THE EFFECTS OF HOME-BASED CARE OF HIV/AIDS PATIENTS ON CAREGIVERS: A CASE STUDY OF MAFIKENG

by

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Dissertation submitted in fulfillment of the requirements for the Master’s degree in Social Work in the Faculty of Human and Social Sciences of the North-West University, (Mafikeng Campus)

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November 2015
DECLARATION
I declare that this dissertation submitted in fulfillment for a Master’s degree in Social Work has not been submitted for a degree at this or any other university. I also declare that all the sources I have used have been indicated and acknowledged by means of a complete list of references.

Funky Segomotso Tsheboeng..................................Date..................................
DEDICATION

This dissertation is dedicated with love and acknowledgement to my partner, Mr. Gregory Anthony July in the United States, who has been assisting me and very supportive, my friend Professor Collins Miruka for their utmost encouragement to date. It was not an easy exercise, but I managed through their encouragement. Above all, glory be to the Almighty God who gave me the strength to complete this research.
AKNOWLEDGEMENTS

My sincere gratitude and honour goes to the Almighty God, who gave wisdom and knowledge without compensation for the completion of this research.

Furthermore, I also wish to acknowledge and extend my special thanks and appreciation to the following people for their contribution:

Dr. Mariette de Chavonnes Vrugt, my supervisor, my mentor, my advisor, and guider, who tirelessly encouraged and supported me throughout the entire research period.

Professor Graser for his guidance at the initial stages of this research until 2011 when he retired.

Dr. T. Ratefane for the motivation and support when the Topic changed five times. She really believed in me, and assured me that the research will contribute positively to the HIV/AIDS studies.

Professor Phethlo-Thekisho for her friendly encouraging words especially when I was on the verge of giving up in this research.

Professor B.M. Setlalentoa for being a real parent who saw in me potential to an extent of affording me a chance of facilitating my admission for Master in Social Work

Professor Collins Miruka for his encouragement and support through imparting with the necessary research skills that enabled me to complete the study.

Professor Kgwadi for allowing me to register after the frustrations that I experienced with the Department of Home Affairs pertaining to my study permit.

All members of the Danville, Love Ministries and Lomanyaneng Home Based Care Caregivers for their cooperation and assistance during the research.
ABSTRACT
The aim of the study was to investigate the effects of home based care of HIV/ AIDS patients on caregivers. The following were the study’s main objectives: to explore the support systems available to assist caregivers; to investigate the challenges, experiences and stress encountered by the caregivers. A qualitative research method was used in the study to explore the support systems available for home based caregivers as well as their challenges during the process of care giving.

The study investigated factors contributing to the care process and factors contributing towards quality care of caregivers towards HIV/ AIDS positive clients which amongst others are; stress and burnout, gender dimension of caregivers, lack of training, lack of caregiver motivation or incentives, lack of caregivers involvement in decision making process and inadequate community support networks. The study also answered the researcher’s questions such as whether the caregiver’s contribution to the care process is highly marginalized and whether this really affects the quality of care, whether caregivers are overwhelmed, frustrated, stressed and suffer burnout due to lack of psychological support and whether lack of training caregivers contributes largely to poor service delivery.

The following were recommendations from the study in order to assist care givers to render quality, effective and efficient services to the HIV/ AIDS patients; offering caregivers a formal training, civil society participation, recognition of caregivers by the wider communities, involving caregivers in decision making, taking them to debriefing workshops and team building exercises and initiating Caregiver’s Support groups. There is also a need for supportive supervision from the managers and coordinators within the home based care setting.
LIST OF ACRONYMS

AIDS: Acquired Immune Deficiency Syndrome

ART: Anti-Retroviral Therapy

CBO’s: Community Based Organization

CCG’s: Community Care Givers

CHBC: Community Home Based Care

CNSA: Committee on a National Strategy for AIDS in USA

DOH: Department Of Health

DOT’s: Directly Observed Treatment

DTA: Domiciliary Therapeutic Assistance

HBC: Home Based Care

HBM: Health Belief Model

HCBC: Home Community Based Care

HIV: Human Immuno-deficiency Virus

HCT: HIV Counselling and Testing

NGO’s: Non-Governmental Organization

NDoH: National Department of Health

MSM: Men sleeping with other men

OVC: Orphan and Vulnerable Children

PHC: Primary Health Care

PLWA: People Living With HIV/ AIDS

UN: United Nations

UNAIDS: United Nations on AIDS

PMTCT: Prevention of Mother To Child Transmission
TB: Tuberculosis

UN: United Nations

UNAIDS: United Nations on AIDS

UNDP: United Nations Development Plan

USA: United States of America

WBOT’S: Ward Based Outreach Teams

WHO: World Health Organization

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CHAPTER 1
INTRODUCTION AND GENERAL ORIENTATION TO THE STUDY

1.1 INTRODUCTION AND BACKGROUND
Undeniably, medical facilities all over the world are burdened by the demand to care for chronically ill patients, including HIV/AIDS patients. Several organizations have addressed the problem of long term care by utilizing caregivers in different home-based care programmers. According to Ncama, (2005:33), a number of community/home-based care models and services have been actively trying to assist to eliminate the HIV/AIDS death rate in responding to this need.

Although positive outcomes such as feelings of reward and satisfaction do occur for caregivers, they still experience negative psychological, emotional, social and physical outcomes (Wright cited in Andrews & Boyle, 2007:23). This study focuses on the challenges and experiences of caregivers in caring for HIV/AIDS patients in Mafikeng, North West Province, South Africa.

Community members and different government departments recognise that family caregivers assist communities by caring for their loved ones who are HIV/AIDS positive and also provide financially in the care for HIV/AIDS positive patients. Today, there are sustainable and well rooted based care systems in most African countries (Spier and Edwards, cited in Uys & Cameroon, 2003:17). In Botswana, where most cases of HIV/AIDS is among the highest in Africa, the type of home-based care model adopted is the integrated home-based care model. The model ensures that there is a relationship between home-based care centers, HIV/AIDS positive patients and their families to ensure effective and quality care to HIV/AIDS patients (Spier and Edwards, cited in Uys & Cameron, 2003:17). It endeavors to enhance mutual support and collaboration between the different components, families, community caregivers (CCGs), clinics, and support groups, NGOs and Community / Home- Based Organizations (CBO).

Observably, caregivers are needed everywhere around the world as the role they play is crucial in the community. However, the countries differ in the way they support caregivers. Care giving plays a pivotal role in each and every family set up because a family is a system: if one family member is sick, the entire family will be affected. Appreciably, several nations of the “developed world” have addressed care giving through their legislative process. Countries that have legislated on care giving include Australia, Canada, Ireland, Israel, Japan, the Netherlands, United States, Sweden and the United Kingdom. This study
investigates the challenges, the contribution and the support systems available from the
community structures and government policies in place for health care giving as
implemented in developing nations in order to tap on those experiences for adaptation
(UNAIDS, 2012:15).

Care giving means caring for friends, relatives or any member of the community who has
health problems or disabilities and needs help. According to Andrews and Boyle (2007:
22), care giving is ensuring that the sick person is well taken off over a period of time until
that person recuperates. Undeniably, caregivers provide many kinds of assistance, from
grocery shopping to helping with daily tasks. According to Ahmed (2012:56), caregivers
are often utilized to assist the old, the sick and the terminally ill people including people
living with HIV/ AIDS. This is mainly because health services are quite strained and have
begun to buckle under the weight caused by the fast growing HIV/ AIDS cases in South
Africa. In South Africa, the prevalence of HIV/ AIDS for people aged 55-59 increased
rapidly between 2008 and 2012, from 7.7% to 12% among women, and from 6.2% to 6.9%
in men. There is a need for the Department of Health to strengthen its
prevention
strategies towards the scourge of HIV/ AIDS so as to minimise an increase in the HIV/
AIDS infection rate (Department of Health, 2013:15).

According to Spier and Edwards, (cited in Andrews and Boyle, 2007:55), the mounting
morbidity of HIV/ AIDS has placed an increasing burden on the already overburdened
South African health services. Because of the overburdened health services, the burden of
caring for HIV/ AIDS patients has shifted to the community and family. Furthermore,
people living with AIDS (PLWA) need “counseling, lots of personal contact, empathy and a
sense of belonging, (and) this can be given at home.” This shift eventually contributed to
the establishment of Home Community Based Care (Uys and Cameroon, 2003:18).

In this study, the focus is on the voluntary caregivers who are doing voluntarily work in
Mafikeng (North West Province) and with institutions like Home Based Care Centers and
some of them are receiving a stipend from the Government after a period of volunteerism.
The Department of Health in the North-West Province as well as the Department of Social
Development is funding the Home Based Centers: after a thorough assessment has been
done. The voluntary caregivers report directly to these Departments. Their stipend differs
according to their years of experience. Some receive an allowance between R1500 and
R2000 per month.
In Mafikeng, the changing demographics of the HIV/ AIDS epidemic caused a shortage of resources, workforce and services. To ensure effective primary health care, health facilities now incorporate voluntary services of non-governmental organizations (NGOs) and other organizations outside the health care institutions, as well as community organisations using volunteers. Therefore, volunteering does not happen unsystematically but is done in established settings that are either formal or informal, depending on the nature of the response to the need. Such settings include community-based organizations, church-based organizations, home-based organizations and hospices. This study focuses on HIV/ AIDS home-based and community-based organizations.

Home-based care (HBC) programme was first practiced in America and Europe when it was clearly discovered that hospital admission to HIV/ AIDS positive patients is costly due the fact that the HIV/ AIDS positive patients stay a longer period in hospital as compared to patients with other conditions. It is difficult for the families to assist their family members who are living with HIV/ AIDS and at times bedridden (Spier and Edwards, cited in Uys and Cameron, 2003:1). Andrews and Boyle, (2007:11) further state that because of the overburdened health services, the burden of caring for HIV/ AIDS patients has shifted to the community and family.

1.2 PROBLEM STATEMENT

South Africa has an extremely high percentage of people living with HIV/AIDS virus standing as even one of the highest in the African continent (Grabbe and Demi cited in Uys and Cameron, 2003:13). The statistics derived from Strydom and Wessels (2006:3) indicate that there are about six million infected out of a population that stands at forty nine million. The presence of the debilitating disease, linked with poverty and inadequate health facilities, hinders sustainable development and renders communities vulnerable.

Statistics South Africa (2013:15) indicates that in 2012, an estimated number of 6,422,000 people were living with HIV/ AIDS in South Africa. Out of this 6 million, females made up 34.7% while the male figure was 25.7% of cases that had accessed ART treatment. HIV/ AIDS-infected children aged 0–14 years and adults 50 years and older were under antiretroviral therapy, 45.1% and 42.7% respectively. Youth aged 15–24 years living with HIV/ AIDS had a lessor number of new infections of 14.3%. ART exposure in the HIV/ AIDS positive population aged 15–49 years was 28.9%. This revelation is indicative of the high exposure to HIV/ AIDS and the alarming number of young persons who are not receiving ART.
According to a survey study by the department of Health, 36,000 women attending 1,415 antenatal clinics across all nine provinces, the Department of Health (2013:25) found that 29.5% of pregnant women (aged 15-49) were living with HIV/ AIDS in 2011. The provinces in South Africa that recorded the highest HIV/ AIDS rates were KwaZulu-Natal, Mpumalanga and Free State. South Africa is one of the countries with the highest HIV/ AIDS cases in the world, but the infection rate now appears to have been stabilised among teenage girls as the rate fell from 15.9% in the 2005 survey to 13.7% in 2006, possibly indicating a decline in the rate of new infections (UNAIDS, 2012:6).

The HIV/ AIDS pandemic has changed the face of care giving (Mullan, cited in UNAIDS, 2012: 713). The care for an individual with HIV/ AIDS/ related disease is usually time consuming and burdensome. The condition of the patient is quite often difficult to predict and it is this aspect that complicates the care giving process. It is a condition that does not only stigmatise infected individuals, but also people who do not have HIV/ AIDS, i.e. caregivers who work directly with HIV/ AIDS infected patients. This deprives caregivers of the support and encouragement they expect from family and community. According to Daigle et al (1999: 575), the work is often a connection between the caregiver and very ill people and this requires considerable commitment and psychological strength in order to cope. The quality of care that caregivers provide and their ability to do care giving on daily basis depend on their physical and psychological wellbeing and the energy levels they have each day when they wake up.

Uys and Cameroon (2003:14) are of the view that although caregivers are seen as the key providers of care in the health system, limited support has been given by the South African Government to empower and capacitate these caregivers. Uys and Cameroon (2003:13) also argue that as the epidemic spreads, it overwhelms the capacity of the health services to cope with the situation as care giving for people living with HIV/ AIDS requires intensive care and there is shortage of personnel in health facilities. Caring for people living with HIV/ AIDS is usually done by the family and the community members. Some bedridden HIV/ AIDS patients may desire to stay home to receive care or alternatively to die. In some cases, people who are bedridden with HIV/ AIDS decide to stay home and to some extent wish to die instead of being taken to the clinic or hospital for further management of their HIV/ AIDS condition. This shows that caregivers are life saviours of these individuals and there is a need for more establishment of community home-based care programmes for people living with HIV/ AIDS. Caregivers are in most instances women or girl children willing to take care of the sick on full time or part time basis.
South Africa has a very high number of people living with HIV/AIDS and this challenge is exacerbated by the need to provide home-based care to such people. The central problem investigated is connected to exploring the support systems available to assist caregivers: to investigate the challenges, experiences and stress encountered by home based caregivers as well as their challenges during the process of care giving.

During the process of care giving, caregivers demand information and skills that will make them cope with their daily challenges during the process of care giving. Such information, when it is made available to the caregivers, helps them to feel more confident. This makes them feel very important and proud of themselves and they get an assurance that they are doing the best for HIV/ AIDS positive patients. Caregivers at the end instill hope to the dying HIV/ AIDS patients that they will never die as long as they keep on taking their anti-retroviral treatment as prescribed by the clinicians. (Russells and Schneider, 2001:215). There is anecdotal evidence that, training does wonders in coping and management of stress levels. Caregivers need to be taught and assured that the work they do is appreciated by the community so that they do not feel discouraged in what they are doing. They also need to be acknowledged on the hard work they do as care giving poses risk to them and expose them to HIV/ AIDS. Home-based care programmes have been established across the world and in South Africa to assist families in caring for people who are ill. However, these care programmes receive very limited support from the government (McInerney & Brysiewicz, 2004:23). Few studies in South Africa have documented the burden associated with care giving (UNAIDS, 2012:5). Very little is known about the stress, experiences and challenges that caregivers come across. According to Ahmed (2012:179), caregivers often present the extended, reconstituted, or even substitute family for people with HIV/ AIDS.

The study investigated factors contributing to the care process and factors contributing towards quality care of caregivers directed at HIV/ AIDS positive clients which amongst others are; stress and burnout, gender dimension of caregivers, lack of training, lack of caregiver motivation or incentives, lack of caregivers involvement in decision making process and inadequate community support networks.

1.3 AIM AND OBJECTIVES
The aim of the study is to investigate the effects that care giving of HIV/ AIDS patients has on caregivers in the home-based care programme.

The specific objectives of the study are:
• to explore the support systems available to assist caregivers of HIV/ AIDS patients.

• to investigate the challenges, experiences and stress encountered by the caregivers of HIV/ AIDS patients.

1.4 RESEARCH QUESTION
What are the effects of home based care of HIV/ AIDS patients on caregivers and to what extent do these home caregivers receive support from the community?

1.5 SIGNIFICANCE OF THE STUDY
The significance of the study lies in the fact that it explores the contributions of caregivers to the home-based care programmes and exposes the challenges, experiences and strategies employed in coping with the challenges. The study also identifies the training needs of the caregivers with the hope of strengthening the Community Home Based Care programmes as well as meeting their needs and challenges. The significance was also highlighted in a study of (Barjis et al, 2013:224) on a more related topic to the researcher’s. This is important as most literature on caregivers seem to attribute part of their working inadequacies to lack of training (Uys and Cameroon, 2013:50).

The research findings of this study are also important to confirm, augment or supplant some of the theories advanced in the care process. The research can also attract other researchers to the topic, thus helping to widen the scope of the research in the field of care giving. The information generated by the study can also assist policy makers formulate favourable working programmes, especially those addressing the needs of caregivers and clients. Identification of the gaps in the needs and capacities of caregivers can also assist donor agencies to contribute to home based care programmes.

The research study can assist both the Departments of Health and Social Development to intensify home-based care programmes and be able to equip the home-based caregivers accordingly. The result contributes to the existing knowledge and develops literature to understand the concept care giving. The insight and knowledge gained from the training should assist the home-based caregivers to render quality care giving which is proper and to cope with their work as they become well equipped and knowledgeable in what they are doing.
1.6 RESEARCH ASSUMPTIONS
The following assumptions inform the study:

- Caregivers are normally stressed during their duties of caring for HIV/AIDS patients. This due to the fact that the aftermath of the patient is known to them if the patient is not cured.

- Thence, the training of the caregivers on HIV/AIDS will reduce their stress levels.

1.7 DEFINITION OF KEY CONCEPTS

1.7.1 HIV
The virus that causes AIDS is an acronym for Human Immunodeficiency Virus. The HIV can be spread through contaminated body fluids, unprotected sexual intercourse with HIV/AIDS infected partner, during birth (mother to child transmission) and through blood transfusion or organ transplant.

1.7.2 AIDS
According to Van Dyk (2008:4), AIDS is an acronym for Acquired Immune Deficiency Syndrome. It is caused by the Human Immunodeficiency Virus. Immunity is when the body is able to resist the human virus and is strong enough to fight the virus. Deficiency refers to the fact that the body’s immune system is weakened to such an extent that it can no longer fight the HIV/AIDS virus. This ultimately gives a chance for the opportunistic infections to develop as the immune system is weakened. AIDS is the last stage of HIV/AIDS virus. Many people live longer with HIV without developing AIDS. The immune system is destroyed by HIV/AIDS gradually falling to levels that leads to the body succumbing to infections. The deteriorations are measured through blood testing and if it deteriorates to clinical level 4 with the blood level count known as CD4, the person qualifies for antiretroviral treatment. The cell count refers to the laboratory indicator of the deficiency of a person’s immune system and CD4 cells remain the strongest predictor of HIV/AIDS progression.

1.7.3 CAREGIVERS
Caregivers are people who take care of the sick patients either in caring institutions like hospitals, hospices, nursing homes, caregivers’ residences or the clients’ place of abode. In this study, the focus is basically on voluntary caregivers situated in Community Home Based Care Centers assisting willingly with or without any remuneration. According to
Gordon (1996:1), care giving sustains life and must be a way of life. Care giving arrangements are based on the project of giving and receiving care. Caring is a relationship between the one who provides the service and the recipient of such care to the extent that there is an almost symbiotic relationship that is nurtured.

Caregivers, therefore, may be formal employees like nurses, social workers, family welfare educators and formal volunteers who usually work formally under the direction of a central caring unit like a hospital or can be informal caregivers who usually support and care for their clients, either at home or the homes of the sick client without necessarily being directed by any caring institution.

Caregivers play an important role in providing home care for people living with HIV/AIDS. They provide care outside the formal health care setting but are not permanently employed. They also receive minimal financial compensation for their services (Uys and Cameroon, 2003:3). For the purpose of this study, caregivers provide care to siblings, parents, spouses and community members living with HIV/AIDS. Caregivers receive voluntarily or minimal remuneration known as a stipend.

### 1.7.4 BURNOUT

Majority of the work environment with a high workload has a psychological, emotional and physical impact on its employees and in this case burnout is the impact. According to Mashau et al (2009:41), burnout is defined as when a person who works with traumatic situations no longer has the skills to cope and requires the skills of a competent and qualified professional psychologist or a social worker trained on debriefing, stress and trauma management. Mashau et al (2009:41) further suggest that burnout entails both physical and emotional exhaustion. The caregivers experience such extremes in the course of providing care to HIV/AIDS patients and this often leads anxiety and disinterest to continue providing home-based care.

### 1.7.5 HOME-BASED CARE

Mashau et al (2009:41) defines home-based care as a system in place to assist people living with HIV/AIDS virus to cope with their condition and being managed well for quality outputs. In home based care setting, there is an assurance that the patient adheres to ART as the caregivers do monitor HIV/AIDS patients on daily basis and does pill count to ensure proper adherence to treatment.

According to Russels and Schneider (2001:4), home-based care is defined as the provision of comprehensive services which include health and social services by formal
and informal caregivers/ volunteers in the home based care centers or at the home of the patient. This ultimately promotes, restores and maintains a person’s maximal level of comfort. The patient’s social functioning and healthy lifestyle also get improved through the provision of home-based care. This practice is characterized by preventative, therapeutic, rehabilitative and long term maintenance services. All in all, there is also an aspect of palliative care that adds to the range of home-based care characteristics. It is an integral part of the community-based care.

Home-based care is the care that the consumer can access near to their home which encourages participation by people, responds to the needs of the people and encourages traditional community life and creates responsibilities for the people living with HIV/ AIDS by the community members (Ncama and Uys, 2006:13). Home-based care can be rendered to people with different illnesses, but for the purpose of this study, it is related to HIV/ AIDS patients. Although the words, home-based care and community home-based care are used interchangeably by various researchers, the present researcher uses the concept of home-based care in this study.

1.7.6...DEBRIEFING
Debriefing means an effective intervention to assist individuals or groups who have been exposed to some form of trauma. The goal of debriefing is to alleviate the likelihood of post-traumatic stress disorder. According to Mashau et al (2009: 41), debriefing is a process through which HIV/ AIDS home-based caregivers state their fears, describe their pain and narrate their problems to a professional psychologist who will ultimately assist them to get the required treatment.

1.8 LIMITATIONS OF THE STUDY
The limited education of some of the participants was identified in this study. With the interview schedules being written in English and the content of some of the items being abstract and not specific, it was difficult for some of the participants to fully understand and orally answer all questions comprehensively.

Another limitation was the length of the data collection instrument. Due to the limited time available to caregivers, some of the participants felt the research interview was time consuming. The interviews were done mid-day in most cases, in the months of September, October and November and these warm temperatures were not always suitable for the research participants who complained of excessive discomfort. The other limitation is that
findings obtained from 20 participants in one town cannot be generalized to the rest of the perceptions that caregivers hold.

1.9 DIVISION OF THE DISSERTATION

Chapter 1: Introduction and general orientation to the study

Chapter 2: Literature review/Theoretical framework

Chapter 3: Research methodology

Chapter 4: Analysis, interpretation and presentation of findings

Chapter 5: Discussion of the findings, conclusions and recommendations

1.10 CONCLUSION

This chapter presented the background of the research, problem statement, objectives, significance, and scope of the study as well as assumptions. The next chapter offers an overview of the literature pertinent to this study.
CHAPTER 2

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 INTRODUCTION AND BACKGROUND

This chapter reflects on the existing literature and theoretical framework in order to clarify the challenges associated with caring for an HIV/AIDS positive person. The roles and challenges of caregivers are explored and thoroughly investigate the findings of other researches on a similar and related phenomenon of offering care to HIV/AIDS patients, the experiences of caregivers during the process of care giving and the impact of caring for HIV/AIDS patients.

According to the Department of Health (2013:14), over 6 million black Africans in the African continent contracted HIV/AIDS in 2013, with over 30.9% receiving ART treatment. The percentage of ART exposure among people in the other race groups apart from the blacks was at 41.3%. There was no huge difference in the percentage of treatment exposure among all HIV/AIDS positive people living in urban and rural areas, 28.3% and 27.4% respectively. Rural informal settlements in the North-West Province showed a higher percentage of treatment exposure than rural settlements population (35.3% vs. 28.7%), but the difference is not statistically significant (Department of Health, 2013:14).

The fact that there are people who are living with HIV/AIDS in our communities and societies means that everyone in South Africa is affected by this pandemic. Caregivers though they are not professionally trained, takes the burden of care for HIV/AIDS patients (Naidu and Sliep 2012: 143). A study by Mashau et al (2009:40) states that the growing HIV/AIDS pandemic continue to make a huge impact on all the counties throughout the world. The study further indicated that globally, countries have responded to the HIV/AIDS pandemic by allocating money to fight the disease, but the impact is even greater in developing countries of Sub-Saharan Africa, including South Africa (Department of Health, 2013: 2).

Leake (2009:1) observes that Health Care services in South Africa are unable to cope with the increasing number of HIV/AIDS patients, and therefore patients are discharged earlier from hospitals to be cared for either at home or in a Home Based Care Centre. Some hospitals in South Africa are reported to have eventually decreased the patients’ average length of stay in hospitals from 14 days to just 3.5 days whilst referring patients to home-based care organizations. According to the (Department of Health, 2013:2), in South Africa,
HIV/ AIDS home-based care is almost always provided by the community volunteers who are unemployed.

Hunt, (cited in Van Dyk, 2008:5) stated in their study that care giving does not cause depression, nor did everyone who provided care experience the negative feelings that go along with depression. Furthermore, he found that in an effort to provide the best possible care for a family member or friend, caregivers often sacrificed their own physical and emotional needs and that the emotional and physical experiences involved in providing care could strain even the most capable person (Van Dyk, 2008:99). The feelings of anger, anxiety, sadness, isolation, exhaustion and then guilt for having these feelings can exact a heavy toll. The caregivers feel that they have an obligation to care for the sick relatives or friends. In the process, they get overburdened by the responsibilities, causing feelings of anger, exhaustion and sadness. This feeling of anger in turn makes them feel guilty. McInerney and Brysiewicz (2004:34) identified the negative psychological, emotional, social and physical outcomes that are likely to affect caretakers as the risk of infection, stigma, fear and the omnipresence of death. The authors made the observation that caregivers are usually women, and they are generally believed to be more caring and sympathetic than men.

The concern remains that most caregivers are neither well trained nor well educated on care giving and often lack formal and informal support. They are partly trained on how to recognise health problems. This implies that they are aware of conditions they can treat themselves. They are also aware of worsening conditions that are beyond their scope and they refer such cases for professional care. Since care giving is not an easy task, caregivers therefore need to be equipped with the knowledge and skills on how to take care of the HIV/ AIDS positive patient. They also need to be empowered and capacitated on psycho social management of the HIV/ AIDS patient, adherence skills as well as the overall counselling skills (UNAIDS, 2012: 16-19).

Amoteng, Kalula-Sabiti and Oladipo (2015:1) stated that, there has been a steady and unprecedented growth in research on the HIV/ AIDS pandemic since its discovery some thirty years ago. Their study demonstrates that more needs to be done to curb the pandemic. Connor (cited in Uys and Cameroon, 2003:3) indicates that care giving is stressful. Caregivers are prone to physical health problems as they handle HIV/ AIDS patients on a daily routine. In addition to the physical challenges, they are also exposed to emotional distress and psychiatric disturbances. This is further confirmed by Kelesetse (1998:223) who indicates that care giving also affects the economy of the family as more
resources are needed in caring the HIV/ AIDS infected person. There are some cases that the family will be compelled to spend more money on daily basis in purchasing items like pampers for use by a bedridden HIV/ AIDS patient. These are factors that tend to impact on the contribution of caregivers to the care process.

Since the incidence of HIV/ AIDS is often higher among the poor, Akintola (2004:45) contends that it becomes so burdensome for caregivers to witness the struggle of families to meet their most basic needs. The psychological and emotional stress is often compounded by the fact that the caregivers themselves work in the same stressful situation and some end up with physical strain. The UNAIDS (2012:29) concurs with the above statement in alluding to the fact that it is common for the caregivers to spend the entire day while conducting field work visiting their HIV/ AIDS clients without food. From the researcher’s point of view, caregivers on many occasions do not have money for transport to visit the sick clients or fetch their drugs in clinics and hospitals, buying stationery for record keeping and purchasing rubber gloves for handling sick clients. This undermines their ability to do their work and makes them feel inadequate. Sometimes their own families are resentful of the fact that they are working for little money (UNAIDS, 2012:29).

Ross cited in Russels and Schneider, (2001: 13), states that besides being preoccupied with personal hardships, the dependence of HIV/ AIDS programmes on donors is a constant source of stress to many caregivers. HIV/ AIDS management requires the basic care giving skills, knowledge on issues surrounding palliative care as well as commitment to HIV/ AIDS patients (UNAIDS, 2012:7).

During the process of care giving, caregivers demand information and skills that will make them cope with their daily challenges during the process of care giving. Such information, when it is made available to the caregivers, helps them to feel more confident. This makes them feel very important and proud of themselves and they get an assurance that they are doing the best for HIV/ AIDS positive patients. Caregivers at the end instill hope to the dying HIV/ AIDS patients that they will never die as long as they keep on taking their anti- retroviral treatment as prescribed by the clinicians (Russels and Schneider, 2001:215). There is anecdotal evidence that, training does wonders in coping and management of stress levels. Caregivers need to be taught and assured that the work they do is appreciated by the community so that they do not feel discouraged in what they are doing. They also need to be acknowledged on the hard work they do as care giving poses risk to them and expose them to HIV/ AIDS. Home-based care programmes have been established across the world and in South Africa to assist families in caring for people who are ill. However, these care
programmes receive very limited support from the government (McInerney and Brysiewicz, 2004:23). Few studies in South Africa have documented the burden associated with caregiving (UNAIDS, 2012:5). Very little is known about the stress, experiences and challenges that caregivers come across. According to Ahmed (2012:179), caregivers often present the extended, reconstituted, or even substitute family for people with HIV/ AIDS.

2.2 INCIDENCE OF HIV/ AIDS

2.2.1 Incidence of HIV/ AIDS in the world

According to UNAIDS (2013:13), by the end of 2013 an estimated 35 million people were infected by HIV/ AIDS. However, deaths as a result of HIV/ AIDS have decreased by 35%. Importantly, tuberculosis continues to be the leading cause of death among people living with HIV/ AIDS. New HIV/ AIDS infected children have decreased by 58% from 2001 and further decreased numerically under 200 000 in 21 predominantly affected states in Africa inclusive of South Africa (UNAIDS, 2013:13). Further, Asia and the Pacific were recorded to have the second largest population infected by HIV/ AIDS in the world from Sub Sahara which is the highest in the world, having an estimation of around 4.8 million of its population infected (Alcober, 2014:1). In the first report of its kind, the UNAIDS (2013:15) suggests that there is need to establish connections between a population’s exposure to the likelihood of infection and the regional location of such population. Some people are exposed to high risk while others, especially in developed economies, are apparently less at risk. The report also indicated that there is a need for an integration of the three intervention strategies which are prevention, treatment as well as care and support. The report ultimately recommends that attention ought to be directed on populations that are under-serviced and at higher risk of HIV/ AIDS. The report suggests that this is likely to lessen the incidence and impact of the AIDS epidemic.

“There will be no ending of HIV/ AIDS without putting people first, without ensuring that people living with and affected by the epidemic are part of a new movement,” said Mr. Sidibé, one of the research participants in WHO study (2010:12). “Without a people-centered approach, we will not go far in the post 2015 era.” According to UNAIDS (2013:16), countries and regions in Sub-Saharan Africa have multiple and varying epidemics. The UNAIDS report (2013:15) outlines that having country targets and sound policies in place creates space to address complex micro-epidemics with tailored, bite-sized solutions that help reach people faster with better HIV/ AIDS services. The UNAIDS report (2013:15) also note that cities and communities will play an increasingly major role in effective scale-up.
However, UNAIDS (2013:16) also indicated that there are a number of challenges associated with the HIV/AIDS pandemic. Data and information about the people most affected is difficult to establish. There is the stigma associated with such people that also exacerbates the lack of substantiated detail. Added to these foregoing observations are punitive legal environments, barriers to civil society engagement and lack of investment in tailored programmes that also curtail positive results. It confirms that countries that ignore discrimination and condone inequalities will not reach their full potential, and face serious public health and financial consequences of inaction. The report emphasizes the need for equal access to quality HIV/AIDS services as both a human rights and public health imperative. UNAIDS (2013:17) further reports that the lowest levels of new HIV/AIDS infections in 2013 were at 2.1 million in Sub Sahara. In the last three years alone new HIV/AIDS infections have fallen by 13% since 2013.

According to UNAIDS (2013:14), people living with HIV/AIDS who were initiated on ART in Western Europe and North America have increased by 51%, and in Latin America, by 45%. However, coverage of people living with HIV/AIDS was lowest in the Middle East and North Africa, at just 11%. New HIV/AIDS infections declined most in the Caribbean—by 40% since 2005. However, new HIV/AIDS infections have risen by 7% in the Middle East and North Africa and by 5% in Eastern Europe and central Asia since 2005 (UNAIDS, 2013:15).

According to UNAIDS report (2013:17), AIDS-related deaths reached alarming proportions in 2013. A 65% increase was recorded in the Middle East and North Africa. The only other region where AIDS-related deaths are increasing is Eastern Europe and central Asia, where AIDS-related deaths rose by 5% between 2005 and 2013. The UNAIDS report (2013:15) drives the point that there is need for urgent interventionist research into both prevalence and the national laws of affected states where the aim is to ensure that this promotes freedom and equality for all people. To this ends the advantages of home-based care are many and varied. This is because hospitals in many African countries cannot cope with the influx of HIV/AIDS cases.

The HIV/AIDS epidemic, however, has created a dramatically different picture of informal care. Persons who are HIV/AIDS infected in the United States are typically young, predominantly male, and often stigmatized for engaging in risky behaviour deemed unacceptable by their families and society. Friends, partners, neighbours, and co-workers are more intimately involved in caring for those with AIDS than is typical for most other chronic conditions (Pearlin et al 2015:10). According to Carlie (2000:753), many people living with HIV/AIDS were alienated from their families of origin long before they were
diagnosed. As a result, substitute families of choice are forged to provide the support and security afforded by a kinship network. Even those who retain physical and emotional ties with families of origin often redefine family boundaries to include their chosen kin. Many men assume primary care giving responsibilities for friends, partners, and traditional family members, providing greater levels of assistance than is common among caregivers for other conditions (Pearlin et al., 2015:11).

Andrews and Boyle (2007:2) stated that in the United States of America, more than 1.2 million people living with HIV/AIDS infection, and almost 1 in 7 (14%) are unaware of their infection. Homosexual, bisexual, and other men who have sex with men (MSM) particularly young African American men who sleep with other men are most seriously affected by HIV/AIDS. As a race, African Americans face the most severe burden of HIV/AIDS (Andrews and Boyle, 2007: 2).

### 2.2.2 Incidence of HIV/AIDS in Africa

The study investigated factors contributing to the care process and factors contributing towards quality care of caregivers directed at HIV/AIDS positive clients which amongst others are; stress and burnout, gender dimension of caregivers, lack of training, lack of caregiver motivation or incentives, lack of caregivers involvement in decision making process and inadequate community support networks.

According to UNAIDS (2013:15), determination of the prevalence and incidence of HIV/AIDS infection is detrimental in monitoring the scope of the HIV/AIDS epidemic. During the late 1980s, HIV/AIDS seroprevalence studies and surveys were conducted in most countries in Africa. Regardless of some problems, seroprevalence studies in many African countries continue to be important advocacy tools for securing or increasing support for HIV/AIDS prevention activities and contribute towards understanding the spread of the pandemic. According to Mulder et.al, (1994:89) there have been studies to determine the incidence of HIV/AIDS infection in Africa, for an example, the research by Kalipeni et al (2004) who investigated on the HIV/AIDS beyond epidemiology, mainly because of the lack of well-established cohorts, although data on incidence have recently become available. UNAIDS (2013:15) reviews HIV/AIDS seroprevalence and incidence reports from Africa, published or presented at scientific conferences in 1990, and provides a discussion on the interpretation and use of the data. The prevalence of HIV/AIDS antibody in Africa is discussed among general population groups, convenience samples of selected groups of individuals, pregnant women attending antenatal clinics, female prostitutes, STI clinic attendees, and hospital patients.
Academic and sociological research studies show that in sub-Saharan Africa, there are 76% of people on ART whose viral load has significantly gone down due to ART treatment. These individuals are unlikely to transmit the virus to their sexual partners (UNAIDS, 2013:18). According to UNAIDS (2013:14), for every 10% increase in ART treatment coverage, there is a 1% decrease in HIV/ AIDS new infections among people living with HIV/ AIDS meaning that ART save lives. The UNAIDS report further highlights that efforts to increase access to ART in clinics and hospitals are working. According to UNAIDS (2013:15), in 2013, 2.3 million people in Sub- Saharan Africa had access to ART treatment in clinics and hospitals. This brought the global number of people accessing ART to nearly 13 million by the end of 2013. (UNAIDS, 2013:19).

Amoateng et al (2015:131) reflected that 34 million people were living with HIV/ AIDS by the end of the year 2011. The impact of the disease on patients, significant others and society in general is significant. For example, HIV/ AIDS leads to financial, resource and income impoverishment, which places severe strain on individuals and households (Barnett and Whiteside, cited in Amoateng et al, 2015:131).

UNAIDS (2013:17) indicates that in July 2013, as many as 13 950 296 people were accessing ART. The Geneva Report eluded that only 15 countries account for more than 75% of the 2.1 million new HIV/ AIDS infections that occurred in 2013. The report also finds that there are three or four countries that bear the burden of the epidemic. In sub-Saharan Africa, just three countries, Nigeria, South Africa and Uganda account for 48% of all new HIV/ AIDS infections.

According to UNAIDS (2013:16), HIV/ AIDS prevalence is estimated to be 28 times higher in Africa among people who inject drugs, 12 times higher among sex workers, 19 times higher among gay men and other men who have sex with men and up to 49 times higher among transgender women than among the rest of the adult population. In sub-Saharan Africa, adolescent girls and young women account for one in four new HIV/ AIDS infections. The UNAIDS report (2013:17) investigated why certain populations are not accessing HIV/ AIDS services and outlines the urgent need to address their specific needs.

2.2.3 Incidence of HIV/ AIDS in South Africa

In a national HIV/ AIDS survey compiled by the Department of Health of South Africa (2013: 8), the researchers estimated that 10.9% of all South Africans over 2 years old were living with HIV/ AIDS in 2008. A high percentage of 16.9 was recorded among females between 15 and 49 years old, while the HIV/ AIDS prevalence among males is highest in those between
25 and 29 years old. Among males, the peak is in the group aged 30-39. According to these results, infected males aged 15-49 years old occupies a larger proportion of 58% as compared to other age groups, e.g. children under the age of fifteen years and adults over forty nine years old. Males are likely to be infected lesser than females in the same age group, 11.7% in men versus 20.2% in women (Department of Health, 2013: 26).

According to South African Government News Agency dated 30\textsuperscript{th} August 2015, President Jacob Zuma launched the national HIV/ AIDS, Counseling and Testing (HCT) campaign in April 2008 as part of government's accelerated HIV/ AIDS and Aids prevention and treatment plan. The objectives of this new alarm were to reduce the rate of infection by 50 percent by 2011, and to provide ARV treatment to 80 percent of those who need the treatment. The objectives as well as the goals of the HCT campaign are met. Up to so far as many people are now willing to do an HIV/ AIDS rapid test in large numbers and the HCT statistics has gone up. Other objectives of the implementation plan include more emphasis on prevention through information, education, widespread distribution of condoms and mobilization of millions of South Africans to know their status (South African Government News Agency: 30\textsuperscript{th} August 2015).

\textbf{2.2.4 Incidence of HIV/ AIDS in North-West}

According to SA Government News, dated 30\textsuperscript{th} August 2015, more than one million people have tested for HIV/ AIDS in the North-West as part of government's efforts to stem the pandemic. Provincial health department spokesman for the North-West Province, Tebogo Lekgethwane, said on Monday, 30th August 2015 that "the province's target was to achieve 998 859 tests, with the national target being 15 million."

"We are proud our province is the first in the country to achieve its target. We have so far tested more than a million since the campaign was launched last year," said Lekgethwane (Government News, 2015:2).

"In 2008, the national HIV/ AIDS prevalence among pregnant women attending ante-natal classes was 29, 3 percent across the country. In the North-West, the prevalence was 31 percent, with Dr. Kenneth Kaunda district municipality being the highest at 35 percent," said Lekgethwane (Government News, 2015:2).

"In our latest testing, we are seeing changes with HIV/ AIDS prevalence in pregnant women now at 30 percent. "Lekgethwane (Government News, 2015:2) added that the North-West
province has also established more Health Care facilities that are accredited to offer ARV treatment, and increasing ARV distribution sites from 29% to 80% (Government News, 2015:2).

Statistics from the UNAIDS report (2012:7) shows that in the North-West Province, the estimated HIV/ AIDS prevalence among antenatal clinic attendees is as follows:

Table 1: North-West Province: Prevalence of HIV/ AIDS among antenatal clinic attendees.

<table>
<thead>
<tr>
<th>Year</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV/AIDS prevalence (%)</td>
<td>29.1%</td>
<td>29.4%</td>
<td>29.3%</td>
<td>29.4%</td>
<td>30.2%</td>
<td>29.5%</td>
</tr>
</tbody>
</table>

(Retrieved from the Department of Health, 2013:15)

Clearly from the given statistics is the fact that there is an exceptionally severe epidemic of HIV/ AIDS in the North West Province. This epidemic affects the total population, though women and children are more likely to be infected or identified during routine attendance of antenatal services. The reason why the statistics show a higher number of females who are infected could be that women do compulsory tests during their ANC (antenatal) visits. Women are educated thoroughly during ANC visits and in some other forums including PICT (Provider Initiated Counseling and Testing): (UNAIDS, 2013:16).

2.2.5 Incidence of HIV/ AIDS in Mafikeng

In the unpublished District Health Information (DHIS) monthly report retrieved on the 1st September 2015 for Mafikeng Sub District the following were reported:

- 232 people were initiated on ART treatment for the month of August 2015
- 17,456 people are receiving ART
- 15 children were initiated on ART in August 2015
- 368 children are receiving ART treatment in Mafikeng Sub District
- 247 adults were initiated on ART in August 2015.
- 17,824 adults and children are receiving ART treatment in Mafikeng Sub District.

These figures raise similar concerns on the prevalence of incidents of HIV/ AIDS as a rising scourge. Amoateng, Kalule-Sabiti and Oladipo (2015:132) make similar observations and argue that caregivers experience immense psycho-social stressors while taking care of people living with HIV/ AIDS.
2.3. TREATMENT OF HIV/ AIDS

HIV/ AIDS can be perceived as a national disaster, being a major cause of morbidity mortality in East, Central and Southern Africa. Some of the HIV/ AIDS patients are taken care of either at hospice centers, home-based care centers or in their homes currently and this is a trend that might continue in the near future. In response to this demand, several home-based care programmes have been devised with the intention of providing care and ancillary services to HIV/ AIDS patients (Akintola, 2004:5). These services, in most cases, are provided by community members who are volunteers who have a passion to assist sick patients. The volunteers, at a later stage, graduate from being volunteers to being caregivers. In most instances they are rewarded with a stipend and taken to palliative care short courses by the Government after serving for a longer period as a volunteer.

Caregivers in Mafikeng face a number of challenges and negative effects associated with providing care to people living with HIV/ AIDS on a daily basis. The physical and emotional demands of caring are overwhelming and as a result, they lead to daily challenges and burnout.

2.3.1 Treatment of HIV/ AIDS in the World

According to Akintola (2004:15), there are one and half million people in the world who contract HIV/ AIDS annually. The number does not decrease but instead it escalates on an annual basis. Caring for AIDS patients is so costly and it has drained most governments. This led the health system to develop a policy that allowed HIV/ AIDS patients to be taken care of at home based care centers. In some instances, families are encouraged to care for them at home to allow other people with related chronic illnesses to HIV/ AIDS to be admitted in hospitals as bed occupancy for HIV/ AIDS patients was high.

Many patients prefer being at home as compared to being in hospitals (Akintola, 2004:15). Caring for people with HIV/ AIDS in the community can be a powerful way to break down prejudice and to inform and educate people about HIV/ AIDS. There are public and social sources of discontent which criticise home-based care as being simply an excuse for governments to opt out of caring for people with AIDS altogether. These critics suggest that many people with AIDS are not cared for and die from neglect, both in hospitals and at home. However, the reality is that home based care programmes are reasonable in prices as compared to when a patient is cared for at hospital setting (Akintola, 2004:16).
2.3.2 Treatment of HIV/ AIDS in Africa

According to Statistics SA (2012:12) and Strydom and Wessels (2006), in 2012, 68 percent of people living with HIV/ AIDS in sub-Saharan Africa had access to antiretroviral treatment (ART). Ten countries reported reaching universal access (at least 80 percent of adults eligible for ART) (WHO, 2010:13). The new WHO guidelines have increased eligibility criteria for ART by expanding the CD4 treatment initiation to 500 cells/mm3. In case of ART initiation in children under the age of fifteen, they automatically qualify for ART initiation immediately after testing HIV/ AIDS positive despite their CD4 count.

There are more people in hospitals who are admitted for HIV/ AIDS related ailments as compared to other chronic illnesses in East, Central and Southern Africa (UNAIDS, 2013:14). According to Kang’ethe (2010), in Zambia, the bed occupancy rate stands at 70% and Zambia should implement the referral system to the home based care centers so that at the end of each year, there is a decrease in bed occupancy rate for people living with HIV/ AIDS in hospitals (UNAIDS, 2013:15). Despite a dramatic increase in the provision of antiretroviral therapy in sub-Saharan Africa, there are disparities between regions as well as between individual countries. For example, ART coverage in Botswana is over 95 percent, but only 38 percent in the Democratic Republic of Congo (UNAIDS, 2013:16). Of the 21.2 million people living with HIV/ AIDS on the entire African continent (the vast majority in sub-Saharan Africa), only 7.6 million were reached by anti-retroviral treatment in 2012. (UNAIDS, 2012:14).

Moreover, even where the number of people receiving ART is on the increase, roughly 75 percent of the adults living with HIV/ AIDS in sub-Saharan Africa have not achieved viral suppression. (Kalipeni et al, 2004:2). This viral suppression has been linked to treatment gaps in the provision of ART. Observably, effective ART treatment reduces viral loads in people living with HIV/ AIDS.

Kalipeni et al (2004:15) further alluded that access to antiretroviral drugs is particularly low for certain groups. For example, children living with HIV/ AIDS in sub-Saharan Africa are only half as likely to receive treatment as HIV/ AIDS positive adults. The study by Kalipeni et al (2004:2) found that in 9 out of 21 countries that were the sample for the Southern African study, fewer than 25 percent of children living with HIV/ AIDS received antiretroviral treatment in 2012.
Moreover, adolescents (10-19 year olds) were the only group with an increase in AIDS-related deaths between 2001 and 2012. It was observed that AIDS-related deaths doubled between 2005 and 2012 in the same study (Kalipeni et al, 2004:2).

In Uganda, caregivers include not only community health care workers, for instance, community caregivers and community counselors, but also assistant nurses, enrolled nurses, staff nurses, professional nurses, assistant managers in nursing and matrons assist in issues of care work and ensure that there is an integrated service delivery plan in place to assist HIV/ AIDS positive people on daily basis with their challenges. The emphasis in this regard is given to those who have been admitted to the home-based care programme (Kipp, cited in Akintola, 2004:56).

There are several provisions for people living with HIV/ AIDS towards assisting them to cope with their HIV/ AIDS condition. They also may decide to be treated at home or at home based care facilities. There is an option for them to consult at outpatient department (OPD) in hospitals, to be treated in Wellness centers situated in various hospitals as well as to choose where they feel comfortable to be treated at. Hospitals have a good working relationship with the existing registered home based centers across the majority of hospitals in the world (Kipp, cited in Akintola, 2004:56).

Akintola (2004:22) describes the main functions of home based care centers, outpatient department and hospitals as follows:

In a hospital setting, the patients are assisted according to triage whereby those patients who are too weak will be assisted first and get admissions and those who are not too weak are attended and discharged. Some will be referred to home based care centers for further monitoring and management.

Outpatient departments deal with an ongoing system of allowing the HIV/ AIDS positive patients to be managed medically by ensuring that they come back every three months to be examined and accessed by the clinicians to ensure compliance to ART.

Home based care implies the care that is given to HIV/ AIDS positive patients outside the hospital environment. Palliative care, support systems are rendered by the caregivers in ensuring that the HIV/ AIDS patients are coping well and adheres to treatment (Akintola, 2004:23)
2.3.3 Treatment of HIV/ AIDS in South Africa

According to Maartens et al (2014:13), there are over two million South Africans who have been enrolled in Anti-Retroviral Therapy (ART). The ART programme in South Africa has been evidenced as the highest in the ART uptake globally. The effectiveness of ART programmed in South Africa is estimated to be at 81%. There is also evidence that ART prolongs life when it is taken accordingly. The life expectancy in KwaZulu-Natal has improved from 49.2 years to 60.5 years in 2011. This therefore means that the programme is working and is effective (Asner-Self et al, 2011:14).

The National ART Guidelines of the Department of Health (2013:25) stipulates that, it is imperative to discuss the patient’s willingness, ability and readiness to start ART. Patients should also be taught positive living, behavior change as well as adherence to ART. Patients should be well educated on the benefits of ART and explained thoroughly possible side-effects of ART. Clinicians should consider the nutritional status of the patient, the weight of the patient, co-morbidities and possible drug-interactions, and address any mental health and substance abuse issues if any(National ART Guidelines of the Department of Health 2013:25).

According to the National ART Guidelines of the Department of Health (2013:25), in a case whereby the child is the one receiving ART, a caregiver will be responsible to ensure that the child who takes ART treatment adheres to clinic appointments. A comprehensive nutritional, growth and development assessment for children and adolescents is vital and needs to be done on a quarterly basis before they are enrolled on antiretroviral therapy and throughout the process as long they are still enrolled on ARV programme. Behaviour change counseling and combination HIV/ AIDS prevention strategies should be emphasised including safe sex practice, availability and use of condoms (especially during pregnancy), contraception and future fertility.

Kaplan et al (2014:2) states that there is a lot of improvement when it comes to the Prevention of Mother to Child Transmission (PMTCT) programme in relation to HIV/ AIDS. 90% of all the newly diagnosed mothers are initiated in ART immediately after diagnosis in order to prevent the child from contracting the virus. There is no waiting period for them irrespective of the CD 4 count. The HIV/ AIDS infection rate has decreased with 67% from 2009 to 2012. The new PMTCT guidelines clearly stipulates also there the lives of the new born HIV/ AIDS exposed babies are prolonged despite the fact that they are being breastfed by the very HIV/ AIDS positive mothers. The ART eligibility criteria for children have been
revised and it has increased now to 67%. The South African Health Department introduced a third-line regimen of the ART programme (Maartens et al 2014:13). This was designed to assist patients who developed resistance to second line regimen of the ART treatment and moved to third line regimen.

According to Rebe and McIntyre (2014:14), the South African former president, Mr. Thabo Mbeki did not agree with the statement that ARV’s and not HIV/ AIDS contributed to the lack of capacity building and promotion of nutrition as a contributory factor in a cure against HIV/ AIDS. These were the efforts of South African erstwhile Dr. Manto Tshabala-Msimang and her efforts were blessed by people living with HIV/ AIDS, community members, friends and relatives as well as community healthcare workers. According to Hagemeister (2014:3), civil society, non-governmental organisations, faith based organizations and the support groups for people living the HIV/ AIDS played a significant role in negotiating with the government (department of health) to implement ARVs for PMTCT programme, and at a later an ART programme. The ART programme is now fully promoted and fully effective and the public sector responded well (Hagemeister, 2014:15).

Rebe and McIntyre (2014:15) stated that, funders networked and intervened with the assistance of the technical partners and funders such as the Global Fund in fighting HIV/ AIDS, TB and malaria. The National Department of Health is responsible for funding the ART programme throughout South Africa. In implementing the programme, the national office give a directive mandate to the provincial office, the provincial then inform the districts and the districts inform the sub districts of the latest protocols and guidelines in ART.

There are many health facilities that have been established solely to assist with the provision of ARV’s as well as effective monitoring of patients receiving ART. The donor funded projects assisted a lot in ART Wellness clinics across the country and there is feasibility as well as accessibility in these centers (Rebe & McIntyre, 2014:15). Recently there are more ART and Wellness clinics which are accessible to all as compared to the three clinics which were established in 2001.

2.3.4 Treatment of HIV/ AIDS in North-West

According to the Department of Health (2013:1), 88,288 people were on ART in 2009/10, while 132,967 people were on ART in North West Province in 2011. The targets estimated the number of ART patients in care for North West Province to be 232,488 in 2012/13.
The Department of Health (2013:2) further indicates that in 2007, the North-West Province spent R547.3 million on the treatment of HIV/AIDS and the budget for HIV/AIDS treatment increased by 30% in 2008/09. In 2010, the amount increased again by 24% to reach R881.8 million bearing in mind that not all the external funds are not accounted for at a provincial level. (Department of Health, 2013:3).

Statistics retrieved from the North West Department of Health HAST Report July (2011:1) shows that there was a total of 31 ART initiation sites by the end of July 2011 in the North West Province and a total of 78 238 people were receiving ART treatment. Initiation sites in this case means the facilities and hospitals nominated by the Department of Health to render Anti-Retroviral Therapy after an intensive training on ART has been done.

2.3.5 Treatment of HIV/AIDS in Mafikeng
According to an unpublished report of the Ngaka Modiri Molema District Health (District Health Information System report, there were 143, 250 patients who were initiated on Anti-retroviral treatment since January 2015 until the end of August 2015 in Mafikeng as outlined below.
Table 2: Mafikeng District (District Health Information System) Report: Source: DHIS Report (17th September 2015)

<table>
<thead>
<tr>
<th>Data Element Name</th>
<th>Period</th>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
<th>Apr</th>
<th>May</th>
<th>Jun</th>
<th>Jul</th>
<th>Aug</th>
<th>Grand Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult started on ART during this month naïve</td>
<td>2015</td>
<td>272</td>
<td>275</td>
<td>322</td>
<td>238</td>
<td>233</td>
<td>177</td>
<td>231</td>
<td>232</td>
<td>1,980</td>
</tr>
<tr>
<td>Adult remaining on ART at end of the month – total</td>
<td>2015</td>
<td>15,903</td>
<td>15,574</td>
<td>19,303</td>
<td>17,626</td>
<td>17,494</td>
<td>17,316</td>
<td>17,349</td>
<td>17,456</td>
<td>138,021</td>
</tr>
<tr>
<td>Child under 15 years started on ART during this month</td>
<td>2015</td>
<td>10</td>
<td>11</td>
<td>6</td>
<td>7</td>
<td>9</td>
<td>11</td>
<td>7</td>
<td>15</td>
<td>76</td>
</tr>
<tr>
<td>Child remaining on ART at end of the month – total</td>
<td>2015</td>
<td>713</td>
<td>715</td>
<td>739</td>
<td>353</td>
<td>773</td>
<td>770</td>
<td>798</td>
<td>368</td>
<td>5,229</td>
</tr>
<tr>
<td>Total clients started on ART during this month naïve</td>
<td>2015</td>
<td>282</td>
<td>286</td>
<td>328</td>
<td>245</td>
<td>242</td>
<td>188</td>
<td>238</td>
<td>247</td>
<td>2,056</td>
</tr>
<tr>
<td>Total clients remaining on ART at end of the month</td>
<td>2015</td>
<td>16,616</td>
<td>16,289</td>
<td>20,042</td>
<td>17,979</td>
<td>18,267</td>
<td>18,086</td>
<td>18,147</td>
<td>17,824</td>
<td>143,250</td>
</tr>
</tbody>
</table>
The treatment of people indicated in Table 2 is rendered at 30 health facilities in the Mafikeng Sub District as well as Mafikeng Provincial Hospital. These clinic are: Unit 9 clinic, Setlopo clinic, Ramatlabama clinic, Dithakong clinic, Montshioa town clinic, Montshioa stadt clinic, Mocoseng clinic, Lekoko clinic, Maureen Roberts Memorial clinic, lonely park clinic, Seweding clinic, Masuthe One clinic, Masuthe Two clinic, Rapulana clinic, Dithakong clinic, Magogoe clinic, Madibe Maruping clinic, Gelukspan Gateway, Mafikeng Provincial Hospital Gateway, Lokaleng clinic, Mogosane clinic, Modimola clinic, Weltevrede clinic, Tlapeng clinic, Tshunyane clinic, Madibe a Makgabana clinic, Modimola clinic, Tsetse clinic, Miga clinic and Motlhabeng clinic. There are also four mobile clinics that attend to inhabitants of Ramatlabama, Unit 9 clinic, Montshioa Stadt clinic and Lekoko clinic.

The above table also reflects that 232 adults were newly diagnosed with HIV/ AIDS and were initiated on ART while 15 children also tested positive and were eligible for ART hence initiated immediately in the same month (August 2015).

The Mafikeng Provincial Wellness Centre is situated in Mafikeng Provincial Hospital that renders primary health care providing HIV/ AIDS, and TB-related treatment. The Wellness Centre seeks to address all issues surrounding HIV/ AIDS Care and Treatment and amongst others, renders the following services:

- Has a community oriented primary health care programme which monitors.
- And proactively works towards the improved health and well-being of families in Mafikeng.
- Is an accredited antiretroviral (ARV) treatment initiation and on-going treatment site.
- Refers patients to Mafikeng Provincial Hospital wards for further treatment and Management.
- Gives fortified porridge to malnourished, TB, HIV/ AIDS patients. A social worker is available to help people apply for identity documents, birth certificates and social grants and social problems.
- Provides assessments and referrals, rehabilitation programmes and therapy for people with mental health issues.

Provides maternity services for pregnant women (antenatal care) (Webb-Robins, 2008:7) In the Mafikeng Local Municipality area, there are twenty home-based care centers that have been established and some of them are partly assisted financially by the Department of Social Development and the Department of Health. The two Departments oversee proper utilization of funds and monitor and evaluate on monthly basis the finances through an audit.
The caregivers situated in the Home based care centers have a role to ensure that HIV/ AIDS patients are well cared for, bathed and given their ART medication at all times.

2.4 ROLE OF CARE GIVING IN ADDRESSING HIV/ AIDS

According to Webb et al (2008:6), thousands of caregivers (both men and women) experience a warm welcome as caregivers arrives to start their shifts, watching over or caring for the sick, the disturbed, the lonely and the elderly or the very young, all of whom require caregivers. Care giving is a never ending cycle that calls for untold numbers of dedicated workers. The caregiver, whether in the home, the hospital, nursing home and home health agency, home based care setting or a rescue squad has become one of the most important people in the health field. Thousands of families could not properly care for a sick family member and the need for having caregivers arises as sick members of the families ended up dying due to lack of care by the family members (Webb- Robbins and David 2008:6).

Paradis (cited in Akintola, 2004:1), submits that caring is not a psychological state or innate attribute, but a set of relational practices that foster mutual recognition and realization, growth, development, protection, empowerment and possibility. Caring relationships are also those that foster wellbeing in the midst of change, crisis, vulnerability or suffering. Caring practices always involve reciprocity, receptivity, engrossment, attunement, engagement and intelligence.

According to Ahmed and Ahmed (1992:23), care giving in fact demands an intricate combination not only of abstract learning and reasoning but also rational intelligence, social learning and skilled knowledge as well. The quality of any care giving relationship depends solely on the skills and receptivity of the caregiver and response of the one cared for. Caring practice is a skill that is embodied and embedded in social practices. It has often been said that care giving traditionally is women’s work, is inherently conservative like the traditional stereotype of the woman in the home trying to protect her domestic haven from external invasion (Akintola, 2004:5).

Van Dyk (2008:323) articulates that it is stressful to care and counsel patients or clients with HIV/ AIDS infection. Caregivers and patients are equally anxious that are linked to the vulnerability of youth, continuous physical and psychological deterioration, their own mortality, the fear of contacting the disease and death. The latent message is that caregivers should learn how to care for themselves: otherwise they will not survive the debilitating effects of the AIDS pandemic.
Symptom control demands specialist input and specialist organizations such as the Hospice Association can make an important contribution. According to Mak and Clinton cited in Akintola (2004:26), the following five elements should be included in terminal care, comfort, openness, completion, control, readiness and choice of location.

2.5 CHALLENGES ASSOCIATED WITH CARE GIVING

There are a number of challenges that the caregivers in Mafikeng face. Home based care programmes play a vital role which cannot be overlooked in Mafikeng area. The caregivers around Mafikeng area are determined to support and assist people with HIV/ AIDS, but there are some limitations along the way that demoralise them from doing their level best. Some of these caregivers are relatives and family members who are passionate to assist those in need of palliative care.

Leake (2009:1) observes that Health Care services in South Africa are unable to cope with the increasing number of HIV/ AIDS patients, and therefore patients are discharged earlier from hospitals to be cared for either at home or in a Home Based Care Centre. Some hospitals in South Africa are reported to have eventually decreased the patients' average length of stay in hospitals from 14 days to just 3.5 days whilst referring patients to home-based care organizations. In South Africa, HIV/ AIDS home-based care is almost always provided by the community volunteers who are unemployed.

According to Andrews and Boyle (2007:2) in the USA, National Alliance for Care was established in 1996 focusing on issues of family care giving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency and corporations (O'hara, 2010:55). The National Alliance mission is to be the national resource on family care giving with the goal of improving the quality of life for families and care recipients. The National Alliance was created to conduct research, do policy analysis, develop national programmes, increase public awareness of family care giving issues, work to strengthen state and local care giving coalitions, and represent the United States care giving community internationally.

In a journal article, Kipp, cited in Akintola (2004: 56) states that caregivers are experiencing challenges which mostly impede their care work. These challenges include the social, economic, psychological, medical and emotional challenges. Care giving is strenuous and the person who does care giving requires debriefing sessions and empowerment skills. This therefore requires an integrated approach by a multi-disciplinary team. Most countries which
are poor resorted to care giving as it is common in sub-Saharan countries, both in rural areas, far flung areas and in urban areas. (Kipp, cited in Akintola, 2004:56).

Until recently, the role of preventive care and health promotion in minimizing caregiver stress has been neglected. Research and service programmes have had delayed institutionalization and financial savings as their primary focus, rather than the wellbeing of caregivers. However, the continued ageing of society, an improved knowledge of the problems experienced by the family caregivers and the heightened awareness of these problems amongst service providers as they have been brought to their attention through various advocacy groups, is changing the situation. Now, the emphasis has shifted towards accepting that family caregivers have rights of their own to a certain quality of life and to the limit of stress to which they have been subjected (Kennie cited in Akintola, 2004:8).

Akintola (2004:12) indicated that there are traumatic incidences experienced by caregivers in the process of care for people living with HIV/ AIDS. This is evidenced when caring for a bedridden and psychotic HIV/ AIDS positive patient. Another challenge emanates from the caregiver-patient relationship. If the two are not on good terms, it means there will be some characteristics of not needing one another, arrogance and a sense of ownership and independence on the part of an HIV/ AIDS positive patients. They end up having interpersonal relationship challenges that generate extensive psycho-social threats and becomes a source of anxiety.

Caregivers and people living with HIV/ AIDS have experienced discrimination and hostility in the communities they reside ever since the first episode of HIV/ AIDS incidence. Thampanichwat cited in Amoateng et al (2015:2), states that previous research on people living with HIV/ AIDS reported that the three main impacts of HIV/ AIDS in Asia including Thailand are loss of social and family support, stigma and discrimination, decreased access to health and education and social services (Mill et.al, 2013). Amoateng et al (2015:2) further said health care providers and policy makers need to understand the challenges and obstacles of caregivers for patients living with HIV/ AIDS and elicit support.

According to Amoateng et al (2015: 3), the principles of narrative analysis clearly outlined feelings and challenges caregivers undergo on daily basis. Caregivers can assist the health care providers and policy makers to more deeply understand the situation of people living with HIV/ AIDS and to act in order to improve health care and support for people living with HIV/ AIDS who needs palliative care.

According to Kipp et al (2007:23), the following are general caregivers’ challenges:
• They work in isolation.

• They do not have a voice in decisions that affect them and their work.

• The finances available for care giving and important prevention projects are often cut drastically.

• Creativity is discouraged because innovative ideas and suggestions are not implemented.

• Sometimes, caregivers have to sacrifice their previous career or income to look after the patient on a part time or full time basis.

• They have too little autonomy and responsibility.

• The necessary supportive infrastructures are not always in place.

• Training and preparation for the work are often inadequate.

• The resources are limited for caregivers.

• According to Van Dyk, (2007), there is lack of medication, health care materials, equipments and lack of the key resources to observe universal precautions.

• Referral mechanisms are often not available.

Caregivers often struggle with over involvement and lack of boundaries between themselves and their clients. This results in stress, burnout and resignation.

2.5.1 Cultural challenges

Home-based care, as adapted in South Africa, faces several cultural challenges. This stems from the fact that South African culture and ethnicities tend to influence beliefs, attitudes and perceptions of what is accepted and what is sickness, as well as what care giving actions should entail. Uys and Cameroon (2003:2) articulate that culture influences how caregivers perceive care giving, how families perceive caregivers and how patients themselves perceive the process of care giving, thus impacting on the contribution that caregivers can make. In addition, cultural aspects influence the health care system on care giving since care giving is normally undertaken under the auspices or in collaboration with the primary health care system (Russels and Schneider, 2001:16).
Researchers on Community Home-based care in resource limited settings assert that care giving greatly strains everyone involved (Kipp, cited in Akintola, 2004:57). Families, children, friends, communities, health and social service workers, community volunteers and other people are all affected. Emotional and spiritual support and guidance should therefore be available for the person who is ill, immediate family members as well as the caregivers. People with HIV/ AIDS sometimes suffer from confusion and dementia and often die at a young age. Several family members may also be infected. In addition, many health and social service workers and caregivers are either infected themselves or have family members who are. Such experiences put an added strain on caregivers.

2.5.2 Stigma and discrimination challenges

According to Amoateng et al (2015:2), caregivers even if they are HIV/ AIDS positive or not, suffer from discrimination and as a result they opt to keep their HIV/ AIDS status a secret. In areas where there are a large numbers of HIV/ AIDS infected people for instance (farms and rural areas), members of the community may fear to become infected including caregivers themselves. As a result, some caregivers have been rejected or abandoned even by their family members, when they disclose their own HIV/ AIDS status. Consequently, they receive little support from their communities.

The research on care giving conducted by Amoateng et al (2015:2) established that caregivers themselves, whether or not HIV/ AIDS positive themselves, suffer from discrimination and as a result, families may keep the sick person’s HIV/ AIDS status as a secret. Amoateng further alluded that in areas where there are large numbers of HIV/ AIDS infected people, other members of the community may fear becoming infected. As a result, some caregivers who have sought help have been rejected or abandoned even by the family members (Zimba and Mc Inerney 2001:9).

2.6 HOME BASED CARE

According to Van Dyk (2008:323), the principal goal of any home-based care programme is to assist people living with HIV/ AIDS with a sustainable care plan and ensuring that all the resources they need are being catered for as well as provision of food, medication and bathing the patients. There are various objectives for establishing the home based care centers and amongst others home based care does the following:

- Assist and support the family to cope with the sick HIV/ AIDS patients by educating them about the coping mechanisms and strategies of coping when you have an HIV/ AIDS infected patient at home.
• Provide knowledge base to community members on issues surrounding HIV/AIDS and its prevention strategies.

• Provide support to all the affected family members as well as the relatives.

• Assist the affected families with their care giving roles, i.e. bathing of patients.

• Ensure that all the HIV/AIDS positive individuals who are on ARV’s adhere to treatment.

• Educate those HIV/AIDS positive patients who are not yet started on ART to live positively with the virus and to accept their HIV/AIDS status.

• Collect ART on behalf of the bedridden patients.

Initially home based care programme started in America and Europe and Africa copied the best practice models for home based care from them (Uys and Cameroon 2003:1).

2.6.1 Benefits of home-based care

According to Uys and Cameroon (2003:5), there are advantages in home based care establishment and these can be easily noticed. Firstly, by allowing the infected individual and the relatives to recognise the inevitability of death. Secondly, these researchers argue that it is less expensive when the patient is cared for by the relatives in the home. Costs of transporting the ill and incapacitated to hospital are substantially reduced. The third suggestion that the researchers make is that caregivers must be trained in the practice so that they too can provide the support needed in a professional manner (Uys and Cameroon, 2003:5).

• Home-based care is sensitive to the culture and value system of the local community- a sensitivity that is often missing in clinical hospital settings. The African communities for instance treat HIV/AIDS as something that is still secretive and most African people prefer to do palliative care in their own homes than treating them in Hospice Centers and Home-based care centers.

• Home-based care HIV/AIDS caregivers expose of varying family types and do not single out all the child-headed families due to HIV/AIDS as well and everyone else from the community who come to the caregivers seeking their help and intervention (Akintola, 2008:9).
• Home-based care is empowering. This means that people take responsibility for and control of their own lives and communities (Department of Social Development, 2002:5).

• Home-based care offers a comprehensive package to all HIV positive patients that includes among others preventive, curative, rehabilitative and palliative care (WHO 2008:1).

The home based care centers believe and ensure that problems are to be managed at an earlier stage before they become excessive and intense. For example, the sick HIV/ AIDS patient will be prevented through Home-Based Care intervention programme to spread the virus to other innocent members of the community more especially in the Tswana tradition and culture, where the community believe in bathing a patient without putting on protective gloves believing that it’s a form of discrimination and labeling when it is done that way. The current connections to my research are that the Government of South Africa and the researchers are investigating on the effects of home-based care initiatives.

2.6.2 Models of home-based care

Over the years, a number of different systems have been developed to offer home-based care, namely:

2.6.2.1 Integrated home- based care model

According to Uys and Cameroon (2003:1), in 1999-2000, the implementation of Integrated Community-Based Home care model for the care of people living with HIV/ AIDS in communities occurred in seven sites across the country. The post-implementation evaluation showed that most participants felt that the model could be replicated if a functioning and informed network including all partners, and a strong management team were in place. The effects of the project were mainly positive for all stakeholders (home- based care Centre, clinic, hospital, PLWA and their carers, professionals and other community members). Hospitals and community-based services became more aware of and involved in the needs of PLWA and felt that the model enabled them to address these needs. PLWA and their carers felt supported and respected.

Bartlett (2002: 10) also indicated that non-adherence is one of the primary obstacles to successful antiretroviral therapy in HIV/ AIDS positive patients worldwide. In Brazil, the Domiciliary Therapeutic Assistance (DTA) is a multidisciplinary and integrated home-based assistance programme provided for HIV/ AIDS positive patients confined in their homes due
to physical deficiency. The aim of the study was to investigate ADT’s ability to monitor the effectiveness of ARV’s and promote proper adherence to ARV therapy. In Bartlett’s study, fifty-six individuals were recruited from three study groups: Group 1 - patients currently in the ADT programme, Group 2 - 21 patients previously treated by the ADT programme, and Group 3 - 20 patients who have always been treated using conventional ambulatory care. Using multivariable self-reporting to evaluate adherence, patients in the ADT programme had significantly better adherence than patients in ambulatory care (F = 6.66, p = 0.003). This effect was independent of demographic and socioeconomic characteristics as well as medical history. Patients in the ADT programme reflected a slight change towards greater therapeutic success than ambulatory patients. These results suggest the incorporation of characteristics of ADT in conventional ambulatory care as a strategy to increase adherence to ARV therapy Bartlett (2002: 10).

2.6.2.2 Single service home- based care model

The recruitment of volunteers is done by either a hospital, clinic or an NGO. The recruiters start first by capacitating and empowering all the volunteer caregivers, people living with HIV/ AIDS as well as their immediate family members. The focus here is on the bedridden HIV/ AIDS positive patients who are taken care of in their own homes by the significant others.

An in-service training is offered to the carers at home so that they are equipped on how to take care of the infected family members and safe measures to avoid being exposed to the HIV/ AIDS virus by the carer. The process will unfold until such a time the home based care receives funding from the department. During the establishment of home based care centers, there is no specific training or external support from the donors yet until the home based care centre is registered as a non-profit organisation.

Uys and Cameroon, (2003:5-7) identifies the following three home- based care models. They start with a linkage of all the service providers involved and the community at large. The collaboration ensures that there is an effective home based care service delivery as the relevant stakeholders would be playing a part towards assisting people living with HIV/ AIDS. As a result, there will be effective coordination of caregivers, empowerment as well as supportive supervision which is key in all the home based care settings. This approach does not only focus on assisting an individual infected with HIV/ AIDS, but it goes an extra mile to the patient’s immediate family members. The family members who do the care work are also capacitated on how to take a good care of a terminally ill HIV/ AIDS patient and offered skills
on how to take care of themselves as well as to avoid getting or contacting the HIV/ AIDS virus as well. The model also focuses on the different care services to assist each other in improving care. However, one often has to start by taking the individual service approach until other partners can be recruited and involved. Informal care is very taxing since the family caregiver may lack the necessary skill, knowledge and emotional support. The integrated home-based model is the ideal model for quality physical care and psychological support for the person living with HIV/ AIDS and his or her family.

2.7 EFFECTS OF CARE GIVING ON CAREGIVERS

During the process of care, caregivers get attached to the people whom they care for. It then becomes difficult for them to part ways with a person they are used to care for, and it will not be easy for them to accept that the person they used to care for is late or deceased. In situations whereby the HIV/ AIDS positive patient dies, most caregivers undergo a grieving moment and it becomes very difficult for them to accept the loss (Frankil cited in Akintola, 2004:8). Frankil further discussed anticipatory grief as a helping mechanism in discussing the likelihood of death before the person who is taken of dies. This will also assist in getting used to the role changes as the roles will be clarified. The process of anticipatory grief should be started as soon as the patients start losing appetite in food, cannot take medication or vomits when medication is given, losing weight unintended and others are unable to speak and suffer dyspnea.

Brown and Powell (1993:15) are of the opinion that caregivers suffer from the feeling of hopelessness, helplessness, denial and despair during the time of grief. Even though they know that a patient on the last HIV/ AIDS stage may die anytime, it is not easy for them to cope during death.

2.7.1 Burnout

Burnout is defined by Uys and Cameroon (2003:280), as a time in life where by an individual can no longer cope with the life challenges and stressors in life. This individual would start to escalate an element of negativity in everything he or she does. The person will not have the energy to do work than before and will be discouraged in all what she or he does.

2.7.2 Debriefing

According to Maselesele and Mashau (2009:41), debriefing is a process that involves venting out feelings, emotions as well as fears in order to relieve oneself in the stress encountered previously. Maselesele and Mashau further alluded that these interventions
can be addressed by either a professional psychologist, counselor or a social worker for intervention and management.

Van Dyk (2008:323) articulates that nothing can be more stressful and draining on the caregiver’s resources than caring for or counseling patients or clients with HIV/ AIDS infection. Caregivers and patients are faced with frightening issues such as the vulnerability of youth, continuous physical and psychological deterioration, their own mortality, and the fear of contacting the disease and death. If caregivers do not also learn how to care for themselves, they will not survive the onslaught of the HIV/ AIDS pandemic.

According to a Master’s thesis by Primo (2009:21), care giving is a demanding job and the responsibilities cannot be shirked, nor can it always be delegated. It requires physical and emotional reserves that occasionally exceed those of even the healthiest persons. Besides the physical toll, HIV/ AIDS survivors and service providers both encounter similar challenges of post-traumatic stress syndrome emanating from death of an HIV/ AIDS positive patient which at times is associated with labeling and stigma (Ross et al, 2001:20).

AIDS pandemic does not only affect individuals or families, but threatens entire communities more and more (Parker et al, 2009). This makes a community approach and the need for community home based care programmes essential in caring for the HIV/ AIDS patient and his/ her family (Parker et al, 2009). Miller et al (1995:17) is of the opinion that being a caregiver can be a deeply meaningful way to spend one’s days on earth, but it is also not easy to be a caregiver. As the person with AIDS battles in his or her effort to remain effective in the delivery of care vulnerable to many physiological, social and emotional affronts, the caregiver may also faces numerous.

According to O’Neill and Kinney, cited in Miller (1995:23), psychologists use the term “caregiver burden”, to describe the physical, emotional, financial and social problems associated with care giving. It is also used to explore the physical and emotional effects that caring for the HIV/ AIDS patient has on caregivers. Caregiver stress can be divided into primary and secondary stress that comes from everyday care giving duties, such as assisting the patient with bathing, toileting and managing the patient’s difficult behaviour as well as planning of daily care. Causes of secondary stress include caregiver conflict with other family members (own family or patient’s family), economic hardship e.g. loss of work and income, limitations on personal leisure and social activities. Care giving places limits on the caregivers’ social life in the sense that they receive fewer visits from their friends, spend less time with their hobbies and in their house of worship and their vacations often suffer.
2.7.3 Physical effects
According to the researcher’s understanding, the multiple tasks performed by caregivers often result in them neglecting their own self-care, such as nutrition, exercise, socialisation and sleep (Primo, 2009). They have the tendency to develop negative health behaviour such as overeating, smoking, not exercising and sleep patterns are disturbed (sleep less than non-caregivers) (Primo, 2009). Some caregivers, especially women, gain weight. The caregivers’ immune system weakens and the healing of wounds is often affected (Primo, 2009).

2.7.4 Emotional effects
According to Ross et al. (1993:92), the psychosocial issues for professionals, but also for other people working in the field of HIV/ AIDS generally include:

2.7.4.1 Discriminatory attitudes towards socially stigmatised groups
Many family members and patients have reported that they have experienced discrimination and negative attitudes and behaviour from service providers (Ross et al., 1993: 94). This lowers both the morale of the HIV/ AIDS positive patients as well as the people taking care of them. In most instances, the stigma is derived from association of these individual with poverty and assigning of negative characteristics to patients belonging to certain racial groups. The community assumes that all the HIV/ AIDS positive patients who are bedridden and taken care of in home based care settings were promiscuous and deserve what they are going through. It is also believed that this emanates from failure to render efficient and effective home based care services to the population sub-groups, most likely to be infected with HIV/ AIDS (Ross et al. 1993:95).

2.7.4.2 Homophobia
The community has a negative attitude towards people with transgender inclinations, the lesbians and the gays. These people are not appreciated in some communities and as a result, they suffer from homophobia, stigma and discrimination. Caregivers often experience challenges and discomfort when dealing with these individuals. The way they dress also poses a challenge to many people as they get confused whether to address them as males or females. To some extent, lesbians and gays also in return display the very same attitude to caregivers and this affects their service delivery a great deal. As opposed to the people living with disabilities, the community rather hates homosexuals and believing that when they contract HIV/ AIDS, it is a punishment to them for their unacceptable sexual acts. The act of
homophobia poses stress and burnout on caregivers and impede on the effective service delivery on patients living with HIV/ AIDS (Ross et al, 1993: 96).

2.7.4.3 Human sexuality

There is a discomfort amongst health care workers in dealing with sexuality in general and with a disease such as HIV/ AIDS, that is usually sexually transmitted in particular (Ross, et al, 1993:96). This discomfort creates a bridge in the relationship between a caregiver and patient living with HIV/ AIDS. The care giving relationship can influence the recording of the patients’ progress. There is a dire need for a caregiver to accept the sexuality of the patient because failure to do so will result in disintegration of the patient’s family system and the home based care and this will lead to improper patient care and distorted barrier in communication. The counter transference reactions of a caregiver in as far as his or her past sexual experiences were, should not affect the current relationship with the HIV/ AIDS positive patient.

2.7.4.4 Fear of contagion

In a health set up, people fear to work closely with HIV/ AIDS positive individuals as they believe it poses a high risk of contracting the HIV/ AIDS virus (Asner- Self et al, 2011:44). This fear will still exist in health settings as long as the measures of infection control and prevention are not strengthened and practiced thoroughly. Irrespective of the health talks on modes of HIV/ AIDS transmission, there are still health care workers who are convinced that one can contract HIV/ AIDS through hugging, washing patient’s clothing, shaking hands, sharing a plate with an HIV/ AIDS infected patient and sharing a cup. According to Asner-Self et al (2011:45), this fear may result in fearing to stay next to an HIV/ AIDS positive person or even share a meal with. Other people believe that HIV/ AIDS positive people are filthy and do not even want to come near them. This will therefore contribute to withdrawal of the caregiver in rendering quality care services to the patients. Some caregivers get confused not knowing who is telling the truth as there are so many myths surrounding HIV/ AIDS.

2.8 TRAINING OF CAREGIVERS

HIV/ AIDS have placed a great strain on the health sector, resulting in new care needs and a crisis in health and other services. The Government has embarked on a programme of re-engineering Primary Health Care (PHC) and Ward Based Outreach Teams (WBOTs) to create a more efficient and cost-effective health system in South Africa (Malahlela, 2013:1)
The two teams conduct door to door daily campaigns to assist people living with HIV/ AIDS as well as tracing TB Defaulters. These teams are recruited and paid by the Department of Health to assist caregivers. At the forefront of this is a cadre of people, mostly women, who provide home-based care in communities. In many cases, these workers are not consistently and appropriately recognised and the current Home-Based Care Policy isn’t clear about the future of these hard-working, unsung heroes (Malahlela, 2013:1). There are short courses and in service training that are conducted on quarterly basis for caregivers by both the Department of Social Development and the Department of Health such as Palliative Care, Home Community Based Care (HCBC) training, Directly Observed Treatment (DOTs) training, Care and Support, 69 Days on HCBC, Integrated Access of Care and Treatment (IACT), Frail care training, Child care training and Ancillary Health care training.

2.9 SUPPORT OF CAREGIVERS

In ideal circumstances, family and community caregivers are supported by a multi-disciplinary team that can meet the specific needs of the individual and the family. The team consists of all the people involved in the care and support, and may include a medical practitioner or a professional nurse, a social worker or trained counselor, a pastor or spiritual leader, volunteers, a traditional healer, friends and neighbours and community members (Loius et al, 2008:31). Amoateng et al (2015:1) discovered that caregivers need to collaborate with the public health sector to provide education and support for themselves, their communities and their patients in home-based care centers.

2.10 THEORETICAL PERSPECTIVES

2.10.1 Attachment Theory

The researcher explores three theories and one model which are linked to the process of care giving. These theories, namely, attachment theory, systems theory, ecological perspective and health belief model are relevant to home-based care settings.

The theory of attachment finds relevance to caregivers who, most of the time, grieve in anticipation for the terminally ill patients before and after death. Most caregivers have developed a bond with their patients and they find it very hard to lose them through death. Through grief counseling, the caregiver could be assisted to go through the pain in order to avoid depression and breaking down. The caregivers must accept the reality of the inevitable loss and go through the grieving process successfully without denial (Eneh, 2010:5).

Creswell (2009:85) does not believe that attachment bonds between individuals develop only in order to have certain biological drives met, but also from the need for security and safety.
These bonds develop early in life and are usually directed towards specific individuals and tend to endure throughout a larger part of the cycle. If the goal of the attachment is to maintain an affectionate bond, situations that compromise this bring loss and grief. All human beings grieve at the occasion of loss and the pain of the loss can be physical, emotional or behavioural (Anderson cited in Payne, 2005:142)

2.10.2 Systems Theory

The term system comes from a Greek word “systema” meaning to combine. In contemporary usage, system refers to a regularly interacting or interdependent group of items forming a unified artifact (Sample, 2009:35). It can be a group of interacting bodies under the influence of related forces that is in or intends to achieve an equilibrium. In systems theory, the whole is more than the sum of its parts. We cannot adequately understand a problem in social functioning by simply adding together a separate assessment of the environment. Rather, we strive to understand the complex interactions between the client and other social systems (Ingram, 2007:2).

Compton and Galaway (2005:28) state that systems theory enables the client and the professional helper to understand the problem of concern within the context of the person-in-situation and contribute to the problem solving process. Systems theory meets one of these requirements by shifting attention from linear cause and effect relationships to the person and situation as an interrelated whole. It is less interested in whether the environment causes the person to behave in a particular manner or the person affects the environment in a certain way. The person is often viewed as an integral part of his or her total life situation.

Systems theory emphasizes care of individual patients or clients in interpersonal relationships between human beings. Anderson cited in Payne, (2005:142) emphasizes that “the systems theory integrates the atomistic-holistic continuum.” The social and personal elements in any social situation consist of elements that interact with each other to integrate into a whole. In this research, caregivers explore and interact with the HIV/ AIDS patients also form part of the system. If they are affected, it means that the entire community shall also be affected.

The application of the systems theory enables the researchers and social workers to identify problems in the dynamics, processes and transactions of the system as a whole. This is different from thinking of problems as forms of individual or family pathology. The term dysfunctional individual or dysfunctional family is incongruent with a systemic view because they do not reflect the interactional nature of individuals, families and their environments.
Systems perspectives assist social workers to consider new change strategies for old problems and to identify different points of intervention.

2.10.3 Ecological perspective

According to Germain cited in Payne (2005:342), ecological perspective studies indicate the sensitive balance which exists between people and their environment and the way in which this balance can be maintained and enhanced. This science is concerned with the adaptive fit of organisms and their environments and with the means by which they achieve a dynamic equilibrium and equality. If ecology is adopted as a metaphor for practice in social work, then the unit of attention is that complex ecological system which includes the individual, the family, the environment and the transactional relationship among these systems.

Compton and Galaway (2005:28) articulate that within social work, it is important to understand all the factors in the environment that affect the client system. The ecological orientation dictates that the individual cannot be understood outside the context of the intimate environment (the family- and the family can be understood only in the context of the larger sociological matrix). Compton and Galaway (2005:28) state that ecology is a form of general systems theory. Ecologists have always been system thinkers concerned with the relations among living entities and between entities and other aspects of their environment. The ecological perspective provides insight into the nature and consequences of such transactions both for human beings and for the physical and social environment.

The ecological perspective is concerned with the growth, development and potentialities of human beings and with the properties of their environments that support or fail to support the expression of human potential. In other words, all the time, people manipulate the environment so that they can cope with it (Germain, cited in Payne, 2005:344). The ecological approach studies the sensitive balance between the life supporting qualities of the environment. When reciprocal adaptation falters, the physical environment becomes polluted by man’s release of non- biodegradable matter produced by his technology while social environments become polluted by poverty, discrimination and the stigma produced by man’s social and cultural processes.

According to Compton and Galaway (2005:5), social work practice is built on three core themes which are, the ecosystem (person in situation) perspective, the problem solving process and the client and worker partnership. These themes reflect well established traditions within social work and provide an integrated framework for practice with diverse
populations in various settings. The ecosystem perspective with its emphasis on person in situation emerged as a framework for social work practice and has gathered philosophical and intellectual momentum within the profession ever since.

The ecosystem perspective facilitates interaction between people in their environment. People enlarge their competence and increase their problem solving and coping abilities and influence social and environmental policy. This approach can also be used to help people address problems, needs and aspirations associated with the three social dimensions that are: life transitions, the environment and obstacles that impede successful accomplishment of transitional and environmental tasks (Jackson, 2013:2).

The ecological perspective can be applied to care giving of HIV/ AIDS patients by ensuring that HIV/ AIDS patients are well cared for by the caregivers as the ecological perspective strive for the support as well as caring for others problems as a holistic. If one person in the community is infected by HIV/ AIDS, it means everyone in the community will be affected.

2.10.4 Health belief model
Archer (cited in Payne, 2005:212) reported that the Health Belief Model (HBM) was developed in the 1950’s by a group of social psychologists. The HBM is characterized as a threat reducing and predicting that an individual is more likely to take a health action if he or she perceives personal susceptibility to a disease or illness and perceives that disease to be serious. These perceptions can be modified by various cues provided to the individual, such as advice from friends, newspaper articles and postcard reminders from health professions. In addition to personal perceptions, personal factors and cues, the individual will be more likely to take appropriate action if he or she perceives it as beneficial if the threat of the disease and the costs of taking the action do not outweigh the benefits (Archer cited in Payne, 2005:212).

Archer cited in Payne (2005:213) continues to articulate that one of the characteristics in the Health Belief Model is “perceived susceptibility”. It is defined as the individual’s perceived risk of an illness e.g. contracting HIV/ AIDS virus. The individuals who do not feel that one day they will be HIV/ AIDS positive will not be likely to prevent infection as those who feel they are very likely to be infected by HIV/ AIDS.

According to Archer cited in Payne (2005:214), "perceived severity" was defined as the definiteness of people and the hardship that would result if contracting HIV/ AIDS was to occur. “Perceived benefit” was defined as the belief that the use of a condom would be effective in preventing the spread of HIV/ AIDS. If the individual believes that the use of a
condom is 99% effective in preventing HIV/ AIDS, people will be more likely to use it than if they believe it is only 50% effective. Finally, "perceived barriers" implies that using family planning methods could involve the cost of obtaining the methods, distance and availability of transportation and friends' opinions regarding family planning.

Assessing clients’ level of perceived susceptibility, severity, benefits and barriers are important and can be valuable in facilitating clients’ preventative actions. Clients however, have the freedom and responsibility for their own behaviour choices. Ultimately, they choose whether or not to engage in a given behaviour based on their own perceptions of its value to them.

The role of professionals and caregivers is to provide clients with the information they need to make informed behaviour choices and to support them in these choices and their consequences. Granting client choices foster their competence and active coping behaviour which, in turn, result in clients’ taking better care of their own health. The responsibility for health behaviour belongs to the client.

Although both the natural history of the disease model and the Health Belief Model can help the community health nurse and the caregiver to understand client’s illness prevention behaviour, it is important to note that these models are limited to illness prevention behaviour. They depend on the presence or threat of the disease; therefore they are not adequate for explaining health behaviour practiced in the presence of any disease threat.

The Health Belief Model can be applied to care giving of HIV/ AIDS patients is centered around behavior change of the HIV/ AIDS patients themselves, to conduct themselves in a manner that would prevent themselves to be re infected. HIV/ AIDS patients need to ensure that their viral load is controlled and should not think of having unprotected sex when they recuperate as this will increase the viral load and multiply the virus in the cells.

2.11 CONCLUSION

Chapter two explored literature on: care giving is with specific focus on care giving for HIV/ AIDS patients and it was related to practices surrounding palliative care, models of care giving and interrogated the relevant literature studies to the topic as well as the theories, models, approaches applicable and relevant to this research study.
CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION
By employing qualitative research design, the researcher seeks to assess the participants’ experiences, perceptions, feelings and thoughts about home-based care for HIV/ AIDS patients. In qualitative research, people’s words and actions are examined in descriptive ways to represent the situation as they experience it.

3.2 RESEARCH APPROACH
The research followed a qualitative approach. Qualitative research produces descriptive data in the participant’s own written or spoken words and involves the identification of the participant’s beliefs and values that underlie the phenomena (De Vos et al, 2007:79). In line with a qualitative research approach, the goal of this study is to explore the impact of giving care to HIV/ AIDS patients on their caregivers, and further to investigate their experiences as far as care giving is concerned (Soliman and Almotgly 2011: 885). Rubin and Babbie, (2013:47) argue that qualitative research methods allow researchers to explore the subject of enquiry deeply since the techniques of observation are intended to generate rich insights. Observational techniques frame an inquiry that begins with assumptions, world views and extends into explorations into meanings of what individuals or groups describe as a social or human problem. Furthermore, the key informants (voluntary caregivers) can provide their view and opinions as well as their experiences on the issues surrounding caring for HIV/ AIDS patients.

3.3 RESEARCH DESIGN
The study is qualitative and descriptive in nature. The study explores and describes a range of perspectives about the effects of care giving of HIV/ AIDS patients. Interviews were used to answer research questions. The questions probed the sensitive nature of the relationships between caregivers and patients and also allowed the generation of in depth knowledge on the issues to be investigated. The specific research design that the researcher applied in the study was a case study. The term “case study” has multiple meanings. It can be used to describe a unit of analysis or to describe a research method. Depending upon the underlying philosophical assumptions of the researcher, case study research could be positivist, interpretive or critical. A case study is defined by the fact that it is a bounded system (Merriam, cited in Maree 2008:75) and that it does not necessarily mean that one site only is studied. In this study, case study was used to address the biographical life histories of the
participants and their everyday practices as well as their daily challenges. It was also used to address their experiences adequately, to make it easy for the researcher to analyze everyday knowledge, accounts and their life stories.

### 3.4 TYPE OF RESEARCH

The type of research the researcher used is applied research. According to Palmer (2004:5), applied research refers to scientific study and research that seeks to solve practical problems, in this case HIV/ AIDS related problems. Applied research attempts to find solutions to observed everyday problems, cure illness, and develop innovative technologies. Sociologists and psychologists working with organizational fields often use applied research to investigate realistic problems. The focus of applied researchers is often concerned with the external validity of their studies. This means that they attempt to observe behaviors that can be applied to real-life situations (McBride, 2013: 88).

### 3.5 POPULATION

The population for this study includes all the caregivers that care for HIV/ AIDS patients in the Mafikeng area, North West Province. A similar view was articulated by Feitsma (2007) on issues of population in a study focusing on population comprising of poverty stricken people. There are about fifty existing home-based care centres in Mafikeng and surrounding villages. All these home based care centres are registered with the Departments of Social Development and Health. There are about 800 caregivers rendering some voluntary service at the centres with or without a stipend in Mafikeng.

### 3.6 SAMPLING

Sampling refers to the process of selecting a portion of the total population for in-depth analysis and investigation into features and characteristics that are then generalized and applied to the entirety of the population. This suggests that a sample must be representative of the entire population. Qualitative research is generally based on non-probability and purposive sampling rather than probability or random approaches. Purposive sampling simply means that participants are selected because of some defining characteristics that make them the holders of the data needed for the study (Maree, 2007:79). Sampling decisions are therefore made for the explicit purpose of obtaining the richest possible source of information to answer the research questions. Qualitative research usually involves smaller samples than quantitative research studies. Sampling in qualitative research is dependent on the nature of enquiry, the magnitude of the population and often continues until no new themes emerge from the data collection process - called data saturation.
Purposive sampling decisions are not only restricted to the selection of participants but also involve the funding, the settings, the incidents, and activities that a researcher undertakes in this data collection technique. With purposive sampling, the participants are deliberately selected because they show specific characteristics that make them relevant for the detailed study. The units of analysis in the study will therefore be selected for the explicit purpose of obtaining the most relevant possible information in order to answer the research questions.

The research domain was three of the fifty existing home-based care centers in and around Mafikeng. The centers were Love Care Centre, Lomanyaneng and Danville home-based care centers. The researcher resorted to choosing these home-based care centers on the basis of their effective functionality as perceived by the researcher and also as reported by the caregivers. They are monitored on full time basis by the Department of Health and the Department of Social Development but they are not the only home based care centers which are monitored by the two departments. They are also funded by these Departments in order to achieve their intended mission and vision of caring for HIV/ AIDS patients.

All three institutions are non-governmental and non-profit organizations which depend on the financial assistance of the Department of Health as well as the Department of Social Development. The three home-based centres are situated close to Mafikeng city centre. Danville is 5km away from Mafikeng, Lomanyaneng home-based is 10km from the city centre, Love home-based care is 5km away from the city centre. Lomanyaneng home-based care is a well-designed structure with beds to admit 15 patients who are on daily basis taken care of by the volunteer caregivers. Love and Danville home-based care centres are centres that do not admit patients and are out-patients centres. The caregivers placed there do home visits on daily basis to bath, feed the HIV/ AIDS patients in their homes, thus palliative care.

The sample consisted of twenty (20) volunteers who were interviewed individually and ten (10) volunteers who participated in a focus group discussion. The participants were all the caregivers present at the care centres on the day of the fieldwork reported in this study. For Danville home based care, ten participants who were present were interviewed out of the fifteen employed at the centre. At Love home based care five were also interviewed out of eight caregivers employed by the centre. Lastly, five were also interviewed at Lomanyaneng home based care which utilizes twenty caregivers.

Fifteen (15) were females and five (5) of them being males. All the participants originate from Mafikeng. The interviews were audio taped, transcribed and analysed using a narrative
analysis. Qualitative study of subjective experiences and common dialogue of the caregivers’ story telling was appropriate in this study because it captured the essential narratives of the caregivers’ experiences.

A purposive sampling method was used. According to Richter and Peu, (2004) purposive sampling involved conscious decision by the researcher, of certain subjects or elements needed to be included in the study. The participants were purposefully selected, particularly willing individuals and those that were present at work on the date of field work. According to Burns and Groove, (cited in Richter 2004: 32), cases were handpicked. The informal caregivers who regularly provide the service were included in the study to provide the information necessary for the study.

3.7 DATA COLLECTION
The researcher compiled an interview schedule with open ended questions that focused on the effects of home-based care of HIV/AIDS patients on caregivers. The same schedule was used for both individual and focus group interviews in order to confirm and validate the experiences and views that caregivers had with different patients. An interview schedule was drawn up in order to guide the researcher. This provided the researcher with a set of predetermined questions that might be used as an appropriate instrument to engage the participants and designate the narrative terrain (Holstein and Gubrium cited in De Vos et al., 2007:296). Producing a schedule beforehand forces the researcher to think explicitly about difficulties she hopes the interview might cover.

3.8 METHODS OF DATA COLLECTION

3.8.1 Interviewing
An interview is a two way conversation in which the interviewer asks the participants questions to learn about the ideas, beliefs, views, opinions and the behaviour of the participants. Qualitative interviews enable the researcher to see the world through the eyes of the research participants. In this regard, research participants are valuable sources of information. The aim is always to obtain rich descriptive data that facilitates, in both the researcher and the audience, an understanding of the participants' construction of knowledge and social reality.

Examples of open ended questions were: Explain in detail how you render your services to the clients? Do you receive any supervision for your care giving? Explain who does it and how it is done? What impact does care giving have on you as an individual caregiver? Do you encounter any physical impact, psychological impact, emotional impact, economic
impact and any other impact? If it is applicable, specify? What are your daily challenges as a
caregiver? Each interview was discussed and recorded within 30 minutes.

Specifically, this study intended to interview caregivers using a semi-structured interview
schedule. These interviews sought to observe some behaviour patterns associated with
experiences and challenges of care giving. The researcher used semi-structured interviews
in order to gain a detailed picture of caregivers’ accounts of their experiences with HIV/
AIDS/AIDS patients and the challenges that they faced (De Vos et al, 2007:296). The
advantage of the interview method was that it gave the researcher and participants much
more space and flexibility in the voicing of their individual experiences. The researcher was
able to follow up particular and interesting avenues that emerged in the interview and the
participants were able to give a fuller picture of how they felt about their care giving
responsibilities.

3.8.2 Focus groups
Focus group discussions formed another strategy that the researcher adopted in the course
of the field work. In a focus group, a small group of people discussed different topics of
interest to the researcher. De Vos (2007) recommends 12 to 15 people; other researchers
recommend not more than 8 are brought together in a room to engage in a guided
discussion of a specific topic. A researcher creates an environment that encourages the
participants to express their perceptions, points of view, experiences, wishes and concerns
without coercing them to agree with each other. The researcher only serves as a facilitator of
the events that unfold (De Vos et al., 2007:299).

The researcher conducted a focus group discussion with two focus groups with 12 members
in the first group and 8 members in the second one. The groups comprised of both males
and females. The two groups explored their experiences on care giving, their challenges as
caregivers and the effects/impact of care giving of HIV/AIDS patients on them. The
participants also outlined the support systems available for them and trainings they had
undergone. Individual interviews were conducted first on different dates at the three home
based care centers followed by the focus groups. The focus groups were conducted at
Lomanyaneng home based care center because it is the only center amongst the three
centers that admits patients, therefore more caregivers are employed there.

3.9 DATA ANALYSIS
The data were analyzed by themes. Thematic analysis is highly inductive, that is, the themes
emerge from the data. According to Maree (2007: 99), qualitative data analysis is usually
based on an interpretative philosophy that is aimed at examining meaningful and symbolic content of qualitative data. The researcher grouped common words, phrases, themes or patterns that aided researcher’s understanding and interpretation of the research question (Maree, 2007:100). Using this method, data from different people was compared and contrasted for evolving themes. Both comparative and thematic analyses were used in this project, with the researcher moving backwards and forwards between transcripts, memos, notes and the relevant literature.

The narrative data was thereafter analysed confirming the researcher’s understanding by asking comprehensive questions, re-reading the narrative accounts in conjunction with the questions, articulating more explicit questions based on these readings and creating codes that reflected the narratives discerned in the interviews.

The data was in the form of written notes that were taken during data collection and translated transcriptions of the recorded interviews. Data was analysed manually. The process of data analysis was an ongoing process throughout data collection, which began the moment the researcher began to talk to the 20 participants. Ghauri and Gronhaug, (2002: 28) regards the process of data analysis as an intellectual struggle with the raw data collected. The content of the transcribed notes was read and the English audiotapes listened to several times to familiarise the researcher with the content and to understand the data. Each transcript was carefully read through and scrutinised. This was done sentence-by-sentence, and phrase-by-phrase.

The researcher wrote down comments regarding the data that she felt was in some way relevant to answering the research question (Merriam, 2014:5). In so doing, the researcher was using codes that Miles and Huberman (2002:22) explain are tags or labels which can be attached to words, phrases, sentences or whole paragraphs so as to assign units of meaning to the text. Each page of transcriptions and field notes was coded in the upper right-hand corner to ensure a simple way of quickly identifying the various sources. Each paragraph of data was reviewed, one line at a time, with important chunks being highlighted with different coloured markers and codes being written alongside the relevant lines.

As new chunks were identified, a tentative list of categories was developed simultaneously on a separate page. This level of coding summarised the data on a descriptive level (Miles & Huberman, 2002:44). Below each code, the researcher wrote the page number so that after the photocopies were cut up and pasted onto data cards, it would be easy to locate the original source (Maykut & Morehouse, 1994:47). At this stage the researcher cut the various
units of meaning he had identified, apart. Some units were only single sentences, while others were paragraphs.

The next step in the process was placing the information into categories. Differences, similarities and linkages of these categories that came out of the different groups of participants were then explored and compared. By doing this, the researcher identified with what Miles and Huberman, (2002:69) refer to as “…repeatable regularities …” which, in relation to this study, required looking for commonalities, categorizing, and identifying themes to make sense of the information.

Content analysis was adopted because of its unique interpretation on qualitative interviews. According to Babbie and Mouton (2007:356), content analysis is a social research method appropriate for studying recorded human communication. It is also described by Bryman cited in (Babbie and Mouton, 2007:357) as an “approach to people, documents that emphasizes the role of the investigator in the construction of meaning of and in text. There is an emphasis on allowing categories to emerge out of data and on recognising the significance for understanding the meaning of the context”. Content analysis was used following the process of data analysis outlined in De Vos et al, (2007:334-337). The process suggested entails setting an itinerary for the recording of all data, making a pilot study where preliminary data is collected and analysed to test the feasibility of the study and finally managing and organizing the data. In this research, the process involved transcribing the tape recordings and then scrutinizing these notes. The end purpose was to highlight the most important information, organizing this into themes and extrapolating the meanings into clusters for interpretation.

Each response was analyzed to see whether any trends developed or appeared. The responses to the open-ended questions were grouped in terms of common content and converging themes. These groupings were analyzed qualitatively. Data was categorized and interpreted in terms of common themes. Tabulations, categorizations, observations and other qualitative techniques were used in data analysis.

The outcomes of this method were related to the theoretical base described in the literature review and is designed to ease out interesting turn of events that employees may develop in their strategies to cope with the challenges of care giving. The study was also interested in the coping mechanisms or ‘resistance’ that caregivers develop in order to be effective. Leedy and Mood, (2010: 12) stated that the interpretation of data is the most important aspect of the research.
The researcher analysed data by examining, organising, combining, and categorizing the patterns in such a way that the research objectives for the study were addressed. The in-depth interview data as well as the information obtained from the focus groups were thematically ordered so that in the interpretation, this approach allowed the researcher to identify similarities, differences and exceptions, thus letting the reality of the care giving problem to emerge and provide explanations. The ordering of the data was done in such a way that each question was ranked in accordance with how participants answered; similarities in answers given identified and grouped together under one theme; differences also identified and grouped in one theme; strong suggestions rated; and a conclusive discussion followed to give a better interpretation of the results.

### 3.10 DATA VERIFICATION

According to Ghauri and Gronhaug (2002: 28), in qualitative research the following types of validity are often emphasized: In this study, the researcher investigated on whether care giving has effects on caregivers and explore on the challenges encountered by caregivers during the process of care giving.

**Descriptive.** Descriptive validity refers to the degree to which the actual description holds true. In this study, the narratives of caregivers were transcribed verbatim from the audio-recordings made during individual and focus group discussions. The narratives were selected for the connectedness in themes and no fabrication was attempted and this therefore gave the findings an element of descriptive validity.

**Interpretive.** Themes and patterns were identified and the interpretations were based on actual and verifiable data. Consequently, interpretations become interpretively valid as the data corroborates these assertions.

**Generalisable.** As a limited study conducted in North-West province, the study’s findings may not be generalised to the entirety of the country. Ghauri and Gronhaug, (2002: 28), argues that internal validity in quantitative research refers to the establishment of cause-and-effect relationships. Internal validity places emphasis on constructing an internally valid research process and in establishing phenomena in a credible way. Qualitative research intends to explore generative mechanisms looking for the confidence with which inferences about real-life experiences can be made.

### 3.11 RELIABILITY

The concept of reliability, according to Ghauri and Gronhaug, (2002: 28), depends on the extent of findings being possibly replicated *ceteris paribus*. According to Ghauri and
Gronhaug, (2002: 28), theory is generated that places single data in a broader context and that when conceptualization has taken place, but not been extended enough to provide a context, one risks losing knowledge through misunderstanding and misuse. In this study, the researcher interviewed the participants and used the information thereof to establish the truth in issues of care giving and caregivers’ challenges and experiences when dealing with HIV/ AIDS positive clients.

3.12 RESEARCH PROCEDURE

The research procedure started with writing of proposal for consideration and approval by the Higher Degrees Committee and Ethical committee of the Human and Social Science faculty of the North-West University (Mafikeng campus). When the proposal was accepted, the researcher sought permission to conduct the study from the three home based care centres. The consent and orientation of participants was subsequently followed by collecting data that answered the two research questions set at the onset of the study. After interviews, starting with the individual ones which were subsequently followed by the focus group ones, all the data that was in Setswana was translated into English by a translator the researcher identified from the North-West University. The researcher analysed the data, formulated findings and made recommendations that were informed by the data.

3.12.1 Trustworthiness

Trustworthiness is based on the systematic collection of data and allowing the procedures and findings to be open to critical analysis from others. To establish trustworthiness, Babbie and Mouton, (2001:66), suggests the concepts of credibility, transferability, dependability, and confirm ability as essential decisive factors for quality in qualitative research. In this study, trustworthiness was established through the recording of the interviews and the field notes so that these could be checked. The records that the researcher holds are part of the credibility and can be depended upon as accurate records of the interviews and focus group discussions.

3.12.2 Credibility

To ensure credibility, the methods and procedures for identifying participants were described. Approximately six weeks after the interviews were completed, 20 transcribed data was presented to the caregivers to validate emergent categories and themes and confirm the accuracy of the interview transcripts. Caregivers confirmed the accuracy of their transcripts and the interpretation of their comments. In order to verify the data, member
checking reflected the participant’s actual experience provided during the interview as it is the art of confidence in the truth of data (Smith, 2004:12).

To maintain referential adequacy, a tape recorder was used during each participant’s interview as suggested by Mouton, (2001:45). Allowing participants to analyse what was shared between the interviewer and interviewee, is mentioned by Smith and Rapkin, (1996:55) as one of the most important steps for establishing “truth”. Additionally, sufficient time was spent with each participant during the individual interviews until the data was saturated.

3.12.3 Transferability

The results section provides verbatim quotations to permit the reader to assess transferability (Le Roux-Kemp, 2013:12). According to Marshall and Rossman, (2014:45) transferability is the extent to which results can be transferred to another context. This was done through detailed description of the research procedure. This study utilised multiple methods of data collection including individual interviews and focus groups.

3.12.4 Confirmability

The researcher compared raw data, analysis notes, process notes and personal notes. The researcher thus demonstrated the neutrality of the research interpretations through the comparison of data. The process of data collection and analysis are also described in detail so that the reader can follow the research trail. Findings and conclusions can be justified in relation to the material.

3.13 ETHICAL CONSIDERATIONS

Ethical clearance was granted by the North-West University Research Ethics committee to undertake field work. In preparation to conduct interviews, the researcher wrote a letter to the Love, Lomanyaneng and Danville home based care managers indicating the background of the study and requesting permission to conduct interviews based on the topic of the research. The letter to the management of the home based care centers highlighted that total confidentiality was guaranteed and that all that was required was an honest opinion on their experience for academic purposes.

Thus, the letter indicated that the researcher would handle the interviews and focus groups with utmost confidentiality and that the names of the participants would not be revealed. It was also important for the researcher to assure potential participants they were not obliged to answer questions they find intrusive or that make them uncomfortable even though
responses to all the questions would add value to the study and most certainly assist in developing a better understanding of the subject. The final report was made available to all participants who may want a copy.

According to Strydom in De Vos et al., (2007: 24) a researcher needs to pay attention to the following aspects in order to ensure that the study is in fact ethical. The ethical aspects adhered to in this study are:

3.13.1 Potential harm to participants
Strydom in (De Vos et al: 2007:64) asserts that subjects may be affected either physically, psychologically or even emotionally. The researcher ensured that the participants were interviewed in a safe environment. The researcher also intervened and referred one caregiver who recalled traumatic experiences resulting in disturbance and emotional torture to a professional counselor.

3.13.2 Informed consent
Informed consent implies availing to all participants’ information regarding the nature and the extent of the inquiry at the disposal of the researcher. The prescribed procedures that were adhered to prior to the field work, during field work and on completion of field work by the researcher. Observation was done to ascertain the pros and cons of the research study, achievements, limitations and shortcomings to which participants were exposed. Informed consent was requested from potential subjects (De Vos et al, 2007.65).

The researcher did not force the participants to be part of the study. She obtained written permission from each volunteer to participate in the research field work. Permission for allowing the Masters student to carry out field work was granted. The aims and objectives of the study were articulated by the field worker and the participants were given liberty to withdraw as and when they wished during the process of field work. The researcher also ensured participants’ full knowledge of the intended study, sought the cooperation of the participants and dealt with any possible tension, aggression, resistance or insecurity of the participants.

3.13.3 Violation of privacy/ anonymity/ confidentiality
These three elements of ethical consideration are similar and more or less related to each other. De Vos et al, (2007: 67) define privacy as “that which is normally not intended for others to observe or analyze”. This confidentiality principle can be violated in a variety of ways and researchers are duly reminded of the importance of safeguarding the privacy and identity of participants and to act with the necessary sensitivity and where the privacy of
subjects is relevant. The researcher did not violate privacy, anonymity and confidentiality aspects as proposed in the research ethics.

3.13.4 Deception of participants
According to Strydom (in De Vos et al., 2007:66), deception means keeping information to yourself and not dishing it out to people who need it and at times providing them with the wrong information to try and convince them. Leedy (1993:56) describes the deception of subjects as “deliberately misrepresenting the facts in order to make another person believe what is not true, violating the respect to which every person is entitled”. In this study the researcher put more emphasis on participants to be aware of the goal of the study, the objectives and her expectations. The researcher also ensured that their right to self-determination was respected.

3.13.5 Actions and competence of the researcher
Leedy (1993:56) articulates that “even a well-planned research can fail or can produce invalid results if the researchers and / field workers are not adequately qualified and equipped and if there are no adequate resources in the project. The researcher was ethically obliged to exercise competency and be adequately skilled to undertake the proposed investigation. The researcher ensured that the research project ran its course in an ethically correct manner. The researcher intended to exercise competence and her skills in all respects.

3.13.6 Debriefing of participants
Leedy (1993:56) mentions that through debriefing, problems generated by the research experience can be corrected. He further articulates that the easiest way to debrief participants is to discuss their feelings about the project immediately after the session or to send a newsletter telling them the basic results of the study.

From the researcher’s point of view, debriefing is an ideal situation more especially when dealing with caregivers as they go through very traumatic and stressful situations in their tasks of caring for HIV/ AIDS patients. Although debriefing was time consuming as there was a likelihood of having mostly emotionally affected caregivers amongst the participants, the researcher create enough time to cater for those individuals. Those individuals affected emotionally were assisted by the researcher as she has been trained in debriefing of caregivers. The researcher minimized possible harm that may have been done in spite of all precautions taken against such harm.
3.14 LIMITATION OF THE STUDY

This study has been limited to caregivers of HIV/AIDS patients in Mafikeng and the findings cannot be generalized. Some of the responses of the participants could have been influenced by the fear of the participants to be excluded from care giving.

3.15 CONCLUSION

In this chapter, the researcher discussed the research methodology in which a descriptive research design utilizing a qualitative approach was pursued. The research design, research setting, study population and sampling, the inclusion criteria, research procedure and the methods employed to analyse and verify the data were described. Finally ethical considerations were presented. The findings of this study are presented in the following chapter.
CHAPTER 4
DATA ANALYSIS, INTERPRETATIONS AND PRESENTATION OF FINDINGS

4.1 INTRODUCTION
The data of this study are presented in two parts. The first part presents the background information on the caregivers while the second part presents the opinions and experiences of the research participants. Each research question’s exploratory nature is examined in a descriptive nature but combined with illustrations of diagrams. The open ended questions meaning has also been inferred. The individual and focus groups findings were grouped together and the emerging themes discussed. These are presented below.

4.2 DEMOGRAPHIC INFORMATION OF PARTICIPANTS
The demographic data provided information on the caregivers' age, educational background and the experience in the care work in order to have an understanding of care giving experience.

4.2.1 Age of participants

Table 3: Age of participants

<table>
<thead>
<tr>
<th>AGE</th>
<th>NUMBER</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-20</td>
<td>3</td>
<td>15%</td>
</tr>
<tr>
<td>21-25</td>
<td>3</td>
<td>15%</td>
</tr>
<tr>
<td>26-30</td>
<td>4</td>
<td>20%</td>
</tr>
<tr>
<td>31-35</td>
<td>5</td>
<td>25%</td>
</tr>
<tr>
<td>36-40</td>
<td>5</td>
<td>25%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>20</td>
<td>100%</td>
</tr>
</tbody>
</table>

The age of the participants ranged between 20- 40 years. Half of the participants were younger than 30 while the other half were between the ages of 31 and 40. This fact confirms the fact that caregivers are young and therefore often vulnerable to trauma as they have to provide to ailing patients more likely to be older than them.
4.2.2: Gender of participants

Table 4: Gender of participants

<table>
<thead>
<tr>
<th>AGE</th>
<th>MALE</th>
<th>FEMALE</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-20</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21-25</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>26-30</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>31-35</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>36-40</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5</td>
<td>15</td>
<td>20</td>
</tr>
</tbody>
</table>

The caregivers shared the view that men in general see other men as easy to relate to and as confidantes. They felt that many of those not infected tend not to share a lot of their domestic problems and frustrations with their partners but will readily open up. Due to this discomfort, male patients are reluctant to receive care from female caregivers. Male patients also have the fear that women will gossip about their genitals after bathing them. Hence the caregivers were motivated by the fact that others and the community in general appreciate their role where they stick to confidentiality and hardly ever disclose the conditions of those that they look after.

The need for gender equality crusade motivates people of all genders to become caregivers. Literally, all the interviewed people shared the view that in this era of HIV/AIDS, care can no longer be left to the women alone.

However, due to culture, the community is divided in terms of what men’s and women’s roles and responsibilities should be. Consequently, the burden of looking after the sick is generally left to women, but when men are terminally sick, they do not want to receive care from women. Hence some caregivers during focus group discussions felt that they needed to do something to encourage others to get involved in HIV/AIDS care. Sometimes female patients are reluctant to be cared for by men, and then caregivers organize female caregivers to take care of the patients.
Although male caregivers said they do not choose whom to provide care for, they felt comfortable caring for male patients because these patients easily opened up to them. However, they were obliged as part of their duty to provide care to even the female patients without discrimination because their work ethics demand them to do so. A very revealing statement was offered by one caregiver on the question of whether they preferred specific gender providing care to HIV/AIDS patients: “...I do not mind the identity and sex of the person who I look after. They can be equally nice or difficult. It depends.”

The study revealed that although five of the male caregivers bathed and changed female patients, they didn’t do it out of choice, but because their work ethics demanded. All the caregivers were comfortable washing and changing patients irrespective of the gender of the patient. However, two male caregivers admitted that they were unwilling to wash and change their female patients admitting that although some female patients would like to be cared for by men, they prefer them to lift and move them than wash and clean their bodies. The researcher observed that in both the interviews and focus group discussions, caregivers were comfortable to bath and change female patients. The caregivers therefore sometimes go out as teams and attend to patients as couples.

Male caregivers are also challenged by female caregivers’ attitude especially when they have to deal with the ablution challenges of the patients. One caregiver felt that female colleagues felt uncomfortable with their male counterparts doing some of the chores that ‘are meant for women’.

Although culturally, care giving is not a male domain, nonetheless there are some cultures that do not perceive it the way African culture do. They see all being equally important.
4.2.3: Educational level of participants

Table 5: Educational level of participants

<table>
<thead>
<tr>
<th>Educational level</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 1-5</td>
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<td>5%</td>
</tr>
<tr>
<td>Grade 6-8</td>
<td>3</td>
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</tr>
<tr>
<td>Grade 9-12</td>
<td>16</td>
<td>80%</td>
</tr>
<tr>
<td>Tertiary</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>20</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

Sixteen participants completed Grade 12, but one participant went to school until Grade 5, three participants went to school up to Grade 8, and none furthered their studies up to a tertiary level. The educational level of participating caregivers differs from Amoateng (2015: 134) where a significant 5.7% of the caregivers had attained a tertiary education.

4.2.4: Marital status of participants

Table 6: Marital status of participants

<table>
<thead>
<tr>
<th></th>
<th>Single</th>
<th>Married</th>
<th>Widower</th>
<th>Divorced</th>
<th>Separated</th>
<th>Cohabiting</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>MALE</td>
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<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>FEMALE</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
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<td>4</td>
<td>4</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>20</td>
</tr>
</tbody>
</table>

Most caregivers are single as compared to those who are married, widowed, divorced, and separated and those who are cohabiting. Amoateng (2015:137) mentioned that most caregivers are single and in some cases female caregivers may engage in commercial sex work to meet financial needs and this may lead to high risk of contracting HIV/ AIDS/ AIDS and further compounding the situation.
4.2.5: HIV/ AIDS status of the participants

Table 7: HIV/ AIDS status of participants

<table>
<thead>
<tr>
<th></th>
<th>NEGATIVE</th>
<th>%</th>
<th>POSITIVE</th>
<th>%</th>
<th>NON DISCLOSURE</th>
<th>%</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MALE</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NEGATIVE</td>
<td>2</td>
<td>10%</td>
<td>1</td>
<td>5%</td>
<td>2</td>
<td>10%</td>
<td>5</td>
</tr>
<tr>
<td>FEMALE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NEGATIVE</td>
<td>5</td>
<td>25%</td>
<td>3</td>
<td>15%</td>
<td>7</td>
<td>35%</td>
<td>15</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NEGATIVE</td>
<td>7</td>
<td>35%</td>
<td>4</td>
<td>20%</td>
<td>9</td>
<td>45%</td>
<td>20</td>
</tr>
<tr>
<td>TOTAL</td>
<td>%</td>
<td></td>
<td>%</td>
<td></td>
<td></td>
<td></td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>35%</td>
<td></td>
<td>20%</td>
<td></td>
<td>45%</td>
<td></td>
<td>100%</td>
</tr>
</tbody>
</table>

Nine of the participants did not disclose their HIV/ AIDS status. 20% of the caregivers admitted that they are HIV/ AIDS positive.

4.2.6 Caregivers’ work experience

Table 8: Caregiver’s work experience

<table>
<thead>
<tr>
<th>CAREGIVER’S EXPERIENCE</th>
<th>NO OF CAREGIVERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 11months</td>
<td>8</td>
</tr>
<tr>
<td>12 - 23 months</td>
<td>7</td>
</tr>
<tr>
<td>24 - 35 months</td>
<td>2</td>
</tr>
<tr>
<td>36 - 47 months</td>
<td>2</td>
</tr>
<tr>
<td>48 - 60 months</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>20</strong></td>
</tr>
</tbody>
</table>

The participants agreed that they lack comprehensive experience to perform their tasks effectively. Half of the participants said that lack of experience hindered their performance but they continue to improve through continuous training they receive from the home- based
care centers as well as the funders. The newly employed caregivers on average attend to 15 patients in a month while the more experienced caregivers on average attend to 45 patients in a month. The more experienced caregivers receive a better stipend as compared to the less experienced. It could be argued that since the more experienced caregivers receive a better stipend, they are inclined to regularly come to work and go into the field on a daily basis, while the less experienced ones are sometimes forced to supplement their income with other part-time employment in order to get some income. A succinct statement in this regard was captured from one respondent: “I have been doing this for many years now. I know how to deal with each case because you can see patterns. And when you see this you know how to handle your patient. Of course doing more patients also means some more money for things at home.”

Nine of the participants did not disclose their HIV/AIDS status. 20% of the caregivers admitted that they were HIV/AIDS positive.

4.3 OPINIONS AND EXPERIENCES OF PARTICIPANTS

4.3.1 Treatment of HIV/AIDS in Mafikeng
From medical records held at the provincial hospital, the incidence of HIV/AIDS is high in Mafikeng. (DHIS Report, retrieved on the 12th August 2015). As a result of the high incidences of HIV/AIDS, caregivers find themselves overwhelmed by bedridden patients that they have to attend to. One of the research participants said “……People are sick but they only go to hospital when they can’t walk or talk. This time it is late. It is very late and the hospitals say they must go home. That is when the caregivers come from family members.”

Another indicator of this epidemic came from one participant who said “……some ill people do not show too many signs. Some can be fat and big but inside they are already eaten by the disease.” This respondent indicated that it is victims of the disease who do not show any outward manifestation of the dreadful disease that suddenly collapse and call for the assistance of caregivers because they hate and fear the public labeling and stigmatising people who are HIV/AIDS positive.

4.3.2 Association with patients
This study established that participants were motivated to become caregivers to care for relatives (9) and friends (7), rather than caring for individuals they do not know. (4). A statement from one of the first nine participants said “….Who else could look after my brother if I did not. I find many challenges, but you see, he is my mother’s child, my brother. I have to look after him”. Caregivers agreed that care giving can no longer be left to the families of the
sick alone because they also get infected and are then in need of home based care themselves, therefore money or earning a living was not the most motivating factor. In this regard, one of the participants was very clear in suggesting “……I look after a sick person who can’t even help himself. Many times I clean him everywhere. He is not my relative and I know I get something to feed my own siblings when I am done with the day.”

This is further highlighted in chapter two by Compton and Galaway (2005:5) who believes that there is an interaction in human beings and their environment. This was emphasized by caregivers when they cared for the HIV/ AIDS patients and strive to see them well irrespective of the relationship they had with them. There was a holistic and compassionate care and support that prevailed between the home-based care caregivers and the HIV/ AIDS patients.

4.3.3 Stigma and discrimination

Stigma and discrimination is still a big challenge, even among the caregivers. Sixteen (16) participants agreed that they became caregivers because of the need to care for their own relatives and families, only four participants disagreed that it was because of the need to care all South African citizen regardless of the relationship they have with the patient. These four caregivers believed care giving is a call that inspires them to become caregivers. However, in African communities, the two words ‘family’ and ‘relative’, can be used interchangeably where one may use the term ‘relative’ to refer to ‘family’. The participants might have hidden from disclosing HIV/ AIDS in their immediate families and opted to use the term relatives. This is an indication that even among caregivers (people we expect to speak freely about the pandemic), there are those that are still not comfortable with disclosing HIV/ AIDS in the family due to the stigma.

One caregiver during the focus group discussion openly admitted that he became a caregiver after a family member had contracted HIV/ AIDS. He highlighted that it dawned on him as a man that he needed to get involved in care giving, when he a family member was diagnosed with HIV/AIDS.

However, caregivers are working towards addressing the stigma attached to HIV/ AIDS/AIDS and that constitutes one of the reasons why they joined care giving. According to the caregivers, many people within the community had the perception that persons who work with people living with HIV/ AIDS are themselves HIV/ AIDS positive. This makes it even harder for community members to discuss the pandemic freely and to access care giving services. Some participants stated the reason for becoming caregivers as wanting to change
people’s mindset on the prevention of HIV/AIDS. A participant at the focus group discussion explained that for him, he wanted to see change in his community.

Some people within the community are committed to the wellness of their communities in order to curb the issues of stigma and discrimination and encourage individuals to test for HIV/AIDS without fear. They therefore become caregivers in order to help their community members who are in need of help after being diagnosed with HIV/AIDS. Many people are less knowledgeable of HIV/AIDS issues because they do not gain knowledge or attend HIV/AIDS workshops.

4.3.4 Roles performed by caregivers

4.3.4.1 Emotional support

Out of the 20 participants, 11 (55%) admitted that they give emotional support to people living with HIV/AIDS. Participants often linked emotional support to spiritual guidance. “…Each time we start with praying. I am used to it. When we do not start with a prayer, she asks in her small voice why we could not. Then we kneel and say healing words, at time reading some scripture in her language.” According to Dejong (2003:58), the caregivers are also overburdened with activities. Once they have assisted a family, they raise the families’ expectations and therefore the family members keep on requesting for a wide variety of assistance from caregivers.

4.3.4.2 Physical support

Ten participants (50%) were involved in food parcel distribution and bathing, changing and feeding of patients and attending to pressure points and exercising patients. One of the participants indicated the occasion when parcels are distributed makes a huge impact “…When you have some parcels for them, they get relief. Somehow, the parcels do not always have the patient’s favourite food, but if you are lucky, hey, they really enjoy. And you also feel they are getting better.”

Due to poverty and lack of enough funding for home based care projects, caregivers are sometimes forced to personally contribute to the basic needs of the patients. At times, caregivers are forced to contribute whatever little they have from their own pockets to contribute to the basic needs of the patients.

The researcher noticed that there is an attachment that exists between caregivers and the HIV/AIDS positive clients they care for.
4.3.5 Educational roles of caregivers

The caregivers’ role within the community was not limited to the treatment and care but also included prevention and the education of those already infected and that of the community at large. Some caregivers took a leading role in a myriad of prevention initiatives including organizing campaigns, peer education, health promotion, and referral of patients to other service providers as well as accompanying patients to the clinic. Other caregivers perform counseling, caring for the orphaned and vulnerable children and do health promotions through condom distribution and sex education. They also participate in radio talk shows and forums and organize sporting activities for the youth both in and out of school. Caregivers provide education to the youth focusing amongst other topics on their problems and how they can help each other. They also distribute information, education, communication materials and condoms.

Caregivers organize and conduct a number of campaigns including door to door campaigns and campaigns targeting industries e.g. the taxi industry. The participants highlighted an awareness campaign for taxi drivers with a view of changing the mindsets of taxi drivers on gender equality and how they treat sick people. Some taxi drivers do not have patience with the sick commuters using their taxis. They would sometime put money first before human life or continuously harass sick people. In collaboration with the community radio station, caregivers conduct talk shows to educate community members on gender equality, human rights and many other issues affecting their community. Open days and talk shows are utilised to extend the knowledge of the community including the HIV/AIDS patients. During these shows they urge all community members to participate in providing care for their families by taking the kids to clinics when they are sick or even by just accompanying their partners.

4.3.6 Support groups

Caregivers, has identified in this study, that running support groups for people living with HIV/AIDS and for people affected directly and indirectly by HIV/AIDS. One of the participants said, "... I am the one who initiated the formation of the support in the home-based care programme. We initially requested the government to intervene and assist us, but they are so reluctant." They encourage members of support groups to live positively and tackle issues of stigma. Caregivers are also engaged in the support of orphans and vulnerable (OVCs) through feeding programmes, helping in school matters, assistance in accessing social grants and identity documents. Majority of these orphans lost their parents due to HIV/AIDS.
4.3.7 Attitude towards caregivers

Crisis situations like HIV/ AIDS, massive unemployment and poverty has led to increased dialogue and efforts to get community members involved in combating social problems. In South Africa this is culturally complicated since decision-making has been the domain of males derivative from its patriarchal outlook.

In this study, caregivers made decisions to join this vocation at the cost of their being rejected by their own communities. Caregivers submitted to the researcher that they were ridiculed by their own society as they perceived the vocation as not worthy of their service. One of the participants said, “…communities are reluctant to care for their ill patients, we are the ones’ bathing them, ensuring that there take their treatment on daily basis but we are not even recognized in our community”.

4.3.8 Stigma associated with participants

A general view held by participants is that stigma for people living with HIV/ AIDS is still very high in the community hence some people who are in need of services rendered by caregivers are reluctant to access it because of the anxiety of being labeled or their status disclosed. Some patients are abandoned by their families once their status is known to be HIV/ AIDS positive. Some community members are reluctant to allow caregivers into their homes to avoid neighbours and relatives to label them as HIV/ AIDS positive. When neighbours and relatives talk, one interviewee added, ‘the walls have ears and thus the negative and stigma words said quickly reach the patient. When they hear it, the patient is hurt and very low emotionally.’

To deal with minimizing the stigma during home visits, care workers take a comprehensive care approach where they include the care and visits of patients with other chronic diseases in the community like diabetes, malaria, etc. According to Makubalo and Msiska (1995:22), this approach has also been proven successful by Topsy Foundation, a community based organization in Mpumalanga to encourage AIDS patients to access services of caregivers. The comprehensive approach helps to reduce victimization and the stigma for those visited and those living with HIV/ AIDS (Letamo, 2011). This is supported by Akintola study that established that care programmes in Uganda and rural South Africa included the care of patients with other chronic ailments (Akintola, 2004:32).

4.3.9 Lack of cooperation from the health professionals

The participants complained that the health professionals at the government clinics were not very helpful. They do not always recognise the complementary role that the caregivers play
and hence don’t always provide much support to caregivers. For example, when caregivers take patients to the clinic, they are forced to queue with patients. They therefore waste time in the clinic that could have been utilised to help sick patients in the community. The caregivers are not given preference at the clinics and waste time in long queues collecting medication for the HIV/ AIDS patients at clinics and hospitals. The majority of caregivers who have experienced such demeaning experiences captured this in the following statement: “….I am not ill. I go to the clinic to assist a patient. But yoh! The nurses make you stand in the line as if you too are sick and have to wait your turn”.

The caregivers also complained that the staff at the clinic is not friendly; hence the caregivers are discouraged from accompanying their patients just going to the clinics for voluntary testing and counseling. One of the participants said” the nurses do not consider us as important or doing a responsible job. They just treat us as cheap”. This is supported by a study conducted by Dejong (2003:54) which revealed that it is possible to get men involved in the reproductive health care of their partners but the challenge remained with the health system Dejong (2003:55), Due to lack of friendliness, men did not benefit from the knowledge given to their partners during their partners’ visits to the clinics. Even in places where men get involved in maternity care, little attention is given to the relationship between father and baby and little information is provided on the topics relevant to them.

Men are not diagnosed early and continue to spread HIV/ AIDS to their sexual partners. The health policy on medicine distribution for home- based care is also not conducive. This was justified by one of the participants who said “many times the men just talk among themselves. Only when they see that they cannot hide anything anymore do they go to the nurses to tell them.” Caregivers cannot give pain killers to patients as this has to be done by the nurses or other medical practitioners. Hence patients suffer as they cannot be given basic medicines by the caregivers. This was established by Akintola (2004:22) in his comparative study where volunteer caregivers in South Africa cannot administer any drugs as opposed to their colleagues in Uganda.

4.3.10 Overburdened

Sometimes the caregiver’s intention may be to provide care but when they consult with the patients, they also realize that they also need psycho-social assistance. Some of the patients are foreigners and lack the legal documents that can enable them access government medical facilities. The caregivers then have to go an extra mile to assist them secure the right documents and refer them to the right resources. One of the participants
alluded that “I am so overwhelmed by the fact that I go all out to assist my patients. I am the one who ensures that they get their treatment, their social grants and ensuring that they adhere to treatment on daily basis.” Some of the patients have been abandoned by their families hence it is not easy to trace their next of kin and when they die, the community or their relatives will approach the caregivers requesting them to organize their burial. Akintola (2004:28) documented that some volunteers assist with house chores like cleaning the houses, washing, cooking and running errands.

4.3.11 Lack of transport

Some of the participants lacked transport and therefore use public transport or walk. Sometimes they have to endure harsh weather to reach their patients. They also do not have reliable transport to respond adequately to the needs PLWHAs. Sometimes they receive calls late at night but because they do not have transport they cannot assist them. Sometimes they don’t even have airtime on their cellphones to respond to the emergency calls. In addition, they end up having to carry the bedridden patients to the clinic or walk long distance with them to the taxi ranks.

4.3.12 Lack of funding

A majority of the caregivers alluded that the Department of Health and Social Development do not fund the three home-based care programmes sufficiently on an annual basis. At times the two Departments encounter budget problems and that affect their financial support for home based care programmes. One of the participants said “…… In 2010, we were not funded by both the Departments and it was tough, I walked every day from Motlhabeng village to Lomanyaneng. At times men would offer me a lift with a tit for tat attached to the lift. If there is no funding, we cannot even have a cent to even purchase fat cakes for breakfast and we end up eating a patient’s meals.” It is evident from this statement that even the caregivers are susceptible to infections when they trade their bodies for transport. It appears imperative that funding should therefore be adequately budgeted for so that caregivers can execute duties without compromising their health status and the work that they offer to do.

4.3.13 Insufficient remuneration

Caregivers have financial pressure from their families and have to provide for their families, male caregivers cope better than their female counterparts. Participants said they receive a stipend between R2 500 and R3 000. However, all participants agreed that they are under
intense pressure to provide for their own family needs. Although they receive stipends, the family expenses and expectations are often higher than their income.

Caregivers love what they do, they work long hours, attending to very sick people and by the time they get home they are very traumatized. This exhaustion is also exacerbated by the low stipends that they receive. One respondent said, “....What do you do with R1 500? If you buy things to eat, all the money is gone and tomorrow you have not enough to visit the patients. They need us but, eish, they pay little. So little at times you feel it is better just staying at home.’ However, they always have debriefing sessions every Monday to help cope with the psychological effects arising from the inadequacy of the stipend that they receive.”

Although they are not compensated commensurately, the caregivers, through the training they have received, feel empowered and will continue to provide care as long as there is still need within their community and as long as there is no cure for HIV/AIDS. They felt that due to their love for their community, they will continue to work towards an HIV/AIDS free generation.

Banks, NGOs, churches and department stores, Department of Health and Social Development are some of the agencies that provide material and spiritual support to caregivers. However, because these are not systematically coordinated, the challenge of adequate funding remains unresolved. It emerged from the interviews with the participants that a systematic and streamlined support fund is needed in order to get the whole activity running smoothly. Radio stations and other public enterprises join the funding pool when they have some excess from their own funding programmes need to be harmonized and synchronized for a robust care giving programme operational at municipal and national levels.

In terms of economic impact, the complex intersections of inadequate funding and low stipends generate multiple anxieties. One participant summed this clearly: “.....Money is always a problem because the stipend we receive is too little to meet our basic needs. We receive our stipend only for twelve months. When the stipulated time lapses we do not get anything but have to continue rendering services freely to our clients so that they do not suffer. Food parcels will not be provided when the allocated funds are exhausted.” The impact here is dual: on the patients and the caregivers. When such a conflation of negative elements occurs, then the task of care giving is compromised in heavy ways. The stipend is only for twelve months because the home based care programme should benefit the majority
of young people in the community and they should give others a chance also so that at the end of the day they are all equipped and capacitated in home based care programmes.

4.3.14 Rejection by family and community members
Because HIV/AIDS is not fully understood, caregivers suffer a double alienation from family members and communities at large. There is a general perception that caregivers can only be HIV/AIDS sufferers themselves if they have the courage to look after infected individuals. One respondent said, “....They look at us with eyes that say, even you! You know, when they don’t say it in words, you can see their eyes accusing you. And it’s so bad because some of us are clean.” The general perception, which is medically unfounded, traumatizes caregivers and it is more painful because these accusations come from members that they are closest to, members who ought to be providing moral courage and support.

4.4 EFFECTS OF CARE GIVING ON CAREGIVERS

4.4.1 Psychological impact
The participants in this study made statements that certainly show there are consequential psychological effects emanating from the work that caregivers do with HIV/AIDS patients. One participant stated that: “...If our clients do not get better, it poses stress to us. And it is as if we are not doing enough as caregivers. Our minds get disturbed more especially when our patients die whilst still receiving our care.” It is evident in this remark that caregivers are assailed by many psychological challenges, and the worst is the inevitable death of those in their care.

Care giving is obviously not just a physical activity but it is also emotional engagement. Pity, sorrow, fear and anxiety are staple feelings conjured in the connection between the ailing patient and the caregiver. The following captures the voice of one caregiver: “....At times we tend to sympathise with our patients instead of empathizing with them. When our patients are too weak and bed-ridden, we feel so sorry for them and wish they could recover soon. This anxiety also becomes a psychologically indelible experience that haunts the caregivers on endless occasions.”

4.2.2 Physical impact
Three participants emphasized that they get physically drained in walking to visit the patients. In their words, “....we believe walking is part of an exercise as we are used to it every morning although some of us get exhausted during the visits and after. Sometimes the
legs get swollen after home visit because we have to walk far areas such as Setlopo, Majemantsho and GaSehuba to carry out our home visits." Over time this tiredness has a cumulative effect on the well-being of the caregivers.

4.5 CONCLUSION
Data gathered in this study revealed that the volunteer caregivers are young, below the age of 30 years and provide care to relatives and friends and provide emotional support such as counseling. Other roles include distribution of food parcels, bathing, changing and feeding patients and lifting and accompanying patients to health facilities. They also participate in campaigns, talk shows and support groups and their work extends to the provision of care to AIDS orphans.

The data also revealed that men felt comfortable caring for others because patients easily opened up to caregivers. Women caregivers were also reluctant to be cared for by men. Hence male voluntary caregivers preferred to bath and change male patients.

The stigma associated with HIV/ AIDS still remains a big challenge not only for the patients but also for caregivers and the health professionals. However, men’s involvement in care giving is helping to change the mindset including reducing the stigma. Culture and tradition hinder the provision of care by voluntary caregivers. However, the study revealed that other people in the community are beginning to change (‘soften’) in the way they perceive male caregivers. They are shifting and beginning to treat them with respect.

The negative attitude of the health professionals can be a major challenge. Health professionals have not recognised and appreciated the complementary role of caregivers and hence are not supportive.

It was also observed that male caregivers are less experienced compared to their female counterparts. The less experienced the voluntary caregivers is, the less number of clients he provides care for in a month. In addition, more experienced voluntary caregivers received higher stipends compared to their less experienced colleagues. This compromised the quality of care and made care giving unreliable as those on lesser stipends and reported daily were overburdened.

All in all, voluntary caregivers felt determined to continue providing care and are able to cope with family responsibility pressures. Through the training that caregivers have received, they felt empowered and promised to continue with providing care as long as there is still need in their community and as long as there is no cure for HIV/ AIDS.
In chapter 4 only data from participants was compared to literature. In chapter five the data under each heading was summarised— one of two sentences and that is the findings and then the conclusion on opinions about each one of topics. Chapter five gave recommendations on each conclusion and was a conclusion based on:

- practice of caregivers
- social work knowledge extension based on this study
- suggestions for policy changes
- suggestions for future research
CHAPTER 5

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

Chapter five seeks to draw conclusions on the research topic and to make recommendations thereof based on the knowledge, experience and information gained from the data reflected in chapter one up to chapter four. Chapter five indicates whether set research aim and objectives at the beginning have been met or not. It also answers the research question: What are the effects of home-based care of HIV/AIDS patients on caregivers and to what extent do these home caregivers receive support from the community? Motswasele (2008: 24) is also of the opinion that at the end research report, all the research questions should be answered.

The interpretations of this study are based on the data gathered during the interviews with the twenty participants as well as the ten members of the focus group discussions. Calvin (2007:56) also shares the same sentiments that data should inform the final results of this investigation. Focusing on the aim of this study, namely to investigate the effects of home-based care that care giving has on caregivers in the home-based care programme, the researcher investigated factors that contributed to stress and burnout of caregivers during the process of care giving. Kang’ethe (2010:32) also pursued a more related study on palliative care giving and investigated on the validation on care giving in Botswana.

5.2 RESTATING THE OBJECTIVES

This study set two objectives at the onset and these are restated as follows:

- To explore the support systems available to assist caregivers of HIV/AIDS patients.
- To investigate the challenges, experiences and stress encountered by the caregivers of HIV/AIDS patients.

- The above objectives were tested against the following assumptions

  - Caregivers experience challenges during the process of caring for HIV/AIDS patients because they are stressed by the fact that the HIV/AIDS patients are ill and their mortality is almost certain.
  - Palliative Training serves as a tool that contributes towards eliminating their stress levels.
The main objectives of the study were fulfilled in the sense that the challenges experienced by caregivers were fulfilled and examined through identifying intervention strategies that the government should embark on in order to empower caregivers. Amongst others, the intervention strategies include:

- Training on palliative care and Directly Observed Treatment (DOT’s) support for caregivers.
- Empowerment and capacity building through skilling caregivers on HIV/ AIDS palliative care.

Accordingly, the study notes that training is imperative to address challenges experienced by caregivers - amongst others eliminating their stress levels. Van Dyk (2008: 12) also verified in his study that young people do not want to use condoms. As the number of people living with HIV/ AIDS increase the numbers of caregivers will have to increase.

Creswell (2009:85) also finds relevance to caregivers, who most of the time, grieve in anticipation for the terminally ill patients before and after death. This shows that there is synergy and a good relationship prevailing between caregivers and their patients. This also confirms the admission that Akintola (2004:20) also recognises in his study on the attitudes that communities have towards caregivers. This was also confirmed during the focus group discussion.

5.3 MAIN FINDINGS

5.3.1. Support systems

With more than half of the people living with HIV/ AIDS being in Sub Saharan Africa and HIV/ AIDS adversely affecting families by taking away the bread winners and continuously perpetuating the cycle of poverty, it is imperative that individuals, communities and governments leverage on all prevailing opportunities to combat the pandemic.

The literature study in chapter two of the study indicated that South Africa is one of the countries in the world that has high cases of with the highest incidence of HIV/ AIDS. Identification of people living with HIV/ AIDS reduced slightly despite the government having a clear national strategy to combat the pandemic. The public health sector cannot cope with the number of AIDS patients that require admissions in to the hospitals and hence many patients are being sent home either to die or for families to take responsibilities.

A number of NGOs and community organizations have been established to address and attend to the repercussions of HIV/ AIDS pandemic. Many of them have set up Home Based
Care programmes to look after people infected and affected by HIV/AIDS. However, many caregivers are women, which present an additional burden for women. An opportunity exists for all these interventions as this study has shown to improve home based care through teams of female and male caregivers working in partnerships. Therefore involving more men as caregivers could bolster the interventions to another level and increase the quality of care.

Majority of the research participants felt too much work and extra effort needs to be done in order for the health sector to reach their intended objectives for people living with HIV/AIDS (PLWA). It is very crucial to maintain funding or sponsorship as failure to achieve such may result in donors withdrawing from assisting the ART programme. Up to this far, there are limited intervention mechanisms to assist caregivers to provide quality care giving from the government side. The government needs to appreciate their hard work and accept the fact that their work is stressing and with very limited resources. Caregivers also need supportive supervision to boost their morale and to guide them effectively on their daily duties.

Enlisting people into care giving will require a combination of approaches in recruitment. Communities are very sensitive and volunteers from outside their communities are bound to be received with resistance whereas volunteers from their own communities will have higher chances of being accepted. If community members especially community leaders are involved in the recruitment and accompany the voluntary caregivers while dispensing their duties, it is bound to have a multiplier effect as it helps to reduce stigma and encourage other people to become caregivers. Due to limited funding by home-based care programmes, recruiting locally helps to retain voluntary caregivers as it can minimize burnout as the local people do not encounter more financial constraints in renting homes as they are staying in their own home or with relatives. When people enlist as voluntary caregivers, it is important to continuously provide training and regularly hold debriefing sessions in order to empower them as well as counsel them. Most people are inexperienced when they become volunteers and this can compromise quality. Going to the field in teams of equal number of male and female caregivers can be an effective way of providing care giving.

There is also a need to have clear cut roles for voluntary caregivers since currently; they are performing a myriad of activities ranging from physical care, psychosocial care to prevention through community awareness. In some instances these roles are performed by the same caregiver. This approach lacks professionalism and is not the best way to elicit the best care from individuals. This further contributes immensely to overburdening of the caregivers with the roles they need to perform. In some instances, clients end up passing their
responsibilities of taking care of their families and the significant others to the caregivers. A lack of clarity in the career combined with inexperience and lack of training can result into an ad hoc approach that undermines the quality of services provided. Voluntary caregivers need continuous support, i.e. debriefing and training. Funding is needed to provide stipend to the caregivers. Resources such as cell phone airtime, bicycles and medicine can increase the reach of voluntary caregivers. Health professionals need to acknowledge that voluntary caregivers complement their work and perhaps it would help if policy would have to elevate care giving to a full-fledged profession.

There is support system for volunteer caregivers from the Government departments, NGOs and FBO's but it need to be strengthened. This was argued in chapter two of this study by Amoateng et al (2015: 137), that caregivers of PLWA are still faced with psycho- social challenges, including insufficient support, financial, and food shortages. Amoateng further alluded that caregivers are experiencing little support also from the relatives of the HIV/ AIDS positive patients and preferred to seek spiritual assistance more than medical or professional counseling in order to cope.

5.3.2. Challenges and experiences of caregivers
Caregivers and people living with HIV/ AIDS have experienced discrimination and hostility from members of the community. The stigma is not only a challenge that caregivers are battling to change, but is equally a challenge which government is also striving to change to mitigate the impact of HIV/ AIDS. The National Strategic Plan for HIV/ AIDS, STI and TB (2012- 2016:15) strives to address issues of stigma and discrimination for people living with HIV/ AIDS by ensuring the protection of human rights and improving their access to justice. Therefore, healthcare providers and policy makers need to understand the challenges and obstacles that caregivers experience while looking after people living with HIV/ AIDS. This is supported by a study by Dejong (2003:55), which observed that men may also be seen as the principal vectors of their partners’ sexual health regarding STIs.

The confidentiality clause also makes it difficult for caregivers to provide care people who need the service. Sometimes within the communities, they will be individuals who are able to see others with the same condition of HIV/ AIDS, since well they are not identified and have not been referred by medical practitioners, they cannot be helped by caregivers. Such people will still be in denial and do not want any association with the caregivers.
Care giving for HIV/ AIDS programme has emerged at community level involuntarily and the commitment showed by the caregivers makes it an evolving profession still at infancy. In some countries like Uganda, care giving has emerged as a career for those in the field. This is an opportunity that the South African government can capitalize on and fast track the process of making it as a recognised career to improve the quality of service delivered especially that caregivers complement government efforts.

The observation above is also highlighted in the literature segment of this study where Mashau and Maselesele et al (2009:43) argue that caregivers can suffer from segregation and stigmatization. Archer cited in Payne (2005:213) also has articulated views on perceived susceptibility which caregivers found and established as a risk to contract HIV/ AIDS virus as they bath HIV/ AIDS positive patients daily. This was highlighted by the caregivers who revealed that they were HIV/ AIDS negative and believed that they will not contract the HIV/ AIDS virus as long as they to continue to take a good care of them as opposed to those who did not know their HIV/ AIDS status and believed they are vulnerable and susceptible to the disease. This study empirically established stigmatization in instances where caregivers stated that it is not easy for the caregivers to be attended to politely during their first visit at home by both the patient living with HIV/ AIDS and the family members. According to Makubalo and Msiska (1995:22), some men are even comfortable to label women as the carriers of HIV/ AIDS and ready to blame them when the men are HIV/ AIDS positive themselves. People in the community are not readily talking about HIV/ AIDS as it is still considered a taboo and that only promiscuous people get it. Due to this, some community members do not want to welcome caregivers in their homes.

In his study, Akintola (2004:55) observes that the stigma is still very rife in South Africa and has very negative implications for caregivers, people living with HIV/ AIDS and home based care programmes. While PLWHAs are abandoned by their families, the caregivers sometimes assume the burden of caring for the sick and because of the confidentiality clause they keep quite. On the other hand those who need the services are reluctant to access it due to the stigma.

5.4 RECOMMENDATIONS

Under normal circumstances multidisciplinary team including but not limited to medical professional such as doctors and professional nurses, pastors and spiritual leaders, trained counselors and community offer support to families and community caregivers in accordance with their specific needs. Hence, Amoateng et al (2015:1) discovered that caregivers need to
collaborate with the public health sector to provide education and support for themselves, their communities and their patients in home-based care centers.

The following should be implemented in all existing Home-based centers in Mafikeng as well as by the Department of Social Development to ensure quality services rendered by the caregivers to HIV/AIDS patients:

- The two government departments (Health and Social Development) should strengthen their support services as far as home based care programmes are concerned by providing transport for home visits daily.

- The voluntary caregivers should be provided with a relief grant to assist them financially as their remuneration is not enough to cater for their basic needs.

- Home-based caregivers should be professionally recognised by healthcare professionals for the vital work they do and properly consulted on the policy.

- A clear role definition and responsibilities of each of the home-based caregivers and how they fit into the district health system must be defined and applied to all health authorities in the country.

- A defined scope of employment with standardized remuneration and conditions should be developed.

- The home-based caregivers’ continued training, supervision and career development strategy process must begin urgently.

- Local leadership is important in motivating and supporting male caregivers.

- Standardized remuneration can encourage people to choose and stay in care giving as a career. Remuneration is a necessity. The stipend ought to be replaced with a salary to show recognition. If issues of remuneration are addressed, the impact of stressors outside work or secondary stressors can be minimized.

- Educate the health professionals on the role caregivers play to complement in and outpatient treatment.
- Home-based care programmes should form teams of both male and female caregivers to improve the quality of service.

- Use culturally sensitive approaches in challenging the cultural and traditional norms on care giving and HIV/AIDS related issues.

- Home-based care programmes should employ a comprehensive and integrated community approach. When caregivers function in the community, they should not only aim at identifying and assisting HIV/AIDS patients only but should go out to provide care to patients with other illnesses e.g. T.B, diabetes and alcoholism. Establish working relationships between health facilities with home based care programmes to speed up service delivery through referrals.

- Policy to allow caregivers to dispense basic medication like pain killers.

- Training on patient care is suggested, especially when the patients deteriorate to stages that are likely to cause trauma for caregivers.

- Caregivers need to be encouraged to utilise support structures, to deal with the negative effects of stress and burnout.

- Proper selection procedures have to be identified in making sure that those who are recruited have a minimum level of education. Training to equip volunteer caregivers well for the work should then commence thereafter. Anyone who did not complete mainstream schooling should be encouraged to register with any ABET centre. The ABET centers may conduct placement tests to determine the learner’s abilities and competency levels.

- Training them, for example as HIV/AIDS counselors, should be followed by encouraging them to have a clear career path or career security, than being seen as mere “volunteers” or temporary workers.

- Financial planning, budgeting and accountability of NGO’S should be encouraged; Budget shortages can be addressed with organised fund raising.

- Caregivers should register with health authorities. The requirements for registration should include in-service training, supervision and accountability.
• Working conditions to provide for conducive environments that are amenable for the provision of quality service of the care givers.

• It is recommended that future research on the effects of care giving on caregivers should be more extensive in terms of covering the all Provinces since this research was only limited to Mafikeng in the North West Province.

5.5 MAIN CONCLUSION
Volunteer caregivers during the interviews expressed high levels of stress associated with external stressors, as well as high burnout. The volunteers reported using a variety of coping strategies that include active coping to deal directly with challenges, dysfunctional coping and avoidance, which represent doing nothing to deal with situations in their lives as caregivers. There are also registered high levels of burnout associated with the three defined ways of coping, while no specific coping strategy could be linked with low burnout. This suggests that support is needed to help volunteers to deal with challenges of care giving. Capacitating through training in problem-solving skills, exposure to different forms of coping, counseling and psychosocial support will help caregivers to face their challenges without masking or pretending to be coping well. Government and public lobbying for support, registration with relevant professional bodies, furnished offices, reasonable recruitment requirements and compensation are needed to prevent environmental stressors from putting pressure on volunteers, causing them to experience stress and then burnout.

In a case where disclosure for an HIV/ AIDS patient’s status is done, the professionals should exercise appropriate confidentiality skills and in issues of shared confidentiality, there should be an element of sensitivity on the part of the patient who, for example, in cases where the patient is a danger to himself or even to the entire community. Failure to practice that would result in unfair treatment by the community to the patient, the patient might as well be exposed to sexual harassment, assault or even rejection by the family and the entire community. Health care workers should all take an oath and solemn declaration to ascertain the professional bodies that they are affiliated to those issues of confidentiality are legally binding and failure to comply would mean a serious sanction.

The provision of the Bill of rights, which is chapter two of the RSA constitution, 108 of 1996 should be fully implemented in as far as an individual’s right to privacy unfair discrimination are concerned. The issues of confidentiality and the right to privacy do not only address the needs of an individual, but it also protects the public sectors from the litigations which will cost the government millions of rands to redress the situation. The image and the reputation
of the health sector would be tarnished as soon as there is breach of confidentiality. Both the affected and infected individuals who recognises that there is privacy and confidentiality prevailing in health institutions will be able refer their loved ones, colleagues, friends and relatives to come to the health sectors and look for assistance, diagnosis, treatment and ART management.
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Dear Sir/Madam

SUBJECT: MASTERS RESEARCH FIELDWORK

I am currently pursuing my final year (Masters in Social Work) registered with the North-West University. I am investigating the impact of Home-based Care of HIV/AIDS patients on caregivers using Mafikeng as a case study.

This letter serves to request your management to allow me to carry out my research interviews on the information provided by the caregivers will assist me in my findings on the subject matter and will enable the researcher to come up with informed conclusions and recommendations as far as care giving in H.C.B.C’s is concerned.

I will appreciate if I can be able to interview five (5) caregivers from your organization.

Your assistance will be greatly appreciated.

Ms Funky Tsheboeng
(MA Student – NWU- Mafikeng)

Dr M. De Chavonnes-Vrugt (Supervisor)
APPENDIX B

TOPIC: THE IMPACT OF HOME – BASED CARE OF HIV/AIDS PATIENTS ON CAREGIVERS: A CASE STUDY OF MAFIKENG

INTERVIEWS SCHEDULE

DATE …………………………………………..

NAME OF THE ORGANISATION ………………………………………………………………………..

1. SOCIO-DEMOGRAPHIC INFORMATION

A. AGE…………………………………………..
B. GENDER ……………………………………
C. MARITAL STATUS ……………………..
D. HIGHEST QUALIFICATION OBTAINED …………………………………………………………

E. TRAININGS IN HCBC
   I. …………………………………………….
   II. ……………………………………………
   III. ……………………………………………
   IV. ……………………………………………
   V. ……………………………………………
   VI. ……………………………………………

F. EMPLOYEMENT STATUS ………………………………………………………………..

G. LENGTH OF TIME …………………………………………………………………………

H. SALARY / STIPEND AND AMOUNT …………………………………………..

I. ANY SOCIAL GRANT RECIVED YES/NO

J. IF YES, PLEASE INDICATE TYPE AND AMOUNT………………………………………………………………………

K. ANY OTHER INCOME …………………………………………………………………………………

2. What is your understanding of care giving?
3. Whom do you care for?

4. How frequently do you see your patients/clients

5. What services do you render to your clients?

6. Explain in detail how do you render such services?
7. Do you receive any supervision for your care giving? Please explain who does it and how it is done.

8. What impact does care giving have on you as an individual care giver?
   a. Physical impact
   b. Psychological impact
c. Emotional impact

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d. Economic impact

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e. Any other impact (if any)

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9. How many males who are HIV/AIDS positive receive your care?

10. How many females who are HIV/AIDS positive receive your care?

11. What are your daily experiences as a care giver?

12. What are the challenges experienced during the process of care giving?
13. What stresses you the most as a care giver?

14. What coping strategies/mechanisms do you normally resort to in order to cope with the challenges you face in providing care?

15. What support systems are available to assist the home-based caregivers?
16. Do caregivers find the available support systems adequate?

17. If no, justify your answer

18. In your view, what should be done to make your work as a care giver more effective and less stressful?

19. Do you have any other views on the matter of care giving?
“Thank you for your participation and may God bless you

Date………………………………..