

**CHALLENGES EXPERIENCED BY COMMUNITY HOME-BASED CAREGIVERS  
CARING FOR PEOPLE LIVING WITH HIV/AIDS: A CASE OF TSIANDA VILLAGE,  
IN MAKHADO MUNICIPALITY, SOUTH AFRICA**

**BY**

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## DECLARATION

I, Mulalo Mahlophe, declare that the mini-dissertation titled “**Challenges experienced by community home-based caregivers caring for people living with HIV/AIDS: A case of Tsianda village, in Makhado Municipality, South Africa**” hereby submitted by me for the degree, Master of Public Health (MPH) at the University of Venda has not been submitted before by me at this or any other University and that it is my own work in design and execution. All the sources that I have quoted and cited have been indicated, acknowledged and referenced.

**Signature** ..... **Date**.....

M Mahlophe

## DEDICATION

I would like to dedicate this mini-dissertation to my mother Mrs. Meriam Mahlophe, for her love, encouragement and support she gave to me throughout my studies. May God continue to bless her.

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## LIST ACRONYMS AND ABBREVIATIONS

AIDS:	Acquired Immunodeficiency Syndrome
CBC:	Community-Based Care
CBO:	Community-Based Organisation
CHBC:	Community Home-Based Care
CHBCGs:	Community Home-Based Caregivers
CHBCO:	Community Home-Based Care Organisation
DOH:	Department of Health
HBC:	Home-Based Care
HBCO:	Home-Based Care Organisation
HIV:	Human Immunodeficiency Virus
NGO:	Non-Governmental Organisation
NPO:	Non-Profit Organisation
PLWHA:	People Living with HIV/AIDS
PPE:	Personal Protective Equipment
TB:	Tuberculosis
UNAIDS:	United Nations Programme on HIV/AIDS
UK:	United Kingdom
USAID:	United States Agency for International Development
WHO:	World Health Organisation

## ABSTRACT

Human Immune Deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) place a significant burden on the caregivers for people living with HIV/AIDS (PLWHA). Caring for PLWHA is usually carried out by community members who are recruited from the same community as the PLWHA. These community members are trained to provide services as volunteer caregivers. The caregivers face various challenges in the process of giving care to PLWHA, often inadequately assisted by relatives, friends, neighbours, private individuals, grassroots traditional and political leaders. This results in caregivers being overwhelmed by their responsibilities, making their coping process even more difficult. The aim of this study was to explore the challenges experienced by community home-based caregivers (CHBCGs) caring for people living with HIV/AIDS at Tsianda Village, in Makhado Municipality, South Africa. This study adopted a qualitative explorative design. The population for this study were all CHBCGs caring for PLWHA. Non probability purposive sampling was used to select the community home-based caregivers working at Tsianda Community Home-based care organisation. In-depth interviews, using a semi-structured interview guide, was conducted by the researcher and a voice recorder were used to record data from participants. Data saturation was reached at the 11<sup>th</sup> participant. This is when the participants were no longer giving new information. The data collected from the study were analysed thematically. The following themes emerged from data analysis: Challenges for community home-based caregivers, perceived support for community home-based caregivers, coping strategies for community home-based caregivers. Measures to ensure trustworthiness and the code of ethics to protect the rights of the participants was applied and observed. The findings of the study revealed that community home-based caregivers experience various challenges which have a negative impact on their personal life, as well as their physical and psychological well-being. Community home-based care also uses different strategies to cope with these challenges. It was concluded that the community home-based caregivers are experiencing serious shortages of personal protective equipment, which makes them work with the fear of being infected with the diseases. It is recommended that the DOH should take it into consideration to provide the CHBCG's organization with enough personal protective equipment for their safety and working without fear of being infected with deadly viruses.

**Key words:** *challenges, home-based caregivers, HIV/AIDS, PLWHA*

## CHAPTER 1

### INTRODUCTION

The Human Immune Deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) has become a very serious concern in South Africa. The increase in people becoming infected with HIV has brought a significant burden on hospitals as a result of the shortage of beds, health personnel and medication, as well as an increase in the care demanded by the patients. In most cases care for people living with HIV/AIDS in South Africa is provided by community home-based caregivers, who are recruited and trained as volunteers within the environment of the patients. It has been indicated that the caregivers experience emotional and physical challenges, such as stress, grievances and physical strain when rendering care to the patients confined to their beds (Motswasele, 2008; Sips, Mazanderani, Schneider, Greeff, Barten & Moshabela, 2014; Friedman, Mothibe, Ogunmefun & Mbata, 2010).

#### 1.1 Background of the study

United Nations Programme on Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome (UNAIDS) (2016), reported that approximately 36.7 million people were living with HIV/AIDS (PLWHA) worldwide at the end of 2015. According to the World Health Organisation (WHO) (2016), Sub-Saharan Africa was the highest with 25.6 million people living with HIV/AIDS in 2015. It was further reported that sub-Saharan Africa accounts for two thirds of the worldwide total of new HIV infections. Furthermore, WHO (2016), reported that 35 million people have died from AIDS-related illnesses since the start of the epidemic, including 1.1 million in 2015. In some countries (Botswana, South Africa, Zambia and Namibia) in Sub-Saharan Africa, many children continue to live in homes and communities which are ravaged by the effects of HIV and AIDS (Nyaphisi & Obioha, 2015). Four African countries, namely, Botswana, Lesotho, Swaziland and Zimbabwe have a national adult HIV prevalence rate exceeding 20% (United States Agency for International Development, 2015). The HIV/AIDS rate in South Africa is also a prominent health concern, UNAIDS (2016), reported that South Africa has the biggest and highest profile of the HIV epidemic as compared to other countries in the world. It is estimated that 7 million people were living with HIV/AIDS in 2015, with 380, 000 new infections, while 180, 000 died from AIDS- related illness (UNAIDS, 2016).

Browning (2008), mentioned that in Botswana, the needs for HIV/AIDS patients have created a demand for health care that is beyond the capacity of the hospitals and clinics, whereby

patients with HIV/AIDS occupied more than one half of the beds in the main referral hospitals. The study further found that in response to the increase in HIV/AIDS patients, the Botswana government initiated the Community home-based care (CHBC) programmes, which is a strategy for giving care to patients in their own living environments by the community and family members of the patients (Browning, 2008). Nyaphisi and Obioha (2015) reported that in Lesotho, 50% of the outpatients visits to hospitals were from AIDS-related ailments, and more than 60% of the inpatients were in hospital due to AIDS-related illnesses. The authors further mentioned that the number of orphans is rapidly increasing due to HIV/AIDS-related deaths (Nyaphisi & Obioha, 2015). HIV/AIDS and other related diseases, such as Tuberculosis (TB), Gonorrhoea and cancer in Lesotho, have resulted in a large number of people queuing at hospitals for health services and congestion in the hospital wards. Therefore, Community home-based care under the umbrella of the primary health care system came as an intervention in which patients are taken care of at their homes and through community action by their own families and extended families or other people of their choice, as members of the community (Nyaphisi & Obioha, 2015).

Sips et al. (2014), reported that South Africa's Health system struggles to cope with the collision of excessive health burden such as HIV/AIDS, TB and other communicable diseases. This results in increased pressure on health resources and the health budget getting too smaller. Deficiencies in the health care system are caused by a combination of factors, such as inefficient government spending, shortage of material and human resources, particularly in rural areas, as well as lack of policy reform (Sips et al., 2014). Such factors increase the pressure on the already vulnerable and weak health care system, with a particular negative impact on the rural areas. The principal responsibility of rendering care to people with chronic conditions, including HIV/AIDS, has subsequently shifted from the health care system to local community and households (Sips et al., 2014).

Due to the shortage of health care personnel in South Africa, the government had to adopt the home-based care (HBC) approach as an alternative to hospital care for people living with HIV/AIDS (Akintola, 2008a). WHO (2016), reported that 80% of the deaths related to AIDS occur at home and 90% of care is being provided at home, which is also linked to health care services. HBC programmes were developed with a view to assist family care givers in providing AIDS-related care, as the public health service could not cope with the increasing demand for treatment and care (WHO, 2011)

In 2001, the South African national government started to allocate ring-fenced grants, to strengthen home-based and community-based care projects. This led to a rapid growth of state-supported non-profit organisations (NPO) employing community care-givers (Sips et al.,

2014). Friedman, Mothibe, Ogunmefun and Mbata (2010), reported that caring for PLWHA is usually carried out by family members who serve as the 'primary caregivers' and the community members who are recruited from the same community as the people living with HIV/AIDS and trained to provide services as volunteer caregivers. It has been observed that the burden of caring for PLWHA, as either primary caregivers or volunteers, is largely carried out by women (Kathuri-Ogola, Mugenda & Kerre, 2014). Caregivers have been associated with various challenges during the process of caregiving (Stajduhar et al., 2010). A study by Mashau and Davhana-Maselesele (2009) revealed that caregivers experience emotional difficulties, such as fear of contracting HIV and TB while providing care and a feeling of guilt, frustration and helplessness in the face of death. In the study conducted by Nyaphisi and Obioha (2015), it was found that due to lack of transport in the community-based organisations (CBO), the CHBCGs are unable to reach some of the patients living too far away from the organisation. This made them feel helpless and they blamed themselves for not reaching the needs for their patients. Caregivers are often inadequately assisted by relatives, friends, neighbours, private individuals, political leaders, and other service delivery networks such as non-governmental organisations (NGO) (Friedman et al., 2010). Such challenges make the CHBCGs feel overwhelmed with their responsibilities and also make them struggle to cope effectively with them (Friedman et al., 2010).

## **1.2 Problem statement**

Public Hospitals in South Africa and other developing countries all over the world are not coping well with the increasing number of PLWHA and other chronic illnesses (TB and cancer). This has resulted in a shift in the caring of PLWHA and those with other chronic illness from the health care system into the local home-based care organisation (HBCO), which mostly operates as NPO. Due to a shortage of beds, space and resources in hospitals, most PLWHA are cared for in their families by their family members and CHBCGs, who often experience stressful social, economic, medical, and psychological implications situations (Kathuri-Ogola et al., 2014).

The present researcher worked as an intern social worker at Ha-Mutsha Clinic under the Department of Social Development. During his internship programme, the researcher co-facilitated a support group meeting with CHBCGs and often observed that many caregivers are dropping out from the service and did not want to return there. As the HBCO services are broadly directed to vulnerable groups (orphans, people with disability, and elderly people), as well as other terminally ill people, such as PLWHA, the researcher became interested in

finding out the challenges experienced by CHBCGs when taking care of people living with HIV/AIDS, specifically.

### **1.3 Rationale of the study**

There are several studies in relation to CHBCGs that have been conducted in different provinces and municipalities in South Africa (Munwaniki, 2013; Mashau, Mudau & Netshandama, 2014; Motswasele, 2008). However, there is no known study that has directly focused on the challenges experienced by community home-based care givers caring for people living with HIV/AIDS in Tsianda village Vhembe District South Africa. This study therefore sought to address a gap in knowledge about the challenges experienced by the community home-based caregivers caring for people living with HIV/AIDS.

### **1.4 Significance of the study**

The findings and recommendations of this study may assist the Department of Health to come up with appropriate measures to reduce the challenges experienced by CHBCGs when taking care for PLWHA. The CHBCGs may benefit from the measures taken by the Department of Health in dealing with the challenges experienced when caring for PLWHA. When the challenges for CHBCGs are addressed by the Department of Health, community members may benefit in receiving quality service from the CHBCGs.

### **1.5 Aim of the study**

The aim of the study was to determine the challenges experienced by community home-based caregivers caring for people living with HIV/AIDS at Tsianda Village, in Makhado Municipality, South Africa.

### **1.6 Objectives of the study**

The objectives of the study were to:

- Explore and describe the challenges experienced by community home-based caregivers when caring for people living with HIV/AIDS
- Explore and describe the perceived support for Community home-based caregivers when caring for people living with HIV/AIDS
- Explore and describe the coping strategies used by the community home-based caregivers in dealing with the challenges they experience when caring for people living with HIV/AIDS.

### 1.7 Definition of terms

**Community:** is a place where people live and a source of support to individual and families in need (WHO, 2002). In this study a **Community** is a place where community home-based carers are helping people living with HIV/AIDS.

**Community home-based care:** is the provision of health services by formal and informal caregivers in the home of the patients in order to promote, restore, and maintain a person maximum level of comfort, functioning and health, including care towards a dignified death (Campbell & Foulis, 2004). In this study **community home-based care** is any kind of help and support given to people living with HIV/AIDS by the community caregivers in Tsianda Village.

**Caregivers:** are the individual who render the majority of care or much of the responsibility of providing help or support to family members, friends or neighbours (Funk, Staduhar, Toye, Aoun, Grande, & Todd, 2010). In this study a **caregiver** is any individual who gives care to people living with HIV/AIDS, either paid or unpaid.

**Challenge:** is anything that makes it difficult for something to happen (Funk et al., 2010). In this study a **challenge** is anything that makes it difficult for the home-based caregiver to provide care to people living with HIV/AIDS.

### 1.8 Subsequent chapters

This study is made up of five chapters, each with specific subject matters, as follows:

Chapter 1: Introduction

This chapter covers the introduction and background of the study, problem statement, rationale of the study, significance of the study, aim and objectives of the study, definitions of terms and ends with the subsequent chapters.

## Chapter 2: Literature Review

This chapter focuses on the review and discussion of relevant literature in relation to the study. The researcher reviewed the literature from relevant sources such as journals, academic books and articles. This chapter helped the researcher to become aware of what other researchers have found in the same topic or related to it.

## Chapter 3: Research Methodology

This chapter includes an introduction, research design, target population, study setting, sampling method and sampling procedures that was used. This chapter also focus on the data collection instrument, pre-test, data collection procedure, data analysis method, measures taken to ensure trustworthiness, dissemination of findings as well as summary.

## Chapter 4: Presentation and Discussion

This chapter contains the presentation and discussion of the findings as presented by the participants.

## Chapter 5: Limitations, Conclusions and Recommendations

This chapter includes the limitation, conclusions, recommendations, and ends with a summary.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 Introduction

In this section, the researcher reviewed available literature from different schools of thought on the challenges experienced by community home-based caregivers, the level of support that they receive from the community and the family members of the people living with HIV/AIDS as well as the coping mechanism that the caregivers utilise when caring for PLWHA.

#### 2.2 Overview of community home-based care services globally

Nyaphisi and Obioha (2015), defined to CHBC as the kind of health care which is given to individuals in their own families, where they are supported by their families, extended families or people of their choice as members of the family. CHBC is goal-directed and aims at providing hope through high quality and appropriate care that assists the family caregivers and family members who are sick, in order to maintain their independence and achieve the possible quality of life (WHO, 2011). The CHBCGs represent the backbone of health and social care delivery in countries throughout the world, including western or developed countries (Stajduhar, et al 2010).

It is estimated that CHBCGs provide 80% to 90% of all care provided to individuals in home settings in Canada, while in Australia, unpaid workforce of CHBCGs has been estimated at about five times the equivalent of a full-time paid care provider work force and would cost about \$30.5 billion if substituted with formal paid care (Stajduhar et al., 2010). An estimated 500, 000 people provide care at the end of life in the United Kingdom (UK). In addition, the overall number of caregivers is equal to the number of those employed by the National Health Service (Stajduhar et al., 2010). Undoubtedly, there is a great need for services and support provided by the CHBC programme to persons infected and affected by HIV/AIDS. In Sub-Saharan Africa, where the HIV/AIDS epidemic is of paramount concern, the nature of the disease, weak public health infrastructure, spiralling health costs, and lack of resources, have made CHBC a necessity in the continuum of care in Sub-Saharan Africa (Oramasionwu, Daniels, Labreche & Frei, 2011). CHBC is regarded as an effective method of giving cost-effective, empathic care to those infected and affected by HIV and AIDS. The CHBC is not a replacement for hospital care, but instead is part of a spectrum of care that includes preventive, curative and rehabilitative care (National Guideline for community and home-based care. 2015).

HIV/AIDS is a devastating reality in southern African countries such as Swaziland, Zimbabwe, Lesotho and Botswana. These countries have the national adult HIV prevalence rates of approximately 24.1%. The mounting morbidity and mortality of the epidemic has placed increasing pressure on these countries' public health sector. In addition, the needs of PLWHA have created a demand for healthcare that is beyond the capacity of hospitals and clinics, forcing the state to develop the CHBC programme (Browning, 2008). The burden of HIV/AIDS in Lesotho is overwhelming: for instance, it was reported that more than 50% of the outpatients to the hospital were for AIDS-related ailments, and that more than 60% of inpatients are in hospital due to AIDS-related illness (Nyaphisi & Obioha, 2015). Due to the increase in the number of PLWHA and other chronic diseases such as TB, Cancer and many others, in Lesotho, large numbers of people queue at hospitals for health services and congestion in hospitals wards has resulted in the development of CHBC, to serve as the intervention, whereby patients are taken care of in their own homes by the community (Nyaphisi & Obioha, 2015).

### **2.3 Community home-based care in South Africa**

Sips et al. (2014), reported that NGOs and faith-based home-based care projects have emerged all over South Africa, using lay workers to provide palliative care to people who are infected by HIV since the late 1990's. The authors further stated that even though the CHBC was originally established to provide palliative care to PLWHA outside of the hospital settings, it has been evolving into a more general health and social support sector, and a safety net for vulnerable individuals and households. However, it was only in 2001 where the South African government started to render some funding to strengthen the community home-based care project, which has resulted in a rapid growth of state-supported NPO employing community care givers (Sips et al., 2014).

Mashau, Netshandama and Mudau (2016), reported that the establishment of CHBC in most developing countries, including South Africa, has resulted in the shift burden from hospitals to the community where palliative care is provided by voluntary home-based caregivers. The authors further reported that the CHBC programmes are directed at vulnerable groups such as older people and disabled people, people recovering from illness who are in need of assistance, terminally ill people as well as PLWHA or any other chronic diseases.

In South Africa, HBC is regarded as one of the best way for many individuals who are sick to receive quality care. Munwaniki (2013), stipulated that Community home-based care makes a significant contribution to relieving the burden of care resulting from HIV/AIDS on the health

sectors. Streid, Harding, Agupio, Dinat, Downing, Gwether, Ikin, Mashao, Mmolede, Moll, Sebuyira, Higginson and Selman (2014), reported that CHBCGs play an important role in improving the quality of life of patients and families facing the problems associated with life-threatening illness such as HIV/AIDS and TB.

## **2.4 Challenges experienced by community home-based caregivers**

Kathuri-Ogola et al. (2014), reported that caregivers may be community members, mostly women, who are recruited from the same community as the PLWHA and trained to provide care services as the caregivers volunteer (Kathuri-Ogola et al. 2014 & Mashau et al., 2014). Mashau, Netshandama and Mudau (2015), stated that CHBCGs visit the homes of PLWHA and carry out duties such as positioning, and mobility, bathing, cleaning wounds, skin care, support for nutrition, according to the needs of the person and also ensuring that the person adheres to his/her medication correctly. The CHBCGs often experience various challenges resulting from limited resources settings whilst proving care to people living with HIV/AIDS (Mashau et al., 2015). These include emotional challenges and stress, gender imbalances, lack of resources, lack of supervision, poverty, lack of motivation and incentives.

### **2.4.1 Emotional challenges and stress**

The WHO (2011), reported that taking care of people who are sick, particularly PLWHA, is an emotionally challenging task; it may result in depression, anxiety, anger, frustration, excessive guilt, sense of lack of competence and self-blame. The CBCGs often develop a strong bond with their patients during the caregiving process and this has a devastating effect when they lose their patients (Akintola, 2008a). Caregivers experience a great loss when a sick person dies and they also experience sadness, grief and anxiety about the family left behind, especially if there are children (Nyaphisi & Obioha, 2015).

Kathuri-Ogola et al. (2014), reported that the main source of stress for most home-based caregivers was worried about the ill person and their children and/or the inability of the caregiver to adequately provide for or help the PLWHA as well as the other dependants in the family. The researcher further reported that most of the caregivers often experience sleeping problems, anxiety, persistent headaches, feelings of frustration, loss/increase of appetite and poor concentration (Kathuri-Ogola, et al., 2014). The CHBCGs often express feelings of guilt, helplessness, anger and alienation. It was reported that some of the CHBCGs witness death,

which leaves them in emotionally drained, yet no counselling programmes are given to assist them. Thus they have to seek help from other sources on their own (WHO, 2011).

The WHO (2002), stipulated that the mental health of the CHBCGs is very important and they can live a quality life if they can be provided with emotional support and individual or group counselling. Kangethe (2009), reported that lack of support amongst the CHBCGs increases stress, leading to the risk of burnout, with many caregivers having to leave their caregiving work and find other/ alternative work. Burnout is a result of excessive emotional and physical strain without the necessary care to support the caregivers (Kathuri-Olga et al., 2014). This may lead to excessive fatigue, lack of motivation, anxiety and depression. It was reported that female CHBCGs, especially those visiting men who are staying alone, experience much fear of being sexually abused and raped (WHO, 2011).

#### **2.4.2 Gender Imbalance**

CHBCOs often experience a problem of gender imbalance where the majority of the care givers are females and very few males are willing to be caregivers. The gender imbalance imposes a great burden for female caregivers as they will have to take care of both female and male sick people (Nyaphisi & Obioha, 2015). WHO (2011), reported that PLWHA may not want to be given care such as being bathed by someone of the opposite sex. Thus, Female caregivers usually experience challenges when comes to lifting and carrying for a sick person (WHO, 2011).

#### **2.4.3 Lack of resources**

Resources are very much important when giving care to PLWHA. Without resources CHBCGs will not be able to be there for the sick people when needed or be able to give quality care. In the study conducted by Nyaphisi and Obioha (2015), it was found that CHBCGs often experience stress due to lack of resources within the organisation, such as transport that take them from the organisation to the patient in need of help. Thus, the caregivers are forced to walk in extreme weather conditions for a very long distance. Without a transport some of the PLWHA who are living in remote areas cannot be easily reached or receive many visitations (Nyaphisi & Obioha, 2015). In the study conducted by Valjee and Van Dyk (2014), it was found that caregivers from some organisations felt that transport was their main challenge, as it could not always be provided by the organisation. The researchers further stated that the

caregivers complained that some of the place they conducted visit was not safe and very far from their organisation.

The study conducted by Mashau et al. (2014), revealed that the CHBCG experience challenges with regard to a shortage of home-based care kit. The researchers explained that the caregivers often find themselves working without personal protective equipment (PPE), such as hand gloves and face masks. Nyaphisi and Obioha (2015), also reported lack of personal protective equipment, such as hand gloves to use in the process of helping the patient go to the toilet, bathing and turning them, places CHBCGs at risk. The challenge of lack of resources makes caregivers feel reluctant to visit the patients at their homes because there is no point in visiting them when caregivers cannot help them with their bare hands (Nyaphisi & Obioha, 2015). Thus, without enough resources, CHBCGs are more vulnerable to various risks when giving care to PLWHA.

The health and safety of the caregiver is of paramount importance while taking care of people living with HIV/AIDS. For example, The CHBCGs are at risk of being infected with TB and HIV when they come into close contact with the patients who have sores and the vomit of the patient, without appropriate personal protective equipment (Mashau et al., 2014). CHBCGs have a feeling that they are putting their own lives at risk of infection each time they go to work because they do not have the necessary equipment to protect themselves against infection (Mashau et al., 2014).

#### **2.4.4 Lack of Supervision**

Regular supervision of CHBCGs by the relevant stakeholders is essential for the purpose of providing quality care to the PLWHA. Qalinge (2011), reported that most of the caregiver rarely receive supervision by the health care professionals and felt inadequately equipped without guidance while doing their work. The study conducted by Kangethe (2009), in Botswana, also shows that caregivers are not receiving enough supervision from the health care personnel as a result, they end up using their own instincts when giving care to the PLWHA.

#### **2.4.5 Poverty**

Most of the CHBCO rely on unemployed volunteers, who are usually females and unpaid or in few cases, paid stipends. Caregivers visit patients, spending long days without remuneration, instead of looking for jobs that can pay them (Kathuri-Ogola et al., 2014).

Browning (2008), stipulated poverty as the main obstacle in the provision of care. The present researcher also found that most of the caregivers in the study indicated that there is no one holding a paying job and most of them were not formally employed; hence, some of them were earning a small income through small-scale farming or running tuck shops ( Browning, 2008).

Mashau, et al. (2014), stated that CHBCGs experience frustration and feelings of helplessness when they are unable to meet some of the basic needs for PLWHA such as food and clean water. It was reported that the CHBCGs feel sad when they see the patients' situation. Sometimes CHBCGs use their own resources to care for the patients. In addition, they share their food and income, which in turn increases stress and poverty on their part (Kathuri-Ogola et al., 2014 & Mashau et al., 2014).

#### **2.4.6 Lack of motivation and incentives**

Lack of motivation and incentives is another challenge that caregivers experience in the process of giving care to PLWHA. Friedman et al, (2010), found that care-giving to people living with HIV/AIDS with lack of incentives, rewards and recognition, is often demotivating and demoralizing. This results makes coping even more difficult. Lack of incentives was one of the main reasons why care-giving does not attract young women and men. Providing incentives could include giving stipends, bonuses, supportive words, food items, toiletries, relieving somebody before he or she gets overwhelmed, allowing caregivers to work in turns, and monetary payments (Friedman et al, 2010). Qalinge (2011), reported that the CHBCGs are sometimes forced to utilise their resources for the benefit of their patient, even though they do the work on a voluntary bases, without receiving any form of incentive or any strategy that can motivate them to keep doing the good work.

### **2.5 Perceived support for Community home-based caregivers**

Providing care for people living with HIV/AIDS is a demanding and exhausting work. Most of the community home-based care organisations rely on few voluntary caregivers who are severely over-worked. They are on the front line, dealing with the epidemic, and they need to be supported in their work, so that they may continue giving quality care to people living with HIV/AIDS (Kathuri-Ogola et al., 2014).

#### **2.5.1 Family support**

Kangethe (2009), conducted a study in Botswana on the critical coping challenges facing caregivers of person living with HIV/AIDS and other terminally-ill people. The results showed that caregivers receive inadequate support from friends, neighbours, private individuals, as well as grassroots traditional and political leaders and other service delivery networks such as NGOs and CBOs. The author further reported that the relatives and family members of the PLWHA do help them wherever possible, but get very little assistance. Furthermore, they neglect or leave all the burden of caregiving in the hands of caregivers alone (Kangethe, 2009). It was also reported that family members of the ill patients are faced with the challenge of stigma, fear and uncertainty with the disease, and this can result in total reliance on the CHBCGs (Motswasele, 2008). Finally, it was reported that family members of the PLWHA refuse to cooperate with the CHBCGs by continuing with care in their absence. As a result, the caregivers felt overwhelmed and frustrated, more especially when they need to take their time off and leave their patients (Motswasele, 2008).

Qalinge (2011), found that the caregivers feel neglected and abandoned when they have to undertake all the care-giving work with very little assistance and support from the family members of their patients' family. The author further mentioned that this makes them feel unappreciated. The author further reported that the caregivers sometimes feel overwhelmed with the magnitude and multiple tasks they have to perform, which results in caregivers suffering from exhaustion, depression and psychological distress, head and body aches. Due to the little support that the CHBCGs receive from the family members, they fail to get time to complete their own errands, as they will have to be with the patients the whole day, taking care of them (Qalinge, 2011).

The CHBCGs observed the stigmatisation and discrimination that PLWHA experience. The stigma towards HIV/AIDS has resulted in PLWHA being hated and being seen as outcasts. This is because nobody wants to be near to such people, and many may feel as if it is impossible to take care of PLWHA. CHBCGs also experienced rejection from neighbours because they do not want to speak against people who are afflicted with PLWHA (Motswasele, 2008).

### **2.5.2 Government support**

Government and many other different organisations and community agencies develop and run CHBC programmes. Provincial and local government and national and international donor agencies have been involved in developing and administering CHBC programme, as well as providing them with funding and resources, so that the home-based caregivers can provide

quality care to people who are sick in their own homes (WHO, 2002). The support provided by the government includes funding and training.

### **2.5.2.1 Funding**

Funding is one of the most challenging experiences that the CHBCGs are faced with on a daily basis, when taking care of sick people. It is thus essential for the CHBC programme to be funded, so that it can be sustainable in the long-term. In some countries the responsibility of funding the programme in other countries is carried by the government, while in other countries it is done by the national or international donor agencies, NGO's and faith-based organisations (WHO, 2002; Akintola, 2008b). Qalinge (2011), reported that CHBCGs sometimes feel neglected and abandoned when they have to take care of people who are sick and receiving very little assistance and support from the government. The author further stated that this made them feel alone, unappreciated and overwhelmed (Qalinge, 2011). The situation is exacerbated by the high number of PLWHA per caregivers and the lack caregiving equipment such as surgical gloves, diapers, masks, antiseptics and basic medication, which has to be provided by the government (Qalinge, 2011). In South Africa, there only few CHBCOs that receive funding from the Department of Health or social services at national or provincial level. In addition, the salaries paid to the caregivers differ from organisation to organisation (Department of National Health, 2002).

Government assistance does not include the payment of any form of compensation to volunteers in their policies; however, some governments allow for stipends that cover the community home-based caregivers' costs (Akintola, 2008b). The study conducted by Mashau et al. (2015), revealed that community home-based caregivers do receive a stipend from the Department of Health. However CHBCGs were much concerned that it does not cover all their basic needs. It was further reported that the HBC imposes a burden to the home-based caregivers, as they sometimes have to spend the little money they have to serve the needs of the patients (food and medication) from the little stipend they get from the government (Kathuri-Ogola et al., 2014 and Mashau et al., 2014).

### **2.5.2.2 Training**

It is important for the CHBCGs to receive training before they can start with their work of caregiving to the patients (Qalinge, 2011). The HBCO, together with the government, is responsible for training the community members who volunteer to provide care for PLWHA (Mashau et al., 2014). The study conducted by Qalinge (2011), in South Africa revealed that most of the caregivers in his study were illiterate or had a low level of education. The author reported that the training was given only on an intermittent basis and to few caregivers.

In the study conducted by Mashau et al. (2015), it was found that the majority of CHBCGs did not have a grade 12 education, but they were able to read and write. The authors further found that most of them were trained but they were not receiving regular training to update their skills required to assist them in understanding the condition of the people that they were giving care to (Mashau et al., 2015). Cameron, Coetzee and Ngidi (2009), as cited by Qalinge (2011), reported that community home-based caregivers need training in home care, palliative care, infection control, psycho-social support as well as record keeping.

## **2.6 Coping strategies used by the community home-based caregivers.**

Mitrousi, Travelos, Koukia and Zyga (2013), define coping as "on-going cognitive and behavioural efforts to manage specific (external and/or internal) demands that are appraised as taxing or exceeding the resources of the individual". Kangethe (2009), defines coping as any action that the individual and animal takes when faced with the stressful events in order to lessen the threats to them. Stress is a state of tension felt in the presence of an object or a task that is presenting as a challenge to one's safety or self-esteem. Thoits (2011), defined coping strategies as the methods or mechanisms people use to deal with minor or major stress, trauma, pain and natural changes that they experience in life. Some of these strategies are unconscious, others are skills consciously mastered in order to reduce stress, while yet others are learned behavioural patterns used to cope with the situation. People are not always able to cope with the difficulties that they face, as not all coping mechanisms are equally effective.

CHBGs are faced with numerous challenges when caring for PLWHA. Kathuri-Ogola et al. (2014), reported that the majority of caregivers in his study adopted some strategies to cope with the challenges of caregiving and very few were struggling to cope. The coping strategies used by most CHBCGs as individuals include; prayers, withdrawing attention from the situation, developing a thick skin and hope.

### **2.6.1 Prayers**

The UNAIDS (2014), reported that the first thing that the CHBCGs mentioned when asked how they coped with the challenges they experienced when taking care of PLWHA, is that they talked to God through prayer and read the bible. Kathuri-Ogola et al. (2014), stated that most caregivers use prayer to seek divine intervention, so that they could perform their work well. The CHBCGs also went to church for spiritual support as a strategy to ease their minds when they experienced different challenges when working with PLWHA (Kathuri-Ogola et al., 2014).

### **2.6.2 Withdrawing attention from the situation**

Due to lack of competence, CHBCGs could not reduce or remove the pain and suffering that their patients go through, the CHBCGs had to watch many of their patients dying without being able to administer any pain-relieving life-saving medication (Akintola, 2008a). As a result, the caregivers had to suffer emotionally, feel discouraged and find it difficult to carry on with the job to such an extent that some even contemplated quitting. It was also reported that CHBCGs deal with these challenges by withdrawing their attention off the situation and paying much attention to other work and talking to their colleagues or religious professionals about it (Akintola, 2008a). Most home-based caregivers cope with the challenges by talking to each other about the challenges. For example, if someone amongst the home-based caregivers has grievance they sit down and talk it through immediately and comfort each other (UNAIDS, 2014).

### **2.6.3 Developing a thick skin**

Browning (2008) and Akintola (2008a) mentioned that due to poor remuneration, which did not satisfy all the needs of the caregivers, some of the CHBCGs do not stop giving care to their patients; rather they become more committed into their work and get used to the situation they experience every day in their working place. The study conducted by Qalinge (2011), revealed that some of the caregivers felt positive about the contribution they make. Most of the caregivers cope with the challenges they experience by making themselves strong and controlling their feelings, more especially when they were in the company of their patients (Snyder, Fauth, Wanzek, Piercy, Norton, Corcoran, Rabins, Lyketsos & Tschanza, 2015).

### **2.6.4 Hope**

Even though the caregiver feared death, feelings of helplessness, and feeling confused, there is a time where they used hope as a coping strategy, hoping for the best for their patients, that they will get better soon (Snyder et al., 2015). However, they found it difficult to cope with the poverty and the complex challenges they experienced when caring for PLWHA. Some of the CHBCGs from low social-economic status are driven by hope that one day it will lead to a paid job or other benefits (Qalinge, 2011).

## **2.7 Conclusion**

In dealing with the challenges regarding the health care for PLWHA, community home-based care has been identified as the best strategy for rendering quality care for PLWHA. The literature review reveal that many CHBCGs feel overwhelmed and wish to withdraw from the service due to the challenges they experience in the process of giving care. Challenges such as lack of resources, transport, supervision and support make it very difficult for the caregivers to provide quality care to their patients. Therefore, the community home-based caregivers should receive proper support that will assist them in reducing these challenges, so that they can feel motivated about their work and provide good and quality service for their PLWHA.

## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

### **3.1 Introduction**

This chapter covers the following aspects: research design, outline the target population as well as the setting in which the study had been conducted; sampling method and sampling procedures that was used. Furthermore, this section also focuses on the instrument and method that the researcher used to collect data, as well as the measures that were taken to ensure trustworthiness of the data collection instrument. Plan for data analysis and how ethical issues were observed to ensure safety of the participants will also be discussed.

### **3.2 Research design**

Research design refers to a plan or a blueprint of how one intends conducting the research (Corbin and Strauss, 2015). In this study, the researcher used qualitative research approach using the exploratory design. Qualitative research is a research method that obtains data in the form of descriptive narrative in order to understand a phenomenon from the perspective of the research participation and gain an understanding of the meaning of people give to their experience (Swartz, Delarey, Duncan & Townsend, 2008). This approach allows the researcher to gather an in-depth understanding of the phenomenon. The researcher used qualitative approach in order to obtain a deeper understanding through probing on the challenges that the community home-based caregivers experience when caring for people living with HIV/AIDS at Tsianda village on a daily basis.

Explorative design aims to establish facts, gather new ideas and determine whether there are patterns in the data (Corbin and Strauss, 2015). The researcher used an exploratory design, in order to gain more information on the challenges that community home-based caregivers at Tsianda Village encounter as they care for people living with HIV/AIDS on a daily basis.

### **3.3 Study setting**

The study was conducted at Tsianda Community home-based care organisation. Tsianda Community home-based care organisation is situated at Tsianda village in Makhado Municipality, Vhembe District, Limpopo Province, South Africa. According to Census (2011), Tsianda Village has an estimated population of 7,578 people (4141 females and 3437 males) and 188 households. Tsianda Village is divided into five communities; namely, ha-Mashamba, Tshifhahani, ha-Muhanelwa, Govha Magidi and Govha Thondoni. Each community has its own Headman. The headman which are all under the leadership of the Chief. The local

language spoken in this area is Tsivenda. Tsianda Community home-based care organisation is situated in Govha Thondoni along the Punda Maria road, about 24km from Thohoyandou business centre. The community members rely on Tshilidzini regional hospital, situated at Tshisaulu village next to the Limpopo College of Nursing Thohoyandou campus and Christ Worship centre, which are 11km from the study area. There is a government Primary Health Care institution where community members use. The government Primary Health Care institution is situated at the neighbouring village called Ha-Mutsha village, which is next to the tar road and about 1km from the study area. Tsianda Community Home-based care organisation is the only organisation around the village serving all the communities in the village. The organisation provides its services to PLWHA, people with disabilities, orphans and elderly people. The Tsianda community home-based care organisation consists of twenty-three caregivers, one manager and one financial co-ordinator. The organisation opens at 07h30 and closes at 16h30 and it operates during the week only.

### **3.4 Study population and sampling**

#### **3.4.1 Population**

Population refers to the abstract idea of a large group in many cases from which a researcher draws a sample and to which results from a sample is generalised (Neuman, 2011). The population of this study include of all community home-based caregivers working in Tsianda community home-based care organisation.

#### **3.4.2 Sampling**

According to Monette, Sullivant and Dejong (2011), sampling refers to the process of selecting a sample as a small portion or subject from defined population with the intention of presenting the particular population. The researcher used purposive sampling under non-probability sampling because of the special characteristics that the participant possessed. Brink, Van der walt, and Van Rensburg (2012), define purposive sampling as a method based on the researcher's judgement with regard to the subjects or objects that are representative of the topic being studied. Grinell and Unrau (2010), defined non probability sampling as a procedure in which all people, events or objects have unknown and usually different probability of being included in the sample. The researcher used purposive sampling in order to select the organisations after looking at the other organisation around the community and found that it is the only one dealing with people living with HIV/AIDS.

In this study, for a participant to be included in the sample, he or she was supposed to meet the following criteria:

- Be working at Tsianda Community home-based care organisation as a Community Home-base caregiver.
- Have at least six months' experience in caring for people living with HIV/AIDS.
- Be willing to participate in the study.

Managers, co-ordinators and community caregivers without any experience in caring for people living with HIV/AIDS were excluded.

Caregivers that met the set criteria were eighteen. The number of participants was determined by data saturation which were reached on the participants number eleven where by the participants were no longer giving new information. However, the researcher continued to collect data and stop at the participant number sixteen.

### **3.5 Data collection instrument**

The researcher collected data from participants through an unstructured interview guide with one central question which is **“what are the challenges do you experience when taking care for people living with HIV/AIDS”** (Appendix A). The interview guide comprised of guiding open-ended question that had allowed the researcher to probe for more information. The interview guide was prepared in English.

### **3.6 Pre-test**

The researcher conducted a pre-test with two caregivers from the population. The pre-test assisted the researcher to check if the study questions helped to get needed the information. The pre-test also assisted the researcher to rephrase some questions on the interview guide. The two participants selected for pre-test also formed part of the main study as they have given reliable information.

### **3.7 Data collection procedure**

After getting the ethical clearance and permission to conduct the study from the HBC manager, the researcher proceeded to make appointment with the participants for data collection. The

researcher made appointments with the participants and availed himself on the agreed time, date and venue convenient for the participants. The researcher conducted the individual interview in a private place and at a time convenient to the participants. All the interview sessions were conducted in Tshivenda language as it was the language preferred by the participants. The researcher developed rapport to make the participants comfortable. Individual in-depth interviews were conducted for approximately 45 – 60 minutes. The demographic information of the participants was also collected.

The researcher used various techniques such as taking field notes, observation and a voice recorder for data collection. The researcher used field notes and observation in order to record the non-verbal cues displayed by the participants during the interview, such as sighing and nodding. A voice recorder was also used with the consent of the participants, to record the conversation between the participants and the researcher during interview. The voice recorder was tested to check if it is working properly before it is used for data collection and the participants was shown a stopping button so that they can stop the recording whenever they are no longer comfortable with it.

### **3.8 Data analysis methods**

The researcher used the thematic analytical approach to analyse the data (Braun & Clarke, 2006):

- **Becoming familiar with the data**

The researcher familiarised himself with the depth and breadth of the content. He listened to the voice recorder and read through the entire data set at least once before coding, as the ideas, as well as the identification of possible patterns, was shaped in the process of reading through.

- **Transcription of verbal data**

Transcription of verbal data informs the early stages of analysis, and researcher developed a far more understanding of the data through having transcribed it. The researcher transcribed the verbatim of the interview of the audio tape exactly it has been spoken by the participants during the interview.

- **Generating initial codes**

The researcher initially coded and collated data, and make a list of different codes that was identified across the data set. The researcher sorted the different codes into potential themes, and collate all the relevant coded data extracted within the identified themes.

- **Reviewing themes**

The researcher devised a set of themes and also refined them. Some of the themes collapsed into each other, whereas others were broken down into separate themes.

- **Defining and naming themes**

The researcher had a satisfactory thematic map of his data. At this point, the researcher defined and further refined the themes that were analysed. The researcher identified the essence what each theme is about, and also determined the aspect of the data each theme captures.

- **Producing the report**

It is important that the analysis provides a concise, coherent, logical, non-repetitive, and interesting account of the story the data tell within and across themes. The write-up provided sufficient evidence of the themes within the data.

### **3.9 Measures to ensure Trustworthiness**

As a way of ensuring trustworthiness, the concepts credibility, dependability, transferability and confirmability was applied (De Vos., Strydom., Fouche., and Delport. 2013)

#### **3.9.1 Credibility**

It is correlated with internal validity and its main goal is to demonstrate that the enquiry was conducted in such a manner as to ensure that the subject was accurately identified and described (De Vos et al., 2013). To ensure credibility, the researchers prolonged an engagement with the participants through building trust and rapport in their own language and had actively participated in the collection of data. The researcher ensured that each interview takes approximately 45-60 minutes. The researcher ensured credibility through triangulation wherein he made use of multiple methods of data collections such as interview guides, voice recorder, fields note and observation during data collection process. The researcher also ensured credibility through member checking by re-interviewing the participants as a way of confirming the information that the participants shared during data collection.

### **3.9.2 Dependability**

It seeks to determine whether the findings are consistent if replicated with the same subjects or a similar context (Marshall & Rossman, 2016). The researcher ensured dependability by applying peer examination. The researcher also requested an independent coder to ensure dependability. The independent coder had also examine the findings, interpretations, and recommendations; and attest that it is supported by data. Member checking was conducted by doing a follow up interview in order to confirm the responses given by the participants during data collection.

### **3.9.3 Transferability**

Bryman (2016), stated that the description of data gathering must be inclusive enough to enable findings to be transferred to other situations. In other words, the descriptive interpretation from data analysis should apply to other areas. The researcher also provided a complete description of the research methodology, findings and verbatim quotes from individual interviews to ensure applicability of the study to other contexts. The researcher requested the independent coder to randomly read through selected transcripts and identify major categories, so that readers may have a clear picture of the findings.

### **3.9.4 Confirmability**

It emphasises freedom from bias in the research procedures and results (Marshall & Rossman, 2016). The researcher ensured confirmability by guarding himself against imposing his ideas on the participants in order to ensure accuracy, relevance and meaning. The researcher also used reflexivity through making use of field notes to identify the characteristics and elements relevant to the study and monitoring non-verbal cues. The researcher also analysed raw data and conclusions were formulated to ensure confirmability.

## **3.10 Ethical considerations**

### **3.10.1 Permission to conduct the study**

The researcher presented the proposal to the School of Health Science Higher Degree Committee for quality checking. The proposal was further submitted to the University of Venda Higher Degrees Committee for quality check and approval and then also submitted to University of Venda Ethics Research Committee for ethical clearance. After getting the ethical clearance from ethics committee, the researcher sent a permission letter (Appendix B & E) to conduct research to the Chief of Tsianda Village and the Home-based care organisation to conduct the study and the permission was granted.

### **3.10.2 Informed Consent**

The researcher used of the information sheet (Appendix C) in order to inform the participants about the nature of the study, the importance of the study and what is expected from them as the participants. The researcher also informed the participants about their rights to form part of the study as well as withdraw when they feel like they want to. The participants provided a written informed consent (Appendix D) as an indicator that they have agreed to form part of the study. The participants was also informed about the use of a voice recorder and was shown the stop button, so that they can stop the recording if ever they feel uncomfortable with the questions.

### **3.10.3 Confidentiality and Privacy**

Confidentiality is the ethical protection for those who are studied, by holding research data in confidence or keeping them secret from the public (Neuman, 2011).

To ensure confidentiality, the researcher ensured that whatever information he collected from the participants be kept confidential and only the researcher and the supervisors had access to the data. The voice recorder cassette was also placed in a safe place where no one can access it. The researcher also ensured privacy by asking for a separate office to be used during the interview process.

### **3.10.4 Anonymity**

According to Brink et al. (2012), anonymity is the ethical principle of not providing the identifying details of the participants on any research record

The researcher conducted field notes without the use of personal identification information of the participants. In addition, the researcher ensured anonymity as an ethical principle for the

study by make use of false names instead of names of participants so that the information remained anonymous. The findings were not displayed in public or in a way that can link specific individuals to it.

### **3.10.5 Voluntary participation**

The researcher explained the nature and importance of the study to the participants and informed them about their rights to or not to form part of the study, so that they could decide whether to participate or not, without forcing them. The participants was also informed that they could withdraw from the study at any time if they felt they were no longer comfortable with carrying on.

### **3.11 Dissemination of findings**

The final copy of the study was submitted to the library of the University of Venda, so that other researchers can use it for referencing. The results of the study will be presented at national and international conferences and published in accredited journals. A copy of the study was also submitted to the Home-based care organisation and the Department of Health.

### **3.12 Summary**

This chapter was about the research methodology. It covered different key areas, including, the research design study setting, study population and the sampling method that was used in selection of the participants. Data collection, data collection procedures were also discussed in this chapter. The method used to analyse data, measures to ensure trustworthiness and the ethical considerations, are also covered in this chapter.

## **CHAPTER 4**

### **PRESENTATION AND DISCUSSION OF FINDINGS**

## 4.1 Introduction

The chapter discussed previously outlined the research design and methodology. The purpose of this chapter is to present the findings of the study, the findings are prepared in terms of themes and sub-themes in order to reflect the participants views on the challenges they experience when taking care for people living with HIV/AIDS at Tsianda village.

The aim of the study is to determine the challenges experienced by community home-based caregivers caring for people living with HIV/AIDS at Tsianda Village. The objectives of the study were to:

- Explore and describe the challenges experienced by community home-based caregivers when caring for people living with HIV/AIDS
- Explore and describe the perceived support for Community home-based caregivers when caring for people living with HIV/AIDS
- Explore and describe the coping strategies used by the community home-based caregivers in dealing with the challenges they experience when caring for people living with HIV/AIDS.

Table 1, presents the demographic profiles of the participants. Sixteen caregivers participated in the study and the participants' age ranged from 34-57 years. Most were in the age range 30-39 (43.6) and 40-49 (37.5%). The majority (87.5%) of the participants were married and their highest level of education was secondary education. All the participants were working as caregivers and had more than six months' working experience with PLWHA.

Table 1: Demographic profiles of the participants

Variables	Number of the participants	Percentage
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<b>Age distribution</b>		
30-39 years	7	43.6%
40-49 years	6	37.5%
50-59 years	3	18.1%
<b>Marital status</b>		
Married	14	87.5%
Not Married	2	12.4%
<b>Working experience</b>		
9 years	5	31.3%
10 years	5	31.3%
11 years	3	18.8%
13 years	3	18.8%

## 4.2 Summary of study findings

The focus of the study was to determine the challenges experienced by the community home-based caregivers taking care for People living with HIV/AIDS, a case at Tsianda Village, Makhado Municipality, South Africa. Data was analysed using thematic analytical approach, which is detailed on the previous chapter. One main theme with five themes and sixteen sub-themes were derived from the data analysis summarized in Table 2.

Table 2: Themes emerged from the findings

Main themes	Themes	Sub-themes
4.2.1 Challenges experienced by community home-based caregivers.	4.2.1.1 Lack of resources	4.2.1.1.1 Lack of personal protective equipment 4.2.1.1.2 Lack of transport
	4.2.1.2 Financial problems	4.2.1.2.1 Low stipend 4.2.1.2.2 Irregular payments
	4.2.1.3 Patient-related problems	4.2.1.3.1 Lack of food 4.2.1.3.2 Death of patients 4.2.1.3.3 Fear of infection
	4.2.1.4 insufficient support	4.2.1.4.1 Inadequate support from Supervisor 4.2.1.4.2 Inadequate family support 4.2.1.4.3 Inadequate government support
	4.2.1.5 Coping strategies	4.2.1.5.1 Prayer 4.2.1.5.2 Withdrawing attention from the situation 4.2.1.5.3 Debriefing meetings 4.2.1.5.4 Developing a thick skin 4.2.1.5.5 Hope 4.2.1.5.6 Financial security

#### 4.2.1 Challenges experienced by community home-based caregivers

The community home-based caregivers described various factors as the challenges they experience when taking care for people living with HIV/AIDS on a daily basis. Five themes emerged as follows: Lack of resources, insufficient support, financial problems and patient-related problems and coping strategies.

#### 4.2.1.1 Lack of resources

Community home-based caregivers taking care of PLWHA at Tsianda village are experiencing a serious challenge of working without proper resources which makes it difficult for them to provide service to their patients. The following sub-theme were identified from the theme: personal protective equipments and lack transport.

##### 4.2.1.1.1 Lack of personal protective equipment

The findings of this study revealed that working without proper resources such as hand gloves and masks is very difficult and hazardous to health of the participants. The participants also indicated that they were sometimes unable to provide care to the patients because of lack of resources. They also mentioned during the interview that they are forced to wear condoms on their hands or plastic bags in the place of gloves, in order to assist their patients, as they could not leave them as they are.

Participant A said “**(Sad)** we do not have enough resources in our organisation and working without resources, more especially hand gloves and mask is very difficult and become hazardous to our health. Some of the patients are suffering from both HIV/AIDS and TB. You have to enter his room, where you have to take care of him without wearing mask (**silent a bit**). Eish to be honest this job has got lots of challenge.”

Participant F said “The main challenge is that most of the time we go to the field without gloves and you will find that the patient is vomiting, would you touch him with your bare hands? (**She asked, with eyes wide open**), we don't touch them without gloves because sometimes we also have to think about our health”

Participant M said “The main challenge that I encounter is the shortage of resources; we do not have enough resources in our organisation and this forces us to assist our patients while wearing condoms in our hands, in order to protect ourselves which is also not guaranteed”

Participant C added that *“In the situation in which I find myself without resources, and a participant needs my assistance, I will find plastic bags and tie them on my hands, so that I don’t touch the patient’s dirt with my bare hands. I should be safe”*

Participant D said *“My major challenge is that when I go to visit an HIV/AIDS patient and find that he has wounds which need to be cleaned, where as I do not have gloves, how will I assist him without such? (she asked), It means that I won’t be able to assist him.”*

The findings for this study revealed that the community home-based caregivers receive insufficient resources to enable them to provide effective home based services to their patients. Working without necessary materials makes it difficult and unsafe for the caregivers to provide quality care for their patients. WHO (2002), indicated that it is important that the CHBCGs are provided with the requisite supplier and equipment to enable them to carry out their work effectively. It was further stipulated that the CHBCGs must be supported by a team that is situated within the area, has access to health care centre supplies, is well managed and monitored and has in place proper record-keeping procedure, including home-based care kits. Community home-based caregivers are carrying on with their duties of taking care without proper resources, which increase the risk of getting infected by the disease that the patients may be suffering from. The study conducted by Kang’ethe (2010), revealed that the caregivers were stressed and demoralised because of the unreliability of care package facilities in the clinics. The author further reported that the care package offered to the caregivers by the clinics was inadequate, as it did not contain all tools which are necessary for caregiving, this has resulted on the caregivers to use their own money to buy components of the care package, such as gloves or napkins, or provide care without them. Nyaphisi and Obioha (2015), also reported that lack of personal protective equipment such as hand gloves to use in the process of helping the patient go to the toilet, bathing and turning them, places CHBCGs at risk.

#### **4.2.1.1.2 Lack of transport**

The participants indicated that due to lack of transport to take them from the organisation to the home of the patients, they fail to visit some of the patients staying who live too far away daily because they come home very tired. The participants also reported that they even walk for a very long distance in the hot sun, climbing big hills to visit a patient, which results in their body getting extremely tired, itchy and very sore at the end of the day. The Participants also reported that walking for a long distance to visit a patient makes them unable to go back and perform their house chores and complete their errands and all that they do is to take a shower and sleep.

Participant H said *“Some of our patients stay too far from our organisation, and we don’t have a transport to take us to there, so we are forced to walk for a very long distance without even an umbrella.”*

Participant N added that *“I walk for a very long distance to visit a patient, climbing very big hills. When I come back home I will be very tired, in such a way that I even fail to go and attend prayer meetings after work”*

This was confirmed by Nyaphisi and Obioha (2015) who found that community home-based caregivers often experience stress due to lack of resources within the organisation, such as transport, to can take them from the organisation to the patient in need of help. The authors further mentioned that due to lack of transport in the community-based organisations, the CHBCGs are unable to reach some of the patients living too far away from the organisation. Thus, the caregivers are forced to walk in extreme weather conditions for a very long distance. In the study conducted by Valjee and Van Dyk (2014), it was found that caregivers from some organisations felt that transport was their main challenge, as it could not always provided by the organisation. The researchers further stated that the caregivers complained that some of the places they conducted visit were not safe and very far from their organisation. Without transport, some of the PLWHA who live in remote areas cannot be easily reached or receive inadequate visitations. Furthermore the caregivers sometimes feel overwhelmed with the magnitude and multiple tasks they have to perform, which results in caregivers suffering from exhaustion, depression and psychological distress, head and body aches (Qalinge, 2011).

#### **4.2.1.2 Financial problems**

During the interview, the community home-based caregiver described how concerned they were about the amount of money they receive as they doing their work. The data collection revealed that the community home-based caregivers are receiving a very little stipend of which they receive after the period of three months. The sub-theme discussed below were identified from the theme: low stipend and irregular payment.

##### **4.2.1.2.1 Low stipend**

The study findings revealed that the community home-based caregivers receive a small stipend, which does not cover all the needs of their family. The participants complained that

the Department of Health is giving them money which they feel they do not deserve, considering the kind of job they do. The study findings also show that the caregivers become worried when they realise the workload they need to carry, compared to the amount of money that they receive.

Participant C said *“I receive a stipend of R1700. This money is not enough (**shaking head**) because it does not do anything at all. To tell you the truth, the children of Home-based caregivers will never be successful in their lives (**sad**) because as I am earning R1700 my children need better education, clothes, food and school uniforms. I also have my own needs; I should bath when I wake up in the morning and also smell good.”*

Participant I added that *“The money that I receive is not even enough considering the workload and the kind of job we do; it is a very big responsibility to bath a patient and treat his wounds without proper resources”*

Participant D said *“I only receive the thank you money which is not even enough at all, not at all (**shaking head**) it is so difficult to tell you the truth, as I am I have kids to look after, my husband is not even working, I feel like this money is not helping me at all.”*

According to the literature review, most of the community home-based care organisation rely on unemployed volunteers who usually unpaid or in few cases paid a stipend. The study conducted by Mashau et al. (2015), revealed that community home-based caregivers do receive a stipend from the Department of Health. However CHBCGs were much concerned that it does not cover their basic needs. The participants indicated that the job that they do is difficult, stressing and much more demanding compared to the stipend that they receive; so, it would be better if the government would increase the stipend they receive to R2500 or maybe give them permanent jobs rather than have them as volunteers for the rest of their lives. Kweneng and Stegling, (2001) as cited in Browning (2008), mentioned poverty as the main obstacle in the provision of care. The present researcher also found that most of the caregivers interviewed in the study complained that no one among them was holding paying job and most of them were not formally employed; hence, some of them were earning a small income through small-scale farming or running tuck shops (Kweneng & Stegling, 2001 as cited in Browning, 2008).

#### **4.2.1.2.2 Irregular payment**

The findings of the study also revealed that the participants that experienced much poverty because they sometimes received their stipend once in three months, meaning that they could

sometimes work for without getting paid. This was also confirmed by Kathuri-Ogola et al., (2014), who reported that caregivers visit patients, spending long days without remuneration, instead of looking for jobs that can pay them.

Participant L said *“We get paid a very small stipend after a period of three months and this is why our poverty is increasing instead of decreasing.”*

Participant M said *“The stipend that we receive does not come every month, sometimes it comes once in three months.”*

Participant O added that *“I can’t even see the value of the money that I receive because by the time I receive it, I will have to pay the debts that I have accumulated. Also, i receive this money after a period of three months, meaning that between these two months there will be no any income.”*

#### **4.2.1.3 Patient-related problems**

The data collection revealed that the community home-based caregivers are facing a serious challenge with regard to their patients. The participants revealed how frustrated they become when the patient refuses to take their medication due to hunger. The interview also revealed that the participants also feel touched when they see their patients getting very sick or dying. The sub-themes discussed below were identified from the theme: lack of food, death of the patients and fear of infection

##### **4.2.1.3.1 Lack of food**

The findings of the study revealed that participants sometimes use the little money they get to benefit the patient, which in turn increases poverty on the caregivers’ side and also stress them. Community home-based caregivers indicated that it breaks their hearts when they see a patients sleeping because of hunger, where-as he need to take his medication. The participants mentioned that they sometimes take maize meal from their homes and made a soft porridge for the patient, so that he/she can take his medication.

*Participant B said “sometimes the participant tells us that we should bring them lunch box from our homes because they feel that the food they eat at home makes them sick. This gives me a lot of pressure and stress, thinking about where I will find the food because where I am coming from there is no enough food.”*

Participant M said *“you know it also breaks my heart when I hear my patient saying that she did not take medication because there was nothing to eat, I feel touched about this and take the last money I have and use it to buy bread for the patient.”*

Participant O said *“I am a poor person and sometimes I will have to share the little I have with the patient so that he can be able to take his medication.”*

Participant F said *“with this little money we receive, sometimes you will visit the patient and find that he does not want to take his medication, when you ask him why he will tell you did not eat anything. This situation forces us to use the little we have to buy bread for them, so that they can take their medication and life goes on. We are doing so much for this government but still it does not realise it or appreciate our by work increasing our stipend or at least promoting us to become permanent caregivers. Sometimes you can tell yourself that you won't buy anything for the client, but when you look at him you will feel the pain and get touched that you need to do something for so that the client can eat and take his medication”.*

Participant P added that *“Sometimes I will look around trying to figure out what I can give to the patient to eat before he can take his medication and i will not find anything, meaning that I should go back home take some few maize meal that I could can find to make soft pap for him, so that he can take his medication.”*

Participants L said *“some of our patients will be saying that they do not have food and ask us to bring them food when we visit. It pains me when I also see that there is nothing I can help with because even me I don't have what the patient need”*

In the study conducted by Kang'ethe (2010), it was found that majority of the participants were poor and did not have any other source of income to support themselves. The present researcher further mentioned found that almost all of the participants reported the challenge of lack of adequate and necessary nutrition for their patients. It was reported that the home-based care organisation imposes a burden on the home-based caregivers, as they sometimes have to spend the little money they have to serve the needs of the patients (food and medication) from the little stipend they get from the government (Kathuri-Ogola et al., 2014 and Mashau et al., 2014). The researcher further found that community home-based caregivers experience frustration and feelings of helplessness when they are unable to meet some of the basic needs for PLWHA such as food and clean water. The current study revealed that the community home-based caregivers receive a little money sometimes after three month. However they get touched and use it towards the needs of the patients, so that he/she can take his medication, which also increases the pressure and poverty on their side.

#### 4.2.1.3.2 Death of the patients

The study findings also revealed the participants experience emotional challenges and psychological stress when they have lost a patient. The participants reported that working as caregivers makes them build a strong relationship with their patients such as siblings. They added that they worry a lot and even fail to sleep properly whenever they see their patients getting sicker or dying. In addition, the participants reported that a death of the patient makes them experience a great loss and pain inside their hearts.

Participant C said “**(with a voice very low and looking down)** you know what, these people (patients), we take them as our own relatives, when the patient dies you can feel within your soul that something is gone; someone is gone because you would already have built a good relationship with them; you will plan a day with your patients that you going to be sharing stories but when you arrive there to find that the patient is very sick or has passed away, you become sad and experience headaches for the whole day, stressing about the death of the patient.. You feel like it is not happening. This job is so painful, uh uh uh (with **sad** and **shaking head**). ”

Participant E said “I feel a lot of pain and experience a great loss in my life, as if one my own of my siblings has passed away. I assist them and get used to them as if they are my own relatives”

Participant M said “I feel very bad about the death of my patient. It is just that there is nothing i can do when a person is dead, and sometimes I feel like that I did not do enough work to assist him.”

Participant F added that “**(Shaking head)** ey! It is very painful to lose a patient more especially one in your care, it is very painful because when you assist a patient, the main purpose is that you want him to live. One of my patients died during December holiday, when we were on leave. He died because no one was taking care of him. Sometimes when we went to visit him we would find him sleeping and we would know that he was sleeping because he was hungry. Then we would quickly buy him bread and stir it up so that we could give him to eat and take his medication. This patient was found very sick by a relative and taken to hospital, where he passed away. I really blamed myself that I should have gone to check on him, even when I was on leave. Maybe he would have not passed away. I couldn't sleep during the first week because I was very close to this patient”

According to WHO (2011), taking care of people who are sick, particularly PLWHA, is an emotionally challenging task; it may result in depression, anxiety, anger, frustration, excessive guilt, sense of lack of competence and self-blame. The CBCGs often develop a strong bond with their patients during the caregiving process and this has a devastating effect when they lose their patients (Akintola, 2008a). Caring for PLWHA has got its challenges brought about the patients' condition and their functional level (Ramuhaheli & Erasmus, 2012). The community home-based caregivers experience a great loss when a sick person dies and they also experience sadness, grief and anxiety about the family left behind, especially if there are children (UNAIDS, 2000 in Nyaphisi & Obioha, 2015). Kathuri-Ogola, et al., (2014) reported that most of the caregivers often experience sleeping problems, anxiety, persistent headaches, feelings of frustration, loss/increase of appetite and poor concentration.

During the interview, the participants reported that they sometimes watch a patient dying. They reported that they when it happens they cannot even eat or sleep for days. The participants reported that even though they watched the patients dying, they do not receive any counselling from the health officials such as social workers or psychologist.

Participant A said “**(Sad)** *I still remember the other day a patient died in my hands when I went for a visit. I became very stressed and hurt, I went two days without food appetite.*”

Participant E said “*I sometimes witness my patients dying, this makes me feels somehow. It sometimes develops a feeling of quitting this job because what we see in this job is too stressful and traumatising.*”

Patient M added that “*This job has a lot of challenges; sometimes I will witness the patient dying and still not given any counselling by social workers or psychologist.*”

The findings for this study revealed that the community home-based caregivers are negatively affected by the death of their patients, more especially when they are dying in their hands. The participants mentioned that they sometimes watch their patients dying which as a results leave them traumatised and yet no counselling was given to them, just to show that the government cares about their emotional well-being. Counselling helps the caregivers to come to clutches with the reality of the situation, makes him/her feel she or he is not going crazy, implants hopes and confidence, and makes him/her free to seek support and share with others, with the results that the psychological or emotional burden is reduced (Kang'ethe, 2010). WHO (2011), also reported that some of the CHBCGs witness deaths, which leaves them in emotionally drained, yet no counselling programmes are given to assist them. Thus they will have to seek help from other sources on their own.

#### 4.2.1.3.3 Fear of infection

The participants complained that working without resources is very risky. They mentioned that working without proper resources makes them develop fear that they might also get infected with HIV/AIDS or TB.

Participant M said “.....*We work without proper resources which also put our life at risk of having HIV and TB.*”

Participant F said “**(shaking head)** *Mxm, working without resources makes me fear that I might also get infected. This makes me go to clinic all the time to get tested if I am still healthy. There is a time when I got sick and suspected that I might be having TB, I went to clinic and get checked but I was lucky it was not TB but just flu.*”

Participant A added that “*Eish, I feel putting my health at risk of being infected by HIV/AIDS. (Shaking head), there was a time I once treat the wounds of the patient with my bare hands and I felt very bad about it but there was nothing i could have done because the patient needed me and I could not leave him just like that.*”

Patient O added that “*You know, sometimes you will be given a patient who is suffering from HIV/AIDS plus TB, and you are supposed to assist him even though you don’t have a mask to cover your face. I was once given an MDR patient (person who is very sick from TB), to accompany him to the hospital and I was not even aware of it. When I arrived at the hospital, it came as a surprise when the Doctor said this patient is a serious MDR and they (doctor and nurses) quickly took hand gloves and masks to put on but did not give us any. Imagine this person was vomiting and I used to clean up his mess without being aware of it, I was very scared that I might also be infected.*”

Participant D said “*I would visit the participant who uses nappies in the evening and find that the nappies have not been changed since morning or the day before. This meant that i should remove them and put new ones, I would do it without a mask on my face. The smell would not be good for my health.*”

Participant C said “*People suffering from this disease (HIV/AIDS), when they get sick, they also get TB, are you aware of that? (She asked). You have to enter his (patient) room, where he be sleeping, you start by opening the windows and they will ask you why you are opening windows. You will have to explain to him that it is important to wake up and open the windows for fresh air in the morning. Sometimes we tell them that we (participants) are afraid that we*

*might be also sick and we might infect you with our diseases and make you to suffer worse, I say this to make it sound nice to the patient, when I know fully well that the person who is at risk is me (participant) because I am the one entering his room.*

Community home-based caregivers are confronted with considerable and huge risk in reflection to health and safety risks. They do their work under a threatening conditions and are also exposed to infections. Lack of personal protective equipment such as hand gloves to use in the process of helping the patient go to the toilet, bathing and turning them, places CHBCGs at risk (Nyaphisi and Obioha, 2015). Mashau et al., (2014) stated that the health and safety of the caregiver is of paramount importance while taking care of people living with HIV/AIDS. The authors further stated that the CHBCGs are at risk of being infected with TB and HIV when they come into close contact with the patients who have sores and the vomit of the patient, without appropriate personal protective equipment's (PPE). A study conducted by Mashau and Davhana-Maselesele (2009) revealed that caregivers experience emotional difficulties such as fear of contracting HIV and TB while proving care to people living with HIV/AIDS. Ramuhaheli & Erasmus (2012), reported that the community home-based caregivers can contract diseases such as TB and HIV while on duty if not appropriately covered and protected by gloves and also compromised their own safety for the sake of their own patients. The present study also revealed that the participants are working without proper personal protective equipment, such as masks and hand gloves which puts their health at risk of getting infected with the diseases that the patients may be suffering from. The participants work in fear every day, that they might also get infected. This is why they are using condoms and plastics bags from different shop in an attempt to deal with the challenge they are coming across. The participants also indicated that they are also afraid of developing the skin cancer as they are more exposed to sunlight when walking for a long distance following the patient.

Participant I said *“walking in the sun light for a long distance to visit a patient put our health at risk of having disease such as skin cancer”*

#### **4.2.1.4 Insufficient support**

The participants complained about the low level of support they received when taking care of people living with HIV/AIDS. The findings further revealed that participants do not get enough support from their supervisors, family of the participants and the government. The following sub-themes were identified from the theme: supervisor, family and government.

#### **4.2.1.4.1 Poor supervision from supervisor**

The study revealed that very few participants get support from their supervisors, and the majority of participants mentioned that they do not get support with regard to the work that they do. The participants further reported that when they are in need of advice from the nurses they are told to just continue working using their to their own ideas. The participants indicated that in such situations they just assist the patient using their own knowledge and they would not be sure if what they are doing is the right thing or not.

Participant F said *“we work without getting any supervision, when I am stuck I call the nurses to assist me and they will tell me that I should leave the patient or just use my own idea. This makes feel like I am all by myself in this job”*

Participants L added that *“some of the challenges we come across in the field require us to call the nurses from our local clinic, but will be told that we should just work according to our knowledge.”*

Qalinge (2011), reported that most caregivers rarely receive supervision by the health care professionals and felt inadequately equipped without guidance while doing their work. The study conducted by Kangethe (2009), in Botswana, also shows that caregivers are not receiving enough supervision from the health care personnel. As a result, they end up using their own instincts when giving care to the PLWHA. The majority of the participants also reported that they do not get enough supervision from the nurses at the local clinic; hence, some of the challenges they come across will require them to get information from the nurses. They reported that they just assist their patient without any proper knowledge and guidance. They mentioned that whenever they are stuck they call their manager and coordinator and inform them about the challenge, so that they can offer them some assistance. Some of the participant also indicated that their manager sometimes go with them where there is a challenge and help in addressing the challenge experienced.

#### **4.2.1.4.2 Inadequate family support**

During the interviews the researcher found that the majority of the participants receive a very little assistance from the family members of the patient. However, some participants reported that the family members assist in bathing the patient and turning them on the bed; hence, some will only be there when caregivers are doing their job. The majority of the participants

complained that the family members tend to reject and leave their patients into their hands, which also puts them under a lot of pressure, as they will have to work for many hours in order to monitor the patients' situation. The study findings also revealed that the way the participants leave patient yesterday will be the same when they visit the next day. The community home-based caregivers complained that they have to perform lot of work, assisting one patient, which in turn leaves them very tired at the end of the day.

Participant A said *“Some of the family members do assist us, for example, with turning the patient on the bed and bathing them but some do not help at all. They do not care about the condition of the patient because the way you leave the patient on Friday will be the same way you find him on Monday. His room will not be cleaned, didn't bath for the past two days and the plates that he used for his food will still be there. This makes me to stay for a long time assisting one patient and also make me feel tired at the end of the day which makes me fail to perform some of my duties at home”*

Participant M said *“Some family members will not assist you with anything; we are suffering from high workload and they are there. I will have to do everything, starting from cleaning his room up to bathing him and feeding him alone. Sometimes I go home very tired, I will even faint to go and attend some of the things, such as ladies prayer in our church.”*

Participant G added that *“Some families leave their patient to us and do not want to assist us with anything, which means that if we do not visit, we will find the participant the same way we left him the previous day. Sometimes we would go for training for maybe a week or two, when we come back his room will be very dirty, and smelling with left overs with worms.. Hey we come across difficult situation to be honest.”*

Participant D said *“Some families do not want to get involved; they just like watching us do the job. To be honest, this does not treat me well at all. They will only assist you by showing you where the patient is. They tend to leave the patient to us and want us to be the ones doing everything, they don't even bother to wake up and bath their patient or even open the windows, they will wait for us to arrive and do everything. If the patient uses nappies, he won't be changed until we arrive. Sometimes I fail to attend some of the things at home which needs my attention because I take all the time and give it to the patient the whole day, when I go home I will be very tired, meaning that what I will have to do is to take a shower and sleep”*

Participant E said *“The family members of the patient does not do anything to show us support, instead they will push and reject the patient as if he is not a relative and make him ours. They separate themselves from him. I feel a lot of pain about this thing, it makes me work even*

*more extra hours trying to monitor the participant's situation because once I leave his place I know that there is no one who will take of him."*

The findings of the study revealed that the caregivers came across the challenge of high workloads as a results of lack of support from the family members of their patients. The patients experienced a serious challenge. Akintola et al. (2013) reported that the community home-based caregivers experience a pressure and feel very tired as a results of a heavy workloads they carry out on their daily basis. the study conducted by Kangethe (2009) at Botswana, it was found that that caregivers receive inadequate support from friends, neighbours, private individuals, as well as grassroots traditional and political leaders and other service delivery networks such as NGOs and CBOs. The author further reported that the relatives and family members of the PLWHA do help them wherever possible, but get very little assistance; they neglect or leave all the burden of caregiving in the hands of caregivers alone. It was also reported that the family members of the PLWHA refused to co-operate with the CHBCGs by continuing with care in the absence of the caregivers. As a result, the caregivers felt overwhelmed and frustrated, more-especially when they needed to take some time off and leave their patients (Motswasele, 2008). Due to the little support that CHBCGs received from the family members, caregivers also failed to get time to complete their own errands, as they had to be with the patients the whole day, taking care of them (Qalinge, 2011).

During the interview, the participants reported that it pained them when they saw how some of the family members treating their patients. They reported that the patient would be given his own cup and plate specifically for him, for fear that they could also get sick if they shared the same cutlery with the patient. The participants revealed that some of the family members found it difficult to understand and accept the sickness of the participant, of which hurt their patients even more and also their health to deteriorate. In the study conducted by Motswasele (2008), it was found that family members of the person living with HIV/AIDS are faced with the challenge of stigma, fear and uncertainty with the disease, and this can result in total reliance on the CHBCGs.

#### **4.2.1.4.3 Inadequate government support**

The study findings revealed that the government was providing the participants with a stipend of R1700 and resources such as hand gloves, Nappies Training and workshop. However the participants indicated that all these resources that the government was proving were not enough. The participants also complained that the money that they received is very little, compared to the work load that they needed to carry out on a daily basis. Due to the small

stipend they received, the participants mentioned that they feel like the government does not care about their feelings.

Participant A said *“The government is only assisting us with stipend of R1700 and the resources that we receive through the clinic. The problem is that the resources we receive are not enough. For example, sometimes we run short of resources and we will have to utilise plastic bags and condoms as the hand gloves.”*

Participant G said *“...Is the government giving me any support? (**She asked looking at the sky**). No I don't see any kind of support I receive from the government. This job is too much and the government is giving me a stipend of just R1770. I do a lot difficult work here, which and it is stressing. Out there we are coming across many challenges. Hence the government is not doing anything much about it. The government should have at least increased our stipend, so that we can also feel motivated in doing our work.”*

Participant M said *“This government of ours, to tell you the truth, does not appreciate our hard work because it neglects us like it does not know us. We work very hard and get a very small stipend”*

Participant L added that *“Yah neh....speaking from my side, I don't see any kind of support that the government is giving to us. We get paid a very small stipend after a very long time, we work without resources; we are the ones who need to be creative and use plastic bags and wear condoms on our hands in order to assist the patients.”*

Participant D said *“(Silent a moment....) Haaay, the government is not doing anything to give us support; it should have already created permanent employment for us. It is not doing anything except giving me a stipend with which it is expecting me to live for 50 years earning it. Sometimes I feel like does not care about our feeling. It should already have increased our stipend into something better just to show appreciation”*

Even though the participants indicated that they receive a stipend and resources such as masks and hand gloves, they reported that they do not get enough resources and the money that they receive is too little considering the job that they perform on their daily basis. They indicated that they are forced to work without gloves, masks and even transport that can take them from the organisation to the homes of the participants. However the participant revealed that even though there is no resources they still continue to go to work and help their participants. They added that they wear condoms or tied plastic bags around their hands so that they could carry on with their duties. The study conducted by Mashau et al. (2015), revealed that community home-based caregivers do receive a stipend from the Department of

Health. However CHBCGs were much concerned that it does not cover all their basic needs. Qalinge (2011), reported that CHBCGs sometimes feel neglected and abandoned when they have to take care of people who are sick and receiving very little assistance and support from the government. The author further stated that this made them feel alone, unappreciated and overwhelmed.

It was also revealed that the government runs workshops and training; however the participants complained that it takes time for them to be given such workshops which are meant to increase their skills and knowledge about their work and how they can deal with all the challenges they come across, the participants also indicated that they sometimes work according to their instinct when they come across various challenges at work. Some of the participants mentioned that they can't even remember the last time they went to a workshop.

Participant E said "It has been a very long time since the government took us to a workshop, the last time we went for workshop was in 2016. This makes us work without proper knowledge in some of the challenges we come across."

Participant F added that *"Tjo, I can't even remember the last time we went to training, I think the last time I went to training was last year (2016) and this gives us problems when we come across some challenges at work we do not know how we should handle them. Sometimes the patient will ask us difficult question in relation to HIV and we do not know what to say. It's every embarrassing"*

The literature review indicated that it is important for the community home-based caregivers to be given training before they start with their work of giving care to the patients (Qalinge, 2011). Trainings will empower and equip volunteer caregivers with additional skills, confidence and in some instances opportunities for formal employment (Kang'ethe, 2010). Training may also assist them to do their jobs properly because they would be able to understand and clearly explain the scope of their practice to the people receiving their services. It was reported that most of the community home-based caregivers were illiterate and were also trained on an intermittent basis. It was further found that the majority of CHBCGs did not have a grade 12 education, but they were able to read and write. Mashau et al., (2014), mentioned that it is the responsible of the community home-based organisation and the government to ensure proper training for the caregivers. In relation to the study findings, Mashau et al., (2015), reported that most of the CHBCGs were trained but they were not receiving regular training to update their skills required to assist them in understanding the condition of the people that they were giving care to. Cameron, Coetzee and Ngidi (2009), as cited by Qalinge (2011), reported that community home-based caregivers need training in home care, palliative care, infection control, psycho-social support as well as record keeping.

#### 4.2.1.5 Coping strategies

The study findings revealed that the participants had their own strategies to use when dealing with the challenges they come across when taking care of PLWHA. It was also revealed that the participants tend to adopt various coping strategies as a way of coping with the everyday challenges at their work place. According to Kangethe (2009), coping is any action that the individual and animal takes when faced with stressful events, in order to lessen the threats to them. Stress is a state of tension felt in the presence of an object or a task that is presenting as a challenge to one's safety or self-esteem. The theme is further discussed under the following sub-theme: prayer, withdrawing attention from the situation, debriefing meeting, developing a thick skin, hope and financial security.

##### 4.2.1.5.1 Prayer

The findings of this study revealed that the participants make use of prayer as a way of coping with the challenges they come across when doing their work. They also reported that when they are stressed by their work they pray and ask God to intervene. The participants also reported that after when they have experienced a death of the patient they hardly sleep at night and spend some few days without eating. However, they have indicated that they have indicated that they pray and ask God to give them strength, so that they can be able to cope better and continue providing care to their patients.

Participant A said *"I prefer praying whenever I am experiencing some difficult time at work, I also pray for the patient when I see that he is very sick so that God can intervene, I just believe that there is nothing impossible with God and he is also the reason why he chose me to be the one taking care for these people."*

Participant E said *"there is nothing that I do except praying, I lay each and every situation I come across on the hands of God so that he can be able to interfere and also set me free from stress."*

Participant F added that *"I believe that God only knows, as for me I prefer praying, some of the things are beyond a human power and control like when you see the pain that the patient is going through, there nothing you can do, I just pray about it so that God can intervene"*

Participant G said *"I pray and put every situation on the hand of God hoping that he is the one with the solution of everything and that he will intervene and give me new strength"*

The findings of the study revealed that the community home-based caregivers uses prayer as a way of coping with challenges at work. They believe that God is the only one who can assist them in the situations which are beyond their control. UNAIDS (2014), reported community home-based caregivers mentioned that they use prayer to speak to God and also read the bible as their first response, when asked how they cope with the challenges they come across in taking care of people living HIV/AIDS. A study conducted by Kathuri-Ogola et al. (2014), revealed that most community home-based care givers uses prayer to seek divine intervention so that they can be able to perform their work well adequately.

#### **4.2.1.5.2 Withdrawing attention from the situation**

During the interview, the participants reported the death of a patient as the most painful thing that makes them struggle to cope when they are faced with it. However, they indicated that they fight by all means to find something to keep them busy as a way of withdrawing attention from stressing too much.

Participant A said *“sometimes I will go home and find something that can keep me busy up until I get tired and sleep so that I can be able to not think about what happened.”*

Participant K said *“I try by all means to take my mind away from what happened at work, I keep my busy with doing the house chores and playing with my children”.*

Participant L said *“you know in this work, we work in pairs of two, so whenever I have a challenge we will try to find something that we can talk about in order to forget about what happened at work, sometimes we tell our manager who will invite all other caregivers and speak about the situation”*

The literature review confirms that community home-based caregivers may suffer emotionally, or even feel discouraged and find it difficult to carry on with their duty after observing the pain that the patient is going through or even death of the patient. Akintola (2008a), reported that CHBCGs deal with these challenges by withdrawing their attention off the situation and paying much attention to other work and talking to their colleagues or religious professionals about it.

#### **4.2.1.5.3 Debriefing meetings**

The participants also mentioned that they group together and sit down as colleagues with the manager and speak about the situation up until they feel like they are strong. The findings of

this study revealed that the community home-based care manager will try by all means to sit her staff down and try to comfort them and give them courage and motivation to go on.

Participant H said *“Death of the patient is of the most thing that gives me stress, imagine you were talking very well with the patient on the previous day and midnight you receive a call from one of the patient’s family members reporting to you that the patient has passed away. You will not even go back to sleep but our manager will group us as colleagues and try to talk to us about it, comforting us so that we can be able to accept and not cry in front of the family members.”*

Participant C added that *“If we have a patient who get very sick and end up dying, we tell our manager, she will try by all means to comfort us and encourage us to be strong for the sake of the remaining family members of the patient more especially children”*

Participant E said *“I will sometimes have to witness my patient dying and get traumatised, this makes me feels somehow, and I sometimes develop the feeling of quitting this job because what we see in this job is too much. Our managers will be the one who will sit down with us and try by all means to comfort us and make us strong.”*

The participant indicated that they sit down as the organisation and have a debriefing meeting with their supervisor to ease the pain of loss so that they can be able to cope better with the pain of a patient. This was in contrary with the finding of the study conducted by Valjee and Van Dyk (2014), who reported that majority of caregivers felt that they were not appreciated or supported by their organizations, and did not have sufficient managerial support. This often affected their ability to do their jobs.

#### **4.2.1.5.4 Developing a thick skin**

During the interview with the participants, it was revealed that participants turn develop a thick skin and continue to work even when they come across various challenges at their work place. During the interview, the participants complained about the stipend that they received from the government, which it is too small and it cannot meet their basic needs. They indicated that they felt that there is nothing that they can do about it except to be strong and accept whatever they were getting and carry on with their duties

Participant A said *“There is nothing I can do about this, all I do is to be strong and carry on with my everyday work”*

Participant E said *“To tell you the truth this job is difficult, it just that I am used to it, even when you are hurt or worried about some of the things which are not going well, you will just have to be strong and not show it to your patients”*

The findings of the study revealed that despite the little stipend, which did not satisfy all the needs of the caregivers, some of the CHBCGs do not stop giving care to their patients; they rather become more committed into their work and get used to the situation they experience every day in their work place. Most of the caregivers coped with the challenges they experience by making themselves strong and controlling their feelings, more especially when they were in the company of their patients (Snyder, et al. 2015).

#### **4.2.1.5.5 Hope**

The participants were concerned about the minimum support they received from the family members of the patients and government. They reported that the family members of the patient neglect their patients and expects the caregivers to do everything for them without any assistance. The participants further indicated that they always kept hope that one day their patients will be able to get better and rise again and be able to be independent.

Participant L said *“even though I don’t receive any support from the family members of the patient, I do not stop giving care to my patients because I always hope that he will one day be able to rise up and be independent again”*

Participant A said *“it is very much painful to work without being assisted in this job, but there is nothing that I can do, I just hope that the patients I am assisting will get better and be able to rise on their feet again”*

Participants M added that *“it stress me a lot when working without any assistant from the family members of the patient but I always work with hope that my God is able, he will assist me to assist my patient to stand up and be independent”*

The findings concur with, Snyder et al., (2015), who reported that even though the caregiver feared death, feelings of helplessness, feeling confused, feeling neglected and abandoned by family members of the patients, there is a time where they used hope as a coping strategy, hoping for the best for their patients, that they will get better soon.

The findings of for this study also revealed that the participants were concerned about the little stipend that they received. They emphasised that it does not fulfil all their basic needs. However, the participants also indicated that even though they come across such challenges,

they do not stop taking care of their patients because they hoped that everything will be okay one day.

Participant E said *“I always have hope that one day the government will see us with a good eye and give us permanent position and also receive a salary not a stipend”*

Participant F said *“I just believe that God is seeing us struggling, he is the one who sent us to go and assist people, I have hope that the same God will also touch who ever have the authorities and give us permanent positions where we will be paid salary but not a stipend”*

Participant C said *“It has been long working as a volunteer, I worry about the amount of stipend I receive but I just believe that one day the government will give us permanent position and start receiving a visible salary”*

Participant A added that *“I believe that one day is one day, the government will hire me as a permanent employee and also receive a salary not stipend”*

The findings of the study revealed that the participants worry about their positions of working as volunteers and that they receive a small stipend. However they also hoped that one day the government will hire them as employees who will receive a salary, not a stipend. UNAIDS (2010), reported that the community home-based caregivers are motivated to take care for their patients by a hope for a well-paid income, compassion, a sense of religious duty and also a self-interest. Some of the CHBCGs from low social-economic status are driven by hope that one day it will lead to a paid job or other benefits (Qalinge, 2011).

#### **4.2.1.5.6 Financial Security**

Even though a few participants complained that the government was giving them a very small stipend, the majority of them mentioned that they feel that the money which they receive makes difference in their lives because they would not find it anywhere if they were just sitting at home doing nothing. Some participants also reported that the stipend that they received from the government also helped in motivating them to keep on carry on with their work. The respondents indicated that they also received motivation from their managers, who always gave them support and encouraged them to carry on doing their job

Participant H said “*The government give me stipend which also gives me the courage to wake up in the morning and go to work, even though it is not enough I feel that I am not the same as a person who is not getting anything during month end*”

Participant P added that “*There is nothing more give me strength except the money that I receive because there is no one who can come and give me this stipend if I am just sitting home*”

The findings of the study revealed that the remunerative that the community home b-based caregivers received also motivate and give them courage to go to work regardless of the various challenges they come across. Friedman et al, (2010), mentioned that care-giving to people living with HIV/AIDS with lack of incentives, rewards and recognition is often demotivating and demoralizing. The author further reported that incentives could include giving stipends, bonuses, supportive words, food items, toiletries, relieving somebody before he or she gets overwhelmed, allowing caregivers to work in turns, and monetary payments (Friedman et al, 2010).

### **4.3 Summary**

This chapter was about the discussion of the findings of the study. Raw data was analysed and reduced into themes, and sub-themes, in order to reflect the view on the challenges that the community home-based caregivers experience when taking care of people living with HIV/AIDS at Tsianda village. The participants for this study were given false names in order to keep them anonymous. The findings for this study revealed that the community home-based caregivers taking care for people living with HIV/AIDS at Tsianda village are experiencing various challenges on a daily basis when giving care. The challenge of shortage of resources, such as transport and personal protective equipment (hand gloves and masks) was identified as major challenge and was associated with caregivers working with the fear of putting their health at risk of being infected with diseases. The caregivers who participated in this study were those having more than six months experience in caring for people living with HIV/AIDS.

## **CHAPTER 5**

### **LIMITATIONS, CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1 Introduction**

The previous chapter discussed the data analysis in relation to the challenges experienced by community home-based caregivers taking care for people living with HIV/AIDS at Tsianda village. The discussion of the study findings was controlled by the literature from several authors opposing and supporting the findings. This chapter focus on the limitation, conclusion and recommendations based on the study findings of the study.

## 5.2 Limitation of the study

This study focused on the challenges experienced by the community home-based care taking care for people living with HIV/AIDS at Tsianda Village. This could affect the generalisations of the study findings to other caregivers outside the area and the organisation. The researcher encountered some challenges when it came to setting appointments with the participants, due to their busy schedule. Some of the participants would tell the researcher to come and conduct an interview on Saturday morning, but when the researcher called to confirm the appointment on the Saturday morning, he would be told that they were going to attend a funeral and will come back late and reschedule for another Saturday, which was a bit time-consuming for the researcher. The participants preferred that interviews be conducted in their own homes, which were too far from the organisation and tar road. Thus the researcher had to walk for a very long distance to reach them. This resulted in the researcher arriving for the interviews very tired.

## 5.3 Conclusions

The study concludes that the community home-based caregivers were experiencing various challenges when taking care for people living with HIV/AIDS. Community home-based caregivers were more concerned about lack of resources, ranging from transport and personal protective equipment such as gloves and masks that they used when taking care of the patients. The participants also felt that they were putting themselves at risk of being infected with diseases such as HIV/AIDS and TB. The community home-based caregivers sometimes wore condoms on their hands and also tied plastic bag in attempt to deal with the challenge of lack of personal protective equipment.

The study further revealed that the community home-based caregivers receive a stipend of R1700, of which they were concerned that it is too small in such a way that it does not meet all their family and personal needs. The community home-based caregivers were also had to buy bread or bring food from their home to feed the patient which in turn increase their poverty and pressure. In addition, caregivers sometimes had to wait for three months to receive this stipend.

The study concludes that community home-based caregivers get used of their patients and build strong relationships with them which results on them experiencing emotional disturbance when they see the patient getting sicker or dying. The caregivers sometimes witnessed the

death of the patients, which made them feel a great lost, self-blame, having sleeping problems, loss of appetite and also feel incompetence in terms of doing their work hence because there is no counselling given to them.

It was also noted that the caregivers experience a serious challenge in terms of supervision, which results in them getting stuck at work. This made the caregivers more confused and work without being sure whether what they were doing is right or not. The community home-based caregivers are also experiencing serious challenges with regard to the support they get when taking care for people living with HIV/AIDS. They are faced with heavy workloads and working for extra hours due to lack of support from the family members of their patients. Furthermore, the family members neglect their patients and leave the patient in the hands of the caregivers and let them do everything. This results in the caregivers getting too exhausted, which made them fail to perform their own house chores at home and not perform some of their errands such as attending the women's prayer.

Though the government sometimes took the caregivers for training and workshop, it was problematic that the government was giving them workshops or training after a very a long period of time to update their skills and knowledge about their work. This made caregivers to work according to their instincts, as they would not know what to do when confronted with some difficulties at work.

The findings of the study also revealed that community home-based caregivers experienced various challenges, which had a negative impact on their personal life, physical and psychological well-being. However, even though the caregivers experienced such challenges, they continued going to work and providing care for people living with HIV and AIDS. The community home-based caregivers used various coping strategies, such as prayer, withdrawing attention from the situation, debriefing meetings, developing a thick skin, hope and financial security.

It was noted that community home-based caregivers rely on prayer to seek God's intervention in some of the challenges they felt like they were beyond their control. The community home based caregivers struggled to cope with the death of the patients, but they tried to stop thinking about losing their patients or even have a debriefing meeting with the supervisors so that they accept and move on.

Even though the caregivers were concerned about the amount of money they received, some reported that they felt that the stipend gave them courage to wake up and go to work, as there was no one who can come and give it to them.

## **5.4 Recommendations**

The following recommendations are made based on the challenges mentioned by the community home-based caregivers.

### **5.4.1 Recommendations for community home-based Caregivers**

- It is recommended that the caregivers should get counselling from professional officials, such as social workers and psychologist following traumatic event for their emotional and psychological well-being.
- Since the CHBCG's complain about the lack of support from family members, it is recommended that the caregivers should explain their duties to the family members, inform them about their working hours.
- It is also recommended that community home based caregivers should negotiate with their managers to organise a support groups with their area social workers where they can be able to discuss their challenges and gain knowledge on how they can cope better with them.
- It is also recommended that the community home based caregivers regularly attend training and workshops, in order to gain more knowledge and understanding on the certain challenges that may disturb them when doing their job.

### **5.4.2. Recommendations for the Community home-based care manager**

- It is recommended that the community home-based care managers should try to develop ways of fund-raising, to buy umbrellas for the community home-based caregivers to cover themselves during on sunny and rainy days. The funds should also be raised to pay for transport to take the community home-based caregivers from the organisation to the homes of their patients, so that they can arrive there and perform their duties easily.
- Since the community home-based caregivers sometimes witness the death of the patients, it is clear that the caregivers suffer emotionally and may need psychological support, it is recommended that the community home-based care managers regularly

organise the support programme that will assist the caregivers with counselling services maybe for each and every three month so that the caregivers can be able to provide quality care to their patients without the burden of psychological problems.

- The managers should also organise clinic nursing professionals to provide the workshop and training to caregivers to empower them about the new information regarding HIV/AIDS and skills on how they can cope better with certain challenges that might interfere with the work that they do.

#### **5.4.3 Recommendations for the Department of Health**

- The DOH should create more workshops and training for CHBSG's more often, so that they can be also to learn and understand how to handle certain issues when working with the PLWHA and also get new update regarding HIV/AIDS.
- As the CHBCG's complained about working without proper resources, it is recommended that the DOH should take it into consideration to provide the CHBCG's organization with enough personal protective equipment for their safety and working without fear of being infected with virus diseases.
- It is also important for the DOH to create an event towards the end of the year that will be focusing on rewards giving as a way of motivation and appreciating the work that they are doing so, that they can also feel recognised.
- It is also important for the DOH to develop a program that will render a psychological support which include debriefing, individual and group counselling for the caregivers taking for PLWHA.

#### **5.4.4 Recommendations for further research**

This study focused at the challenges experienced by the community home-based caregivers taking care for PLWHA at Tsianda village in Makhado Municipality. The findings for this study revealed that community home-based caregivers taking care for people living with HIV/AIDS at Tsianda village are experiencing various challenges on a daily basis when giving care and were affected emotionally and physically by these challenges. The researcher therefore,

recommends that further research be conducted on the other areas and organisations in relations to this topic, so that the findings can be compared in order improve the generalisation.

## 5.5 Summary

This was a qualitative study, it was on challenges experienced by community home-based caregivers caring for people living with HIV/AIDS at Tsianda Village, in Makhado Municipality, South Africa. The study objectives were to explore the challenges experienced by community home-based caregivers when caring for people living with HIV/AIDS, describe the perceived support for Community home-based caregivers when caring for people living with HIV/AIDS, as well as to describe the coping strategies used by the community home-based caregivers in dealing with the challenges they experience when caring for people living with HIV/AIDS were achieved. The conclusion of this study is that community home-based care are experiencing various challenges in their everyday lives at their working environment. The recommendations were also made based on the various challenges that the community home-based caregivers experience in their working activities. Recommendation for future researchers to further research in relation to this study were also discussed in this chapter.

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## **APPENDICES**

### **APPENDIX A: INTERVIEW GUIDE**

**Title: “Challenges experienced by Community home-based caregivers caring for people living with HIV/AIDS: A case of Tsianda village, in Makhado Municipality, South Africa”**

#### **Demographic information**

1. How old are you?
2. Are you married?
3. What is your educational status?
4. What is your current position?
5. How long have you been working?

## Central Question

What are the challenges do you experience when taking care for people living with HIV/AIDS?

## Guiding questions

1. Describe the support that you get when you are caring for people living with HIV/AIDS?
2. What do you think are the coping strategies to deal with challenges that you experience when caring for people living with HIV/AIDS?

## APPENDIX B: LETTER REQUESTING PERMISSION TO CONDUCT RESEARCH

The Managing Director

Tsianda Community home-based care organisation

### RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I, Mulalo Mahlophe, a Masters Student at the Department of Public Health of the University of Venda hereby request for permission to undertake a study at Tsianda Community home-based care organisation. My research study is entitled: **Challenges experienced by community home-based caregivers caring for people living with HIV/AIDS: A case of Tsianda Village, in Makhado Municipality, South Africa.** This study has been prompted by the challenges that the community home-based caregivers come across when they caring for people living with HIV/AIDS, especially in rural communities.

Attached is the ethical clearance from the University of Venda. Arrangements with the participants will be made regarding a convenient time, to avoid interfering with their work.

Please do not hesitate to contact me for further details.

Yours faithfully

Mulalo Mahlophe

Cell: 0703 4034 185

E mail: mmahlophe@gmail.com

## **APPENDIX C: INFORMATION SHEET**

### **Dear Participants**

My name is **Mahlophe Mulalo**. I am a student at the University of Venda, registered for the Master of Public Health degree (MPH). My research focuses on the **Challenges experienced by Community home-based caregivers caring for people living with HIV/AIDS: A case of Tsianda village, in Makhado Municipality, South Africa**. You are kindly requested to take part in this study because your participation is very important in improving your working condition as the caregiver.

Research data will be collected by the researcher. Before data collection, I will explain the purpose, and the ethical principles to be adhered to. Furthermore, you as the participants will be required to give informed consent. I will use the interview guide as means of collecting information from those who meet the inclusion criteria. Data will be collected individually in a

separate office, to maintain privacy and also use codes rather than participants' real names to ensure anonymity.

In this research project participation is free and voluntary. You are allowed to withdraw from the project at any time should you feel uncomfortable or threatened in any way to continue participating in the study.

During the research I will ensure that the benefits surpass the risks. I will also ensure that no physical, psychological or emotional harm is inflicted on you during the course of the study. Other possible dangers will be looked at and the researcher will guard against them. In addition, in case you are harmed, the researcher will do follow up and refer you to appropriate health workers for treatment. Your positive response to participate in the study will enable the researcher to draw conclusions from the findings and be able to give recommendations that may assist the Department of Health to come up with appropriate measures that may reduce challenges experienced by Community home-based caregivers when taking care for people living with HIV/AIDS.

For more information contact Mahlophe M (Researcher)

Cell: 073 403 4185

Email: mmahlophe@gmail.com

## **APPENDIX D: CONSENT FORM**

I ..... confirm that the person asking my consent to take part in this study has told me about the nature, processes, and benefits of the study. I am aware that the results of the study including personal details will be anonymously processed into research reports. I have had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study. I have read and understood the contents and terms of this invitation to participate in this study. I am hereby declaring that I am voluntarily participating in this research.

Participant signature.....

Date.....

## **APPENDIX E: REQUEST TO CONDUCT RESEARCH**

University of Venda  
P.O Box X5050  
Thohoyandou  
0950

The Chief  
Tsianda Village  
Makhado Municipality  
Vhembe District.

Dear Sir

**RE: REQUESTING PERMISSION TO CONDUCT A RESEARCH IN TSIANDA VILLAGE ON CHALLENGES EXPERIENCED BY COMMUNITY HOME-BASED CAREGIVERS WHEN TAKING CARE OF PEOPLE LIVING WITH HIV/AIDS.**

I, Mulalo Mahlophe, a Masters' Student at the Department of Public Health of the University of Venda hereby request for permission to undertake a study. This is a requirement for the partial fulfilment of my degree of Masters in Public Health (MPH). The study is entitled: **Challenges experienced by community home-based caregivers caring for people living with HIV/AIDS: A case of Tsianda Village, in Makhado Municipality, South Africa.** This study has been prompted by the challenges that the community home-based caregivers come across when caring for people living with HIV/AIDS, especially in rural communities. HIV and AIDS places a significant burden on Community home-based caregivers who care for people living with HIV/AIDS, resulting in the caregivers being stressed and overwhelmed by their responsibilities

The study will involve the following:

Identifying the participants, giving of information to them about the aim of the study and eventually interviewing them individually. All information gathered in this study will be kept strictly confidential, and no information will be used for the purposes other than those it is intended for. A participant's decision to participate in this research will be voluntary and withdrawal from the study at any time will be allowed. Anonymity will be assured through the use of numbers instead of names.

I hope my request will be granted. Your assistance in facilitating the research will be highly appreciated.

Thanking you in advance for your assistance.

Yours faithfully

Mahlophe Mulalo

Student number: 11600035

Cell: 0734034185

Email address: mmahlophe@gmail.com