed to resource constraints and the straining of caregivers.

LACK OF MOTIVATION AND INCENTIVES

It is socially constructed in African societies that care giving is largely dominated by women and therefore regarded as unpaid domestic or voluntary work. Traditionally, the African women is relegated at the lowest ends of economic hierarchy as explained by the Marxist feminism theory and the African feminism theory of which recently, caregiver motivation has become a critical matter of concern in CHBC programming, in the face of increasing number in clients and high cost of living. Motivation can be material (monetary or non-monetary) or

non-material. The debate on caregiver has begun receiving much attention despite the absence of national guidelines and standards on this component. Therefore, caregiver motivation varies from programme to programme. The forms of benefits /incentives that can be given to volunteers are food hampers, soap, uniforms, bicycles, petroleum jelly and monetary allowance.

However from the study, the researcher was enlightened that the caregivers are no longer receiving any incentive or benefit rather they are working for no benefit hence no motivation. When the caregiving program started they used to get money allowances, food hampers, uniforms, hats and bags with Hope Humana Logo but with time Hope Humana Project stopped providing for the caregivers which eventually led to some caregivers dropping out of the program. Currently there are only 10 caregivers under Hope Humana but when they started they were 30. As the researcher was carrying out interviews she was also carrying out participant observation and from the research the observation was that caregivers no longer have that interest and zeal for work because of lack of motivation and false promises from Hope Humana Care Program. They are just doing it for the sake of helping.

All caregivers trained under Hope Humana Project indicated during the discussion, that they are not exposed to any motivation in their care-giving work. The program is reported to be demotivating, demoralizing, lacking in incentives, recognition, rewards, or any strategy to motivate the caregivers. This has the effect of making coping immensely challenging. From the caregivers' reports, lack of incentives was the reason why care giving does not attract young women and men. Giving incentives, according to the respondents, could include giving stipends and rewards, bonuses, encouraging words, food packages, toiletries, visits and supervision, relieving somebody before s/he gets overwhelmed, allowing caregivers work in turns, and monetary payments. This lack of motivation is making things difficult for the caregivers in the caregiving process and is the reason why people are no longer volunteering to help the sick in communities. This is supported by one of Hope Humana informant' s sentiments when he said "If you want men and young women to participate in care giving, give them incentives." Incentives are there to encourage the caregivers so from the research, Lack of incentives proved to be one of the serious challenges facing CHBC of people living with HIV/AIDS.

From the interviews, both caregivers who were interviewed lamented that they were promised bicycles because they walk long distances to some clients. However it ended up in

theory, they never were given the bicycles which disappointed all caregivers. Most of the caregivers are located in Mabvuku but some of their clients are in Tafara, another location in Mabvuku which is about a 3km distance from Old Mabvuku, so the caregivers walk long distances sometimes, which in the long run demotivates them because caregiving is now a tiresome work as they walk all day long and walk long distances to attend clients or people living with HIV/AIDS but in the end they receive nuts.

The researcher noted that Lack of or poor incentives have led to serious caregiver dropout rates in the caregiving program as caregivers join programmes with better incentives. Out of the thirty (30) people trained under Hope Humana project, twenty (20) caregivers have turned back. They used to be 30 when the caregiving was initiated but only ten (10) of them are left.

“We wish if these NGOs would prioritize giving us allowances and food packs every month so that our husbands appreciate the need for us to continue with the programme. We also need uniforms with Hope Humana logo so that it becomes a formal and valuable program in the community and also for quick identification by community members because people hardly recognize us when we are in our casual clothes” said the caregivers.

Limited funding for both programming and administration has compromised the quality of service delivery, for example in training of service providers, quality of CHBC kits, retention and motivation of caregivers. The lack of motivation and incentives make it difficult for less resourced organisations such as Hope Humana Care program to operate effectively. As the number of patients requiring attention increases care givers reported burnout.

Non standardization of caregiver incentives has also led to competition for caregivers among programmes thereby depriving the caregiving program of HIV/AIDS infected people and their families. This is the reason behind the high death toll in Mabvuku and the whole of Zimbabwe.

POVERTY AND INADEQUATE NUTRITION

The CHBC program is aimed at reaching the most vulnerable people, the poorest households with PLWHA. The home care programme focusses on addressing the immediate needs of PLWHA. All caregivers indicated that the caregiving sad experiences, dilemmas and difficulties occur because almost all of the caregivers are poor. The most common problem quoted by almost all the respondents including the affected families was lack of adequate and necessary nutrition for their clients. Caregivers indicated that Hope Humana is no longer

offering anything in their food basket for their clients, On the other hand, the recurrent droughts and food shortages have become a major challenge for chronically ill clients, and therefore clients are not meeting their nutritional needs adequately.

This poses serious implications and challenges on the health of some clients considering people on antiretroviral (ARV) drugs need special diets. This means the caregiver would have to look for supplementary feed, which may not be available. This is made worse by the fact that the social workers' assessment results for the food basket takes too long to be released. This situation constrains the caregivers given the fact that different patients have different food requirements due to varying levels of ailments.

Due to poverty, caregivers reported that they are not able to provide what their clients desired. They alluded that, the challenge comes when the patient does not understand. To clarify the point, one of the key informants said ‘You give him/her the food you have, s/he refuses yet you have no money to buy her/him what he/she wants as you are unemployed and have nothing else to do in this crippled economy except caregiving, the client wants good food, you give him/her thick sorghum porridge (one of the common staple food for an ordinary Zimbabwean) s/he vomits.’ This stresses the caregiver as he or she will be having nowhere to look up to considering the caregivers do not get anything from their mother board.

Food is inadequate and does not meet the needs of the clients.” Hope Humana Project should cater for the clients in terms of food supplies and other basics but food items are not there in the food basket supplier shop. The sick clients and their caregivers are suffering and they need help.

Because most of the patients are poverty stricken and need food assistance, caregivers move around begging for assistance which is so humiliating on their part. The report is that they are sometimes given stale and expired food items by shop owner. This worsens the health condition of the patients. They are to be given rich and nutritious food but due to inadequate food supplies and poverty, the patients end up consuming stale food which in turn deteriorates the caregiving standards. It all affects the caregivers who most of our clients need food assistance.

More to that, caregivers alluded that less time is available for agricultural production, including animal husbandry, due to the time spent on caring for the ill. Production methods, which are less labour intensive but which produce food that is just as nutritious, therefore

need to be developed. Poor households are very often unable to find paid employment, which would enable them to purchase the food they need. The caregivers end up depleting their assets in attempting to buy medicines and services to help PLWHA. Increasing access to income could play a key role in improving food security. Growing needs and an increasingly diverse set of priorities within the CHBC mean that the voluntary caregivers of people living with HIV/AIDS are stretched to their limits.

In literature related to the subject, Narayan (2000) concurs that poverty is pain, poor people suffer physical pain that comes from little food and long hours of work, emotional pain stemming from the daily humiliations of dependency and lack of power. The HIV/AIDS epidemic has introduced a new long term trend in impoverishment especially in the developing countries. If the victim of the epidemic is the breadwinner, the household of the victim if s/he lacks family support becomes poorer. This then strains the caregiver of the victim as he or she will be forced to cater for the food expenses, expenditure on travel to get the antiretroviral drugs and hospital fees. Due to lack of funds, the caregivers sometimes travel long distances to reach their clients' places. This clearly shows that Community Home Based Caregiving is not a cheap task for the families and the care givers involved.

Steinberg et al (2002) shared the same sentiments when he said ,where someone was either sick or had died due to HIV/AIDS related illnesses, more than 20% of the caregivers had diverted time from work or informal income generating activities to provide care in the home. They also asserted that paying for medicine or hospital bills especially once the opportunistic strike had taken up most of the income. The caregivers more often than not meet every cost. Therefore literature reveals some of the economic constrains caregivers face as they look after the chronically sick in communities. This does not motivate the caregivers but rather demotivates them and cause some of them to retire from the caregiving work.

In support of the point, Jackson and Anderson (2001) adds on to say, AIDS is a major factor in the impoverishment of families as they lose productive household and subsistence labour. The Botswana Human Development Report (2000) supports the assertion as it goes on to state that, 47% of the population in Botswana is reported to have been living in poverty. The poor sanitary conditions in both urban and rural areas pose real danger to both the patients and caregivers as well. This shows that financial constraints on the part of the caregivers is one of the major impediments in the caregiving of people living with HIV/AIDS hence the challenge is to be addressed.

LACK OF MALE INVOLVEMENT IN CAREGIVING PROGRAMS

In Zimbabwe, male involvement in CHBC programming is still low, especially in the urban areas although it is now emerging in isolated programmes. The research carried out in Mabvuku indicated that there is still low involvement of male caregivers which is a challenge to the caregivers as will be addressed.

Being a male caregiver has its challenges and that has contributed to low statistics of male caregivers of Hope Humana Project. It is socially constructed that women are meant for household duties and for looking after the sick of the families and in communities. Patriarchy considers men as the dominant family figures who should only provide for the family and delegate duties such as caregiving to women and girls. This is elaborated by the Radical feminism theory which is anti-patriarchy. One respondent from an affected family testified that, the one and only caregiver who is male out of the ten is mocked by friends and other people in the community.

Even though people are now learning to accept and accommodate male caregivers, the research helped in coming to realise that male caregivers were initially mocked by other men in the community who accused them of being lazy for wanting to do women's work, rather than going out to look for proper jobs or finding other means of generating their own income. They were also mocked when they expressed views in support of gender equality, especially when they challenged men to care for their wives and not send them back to their maiden homes when they were ill, as often happens. This view of male caregivers hindered or demotivated men to join the caregiving program.

Some HIV/AIDS affected families answered in the questionnaires that they still do not accept male caregivers to attend their HIV/AIDS infected loved ones. For instance some families think a man cannot take care of their ill sister or wife. In the African culture, society is constructed in a way that men cannot take care even of their ill wife or sister, rather a sister or mother of the sick person would have to come to look after the sick person. Some are still attached to the African culture which believes a man cannot give a bed bath to a female patient especially for women if the husband is not at home. This was revealed when one HIV/AIDS male patient clearly stated that he would not want a female caregiver to come and assist him, rather if the male caregiver is not around he would strive to bath himself alone even if he is bedridden. This is a clear picture of how gender issues have distracted the caregiving services.

This is a challenge faced by the male caregivers in Mabvuku. Even if they have the will to assist the sick in community, they are demotivated and discouraged by the social construction. That is the reason why there is only one male caregiver out of the ten (10) caregivers trained under Hope Humana Project in Mabvuku.

From further researches into literature, it is observed that women occupy the bigger percentage of those who are into caregiving even there is little scholarly attention on issues of Gender in Community Home Based Care. In Zimbabwe, Irish Aid report of Community Home Based Care (2000) alluded that out of the 300 caregivers, there were only 6 men and the rest were women. The issue of gender imbalance poses to be a serious challenge facing community home based caregivers not only in Mabvuku but in many African countries, considering the position women hold in African societies as elaborated by the feminist theories. When there is gender imbalance the caregivers find it difficult to deliver the appropriate and required services to clients, for instance a female caregiver cannot bath a male client and vice versa even when there is need because maybe the female client or the affected family is not comfortable.

This is an indicator of women being left solely to handle care-giving tasks to either float or sink. This has for long compromised the caregivers' coping process and strained the female caregivers. This, according to feminists such as Finch and Grove constitutes exploitation of the female gender as elaborated also in feminist theories. Therefore, from this observation, gender bias in society and the way the African society is constructed pose to be a challenge in Community Home Based Care for people living with HIV/AIDS.

EMOTIONAL HARM

Caregiving requires full commitment by the caregiver and total surrender of self in order to manage the sick persons. It requires a significant emotional and spiritual commitment from caregivers and that is the reason in many Organizations, caregivers have developed networks of support among themselves and within the Organisations to address this concern. Caregivers of chronically ill people are exposed to various sad experiences which traumatise them so they need relief which comes through counselling.

The Caregivers reported that, due to lack of support and frequent counselling, they get emotionally injured too when their clients get in pathetic situations and when a client dies.

This was evidenced by the researcher during an interview with one of the caregivers who broke in tears whilst trying to explain the sad situation of one of her clients. The report was that one of her clients, a certain old aged woman of approximately sixty (60) years of age was left to stay alone at her home by all relatives including her own children because they claimed that she is restless and no one can afford to stay with or look after her. No one is there to cook for her or wash her clothes if the caregiver does not do that. Sometimes she is said to even spend the whole day without eating anything in the event that her caregiver has travelled or has been tied up with something. As their patients suffer, the caregivers suffer too. This affects the caregiver emotionally hence need for constant counselling of both the caregiver and client.

They also are haunted emotionally by affected families who abdicate family responsibility for the sick in family to the caregiver, forgetting that the caregiver also needs time for their own families and time for generating income. This puts too much pressure on the caregivers thereby haunting their emotions since they have an intimate bond with patients.

The other caregivers also reported that stress comes when there is lack of cooperation from the patients. Other patients refuse to take drugs and some lie that they have taken the medicine whilst they have not. From the information gathered in questionnaires, one of the caregivers said she is facing problems with one client who sometimes hides tablets under the pillow and gets terribly sick as a result of withdrawal. This does not only harm the health of the patient but it affects the caregiver emotionally, as he said. This means that if the caregivers are not given adequate support as what happens in most cases, they suffer too when their patients suffer so there is need for constant counselling of the caregivers and the HIV/AIDS patients as well.

FEAR OF DEATH

The fact that HIV/AIDS has no cure is a serious threat to the caregivers. Another challenge haunting caregivers as identified from the research is Caregiver's fear of death. For untrained care givers, another potential risk associated with caring for HIV I AIDS clients is the increased probability of contracting the virus due to exposure and lack of knowledge on how to give care to the seriously ill patients who need help from bathing, eating and using the toilet. This instils fear in the caregiver which is not healthy. It was observed that depressed

caregivers perceive caregiving problems to be more severe and resources seem less available to them than they really are.

More to that when the caregiver experiences an actual or perceived lack of support, it intensifies the impact of negative feelings. It is a challenge to the care givers especially elderly people as they would be worried of what would happen to the terminally ill person and wondering if they should die before themselves. The major source of caregiving suffering is that fear of the inevitable death of clients suffering from HIV/AIDS. Although many believe that death is part of life, caregivers have faced difficulties in dealing with the losses currently experienced as a result of the pandemic.

Therefore it is noted that if not well counselled, Community home based care givers always suffer from depression as they fail to accept the reality of life and the depression may further negatively impact the caregiving process by reducing the energy to build and maintain supportive relationships with clients.

LACK OF SUPPORT

Caregivers reported that their families were happy that they are doing what they wanted to do because their families could not afford to let them do other courses. Their families are supportive but it is unfortunate that there is lack of support from the community and Hope Humana Project, which is their mother Organization. Hope Humana informants gave a case study of a female caregiver whom they said she testified that before being trained to be a caregiver, she had opted for commercial sex work as a survival strategy but when she attended the commercial sex workers' workshop that was being facilitated by Hope Humana Staff, she was enlightened of other life skills and decided to join the caregivers network.

The challenge now comes when they are not receiving adequate support from the HIV/AIDS affected families and the community at large. One of the female caregivers said another challenge they are encountering is of difficult patients and families who surrender their responsibility of care for the HIV/AIDS infected family member. They abdicate that responsibility to the caregivers and the report from all caregivers is that, some family members want the caregivers to care for the patients 100%. Some families forget that caregivers are also humans who also have their own families who need time with them and

they also need time to generate income. The caregivers emotionally said that it puts too much pressure on them.

The research findings indicated that caregivers are inadequately assisted by relatives, friends, neighbours, private individuals, grassroots traditional and political leaders, and other service delivery networks like the NGOs. The caregivers echoed “*Relatives and family members help here and there, but very little*”

This shows that there is a big challenge because caregivers could get overwhelmed making the coping process difficult. They indicated also that the families they are helping and community members have a tendency of neglecting or leaving care giving in the hands of the caregiver alone. The caregivers suffer pain and agony as they carry out care giving alone. A female caregiver during the interview broke into tears explaining how the family she is helping left her alone to take care of their ailing old mother. She went on to say, *‘I no longer have time to do other things and to spend with my own family, I am left alone with all the responsibility of looking after the old women who is bedridden and cannot do anything without someone’s assistance, all the relatives went for good and I am struggling with care giving’*. This is a sad experience being encountered by caregivers.

Caregivers also need financial and material support from the Government, NGOs and other Social organizations. They need stuff like first aid kits, bandages, gloves, soap, buckets and other basics needed to cater for the chronically ill in society but from the findings, the indication is that caregivers just receive empty promises and they are lacking support from the community and the mother Organization. Staff from Hope Humana Project indicated that there is a massive lack of support from their Organisation because currently they mentioned that the Organization is not receiving donor funds. It is sustained by the few income generating projects they are managing. This causes a negligent attitude towards the caregiving program.

The same challenge was identified by Noberck et al (1991), Shaibu (1997) who asserts that caregivers experience a lot of difficulties while caring for their loved ones which include acceptance of the patient’s diagnosis, lack of commitment by others to the patient, informational needs related to the illness and management for helping accessing resources, need for respite care and direct help with care giving activities. In some instances however the community home based care givers lack support and commitment by even the client or patient being looked after.

STIGMA

Stigma in community is the other key challenge facing caregivers. They are degraded in some instances by members of the community. All caregivers indicated that it was difficult at first to be a caregiver and to open up to people that they are caregivers. One of them testified when she said, *'I am still ashamed to open up and tell my friends and neighbours that I am a giver because of the way we are regarded as in community'*.

Since most of the caregivers are women, some people especially the elderly people regard them as those who sell their bodies/prostitutes so that negative eye people have made the caregivers feel less or degraded hence in some cases lack confidence and courage to confront people and partake the caregiving tasks..

Since they are emotionally attached to their clients, they suffer the stigma of the clients too when they are discriminated in society. From the research carried out in Chizhanje, another small segment in Mabvuku, an HIV/AIDS patient of early 30s of age stated clearly that he is discriminated and bad mouthed by people in the surrounding area and sometimes by his friends because he is HIV/AIDS positive. If someone is suspected to have HIV, they are excluded in some activities because some people still fear that they can be infected by being near them. Said one affected family member.

Stigma prevents people living with HIV/AIDS from accessing health care services. It was reported that some families have refused care because they did not want their neighbours to see an NGO or Community Home Based Care team member enter their homes, for fear of isolation. This therefore can be a challenge to the caregivers who are supposed to look after HIV/AIDS infected members of such families as they sometimes lack motivation, encouragement and support from the families. Findings from caregivers' studies of stigmatised conditions also show a consistent pattern reflecting lack of support. This therefore strains and demotivates the caregivers.

STAFF TURNOVER

The professional support of supervision and monitoring is desperately needed in CHBC, without that the caregivers will be overstretched and the caregiving program will be at stake. However in Zimbabwe, due to the economic crisis, nurses are leaving the country to work abroad of which they are the corner stone for health care delivery system. This has tightened

the situation for the caregivers of people living with HIV/AIDS. They know some of the things or information required to care for HIV/AIDS patients but they also need expert advice for the caregiving work to be easy and manageable.

WHO (2000) reports that caregivers themselves die after caring for family members and the community sick people because many caregivers are themselves ill so they need support and counselling from the health personnel around them. It is of importance because if they get overloaded it becomes difficult for the caregivers to reach out to other families with AIDS patients in the community. In Hope Humana Care program, staff turnover is evidenced as twenty of the caregivers dropped off.

INADEQUATE SUPERVISION AND COUNSELLING

Hope Humana care givers indicated that they are disappointed with the way they are treated by their mother Organisation. It is mandatory that the caregivers should be monitored by those who trained them and other health professionals, however there is too much negligence by Hope Humana staff as far as visiting, counselling, and supervision is concerned. They indicated that there were only a few cases when the project members checked on them, counselled, or visited them and their clients. This has bad implications and a negative bearing toward care giving productivity and coping in general. In some instances the caregivers die after giving care because of the post traumas, from the research one caregiver was reported to have died a mysterious death and that maybe the cause, therefore counselling is of essence.

Considering that these caregivers will be working with different sicknesses, they are exposed to a lot of traumas which in the end lead to emotional injury. They are traumatized by the various sad experiments they encounter as they take care of the sick, especially the bedridden, so they need relief and counselling in order to cope with the stresses they share with their clients. During a discussion with the researcher, one of the a caregivers lamented emotionally when she said, ‘the health professionals at Hope Humana project do not come to supervise us, when they come they visit not all caregivers but just a few who stay nearby their office so we use our limited knowledge to do the caregiving which is difficult for us’.

The caregivers said they desire to be supervised and monitored regularly so that they know they are still in the right track as far as caregiving is concerned. They need that encouragement from the project staff members. They prefer to be visited, supervised, and

counselled rather than doing the caregiving duties alone without a check. Such visits and monitoring would improve the contribution to caregiving and enhance their coping process, however in reality they do not get that support. They rarely get help and encouragement as all the caregivers pointed out that there is lack of psycho-social support like counselling, social support from relatives and community in general, and inadequate care package. This lead to reduced care productivity and coping becomes very challenging for the caregivers.

The research also established relatively limited appreciation of the importance of Monitoring and Evaluation in Hope Humana CHBC programming. The report was that the staff members have limited capacity on Monitoring and Evaluation. This affects the caregivers as there will be needing a frequent check from their leaders to stay motivated and confident with their work.

It is this lack of counselling which also cause fear of death and which has contributed to the ineffectiveness of the program in Mabvuku as there are still high HIV/AIDS related deaths tolls. There should be a constant check on the caregivers and monitoring to see if they are applying the proper caregiving strategies and medicine to patients.

AGE

The other challenge impeding Community Home Based Care givers of people living with HIV/AIDS is defined by age. Age was found to be a crucial factor affecting care giving, because all the caregivers are of an estimated age of fifty (50) years and above. None of them is less than fifty year. The discovery is that due to the African perceptions that women are for taking care of the sick and families whilst men are into income generating projects, most caregivers are women. The findings revealed that most caregivers being women and especially those above 50 years are no longer physically strong enough to stand the care giving demands which thereby makes the caregiving process difficult for them.

Caregiving encompasses a lot of things which include cooking for the patients, monitoring the patient's intake of drugs, fetching water and bathing the bedridden patients among many duties. Therefore these duties have become a burden to the caregivers considering their age, therefore there should be recruitment and training of youths and even children on caregiving strategies so that the secondary caregivers can receive assistance from the young generation to lessen the burden.

RESOURCE UNAVAILABILITY

Unavailability of first aid kits remains a strong challenge for caregivers. It is difficult to attend to a bedridden client without basic tools of necessity such as adhesive bandages, disposable gloves, spirit, scissors, emergency blanket, eye patches, antiseptic wipes or soap, safety pins, tweezers, instant ice packs, sterile gauze pads (dressing), coins for pay phone and the first aid manual and other tools required for emergency. Every caregiver of chronically ill people should be in possession of a first aid kit but the findings were that not even a single person among Hope Humana caregivers of the HIV/AIDS people had a first aid kit. They are years now since they had been promised work tools by the Hope Humana Project but nothing since then has worked. This places the health and wellbeing of the caregivers at high risk of contracting the virus as they will be attending clients without even gloves. It is difficult to bath a wounded infected person without wearing gloves but it is what happens with Hope Humana Care givers. In a discussion with the researcher, the caregivers lamented over the issue of first aid kits.

The quality of care in many HBC activities is severely compromised as a result of significant and unmet needs. HBC programmes are having to make do with very few resources and are in desperate need of material support. The HBC programmes reviewed in detail as part of the current project highlight the many and varied needs of affected people and communities and the manner in which those needs change over time. Local capacities have been mobilized but there is an urgent need for external support to improve the situation of people infected and affected by HIV.

To clearly reveal that attending patients without first aid kits is risky, the Canadian Red Cross recommends keeping a first aid kit readily available at all times. Therefore if the caregivers do not have access to such resources, it becomes a challenge.

ARVs UNAVAILABILITY AT CLINICS

The other thing which strains caregivers of people living with HIV is the unavailability of the ARV drug at local clinics. Sometimes they are referred to go and collect the tablets at clinics and hospitals that are far away from their areas of residence. This overstretches the caregiver who is not given any allowance or bicycles by the coordinating board as the caregiver will be forced to use the little coffers s/he has for the client transport and his or her transport to the

hospital referred to. One of the respondents alluded that ‘most of the time we go with our clients at Mabvuku satellite clinic for the collection of tablets we are told to go to hospitals in town as they always run out of the drugs’.

According to World Health Organization (WHO) estimates, only 91 000 of the 321 000 people currently in need of ARVs have access to them (WHO 2008). In the absence of ARVs, many PLHIV sought out and adopted a wide variety of ‘alternative’ therapies, some of which were ineffective and others even harmful. Some HBC services introduced specific herbal therapies through the establishment of medicinal gardens and hence provided some people with HIV with new hope that they would live longer. This has notably been a challenge faced by the caregivers who cater for the transport costs and each and every movement to be done.

POOR COMMUNICATION SYSTEM AND INFRASTRUCTURE

Poor communication especially in the rural areas has affected effective linkages between health institutions and other CHBC programmes. Poor infrastructure, especially in the rural was identified that it is a challenge to facilitate client referrals to health institutions for the treatment of other opportunistic infections that attack the HIV/AIDS infected people.

Many clients are reported to be using scotch carts and wheel barrows which in most cases is uncomfortable. There is need for CHBC programmes to have their own vehicles.

The burden always falls on the caregiver who takes the patient to the clinic or hospital. S/he is the one who if the client is being taken to clinic by a wheelbarrow pushes the wheelbarrow. Since all caregivers have no formal income generating activities or jobs, they are forced to do anything for the sake of their clients. Therefore from this view one can clearly note the unavailability of resources such as drugs and vehicles strains and affects the caregivers more than even the clients.

POOR NUTRITION AND LACK OF NUTRITIONAL GARDENS

When dealing with health issues, nutrition is of essence. The sick require a specific proper diet however poor nutrition is one of the challenges facing caregivers and their clients. Due to scarcity of water in Mabvuku, only one caregiver has managed to establish a nutritional

garden. The garden helps in providing just but a very few clients with healthy foods such as vegetables, carrots and tomatoes.

There is also inadequate knowledge on nutrition especially the use of locally available food. The other thing is that there is poor communication facilities to foster efficient and effective nutritional support. The occurrence of natural disasters such as droughts which reduce food reserves in the country is also another contributing factor to the poor nutrition.

This lack of good nutrition on the clients triggers various sicknesses thereby meaning more work for the caregivers. This strains the caregivers who will be working overtime and tirelessly to ensure the patients get a proper diet.

WEAK COORDINATION

There is poor coordination between the National Aids Council and Hope Humana Project as the coordinating boards for the Caregivers of people living with HIV/AIDS. Poor communication and feedback systems from NAC structures were highlighted as major challenges in coordination among CHBC implementers. Inefficient use of NAC monitoring activity report forms by Hope Humana Project has compromised the work of caregivers. This was evidenced through the District Administrator who reported that most CHBC stakeholders/implementers were not attending coordination meetings and neither were utilizing and submitting NAC Monthly Activity Report Form.

Poor linkages were also noted among central and private hospitals, which had no direct links and effective coordination with communities as well as health institutions, which were not adhering to the discharge plans and guidelines. The caregivers have to be linked to other health professionals and even to the social services in order to improve their participation and caregiving skills. It is through interaction that people get to learn new and many things, however with Hope Humana Caregivers it is a different case. They only operate as an island and have no time to mix with other caregivers from different health Organizations. This limits them of the access to new skills.

It is also a matter of essence that caregivers should have time to sit and discuss on issues that affect them and on matters arising from their areas of operation. This can help them with various ideas to make the caregiving process interesting. However due to weak coordination there is no time for that and they rarely conduct meetings at Hope Humana office. This means

that all the various challenges each caregiver will be facing in her or his field will not be addressed on time thereby meaning more emotional harm to the caregivers as they will be having no one to their rescue out of the different challenges.

UNAVAILABILITY OF SOLUTION FOR CHILDREN LIVING WITH HIV/ AIDS

Care givers role has been compromised when it comes to the issue of children which makes the caregiving program ineffective. Integration of children's issues in CHBC has been hailed for its ability to holistically address the needs of both the chronically ill parents and their children. Promotion of child involvement is critical in promoting the best interests of children, as they meaningfully participate in issues affecting them. This is complimented by the African charter on children's rights on Article 4 of the charter.

When they were trained on caregiving, the caregivers reported that none of them was trained on how to give care to an infected child. There is limited appreciation of the importance of involving children, including orphans in issues affecting them, and hence their involvement is still limited. Linkages between orphan care and CHBC could however be strengthened by involving orphans in CHBC trainings and refresher courses. Orphans and children under ART should also be incorporated into Income Generating Projects, to enhance their involvement in Community Home Based Care programs.

4.5 Discussion of findings

This section discusses the results presented, that is the challenges facing Community Home Based Caregivers of people living with HIV/AIDS. Findings are presented in accordance to the four research questions. The findings also address the research objectives that is, to identify the challenges facing caregivers and to come up with measures to get rid of the challenges.

The first research question focused on the challenges facing the caregivers of people living with HIV/AIDS. Various challenges have been identified which include stigma, lack of support, gender bias towards caregiving, poverty, age, lack of counselling, emotional injury, fear of death, lack of trainings and refresher courses, weak coordination, poor nutrition and poor communication system among other challenges identified.

This is in line with some few scholars who cited lack of support, fear of death, lack of knowledge and poverty as the major challenges facing caregivers of HIV/AIDS infected people. However these challenges are not all left unattended to, for instance, considering the caregivers receive psycho-social support sometimes from their mother Organisation therefore such facts cannot be ignored.

RESEARCH QUESTION: What are the caring needs of the Community Home Based Caregivers?

For the effectiveness of the caregiving program and for the lessening of burdens on the caregivers, one can clearly note that from the identified challenges the caregivers a lot has to be done and provided for the voluntary caregivers to keep motivated.

There is need for psycho-social, financial and material support. The caregivers need to be given incentives or small allowances to keep motivated and to lessen the burden that they currently have, of generating income in the little space of time they find since much of their time is spend on care giving. They need to be provided with first aid kits to prevent the risk of infection which they are exposed to when working without the proper and required equipment. It is an issue of concern that caregivers should receive counselling in order to cope with the trauma they are exposed to as they take care of the sick. They also need to be trained and monitored regularly, to be provided with resources such as the ARV drugs, uniforms, bags, bicycles, food hampers and seeds as well as grounds for the establishment of nutritional gardens. There should be awareness campaigns concerning the caregiving program to avoid stigma.

HIV/AIDS infected people in communities need close monitoring. They may also need assistance performing tasks that people may take for granted and these include cooking, bathing, washing, feeding, cleaning, using the rest room, purchasing household essentials and other tasks that are not necessarily for ill people only but also for any other person to lead a stable life. They also need assistance in administering, purchasing and adhering to the tablets, ARV drugs specifically for the HIV/AIDS infected people. According to the WHO (2002), helping with nutrition is of essence as the patient's diet may differ from other people. Monitoring of the patient is also important for instance monitoring and recording progress, recording how the patient is eating, recording fluid intake, symptom occurrence and toilet visits. This helps in identifying the person's emotional, physical and psychological needs. All

the above listed tasks should be performed by family and other community home based caregivers.

However more often than not, these caring needs are not addressed or attended to, which has compromised the effectiveness of the caring program.

RESEARCH QUESTION: What is the available type of support from the parent Organization (Hope Humana Project)?

A key informant from Hope Human Project clearly stated during an interview with the researcher, that the only support that is available for the caregivers of the HIV/AIDS affected and infected people is of psycho-social support. As for financial and material resources, the Project life is also at stake since they are not receiving donor funds regularly so they no longer afford to give their assistants incentives or any kind of support except having meetings with them, counselling and visiting their workplaces of which this does not occur frequently.

When asked why they do not offer constant counselling and supervision, the response was that, it ends up bothering and irritating the caregivers to only give them psycho social support without giving them the basic and most required resources needed for caregiving, such as uniforms, first aid kits, food hampers and allowances, so as a result they reduce the visits.

RESEARCH QUESTION: How can the caregivers in HIV/AIDS programs be empowered to deal with the challenges and for the sustainability of Community based care programs for the sick?

Various measures have to be put in place to curb the caregiving challenges. From the various challenges presented, one can clearly note that a lot has to be done and this will be discussed in the next chapter on the section of recommendations.

4.6 Conclusion

The chapter focussed on the presentation, analysis and discussion of data obtained from research on the challenges facing Community Home Based Caregivers of people living with HIV/AIDS.

5.0 CHAPTER FIVE: SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

The chapter answers the last research question which focussed on the measures that can be put in place to deal with the challenges facing caregivers. The chapter also gives conclusion and recommendations to the study. The section of recommendations address the objective of the study, that is, to find the appropriate support or empowerment needed for the caregivers to continue giving care and to recommend measures to curb the challenges.

5.2 Summary

The study identified and highlighted many issues related to Home Based Care for the people living with HIV/AIDS. Through the research carried out, various challenges were identified that include lack of support, poverty, stigma, lack of knowledge, lack of counselling and trainings and lack of motivation or incentives among many challenges stated in the chapter however the key challenges which has caused the ineffectiveness of the caregiving program are lack of motivation and incentives, lack of knowledge and poverty. The challenges have hindered the effectiveness of the caregiving program.

The study sought to come up with various measures to the upheavals befalling caregivers of the chronically ill so that they can cope up with the caregiving duties well. In that regard, needs for the caregivers were identified and they are addressed on that last forum of this chapter, which the researcher hopes will enhance the caregiving skills and the effectiveness of the caregiving program.

There is need for material and financial support to the caregivers, they also need to be given incentives that motivate them, refresher courses and frequent professional counselling in order to cope with the traumas and sad experiences they experience as they look after their clients. Many more suggestions are stated below in the recommendations.

5.3 Conclusion

From the presentation of the challenges facing the caregivers of people living with caregivers, one can note that there are so many challenges encountered by caregivers of people living with HIV/AIDS and a lot has to be done to help or relieve the caregivers of the caregiving stresses. There are dropout cases of other caregivers because of poverty amongst the caregivers, stigma, lack of motivation and incentives, lack of counselling, knowledge, lack of support of moral support, resistance by the clients to take medication, poor nutrition, poor communication system, age, gender bias among many other stated challenges. It was observed that little support is available from the mother organisation hence there is need to implement various measures especially that will address the key challenges which include poverty, lack of motivation and lack of counselling as well as training. The caregivers need to get professional counselling, to be supported financially and morally and to be given incentives among other caring needs addressed on the section of caregivers' needs. Recommendations to the study address measures that should be put in place by all HIV/AIDS organisations and the Government to curb the challenges faced by caregivers of people living with HIV/AIDS in order to ensure the effectiveness of the caregiving programs.

5.4 Recommendations

RESEARCH QUESTION: How can the caregivers in HIV/AIDS programs be empowered to curb the challenges they face as they give care to people living with HIV/AIDS and for the sake of sustainability of the program?

Trainings

Hope Humana Project should create platforms such as public trainings so that all caregivers would gain knowledge about how to care for the caregivers and to look after bedridden clients without risking their health. Training workshops should be conducted regularly, on how to care for the chronically ill and to deal with care giving stresses. There is also need to enhance the capacity of care givers particularly in the area of capturing reports on their work. There is need for CHBC implementers to prioritize training of caregivers in standard reporting writing as well as provision of enough stationery. There is need for simplifying of CHBC standards and guidelines, to make it easy to develop training packages for care givers.

Provision of Refresher courses

Community Home Based Care implementers should also prioritize provision of refresher courses to caregivers of people living with HIV/AIDS, ARVs and drug adherence monitoring as well as other support services for the chronically ill and PLWHA, for the purposes of referrals. There should be development of appropriate IEC and training materials and dissemination to all stakeholders, for the purposes of refresher courses. These materials if possible might be translated into local languages, in Shona for Zimbabweans. These kind of refresher courses will be accommodative to all caregivers hence promoting quality caregiving services.

Counselling of the caregivers

Professional counsellors from various health institutions should be invited to counsel at free will. Caregivers of people living with HIV/AIDS are exposed to many traumatising situations, for instance if one of his or her clients dies the caregiver will definitely be depressed. There is also resistance from clients to take drugs, to bath and to eat which definitely stresses the caregiver and brings out the need for counselling, therefore to relieve them of the stresses they should receive constant counselling.

Seeking Donor funds

On the challenge of lack of resources and incentives, the mother Organisation (Hope Humana Project) should also source donor funds from various ends so that the Organisation can be able to meet the caregivers at their point of need. For instance they need motivation that comes through incentives, food hampers, soap, uniforms, bicycles among many other things stated in the research findings, therefore for those things to be provided for them, the mother Organisation should be financially strong hence there is need for the Project to seek to apply and seek funds from as many donors as possible. This helps in improving the quality of CHBC programs. Motivation strategies should be put in place and adequate care package should be provided for the caregivers.

A systematically integrated approach to care and support is clearly required with government, donor and community-based care organizations combining their respective skills and means to ensure that home-based care works to bring essential change to people's lives. In this respect, the Expanded Support Programme (ESP), a multi-donor common funding mechanism that supports the National Strategy for HIV and AIDS in Zimbabwe, can play a

key role in supporting the varied elements of integrated Key findings and policy recommendations on home-based care in Zimbabwe. Other funding mechanisms at country level must also prioritize funding for HBC programmes.

Gender mainstreaming in caregiving

On low male involvement in caregiving, campaigns against gender bias should be held in communities. It is how the African communities are socially constructed which makes it seem like a taboo for a man to be a caregiver, therefore people have to be shown the green light which only comes through campaigns, trainings and information dissemination through the use of flyers and posters. Hope Humana Project can expose its caregivers to various Organisations that focus on gender issues. They can also engage the Ministry of Women Affairs, Gender and community Development to help them brainstorm people in the communities about gender balance and to mainstream gender issues in Community Home Based Programs. CHBC programmes/stakeholders need to devise strategies for improving male involvement and motivation in CHBC. There is need to mainstream gender issues in CHBC programmes, training guidelines and national policies.

Recruitment of more voluntary caregivers

Patients increase as the rate of HIV/AIDS rises therefore more caregivers should be recruited. Hope Humana Care program should create a platform of even building a community hall that is meant for the caregivers to meet and discuss issues that affect them. Weak coordination of meetings was pointed to be another factor which has weakened the caregiving system therefore if platforms are created for meetings, issues of concern can be easily addressed.

This can even help boost the number of caregivers which will then lessen pressure on the caregivers who are currently caring for more than two families per individual.

Inclusion of all age groups in caregiving programs

To address the issue of Age is a challenge in caregiving, Hope Humana Project should promote and ensure inclusive involvement of all age groups in the caregiving program. For years, only old aged people have been recruited whilst youths and children were excluded of which they can help the secondary caregivers in serving the community since they are still youthful and full of energy. Other caregivers reported that they are struggling to do some of the caregiving duties such as fetching water for clients, cooking and bathing them because of

old age. Involving youths can help deal with the problem. There is need to target youth and young children for CHBC training and to develop appropriate training material for them.

Campaigns against stigma/ community sensitization

To get rid of Stigma for the HIV/AIDS infected people in communities, there is need for Community sensitization. There is great need for sensitisation of communities on embracing the infected and the affected. More awareness campaigns should be conducted to reduce stigma and discrimination of the HIV affected patients. Every member of the community has to enjoy the right of involvement in all activities and programs that may be conducted in communities. Information dissemination should be an everyday practise for Hope Humana staff, so that people get to understand that the infected people need equal treatment with those who are not sick. This will reduce stress on both the patients and caregivers. Caregivers have to be supported with uniforms that have Hope Humana logo, nags, hats and any other accessories for caregiving so that they can be valued in communities.

Inclusion and involvement of PLWHA and the chronically ill in decision- making should be prioritized. The chronically ill and PLWHA need to identify capable cadres among themselves to be incorporated and represent them at strategic levels in some coordinating committees and organisations. Strategies should be devised to ensure that the chronically ill meaningfully participate in issues affecting their lives. This could be achieved through training them in CHBC and establishment of support groups and networks. When they are incorporated into programs, they feel loved which can help reduce the stresses caused by stigma in societies hence reducing the HIV/AIDS related deaths. The National Aids Council and Hope Humana Project should be on the lead in strengthening coordination and networking among stakeholders to foster strong linkages.

Adequate provision of treatment facilities

To curb the hassles caregivers and patients face in order to access treatment, strong linkages between CHBC and access to treatment should be established. For instance, patients or the caregivers who go to collect the ARV drugs should be given a package that covers for at least two months not only one sachet for a single month. This can relieve caregivers of the difficulties in accessing treatment for their caregivers. The Hope Humana Project should take a leadership role in bringing CHBC, access to treatment, testing and counselling as well as nutrition together.

The suggestion is that all relevant health institutions should adhere to the discharge planning guidelines and decentralization of ART so that drugs for the Patients can be easily accessed. Community Home Based Care Programs can only be described as comprehensive and effective if they address issues of AIDS treatment.

Hope Humana should reach the service providers, such as local clinics and other HIV/AIDS Organisations to manipulate them to provide mobile services to remote areas and most high risk and overpopulated areas such as Mabvuku Tafara so that treatment services become easy to access hence assisting the caregivers who sometimes walk long distances to access drugs. There should be advocacy for adherence to the discharge planning guidelines to ensure a strong linkage between health institutions and CHBC programmes.

Monitoring and Evaluation

Monitoring and Evaluation are two critical components in HIV and AIDS programming, including CHBC. These two mutually dependent processes help to measure and assess programme acceptability, efficiency and effectiveness. If the caregivers are not monitored and supervised, the CHBC program may automatically become futile. The caregivers should be visited regularly and Hope Humana staff should accompany the caregivers as they carry out field visits and work to the HIV/AIDS infected or patients in community. Reports should also be written and submitted to the mother Organisation on a monthly basis so that the caregivers' needs are taken to the discussion table by CHBC implementers. This way the some challenges can be quickly addressed which makes the care program a sustainable project.

Nutritional support

To promote good nutrition among the cared for people, Increase awareness on ARVs and nutritional support. Caregivers should integrate nutritional support with herbal therapy, such that the gardens are used for dual purposes. Caregivers should also be provided with seeds, legumes and other nutritional stuff for gardening as well as consumption.

Coordination and networking

Hope Humana Care Program should improve coordination and networking with other Organisations. This will ensure maximum cooperation and participation of CHBC stakeholders, especially in meetings and completing National Aids Council Monitoring and Evaluation tools. This might be fostered by the adoption of an effective registration system of

all CHBC implementing agencies. There is also need for policy review to ensure that the mandate is respected. CHBC implementers should also prioritize establishment of local structures and provision of bicycles to their leadership to facilitate coordination of CHBC programmes. The project should improve on coordination and networking to foster the complementary nature of Community Home Based Care and AIDS treatment

Income generating projects

To eradicate poverty amongst caregivers, the project should also initiate Income generating projects for the caregivers so that they can generate income. More often than not, the caregivers are overstretched to the bone because they do not have any allowance they get from the mother Organisation of which they sometimes support their clients finally. They can engage in sewing, baking or gardening which help them generate income so they need to be given a certain amount for a start. Support groups should also be created to promote unit, cooperation and sense of oneness as caregivers.

Appendix A: Hope Humana key informants' Interview Guide

My name is Evernice Tayisepi. I am a Development studies student at Midlands State University (MSU). I am conducting a research on the topic ‘‘Challenges facing Community Home Based Care Givers of people living with HIV/AIDS, Case of Hope Humana Care program’. May you kindly assist with the information required for the effectiveness of the study. The information you provide shall be treated in strict confidence and will be used for the purpose of this study only. Thank you for taking part in this study.

Research topic: *Challenges facing Community Home Based Caregivers of people living with HIV/AIDS...Case of Hope Humana Care Program*

- 1 How is Community Home Based Care for people living with HIV/AIDS relevant in the running of your organisation?
- 2 How effective is Community Home Based Care in its helping role to your organisation?
- 3 What process or procedure do you take in presenting your views to the patients and caregivers?
- 4 How often do you monitor your caregivers?
- 5 How long do you take to respond to the caregivers' needs?
- 6 What are the major challenges faced by your organisation in the caregiving program?
- 7 Are the caregivers you trained easily identified in community, if yes how are they identified?
- 8 Do you have books in office for the caregivers and other community members to learn more about caregiving?
- 9 On average, how many caregivers drop out of the program if there are any who dropped?
- 10 Is your organisation working with other organisations in the caregiving program?
- 11 Do you have appropriate and required tools/ resources such as first aid kits and medicines to use in the caregiving process?
- 12 What is the caregiver to patient ratio?
- 13 Do you offer incentives or any kind of motivation to the caregivers?
- 14 How often do you train the caregivers?

Thank you

Appendix B: Hope Humana caregivers' discussion questions

My name is Evernice Tayisepi. I am a Development studies student at Midlands State University (MSU). I am conducting a research on the topic ‘‘Challenges facing Community Home Based Care Givers of people living with HIV/AIDS, Case of Hope Humana Care program’. May you kindly assist with the information required for the effectiveness of the study. The information you provide shall be treated in strict confidence and will be used for the purpose of this study only. Thank you for taking part in this study.

Research topic: *Challenges facing Community Home Based Caregivers of people living with HIV/AIDS...Case of Hope Humana Care Program*

- 1 Are there challenges that you face in the caregiving process?
- 2 If any, what are the challenges that you face in the caregiving program?
- 3 How effective is Hope Humana Harare Project in its response to your views or ideas on behalf of the people you represent?
- 4 Do you have workmates (other caregivers like you) who have dropped out of the program due to non-payment of incentives by Hope Humana Project?
- 5 Are you getting frequent training?
- 6 Describe in brief your role in the community as a Voluntary caregiver of Hope Humana Care program?
- 7 What have you done as a Caregiver to ensure that patients' views especially that from your operational area are expressed and heard in the Community and at Hope Humana Project?
- 8 Do you get incentive for the job and if you get does the project pay you on time?
- 9 What does Caregiving mean to you as a Voluntary caregiver of people living with HIV/AIDS?
- 10 Do you have specific uniforms meant for you as caregivers?
- 11 Do you have enough space at Hope Humana office to discuss issues of concern and those that affect you?
- 12 Do you have the required resources to use on patients, such as bandages, gloves, first aid kits among other items required in the work?
- 13 Are these facilities enough? If they are not, how are you coping with the problem?
- 14 What do you think the project should do to further enhance the effectiveness of caregiving for the chronically?

Thank you

Appendix C: Interview guide for the chronically ill

My name is Evernice Tayisepi. I am a Development studies student at Midlands State University (MSU). I am conducting a research on the topic ‘‘Challenges facing Community Home Based Care Givers of people living with HIV/AIDS, Case of Hope Humana Care program’. May you kindly assist with the information required for the effectiveness of the study. The information you provide shall be treated in strict confidence and will be used for the purpose of this study only. Thank you for taking part in this study.

Research topic: *Challenges facing Community Home Based Caregivers of people living with HIV/AIDS...Case of Hope Humana Care Program*

1. How long have you been living in this community?
2. What made you accept caregivers in your circle?
3. Are you in any way benefiting from the caregiving program?
4. What is your relationship with caregivers like?
5. Do you have family members who are also care givers?
6. What do you wish the government could do for you in terms of caregiving services in your community?

Thank you

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