CONSTRAINTS ON THE PROVISION OF HOME- BASED CARE SERVICES TO PATIENTS IN WARD 25 OF THULAMELA MUNICIPALITY IN

LIMPOPO PROVINCE

BY

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DECLARATION

I, **Mashudu Shadrack Sinyela**, hereby declare that the mini dissertation for the degree of Master of Public Management at University of Venda hereby submitted by me has not been previously submitted for a degree at this or any other university. This is my own work in design and execution, and that all reference materials contained therein has been duly acknowledged.

14/09/2015

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DEDICATION

On my personal note, I dedicate this project to my parents, Mr.Amos Muthala and Mrs. Sylvia Muthala. You were there for me all the way.

ABSTRACT

The focus of this study was to assess the constraints to the provision of home based care services to patients in ward 25 of Thulamela municipality in Limpopo province. The researcher was encouraged to do this investigation due to the challenges that home based care givers experience which impact negatively on the quality of their services. The study sought to achieve the following objectives: Identifying the constraints to the provision of home based care, determining the extent to which the constraints are felt by care givers, identifying the coping mechanisms of the care givers and determining the kind of support services required and available to the home based care givers. Ethical issues such as consent and voluntary participation, no harm to participants and confidentiality will be taken into consideration. This study is explorative and descriptive in nature. Data was collected using questionnaire and interview schedule as a method of data collection and it was analysed using statistical package for social sciences (SPSS).

The findings of this study are:

- Home based care givers experience stress in their work place,
- Finance is a challenge to the majority of home based care givers,
- Home based care givers are stigmatized,
- Majority of the respondents agree that the work load of the home based care givers is appropriate,
- There is no shortage of home based care givers according to majority of the respondents,
- Policies to guide home based care givers are available in the centres,

- There is a shortage of working tools for home based care givers,
- The study revealed that home based care givers are attending workshops to capacitate them,
- Home based care givers are not professionally counselled,
- There is a need of continuous training for home based care givers,
- There is a shortage of resources in the home based care centres and
- The study also revealed that the stipend received by home based care givers is not enough.

The recommendations of this study are the following:

- Home based care givers should be capacitated on how to deal with stress in the work place,
- Government and other institutions should assist Home based care centres with finances,
- Communities should be continuously educated about the negative impact of stigmatization,
- The work load of home based care givers should be monitored and managed in order to avoid burnout
- Policies should always be available in the home based care centres,
- Government should ensure that there are working tools in the centres,
- Home based care givers should continuously be capacitated on issues related to their scope of work,
- Department of Health should ensure that home based care givers receive professional debriefing and counselling,

- Government should ensure that there are enough resources needed in the home based care centres and
- Government should consider increasing the remuneration of home based care givers.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
CHBC	Community Home-Based Care
CHBCGs	Community Home-Based Caregivers
CBOs	Community-Based Organisations
FBOs	Faith-Based Organisations
HBC	Home-Based Care
HBCC	Home-Based Care Centre
HBCGs	Home-Based Caregivers
ICBC	Integrated Community-Based Care
HIV	Human Immunodeficiency virus
NGOs	Non- Governmental Organisations
PALHIV	Patients living with HIV
WHO	World Health Organization

CHAPTER 1: ORIENTATION OF THE STUDY

1.1 INTRODUCTION

The increasing incidence of human immune virus (HIV), Acquired Immune Deficiency Syndrome (AIDS) and Tuberculosis (TB) is putting a lot of strain on the health services in many developing countries, including South Africa. The HIV and AIDS incidence has added a burden of complexity to health system across the globe. As 80 percent of South African population makes use of the public sector for their health needs, increase work loads on the health system are a cause for concern (Van Dyk, 2001: 5).

According to the UNAIDS Global report (2006) 5.5 million people were living with HIV at the end of 2006 in South Africa. In Sub-Saharan Africa an estimated 4.3 million people infected with HIV and AIDS need home-based care but only 12 percent receive it. Many governments, including that of South Africa, encourage volunteers to become involved in community health workers' programmes to care for those infected and affected by HIV and AIDS (UNAIDS, 2006: 22).

As many households in South Africa are affected by HIV and AIDS, there is a growing need for assistance with care and support. Increasingly households are faced with the needs of sick family members which include assistance with daily living, treatment and palliative care. Approximately 90 percent of AIDS care takes place in the home and care is mostly given by women and girls. Given the limitation on availability of formal in patient programmes, house holds rely upon informal caregivers (for example, household or family member, friends, community members or voluntary organizations) and home-based care programmes for assistance (UNAIDS, 2006:23).

Home and community-based care (HCBC) has been practiced throughout the ages. Care of homes was provided mostly by women and initially only for their family members. In fact, ancient Hebrew nurses participated in planned visitation programmes of sick people in their homes (Dolan, 1978:15).During the first century of the Christian Church, deaconesses provided care at home. They were called visiting nurses and were the forerunners of community health nursing of which home-based care forms a part (Dolan, 1978:45).

St Francis de Sales was instrumental in the establishment of a voluntary organization which visited the sick in their homes. Consisting of women these organizations dressed patient's wounds and performed basic physical and household care (Dolan, 1978:91). This thread can be traced throughout history and is still evident today in most countries, including North America and Europe (Uys & Cameron, 2003:3). It has taken different forms in different countries based on the availability of resource, cultural issues and context. Due mainly to the inability of the health care system to meet the ever-increasing demand for services to the chronically ill and disabled, the need has once again arisen for HCBC. This has been exacerbated by the advert of the HIV/AIDS epidemic and the increasing aged population (Health and Development Networks, 2001:13).

The Department of Health (DOH, 2001:1) defines home care as "the provision of health services by both formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death". Home care is a comprehensive service and includes preventive, promotive, therapeutic, and rehabilitative, long-term maintenance and palliative care (Van Dyk, 2005:260). The roles and responsibilities of all the role players, particularly the caregivers and nurses, were not clarified. Dealings with current HBC carers and nurses found that, in some instances, health professionals view the service with suspicion in terms of quality of service provide and the possibility that this category of health worker, home-based carer, may take over their work, as many carers do aspire to become health workers. For HCBC to be effective and to provide a quality service provided to the community, it was decided that clarity regarding care-givers' roles should be given. This study will focus on the Constraints on the provision of home-based care to the patients in ward 25 of Thulamela Municipality in Limpopo Province. Home-based care givers in ward 25 of Thulamela Municipality will be the respondents in this study.

1.2 BACKGROUND OF THE STUDY

A few decades ago, a disease, previously unknown to the human race, began to kill people in alarming and terrifying circumstances. The disease is now known as Acquired Immune Deficiency Syndrome (AIDS), which is caused by Human Immunodeficiency Virus (HIV). The first recognized cases of HIV and AIDS occurred in America in 1981 when very rare forms of pneumonia and a rare skin cancer, suddenly appeared simultaneously in several patients (Van Dyk, 2001:5)

Southern Africa remains the region worst affected by the HIV and AIDS epidemic. Combinations of contributory factors have been identified; These include, poverty and social instability, high levels of sexually transmitted infections, the low status of women, sexual violence, high labour mobility (migrant labours), and lack of good governance in many countries. South Africa has the sixth highest prevalence of HIV in the world, with 18.8 percent of the population estimated to be infected. The HIV and AIDS global report, estimated that 320 000 people died of AIDS-related deaths in South Africa during 2005 (UNAIDS, 2006:23).

The increase in HIV and AIDS prevalence across the country has posed a serious strain on caregivers for AIDS patients as caring for someone with AIDS can substantially increase the workload of a caregiver. Many theories about the origin of AIDS have been postulated. They range from a belief that the virus was developed as an instrument of biological warfare to a view that the virus is being used by aliens from outer space to kill the people of planet earth. Now it is generally accepted by scientists that HIV crossed the species barrier from primates to humans at some time during the 20th century (Van Dyk, 2001:6)

According to Van Dyk (2001:6), the HIV/AIDS epidemic is a major threat to social and economic development in South Africa. It is severely impacting on the developmental gains made since 1994 especially with respect to improvement of the quality of life and services rendered to families and children. Services that are in high demand include psychosocial support, material assistance in the form of food parcels, social relief to the distress, burial grants, as well as foster care and child support grants. In Southern Africa caregivers reported stressors that are related to HIV disease such as risk of contagion; stigma and feeling of helplessness. Although HIV can be treated, it is currently an incurable disease. Caregivers were also confronted with inadequate medical resources while experiencing repeated exposure to death, profound grief, loss and ethical dilemmas. According to Grossman and Silverstein (1993:19) social workers, nurses, counselors, caregivers and other health care professionals who work with people infected and affected by HIV and AIDS experience burnout from the excessive demands on their energy, strength and resources. Silverman (1993) raised the possibility of HIV caregiver's stress syndrome, noting that there was a relative lack of attention paid to the stresses experienced by providers of care for persons with HIV and AIDS.

The escalating HIV/AIDS epidemic has increased the need for home care and resulted in a more programmatic approach (WHO, 200a:8). According to the National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa 2006, in Limpopo, the rate decreased from 29,5% to 29,0% (DOH, 2006:13). It was noted, however, that the prevalence rate in the Capricorn district rose from 22.2% in 2005 to 24,2% in 2006. This resulted in an increase of AIDS-related conditions requiring care and support. The inadequate number of medical, nursing and allied health professionals in the public sector, the cost of institutional care, and overcrowding of hospitals compounded the problem. The

DOH (2001:1) has built on the groundwork done by non profit organizations, scaling up and formalizing the programme through the development of guidelines and a training course.

As indicated earlier, community members originally initiated HCBC to assist family and community members in need. Consequently, the care provided was basic and limited to the skills that carers had and was not guided by professional nurses. Thus, community professional nurses were initially excluded and may not have been aware of the importance of their role. This exclusion may have resulted in a lack of cohesion and coordination between carers and professional nurses as well as the quality of care not being articulated.

Home care is a fragile, new field in South Africa requiring support and standardization so as to ensure quality care. Therefore management is essential to ensure the provision of quality care. The professional nurse, as the health professional and team leader with the competence to identify needs and develop plans accordingly, must control the quality(Van Dyk ,2005: 260)

1.3 STATEMENT OF THE PROBLEM

Health facilities are experiencing difficulties partly due to an increase in the number of HIV and AIDS cases. As a result, patients are turned away from hospitals due to limited beds. Households and communities are assuming responsibility for the care of people living with HIV and AIDS. However, there is concern about the communities' readiness to provide the care (Van Dyk, 2008:332)

Community/home-based care is a fairly recent phenomenon in South Africa. Historically, funding and other resources were allocated for preventative interventions. The increasing numbers of people with acute HIV infections have made AIDS more visible and various programs designed to counter this phenomenon have emerged. Unfortunately due to the limited amount of resources available, viz. funding, human resources and material goods, many home-based care givers are ill-equipped to provide quality care services. Although some challenges are common across geographical areas, it is always important to carry out location-specific research so as to generate properly targeted interventions.

According to Van Dyk (2008: 332), HBCGs have difficulty in dealing with all the challenges, which makes them, feel emotionally as well as socially weak and hamper their performance. In general they face challenges that are emotional, financial, physical and social in nature. Thus, this study will explore and describe the constraints on the provision of home based care services to patients in ward 25 of Thulamela municipality in Limpopo Province. The findings in this study will assist in recommending ways of finding strategies to minimize constraints on provision of home based care services.

1.4 AIM OF THE STUDY

The overall aim of the study is to investigate and describe the constraints on the provision of home based care services to patients in ward 25 of Thulamela municipality in Limpopo province.

1.5 SPECIFIC OBJECTIVES

- Investigate the challenges experienced by Home-Based Caregivers in giving Home-Based Care services to patients.
- To determine the kind of support services required and available to the study group.
- To recommend strategies for improving the services of home-based care givers, and

- Investigate the coping mechanisms used by HBCGs in giving HBC to Patients.

1.6 RESEARCH QUESTIONS

- What are the challenges experienced by Home-Based Caregivers (HBCGs) in giving Home-Based Care (HBC) to Patients?
- What kind of support services required and available to the study group?
- What are the strategies for improving the services of home-based care givers?
- What are the coping mechanisms used by Home based care givers?

1.7 SIGNIFICANCE OF THE STUDY

The study comes at a time when different strategies of dealing with HIV and AIDS are being tried and home-based care is one of them. Home-based givers face numerous challenges in their day to day work. This study will contribute to the body of knowledge on home based care and HIV and AIDS. The results will be useful when developing strategies to address the challenges that home-based givers face. The findings will provide direction for further investigation as only limited research has been done on home-based care. The findings would also assist policy-makers to develop policies to address identified issues. Finally, community members will also benefit from the study, as better understanding will result in improved service delivery.

1.8 DELIMITATIONS OF THE STUDY

The study was confined to the constraints on the provision of home based care to patients in ward 25 of Thulamela municipality in Limpopo province.

1.9 LIMITATION OF THE STUDY

This is a case study and the findings of this study have identified and recognized the following as limitation: The sample size in this study was small; but the results can be generalized to other similar situations. Funds for transport, binding and editing was another serious limitation in this study. The study has an element of sensitivity due to stigmatization attached to Home based care givers.

1.10 DEFINITION OF CONCEPTS

For the purposes of this study, the following terms will be used as defined below:

Human Immunodeficiency virus (HIV): HIV is an acronym for Human Immunodeficiency Virus. This virus only affects human beings (Corne, Jones & Powell, 1993:6)

Acquired Immune Deficiency Syndrome (AIDS): AIDS is short for Acquired Immune Deficiency Syndrome, which is acquired because the disease is not inherited. Human Immuno Deficiency Virus which enters the body from outside causes the disease. It is a collection of many different conditions that manifest in the body (or specific parts of the body) because when HIV has weakened the body's immune system it cannot fight the disease-causing agents that are constantly attacking it. Therefore AIDS must be regarded as a syndrome of opportunistic diseases, infections and certain cancers that can kill the infected person in the final stages of the disease (Van Dyk, 2008:4).

Home-Based Care: Home-based care is the care given in the home of a person living with HIV and AIDS. Usually, a family member or friend (the primary care giver), provides the care and is supported by a trained community caregiver. In ideal circumstances a multi- disciplinary team supports family and community caregivers so that they can meet the specific needs of the individual and family. The team consists of all the people involved in care and support, and may include a medical practitioner or professional nurse, a social worker or trained counselor, a pastor or spiritual leader, volunteers, a traditional healer, friends and neighbours, and community members (Van Dyk, 2008:332).

Chronic illness: According to Fox and Fama (1996:10) illness that typically has a fluctuating and unpredictable course with exacerbations and improvements is regarded as chronic. For purposes of this study, chronic illnesses refer to those illnesses that cannot be cured, rather they can only be controlled, for example, AIDS.

Carer: A carer is a person who looks after a sick person at home (Van Dyk 2005:164.323)

Community-based care (CBC): CBC is the care that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, and encourages traditional community life" (Van Dyk 2005:262).

Community-based organization (CBO)

A CBO is an organization situated at community level and addressing community identified needs at this level.

Patients living with HIV (PALHIV): Patients living with HIV are people who have tested positive for HIV and are living with the virus. In this study PALHIV are in different phases of HIV infection. Some are taking treatment because of the decline of their CD4 count whereas some are still recovering and others are fully recovered and self reliant(Van Dyk 2005: 263)

CD4 count: In this study CD4 count is understood in accordance with ACASA (2003) namely that it is a blood test that measures the number of T4 (CD4 cells) in one's blood. It tells one how the immune system is and how much damage the HIV virus has done to the immune system. As the disease progresses T4 count becomes lower. When CD4 count is somewhere between 350 and 200, PALHIV must start taking treatment. These are the PALHIV that this study focuses on.

1.11 ORGANISATION OF THE STUDY

This study is organized as follows:

CHAPTER 1: ORIENTATION OF THE STUDY

This chapter provides a clear picture of the focus of the study. A brief study background, problem statement, hypothesis, research objectives and purpose of the study are also presented in this chapter.

CHAPTER 2: LITERATURE REVIEW

This chapter demonstrates the magnitude of HIV and AIDS, principles and goals of home-based care, as well as the activities and scope of home based care givers. Literature was drawn from books, previous research done, and Government policies.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

This chapter deals with a systematic discussion of types of research and choices for the study purpose. The practicality of the research methods and design are included in the discussion.

CHAPTER 4: DATA PRESENTATION, ANALYSIS AND INTERPRETATION

Data is presented, analyzed and interpreted in this chapter. Data collected through questionnaire was analyzed using SPSS, and data collected through interview was analyzed using thematic process

CHAPTER 5: CONCLUSION, FINDINGS AND RECOMMENDATIONS

This chapter presented the conclusion, findings of the study as well as the recommendations for future research.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents a review of literature pertaining to the constraints on the provision of home based care services. The concept of Home based care has received attention from different authors. The literature review has included related research studies which were done previously in relation to home based care. This chapter also covers conceptual framework of the study, legal and policy issues on the constraints on the provision of home based care services, challenges faced by home based care givers, social support of home based care givers, principles of home based care and models of home based care.

2.2 CONCEPTUAL FRAMEWORK OF THE STUDY

Greene (2008:1) defines a caregiver as anyone who provides help to another person in need. There are various descriptions given of various types of caregivers, which differ from country to country and from institution to institution. Different scholars use different names to define them such as carers, caregivers, community caregivers, health workers and home-based caregivers. All these different names in essence carry the same meaning as the one mentioned by Greene. The difference may only be the location of the patient, for example, at home or at a hospice. Some of the caregivers are unpaid, unaccounted for and undervalued, despite their contribution.

Many caregivers are poor, have large families or are living with HIV themselves and are thereby increasing their susceptibility to the virus, which contributes to their difficulties in coping with their work. Donors provide financial contributions towards communities, who are the implementers of home-based programmes through HBCGs who provide care to PALHIV to mitigate the impact of HIV/AIDS (France 2008:1; Jackson, 2002:250). A distinction between two main types of caregivers should be highlighted for the purposes of this study, namely formal and informal caregivers (Primo, 2007:20).

According to Primo, (2007:20) Formal caregivers include professionals and specialists such as physicians, pharmacists, medical social workers, occupational and speech therapists, doctors and nurses. This category of caregivers also includes trained volunteers, spiritual volunteers, spiritual counsellors associated with AIDS service organisations, AIDS care teams and hospice programmes. Informal caregivers comprise relatives, spouses or partners and friends who provide at-home care on an unpaid basis. They are in some cases not trained at all, or have received very little training. Respected traditional healers in various communities, especially in sub-Saharan Africa, also provide care for PALHIV. The discussion focuses on the constraints on the provision of home based care services to patients in ward 25 of Thulamela municipality in Limpopo province.

2.3 LEGAL AND POLICY ISSUES ON HOME BASED CARE

Given the high prevalence of HIV and AIDS IN South Africa, the Department of Health has adopted the guide to establish a home based care programme (Department of Health, 2004), as a strategy to meet the physical, psychological, spiritual and social needs of people living with HIV and AIDS, those have other chronic conditions and their families.

The Republic of South Africa Constitution (Act 108 of 1996) is the supreme law of the country and all other laws must comply with its provisions. The constitution includes a bill of rights which lists basic human rights that apply to all citizens and therefore also to people living with HIV/AIDS. Under no circumstances should people living with HIV/AIDS be discriminated against on the grounds of their

HIV/AIDS status. Section 10 of the same constitution provides that every person has a right to human dignity. People living with HIV or AIDS have the same basic rights and responsibilities as all other citizens. The charter of Rights on AIDS and HIV which was launched in 1992 is the Bill of Rights of people living with HIV and AIDS. The human rights principles in the Charter are essential to ensure non-discrimination and provide public health in South Africa (Van Dyk, 2008:430).

2.4 ROLES AND RESPONSIBILITIES OF HBCGS

HBCGs see the reality of HIV/AIDS in their area of work and yet strive to ensure that infected and affected people can live with hope and dignity to face the challenge of living with the epidemic, from the time of infection to their eventual death. This is done through provision of medical, emotional and physical support to PALHIV and their families (France 2008:1; Sardiwalla 2004:2).

2.4.1 Physical care

HBCGs provide basic nursing care and comfort measures such as symptom recognition, diagnosis, treatment, symptom management, referral and follow up. Basic nursing care include positioning and mobility, bathing, wound cleaning, skin care, oral hygiene, adequate ventilation, and guidance and support for adequate nutrition. They furthermore identify situations where adequate caregiving such as basic needs of shelter, food, bedding and clothes is not provided (WHO, 2002:35).

2.4.2 Palliative care

HBCGs also provide palliative care, which involves a combination of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life threatening illness. The HBCGs strive to meet the physical, psychological, social and spiritual needs of PALHIV, a task that requires a team approach and that includes the patient, family, health and social welfare workers as well as the HBCG (WHO, 2002:36).

They also assist PALHIV with running of errands, recreational services, companionship, transportation, in-patient services, clerical work, conference participation, public speaking, and counselling among other duties, to lighten the burden of the disease on the client and family. They also accompany the patient to the hospital to obtain medical treatment and negotiate for what they perceive as appropriate treatment based on their experience (France 2008:1; Jackson 2007:22; Makoae & Jubber 2008:41; Sardiwalla 2004:3; WHO, 2002).

According to Jackson (2002:249), the role of caring for PALHIV is very difficult, even to the point where a caregiver may end up feeling a sense of failure, inadequacy, resentment and anger. The role of caring is made more difficult by the fact that PALHIV may get sick, recover, become ill with something else, and again recover, and so on. This could be an endless, confusing circle which can be emotionally exhausting to both the caregiver and the patient. In summary, the roles and responsibilities of HBCGs are to provide basic care and assistance deemed necessary by the conditions of the client. The support HBCGs provide varies widely and depends on the needs and availability of resources.

2.5 Challenges faced by Home based care givers

Home based care givers are faced by many challenges emanating from caring for patients. Caring for patients is associated with high levels of stress, burnout, anxiety, and financial burden, and can be very draining physically, emotionally and psychologically as well as socially. Both caregivers and PALHIV are faced with challenges such as continuous physical and psychological deterioration, their own mortality and the fear of contagion and death. This can challenge a caregiver‘s ability to cope. If they do not learn how to care for themselves, they will not survive the onslaught of the HIV pandemic (Akintola 2004:23; Van Dyk, 2001:282).

2.5.1 Stress and burnout

According to Van Dyk (2001:283), burnout can be defined as a syndrome of physical and emotional exhaustion involving the development of a negative self-concept, negative job attitudes, and loss of concern and feeling for clients. According to Gueritault-Chalvin et al. (2000:149), occupational burnout may occur where work demands especially those of an interpersonal nature lead to chronic emotional exhaustion, depersonalization and a reduced sense of personal accomplishment, such as may happen when caring for PALHIV.

HBCGs work very closely with PALHIV who are dying and this can leave them emotionally and physically drained. According to Ross, Greenfield and Bennet, (1999:729), emotional overload brings unhappiness, over-involvement, exposure to others'grief, death of a client and a feeling of helplessness on the part of the caregiver. When HBCGs feel emotionally stressed they therefore face work related stress, which leaves them very susceptible to symptoms of burnout such as loss of interest in and commitment to work, a lack of job satisfaction, not being punctual and neglecting duties, a loss of sensitivity in dealing with clients or patients, referring to clients in a dehumanized or purely impersonal way, avoidance of clients to limit the time spent with them and frequently but unnecessarily referring clients to other health care professionals, deteriorating relationships with colleagues and friends, tension and distress in their personal life as well as difficulties in getting on with people. These symptoms can lead to a high level of turnover, absenteeism, and reduced productivity, which impact on the general running of the organisation (Jackson, 2002:253; Pendukeni ,2004:14; WHO, 2002:420).

When HBCGs begin to feel that they are not supported, it often leads to burnout. If burnout is not controlled it may lead to depression, which will make them feel despondent and will affect the caregiver‘s ability to provide optimal care to PALHIV. Depression in the context of HIV is caused by many factors including a feeling of a lack of control over one‘s fate, changes in a person‘s self-image, and exposure to stigma. (Simpson 2006:8; Uys & Cameron 2003; WHO, 2002:40). A study by Demmer (2004:524) provided evidence that younger caregivers for PALHIV are more likely to experience burnout than older workers. This may be due to lack of experience as well as to being over-involved in the job. There is no significant difference in burnout based on marital status and sexual orientation in HIV caregiving or a person‘s occupational role.

The following has been found in different African countries: a study in Zambia reported that, despite the fact that health workers were still relatively motivated, emotional exhaustion occurred among 62% of the respondents who took part in the study (Dieleman, Biemba, Mphuka, Schinga-Sichali, Sissolak, Van der Kwaak et al. 2007:1). In one Namibian study, mentioned in Pendukeni (2004:14), it was found that nurses were not prepared to deal with PALHIV, and as a result looked for reasons to stay away from work clearly confirming that stress leads to absenteeism.

Workload also contributes to burnout. According to the study conducted by Dieleman et al. (2007:1) in Zambia, HIV/AIDS has had a negative impact on the workload of carers and has considerably changed or added tasks to an already overburdened health sector. Gueritault-Chalvin et al (2000:158) research reported that the perceived workload was positively correlated to burnout, and even significantly predicted burnout. Stress leads to frustration as a result of HBCGs‘ lack of knowledge and skills in dealing with patients, work demand, lack of competence, and as a result also of their hiding their true feelings, emotions and fear. This could be as a result of a lack of training or understanding in respect of professional conduct and accountability, indicating a need to strengthen monitoring and supervision of the HBCGs (Jackson 2007:76; Pendukeni 2004:14).

According to WHO (2002:71), a Home based care giver from Namibia, described the stress they undergo as carers and their ways of dealing with such stress in the following manner, "I think of our work like holding up a candle of hope to other people. But unless we protect that candle, it will burn out". This shows that certain Home based care givers recognize that they need to care for themselves lest they burn out. According to Primo (2007:22), caregiver stress can be divided into primary and secondary stress. Primary stress comes from the everyday duties of a caregiver such as assisting a patient with bathing, toileting and managing the patient's difficult behaviour as well as the planning of daily care. Secondary stress emanates from the caregiver's conflict with other family members (own family or the family of the patient).

Stress and burnout affect caregivers providing care to patients suffering from various chronic diseases such as cancer and dementia. When considering whether AIDS caregivers experience more burnout than those caring for patients with other chronic diseases, contradictory results are reported. According to Gueritault-Chalvin et al. (2000:150), research on cancer showed that other caregivers experienced similar stress-producing activities as AIDS caregivers. There was no difference in the level of burnout experienced by both cancer and AIDS caregivers. On the contrary, Demmer (2004) highlighted that in countries such as Germany and Italy, the caregivers of PALHIV were more prone to burnout than caregivers working in fields such as oncology. According to Gueritault-Chalvin et al. (2000:158), more research on burnout indicated that health workers who have more concentrated exposure to HIV/AIDS may be more likely to experience burnout.

2.5.2 Physical effects

According to Primo (2007:22), caregiving is burdensome and may compromise a caregiver's health. Symptoms of poor physical health are markedly present among AIDS caregivers and are associated with care-related demands and stressors. The level of depression among caregivers strongly correlates with different physical ailments. The multiple tasks they perform often result in neglecting their own self-care, such as nutrition, exercise, socializing and sleep. They develop detrimental health behaviour such as overeating, smoking, not exercising and disturbed sleep patterns (they sleep less than non-caregivers). Consequent to detrimental health behaviour, certain caregivers, especially women, gain weight, their immune system weakens and the healing of their wounds is often affected. Most caregivers suffered physically as a result of caring and experience headaches, body aches, backaches and exhaustion as common problems.

2.5.3 Financial aspects

In a study by Jackson (2007:76), finance was one of the challenges experienced by HBCGs as their stipend included transport to see a doctor, and transporting patients to hospital. Some therefore leave caregiving after having received training, as they often do not receive any stipend or it is not sufficient to cover their needs and those of their patients. This challenge can be categorized as secondary stressors (economic hardships), which may include loss of employment and income, as highlighted in Primo (2007:22).

2.5.4 Stigma and discrimination

According to Van Dyk (2001:284), and Friedland, Renwick and McColl (1996:16), both infected and uninfected HBCGs working in the HIV/AIDS arena are stigmatised. According to WHO (2002:40), for PALHIV and their family members, the stigma, fear and discrimination often associated with the illness can create barriers to effective care. This was reported in a study mentioned in a WHO report, which revealed isolation, fear and discrimination as common themes that were related to HIV/AIDS. The study also acknowledged that teaching health and social service personnel about universal precautions is not sufficient to reduce stigma behaviour (WHO 2002:49). HBCGs on the other hand are at times avoided or ostracised because they work with PALHIV, and therefore they are deprived of much needed support.

Stigmatisation amongst colleagues working with PALHIV is another challenge faced by HBCGs. Research indicates that employers and employees often discriminate against workers who are suspected to be or confirmed to be HIV-positive. This behaviour emanates from ignorance about the facts around HIV transmission and the progression of the disease, fear by employers or superiors of reduction in productivity and profits, as well as fear of stigmatization of the organisation in the event that clients get to know workers are positive (Pendukeni,2004:17).

2.5.5 Attachment

According to Bennett, Ross and Sunderland (1996:145), many HIV carers expressed fear of getting too involved or attached to their patients and forming close relationships with them. They try to avoid closeness because of the imminent death of the People living with HIV and AIDS.

2.5.6 Risk of contracting the disease

Many studies, such as Primo (2007:23), Pendukeni (2004:12) and Dieleman et al. (2007:23) have identified contagion as one of the serious concerns among HBGC. One major stress producing concern shared by many AIDS workers is anxiety over safety practices and fear of occupational contagion, rooted in occupational exposures to HIV. According to a study conducted by Pendukeni (2004:11), the nurses in her study expressed fear of contagion not only from the PALHIV but also from their colleagues, as is well described by one the respondents: I am scared of getting the HIV virus not only from the patients but from colleagues as well. I know I cannot contract it from sharing cups, and so on, but some colleagues have open wounds and some oozing rushes from the lips and all over the face.

This fear is exacerbated by the difficulties experienced in maintaining consistent and appropriate infection control precautions. HBCGs may also harbour irrational fears of contagion taking place through casual contact, or touching utensils used by a PALHIV, despite their knowledge of the facts about HIV/AIDS. This fear can consequently cause physical or empathetic withdrawal from persons with HIV/AIDS, resulting in deprivation of physical and emotional contact with the PALHIV, which is the most valuable intervention.

In another study of caregivers in Zambia, more than 75% of the respondents expressed fear of infection in the workplace, despite the fact that there are protective measures in place (Dieleman et al. 2007:1). According to Leake (2009:5), close contact with patients faeces, vomit and other bodily fluids create the risk of HIV and tuberculosis infection for the caregiver. The risk is exacerbated by not taking precautionary measures such as wearing rubber gloves. However, even though there are anecdotal reports of caregivers becoming infected with HIV in this manner, there is little documented evidence of this (Gueritault-Chalvin et al. 2000:150; Pendukeni 2004:18; Primo, 2007:25).

In a study by Demmer (2004:526) it was found that there was a higher score on burnout among the HBCGs who experienced fear of contagion as well as those feeling discomfort in dealing with injection drug users and PALHIV (unfortunately this article by Demmer does not state clearly as to where the study was conducted).

2.5.7 Confidentiality and autonomy

Confidentiality is one of the challenges faced by Home based care givers. According to Makoae and Jubber (2008:37), confidentiality has mainly been considered from the perspective of protection of PALHIV from stigmatisation; however, this contradicts the fundamental values of shared responsibility in informing other sexual partner/s so that they can practise safe sex (WHO 2002:48). WHO (2002:42) mentions that some PALHIV do not want their families, including their spouses or sexual partners, to know their diagnosis and the HBCGs should agree to this as it is the human rights of the patients. This is evident in the study by Primo (2007:25), which reported that HBCGs are often designated as the keepers of secrets. The keeping of secrets not only depletes emotional energy and causes inner conflict and isolation, but also affects the ability to provide a professional relationship.

Some patients cared for by HBCGs present obvious symptoms of opportunistic infections but refuse to test for HIV, and the HBCGs cannot force them. All these ethical dilemmas, together with a lack of appropriate community resources and facilities, can make a HBCG in the field of HIV/AIDS experience a sense of inadequacy and exacerbate their difficulty in coping with their work (Primo, 2007:26).

2.5.8 Human sexuality

According to Primo (2007:24), HBGCs struggle with discussions on issues of sexuality with PALHIV, especially because HIV/AIDS is mainly contracted sexually. This discomfort that HBCGs suffer can lead to inadequate sexual history recording, which is necessary for diagnosis and treatment of the PALHIV. The lack of information makes it difficult for the caregiver to respond adequately to the needs of the patient, thereby compromising the quality of care that the patient can receive.

2.5.9 Workload

Health professionals can no longer provide adequate care to patients in public hospitals due to the workload, which is exacerbated by staff absenteeism, attrition resulting from resignations and HIV/AIDS-related deaths. At a time when the efficient staffing levels of the workforce are compromised by HIV, the demand for HBCGs‘services continues to rise, especially from PALHIV. This section has highlighted different types of challenges that HBCGs go through as they provide care to PALHIV. Delays and difficulty in dealing with these challenges can affect the quality of care that they provide to PALHIV (Primo, 2007:24)

2.6 SOCIAL SUPPORT OF HOME BASED CARE GIVERS (HBCGS)

Care giving takes an enormous physical, psychological and economic toll on its providers, for they have to deal with multiple deaths of their patients, as mentioned in Uys & Cameron (2003:23). They therefore need more access to psycho-social support and economic assistance to help them sustain this physically and emotionally draining, yet vitally important service (UNAIDS [sa]). However, providing emotional support is very difficult for HBCGs if they do not feel supported them (WHO, 2002:40).

Without support they may experience burnout and it will be difficult for them to give compassionate care (Uys & Cameron, 2003:28). It is therefore important that caregivers should become proactive and try to guard against potential stressors that could lead to difficulty in coping with work. According to Jackson (2002:250), caregivers need to know when to seek professional help, and to have access to spiritual and counseling support to help them and the patient cope emotionally. A professional relationship in the workplace is also documented to reduce stress at work, therefore enabling coping (Pendukeni, 2004:16).

Primo (2007:29) points out that through talking, sharing feelings or releasing them through crying, laughing, dancing together with other caregivers as they have the same work demands, can help one to cope better with feelings such as isolation, anger, sadness or grief. Social workers are able to connect to caregivers so that they can form spiritual and counselling support groups. The caregiver‘s mental and physical health is vital to the PALHIV, making it critical that the caregiver must be able to strike a balance between taking care of him-/herself first, so as to be able to take care of other people. This can be done through rest and exercise, enough sleep and eating well.

According to WHO (2002:49), the HBCGs need to be provided with an opportunity to express their fear, uncertainties and prejudices provided by the organisation they work for. The organisation must ensure that the environment is conducive for the HBCGs to express themselves. In this way they can overcome negative emotions and learn more about the experiences and challenges facing PALHIV. A study by Dieleman et al. (2007:1) reported that organisational support for caregivers to deal with HIV/AIDS was either haphazardly employed or not in place at all. Demmer (2004:525), in his article on health care workers, mentions that it is important for the caregivers to feel that their organisation or institution is supportive, that it values their contributions and cares about their well-being, listens to their complaints, helps them with their work-related problems and treats them fairly.

Less organisational support, including a lack of support from supervisors and colleagues, is linked to burnout. Support can be in the form of clear policy guidelines, standards and regulations to govern the HBCGs (Jackson, 2007:23), and which are well understood by the HBCGs. These can be well understood if the HBCGs themselves become part of the process of their development.

Adequate resources such as staff, education, equipment and finance need to be made available to ensure successful implementation of such policies and guidelines (Uys & Cameron, 2003:23).

This emphasises that staff support by the employer may reduce the stress and burnout experienced by caregivers for PALHIV (Pendukeni, 2004:16). The more support gained, the more PALHIV begin to open up to others and thereby learn to cope more efficiently and gain more strength and wisdom through the support of others. Recognition and reward from supervisors are known to act as buffers against stressors.

2.7 MAGNITUDE OF HIV AND AIDS

Approximately 30.8 million adults and 2 million children were living with HIV at the end of 2007(UNAIDS, 2008). During 2007, some 2.7 million people became infected with the human immunodeficiency virus (HIV), which causes AIDS. The year also saw 2 million deaths from AIDS a high global total, despite antiretroviral (ARV) therapy, which should reduce AIDS-related death among those who received it. The number of deaths probably peaked around 2005, and has since declined only slightly. The overwhelming majority of people with HIV, some 95% of the global total, live in the developing world. The proportion is set to grow even further as infection rates continue to rise in countries where poverty, poor health care systems and limited resources for prevention and care fuel the spread of the virus.

Globally, around 11% of HIV infections are among babies who acquire the virus from their mothers: 10% result from injecting drugs; 5-10% is due to sex between men; and 5-10% occurs in health care setting. Around half of the people who acquire HIV become infected before they turn 25 and typically die of the life threatening illness called AIDS before their 35th birthday. By the end of 2007, the epidemic had left behind 15 million AIDS orphans, defined as those aged under

18 who have lost one or both parents to AIDS. These orphans are vulnerable to poverty, exploitation and themselves becoming infected with HIV. They are often forced to leave the education system and find work, and sometimes to care for younger siblings or head a family (UNAIDS 2008).

In 2007, around 37,000 children aged 14 or younger became infected with HIV. Over 90% of newly infected children are babies to HIV-positive women, who acquire the virus during pregnancy, labour or delivery, or through their mother's breast milk. Almost nine-tenths of such transmissions occur in sub-Saharan Africa. Africa's lead in mother-to child transmission of HIV is firmer than ever despite the evidence that HIV ultimately impairs women's fertility: once infected, women can be expected to bear 20% fewer children than she otherwise would. Drugs are available to minimize the dangers of mother-to child HIV transmission, but these are still often not reaching the places where they are most needed.

The area in Africa south of the Sahara desert, known as sub-Saharan Africa, is by far the worst-affected in the world by the AIDS epidemic. The region has just over 10% of the world's population, but is home to 67% of all people living with HIV. An estimated 1.9 million adults and children became infected with HIV during 2007. This brought the total number of people living with HIV/AIDS in the region to 22 million by the end of the year. HIV prevalence varies considerably across this region-ranging from less than 1% in Madagascar to over 25% in Swaziland (UNIAIDS, 2008:23).

In sub-Saharan Africa, AIDS killed approximately 1.5 million people in 2007. Average survival in the absence of treatment is around 10 years after infection. ARV drugs can dramatically extend survival, allowing many years of healthy life, but these drugs remain unavailable to most Africans. Unlike women in most other regions in the world, African women are considerably more likely at least 1.4 times to be infected with HIV than men. There are a number of reasons why female prevalence is higher than male in this region, including the greater efficiency of male-to female HIV transmission through sex and the younger age at initial infection for women (UNIAIDS, 2008:34)

HIV and AIDS make tremendous new demands on health services that cannot be met by hospitals alone. Because HIV infection and all its accompanying complications can last for months or years, a person with HIV infection or AIDS may move from the home to the hospital and back again several times. Hospital care is very expensive, and families can often not afford multiple admissions to hospital. Hospitals themselves do not have the personnel and resources to cope with the huge demands that AIDS makes of them.

The only practical and humane solutions are to care for patients in their own homes and communities for as long as possible: to develop an integrated home based care service with professional, community and volunteer caregivers; and to use hospitals as a last resort when patient's condition has deteriorated and professional help is needed. But the demands on families and community do not end with death of the patient. The AIDS epidemic has left behind millions of orphans and other children made vulnerable by HIV/AIDS in Africa and conditions in which these children live are often appalling. If communities do not reach out to help these children, AIDS will also kill our future generation (Van Dyk, 2008:33)

2.8 RATIONALE FOR HOME BASED CARE GIVERS

Due to AIDS epidemic's impending additional impact on communities, in South Africa as a whole, it is necessary to consider how best to provide care for people with diseases and their families. As more people become ill with AIDS-related diseases and other chronic conditions, many are not able to stay in hospitals or hospices. For many, the home is a more appropriate place for care.

It is also recognized that South Africa has limited health care resources. Situations will arise where hospital or other institutional care may not be possible and The Department of Health (2006:6) pointed out the following reasons for that situation:

- Shortage of hospital beds,
- Insufficient medical and nursing staff,
- Not enough money for health care, and
- Increasing demands by other patients who have acute (curable) conditions, which need to be managed in hospital

HBC can also provide support when patients, who should be in hospital, are not admitted or are discharged too early. It is not intended to be 'second class care' for those who cannot afford to be in hospital; there may be benefits in caring for the patient at home. Ill people may choose to go home if they feel comforted in their own surroundings with familiar people around them (Department of Health, 2004:6)

2.9 PRINCIPLES OF HOME BASED-CARE

The Department of Health's guideline for home based care (2004:5) outlines these principles as follows:

- Holistic: physical, social emotional, economic and spiritual. Community needs are addressed, and integrated into existing systems,
- Person-Centered: sensitive to culture, religion and value systems hence respect privacy and dignity (community-driven, customer-centered),
- Comprehensive, interdepartmental and all-encompassing, preventative, promotive, therapeutic, rehabilitative and palliative (multi-sectoral involvement),

- Empowering and allows capacity building to promote the autonomy and functional independence of the individual and the family or caregivers. Leadership is from within the community,
- Ensure access to comprehensive support services,
- Cover total lifespan,
- Sustainable and cost-effective resource responsibilities to be identified and shared,
- Promote and ensure quality of care, safety, commitment, co-operation and collaboration,
- Allow choice and control over what extent partners will participate.
- Recognize diversity,
- Promote and protect equal opportunities, rights and independent living,
- Specific in what needs to be done and achieved,
- Focus on a basic and essential component of Public health care,and
- Adhere to a basic principle in health care and development, namely community involvement.

2.10 THE GOALS AND OBJECTIVES OF HOME- BASED CARE PROGRAMMES.

According to Van Dyk, (2008:33), the main goal of home-base care programmes is to provide the organizational structure, resources and framework that will enable the family to look after its own sick members. Important functions of home based care programmes are:

- To empower the community and family to cope effectively with the physical, psychosocial and spiritual needs of those living with HIV infection and AIDS,
- To educate the community about the prevention of HIV transmission,
- To support family members in their care giving roles, and

- To reduce the social and personal impact that living with HIV infection and AIDS makes on all those concerned.

A very important function of home-based care programmes is to establish a well functioning referral system to hospital, hospices, clinics and other health care facilities in the community (Van Dyk, 2008:33).

2.11 MEMBERS OF THE HBC TEAM

HBC is such an enormous challenge, that no single organisation or profession can deal with it alone. A variety of resources, funds, effort and energy will be needed from the public and private sectors, and from community organisations. Collaboration is key to HBC. For this reason, many people who are ill with different diseases will be cared for home by relatives and community members. Nurses and caregivers are also very important in helping the family and the community to take good care of the patient. (Department of Health, 2004: 6).

The HBC team may consist of family and volunteer community members and a multi-disciplinary team of social workers, doctors, psychologists, nurses, occupational therapists, physiotherapists, educators, caregivers, religious leaders and legal advisors. The team may vary, depending on the resources of each community and the patients' needs. The majority of the team may be volunteers, often from churches and social groups such as youth organisations. The Department of Health realized that if home based care givers can be properly trained and well supported, they can play a major role in closing the gap between professional services and patients (Department of Health, 2004: 7).

In the past, many organisations in sub-Saharan Africa have experienced difficulty with HBC programmes, especially in sustaining the motivation and activities on an ongoing basis. Programmes are often dependent on the participation of volunteers for little or no remuneration. The lack of resources is often the biggest challenge. Creative ways need to be found to overcome these problems (Department of Health, 2004: 7).

2.12 THE SCOPE OF ACTIVITIES OF HOME BASED CARE GIVERS

HBC focuses on all levels of care and not only for people who are ill with AIDS-related diseases. Even a person who is newly diagnosed with HIV can benefit from some form of HBC. Whether HBC is for a person who is healthy or ill, caring for people at home requires more than just taking care of their basic medical needs. It means looking after the person and helping them do what they would usually do for themselves (for example, bathing and eating). HBC should attempt to deal with all aspects of a person: physical, social, emotional and spiritual needs. It aims to help an ill person in such a way that dignity is maintained. The patient should be encouraged to do as such as he can for himself. By involving the community, the HBC team can provide a wide range of services to patients and their families (Department of Health, 2004: 8).

2.13 TYPES OF ACTIVITIES OF HOME BASED CARE

The Collins English Dictionary (1991:244) defines ‘care’ as “to provide physical needs, help or comfort (for); to look after someone and keep them in a good state or condition”. Home care involves the provision of health services by both formal and informal caregivers in the home, in order to promote, restore and maintain a person’s maximum level of comfort, function and health including care towards a dignified death according to the Department of Health’s guidelines on home-based and community based care. Home and long-term care has become necessary due to the advent of HIV/AIDS as well as the increase in chronic illnesses. This is compounded by the spiraling costs of institutional care and the lack of adequate hospital beds. Thus home care is provided to replace acute care to prevent the need for institutionalization and maintain individuals in their own homes and communities, which are familiar to them so that they can enjoy quality of life (WHO 1999:11).

The Department of Health's (DOH 2001:1) guidelines indicate that home based care is comprehensive and includes provision of basic physical, emotional, psychological and spiritual support as well as a preventive, promotive, therapeutic, rehabilitative and palliative care services in the home environment. In the United States of America (USA), home care has evolved to become a prominent sector in the health care system where managed care is provided by agencies (Rappaport 2000:15).

The findings and recommendations of the 1st Southern African Regional Community Home-based Care Conference (HDN 2001:5) defines HCBC as care given to individuals in their own natural environment by their families supported by skilled personnel and communities. Regarding the plight of AIDS patients in rural South Africa, Hardman (2001:13) found that volunteers visit ill patients in their homes and provide holistic care. In Uganda, terminally ill patients are cared for in their homes (Hardman 2001:13).

In a study in Kenya to determine the priority needs and interventions necessary to plan, develop and implement community home –based care and the impact of caring on women and children the World Health Organization found that caregivers are mostly uneducated and need psychological support and Counselling. Furthermore, care to family members and siblings were provided by children, mostly girls but at times also boys.

It was noted that elderly people mostly grandmothers had taken over the care giving role in the absence of or after the death of adult children. Some caregivers did not know the cause of the illness of their clients and had little understanding of diseases. Caregivers mostly work on a volunteering basis and are often linked to NPOs and church groups. Many lack resources and supplies to provide the service and live in poverty themselves. Time spent providing care ranges from two to ten hours daily (WHO, 2001:31-37).

Although men are generally traditionally excluded from providing HCBC, a group in Kenya, Movement of Men against AIDS in Kenya (MMAAK) Provide care to HIV-positive men, which include group therapy and Counselling (Home-based care: 2004:23)

In Zimbabwe where men are not generally involved in soft care as this is traditionally not their role, they increasingly support HIV-positive men and use their influence to advocate for sustainable HCBC (Dongozi, 2005:11). In a study on models of community/home-based care for people living with HIV/AIDS in southern Africa, Ncama (2005:35) found that roles of caregivers vary depending on the service model of home-care offered. Caregivers providing home visits, mainly visit patients and spend time talking to and educating them and their family. They also provide household support, such as cleaning and cooking, and accompany them to health facilities.

In the African context, family member as caregiver has traditionally been the accepted practice especially in the rural setting. Similar practices are found in the UK and USA, although these primary carers are supported to some degree by professional staff, which is not generally the case in Africa (Rice, 2001:24)

- The role of caregivers includes the provision of basic health care, such as changing dressing; physical care including bathing, dressing, changing soiled linen, cooking, and symptom management, fetching wood and water, and cleaning the home (WHO, 2001:34). Home based care givers are also involved in,
- Supporting family members caring for patient or orphans,
- Material assistance (for example, food, clothing, money through the church),

- Building material and labour,
- Basic medical care,
- Basic nursing care,
- Practical help (for example, shopping, baby sitting, cleaning house, washing clothes, transport or accompanying to hospital, provision of safe drinking water etc),
- Emotional and spiritual support (e.g. read bible together/pray),
- Counselling (pre-and post-HIV test counseling, for the chronically ill, regardless of whether they have had an HIV test or not),
- Information and awareness-raising in community,
- Orphan support (for example, practical, welfare, fostering),
- Training women about gender and human rights,
- Legal aid,
- Self-help schemes (i.e. income generation for patients and their families, e.g. vegetable garden, tailoring/bead work),
- Case finding (e.g. routine home visits, observe if coughing, taking 3 sputum samples to nurse),
- Sputum collection during treatment process (i.e. after 2nd, 5th and 8th months of treatment),
- Treatment (daily observation of tablet taking, explaining symptoms and side effects, identifying problems), and
- Record-keeping. (Department of Health, 2004: 9).

2.14 ADVANTAGES OF HOME BASED CARE GIVERS

According to Van Dyk, (2008: 324), the following are the advantages of home based care givers:

- Good basic care can be successfully provided in the home,

- People who are very sick or dying often prefer to stay at home so that they can spend their last days in familiar surroundings-especially when they know they cannot be cured in a hospital,
- Sick people are comforted by being in their own homes and communities with family and friends around them. The ambience of home prevents the patient from feeling isolated and rejected,
- Home- based care allows the patient and family time to come to grips with the illness, and to prepare for the impending death of the patient,
- Home-based care promotes a holistic approach to care. This means that the physical, social, cultural, psychological, emotional, religious and spiritual needs of a patient can all be fulfilled by the family and the health team,
- Home-based care can be comprehensive if it includes rehabilitative, preventive, promotive, curative and palliative care,
- It is usually less expensive for families to care for someone at home. The cost of hospitalization and transportation to and from a hospital can be financially crippling,
- If the sick person is at home, family members can attend to their other responsibilities more easily. It can become very difficult to cope with one's own life if a loved one is in hospital and the caregiver has to make frequent trips to and from the hospital,
- Because the pressure on hospital is reduced by home care, doctors, nurses and other health care professionals can attend to other critically ill patients in hospitals,
- Home car reduces the enormous pressure on provincial and national health care budgets (which are already strained to breaking point),
- The network of health services available in the home-based care programme enables family members to gain access to counseling support for themselves,
- Family and community involvement in the care of their own members create general AIDS awareness in the community and this helps to break

down fear, ignorance, prejudice and negative attitudes towards people with AIDS,

- Home-based care is sensitive to the culture and value systems of the local community - a sensitivity that is often missing in clinical hospital settings,
- The intervention in home-based care is proactive rather than reactive, and
- Home-based care is empowering. This means that people take responsibility for and control of their own lives and communities.

Home-based caregivers are also in the ideal position to identify the needs of children who are affected by the illness of parents or siblings. They can assess issues such as whether the child is involved in the care of patient, and to what extent; whether the child is immunized; whether the child needs health care; and whether the child has time to play. The home-based caregiver is also in a position to know who supports the child psychologically and emotionally; whether the child understands what is going on in the family; and who will look after the child after the death of the parent (Van Dyk, 2008:324).

2.15 POTENTIAL PROBLEMS ASSOCIATED WITH HOME-BASE CARE

According to Van Dyk, (2008:324) the following are the potential problems associated with the home-based care:

- Patients often feel isolated-especially when they are confined to the home or to the bed,
- Many people in communities are not ready for home-based care because of ignorance, superstition and the fear of being stigmatized by other members of the community. For these reasons people might reject the concept of home-based care. This increases the anguish, desperation and loneliness of those living with AIDS,
- Non-compliance with treatment often occurs because the patient or primary caregivers do not know how or when to administer medication

(because they are educationally disadvantaged) or the medication they require is far too expensive and they do not know where to go for financial aid, and

- A lack of knowledge about the disease, treatment, emergency situations and community resources often hampers home based care, and many family caregivers are afraid that they themselves might become infected with HIV.

One of the greatest drawbacks of home based care is that the caregiver might give up because of exhaustion and burnout resulting from the extreme demands of caring for a terminally ill patient. It is absolutely vital for caregivers to have support systems and to know how to care for themselves; otherwise they will be overwhelmed by burnout (Van Dyk, 2008:324).

2.16 MODELS OF HOME- BASED CARE

According to Van Dyk,(2008:324), The following are different models of home based care:

2.16.1 The integrated home-based care model

This model links all the service providers with patients and their families in a continuum of care. The patient and family are supported by a network of services, such as community caregivers, clinics, hospitals, support groups, non-governmental organizations (NGOs) and community-based organizations (CBOs), as well as by the larger community. This integrated model allows for referral between all partners as trust is built and it ensures that community caregivers are trained, supported and supervised (Van Dyk, 2008:324).

The integrated home-based care model is ideal for quality physical care and psychosocial support for the person living with HIV/AIDS (PLWHA) and his or her family (Van Dyk, 2008:325).

2.16.2 Single-service home-based care model

In this model, one service provider (usually a clinic, hospital, NGO or church) organizes home-based care by recruiting and training volunteers then brings them into contact with patients and their families at home. Many home-based care programmes start this way and build their way up to offer integrated care as they recruit other partners (Van Dyk, 2008:324).

2.16.3 Informal home-based care setting model

It is in this model that families care for their sick loved ones at home, with the informal assistance of their own social network. Nobody has any specific training or external support and there is no formal organization or supervision of the care. Informal care can be very difficult because the primary caregivers often lack the necessary knowledge, skills and emotional support needed to care for AIDS patient (Van Dyk, 2008:324).

2.17 THE ROLE OF VOLUNTEERS IN HOME-BASED CARE

Local community volunteers play a very important role in home-based care programmes. Volunteers usually come from a variety of background and they may be trained and experienced professionals, trained community caregivers, family members, or compassionate community members who wish to help those in need.

Many of the perceived disadvantages of using volunteers can be overcome if the volunteers are recognized as key worker in the Programme, if they are chosen by members of the community, and if they are properly trained in basic home care. Volunteers should never be expected to offer home-based care without a good basic training and understanding of the physical, psychosocial, emotional and spiritual conditions that they may encounter and how to deal with these (Van Dyk, 2008:324)

Volunteer programme managers should note the problems and frustrations of volunteer workers and address problems appropriately. The health system cannot afford to have valuable volunteer workers resign out of frustration. According to Van Dyk, (2008:324) the following problems were reported by volunteers working in the HIV/AIDS field:

- They work in isolation;
- They do not have a voice in decisions that affect them and their work;
- The finances available for volunteer workers and important prevention projects are often cut drastically;
- Creativity is discouraged because innovative ideas and suggestions are not implemented; they have too little autonomy and responsibility;
- The necessary supportive infrastructures are not always in place;
- Training and preparation for the work are often inadequate;
- There is often a lack of medication and health care material, as well as a lack of resources to observe universal precautions;
- Referral mechanisms are often not available ; and
- When they work in hospitals they receive little support from nursing staff, mainly because the nurses are overburdened, see counseling as secondary to the clinic's routine, and sometimes feel threatened.
- Volunteer caregivers often struggle with over involvement and a lack of boundaries between them and their clients. This results in stress, burnout and resignation (Van Dyk, 2008:324).

- The burden of caring for people living with HIV and AIDS, as either primary care givers or volunteers, is disproportionately provided by women. Men rarely assist with care giving (Akitola, 2004:34).

2.18 TRAINING OF HOME-BASED CAREGIVERS

According to Van Dyk (2008:324) it is important to train home-based caregivers properly and thoroughly to provide a high standard of holistic care. The training provided will depend on the level of care required, but the following should be included in any training programme:

- Background to home-based care;
- Ethical principles of home-based care: confidentially at all times; respect for the patient's wishes about disclosure, the autonomy of the patient to agree or disagree with treatment; and respect for the patient's choice on issues such as abortion;
- Basic facts about HIV/AIDS and other sexually transmitted infections;
- Knowledge of the signs and symptoms of TB as well as an understanding of Dots;
- Teaching and facilitation skills, especially adult education;
- Communication skills, including communication with children;
- Basic counseling skills;
- Promotion of positive living;
- Spiritual and religious issues;
- Bereavement counseling;
- Gender and cultural issues;
- Infection control in the home-based care situation;
- Basic nursing care principles and the management of common illness;
- Practical procedures to help the patient, for example, wound dressing, mouth care, feeding, bathing in bed, shaving, and using a bed pan;
- Nutrition and problems influencing nutrition. Social support, community support and referral possibilities and

- Care of the caregiver to cope with a very demanding task (Van Dyk, 2008:324)

2.19 SITUATIONAL ANALYSIS OF WARD 25 IN THULAMELA MUNICIPALITY

Thulamela municipality has 40 wards and this study focused in ward 25 which is composed of Vhufuli, Tshitereke, Vondwe and Makhuvha villages.
According to statistics South Africa/ Census 2011 community profiles there are 6847 males and 8479 females in ward 25 of Thulamela municipality. This ward is rural with 1 hospital and 1 clinic. There are 3 secondary and 6 primary schools.

2.19 CONCLUSION

This chapter discusses the literature review conducted for the study. Some of the aspects covered in this chapter are: magnitude of HIV and AIDS, rationale for home-based care principles of home based-care, aims and objectives of home based care, members of home-based care team, scope of home-based care, frame work for home-based care and legal , ethical and policy issues. There is ample research that indicates that caregivers experience many challenges, particularly stress and burnout. Their reactions include emotional exhaustion, despair, depression and helplessness. Many studies on stress and burnout of caregivers have focused more on the negative and difficult aspects of work done by HBCGs, and reward of care and motivating factors that keep HBCGs doing this work are not fully considered. The literature however, acknowledges that caregiving is demanding but rewarding and is dominated by women – hence the presence of challenges and the motivation to care for PALHIV. There is acknowledgement and recognition of what organisations need to do to support and help HBCGs with their work.

It is clear that most studies on coping regard stress and burnout as major challenges that influence the choice of strategies the HBCGs opt for to deal with the challenges they encounter during the course of their work. Mostly studies focus on coping strategies of health workers in hospitals, or of HIV/AIDS patients, but seldom on HBCGs in a HBCC, especially in townships. In light of the above, this study focused on the constraints on the provision of home based care services to patients in ward 25 of Thulamela municipality. The next chapter will cover the research design and methodology employed in this study.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

In the previous chapter, a study of literature was done. This chapter will focus on the research methodology followed in conducting this research. It focuses on the research design, which is qualitative and quantitative in nature. This chapter also provides information about the area of the study, Population of the study and sampling method.

3.2. AREA OF STUDY

This study was conducted in ward 25 of Thulamela Municipality which is part of Vhembe district, Limpopo province in South Africa. This area is mainly rural in nature. It also has a high statistics of people living with HIV and AIDS. The specific areas for the study were three villages, namely, Ha- Makhuvha, Tshitereke and Vhufuli. In these three villages, there are two home based-care centers which are Fhatanani Community against HIV and AIDS found at Vhufuli village and Tshedza Makhuvha Home based care found at Ha-Makhuvha Village. At the time of conducting this research, Fhatanani Community against HIV and AIDS was servicing 408 patients with only 25 Home based carers, whereas Tshedza Makhuvha Home based care was servicing 592 patients with only 28 carers.

These villages are approximately five kilometers apart from each other and approximately twenty five kilometers from Thohoyandou town. In these villages, vegetation is dominated by fruit trees and indigenous plants. The population consists of a high percentage of young people and the aged. The level of unemployment is high in these villages. In most cases the source of income is from government grants, namely, old age grant, foster care grant and child support grant.

3.3 RESEARCH DESIGN

The researcher used exploratory research design as he wanted to explore the constraints faced by home-based care givers in dealing with HIV and AIDS. The researcher explored the socio-economic and physical challenges, psychological challenges, psychological needs and the coping strategies regarding the problem and the kind of social support services required by the study group.

3.4 RESEARCH METHODOLOGY

According to Huysamen (1995:163) research methodology is the creation and development of techniques and strategies to collect data, the development of methods to investigate and improve the psychometric properties such as reliability and validity of the data obtained by means of these techniques and the analysis of such data. In this study, research methodology involves a selection of appropriate research approaches, research methods, sampling procedures, respondents and instruments for collecting and analyzing data.

In this study the researcher used quantitative and qualitative methods. The use of different methodologies according to Babbie (2007:113) to test the same findings is called triangulation.

According to Leedy (2004:38), quantitative approach is based on positivism, in which scientific explanation is adopted .Quantitative data collection methods are based on measurements using verification instruments in order to objectify phenomena understudy. Measuring instruments involves the assignment of numbers, in terms of fixed rules, to reflect differences between them in some of their characteristics.

According to Struwig and Stead (2001:12), qualitative researchers are interested in understanding the issues being researched from the perspective of the research participants. In other words they are trying to see through the eyes of the participants. Struwig and Stead (2001:17) further enforce the above statement by stating that the researcher and the participant are both involved in the research process in qualitative research with the researcher trying to understand and interpret the participant's perspective. McMillan and Schumacher (1993:14) strengthen the above statement by stating that qualitative research is more concerned with understanding the social phenomenon from the participant's perspectives.

In this study a qualitative approach was used as it provided the researcher the opportunity to determine and experience firsthand the challenges, perceptions and experiences of the research participants in their natural settings. The researcher interacted with the research participants by observing them at their schools. Burns (2000:11) states that qualitative forms of investigation tend to be based on recognition of the importance of the subjective, experimental life world of human beings.

The researcher will attempt to report the findings as truthfully and as unbiased as possible taking into account not to lose the value and importance of the information gathered from the participants. Burns (2000:388) states that: The qualitative researcher is not concerned with objective truth, but rather with the truth as the informant perceives it. The qualitative researcher thus tries to understand the meanings individuals give to the world in which they live.

3.5 POPULATION OF THE STUDY

According to Bless and Smith (2005:194), population is referred to as the set of elements that the research focuses upon and to which the obtained results should be generalized. It is also defined as the total set from which the individual or units of the study are chose. Population is also seen as the set of elements that the research focuses upon and to which the obtained results should be generalized (Seaberg, 1988:240). For purposes of this study, all home based care givers found in ward 25 of Thulamela municipality composed the population.

3.6 SAMPLING

According to Wimmer and Dominick (1983:58) sample that is not representative of population, regardless of its size, is inadequate for testing purposes. The results cannot be generalized for the population. Cohen and Manion (1989:10) view a sample as a smaller group or subset of the population from which the researcher attempts to collect information so that the knowledge gained typifies the total population under study. In conclusion, sampling makes it possible to estimate characteristics of a large group by examining the characteristics of smaller groups. The larger group is referred to as a population. The smaller group drawn from the population is called sample. The researcher visited the two home based care centers based in ward 25 of Thulamela municipality in order to access the list of home based care givers from the two center managers. Home based care givers who have less than three years as home based care givers were excluded in the study as their responses would have not been relevant to the study

3.6.1 Sampling Method

According to Kumar (2011:298), sampling method is the way one select the required sampling units from a sampling population. The sample must always be viewed as an approximation of the whole rather than as a whole in itself (Bailey, 1994:84). According to Devos (2005:194), a sample is that which comprises elements of the population considered for actual inclusion in the study, or it can be viewed as a subset of measurements drawn from a population in which one is interested.

Non-probability, purposeful sampling was used to ensure that the respondents are selected based on their knowledge of the phenomenon. Purposeful sampling is done when researchers select the sample based on existing knowledge of the population and the purpose of the research (Babbie & Mouton 2002:166).

In purposive sampling, the researcher does not necessarily have a quota to fill from within various strata, as in quota sampling, but neither does he or she just pick the nearest warm bodies, as in convenience sampling. Rather, the researcher uses his or her own judgment about which respondent to choose, and picks only those who best meet the purposes of the study (Bailey, 1994:96).

3.6.2 Sampling Size

According to Wimmer and Domminick (1988:68), determining an adequate sample size is one of the most controversial aspects of sampling. How large a sample should be in order to be representative of the population has no simple answer (1983:68). Best and Kahn (1993:19) stated that there is no fixed number or percentage of subjects that determine the size of an adequate sample. It may depend upon the nature and the population of interest or data gathered and analysed. Data was collected from 50 Home Base Care Givers and two centre managers.

3.7 DATA COLLECTION METHOD

As noted by Mouton (2002:156), data collection subsists in the use of a variety of methods and techniques of data collection in a single study. Schulze (2002b: 14) maintains that data should meet the requirements of a qualitative or quantitative research design or a design consisting of a combination of these approaches. The data collection methods in this study combined these two approaches. In an effort to acquire different facets of the same problem (symbolic reality) of the participants the following methods were used to collect data. For purposes of this research, open ended interview and survey questionnaires were used.

3.7.1. Interview and Questionnaires Survey

Interview is a method used to collect data in the social science where there is an interaction, either face to face or otherwise, between two or more individuals with a specific purpose in mind (Kumar, 2011:389). For many good reasons, the questionnaire is the most widely used technique for obtaining information from subjects (McMillan and Schumacher 2001: 257). Furthermore, McMillan and Schumacher (2001: 257) note that a questionnaire is relatively economical, has the same questions for all subjects and can ensure anonymity.

A self-administered and self-contained structured questionnaire was designed by the researcher and was used to collect relevant standardised data from all subjects in the sample. McNamara (1997:105) describes the structured or close ended item as the mainstay of survey researches. The questionnaire technique was chosen because it had several advantages. Close ended items are amenable to statistical data analysis with minimal manipulation of raw data. MacNamara (1997:105), states that questionnaires can access a large sample which place minimal demands on personnel, and can be totally anonymous. The reasons for using questionnaires in this study was that as a data gathering instrument it was cost effective, easy to complete and timeliness of responses.

The items asked participants to rate the extent to which they agreed or disagreed with certain aspects of questions. The rating scale had the following designations: 5=strongly agree; 4=agree; 3=Uncertain; 2=disagree; 1=strongly disagree. The Likert type scale was employed because it provided greater flexibility since the scale descriptions varied to fit into the nature of the question (McMillan and Schumacher, 1993:245).

During the interview the likert questions will be used and they will cover the following variables:

- The socio economic and physical challenges faced by home based carers.
- The psychological needs of the study group.
- The kind of support services required and available to the study group.
- The coping strategies of home based carers.

3.8 DATA ANALYSIS

According to Mckendrick (1990:275) analysis of data answers the question: "How shall I arrange and order my findings? In the words of Punch (1998:202), data analysis is a comprehensive source book, describing analysis which is directed at tracing out lawful and suitable relationship among social phenomena based on regularities and sequences that link those phenomena. In this study, data collected through questionnaire was analyzed using Statistical Package for Social Sciences (SPSS) version 22.0

SPSS was based on the idea of using statistics to turn raw data into information essential to decision- making. They also developed it out of the need to quickly analyze volumes of social science data gathered through various methods of research. These three innovators were pioneers in their field, visionaries who recognized early that data and how you analyze it is the driving force behind sound decision-making.

Data collected through interview was analyzed by thematic analysis and information was presented in a narrative form. The researcher adopted the following steps of data analysis by Cresswell (1994: 142) to critically analyze data.

- **Planning for recording data**

The researcher must plan how the information will be recorded before collecting of the information commences. The researcher should show awareness techniques for recording, observing, interaction and interview should not intrude excessively into the ongoing of daily events.

- **Data collection and preliminary analysis**

The researcher must be able to analyze data and make sure that the information collected is rich information that will generate alternative hypothesis and provide basics for shared construction of reality.

- **Managing or organizing the data**

The researcher must put all copies of compiled information during data collection in a safe place.

- **Reading and writing memos**

The researcher is expected to read the whole transcript several times in order to get sense of the whole interview before breaking it into parts.

- **Generating categories, themes and patterns**

The researcher classifies information into categories in order to reduce it to a small management set of themes in order to give a detailed description of the respondent and confidentiality should be maintained.

- **Coding the data**

Coding of data is a formal representation of analytical thinking. The researcher applies some coding scheme to those categories and themes, and diligently marks passages in the data using the code. Code may take several forms of observation of the key words.

- **Testing the data**

The researcher test to establish if information is relevant to the study. A researcher begins the process of evaluating the plausibility of developing an understanding and explores them through data. Part of this phase is evaluating their usefulness and centrality.

- **Search for alternative explanation**

The researcher must find a way to explain to the respondents again only if the respondents have missed something during interview.

- **Writing the report**

The researcher has to write a formal as a proof that he/she has analyzed the data and report must be kept in a safe place. Data is then written in a narrative form on the themes and also stated whether the findings confirmed or contracted the literature of previous authors.

3.9 ETHICAL CONSIDERATIONS

Researchers need to be aware of ethical issues before entering the field (Neuman 2000), especially when dealing with sensitive topics such as those that are HIV/AIDS-related and touch on the emotional and psychological aspects of all human spheres in society. The following ethical issues were considered in this study:

3.9.1 Consent and voluntary participation

The researcher obtained consent from each one of the participants who participated in the study. According to Terre Blanche and Durrheim (1999:66), participants need to receive a full non-technical and clear explanation of what is expected of them so that they can make informed choices to participate voluntarily, or not. An information session was arranged by the centre administrator for the researcher to meet potential participants, where she explained what was expected of them, including all the steps to be followed during the research, and informed them of their right to discontinue their participation at any time despite giving initial consent.

They were therefore granted the opportunity to accept or decline their participation in the study, rendering consent on a voluntary and informed basis. Consent forms were given to all the volunteering participants to fill in and return during interviews. All the participants who were interviewed handed their signed consent forms to the researcher prior to the commencement of the interview.

The participants were also informed that the researcher would always be available if they should need further clarity. Prior to observation, the participants were requested by the researcher to seek consent from the PALHIV to bring her along during visits. According to Babbie and Mouton (2001:520), participants must be informed that they should not expect any special rewards in participating in the study. Clarity on that was also provided during the information session, to avoid creating any possible expectations of being rewarded.

3.9.2 No harm to participants

According to Babbie and Mouton (2001:522), social research should never harm or injure people participating in a study. The researcher ensured that the participants were not exposed to any danger. Interviews were held at the centre, an environment they are familiar with and which is also safe. During observations the researcher drove the participants in her car to visit patients, thereby minimizing any potential danger they might have been exposed to.

3.9.3 Confidentiality

According to Terre Blanche and Durrheim (1999:68), in the consent form that the participants sign, they must be assured of the parameters of confidentiality of the information they will supply and that will be shared with them during the information session. Part of the information shared with participants during the information session included the confidentiality parameters relevant for this study, which were also included in the consent (in English and Tshivenda). In this study no names and addresses are used, HBCGs participating in this study are addressed only as research participants, and pseudonyms are used when referring to them.

3.10 CONCLUSION

In this chapter the research methodology has been discussed for this study. The researcher concluded that the population and sampling procedures as well as research instruments, data collection techniques and data analysis were more appropriate in the methodology. Population and sampling procedures indicated all respondents involved in the research and how they were selected to form a sample. Questionnaire and Interviews were used as data collection instrument to guarantee the success of this research. In Chapter four, the research focuses on research findings, analysis and interpretation.

CHAPTER 4: DATA PRESENTATION, INTERPRETATION AND ANALYSIS

4.1 Introduction

The previous chapter presented the research methodology. The analysis of research data and the findings of this study will be presented in this chapter. Data was obtained from fifty home based care givers and two center managers. The researcher utilized data collection techniques carefully in order to promote quality of the process of obtaining data from participants which has produced credible results. The researcher used a guide to interview participants. It is worth stating that some questions on the guide had to be probed further in order to arrive at the theme of the study. Participants were free to respond in the language that they were familiar with. All participants responded in Tshivenda which is the common language in the study area.

The study was conducted in the months of November and December, 2014. Interviews took place in the home based care centers. At the end of the interviews, participants were given chance to ask questions or to give any comments they had concerning the theme of the discussions.

4.2 Analysis of data collected through questionnaire

In this section, the researcher analyzed the responses collected by the questionnaires and are presented graphically in graphical tabular forms and followed by a brief synthesis of the findings for the item

Section A: Biographical Details

It is in this section where the researcher presented the biographical details of the respondents. The information is presented in a tabular format followed by a synthesis of the findings and the detailed findings are outlined in the next chapter.

Table 4.1: Gender of the respondents

Response	Frequency	Percentage
Male	2	4
Female	48	96
TOTAL	50	100

Out of the 50 participants interviewed, 96% (n =48) were females while only 4% (n = 2) were males. This shows that the majority of the participants were women. Table 4.1 presents the percentage of males and females interviewed.

The AIDS pandemic has presented women with a massive dilemma in their sexual relationship with men, making prevention of HIV transmission through safer sexual practices problematic for them. The Centre for Disease Surveillance and Reporting (2000) has reported that over 95% of all cases and 95% of AIDS deaths occur in the developing world mostly among young adults 20-45 years and increasingly among women.

Table 4.2: Age of respondents

Response	Frequency	Percentage
Less than 20 years	0	0
21 to 30 years	0	0
31 to 40 years	37	74
41 to 50 years	10	20
50 years and above	3	6
TOTAL	50	100

Table 4.2 explains age of the participants' employment status. Five categories of age group were included. The majority of the participants 74 %(n=37) were between 31 and 40 years. 20 %(n=10) of participants were aged between 41 and 50 years. Only 6 %(n=3) of participants were above 50 years. It can therefore be concluded that in this study, majority of the participants are still having a future in the field of home based care.

Table 4.3: Level of education

Response	**Frequency**	**Percentage**
Never attended school	0	0
Primary school	4	8
Secondary school	38	76
Tertiary school	8	16
Total	50	100

Table 4.3 display a total of 76% of all the respondents (n=38) went through Secondary school education. Four participants (8%) had primary school education and only 16 %(n=8) of the respondents went as far as college or university level. It can therefore be concluded that majority of the respondents still need to further their studies.

Section B: Constraints to the provision of Home based care service to patients

Table 4.4: Home based care givers experience stress in their work place

Response	Frequency	Percentage
Strongly agree	18	36
Agree	24	48
Not sure	2	4
Disagree	1	2
Strongly disagree	5	10
Total	50	100

Twenty four (48%) of the respondents agreed with idea that home based care givers experience stress in their work place and 36% (n=18) of the respondents strongly agree with the same idea. Five (10%) of the respondents strongly disagree and only 2% (n=1) of the respondents just disagree with this idea. However, there is another 4% (n=2) of the respondents who were not sure whether home based care givers experience stress in their work place or not. The numbers outline that to a greater extent, majority of the respondents believe that home based care givers are experiencing stress in their work place.

Table 4.5: Finance is a challenge to home based care givers

Response	Frequency	Percentage
Strongly agree	34	68
Agree	15	30
Not sure	0	0
Disagree	0	0
Strongly disagree	1	2
Total	50	100

In view of Table 4.5, 34 respondents constituting 68% of the total sample strongly agreed that finance is a challenge to home based care givers and another 15 respondents constituting 30% of all the respondents agree with the same idea. Only 1 respondent strongly disagreed with the idea that finance is a challenge to home based care givers. It is notable that majority of the respondents are of the idea that finance is challenge to the activities of home based care givers.

Table 4.6: Stigma attached to Home based care givers

Response	Frequency	Percentage
Strongly agree	20	40
Agree	19	38
Not sure	6	12
Disagree	2	4
Strongly disagree	3	6
Total	50	100

HIV and AIDS is affecting many countries and Southern Africa in particular. The presence of HIV and AIDS was accompanied by stigma directed to sufferer of the disease and those who help them. This is well supported by table 4.6, were 38% (n=19) of the respondents agreed that there is still stigma attached to home based care givers, and further 40% (n=20) of the respondents strongly agreed with the same statement. However, 6% (n=3) of the respondents strongly disagreed that there is stigma attached to home based care givers and another 4% (n=2) also disagreed. There is 12% (n=6) of the respondents who were not sure if there is stigma attached to home based care givers.

Table 4.7: Workload of Home based care givers is appropriate.

Response	Frequency	Percentage
Strongly agree	21	42
Agree	25	50
Not sure	1	2
Disagree	3	6
Strongly disagree	0	0
Total	50	100

This study also investigated if the workload of home based care givers is appropriate. Study found out that there is a mixed feeling from the respondents in this matter. Twenty five respondents who constitutes 50% of the total sample agreed that work load of the home based care givers is appropriate and this was also supported by another 42% (n=21) of the respondents who strongly agreed with this statement. However, only 6% (n=3) of the respondents disagreed with the idea that work load of the home based care givers is appropriate and only 2% (n=1) of the respondents were not sure if the work load of home based care givers is appropriate. According to the majority of the respondents, workload of the home based care is appropriate.

Table 4.8: Home based care givers are enough

Response	Frequency	Percentage
Strongly agree	22	44
Agree	20	40
Not sure	0	0
Disagree	5	10
Strongly disagree	3	6
Total	50	100

It seems the majority of respondents believe that there are enough home based care givers. This is clearly visible in Table 4.8 where 22 respondents constituting 44% of the total sample strongly agreed that home based care givers are enough and another 40%(n=20) of the respondents agree with the same idea. Only 10% (n=5) of the respondents disagreed with the idea that home based care givers are enough and another 6% (= 3) of the respondents strongly disagree with this statement. According to this statistics, home based care givers are enough given the total number of patients that they are assisting.

Table 4.9: There are policies to guide home based care givers.

Response	Frequency	Percentage
Strongly agree	10	20
Agree	38	76
Not sure	0	0
Disagree	2	4
Strongly disagree	0	0
Total	50	100

The Home based care givers like any other workers in South Africa are guided by policies as stated by the above table. According to Table 4.9, 38 respondents constituting 76% agreed that there are policies which are guiding their operation. Another 20% (n=10) strongly agreed with the same statement. On the contrary only 2 respondents who constitute 4% of the total sample disagreed that Home based care givers have policies which guide their daily activities. This statistics shows that home based care givers are well regulated by policies.

Table 4.10: Working tools are enough.

Response	Frequency	Percentage
Strongly agree	1	2
Agree	0	0
Not sure	0	0
Disagree	11	22
Strongly disagree	38	76
Total	50	100

It is crucially important to have working tools in the work place if the organizations want to be successful. The above table shows that 76% (n=38) of all the respondents strongly disagree with the idea that there are enough working tools for home based care givers. This was further confirmed by 22% (n=11) who disagree with the statement which state that there are enough working tools in the home based care centers. Only 2% (n=1) of the respondents hold a different view in this regard because this percentage of the whole sample believe that the working tools are enough. It is clear in the above table that much still needs to be done in terms of providing home based care centers with working tools.

Table 4.11: Home based care givers are work shopped

Response	Frequency	Percentage
Strongly agree	11	22
Agree	21	42
Not sure	1	2
Disagree	5	10
Strongly disagree	12	24
Total	50	100

Training plays integral role for the survival of any organization the Home based care cannot be exempted If staff know what they are doing and are properly trained, the organization's productivity can increase with better quality service and more efficient staff. This notion is supported by 21 respondents constituting 42% the total sample who agreed that home based care givers are receiving workshops and this was also confirmed by another 11 respondents constituting 22% of the total sample who strongly agree with the same statement. Lack of workshops and training of home based care givers can render the home based care organizations dysfunctional. It is against this background that 12 respondents who constitute 24% of total sample strongly disagreed with the idea that they are capacitated through workshops. Only 1 respondent constituting 2% of the respondents were not sure if home based care givers are trained or work shopped.

Table 4.12: There is professional counseling sessions for home based care givers.

Response	Frequency	Percentage
Strongly agree	0	0
Agree	3	6
Not sure	0	0
Disagree	28	56
Strongly disagree	19	38
Total	50	100

Table 4.12 shows that majority of home based care givers are not receiving professional counseling after performing their traumatic work of helping the bedridden and critically ill patients. This is confirmed by 28 respondents constituting 56% of the sample who disagree with the statement which says there is professional counseling sessions offered for home based care givers. Out of the whole sampled respondents, another 38 % (n=19) of the respondents strongly disagreed with the same statement. Only 6 % (n=3) of the respondents

agreed that home based care givers receive professional counseling. It is revealed by this statistics that there is a need of ongoing professional counseling for home based care givers.

Table 4.13: Best home based care givers are rewarded.

Response	**Frequency**	**Percentage**
Strongly agree	0	0
Agree	1	2
Not sure	0	0
Disagree	29	58
Strongly disagree	20	40
Total	50	100

Appreciation is a fundamental human need. Employees respond to appreciation expressed through recognition of their good work because it confirms that their work is valued. When employees and their work are valued, their satisfaction and productivity rises, and they are motivated to maintain or improve their good work. This table indicate that majority of the respondents are not rewarded for their good work. The whooping 58% (n=29) of the respondents disagree with the statement that best home based care givers are rewarded and this was further confirmed by another 40% (20) of the respondents who strongly disagreed with the same statement. Only 2 % of the respondents feel that best home based care are rewarded for their good work. It is clear in this table that majority of home based care givers feel that those who are performing well are not rewarded for their good work.

Table 4.14: Home based care givers get advices from colleagues as a way of coping strategy

Response	Frequency	Percentage
Very often	7	14
Often	6	12
Sometimes	35	70
Seldom	0	0
Never	2	4
Total	50	100

Work related stress is a growing problem around the world that affects not only the health and well-being of employees, but also the productivity of organizations. Like any other employee, home based care givers have some coping strategies when they feel stressed in their work place. As outlined in the above table, 70% (n=35) of the respondents sometimes get advices from colleagues as a way of coping strategy, whereas 14% (n=7) of the respondents very often get advices from colleagues. A further 12% (n=6) of the respondents often get advices from colleagues as a way of coping with difficulties in their work place. Only 4% (2) of the respondents do not believe in getting advices from colleagues as a way of coping in their work place. It is clear in this table that majority of home based care givers prefer to get advices from colleagues as a way of coping with difficulties in their work place.

Table 4.15: Home based care talk to superiors as a way of coping strategy.

Response	Frequency	Percentage
Very often	7	14
Often	7	14
Sometimes	4	8
Seldom	0	0
Never	32	64
Total	50	100

Table 4.15 shows that 64% (n=32) of the respondents never talk to their superiors as a way of coping strategy in the work place. However, 14% (n=7) of the sampled respondents very often talk to their superiors and another 14% (n=7) often talk to the superiors as a way of coping strategy in the work place. Only 8% (n=4) of the respondents indicated that sometimes they talk to their superiors as a way of coping strategy. The figures outline that majority of the respondents do not prefer to talk to their superiors as a way of coping strategy whenever there are challenges in the work place.

Table 4.16: Home based care givers remain positive thinking that things will get better.

Response	Frequency	Percentage
Very often	20	40
Often	7	14
Sometimes	19	38
Seldom	2	4
Never	2	4
Total	50	100

The statistics in this table shows that 40 % (n=20) of respondents very often remain positive thinking that things will get better one day in the field of home based care and another 14% (n=7) often remain positive as well. There are 19 respondents who constitute 38% of the sample who sometimes remain positive thinking that things will get better. Only 4% (n=2) of the respondents never remain positive regarding the betterment of things in the field of home based care. The last 4% (n=2) of the respondents seldom think that things will ever get better. Is clear again that majority of the respondents believe that things will get better one day in the field of home based care.

Table 4.17: Home based care givers avoid problem and pretend it does not exist.

Response	**Frequency**	**Percentage**
Very often	20	40
Often	7	14
Sometimes	19	38
Seldom	2	4
Never	2	4
Total	50	100

Table 4.17 displays that 40% (n=20) of the respondents very often avoid problems that they encounter in the work place and pretend they don't exist. Another 14 % (n=7) often avoid problems, whereas 38% (n=19) of the sample sometimes avoid problems. It is evident in the above table that few respondents do not avoid problems in the work place. Only 4% (n=2) of the respondents never avoid problems and another 4% (n=2) seldom avoid problems in their work place. From the above table one can read that majority of the home based care givers are working with problems but they only avoid them and pretend that they don't exist.

Table 4.18: Home based care givers rely on religion to cope with challenges.

Response	Frequency	Percentage
Very often	35	70
Often	12	24
Sometimes	1	2
Seldom	0	0
Never	2	4
Total	50	100

Worldwide many people rely in their religion to cope with challenges and the respondents in this study were no exceptional. Table 4.18 illustrates that 70% (n=35) of the respondents very often rely on religion to cope with challenges in the work place and another 24 %(n=12) of the respondents often rely on their religion. Only 2 respondents who constitute 4% of the sampled respondents never rely on their religion as a way of coping with challenges in the work place. Sometimes only 2 % of the respondents rely on their religion. Majority of the respondents believe in prayer to cope with their work challenges. They pray as a group every morning before they start with their daily activities.

Table 4.19: The center should arrange the ongoing debriefing of home based care givers

Response	Frequency	Percentage
Strongly agree	38	76
Agree	12	24
Not sure	0	0
Disagree	0	0
Strongly disagree	0	0
Total	50	100

The above table revealed that majority of the respondents strongly agrees with idea that there should be ongoing debriefing of home based care givers. 76% (n=38) of the respondents strongly agree with this idea and another 24% (n=12) agree with the same idea. This confirms that there is a strong need of continuous debriefing for home based care givers since they are working in a traumatic environment.

Table 4.20: There should be a continuous training for home based care givers.

Response	Frequency	Percentage
Strongly agree	30	60
Agree	19	38
Not sure	1	2
Disagree	0	0
Strongly disagree	0	0
Total	50	100

Table 4.19 depicts that 60% (n=30) of the respondents strongly agrees with the idea that there should be a continuous training for home based care givers and another 38% (n=19) agrees with the same statement. Only 2% of the respondents were not sure if there should be a continuous training for home based care givers. Majority of the respondents support the continuous training of home based care givers.

Table 4.21: Government should ensure that home based care centers are having resources.

Response	Frequency	Percentage
Strongly agree	26	52
Agree	5	10
Not sure	0	0
Disagree	2	4
Strongly disagree	17	34
Total	50	100

Table 4.21 indicates that 52% (n=26) strongly agree with the idea that government should ensure that home based care centers are having resources, and another 10% (n=5) agree with the same statement. It is again highlighted that 34% (n=17) strongly disagree with the fact that government should ensure that home based care centers are having resources. Only 4% (n=2) of the respondents disagree with the same statement. The statistics shows that majority of the respondents are of the idea that Government should ensure that home based care centers are having resources that will enable them to perform their duties.

Table 4.22: The stipend of home based care givers should be increased

Response	Frequency	Percentage
Strongly agree	49	98
Agree	1	2
Not sure	0	0
Disagree	0	0
Strongly disagree	0	0
Total	50	100

Table 4.22 outline that 98% (n=49) of all the respondents strongly agree with the idea that the stipend of home based care givers should be increased and none of the respondents disagree with this statement. One can deduce from the above table that all the respondents feel that their stipend is not enough to can take care of their basic needs.

Table 4.23: Communities need to be taught about the effects of stigmatizing HIV and AIDS sufferers as well as home based care givers

Response	Frequency	Percentage
Strongly agree	35	70
Agree	5	10
Not sure	0	0
Disagree	7	14
Strongly disagree	3	6
Total	50	100

In this table the statistics shows that 70% (n=35) of the of the respondents strongly agree with the notion that communities still need to be taught about the effects of stigmatizing HIV and AIDS sufferers as well as home based care givers. Another 10% (n=5) of the respondents agree with the same statement. However, 14% (n=7) of the respondents disagree with this idea. Another 6% (n=3) respondents strongly disagree with the same statement. Majority of the respondents believe that there is still a serious need to educate communities on the effects of stigmatizing HIV and AIDS sufferers as well home based care givers.

4.3. ANALYSIS OF DATA COLLECTED THROUGH INTERVIEW

In this section, the responses collected by the interview schedule are presented in a narrative form and the detailed findings are discussed in the next chapter. The interview was used for two center managers.

Question 1: what challenges do you experience when managing home based care centers?

<u>*Respondent 1*</u>: This respondent indicated that there are varieties of challenges that they are experiencing, but she emphasized shortage of resources.

<u>*Respondent 2*</u>: According to this respondent shortage of funds and proper building where they can operate from are the main challenges.

Question 2: What do you do to resolve the problems experienced by home based care givers?

<u>*Respondent 1:*</u> This respondent stated that as a manager of the center, she listen to their concerns where possible they resolve them.

<u>*Respondent 2:*</u> The second respondent indicated that she always encourage them that things will get better one day.

Question3: How does the center assist home based care givers to cope with challenges at work?

<u>*Respondent 1*</u>: This respondent said as the center, they believe in prayer and as a way of coping with challenges they have prayer every morning before they start with their daily activities.

Respondent 2: “Challenges will always be there, but we talk to each other whenever they are there”

Question 4: What would you recommend should be done to deal with problems experienced by home based care givers?

Respondent 1: The first respondent indicated that Government should pay home based care givers like any other government employees and provide resources that will make it easier for home based care givers to perform their duties.

Respondent 2: The second respondent like the first one stated that home based care centers should be seen as a unit of the Department of health and there should be enough resources and budget allocated to home based care centers.

4.4 Conclusion

This chapter presented and discussed the findings of this study. It gave a detailed account of the background of the centers under study, the gender-based profiles of the research participants, as well as the core services of the centers based in ward 25 of Thulamela municipality. The findings highlighted the challenges that HBCGs face on a daily basis as they give support to PALHIV which encompasses the rewarding experiences as well as difficult ones that require intervention of the centre managers. Coping mechanisms adopted by HBCGs as a way of coping with the emotional and physical strain of the job are also mentioned. It is noted that there is support from the centre although it is not always seen to be sufficient.

The following chapter concludes this study. It further gives recommendations based on the findings of the study which are directed to the Home based care givers in Vhembe district and government departments involved with HBC.

CHAPTER 5: FINDINGS, CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter the researcher presents this study's conclusion and recommendations for interventions and future research. This study has shed some light to better understand the strategies that HBCGs in a HBCC use to deal with the daily psychological and social challenges they experience during their caregiving, and the type of social support available to HBCGs from the HBCC to assist them in coping with their work. The study has further identified possible remedies to some of the challenges experienced by HBCGs, which could complement the already existing support available at the centre.

5.2 MAJOR FINDINGS OF THE STUDY

In this section the major findings of this study are outlined per themes. Conclusions were drawn, based on the major findings categorized into those themes. The study revealed the following:

- Majority of the respondents believe that home based care givers are experiencing stress in the work place.
- Finance is a challenge to the majority of home based care givers,
- Home based care givers are stigmatized,
- Majority of the respondents agree that the work load of the home based care givers is appropriate,
- There is no shortage of home based care givers according to majority of the respondents,
- Policies to guide home based care givers are available in the centers,
- There is a shortage of working tools for home based care givers,

- The study revealed that home based care givers are attending workshops to capacitate them,
- Home based care givers are not receiving professional counseling,
- There is a need of continuous training for home based care givers,
- There is a shortage of resources in the home based care centers and
- The study also revealed that the stipend received by home based care givers is not enough.

5.3 Conclusion

The above research findings emanate from a qualitative and quantitative study in which the experiences of volunteers involved in home-based care of people living with HIV/AIDS in the Thulamela municipality were investigated. On the basis of these research findings and the literature control the following conclusions can be drawn:

- There appears to be a lack of coordination, cooperation and collaboration in the field of HIV/AIDS service delivery.
- Volunteers practicing home-based care with people living with HIV/AIDS carry an insurmountable burden of being expected to provide a service with very limited resources and in most instances finding themselves utilizing their own resources because of the client realities they are faced with.
- Home-based care helps the helpless, the abandoned, the vulnerable and the marginalized in a way that improves their quality of life to the extent that others recover from their illnesses and become active members of their families again.

- Lack of resources and infrastructure make life very difficult for both volunteers and those they serve and severely impede the quality of home-based care service rendering.
- The good work done by volunteers is not tangibly recognized by government.
- In this final chapter, the researcher gave a brief summary of the research methodology as applied in the third chapter. This was followed by the conclusions and recommendations concerning the qualitative and quantintative methodology that was used in the study. The researcher then presented the main research findings based on the experiences of home based care givers and managers involved in home-based care of people living with HIV/AIDS. Based on those findings, conclusions were drawn which were followed by recommendations on the study as a whole. The aforementioned findings support the vital role fulfilled by home based care givers in home-based care of PLWHA.

5.4 Recommendations

- The government, the private sector and NGOs pledge financial and material resources every year to fight the scourge of HIV/AIDS but these resources do not seem to reach those who need them most. It is recommended that government; the private sector and NGOs should be transparent in publicizing their policies, procedures and criteria for accessing their financial and material resources so that even those in the remotest rural areas can access these resources. It is further recommended that these policies, procedures and criteria should be user-friendly.

- The prevention, care and support programmes of HIV/AIDS should follow the continuum of care model where the link between the home, the community and the formal government services is established. This model is in the policies of government particularly the Departments of Health and Social development but practically. The government should harness resources both financial and human to implement the continuum of care model.

- It is recommended that the coordination and management of HIV/AIDS programmes receive urgent attention in order to deal with fragmentation experienced in this service delivery area. It is recommended that District AIDS Councils (DACs) at the district level and Local AIDS Councils (LACs) at local municipal levels be functional in the same format as the Provincial AIDS Councils.

- The Department of Health should create a structure within the District particularly at local municipal level that will be populated with competent people to handle HIV/AIDS programmes. To employ just one HIV/AIDS Coordinator or HIV/AIDS and Communicable diseases Coordinator at district level is not enough, in fact, that is why PLWHA and their families suffer the way that was exposed by volunteers in this study. This structure should be designed in such a way that it accommodates and recognizes volunteers because volunteers in the field of HIV/AIDS and home based care in particular are an indispensable human resource. These volunteers should be supplied with the necessities of being an HIV/AIDS volunteer like care kits.

- The use of free volunteers in HIV/AIDS programmes especially home-based care is not sustainable. The government cannot discharge obviously terribly sick people from health institutions to be cared for at home by ‘faceless’ people who are not known and do not account to health authorities and whose competency and proficiency in health care has not been certified or accredited. Potentially un-regulated health care can be a violation of the human rights of PLWHA because health is a constitutional mandate and there is an obligation to provide health care services to South Africans. This responsibility cannot be delegated to free volunteers who are not obliged or compelled to visit and care for any sick person. The government appears to be capitalizing on the vulnerability of the unemployed and their generosity of spirit to provide home-based care. It is recommended that government employ appropriately trained volunteers as fieldworkers or community health workers to address the magnitude of the HIV/AIDS pandemic.

- The fieldworkers/community health workers recommended above should also be charged with HIV/AIDS community education/awareness.
- It is recommended that further research be conducted in the following areas: the experiences of those receiving care and support from volunteers; the challenges faced by home-based care service providers especially CBOs and NGOs in training and retaining volunteers; the accreditation of training for volunteers; the investigation of a sustainable system of volunteering in home-based care and the development of appropriate policies and guidelines for volunteers in home-based care.
- Lack of or minimal support from the senior staff members can cause the HBCGs to suffer emotional fatigue to the extent that they are unable to render quality care for PALHIV. HBCGs also need to support each other and make their voices heard at decision-making level concerning the allocation of resources and manpower and opportunities for growth (Ehlers 2006). They can do so by selecting a spokesperson who will communicate their interests and complaints to management to avoid confrontations in the presence of everyone.

- HBCGs need to be supported with adequate supplies and infrastructure, relevant information and guidelines to be able to carry out their duties to full capacity. The HBCC in ward 25 of Thulamela municipality can try to have team building expeditions, annually if possible, to review and recreate synergy.

- Support groups need to be formalised with time allocation periodically where HBCGs can share their caring experiences with each other. Peer networks can also help; HBCGs from the HBCC in Ha-Tshivhase could interact with others in the same field to share their caring experiences.

5.5 Recommendations for future research

- It is recommended that further research be undertaken to investigate coping mechanisms of HBCGs who care for PALHIV in various HBC programmes in Ha- Tshivhase area of Thulamela municipality. Such a study will enable the researcher to draw a more generalized conclusion about HBCGs in Ha-Tshivhase and can suggest a community-based approach to support the HBCGs. This would therefore address one of the limitations of this study.

- More research should be considered on the impact of the withdrawal of social grants received by PALHIV on their recovery and survival. This kind of research will enable HBCGs to have a better understanding of what leads to withdrawal of social grants and they will be able to make informed choices on how to ensure that grants are not stopped, thereby improving the financial capacity and well-being of their patients and enhancing the quality of their care.

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APPENDIX A

University of Venda

The district Executive Manager

Department of Health

Vhembe district

09.05. 2014

REQUEST FOR PERMISSION TO COLLECT DATA FOR STUDIES-M.S.SINYELA (9523669)

This letter serves to confirm that Mr Sinyela M.S. is a registered Masters of Public Management student at the University of Venda. Mr Sinyela is presently doing his research as a requirement for the completion of his degree. His research topic is **"Constraints to the provision of home based care to patients in ward 25 of Thulamela Municipality in Limpopo Province"**

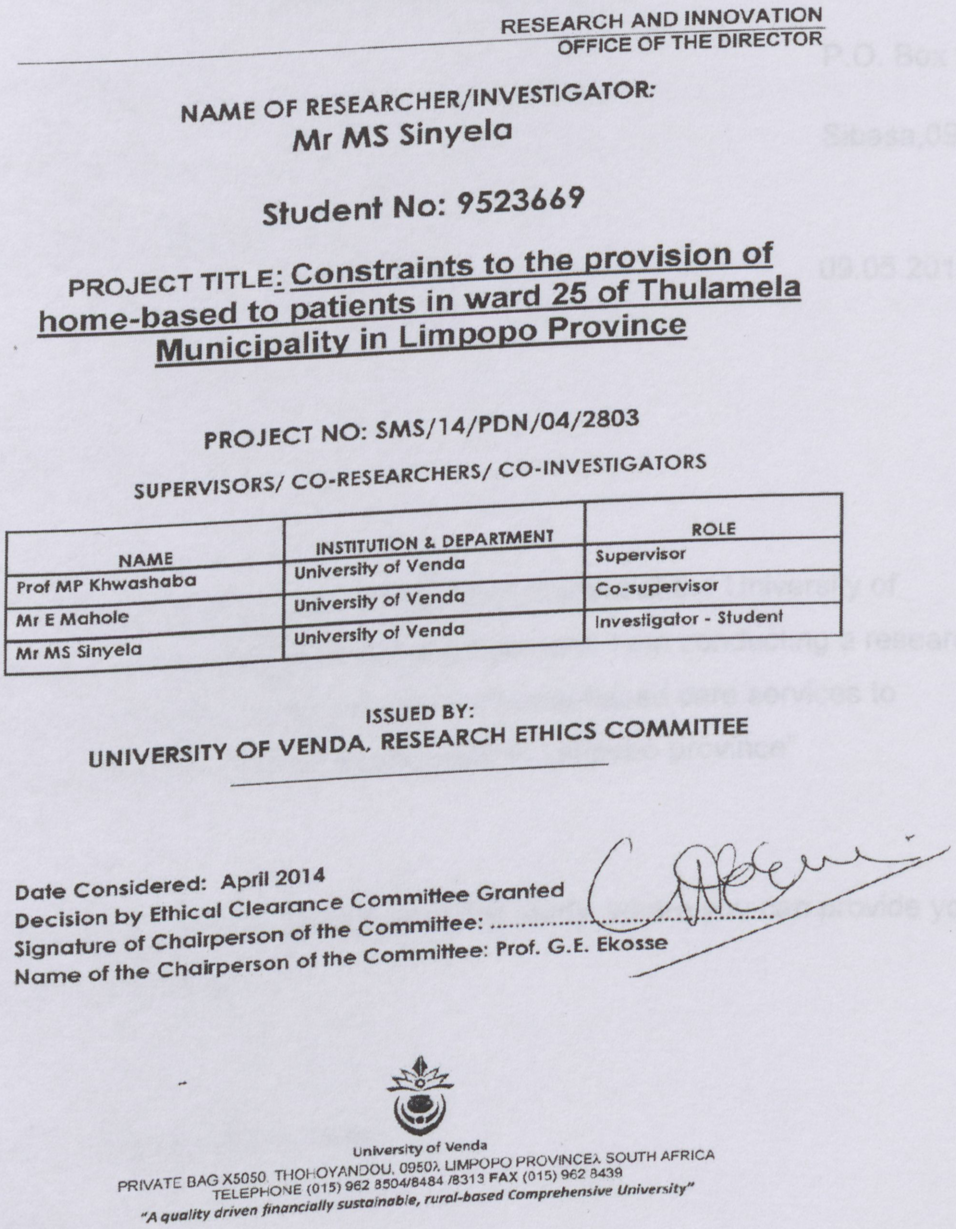
As an institution of higher learning we request your department to give him permission to collect data for his research. We undertake that the information which shall be provided to him will only be used for his research.

Yours faithfully

Prof M.P.Khwashaba

Vice Dean: School of Management Sciences

Appendix B



RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Mr MS Sinyela

Student No: 9523669

PROJECT TITLE: **Constraints to the provision of home-based to patients in ward 25 of Thulamela Municipality in Limpopo Province**

PROJECT NO: SMS/14/PDN/04/2803

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Prof MP Khwashaba	University of Venda	Supervisor
Mr E Mahole	University of Venda	Co-supervisor
Mr MS Sinyela	University of Venda	Investigator - Student

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: April 2014
Decision by Ethical Clearance Committee Granted
Signature of Chairperson of the Committee: ....
Name of the Chairperson of the Committee: Prof. G.E. Ekosse

University of Venda
PRIVATE BAG X5050, THOHOYANDOU, 0950λ LIMPOPO PROVINCEλ SOUTH AFRICA
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"A quality driven financially sustainable, rural-based Comprehensive University"

APPENDIX C

Letter to the respondents

Enquiry: Sinyela M.S
Cell: 0724612348
Email: Ksinyela@gmail.com

P.O. Box 906
Sibasa,0970

09.05.2014

Dear respondent

I, Sinyela Mashudu Shadrack, am a registered student at the University of Venda, registered for Master of Public Management. I am conducting a research study on the “Constraints on the provision of home-based care services to patients in ward 25 of Thulamela municipality in Limpopo province”

This is an opportunity for you to be part of this study, where you can provide your views on the research topic.

I hope you will find this to be in order.

Yours faithfully

SINYELA MASHUDU SHADRACK

STUDENT NUMBER: 9523669

APPENDIX D

RESEARCH INSTRUMENT: QUESTIONNAIRE

TOPIC: CONSTRAINTS TO THE PROVISION OF HOME-BASED CARE TO PATIENTS IN WARD 25 OF THULAMELA MUNICIPALITY IN LIMPOPO PROVINCE

Your participation in this research is appreciated. Please put a cross(x) to the appropriate answer

Section A: Biographical Details

1. Gender of the respondents

Male	
Female	

2. Age

Less than 20 years	
21 to 30 years	
31 to 40 years	
41 to 50 years	
50 and above	

3. Level of Education of respondents

Never attended school	
Primary school	
Secondary school	
Tertiary school	

Section B: Constraints to the provision of Home- based care services to patients

	Challenges experienced by home based care givers	**Strongly agree**	**Agree**	**Not sure**	**Disagree**	**Strongly Disagree**
4	Home based care givers experience stress in their work place					
5	Finance is a challenge to home based care givers					
6	Home based care givers are stigmatized					
7	Workload of home based care givers is appropriate					

8	There are enough home based care givers to deal with the number of available patients					

	Support services available for home based care givers	**Strongly agree**	**Agree**	**Not sure**	**Disagree**	**Strongly Disagree**
9	There are policies to guide home based care givers in their duties					
10	There are enough working tools available					
11	Home based care givers are work shopped on issues related to their responsibilities					
12	There are professional counseling sessions for home					

	based care givers					
13	Best home based care givers are rewarded					

	Coping mechanisms used by Home based care givers	Very often	Often	Sometimes	Seldom	Never
14	Do you get advices from colleagues?					
15	Do you talk to superiors?					
16	Do you remain positive thinking that things will getter better one day?					
17	Do you avoid the problem and pretend it does not exist?					
18	Do you rely on					

	your religion to cope with challenges?					

	Strategies for improving services of home based care givers	Strongly agree	Agree	Not sure	Disagree	Strongly Disagree
19	The center should arrange the ongoing debriefing of home based care givers.					
20	There should be a continuous training for home based care givers in order to keep them abreast with the new development in health matters.					
21	Government should ensure that home based care centers are having resources such as transport and					

	office building.					
22	The stipend of Home based care givers should be increased to can cover their needs.					
23	Communities still need to be taught about the effects of stigmatizing people living with HIV and AIDS as well as Care givers.					

Thank you

APPENDIX E

INSTRUMENT

Interview Schedule

Constraints on the provision of Home based care services to patients in ward 25 of Thulamela municipality in Limpopo Province.

1. What challenges do you experience when managing home based care centers?

____

____

____

____

____

2. What do you do to resolve the problems experienced by home based care givers?

____

____

____

____

____

3. How does the center assist home based care givers to cope with challenges at work?

4. What would you recommend should be done to deal with problems experienced by home based care givers?

Thank you